



Bristol Autism Spectrum Service

Guide to Personal Independence Payment

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Personal independence payment (PIP) is a welfare benefit for people who need support with daily living, communicating and moving around.

To make a claim for PIP requires a phone call followed by completion of an application form PIP2 – ‘how your disability affects you’.

Phone 0800 917 2222 to make this initial claim (PIP1). If you are unable to use a telephone, ask a trusted person to call on your behalf (See How to claim). Or you can write to ask for a paper claim form.

PIP is a non-means tested benefit (in other words your income and savings have no bearing on whether you get the benefit or not)

There is no automatic entitlement to this benefit and there are rules and criteria you have to pass to qualify.

Different rates for Personal Independence Payment

PIP is split into two parts mobility and daily living.

If you are eligible there are different rates depending on your level of needs

Mobility – planning and following a journey & moving around (£21.80 for the standard rate and £57.75 for the enhanced rate)

Daily Living – personal care, engaging socially, communication, making financial decisions (£55.10 for the standard rate and £82.30 for the enhanced rate)

- You will need a minimum of 8 points to qualify for the standard rate and 12 points for the enhanced rate of each part (Mobility and Daily Living)
- It is likely that as well as filling in a form to claim PIP you may also have a Face to face assessment. If you think you could not cope with a face to face assessment write this on the PIP2 form when you make your claim.
- Read the NAS information sheet “*PIP – the points based criteria*” as it has some useful information in it - www.autism.org.uk/pip

Do you qualify for Personal independence payment (PIP)?

Having a diagnosis of autism including Asperger syndrome will not give you automatic entitlement to PIP. However, it may be worth you applying for Personal Independence Payment if you need help with any of the following:

Mobility part of PIP:

- Planning and following journeys outdoors alone in unfamiliar places
- Moving around

Daily Living part of PIP:

- Preparing a cooked main meal for yourself with fresh ingredients
- Taking medication
- Eating/drinking
- Socialising with other people
- Washing
- Getting dressed/undressed
- Managing money
- Reading and speaking
- Using the toilet

How to claim

Claiming is a two-step process. A phone call (PIP1) then completing a questionnaire (PIP2).

Claims are usually started off by making a phone call. Phone 0800 917 2222 Monday to Friday 8am-6pm, to make this initial claim (PIP1).

If you feel unable to make the phone call then ask a trusted person to make the call and you can provide the relevant information such as your name, address, date of birth and national insurance number. You will need to briefly speak to the person at the end of the phone just to confirm you are happy for your trusted person to make the claim on your behalf.

Alternatively, you can request a paper PIP1 form to be sent to you in the post. If you want to use a paper claim form ask for one when you call 0800 917 2222.

Address to post if you complete a paper version of the PIP1 form

Personal Independence Payment New Claims
Post Handling Site B

Wolverhampton
WV99 1AH

What information you need handy when you make your telephone claim for PIP

When you call you will require the following information:

- Your name, address and contact details
- Your date of birth
- Your national insurance number
- Your bank or building society details
- Your doctor or health worker's details
- Your nationality, immigration status and details of time spent abroad (of more than 4 weeks).

Once you have completed the PIP 1 form you will then be sent another form which is more detailed (PIP2) to complete.

You must return this PIP2 form within a month. If you think you will need more than a month contact the DWP and ask for an extension and explain why. It is important to return the form by the date on the PIP2 form and paperwork you receive with this. It is often possible to get an extension but DWP do not have to give you one.

Where to send your PIP2 claim form to?

You will be given a self-addressed envelope to put your application form into.

If you lose the envelope you can always write this freepost address on another envelope:

Freepost RTBS-CBYC-SCZS
DWP Personal independence payment (4)
Warbreck House
Blackpool
FY2 0UZ

Face to face assessments

You may be asked to attend a face to face assessment. These take place in Bristol at one of three locations in BS1, BS15 and BS14.

Always get advice from Bristol Autism Spectrum Service if you are asked to attend a face to face assessment!

You should take someone along with you to the assessment. The DWP or contractor (eg Maximus, Capita or ATOS) must give you seven days' notice of the assessment.

Contact Bristol Autism Spectrum Service and if we are not available then email welfarerights@nas.org.uk for advice about attending the assessment, if you are worried about it.

If you would find attending difficult you must inform DWP. If you fail to attend the interview you may not qualify for the benefit.

Alternatives to a face to face assessment are assessment at your home or over the telephone. You may need to state that because of anxiety, physical health or other reasons you really do not wish to have a face to face assessment – *BUT get advice if you wish to do this from Bristol Autism Spectrum Service on 01275 796 249.*

Questions they may ask during the Face to face assessment

They may ask you general questions such as ‘where did you go to school?’ (they may wish to know if you attended any specialist schools/units)

They assessor may ask you did you get any qualifications (this is because they may believe that if you got some GCSEs you need less support)

They may ask things like “can you manage cooking?”

If you have a £1 coin can you take away 7p how much money do you have left?
If you take away another 7p how much left. If you take away another 7p how much left?

The assessor may ask you to spell a word backwards.

The assessor may ask you to perform a memory test of three words eg clock, door, kettle then ask you to repeat the three words 10 minutes later.

Physical assessment during the Face to face

If you have said you have limited physical mobility the assessor may ask you to perform various activities. These may involve the assessor touching you. If you cannot tolerate touch from another person, request the assessor does not touch you.

If you do allow the assessor to touch you they may ask questions like “can you push your leg out?” (with their hand on your shin) or with their hand on your upper leg – “can you lift your leg up?”

The assessor may ask “Can you move your right/left arm behind your head and behind your back?” and ask you to demonstrate this.

The assessor may also ask you to resist them pushing up or down on your hands (to test how much strength you have in your hands).

If you have been awarded PIP you may be entitled to other benefits

If you receive PIP this can affect the amount you receive of other benefits. So, if you are successful in your claim please contact Bristol City Council Welfare Rights and Money Advice Service 0117 352 1888 or use the NAS welfare rights service - email welfarerights@nas.org.uk.

Other benefits you may qualify for if you get PIP

If you have been awarded 8 points or more in the Mobility 'moving around' activity of PIP you can get a Blue Badge.

If you qualify for PIP at enhanced rate (12 points or more) for the Mobility part you can apply for Vehicle Excise Duty (Vehicle or road Tax) exemption.

If you receive standard rate (8 points) for the Mobility part you can get 50% off your Vehicle Excise Duty (Vehicle or road Tax).

If you or family member or partner living in the same household gets PIP you are not subject to the benefit cap rule.

You may get the Concessionary bus travel pass without further assessment if you receive PIP. Check with Bristol City Council bus.passes@bristol.gov.uk

It is possible to claim PIP and receive JSA / ESA at the same time. (If you receive PIP this may lower the income threshold for eligibility for income based Employment and Support Allowance. In other words, if you get PIP you can have a slightly higher income and still claim income based ESA.)

If you have other questions about PIP you can contact Welfare Rights and Money Advice Service WRMAS on 0117 352 1888 or use the NAS welfare rights service - email welfarerights@nas.org.uk or Bristol Autism Spectrum Service on 01275 796 249. There is also a government enquiry line on 0845 8503 322.

What to do if you are turned down for PIP?

You can ask for the decision to be looked at again (sometimes called being re-considered or reviewed).

If you ask for this you can at the same time send on any additional evidence from professionals or others to support your case further.

If DWP still decide that you do not qualify get further advice as you have the right to appeal. Get advice if you are considering using your right to appeal. Contact Bristol

Autism Spectrum Service 01275 796 204 or Bristol City Council Welfare Rights and Money Advice Service 0117 352 1888 or use the NAS welfare rights service - email welfarerights@nas.org.uk

General tips on filling in the PIP2 form

- Write about what support you need or should be getting as well as what help you actually get
- Think about what help you need with the tasks eg you may be able to have a wash but it takes up to half an hour to prompt/remind/persuade you do so.

Relate the support you get (or need even if you do not always get it) to autism or any mental health difficulty you have such as anxiety or depression.

Use real-life examples in your answers to the questions, to back up your case

- If you can meet other people but it always or usually causes you high anxiety then the answer to: Can you cope with meeting people you don't know? Could well be "NO", so make sure you get help with this question so your answer is truthful to your true situation.
- Consider keeping a diary for three or four days – what help you needed, with timings. Write three columns in a notebook with three headings:

Date - What support you needed? - How long was the support for?

Under the headings fill in the information as you go through the day when you remember to fill in the notes. Do not worry too much if you forget something or it is exactly accurate just make sure you write down the support you get (and any support you need but don't get) during the day. Use the information you have put in the notebook to help you complete the PIP form.

- The person who reads your application form will not know anything about your life, circumstances and everyday difficulties you face so this is your opportunity to fully explain your circumstances.
- Be prepared to be emotionally drained and frustrated with answering all the questions (especially because the emphasis is on writing about things that you cannot do easily rather than your achievements and abilities).
- Make a photocopy of/save online the form before you send them. The Department for Work and Pensions – DWP – occasionally lose forms sent to them so always make sure you have a back-up copy. Also when you come to re-do the form in the future for example when the benefit is reviewed you will not have to start from scratch - you can refer to your photocopy.

- Use supporting info eg Consultant reports, letter from GP if you can get it and if it does support your 'case'. Keep copies of letters. Do not send letters from professionals that focus on your positive achievements and do not adequately explain how difficult everyday life can be.
- As well as using Bristol Autism Spectrum Service and this Guide, you may wish to read the info and advice sheets on completing the forms - www.autism.org.uk/benefits
- We can help completing the form at the Bristol Autism Spectrum Service (book an appointment at our Advice Service – 01275 796 249) or go to Citizens Advice Bureau, or Welfare Rights and Money Advice Service WRMAS on 0117 352 1888 or use the NAS welfare rights service - email welfarerights@nas.org.uk .
- If you want additional help you can always use the phone NAS Autism helpline 0808 800 4104 and book a phone appointment with the welfare rights service. It is usually quicker to get an appointment if you email direct welfarerights@nas.org.uk

Important note about answering some of the key questions in Personal Independence Payment

Personal Independence Payment asks you to comment on a number of what it calls 'descriptors'.

The descriptor (eg can you wash yourself) applies to you if:

- it is true more than 50% of the time over the period of 12 months
- you cannot complete the activity “reliably, to an acceptable standard, in a timely fashion, repeatedly and safely” (this is very important – if you can sometimes do a task but at least 50% of the time you are unable to do the task then you should state that you cannot do the task). Use the words 'reliably' 'safely' etc when you complete the form eg 'I cannot reliably and safely do this task more than 25% of the time'.
- the difficulty you face must have lasted for 3 months at least and be likely to carry on being a difficulty for at least another 9 months

In a timely fashion means less than twice as long as the maximum reasonable time it takes the average person. This is of course a bit vague so if it takes you much longer than most people tell the DWP about it.

In other words on any question where it says please tick YES NO or SOMETIMES, if more than 50% of the time it does apply, tick the YES box.

Definitions of certain words used in the PIP2 form

Assistance is support that requires the presence and physical intervention of another person to carry out an activity.

Prompting is support provided by reminding, encouraging or explaining to an individual to undertake or complete a task but not physically helping them. To apply this only needs to be required for part of the activity.

Supervision is a need for the continuous presence of another person to ensure safety and avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. This support must be for the full duration of the activity.

Unaided is without either the use of aids or appliances or assistance /prompting/ supervision from another.

Examples of how someone with autism/Asperger syndrome might score sufficient points to qualify for PIP

You will need 8 points for the standard rate and 12 points for the enhanced rate of each part (Mobility and Daily Living)

This is where you might score enough points to qualify for this benefit:

Daily Living Activities

Needs prompting to be able to prepare or cook a simple meal (using fresh ingredients) – 2 points

Needs prompting to be able to wash or bathe – 2 points

Needs communication support to be able to express or understand complex verbal information – 4 points

Needs social support to be able to engage with other people – 4 points

Total 12 points = enhanced rate

Mobility Activities

You should explain your difficulties as fully as possible with regard to leaving the house and getting out and about in the community.

It has become harder for someone with autism to get the Mobility element of PIP unless you:

Cannot read maps/timetables due to a learning disability (or sensory loss)

Or you

Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. 10 points = Standard rate.

Daily Living part of Personal Independence Payment

This section will give you some ideas about how to answer questions in the Daily Living part of the Personal Independence Payment form.

Q3 Preparing food

Points system:

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

- I require help with a special diet – for example gluten free
- I need prompts to try new food types, for example I only eat dry food or certain brands
- I refuse to eat in front of others
- I need prompts to eat in unfamiliar surroundings
- I have sensory differences that lead to diet problems – eating too much or too little
- I forget to drink enough
- I eat unsafe food sometimes because I do not check sell by dates
- I regurgitate food if not properly supervised
- I need to follow certain routines about plates or cutlery
- I constantly get up from the table, or only eat whilst walking around
- I have phobias about other people eating near me
- I require monitoring to prevent me bolting my food and getting indigestion
- I eat non-food items (a condition known as ‘pica’) and therefore need supervision when I am in the bathroom, kitchen or outside
- I am at risk of dehydration because I only drink when reminded
- I can only eat certain brands of food
- I am completely intolerant of people coughing/talking or making chewing noises during meals
- I dislike other people eating near me because of the noise or a fear of germs
- I eat meals alone because I do not like people looking whilst I eat
- I cannot eat in certain places/rooms
- I do not understand the need for a balanced diet
- I dislike eating foods with certain colours or textures
- I do not understand about food safety and sell by dates

- I have a specific diet (eg casein or gluten free) that requires meals to be constantly monitored. I cannot check packaging properly to ensure I remain on the diet. If I do not eat a gluten/casein free diet I have major behaviour difficulties
- I have specific food allergies that require me to be monitored and supervised during meals (Explain what happens if you eat the foods you are allergic to.)
- I eat still frozen microwaved food
- I eat stale or mouldy food
- I forget to clean the fridge and so eat food that is unhygienic
- I leave the freezer door open and make food unsafe by defrosting and refreezing food and I leave the oven on
- I forget to wipe food preparation surfaces before eating
- I have given myself food poisoning or stomach upsets from food I have not cooked properly

You may have difficulties with any of the following:

- Carrying out the cooking process in the right order
- Washing, peeling, chopping fresh veg/meat
- Using taps
- Using a cooker
- Set the right temperature
- Use oven gloves
- Using sharp knives
- Easily distracted
- Not knowing what to do if cut self
- Putting food into pans
- Cooking correctly eg not over or under cooking meat
- Knowing how to check food is properly cooked
- Lifting hot pans
- Filling pans with water
- Remembering to cook for right length of time
- I wander off to do something else when I have tried to cook
- I only cook convenience food
- I feel sick at the smell of cooking food
- I cannot cook because I have worries /phobia about making mess
- I find it hard to cook more than one thing at a time so the meal is not ready to eat all at the same time
- I lack motivation to eat due to autism
- I do not have internal sensory feedback that tells me when it is time to eat
- I feel hungry and register hunger but then a minute later forget that I felt hungry and so don't eat all day
- I find it hard to plan or follow a sequence
- I tend to not cook food properly or tend to burn things
- I find it hard to read and so cannot follow a recipe

- I have coordination or dyspraxia problems and can't use a knife / peeler/ hot pan
- I cannot safely use the oven / hob / microwave
- I find using an oven confusing and too anxiety provoking to attempt
- I forget to turn the oven / hob off

Q4 Eating and drinking – taking nutrition

Points system:

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

- I need prompts to try new food types, for example I only eat dry food or certain brands
- I refuse to eat in front of others
- I often forget to drink all day and get frequent headaches
- I do not have internal sensory feedback that tells me when it is time to eat
- I feel hungry and register hunger but then a minute later forget that I felt hungry and so don't eat all day
- I lack motivation to eat due to autism
- I feel sick at the smell of cooking food
- I have high anxiety and depression and these mean I have no appetite, so I need prompts and encouragement to eat/drink
- I find it hard to plan or follow a sequence so I forget to make time for meals and so prefer to not eat otherwise I cannot achieve what I need to
- I cannot co-ordinate knife and fork due to dyspraxia difficulties so eat with my hands
- I cannot use utensils due to dyspraxia difficulties so need adapted cutlery
- I frequently spill drinks and drop food because I have dyspraxia difficulties and cannot physically multi task, so if someone talks to me I often drop my plate or cutlery
- I need my food cut up for me because I have weakness in my hands due to dyspraxia

Q6 Managing medication and therapy

Points system

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

Social Security (Personal Independence Payment) Regulations 2013 (amended 16 March_2017) provide the following definitions:

manage medication means take medication, where a failure to do so is likely to result in a deterioration in your health.

manage therapy means undertake therapy, where a failure to do so is likely to result in a deterioration in your health.

medication means medication to be taken at home which is prescribed or recommended by a registered (a) doctor; (b) nurse; or (c) pharmacist.

monitor a health condition means –

- (a) detect significant changes in your health condition which are likely to lead to a

deterioration in your health; and

(b) take action advised by a (i) registered doctor; (ii) registered nurse; or (iii) health professional who is regulated by the Health Professions Council, without which your health is likely to deteriorate.

Q6 Washing and bathing

Points system:

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

Explain how the help you need and if it is due to any associate physical difficulties state what these are: for example, attention deficit disorder, epilepsy, deafness, bowel problems

- I don't know how often to wash / bath/ shower/ shave/ clean my teeth
- I need verbal instructions to wash/ bath/ shower/ shave/ clean my teeth properly and I need reminders and encouragement to do these tasks
- I need written or verbal instructions to wash/ bath/ shower/shave/ clean my teeth properly and I need reminders and encouragement to do these tasks
- I have problems that mean I don't wash properly
- I have a sensory dislike of the feel of water so need support to wash myself
- I have a strong dislike to the smell of washing products that makes washing difficult
- I need someone else to wash me because I have dyspraxia and cannot reach parts of my body
- I feel the need to wash/ bath/ shower / shave/ clean my teeth very often because I have an obsessive compulsion
- I scrub my skin until it is sore because I have an obsessive compulsion
- I must wash in a certain order, and become distressed if I can't do this or someone interrupts me
- I need help to use tampons/ sanitary towels properly. I frequently have accidents because I cannot remember when my period is
- I have difficulty with sequencing the washing/bathing routine. I need prompting to remind myself what parts of the body require washing.
- I need the bathroom warmed before use
- I refuse to enter the bathroom because of the smells and feel of the floor surface
- I need verbal prompts at each stage of washing

- I resist being touched or rubbed by a towel, resulting in challenging behaviour
- I have difficulties with motor skills which might, for example, make it difficult to get toothpaste onto a toothbrush
- I am hypersensitive to touch or taste, making it difficult and unpleasant to brush teeth, have a shower or brush my hair
- I don't know when I am being scalded or when the water is too cold
- I flood the bathroom unless I am supervised
- I need supervision whilst I am in the bath or I will drink the bath water
- I refuse to get in or out of the bath or take a shower
- I insist on following the same bath-time rituals which means bath-time can take an hour or longer
- I have an obsessive-compulsive hand-washing problem
- I cannot flush the toilet because I have a sensory intolerance to the sound of it
- I have obsessive behaviour relating to toilets. I sit on the toilet for up to an hour
- I don't understand the health benefits of keeping clean so need prompts and reminders to wash
- I am dyspraxic and often make a real mess in the bathroom so it takes up to 30 minutes to clean after I have used it
- I cannot wash properly and hygienically without prompts
- I cannot use conventional soap or shower gel and I need unperfumed non-allergy products to avoid skin reactions
- I need supervision to ensure I use the correct washing materials. I will sometimes use household bathroom cleaners instead of soap because I get confused about labels

Q7 Managing toilet needs

If you have difficulties in this area answer the questions as clearly as you can.

Q8 Dressing and undressing

Points system:

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

- My clothes need to be laid out the night before in a special sequence to ensure I get dressed in the morning
- Getting dressed is a lengthy process
- I have manual dexterity problems that make dressing very difficult without help (eg taking shoes/socks on/off, shirt buttons, zips, bra straps, hooks, laces, shaving, belt loops)
- I cannot manage putting on socks and shoes
- I have difficulty dressing appropriately to the weather I choose unsuitable clothes for the weather
- I put clothes on in the wrong order
- I need a prompt to get dressed
- I have difficulties putting clothes on in right order
- I sometimes put on clothes when they are too dirty to wear
- I only wear certain fabrics
- I must wear tumble dried clothes and only use a certain washing product (if it has sold out or is unavailable I will not dress)
- I must do things in a certain order in the morning that affects my ability to get dressed
- I need help to choose clothes
- I like to wear the same clothes every day
- I need reminding to wash my clothes
- I need help to dress myself
- I have difficulty with the routine of getting dressed For example, clothes go on inside out or in the wrong order, putting socks over shoes
- I need to change clothes several times a day
- I have obsessions about clothes eg spend a long time getting ready and refuse to leave my home if certain clothes are not available or do not look right
- I will only wear certain colours
- I will only tolerate certain fabrics (eg due to sensitive skin)

- I cannot cope with the smell of clean clothes and find this hard to tolerate so need encouragement to dress
- I require special clothes (eg weighted vest or lap blanket)
- I will only wear certain fashion or brand labels due to fear of failure and rejection and my obsessions
- I refuse to wear clothes indoors
- I will become distressed when my favourite clothes wear out or need washing

Q9 Communicating verbally

Points system:

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

If you have learning difficulties such as executive functioning problems due to autism this should count as problems with communication and interaction. It is harder to argue this if you have autism/Asperger syndrome but put down all the help you need from another person regarding your daily communication needs. For example, if you need cannot process language quickly and frequently cannot follow communication.

The Social Security (Personal Independence Payment) Regulations 2013 state that:

“communication support” means support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa;

“complex verbal information” means information in your native language (eg English) conveyed verbally in either more than one sentence or one complicated sentence;

“complex written information” means more than one sentence of written or printed standard size text in your native language (eg English).

- I cannot follow more than one or 2 sentences of what other people say
- I cannot cope with more than one long sentence at a time
- I cannot say more than one sentence at a time
- If people use long words or any word that has more than one meaning I switch off
- I cannot express my thoughts in sentences. I need time to be able to talk at all and cannot therefore converse with people in real time
- I have an auditory processing delay and cannot manage to follow more one sentence without asking the other person to slow down or stop and let me process what they have just said
- 75% of the time I just nod when other people are talking but I do not understand what they are saying as normal pace of speech is too fast for me
- I am unable to connect my thoughts to my speech

- My medication makes communication more difficult I slur my words and feel too lethargic to talk. People cannot understand what I am saying
- I have difficulty communicating with other people, even people in my own family to the extent that I will not come out of my room
- I sometimes have days when I do not talk to anyone at all
- I cannot talk to other people
- Even when I know an answer or know that I should say something I cannot connect my voice to my thoughts
- My processing of sound is affected by autism and means I cannot generate responses to what other people say
- I cannot speak out loud because of anxiety and processing difficulties
- I am mute 75% of the time, because I cannot respond to the words people say
- I find it very difficult to give a simple message especially if it is someone I have not met before. I get the words mixed up in my head and cannot connect or co-ordinate the thoughts in my head with speech
- I find about 75% of the time that I am too anxious to talk at all
- I only have one tone of voice and cannot raise my voice or shout out loud even if there is an emergency
- I am often ignored when I try to talk because I am unable to look at people's faces and have a very quiet voice

Q10 Reading and understanding signs, symbols and words.

Points system:

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

This is about being able to read and understand signs, symbols and words. (If you use Braille you should get 8 points.)

If you have difficulties with reading and/or understanding words make sure you explain how it affects you.

- I have dyslexia and this causes me difficulties
- I am unable to read
- I ignore or misread important signs in traffic situations or other situations eg Stop signs or Unsafe building or Crumbling cliff
- I have difficulties with reading and writing
- I have Irlen syndrome or scotopic sensitivity
- I read words but find am unable to process the meaning from words
- I have other visual difficulties when looking at text
- I get frequent headaches when I look at text
- I find words move about on the page
- I find words merge into one another
- I cannot read words unless I use tinted lenses or see text on specific colours of paper
- My anxiety and stress mean that I cannot understand what words mean and I miss the intent of signs and symbols

Q11 Mixing with other people - Engaging with other people face to face.

Points system:

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

This is about your ability to mix with other people. This question is asking you how well you get on with other people, how much you understand how they're behaving towards you and whether you are able to behave appropriately to them. It includes both people you know well and people you don't know.

Can you mix and engage with other people and do this safely, to an acceptable standard, as often as you need to and in a reasonable time?

Social Security (Personal Independence Payment) Regulations 2013 state that: "engage socially" means –

- (a) interact with others in a contextually and socially appropriate manner;
- (b) understand body language; and
- (c) establish relationships.

Some of the information you put in Q9 can be repeated here if required. Fully describe your difficulties with social contact. Even if you can sometimes mix with other people describe how this causes you stress/anxiety/ psychological distress.

- I have no friends I see outside of my immediate family or partner
- I do not even engage socially with my own family members. I avoid them because I find all conversation and social mixing stressful
- I find all forms of social interaction stressful even with people I know quite well
- I cannot manage social contact without feeling nervous/stressed/anxious/worried I have said the right thing
- Mixing with other people often causes me tiredness, paranoia, anxiety, anger and frustration
- I often refuse to leave the home because I am too stressed/angry/frustrated/worried/paranoid to face members of the public
- I get too pent up and angry to hold a conversation with others
- I do not understand small talk and I cannot make it successfully. People do not understand what I am trying to say.

- I avoid people because I never have successful enjoyable pleasant conversation it always ends in me getting it wrong or feeling judged
- I find it hard to follow what other people are saying
- I get flustered and say the wrong thing
- I find I cannot follow group conversations
- I get too anxious to talk to anyone else
- I find crowds cause you to have panic attacks
- I have behaviour that other people find offensive, threatening, scary so I avoid going out.
- I am likely to say or do something that puts me or others at risk.
- I avoid people because I don't know what to say or how to talk to other people
- I suffer from mutism
- I have a stutter
- I have a speech impediment
- I speak too quietly or loudly for other people
- I am unable to concentrate on what people say
- I am unable to speak up for myself
- I take things that other people say literally and has this led to problems
- I misunderstand the things other people say
- I get into arguments in public because of how I talk and come across to others
- I find that other people often misunderstand me
- I find that you often misunderstand other people
- I find it hard to start a conversation
- I find it hard to end a conversation
- I get angry / frustrated when people misunderstand you
- I fail to read social situations and this often leads to problems
- I fail to understand peoples' facial expressions or body language which leads to problems
- I avoid answering the phone because autism makes me anxious
- I can only speak to certain types of people
- I have no social relationships because of communication difficulties
- I have little contact with my family because of communication difficulties
- My communication difficulties affect my relationship with my partner/ children

Q11a I need another person to help me mix with other people

This question is asking whether you would be able to socialise more if you had someone you trusted at your side to help you feel confident and smooth out any social interactions that do not go to plan or to 'interpret' social situations for you. It does not matter whether or not you actually get this person to support you in real life, it is a hypothetical question to find out what support would (in an ideal world) really help you.

For example, if having a support person on hand to give you prompts or encouragement would help prevent your high level of constant social anxiety and enable you to live more independently then you should probably answer YES to this question.

Q12 Making decisions about money – budgeting

Points system:

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

Social Security (Personal Independence Payment) Regulations 2013 state that: complex budgeting decisions means decisions involving –

- (a) calculating household and personal budgets;
 - (b) managing and paying bills; and
 - (c) planning future purchases.
- I have limited understanding of budgeting and each month run out of money
 - I have very little or no concept of the value of money
 - My parent, partner or other person is Appointee for my benefits
 - I let someone else take all financial decisions because I cannot manage money or cope with it without getting too stressed and upset
 - I suffer high levels of anxiety about money matters
 - I suffer depression and cannot cope with money as it makes me more depressed
 - Because I lack understanding and because of anxiety about money, I store or throw away letters from my bank or building society or any official letters from credit card companies
 - I have got myself into debt eg credit cards or disagreements with council over rent arrears or benefit overpayments
 - I have an obsession about money that affects my ability to budget – my obsession means I spend all spare money
 - I have a gambling habit because of my autism
 - I give money away to people I thought were friends but turned out to not be
 - I have been taken advantage of by emailed or posted offers and special discounts only to find out I have been scammed
 - I lose money/wallet/important possessions on a regular basis
 - I have been taken advantage of by others – I have lost money or possessions

- I do not understand bank accounts and how they work
- I have a general learning difficulty that affects my ability to budget
- I have specific learning difficulties that affects my ability to manage money eg dyslexia or dyscalculia
- I have severe anxiety/depression that affects my ability to manage money
- I have language processing difficulties and so cannot make sense of letters or bills from credit companies
- I often misunderstand the concept of having to pay back money I have been 'given' through credit
- I often have problems paying bills or understanding official letters that involve money
- I have problems with organisation – due to executive functioning limitations so have major difficulties with paying bills
- I cannot understand bills, official letters and I fail to understand statements or interest rates
- I am not able to process information about money because I have poor grasp of maths
- I am unable to budget expenditure or assess the value of goods
- I do not understand bank statements and terms like minimum payment or Annual Percentage Repayment

The Mobility part of Personal Independence Payment

You should explain your difficulties as fully as possible with regard to leaving the house and getting out and about in the community.

It has become harder for someone with autism to get the Mobility element of PIP unless you:

- Cannot read maps/timetables/always get lost/cannot learn how to use buses due to a learning disability, cognitive limitation (or sensory loss)
- Or you cannot undertake any journey because it would cause overwhelming psychological distress. *10 points = Standard rate.*
- Or you have a combination of some difficulties getting out and about and physical mobility difficulties

Many people with autism experience high anxiety and stress whenever they go outdoors. If leaving your home causes severe discomfort such that most days you cannot leave your home without very high anxiety and stress you should write this on the PIP2 form.

How each claim is assessed by the DWP (usually by another agency such as Atos or Capita) will depend on each person's individual needs. Therefore, if you make a claim the information you provide is of vital importance so give as full a picture of any difficulties you experience as possible.

Q13 Going out - Planning and following journeys.

Points system:

- a. Can plan and follow the route of a journey unaided. 0 points.
- b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. 4 points.
- c. For reasons, other than psychological distress cannot plan the route of a journey. 8 points.
- d. For reasons, other than psychological distress cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. 10 points.
- e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. 10 points.
- f. For reasons, other than psychological distress cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. 12 points.

-
- I do not go out more than 50% of the time, even when there is a professional support worker with me
 - I behave in ways that attract a lot of negative attention when out in public
 - I tend to get wound up quite easily and has this led to incidents outside the home
 - I behave in dangerous ways when I'm out of home
 - I cannot go outside because I am dangerous in public because I have extreme views, stand too close to people, interrupt conversations, chat up other people's girlfriends, 'stare' too long at other people, get into fights
 - I get into trouble with the police because of my behaviour in public places
 - I have difficult or challenging behaviour, for example I get angry at people and start shouting at them or hit out if someone brushes past me accidentally
 - I get into trouble for making personal comments when in public. For example, "why are you so fat?"
 - I ignore instruction even when near busy roads/in dangerous situations
 - I cannot go outside of my own home more than once a fortnight due to extreme anxiety
 - I need someone with me when I am out of home to provide a near constant commentary to reassure and to explain what is going on, as this is not available I cannot go outside at all
 - I become anxious or aggressive even with a support person and do not go out
 - I have to be encouraged and prompted to leave my home but even then, I rarely go out of my home because of extreme anxiety
 - I need to take medication to calm myself before I am able to leave my home
 - I am paranoid about people are staring at me and so cannot leave my home more than 50% of the days of the week
 - I am unable to sleep the night before I have to leave my home and usually cannot go outside of my home
 - I feel /am sick before I leave my home
 - I must have someone with me if I leave my home and even then most days I do not go out of my home
 - The reason I cannot go outside is because I have to avoid certain places, noises, or people because I have fears/phobias/intense reactions (Eg I panic if I see a large noisy dog)
 - The reason I cannot go outside is because I am afraid of busy places and noisy people I require extra support, supervision or reassurance and this restricts the places I can go to
 - The reason I cannot go outside is because I suffer from agoraphobia – fear of open spaces/leaving my home
 - The reason I cannot go outside is because I am panicky and refuse to move if confronted by objects of phobias, such as dogs, or thundery weather
 - I am unable to read information eg such as road signs, parking restriction notices, directions or timetables because I have a cognitive impairment

- I get lost in new places
- I cannot cope with more than one turning I get lost and need someone with me to find anywhere more than a street away. This is true even if I have been somewhere before I still get lost and do not know how to ask for help.
- I cannot plan a route of an unfamiliar route
- I cannot read or understand maps and timetables
- I have difficulties working out how to navigate in unfamiliar places
- I get lost in the supermarket, or out in places I have not been before
- If I get lost I panic and have meltdowns
- I am unable to ask for help when I get lost in unfamiliar places
- I ignore or 'not see' road signs even when I am near busy roads or in dangerous situations
- I have limited spatial awareness – I am unable to tell right from left, follow more than one simple direction at a time, or travel beyond end of the road I get mixed up and lost. I have no sense of spatial awareness
- I cannot ask another adult for directions – I am too anxious/ afraid to do this
- I frequently lose track of time and return late or walk into places I am unfamiliar with because I have walked without checking where I am
- I have little awareness of traffic and am frequently unable to judge speeds and crossing times accurately, so I cannot safely, to an acceptable standard, repeatedly and in reasonable time, cross the road
- I understand danger in theory but am easily distracted should something else come along e.g. I will run across a busy street to avoid someone or to look in a particular shop window
- I am easily distracted by what is going on around me and this causes problems eg wandering off, getting lost, being overwhelmed and unable to cope
- I have regular meltdowns tantrums due to hyper-sensitivity to noise, people, crowds, too many questions
- I am unable to use public transport eg fear of other people brushing against me and other social/sensory issues
- I have many sensory difficulties, such as acute hearing, that makes going out difficult If I hear a high pitch noise it hurts my ears and I have a meltdown.

Q14 Moving around

If you have physical difficulties that prevent you from moving about indoors or outdoors without discomfort or pain describe these in this section.

Further information and advice

To book an appointment with a staff member to help you complete the PIP1/2 forms (or other advice relating to PIP) please contact:

Bristol Autism Spectrum Service
Awp.bass@nhs.net or 01275 796 204

Or ...

Bristol City Council Welfare Rights and Money Advice Service 0117 352 1888

Or ...

NAS welfare rights service - email welfarerights@nas.org.uk.

For general advice online see:
National Autistic Society website
www.autism.org.uk/benefits

Organisations that may be able to assist with one to one form completion if you are unable to access the Bristol Autism Spectrum Service or Bristol City Council Welfare Rights and Money Advice Service

(info courtesy of Contact A Family)

Avon and Bristol Law Centre

2 Moon Street

Stokes Croft

Bristol

BS2 8QE

Public Tel 0117 924 8662

Website <http://www.ablc.org.uk>

Service offered

Legal advice, assistance and representation. Telephone advice lines: housing and debt - 0117 916 7730. Welfare benefits - 0117 916 7722. Employment and discrimination - 0117 916 7727. Immigration - 0117 916 7733. Discrimination in goods, services and housing - 0117 916 7704. Also offer legal advice in community care and mental health.

Disability Information and Advice Service - Bristol

Unit E, Link House

Britton Gardens

Kingswood

Bristol

BS15 1TF

Public Tel 0117 947 9911

Website <http://www.wecil.co.uk>

Service offered

Telephone advice and information for disabled people, their families and carers on all aspects of disability, including welfare rights, aids and adaptations, holidays. Appointment system for form filling and Blue Badge.

Filwood Hope Centre

11-13 Filwood Broadway

Knowle West

Bristol

BS4 1JL

Public Tel 0117 9634566

Service offered

Walk-in advice centre with a range of services for the local community in Knowle West and South Bristol. Specialist benefit and debt advice Tuesday 1pm-3pm and Thursday 10am-12 noon from South Bristol Advice Service. Council rent advisor

Tuesday 9.30 –3pm. Age Concern drop-in Wednesday 9.30 – 11-30 am, home visits pm. Counselling available daily.
Area served
Knowle West and South Bristol.

North Bristol Advice Centre
2 Gainsborough Square
Lockleaze
Bristol
BS7 9XA

Public Tel 0117 951 5751

Website <http://www.northbristoladvice.org.uk>

Service offered

Specialist information and advice for the local community on welfare benefits and debt. Community support at home for over 55's in the Lockleaze and surrounding North Bristol area. Outreach Welfare benefits and Debt advice sessions provided at Lawrence Weston, Southmead, Patchway, Kingswood, HMP Bristol and Shirehampton.

Area served

Postcodes BS7, BS9, BS10, BS11, BS15, BS16, BS32, BS34.

Shire Advice Service

115 High Street

Shirehampton

Bristol

BS11 0DE

Public Tel 0117 982 9399

Website <http://www.shireadvice.net>

Service offered

Advice and information for the local community on a range of issues, including consumer, debt, employment, housing and welfare benefits. Drop-in advice sessions at Shirehampton Health Centre, Pembroke Road on Tuesday, Wednesday and Thursday 10am - 12 noon and at St Andrew's Church, Avonmouth on Monday 9.30am - 11.30am.

Area served

Shirehampton, Lawrence Weston, Avonmouth, Sea Mills.

South Bristol Advice Services
Withywood Centre
Queens Road
Withywood
Bristol
BS13 8QA

Public Tel 0117 985 1122

Website <http://www.southbristoladvice.org.uk>

Service offered

Advice and information for the local community on benefits, consumer issues and money/debt provided at a range of venues in South Bristol. Specialist help in debt and welfare benefits. Drop-in outreach services at a range of venues in South Bristol - phone for details.

Area served

South Bristol (BS3, BS4, BS13, BS14).

St Paul's Advice Centre
146 Grosvenor Road
St Paul's
Bristol
BS2 8YA

Public Tel 0117 955 2981

Service offered

Advice and information for the local community on a range of issues, including housing, immigration, money and debt, benefits, consumer rights and employment rights. Representation at social security appeal tribunals. Benefits and debt advice by appointment.

Area served

Fishponds, Easton, St Agnes, St Werburghs, St Judes, St Pauls, Montpelier and surrounding areas.