



Act Now For Autism is a core group of people passionate about the future and well-being of children and adults with an Autistic Spectrum Disorder in the UK. You can contact the administrator on mail@actnowforautism.co.uk

Here is our PIP consultation response, prepared in partnership with a number of autistic adults and parent carers across the UK:

Q1 – What are your views on the latest draft Daily Living Activities?

Autism is an extremely complex condition. Everyone who has a diagnosis of autism will have impaired communication, socialisation and imagination (fixed and rigid thinking) no matter how verbally able they appear to be. These three impairments cannot be weighted or looked at separately because the 3 impairments join together to have an accumulative impact on the lives of autistic adults. Therefore we firmly believe that there needs to be a descriptor for people who have an autistic spectrum condition/aspergers. Without a specific descriptor for people with autism, those with the diagnosis of autism are once again being made to fit into a means of measuring their functionality by a system that was not designed to specifically measure the impact that autism has on their lives.

Will the communication part of the descriptor encompass all forms of communication, including the inability to understand non-verbal communication and literal interpretation of both verbal and non-verbal communication? It is essential that it does.

Communicating effectively is perhaps the biggest issue for adults who have a diagnosis of autism. Autism is a spectrum condition and the communication styles and the need for communication aids can differ significantly from person to person.

Impaired communication and socialisation skills impact on every communication that an adult with autism has.

Act Now For Autism would like to be assured that all of the communication styles and preferences to communicate be accommodated during an assessment.

We would also like to be assured that the assessors will be fully and suitably trained in all of the different communication styles? It can often take a trained speech and language therapist to unpick both the expressive and receptive language of someone with autism.

Adults with autism may appear to be very communicative but can often find question and answer discussions easier than having to use expressive language. As autism affects both receptive and expressive language unless an adult with autism can be assured that they can have an advocate with them throughout the assessment process it may be extremely difficult or impossible for the adult to give accurate answers to the questions that they are being asked.

Some adults with autism do not fully understand how the condition impacts on their daily living. Therefore those adults who have verbal ability but lack an understanding of their own condition and how it impacts on their lives will be placed at a significant disadvantage, and may be at risk of losing a benefit that they are in fact entitled to, unless they have someone with them who can clearly state how the adult is affected by their condition.

Effective communication requires understanding otherwise it serves no purpose. The inability to understand the implications of situations can be as incapacitating as being stuck in a wheel chair when you are trying to get down several flights of stairs.

Face to face assessment are going to be extremely difficult for adults with autism, and we believe that autistic adults will be significantly disadvantaged by this method of assessment.

An adult who finds themselves in an environment which is alien to them, being asked questions by someone they are not familiar or comfortable with, may tell the assessor what they believe they want to hear to ensure that they can be removed from a situation that they are finding difficult as soon as they can.

It is important to note that many verbal adults with autism have often learnt that by giving the answer which they believe might be expected of them, that it can often reduce the amount of answers they are expected to supply.

For example an adult with autism who does not fully understand their condition who is asked how well they thing they can communicate with other people, might respond 'I communicate well'. The adult will have learnt that by giving what they consider to be a positive response to the question, using words included in the question that the person asking the question is less likely to ask additional question therefore reducing the responses they have to provide.

An assessor asking adults with autism questions must also satisfy themselves that the adult has in fact understood the question.

The ability to communicate effectively depends on many factors and will fluctuate depending on the levels of anxiety being experienced by the adult and other stressors including sensory issues.

For example stress and anxiety can impact on an adult's ability to communicate if an adult is given too many commands or questions that require answering.

Adults with autism experience processing problems when they have an overload of information. Having to answer a series of questions can impact on the ability to process the questions and then communicate effectively.

Adults can then becoming hyper focused on trying to process a question and the knock on effect to that can impact on other areas of their functioning. Problems processing information can for example lead to an adult being late for appointments or even catching the wrong bus to attend an appointment because they are too preoccupied trying to process information.

We would like to stress that being able to access written communications does not mean that someone with autism can understand and then act on the information that they have accessed. People with autism often have a very uneven profile of skills. An ability to access written information does not mean ability to process and understand the information.

The socialisation part of the descriptor must also include the difficulties that adults on the autistic spectrum have because they do not understand none verbal communication and because they often have a literal interpretation.

There needs to be clarification regarding the help that someone might need to help them to socialise and the score that will be awarded depending on the support needed.

Some adults with autism will only ever be able to socialise if they are in the company of a trusted person who they know well. It would be unfair if an adult with autism could only ever score 2 points on the rating scale because they can only ever socialise if someone they know well is with them. The person who accompanies that adult is a person who has an in depth knowledge and understanding of that adult and that should qualify as someone who has been trained or has experience. Meaning that the adult with autism could score 4 points on the rating scale.

Socialising can present an adult with autism with a number of internal stressors that they have to cope with in addition to the socialising. Again the ability to socialise can be affected by what is happening in the life of the adult at that moment in time. This is something that can fluctuate not only from day to day but from hour to hour.

Adults with autism often find it difficult to find or maintain social relationships and friendships. This can lead to unwillingness for them to even try to communicate with someone socially.

Any change to plans that have been made to socialise can impact on the adult with autism and can influence their ability to participate or continue with plans that have been prearranged. Social situations can present the adult with difficulties within that situation that then impact on their ability to function. Sensory issues, such as lighting, music, and crowded place will all determine how successful the social communication will be.

Some adults are able to socialise either on a one to one basis or within a small group of people who they know well. However even then the social interaction often has to be facilitated and wrapped around the person with the diagnosis of autism. Social interaction often has to be on the terms of the person with autism which limits the experiences that will prove to be successful for them.

Many adults have social scripts that are learnt which they use in social situations. But often these scripts are practiced and rehearsed and are meaningless to the adult in every other way than asking a series of polite questions that they have programmed themselves to roll out in social situations. When the script comes to an end or the person who has been asked the polite question responds in a manner that the adult is not expecting, that can create anxiety leaving the adult with nowhere to go with the conversation. For some adults this can lead to frustration and aggression and they may then have a verbal outburst.

Adults with autism can often stim when they are being socially overloaded and are finding the interaction too much for them.

For some adults with autism the ideal social life for them is to stay at home and not have to encounter or deal with social situations that are both alien and frightening to them. Many social activities even day to day activities that neurotypical people participate in make no sense and are unwelcome activities for people with autism.

Making financial decisions can be very hard for some people with autism. They can find money and its value confusing. Some adults with autism find it difficult to understand that they have to keep some of their money to pay for example a utility bill as they find it difficult to understand that heating and lighting costs money. For some adults the heat and light source is just there on tap freely for them. Some seldom think of the consequences of having the heating or lighting on all day and all night. The other side of this coin is that some adults worry so much about bills which they might have to pay that they tend not to use any heating and as little lighting as possible to enable them to keep their bills to a minimum. Budgeting can be a huge problem for adults with autism. The prices of food items change on a daily basis which can lead to confusion and frustration.

Communication and socialisation skills also come into play when dealing with financial issues. This can impact on the ability of the adult with autism to successfully handle their own finances. Adults experience huge difficulties if they have to, for example, contact their bank and have to follow a series of instructions before they can speak to a person. Some adults have to ring the telephone number a number of times to give them the time that they need to process each instruction. Speaking to the advisor at the other end of the phone presents its own problems. The adult with autism will often have prepared a script before trying to contact an advisor. If the advisor then tries to veer the adult away from their script this creates confusion and sometimes frustration and the adult will then terminate the conversation without successfully having their query answered.

The following examples of how they find dealing with their finances were given to us by adults with autism who Act Now have got to know very well during the last two years.

'I even have a scientific full-display calculator since if I can't see what I've worked out if there is a complex sum with money to work out, then I tend to stumble and not know how I came up with the result I've had even halfway through. In other words, if the way that a bill for example is worked out, then I cannot understand it very well (hidden language, charges, etc again)'

'Sometimes the way that a bill is worked out is too complicated and bitty (i.e. without saying "this includes VAT" in place of "Sub-total" "Total owed" "Total gained", etc - I need things in plain language'

'The problem is that finances are variable according to what you have to pay, so it is easy to lose track or to add too much onto your expected payments, making it difficult to work out what you've spent, saved, etc'

'I prefer for someone else to work through what I need to pay or buy as it's just too much information to process by myself.'

- **Question 2**

What are your views on the weightings and entitlement thresholds for the Daily Living activities?

It would appear to Act Now that the weighting system that will be used will not measure how severely a person's disability affect them, just how severe their condition may appear to be from a practical perspective. If this is in fact the case then the net result will come down to how well a given assessor can pin point problems. This would be of great concern to Act Now.

Weights by definition are designed to bias the data in a particular direction so that a pattern is exaggerated and thus more visible. So to achieve the right outcome for everyone who has a disability a different set of weights would be required for each type of condition.

There seems to be an assumption that by aggregating the entitlement thresholds for the benefit at a higher level it will simplify the system and thus make it more effective and cheaper to run. Although we are told that each person will be assessed on personal need, it would appear to us that the method is designed statistically to do the opposite.

Each activity is given a weighting which results in an overall score for each person. Our impression is that these weightings are fixed, that is they are by implication giving priority to particular needs.

Our key concern is that the way in which a particular activity will impact on someone's life will depend on their own set of difficulties i.e. one person's communication issues could significantly impact on their daily living just as significantly as another's physical immobility issue would impact on their daily living.

To reflect things more realistically you would need to vary the weighting system based on an individual's ability to function rather the thing that actually inhibits them.

The weighting system will not measure how severely a person's issues affect them, just how severe the condition may appear to be from a practical perspective.

The adults with autism who have helped with our response feel that reconstruction of the weighting is required. They feel that the weighting should be based on overall lifestyle impact, by looking at all areas involved.

All autistic people are entirely individual; therefore their needs and difficulties are going to be unique to them that should be accounted for in the process of assessment and the weighting for Personal Independent Payment.

Q3 – What are your views on the latest draft Mobility activities?

Case study 13 looks at Tom. He has qualified for enhanced mobility due to his inability to plan a journey without support. We would agree with the decision however Tom has no road safety awareness. People with

autism often have no sense of danger either for their own safety or that of others. We would like to see a descriptor with an equal weighting attached for adults with autism who have a limited or no sense of danger?

We would also like to see an additional descriptor allocated with a weighting of a minimum of 12 for people with autism who suffer from anxiety and sensory processing difficulties, who could make a journey with the right transport / support put in place. Without that support or their own familiar vehicle, they may become isolated.

People with autism often have very high levels of anxiety and stress and we believe that this impacts on their mobility.

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

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- **Q5 – What are your views on how the regulations work regarding benefit entitlement?**

We do not feel that we are able to answer this question because we lack the legal knowledge required to make a meaningful response.

Q6 – What are your views on how we are dealing with fluctuating conditions?

A fluctuating condition is just that. We are not sure that it is right to measure a fluctuating condition over the period of a year. We are not sure that there is a suitable timescale with which you could accurately measure a fluctuating condition.

Act Now has grave concerns only being able to use one descriptor as a measurement, if the person has a fluctuating condition, when 3 or 4 descriptors may also be involved. Allowing the use of more than one descriptor would surely show how fluctuating condition that the person has impacts on their life. It would also show the cumulative effect that the condition has on their lives. If a person is having difficulties in 3 or 4 areas of their lives then there must be a way to measure the cumulative effect that this has on the person's life.

Act Now believes that this is an important issue which will need addressing before the PIP assessment goes live.

Official Question:

Q7 – What are your views on the definitions of 'safely', 'timely', 'repeatedly' and in a timely manner?

For an adult with autism any of the words being used **'safely', 'timely', 'repeatedly' and in a timely manner** will be dependent on a number of factors. The ability to function well is dependent on many factors for an adult with autism and this can fluctuate from hour to hour as opposed to day to day.

Sensory issue can impact hugely on the ability of an adult with autism to function well and carry out basic tasks. If someone with autism is experiencing a high level of anxiety, this will impact on their ability to function well throughout the day. Something as simple as the hum from a light bulb can affect the functioning ability of someone with autism. This would mean that simple tasks would take them much longer to carry out and in some cases it would make it impossible for them to carry the tasks out at all.

It is important to be aware that adults with autism often have none transferable skills. This means that although they might be able to do something safely, timely and repeatedly at home and in a timely manner it does not mean that they can transfer those skills to another setting. This would include being in the home of a parent, carer of anyone else whom they knew well.

Act Now would like to know what the DWPs definition of doing something safely means? Does this include the emotional wellbeing of the adult as well as physical injury?

It is vitally important that the definitions of these words are spelt out so that they are understood in the same way by those who will be assessing adults with disabilities and also by the adult themselves. Words that can be interpreted in many different ways by different people are not helpful and are likely to lead to confusion and differences in the scoring that will take place during the assessment.

Act Now would not like to see these words included in the legally binding rules for PIP until it is made clear what the definitions of these words is going to be.

Q8 – What are your views on the definitions in the regulations?

All of the words within the PIP regulations need to be clearly defined with a shared meaning for everyone who reads the regulations.

At the moment many of the definitions are vague and woolly and are open to misinterpretation. This is unacceptable when a person with a disability stands to lose their benefit if they are being measured by a scale that is understood differently by different people.

For example we understand that **“assistance”** means physical intervention by another person.

The dictionary definition of the word assistance is ‘help’ aid’ ‘support’ it is possible to help, aid and support someone without physical intervention. In fact adults with autism who require a great deal of assistance during their day may not respond well to physical intervention. Sensory issues mean that some adults would become distressed, anxious, or physically aggressive themselves if the assistance there were given was by means of physical intervention.

“communicate” means convey and understand information in the claimant’s native language;

It could be argued that autism is the first language for adults with autism. Unlike people who learn a different language and eventually master that language people with autism will always struggle, even with their native language.

“communication support” means either support from a person trained to communicate with people with specific communication needs or support from someone experienced in communicating with the claimant.

It also needs to be accepted that someone who appears to be highly verbal can in fact have complex communication needs and this will need to be embedded into the training that all of the assessors receive.

Will the assessors break these definitions down and use simple language when they are asking the questions. i.e. can you comb or brush your hair, wash your own hair, clean your own teeth.

“groom” means (a) comb or brush one’s hair; (b) wash one’s hair; and (c) clean one’s teeth;

Q9 – Do you have any other comments on the draft regulations?

The issue of providing information about their condition is one of the biggest concerns for the adults who have spoken to Act Now.

It is vitally important that the DWP are not only aware but accept that there are a 'significant number of adults' who will not be able to produce any information from a professional who is deemed to be an acceptable source about their condition and how it impacts on their lives.

Act Now for Autism is very concerned about the importance of 'supportive evidence' for the PIP assessment.

Without supportive evidence autistic adults stand to lose their benefits.

We know there are a significant number of autistic adults and those with Aspergers Syndrome who do not have the supportive evidence they are going to need for either assessment.

We believe this is one of the biggest issues that autistic adults and the autism community across the UK are now facing.

There are concerns being raised about how evidence will be gathered and by whom.

We believe the more important issue is what will happen to the significant number of autistic adults who will not have any evidence to gather?

Having no evidence to gather will be used against our adults.

In 2009 the National Audit Office published a report *Supporting people With Autism Through Adulthood*:

"Around 200,000 adults with autism do not have a learning disability. This group often fails to secure appropriate support, as health and social care services are traditionally configured for people with a learning disability, a physical illness or disability, or a mental health problem (which autism is not)."

"Three quarters of local authorities said adults with autism who do not meet eligibility criteria experience or report difficulties accessing the services they require. Almost two thirds felt that current services for adults with autism are limited."

Three quarters of autistic adults and those with Aspergers Syndrome did not meet the eligibility criteria to access the services they required in 2009. There has been very little progress made to extend service provision for these adults since 2009 so where they get the supportive evidence they need?

Without Health and Social Care provision, autistic adults are left with only their GP's to oversee their care needs. Evidence from GP's will not be considered as supportive evidence as part of a benefit assessment/reassessment, Chris Grayling told us that.

Face to face assessment is yet another big concern for Act Now and the autism community and yet it is highly likely that any adult who cannot produce information about their condition will most certainly be required to have a face to face assessment.

Will a lack of written evidence from professionals who have been deemed suitable to supply evidence, be seen as an indication that the adult with autism is not as affected by their condition as they might be.

It must be understood and accepted that a lack of written evidence does not mean that an adult is not insufficiently affected by their condition that they do not warrant any services, provisions or support. It simply means that there were or is no services, provision or support available to that adult.

Adults with autism are going to find face to face assessment particularly difficult to cope with. As the core impairments of autism cover the two most important skills required when a face to face assessment is undertaken, communication and socialisation, it cannot be stressed enough just how difficult these face to face assessments are going to be for adults with autism.

People with autism struggle to cope when they are in an unfamiliar environment with people who are unfamiliar with them. The pressures of answering questions in an alien environment to them with the questions being asked by people who they are not familiar or comfortable with is going to be enormous.

Act Now is already being contacted by adults with autism who are already extremely anxious at the prospect of a face to face Personal Independence Payment assessment. Some adults with autism have told us that they would rather not have the benefit if it means they have to be asked questions they will not understand by people who they do not know and who do not understand them.

This is seriously concerning Act Now as adults with autism are amongst some of the most vulnerable adults in the UK. Without this benefit many of them will no longer be able to cope or pay for the things that enable them to have the support that they require in their day to day lives.

While face to face assessments in the home might lessen the intense anxiety that adults are already experiencing about these assessments it is essential that anyone who assesses an adult with autism must have an in depth knowledge and understanding of the condition.

Act Now does not see how it is possible to accurately assess someone with autism without including the diagnosis of autism in with the assessment.

We firmly believe that developing a system that will consider the impact of impairments rather than what the impairments are - will not allow for an accurate assessment of someone with autism.

We are also very concerned that this system of assessment will only allow for the primary descriptor to determine the score given for each activity. We believe that rather than picking the most prominent descriptor(s) they need to factor in all descriptors simultaneously where each descriptor is valued according to what is deemed as a suitable level of support. This is the best way to make the result fair and balanced.

Other Comments:

Act Now continues to be concerned about the descriptors and how they will be applied when assessing someone with autism. Autism is a broad spectrum condition that includes many different co morbidities, sensory issues and processing problems. We do not believe that it will be possible to accurately assess someone with autism without the vastness of their condition being taken into account.

We are greatly concerned that without being able to reflect the amount of difficulties that someone with autism will suffer from because of social and environmental factors, that adults with autism will be placed at a significant disadvantage to other adults with disabilities when being assessed for PIP. Especially as adults with autism have a condition that is wrapped around impairments in both communication and socialisation.

Act Now is also very concerned that although someone may have more than one disability, (people with autism often have co-morbidities that run alongside with and impact and interact with their autism) when scoring the assessment only one descriptor will be used to score an activity. What will happen if the person shows an equal amount of difficulty performing an activity in two or more of the descriptors? It is entirely unfair to then choose only one descriptor with which to score them. We feel that this can in no way reflect the level of overall difficulty that the person is experiencing in reality. It is in fact minimising the impact that the problems that that person experiences in their daily living.

The final descriptors must reflect the complex nature and the magnitude of autism. We do not feel that at the moment they do. It is important that ultimately any assessment which will decide the level of benefit that someone with autism is entitled to is fit for purpose when an assessment of that person is carried out.

For and on behalf of Act Now For Autism

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