

## **South Tyneside Council Response to Personal Independence Payment: Assessment Thresholds Consultation**

### **General comments**

Disability Living Allowance has provided a considerable amount of help to many people with disabilities and health problems since it was introduced. Disability Living Allowance has also assisted many disabled people remain in the community and not in residential care. The receipt of the additional income from Disability Living Allowance has also meant fewer demands are made on social services as people are able to make their own choices for the care or assistance they require and maintain their independence.

The aim of a more efficient and effective welfare system for disabled people is to be applauded and agreed with however this will not be achieved with the abolition of Disability Living Allowance.

The main thrust of the reform to Disability Living Allowance has been the stated objective of achieving a 20% cut in government spending on Disability Living Allowance payments and a reduction of 500, 000 benefit recipients. The stated aim is to focus the attention if the new Disability Living Allowance's successor, Personal Independence Payment, on the most severely disabled but many disabled people with significant problems may loose out.

Although it is appreciated that Personal Independence Payment is not a direct replacement for Disability Living Allowance the reduction in the numbers of available components from five to four will result in a cut in income for many disabled people –people who already have the lowest incomes.

Personal Independence Payment introduces a new assessment process with the key criteria of self assessments and a face to face medical assessment. This new assessment process is asserted to be objective and consistent.

The proposed 'points' system is extremely similar to that of Employment and Support Allowance. Significant problems with the Employment and Support Allowance assessment are well documented - similarly this was introduced in part to cut back on expenditure. The significant number of people bringing successful appeals demonstrates that the assessment process and outcomes are not consistent and objective. Over 40 % of decisions are overturned at independent appeals and the medical examinations are problematic - criticisms are widely made of both those carrying out the examination and the assessment criteria itself.

The reform of Disability Living Allowance makes a commitment to introduce a 'personal independence payment' based on points and established criteria yet many disabilities do not fit into the proposed criteria. By being less prescriptive Disability Living Allowance allows more of a holistic approach to be taken. Employment and Support Allowance also accommodates that the whole 'person' be considered. There is provided in the Employment and Support Allowance regulations for some people who not 'fit into the boxes' to allow an exceptional circumstances rule to be used so people can still be deemed to be incapable of work, although technically not passing the Work Capability Assessment.

There are considerable delays in the face to face assessments for Employment and Support Allowance- the prescribed 13 week assessment period is not adhered to due to the large numbers of claimants. This situation is likely to be replicated with Personal Independence Payment face to face assessments.

The appeal system is also at saturation point due to the high numbers of Employment and Support Allowance appeals and it is doubtful if the Appeals Service could cope with the further anticipated numbers of appeals following Disability Living Allowance transfers.

The lessons learned from the Incapacity Benefit migration and Employment and Support Allowance process must not be transferred to the Personal Independence Payment process. The standard of decision making has been heavily criticised and with fewer staff there needs to be considerable resources placed into effective training of decision makers and the medical assessors to ensure decisions are 'right first time', which current they are not.

Due to the length of time Disability Living Allowance has been in existence a substantial amount of case law has been established. This case law assists decision makers and tribunals and ensures consistency in addition to reasonableness and common sense. There is more of case to reform the current system of Disability Living Allowance rather than introduce a new system, which will always be compared to the 'old' system and will make decisions making more difficult for a number of years.

It is asserted that people are left 'unmonitored' on Disability Living Allowance for years - yet this is not the experience of the advice centres in South Tyneside who are working to capacity with the regular review forms that people have to routinely complete. It is acknowledged that fraud is low in Disability Living Allowance claims – increased review periods proposed under PIP will not assist this. Reassessing people is accepted as necessary but for many people suffering conditions that are unlikely to improve or change a re-assessment is an extremely stressful and anxious process.

The introduction of Personal Independence Payments does not represent 'benefits simplification' as it will be relevant only to people of working age. Disability Living Allowance will be maintained for children and Attendance Allowance will continue to exist for people aged over 65. The introduction of a Personal Independence Payment will considerably increase costs, complexity and confusion amongst disabled people.

South Tyneside Council is also concerned at the North East being chosen as the trial for the transfer of Disability Living Allowance to Personal Independence Payment. Obviously 'someone' has to be the initial area but more consideration to spreading the impact of the reassessment would be preferred.

The North East area, including South Tyneside has high levels of people experiencing debilitating health problems and an industrial past has left its legacy on the population's health. There are significant numbers of residents who have already had to undergo the Incapacity Benefit transfer to Employment and Support Allowance, many having their benefit reinstated at tribunals - this has caused considerable anxiety for many and now they will face another stressful process.

## Specific consultation question responses

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

The latest draft has expanded on the initial draft and this is to be welcomed. The addition of communicating, engaging socially and making financial decisions does widen the scope for qualifying for Personal Independence Payment. However reducing the number of 'care' components from three to two will mean many disabled people will lose entitlement - although it is appreciated this is a new test.

The government has responded to some of the consultation outcomes and broadened the assessment criteria. However not all aspects of daily living are covered - only what the government considered the 'essential' aspects. The criteria could be expanded to include other activities that enable people with disabilities to live an independent not isolated life.

The way the threshold levels have been devised for the activities, with the exception of communicating, no one will be able to qualify the enhanced rate of daily living from one activity alone – this should be viewed as too high a threshold to pass through. It is also noted that there remains no distinction between day and night personal care activities. The requirement for assistance at night time is much more disruptive – and much harder and costlier to find support for.

With reference to the required use of aids or appliances there needs to be more consideration as to how this practically will be applied. If during a face to face assessment it is considered that an aid or appliance would assist a person perform an activity – how would this be decided? Would a short term award be based on actual current needs – i.e. an inability to perform the activity - and then the award reviewed after appropriate aids and adaptations have been provided? Will referral mechanisms be developed in such circumstances?

Comments on each activity are provided below-

#### Activity 1- Preparing food and drink

- Current low care rate removed which will impact on up many people as outlined in the consultation documents.
- Preparation of only a 'simple meal' rather than a main meal does not accurately reflect what would be considered an essential part of daily life.
- No account is taken of the physical aspects of preparing meal such as bending to an oven/cooker - many people with physical problems are unable to prepare a meal due to bending difficulties and performing the repeated act of bending to prepare a 'simple' meal could impact on the person's ability to perform other daily activities.
- The use of microwave has been introduced – this would not be viewed by most people as a requirement for a 'proper' meal – but merely a snack. A snack cannot be considered a 'proper' meal for a part of balanced diet required for daily living.
- The need for frequent help throughout the day has been removed - encouragement to eat regularly would have been previously covered under this assistance.
- There is no acknowledgement of the high/ extra additional cost of health related diets some people require.
- Previously people requiring prompting and motivation to cook would have received low care – this aspect of personal care has been omitted.
- It is clear that the old 'cooking test' is not replicated under Personal Independence Payment.

#### Activity 2 - Taking nutrition

- Physical help is required from another person to constitute promoting – this is much stricter test.
- No account seems to be made for memory problems where there is not another person present. Self prompting by use of notes or alarms could provide the prompt despite no person being present.
- The criteria do convey a high level of disability is required.
- Consideration such be given to some medical conditions such as diabetes, depression, anorexia do require frequent attention throughout the day from another person ensure nutrition is taken effectively.
- There is no requirement for supervision or appreciation of any risk of scalding by dropping food.

#### Activity 3 - Managing therapy or monitoring a health condition

- This activity is described in the notes as one of the replacements for the Disability Living Allowance 'supervision' test yet it introduces it with an extremely high threshold.
- The activity proposed under Personal Independence Payment looks as if it will exclude people who self harm, experience suicidal tendencies, experience diabetic comas, and epilepsy as this activity only now gets a very low score. The score of one does not reflect the severe impact on daily living things such as not taking medication or non-attendance of appointments would have.
- It is proposed that the supervision, prompting or assistance must be with reference to prescribed therapy – this is very strict and far too high threshold to reach.
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#### Activity 4 - Bathing and grooming

- The activity of 'bathe' proposed is far too narrow and not realistic. Bathe is not defined as meaning bath but simply to clean face, underarms, hands and torso – this is a considerably much lower test than having a bath or a shower.
- The ability to 'bathe' tests a considerably lower set of physical or mental skills. Being able to take a bath or shower is an aspect of daily life most people undertake or with assistance.
- People with mental health problems with little awareness of personal hygiene issues will be unlikely to qualify under this activity.

#### Activity 5 - Managing toilet needs or incontinence

- Under Disability Living Allowance assistance required with toilet needs and /or difficulties from incontinence would satisfy the frequent attention throughout the day and /or night criteria yet under the proposed Personal Independence Payment requirement 'assistance' scores at a low level.
- Suffering from incontinence often includes the requirement to change clothes and it is felt that this should be accommodated in the activity descriptor.
- To 'manage' incontinence would require effectively changing clothes

#### Activity 6 - Dressing and undressing

- All, apart from F, are very low scoring activities and this is a key aspect of daily living.
- There is no reference to tiredness and lethargy experienced by some people which impacts on their ability to dress- this should be covered by the requirement to take into account 'reliably, timely, repeatedly and safely'

#### Activity 7 - Communicating

- Sensory impairments are covered – but people with communication difficulties due to mental health problems and learning difficulties should also be taken into account.
- The activity proposed does not take into account significant mental health difficulties with communication which will lead to isolation and an inability to actively participate in daily life.

#### Activity 8 - Engage socially

- The proposed activity seems to narrow the established Halliday/ Fairey principles for help with social activities and hobbies. Undertaking a social life was previously viewed as an essential and a required aspect of daily life and assistance should be provided to those who require it.
- Psychological support only seems to be covered in the activity- physical support should also be covered.
- The requirement for actual evidence of 'overwhelming distress' needs to be expanded upon and clarified.

#### Activity 9 - Making financial decisions

- This is a new area which does demonstrate awareness that dealing with financial activities is requirement for day to day life but alone it would not qualify a claimant for an award of Personal Independence Payment.
- As this is an entirely new activity more clarification is required.

### **Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?**

The scoring system and language is very similar to that contained within Employment and Support Allowance rules. The wording contained within the activity descriptors will be subject to interpretation over time and challenge at appeal hearings.

It must be ensured that sufficient consideration is given to the fact of whether activities can be performed 'reliably, in a timely fashion, repeatedly and safely'.

As mentioned above there are high threshold to qualify in some areas that would have previously been covered under Disability Living Allowance frequent attention. A higher score appears to be given to physical assistance rather than verbal assistance whereas both forms can be equally effective at meeting a need.

As the consultation document acknowledges a much wider range of activities will need to be covered in order to qualify for Personal Independence Payment. The examples in the document do give a good representation of the requirements to satisfy entitlement thresholds and obtain an award of Personal Independence Payment. It is also noted that the notes are guidance and not law and there should remain a flexible rather than rigid approach to apply the criteria.

It is assumed that the 'standard' rate places the low mobility/middle care component rate – and enhanced replaces the higher rates yet until the rates are published this will be unclear. Also the link with Universal Credit premiums and elements needs to have clarification to see the real value of the Personal Independence Payment.

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

#### Activity 10 - Planning and following a journey

- Does not take account sufficiently of the impact of unexpected events which will turn a 'familiar' journey into an 'unfamiliar' journey. This is particularly relevant to visually impaired people.
- It would appear difficult for people with physical difficulties to be awarded points in this area.
- The activity appears restricted to mental, cognitive and sensory impairment - physical factors restricting a journey do not seem to be taken into account
- The use of the term 'overwhelming psychological distress' indicates that an extremely high threshold needs to be met to successfully meet the criteria.
- The descriptor does not take the unsettling effect of crowds upon following a journey into account.
- Fluctuating conditions will need to be adequately taken in to account – as set out in the consultation.

#### Activity 11 - Moving around

- The descriptor focuses mainly on low distances – there is no definition of a specified amount in regulations for Disability Living Allowance but 50 metres was accepted as being 'virtually unable to walk' and the required threshold as the result of the development of case law.
- The removal of 'time, speed and manner of walking, severe discomfort' is replicated in part with the introduction of 'reasonably, regularly, safely and in timely fashion '. It must be ensured these elements are actually taken in to account and not disregarded.
- Ability to walk only 50 metres under current rules would mean a high rate mobility component award – under Personal Independence Payment it would appear that such a restricted walking ability would only qualify only for the standard rate.
- People can have severe limited walking abilities due to the speed, walking manner and distance they can cover and not be in wheelchair. The ability to possess a wheelchair can often be restricted to suitable living conditions.
- The activity looks entirely at the physical act of walking – sufficient account is not taken of the severe difficulty sight loss has on moving around. This seems perverse when automatic entitlement to the higher rate of mobility was recently extended to people with a severe visual impairment.
- Moving indoors and outdoors have been combined - these activities were previously distinct tasks. Combining the two further seems to limit entitlement.

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

Many people who currently qualify for the high mobility rate of Disability Living Allowance by being accepted as virtually unable to walk will not qualify for the enhanced rate of mobility under Personal Independence Payment and this is disappointing. The entitlement threshold appears too strict.

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

The regulations appear fine

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

The acknowledgement that people have health problems and disabilities which fluctuate is welcomed. One of the criticisms of Disability Living Allowance and Employment and Support Allowance is that a 'snap shot' of someone's life is taken rather than an overall view.

The use of a '50% of the time' over a twelve period may not accurately reflect some disabilities. Some health problems may be extremely severely debilitating for one week in a month – this would mean that they would not qualify for the Personal Independence Payment.

There has to be a high quality of assessment by the medical assessor to ensure that fluctuating conditions are correctly assessed. People often either underestimate or overestimate their conditions on claim forms and the accurate picture has to be ascertained from the claimant.

In order to establish the varying degree of any conditions information needs to be sought on the frequency; severity and duration of fluctuating conditions and an overall picture established which may not necessarily be 50 % of the time. An exceptional circumstances provision should be accommodated.

The assessment needs to take account and obtain information from the most relevant medical person - often if requests are made, which often do not occur, requests for information are provided by people who have no in depth knowledge of a claimant's condition. Training also needs to be provided to the medical evidence providers to ensure an accurate account of the overall condition is provided.

The difficulty with stipulating 50 % of days in a 12 month does not provide for new conditions - in effect this is providing for a 12 month qualifying period for people with newly occurring fluctuating conditions.

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

The inclusion of the above definitions is welcomed but how it is operated in practice by decisions makers and medical examiners needs to be considered. There will need to be a high level of good quality training in order to ensure that the examination and decision making is carried out well and 'fairly' and again get the decision right 'first time'.

The definition of timely meaning in less than twice the time it would take someone without a disability is welcomed.

With reference to the action of 'repeatedly', pain and fatigue must be taken in to account and the impact upon other activities.

It is vital for medical examiners and decision makers to remember the definitions above so the problems with Employment and Support Allowance decisions are not repeated.

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

The definitions are helpful but in many areas the threshold required will be too high- some of these are covered below –

- Assistance - physical intervention only which is too restrictive.
- Bathe- considerably different to all the activities required to undertake a bath

- Dress and undress- should have inclusion of manual dexterity issues , i.e., the inability to do up laces due to arthritis
- Manage incontinence- should include the problems that occur after an incontinence issue- i.e. changing clothes, washing, etc.
- Manage medication or therapy appear to be a high threshold – ‘undertake therapy’ requires clarification
- Medication - clarification may be required if alternative therapies would be included
- Monitor health- ‘detect significant changes’ needs further clarification – the cumulative effect of missing medication needs taking account of, When does minor move in to significant?
- Overwhelming psychological distress – this is too high a threshold and many significant health disabilities will not be covered
- Prompt – by another person only - memory problems may be coped with by self prompting- notes left around the house, etc,
- Simple meal - more clarification required as this is a substantial difference from the current ‘main meal’ test
- Supervision - continuous presence is too high a threshold and significantly more than continual.
- Toilet needs - incontinence issues do not often occur near a toilet

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

These are covered in the general comments above,