

Ref: scoc response to consultation on PIP/pmr/cons

Standing Commission on Carers

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Response from the Standing Commission on the DWP consultation on assessment criteria for eligibility for the Personal Independence Payment.

Introduction

The Standing Commission on Carers (SCOC) welcomes the opportunity to contribute to Department of Work and Pensions' consultation on the assessment criteria for the introduction of the Personal Independence Payment. .

The Department of Health established the Standing Commission on Carers in December 2007, at the request of the then Prime Minister. The Commission is an independent advisory body, providing expert advice to Ministers and to the Carers Strategy Cross-Government Programme Board on progress in delivering the national Carers Strategy. The Prime Minister invited Philippa Russell to chair the first phase of the Commission, whose members included carers and other representatives drawn from a wide range of public and third sector organizations. The next phase of the Commission began in September 2009, following the formal appointment of the Chair (Philippa Russell) and members in accordance with guidance from the Office of the Commissioner for Public Appointments.

The Carers Strategy was published in June 2008. *Carers at the Heart of 21st Century Families and Communities* is a ten-year cross-government strategy, aiming to ensure that carers have increased choice and control and are empowered to have a life outside caring. *'Recognised, Valued and Supported; Next Steps for the Carers Strategy'*, (published December 2010) updates the 2008 Carers' Strategy, building on, and further developing, the key principles in its

predecessor with regard to developments in policy and practice around carers and support for their roles.

The Government is working with delivery partners in order to achieve our long-term vision that:

'By 2018, carers will be recognized and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.'

The outcomes identified for achievement by 2018 are:

- ***Carers will be respected as expert care partners and will have access to the integrated and personalized services they need to support them in their caring role.***
- ***Carers will be enabled to have a life of their own alongside their caring role.***
- ***Carers will be supported so that they are not forced into financial hardship by their caring role.***
- ***Carers will be supported to stay physically and mentally well and treated with dignity.***
- ***Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods***

In achieving the above outcomes, our members recognise the critical role played by DLA in the past (and by PIP in the future) in enabling them to support their relative at home and in the community. Although PIP will be awarded to the individual needing care and support, it has major implications for family carers. PIP, like its predecessor, DLA, is particularly valued because:

- **It is awarded on the basis of national eligibility criteria and is not subject to local variation in interpretation of entitlement.**
- **It is portable and the individual can move without re-assessment.**
- **It is not linked to employment status. By providing additional funding for support with daily living (eg with transport or personal care), DLA can frequently enable disabled people to enter or remain in work.**
- **It is a cash payment and can be spent in any way that the individual and family feel best.**

- **It is not affected by the family income of the individual concerned and can therefore act as a major incentive to purchase additional support to facilitate employment rather than dependency on means-tested benefits.**
- **There is no National Insurance requirement in order to prove eligibility.**
- **It provides a '*passport*' to other benefits, allowances and services, eg the Carers Allowance; Disability Premiums; transport and more flexible Parental Leave for families with disabled children. Many councils use the level of DLA entitlement as one factor in determining eligibility for social care and support services.**
- **DLA (and its successor, PIP) have an important role in funding the additional care and support for a relative which enables the family carer to remain in employment or to carry out other family responsibilities. Therefore DLA/PIP have a vital *preventive* role in maintaining family life, supporting employment and thereby reducing benefit dependency.**
- **DLA assessment arrangements currently include the views of family carers (although we note with concern that their input is apparently removed in the proposals around the Personal Independence Payment).**

We understand the need to review DLA as part of the Government's wider welfare and benefit reform measures. We also agree with the proposed new name of Personal Independence Payment (PIP), which seems more in line with the thrust towards personalisation.

However, we are concerned that the Government envisages a significant reduction in the number of claimants (potentially by 20%). As noted in the Dilnot Commission's report on the future funding of social care, we expect to see a growing need for care and support in England and Wales, reflecting both the changing demographics and an ageing population and also higher expectations about personalised care and support in the family home and local community.

We also note the greatly improved survival rate of disabled children, largely due to improved neonatal care, but often resulting in life-long substantial needs for care and support. We recognise that economic pressures necessitate a serious reappraisal of all allowances and benefits. But we are keen to underline the importance of DLA/PIP in preventing families from slipping into disadvantage and deprivation (with consequent additional costs for both the NHS and the local authority if the family cannot cope).

Clarity on the role of PIP and potential differences in the purpose and allocation of DLA

With reference to the transition from DLA to PIP, we would welcome clarification about the purpose of the two allowances. Although superficially the same, we note that the purpose of PIP has been described as maximizing and improving independence and self directed care and support. However, historically, DLA has been seen as a way of compensating for (and supplementing) the additional on-going costs of daily living. The costs of daily living and the costs related to independence are of course inter-related. However, there may be differential costs in – for example – supporting a young disabled adult to move out of the family home and achieve more independent living.

Such differential costs could also occur with a person moving out of hospital or residential care back into the family home or community (perhaps after a period of reablement). He or she will still need assistance with the additional costs of long-term living with a disability. But he or she may also need more support during the transition period if the outcome of greater independence is to be achieved. If that investment is made, then the long term returns may be cost savings to the local authority and also benefit to the carers who can still provide support, but at a more appropriate level and (in some instances) resume employment.

Recognising the role of carers within the new assessment arrangements for PIP

We are concerned that the new assessment criteria for PIP (unlike those for DLA) do not include an expectation that the *carer* will make an active contribution to the assessment process. We strongly recommend that the carers' contribution to the new assessment arrangements should be reinstated. We regard the contribution and expertise of carers and families as crucial to any fair and full assessment arrangements and indeed this contribution should be regarded as a valuable resource to the assessor.

The key purpose of the DLA (and its successor, the Personal Independence Payment) is to maximize social inclusion and enable disabled or older people to obtain the additional support necessary for them to remain in their own homes and have good quality lives. Without recognition of (and respect for) the role and expertise of family carers, assessment arrangements cannot be as effective. This is of particular concern when the person undergoing assessment has complex disabilities and high support needs or communication difficulties without assistance from families or friends. This is also important when disabled people have

issues around insight – and may have unrealistic expectations or be unable to acknowledge their limitations or need for support due to their learning disability or mental illness.

Do the new assessment criteria take sufficient account of variable and fluctuating conditions?

We are pleased to note that the proposed assessment criteria will take account of fluctuating conditions. Disabled people with fluctuating or variable conditions (eg multiple sclerosis, ME, some forms of rheumatoid arthritis, mental health conditions, epilepsy) will usually be well-known to their own health practitioners both in primary and secondary care. We note that disabled people with fluctuating conditions are regarded as disabled under both Disability Discrimination legislation and the Equality Act 2010 and suggest that the views of known professionals and family carers should be actively encouraged and supported to inform the new assessment arrangements. It will be difficult for an assessor with no prior knowledge of the individual to adequately assess the impact of a fluctuating condition, particularly if the face-to-face interview takes place at a time when that individual is well and not in immediate need of extra care and support.

The exemplar of epilepsy as a fluctuating condition is offered in the consultation document. Whilst we agree that epilepsy is likely to be a fluctuating condition, we are not clear how it (and other fluctuating conditions) might meet the requirement for an impairment to affect the individual '50% of the time'. In many cases, epilepsy may be usually well-managed by medication. However, there may be periods when the individual is very unwell and needs high levels of support. These episodes, albeit not affecting independence or mobility for much of the time, have devastating impact on the lives of both the individual and the family when they occur. The risk of occurrence may also need ongoing lower levels of vigilance in between acute episodes. The need for 'watchfulness' or supervision is also insufficiently acknowledged in the criteria. Many disabled people will exhibit particular changes in behavior or other physical signals which indicate that a seizure may be imminent. In some cases particular atypical behaviours may be indicators or a possible relapse in the case of mental health. Similar challenges can occur with other fluctuating conditions such as ME. Regular observation and early identification of a potential problem because of the carer's ongoing observation and action can mitigate the impact of the attack or relapse and prevent unnecessary hospitalization or health/social care interventions and as such minimize the cost to public services.

The guidance implies that if an acute high level need for assistance or support occurs less frequently than another more moderate need (which has greater frequency), then that more moderate need should be prioritised. We note that many disabled or older people have a range of inter-linking conditions and disabilities. Whilst an individual impairment may have a lesser impact on day to day living, the impairments when combined together amount to a considerable level of need for care and support.

We would welcome clarification on whether different levels of need for a range of impairments or health conditions can be *aggregated*, thus offering a more holistic picture of the individual's eligibility for PIP.

With reference to the assessment of claimants with fluctuating and non-fluctuating conditions or disabilities, we hope that assessors will have appropriate knowledge of, and expertise in, the disabilities and conditions of those they are assessing. Without such prior awareness, we do not see that the face to face interview can be effective and there may also be issues about the weight attributed to additional evidence submitted by the claimant or family.

We note that the Government is keen to minimize the number of appeals against decisions around award of PIP and suggest that the quality of the assessment will to a large extent determine whether this ambition can be achieved.

Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

We do not consider that aids and appliances should be taken into account in assessing eligibility. The person's underlying disability remains unaltered. Disenfranchising disabled people who have maximised their potential through the use of aids and adaptations could also serve as a deterrent to other disabled people who fear that if they improve their mobility or enhance their independence, they may lose their entitlement to DLA or PIP.

Whilst aids and appliances can transform an individual's life, the underlying disability remains the same. If equipment needs repair, there may be long periods when high levels of personal support are required. Appliances and home adaptations may make some aspects of daily living easier, but they will not remove the overall need for personal support in most cases.

Aids and appliances are currently obtained from different services, Health, Social Care or self funded (sometimes through personal budgets). If they are to be included, then attention

should be paid to the cost of their maintenance and replacement. We also note that many aids and pieces of equipment need careful assessment prior to purchase or procurement.

Individuals or families purchasing aids or equipment will need access to reliable professional advice (and in some cases assessment) to avoid expensive and inappropriate purchases.

The role of supporting evidence within an assessment for PIP The role of supporting evidence for an assessment for PIP.

Current DLA assessment arrangements include a page designated for information provided by the family carer or another person who knows the claimant well. We are very concerned that under the current proposal there appears to be no planned involvement of family carers. We strongly recommend that the views of family carers should be sought, respected and recorded as integral to the assessment process. The views of family carers do not replace the views of the claimant, but complement them. They and the claimant should be also be encouraged to provide information on any relevant professionals, advisers etc. who can help to provide a full picture of the claimant's disability and any needs for personal support.

To accompany the carer's statement, we would also welcome assurances that reports and statements will be actively sought from professionals who also know the person well. As we have noted elsewhere in this response, other EU countries rely primarily on the statements of professionals who know an individual well in order to determine eligibility for particular allowances or benefits relating to disabilities or long-term health conditions. We see no reason not to apply the same approach in the UK. Virtually all current DLA recipients have long and well documented records of health and social care needs, with relevant professionals able to give an informed opinion if required.

With regard to external evidence as part of the assessment process, we note that those individuals will usually be given a minimum of seven days notice for a face to face assessment. We consider that seven days notice will be inadequate in many cases. Firstly the individual and his or her family will need to make arrangements to get to the assessment venue (which in some areas may be a distance from the family home). Secondly and importantly seven days will be insufficient time in most cases for the collection of relevant evidence and background information to support a claim. Thirdly, we also note that in some cases the presence of an interpreter, an advocate or a personal assistant (or indeed a family carer) may be required and seven days may be an inadequate time span in which to make the necessary arrangements.

With regard to the provision of relevant evidence about a claimant's condition and the related need for care and support, we note that GPs will have greatly enhanced roles following the introduction of GP commissioning and are therefore likely to be closely involved in the wider care and support of disabled or older people. GPs will know not only their patients but also any relevant issues relating to the family or community that might be significant in the assessment process. We would welcome further discussion about the enhanced role of GPs in the assessment process before steps are taken to introduce new face-to-face interviews with assessors who will not have the same background knowledge of the claimant and may not be familiar with the condition or disability in question.

We would also like assurances that any evidence or reports submitted will be read and relevant information used within the assessment arrangements. A House of Commons Work and Pensions Committee last year was told that DWP quite rightly wished to minimize the number of appeals against assessors' decisions and to ensure a proportionate, informed and fair assessment at the initial encounter. We share this ambition but have concerns that unless sufficient time (and advance notice) is built into the system, then the number of appeals may increase with associated costs both to individuals, their families and the State.

Will a face-to-face discussion always be necessary?

We are concerned that the face to face interview (which will be strictly time-limited and usually with a person unknown to the claimant or family) may not always be necessary and could indeed be replaced more effectively by consideration of existing evidence from relevant health or other professionals and the family.

We assume that face to face assessments are most likely when the individual has complex needs and there are issues not necessarily about initial eligibility but rather about the most appropriate level of award. In this context we would welcome a clarification of what is meant by 'complex needs'. We have noted elsewhere in this response that a growing number of disabled and older people will have multiple impairments or health needs which impact with each other to create a high level of need, but individually would not necessarily entitle the claimant to a successful application.

It is imperative that the assessor in any face to face interview has relevant and up to date experience of the person's disability that they are assessing, eg that they are able to communicate with people who may have a hearing impairment; severe learning disabilities or

dementia or have knowledge of mental health conditions. In many cases the family carer's involvement will be vital to ensure genuine communication.

As noted above, we have concerns about the seven days notice of such an assessment. If this becomes the norm, many individuals and their families will have insufficient time to prepare supporting information or indeed to make the necessary travel and other arrangements.

We hope that attention will be given to the timing and location of the face to face assessment. Some claimants and their families might wish such an interview to take place in the family home (as has happened with DLA assessments in some cases). Others might prefer a more neutral venue. However, none will wish to travel long distances.

We hope that claimants will be actively encouraged to bring a family member and/or an advocate or adviser with them to any face to face interview. The proactive inclusion of individuals who know the claimant well will greatly enhance the quality of evidence engendered at the interview. However, we are aware of concern by some family carers that considerable costs may be incurred if travel is necessary to the venue in question. Therefore we assume that expenses will be reimbursed not only to the claimants concerned but also for family members or advocates/advisers who may accompany them. We note that some claimants may need to be accompanied by two people in order to manage the travel arrangements and, in some cases, the interview itself.

We note from consultations carried out by the Council for Disabled Children and Every Disabled Child Matters that young people can have widely differing views about representation or support in assessment for PIP. In this respect, they are similar to their adult counterparts and their strong views indicate the need to reflect on how best to inform and advice claimants going through the PIP assessment process.

Some specific concerns about the assessment of children and young people 16-25

Whilst it is accepted that children and adults have some very different needs – the core eligibility criteria for children must be the same as adults to avoid discrimination on age grounds under both Disability Discrimination legislation and the Equalities Act 2010. We have concerns about the implications for young disabled people of the switch from DLA assessment arrangements and related eligibility criteria to PIP assessment arrangements and eligibility criteria during their transition to adult services.

Upon the introduction of PIP, we understand that there will be two different forms of disability related financial support, ie:

- **Disability living Allowance (DLA) for under 16s**
- **PIP for over 16s.**

The transition to adult life and services represents a major change and often a major challenge for young disabled people and their families. The Government recognizes this challenge and we welcome Lord Freud's comments that:

'We have the power and flexibility to treat 16 year olds differently [to adults of working age]. This includes different assessment processes during the migration period. We are working actively now with children's groups to ensure that we have the right migration strategy for young people and to finalise it. We will publish that approach.' [Hansard, 17 January 2012]

Transition to adult life and services is not only a challenge for young people. It is also a major challenge for carers, many of whom will lose services such as the cluster of holiday and childcare provision around schools; children's short breaks and a range of other support services. We consider that age 16 is too early for an arbitrary switch between one assessment system and another and would prefer a recognition that transition lasts from 16 to 25 (as acknowledged within *Support and Aspiration*, the DFE Green Paper on SEN and Disability). We note that the Work and Pensions Select Committee Inquiry on *Government support towards the additional living costs of working-age disabled people* recommends that the cohort of 16-25 year old young disabled people should be the last rather than the first to be introduced to the new benefit, PIP.

The DFE Green Paper (op cit) suggests that:

'In order to reduce the number of assessments that a family has to undergo, we will use learning from these assessments and plan pathfinders in local areas to explore whether a single assessment process might also be used to support claims for the DLA and PIP.'

The pathfinders which are looking at a single assessment model will not report until 2015. However, the ambition to test out the integration of assessments for disability benefits with their health and social care counterparts could have major implications for all concerned, not least in making better use of existing information and evidence and in avoiding expensive and multiple assessments. As we note above, the transition to adult life will also have major implications for carers as well as young people and we hope that the Government will

implement a robust support structure for the first generation of 16 year olds moving onto PIP upon its introduction in 2013.

We also note that a significant number of young people 16-25 will have greatly increased needs for care and support. Whether they have a degenerative condition (with cumulative support needs) or present increased challenges to family carers as they get taller and heavier, there is likely to be a need for increased care and support. Many family carers point out that the cost of dressing, feeding and caring for young adults is expensive. Young disabled people may need more expensive continence products, replacement clothing more frequently than other young people and need more family assistance in moving around out of the home environment. Hence assessment of the young person's needs (and their aspirations for greater independence) must also reflect the additional pressures and costs on families.

We hope that particular attention will be paid to disabled young people during their transition from DLA to PIP procedures. Young people will naturally aspire to achieving maximum independence and lives like their non-disabled contemporaries. However, they may both over-emphasise and under-emphasise their need for supervision and support. We consider that all young people should have the opportunity to receive independent advice from a relevant voluntary agency or advocacy group; from their school or other educational establishment if appropriate or any other appropriate source.

As noted above, we can see from consultations carried out by the Council for Disabled Children and Every Disabled Child Matters that young people have widely differing views about representation or support in assessment for PIP. In this respect, they are similar to their adult counterparts and their strong views indicate the need to reflect on how best to inform and advice claimants going through the PIP assessment process.

What are our views on the latest draft on Daily Living activities?

We welcome the introduction of three new activities, *Communicating, Engaging socially and Making financial decisions*. All three are relevant to the achievement of maximum independence and the indicators permit a more flexible interpretation of the need for care and support.

We also welcome DWP's intention to develop more relevant descriptors and activities around the needs of people with disabilities or other conditions which necessitate care and support.

We have set out a number of comments below on the proposed ten activities.

Activity 1 – Preparing food and drink

We welcome the recognition of the range of ways in which a meal may be prepared, cooked and eaten. However, we feel that some questions are not addressed. For example, preparation of food does not seem to include the choice, purchase and storage of such food. Reference is made to ensuring that food is within date, but not to the wider health and hygiene issues around its safe preparation and the maintenance of the kitchen within which it is prepared.

No specific reference is made to general health and safety (and hygiene) issues in the kitchen. If an individual can prepare a simple meal with prompting, will that prompting also need to extend to clearing away waste, washing up adequately and putting any unused food back in the fridge? Additionally can the individual plan a week's healthy menus?

The failure to acknowledge the need to be able to plan – not just a healthy menu but the whole process of buying, preparing and cooking sufficient and appropriate food and anticipating problems - is a crucial omission. This process is a complex cognitive process and not only the more mechanical process set out currently in the Activity in question.

We also note that some claimants may be on specific diets (eg salt-free, low fat, etc). In some cases they may have allergies or be gluten intolerant etc. Should there be a question with an appropriate points allocation about '*managing any special dietary needs*'? This issue is not adequately covered under G, which specifically relates to manual dexterity and to safely heating food.

Activity 2 – Taking nutrition

We welcome specific mention of nutrition, which is vital to the well-being of us all. We suggest that this Activity, like Activity 1, should also make reference to the need for a balanced diet and for any special dietary considerations to be taken into account.

We note that Indicator B (the need for the use of an aid or appliance to take nutrition or assistance to cut up food) does not fully encompass the requirement on carers who may need to physically feed a person at each meal. This is more than assistance and is direct support. 2 points seem inadequate for someone with a significant eating problem. We note that the supervision of someone with an eating problem may take some hours within the day, whether or not any special aids or appliances are used.

The same Activity does not adequately reflect the need to ensure that any equipment used is clean and fit for purpose.

In order to maintain appropriate levels of nutrition, many people may need a range of expensive foods and food supplements. We think it would be helpful to ask specifically if the individual concerned is using food supplements or following a special diet. We note that although food supplements may sometimes be prescribed through the NHS and therefore free, the majority of families will be purchasing such food and supplements, often at considerable expense.

Activity 3 – Managing therapy, monitoring a health condition

We consider that B, C and D (*'needs supervision, prompting or assistance to manage medication or monitor a health condition'*) appear to make arbitrary differences between the time presumed to be taken, ie no particular time for B, up to 3.5 hours a week for C and 3.5-7 hours for D (going up to 7-14 hours for E). We do not think that the activities involved can be so conveniently broken down into blocks of time.

We are also unclear who would assess the anticipated time taken on such activities. For example, someone with dementia or a mental health condition might regularly refuse to take prescribed medication and take much more family time to persuade than would be expected. Similarly some medication has to be taken at particular times of the day or at prescribed intervals before or after meals. This may necessitate a family member spending an hour or more on a regular basis throughout the day with an individual to provide support and compliance rather than just handing out the pills or other treatment and leaving.

We are aware that the PIP assessment criteria do not break activities down into day-time or night-time requirements. However, we consider that the need to administer or supervise the taking of medicines *in the night* should be considered. This may have major implications for carers who are obliged to wake regularly and may take longer than daytime medication because the individual concerned may have difficulty in waking or be reluctant to accept medication in the night period.

Although we are raising the issue of *night time* care under Activity 3, we are aware that the extra attention required at night for some people will pose wider and considerable additional strain on family members and carers. Some disabled people or people with long term conditions may require regular turning in the night. Their continence and medication requirements may necessitate frequent attention at night. In some cases there may be sleep problems (for example with an autistic spectrum disorders) where the person needing care and support is often awake during the night, and requires constant supervision to ensure his or her safety and to avoid accidental damage to property.

Although aids and appliances are mentioned at various points in the activities, we are unsure how the provision of telecare or telehealth or other assistive technology would be viewed. We would argue that although it increases independence considerably for many people, the family still have to be 'on call' in case of emergency and may actually undertake higher levels of care than would otherwise be the case.

Activity 4 – Bathing and Grooming

Personal hygiene is vital to everyone's well-being. We welcome this descriptor but feel that it could be expanded. We suggest that dental care should be mentioned as a discrete activity.

We also note that there is no mention of shaving, which will in many cases need more than prompting.

We would additionally welcome a reference to foot care. For many older and disabled people, lack of podiatry is a major cause of mobility problems and sometimes of falls.

We would also like to see a wider reference to personal hygiene. Many carers expend considerable time and energy in not only encouraging their relative to wash, shower and generally behave appropriately. They also ensure that the person concerned puts on clean clothes (which are changed regularly) and is generally encouraged to present a positive image to the world. Personal appearance is an important contributor to self esteem, but its achievement may represent considerable effort on the part of family and others.

We also consider that this Activity should differentiate between bathing, washing and grooming. Some claimants may be able to do one or two but not all three.

Activity 5 – Continence needs and Incontinence

We suggest that Descriptor C (*needs prompting to manage toilet needs*) might be amended or have an additional level to include '*supervision*'.

We also feel that there should be a reference (with relevant points allocation) to the need for incontinence aids such as incontinence pads and additional laundry costs. These are continuing and often considerable expenses and many families find that they need to supplement whatever is provided through the NHS, either because of the quantity or because of the inadequacy of the products provided. Additionally, the majority of people using incontinence pads are likely to have other disabilities or health needs and hence outings may be very

challenging if there are no suitable changing facilities. The impact of such incontinence needs on ordinary family life can be very considerable and would merit a descriptor and a rating of its own. Mobility problems associated with incontinence may in turn impact on family budgets because of the impossibility of using the most economic sources of food in the area.

We also note that continence management may necessitate regular attention throughout the night, whether the individual concerned needs physical assistance or prompting to go to the toilet or when incontinence aids (and sometimes clothing) may need to be changed. Although there is a separate Activity for continence needs, attention to these needs will also be paramount in terms of maintaining good personal hygiene for the person concerned. Such attention at night may additionally pose considerable burdens on carers, whose sleep will be regularly disrupted.

In addition to incontinence pads, incontinence can impose considerable additional costs because of the need for extra sets of clothes, bedding etc. and also because of the increased use (and thence more frequent replacement) of household electrical appliances for washing and drying such items.

Activity 6 – Dressing and Undressing

We welcome the reference to *'appropriately select, put on and take off culturally appropriate clothing'*. However, we are aware that many claimants of DLA (and PIP in the future) will need active support in dressing well. We consider that this descriptor should take account of the time involved in some cases in selecting appropriate clothes.

As PIP is intended to help with daily living expenses, we also feel it would be helpful to make reference to the need to purchase (or have made) special clothing. This could include outdoor clothing appropriate for wheelchair use, clothes which are easy to put on and take off, special shoes etc. The costs of purchasing such clothing can be very expensive and is not necessarily met through the usual cheaper High Street brands. Shoes in particular are very expensive if there is a need to purchase them on an individual basis, but appropriate shoes are equally vital for any degree of independence and also for any disabled person wishing to enter or remain in employment.

We also note that many families have a constant battle to replace clothing, shoes and other tools for daily living which wear out more quickly and need more rapid replacement than would be the case for non-disabled people. We have been told by carers of people with dementia who

regularly tear or damage their clothes and of people with a range of physical impairments who can only wear expensive customised shoes.

As noted in our comments on the Activities above, there may be major additional expenses because of continence problems, the need for additional clothing and bed clothes and in some cases additional supervision if the person sometimes wanders in unsuitable clothes (eg when he or she has dementia and may be unaware of the need for warm outdoor clothes, wearing of shoes etc.) In these cases, considerable additional supervision is needed by a carer.

Activity 7 – Communicating

We welcome the Activity around communication, which seems more appropriate to the current emphasis on self directed care and support than the current criteria under DLA.

We note that 8 points are awarded to claimants who *'need communication support to express or understand complex verbal information.'* The exemplar given is the need for individuals who may need a sign language interpreter. However, a person with a learning disability or early onset dementia may also have great difficulty in understanding complex information without support from another person, usually the family carer, to act as facilitator and enabler. The role of the family carer as a supporter should be acknowledged and we would welcome the acknowledgement that *'communication support'* will not only involve an external professional or enabler. In effect, *communication support* may be a vital component in all aspects of daily life.

Assessors should be aware that many people undergoing an assessment may give more positive answers about capacity than is the reality. For example, someone in the early stages of dementia may assure the assessor that he can communicate well, use e-mail, easily navigate his way round shops, doctors etc. when the reality is totally different. A younger person may similarly exaggerate his or her abilities because of a wish to please and a determination to achieve greater independence. Therefore, the role of family carer, advocate or other representative will be important in interpreting responses in terms of eligibility for PIP.

We do not consider that there should be a category (G) of *'cannot communicate at all'*. All people can communicate in some way (albeit not necessarily verbally). However, they may need family carers or trained facilitators to read and correctly interpret eye movements, the use of electronic aids, facial expressions etc and all these approaches take time. Therefore, there should be a higher score for *'complex communication needs'* but no assumption that the individual cannot communicate at all.

We also consider that this activity could usefully offer more explanation as to what constitutes a ‘*complex*’ or a ‘*basic*’ need. Many claimants will have multiple impairments or health conditions but we are unclear if their inter-relationship will be regarded as ‘*complex*’ or whether there will be a narrower assessment.

Activity 8 – Engaging socially

We welcome the recognition of social engagement as an important part of everybody’s lives and an area of life, which may need support in some cases.

However, we have some concerns about that statement that:

‘Social support means support from a person trained or experienced in assisting people to engage in social situations, who can compensate for limited ability to understand and respond to body language, other social cues and assist social integration.’

We would welcome clarification as to how ‘*trained and experienced*’ will be interpreted. In the majority of cases, the family carer will be the key person in determining how an individual can best be supported to engage socially and in facilitating that social interaction. If care and support are needed in a social situation (and if awarded, PIP may well be used for this purpose), it will usually be the family carer who will identify, train and facilitate the role of external supporter.

We would also welcome clarification of how ‘*overwhelming psychological stresses* will be interpreted. The descriptor states that ‘*there must be evidence of an enduring mental health condition, intellectual impairment or cognitive impairment*’ for a claimant to be awarded 8 points. Whilst the latter descriptors would cover a person with a learning disability, the term ‘*enduring*’ as applied to mental health seems more problematic. Could this apply to fluctuating mental health conditions (which are clinically recognized but may be episodic such as schizophrenia) or to Bi-Polar Disease?

With reference to the descriptors, they make specific reference to mental health, learning disability and cognitive impairment (thereby also including older people with dementia and other age-related problems). However, they do not mention physical or sensory impairment in the context of ‘*overwhelming distress*’. In practice, both groups of people might experience such distress if they were abused, bullied or disregarded (as is frequently the case, with the increase in hate crime against disabled people)

We suggest that it should be made clear either within relevant Activities or within the introduction to the Activities that they relate to all disabilities and impairments. The impact of those disabilities and impairments will of course vary according to the individual concerned.

We would welcome clarification as to what '*evidence*' would be acceptable that '*overwhelming distress*' has or would occur? Would the views of the family be accepted as valid evidence?

We also note that many people needing care and support are potentially very vulnerable. In many cases they may appear confident and socially engaged, but in practice may be susceptible to approaches by strangers or to abuse and mistreatment. Hence social engagement requires active support and may present considerable challenges to families who wish to encourage independence but recognize the importance of appropriate support.

It is also important to acknowledge the impact of particular environments on individuals' abilities to interact socially. For example, a person with a hearing impairment may function reasonably well in some environments but be unable to hear and therefore to respond in environments with low level background noise or in busy shops or streets. He or she will therefore need additional support.

Activity 9 – Making Financial Decisions

We are unclear as to how '*prompting*' in the making of financial decisions would be interpreted. Should this be '*support*' rather than '*prompting*' when referring to complex financial decisions?

Because of the importance of financial decisions in terms not only of payment of bills but of the management of benefits and allowances etc., we suggest that this descriptor might have a higher rating.

We suggest that where an individual has an appointee (eg for DWP allowances or benefits), they should automatically be assigned to a higher rating. We also note that there is no reference throughout the activities to the potential role of the Mental Capacity Act and the possibility that an individual is subject to an Enduring Power of Attorney. If this is the case, there will be substantial additional tasks and supervisory activities for the family carers.

We also note that many family carers have a vital role in the financial well-being of their relatives. The various calculations in household expenditure etc. may take considerable periods of time and we suggest that their contribution should be seen as an '*indicator*' of the level of support required.

We additionally note that some claimants may be reluctant to admit that they are unable to manage their financial affairs. For example, someone with dementia may in the earlier stages

be convinced that he can manage his financial affairs without supervision or support. However, his or her family carer may need to be constantly vigilant, negotiating with Banks, DWP etc to ensure that they are not making serious financial mistakes.

Activity 10 – Planning and following a journey

As elsewhere in the activities, we would welcome clarification as to what is meant by '*enduring mental health conditions.*'

In descriptor B, 4 points are awarded for the need for prompting for all journeys '*to avoid overwhelming psychological distress to the individual*'. We are unclear as to why this qualification should be added. The key should surely be whether the individual needs prompting to plan his or her route, to be aware of how and when to use public transport as appropriate and to be able to safely navigate the journey in question. If that person gets lost, makes a mistake en route, loses his or her money or travel pass, they may indeed feel considerable psychological stress. They may also be at risk. But the purpose of the descriptor should be about the need for a prompt to travel safely.

We also query C (where the individual can only leave the home when accompanied by another person). Somebody, eg with a learning disability, may be able to leave the home independently with prompting to make a tried and tested journey to the day centre. They may be quite unable to travel independently to the GP surgery if they have not 'learnt' and practiced the route.

Similarly, someone with a physical impairment may be able to make a number of journeys on his or her own, where the route is reasonably obstacle free and there is ramped or other accessible entry to the destination. They may be unable to leave the home unaided for other destinations without support. In many cases, the claimant will be able to make some journeys independently, but the need for supervision, prompting of planning will apply to others.

In assessing an individual's ability to move around, it is also important to acknowledge the impact of fluctuating conditions. For example, a person with Parkinson's Disease may be able to walk for 200 meters with an aid on four days out of seven, but may have three 'off days' when he or she cannot move at all, or at best can only move very short distances with support.

We feel that there is some ambiguity in the descriptors. For example, B (*needs prompting for all journeys to avoid overwhelming psychological distress to the individual*) attracts 4 points. However, E(i) (*needs supervision, prompting or a support dog to a familiar destination*) attracts 15 points. The difference between the two sets of points is so wide that it would be helpful to

know what additional criteria the assessor might apply in order to determine what rating to award.

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

We agree in general with the definitions. However, we are not entirely happy with the definition of 'in a timely fashion'. The definition interprets '*in a timely fashion*' as taking less than twice the time it would take for an individual without impairment to complete the task in question. We are not confident that there would always be agreement on what constituted '*twice as long*' and would prefer a broader descriptor, eg *taking longer than usual to complete a task*. Both definitions are open to interpretation and we find it hard to be too specific. We do not consider that it would be problematic to demonstrate that a claimant took longer than usual to dress, wash, and prepare a meal or to make a short journey.

We also suggest that '*reliably*' might usefully be replaced with '*competently*' or, if unchanged, at least have some clarification about competency in any guidance notes.

With regard to the other definitions of:

- *Supervision*
- *Assistance*
- *Prompting*

We do not think that '*supervision*' should necessarily require the constant presence of another person whilst the activity in question was carried out. For example, a carer may be in the same house but move out of the room from time to time to carry out other activities. But he or she is nonetheless making regular checks and is available should there be a problem.

Supervision might entail the presence of a person throughout the selection and preparation of food. On the other hand it could include regular checks on the environment of the home (eg ensuring that there are no obstacles on the floor for a visually impaired person) or checks on someone with dementia to ensure that they did not injure themselves by trying to light the fire; play around with electric points etc. Both activities would be regular and repeated but would not necessitate the same level of attention as the preparation of a meal might do.

'Assistance' would seem to us to be lighter touch supervision, with assistance being required for perhaps one part of a task. We agree with the definition of prompting.

We feel it would be very helpful to expand the range of case studies offered in the consultation document (covering a wider range of ages and disabilities/conditions) to illustrate how the new descriptors might work in practice.

How do the regulations work regarding benefit entitlement?

We find Draft Regulations 1-4 to be clear and self-explanatory. However, we suggest that Regulation 4(l) should include a reference to Regulation 7 as part of the determination of an individual's level of ability, as the face to face assessments referred to in Regulation 7 will contribute to the evidence that will be used in determining such decisions.

What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

The majority of successful claimants for the Personal Independence Payment will be well-known to both health and social services. They will have well documented records of their individual needs (often going back many years). Sharing existing information rather than initiating yet another assessment arrangement seems both fairer and more cost-effective than the proposed system. We note that the majority of other EU countries rely much more on evidence from professionals who know the individual well rather than on assessment systems where the assessor may have limited knowledge of either the individual, the family or of the condition that has triggered the application.

In particular, we emphasise the role of family carers in contributing to any assessment. They will have intimate knowledge of their relative's or friend's needs for care and support and are likely to also have copies of relevant professional reports and assessments.

We are concerned that the proposed reassessment and review system will be cumbersome, expensive and most importantly stressful and not necessarily fair to the individual and family concerned. At present, many disabled people are 'passported' to DLA without a regular review. If the individual has a condition such as Down's Syndrome, Multiple Sclerosis, Cerebral Palsy

etc., then their condition is life-long. Even if some conditions such as Multiple Sclerosis or Mental Health problems can fluctuate in severity, we note that Disability Discrimination legislation includes them in its definition of disability and the need for long-term care and support will remain.

We also note the importance of the current DLA in passporting eligible claimants in many cases to:

- Blue Badge eligibility/Warm Front grants
- Disability Facility Grants
- Universal Credit
- Travel Passes
- [In the case of children] enhanced and more flexible rights to Parental Leave
- Tax credits and enhanced income possibilities.
- Carers' and other assessments for care and support carried out by the Local Authority
- Eligibility for short breaks

The proposed changes to DLA and the introduction of the new Personal Independence Payment will require a proactive communication strategy to ensure that all sections of the community (including the BME communities) have accurate and accessible information about the process.

Disability affects all sections of the community and we hope that the Equalities legislation will ensure that new assessment procedures will be fair and appropriate to meet individual needs.

Equalities legislation now offers carers protection from discrimination by reason of association with a disabled person (as established in the Sharon Coleman Case, 2009). Therefore, we hope that the new proposals will offer an opportunity to formally recognise the expertise and contribution of carers and that their views may be incorporated and respected within any new assessment and review arrangements.

In conclusion

As noted above, we welcome the concept of a Personal Independence Payment which would take forward the principles of personalization and choice and control (and maximize

independence) for people of all ages who need some additional care and support. However, we hope that the positive aspects of DLA are retained and that greater prominence can be given in the new arrangements to the contribution and role of carers. With more people with disabilities or long term conditions living in family and community settings, the Personal Independence Payment will become even more important in ensuring that they and their families can live active lives. Access to an allowance which will give them choice and control over extra support for everyday living will be vital in order to achieve this ambition.

We believe that the DLA has represented value for money. We are confident that it has prevented family breakdown and recourse to residential care and it has certainly enabled many disabled people and their family carers to be active citizens, maintain independence and in many cases to enter and remain in employment. We also believe that the Personal Independence Payment will be vital to the Government's ambitions for a new vision for social care that is based on prevention, earlier intervention and support for individuals and families to remain in their family home and make a positive contribution to their local community.

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