

25% ME Group and Stonebird

Neither Reasonable Nor Fair

Response to Consultation on replacing Disability Living Allowance (DLA) with a Personal Independence Payment (PIP), on behalf of people with Severe ME

This is a response to the consultation on behalf of people who are severely affected by the neurological disorder myalgic encephalomyelitis (M.E.). It is estimated that 1 in 4 people with M.E. are severely affected. This response has been jointly prepared by the 25% ME Group, a UK charity supporting people with severe M.E., and Stonebird, a web resource aimed at sharing some of the experience of living with severe M.E. All of those involved in drafting this response have direct experience of this disabling disorder, either as a patient or as a carer.

What do we mean by 'severely affected'? *Those who are severely affected have severe restrictions in their mobility and ability to carry out essential daily tasks and attend to personal care.*¹ There are profound cognitive problems as well as functional disabilities. At its most extreme, people with ME are totally bedbound, in constant pain, unable to tolerate light or noise, and may even suffer paralysis and require to be tube-fed. So this is a response on behalf of people who have a high level of disability.

We believe that it is completely misguided of this Government to replace DLA with PIP under the premise that it is in the best interests of disabled people and society as a whole. The replacement of DLA with PIP, in our opinion, will result in taking cash from vulnerable people who rely on this money to meet additional costs arising from disability, and as such the introduction of PIP is likely to endanger health and exacerbate disability.

PIP repackages prior proposals to 'reform gateway' to DLA² by presenting these under a new 'brand', with the concurrent introduction of yet further barriers to qualification, and presented in an ideological wrapper of dubious validity. We note with concern that the changes previously announced were aimed at cutting expenditure by reducing the number of successful claimants, with projected savings of £360 million in the fiscal year 2013-14 and a further £1,075 million in 2014-15. The intention was *and remains* to make fewer awards of benefit.

We oppose plans that will see disabled people put through a flawed assessment system introduced in order to achieve deliberate and punitive cuts in expenditure, whilst purporting to be in their best interests. We are not convinced that the PIP reflects a serious attempt to understand people's needs and problems arising from having a disabling disorder.

We note that there is considerable expense associated with implementing these unnecessary reforms. This example of the government's maladaptive thinking on '21st century disability' is a waste of taxpayers money that is highly unlikely to benefit the public purse. Not only will there be a spike in costs associated with implementing a new system, but savings achieved through granting fewer awards of benefit and/or lowering the amounts payable to successful claimants will be offset by the higher costs incurred by carrying out regular assessments and by other public services, including costs uncured in response to deterioration in the health and wellbeing of disabled people through the introduction of these punitive reforms.

The government's case for '*The need to reform Disability Living Allowance*' as presented in Chapter 1 of the Consultation Paper is paper thin at best; similarly the arguments that are presented in favour of the PIP proposals in subsequent chapters. Our response incorporates a critique of some of material.

We have reservations regarding the capacity of these Consultation Questions to fairly and thoroughly assess views on the PIP system.

- Some of the Consultation Questions do not relate well to the government's plans as set out in the relevant section of the Consultation Paper – so that a person reading the Question in isolation may well fail to appreciate the nature of the change that they are being asked about. Relatedly, some are ambiguous. Some have covert implications and could even lead people to unwittingly argue for the opposite of what they wish to see.
- Some significant changes are not addressed in the Consultation Questions – perhaps because this consultation is not framed at considering the wisdom of replacing DLA with PIP, but rather at informing '*secondary legislation on the detailed design, including*

¹ Scottish Good Practice Statement on ME-CFS, The Scottish Government, Edinburgh 2010; available at <http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners>

² June 2010 Emergency Budget.

the new assessment process'. We note with concern that the government has already set up a *'group of independent specialists in health, social care and disability'* and has consulted with this group prior to the present phase, meaning that primary legislation has been drafted on the basis of a closed consultation. We deplore the lack of a public consultation on the fundamentals of this change.

Notwithstanding that the present consultation is pitched at the details of implementing replacement rather than the fundamental question of whether or not to replace DLA with PIP in the first place, we *strongly* request that DLA be left in place. DLA in essence is currently meeting the needs of people with ill health and disability. Some aspects of DLA would bear modification, and many people with M.E. – including people who are severely affected - have reported difficulties in accessing benefits to which they are entitled, including DLA. However, there is no compelling case to introduce a completely new system.

As matters stand, neither the consultation process nor the present consultation document represent a reasonable or fair basis upon to which to be making decisions that will have far reaching consequences for people whose lives are adversely impacted by ill health and disability.

Critique of Approach to Reform

This Consultation Question is prefaced by several paragraphs headed ***'Our Approach to Reform'***. We preface our responses to the Consultation Questions by presenting a critique of the stated approach. This is not only relevant to Question 1, but underpins many of the other Consultation Questions and this critique lies at the heart of many of the responses we have provided.

If PIP is intended to *'contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives'* what assistance is to be provided if it is simply not possible for the relevant barriers to be overcome? Against this yardstick, will the most debilitated people qualify for PIP?

- It is profoundly unhelpful to fail to acknowledge that people who are very ill and very disabled simply cannot live full and active lives in the normal sense. How do you define what is a full and active life in a meaningful way without considering the context of a persons disability including, where this is relevant, the impact of severe illness? You must surely clarify what you mean by 'full', 'active' and 'independent' lives and accommodate the situation of those people who need facilitation within this context.

Any move towards *'a benefit that helps contribute to the extra costs of living independently'* must take into account the needs of people who simply cannot live physically independently and require assistance to meet basic needs.

- The concept of 'independence' is highly subjective. Independence to someone with Severe ME may be perceived as a tiny irrelevant life, compared to the normal way of interpreting independence.
- When the consultation paper speaks of 'independence' what does it mean? Physical independence? Emotional independence? Mental independence? Does 'independence' encompass personhood? Or is it simply intended to imply independence in the sense of living in the normal world doing ordinary practical everyday things?
- Attaining independence, as an attitude of mind, takes into account the facilitative role of the carer so that an individual who is bed-bound can still have a presence in the world through the hands and feet, ears and eyes, limbs of the carer. The achievement of independence must include this interpretation to be balanced and relevant to all.

The PIP appears focussed on the situation of people who are disabled but otherwise in good health. The consultation document does not address the situation of a sick person.

- Living with a severe long term illness brings very significant related costs arising from ongoing care and support needs. For those who are tormented by symptoms that are very difficult to bear in themselves and that interfere with everyday functioning - as in Severe ME - any fair system must include the impact of this as a relevant issue in determining financial aid.
- It is not appropriate that the benefit will continue to take account of the social model of disability' while completely ignoring the concurrent and very real and relevant implications of the medical model of disability. If the social model is skewed to only look at ability and independence, then it leads to a completely wrong interpretation of the social model. The social model was never intended to negate the very real impact of disease. These models are complimentary and not mutually exclusive in their explanatory insights. The total reliance on the social model in framing government policy represents a facile misinterpretation and is patently unrealistic.

- It is not legitimate to separate the symptoms and reality of illness from a person and deny their impact. For example, even if suitable physical access arrangements are made this does not yield inclusion, capability, independence and the same freedom to live in the world that a normal able healthy person enjoys.

We are extremely sceptical at the assertion that awards of PIP will be based on '*fairer, objective assessment*'. We can see no evidence to support this. And, while the objective of fair assessment is one that all would share, it is doubtful that these matters can ever be decided on a *purely* 'objective' basis. What, specifically, is implied by 'objective' in this context?

We welcome some of the aims of the PIP, such as basing qualification on need not income. However, both this and most of the other aspects outlined here [Para 5] already apply to DLA. Only one objective is clearly new: '*taking account of the support that disabled people can access to help them live independently*'. We are concerned as to what this might imply.

- Is it possible that, as well as ruling out help for people who experience insurmountable barriers to living independently, PIP will also rule out assistance for people who are able, with support, to minimise or decrease the very real barriers and have already made arrangements to do so - for example, through access to aids and equipment?

Assessment Process

No evidence is presented to back the argument that the existing DLA process "*is based on unclear criteria and often does not make the best use of available evidence.*" Nor that "*As a result, awards can be subjective, inconsistent and do not always focus support on those who need it most.*" In so far as this is the case - and DLA decision making *has* been subject to criticism in terms of failure to grant due awards³ - it is by no means clear the abolition of DLA and replacement with PIP will help surmount such problems. Quite the opposite. And, while there are aspects of the DLA application form that are problematic there has been no serious attempt to address the difficulties when raised with the DWP over the years.

Against this background, it is remarkable to see the DLA application process being slated in order to provide a platform from which to present the 'need' for the changes that the government want to see. We have expressed concerns (see above) about the capacity of PIP assessment to meet the stated aims of being '*fairer*' and '*objective*'. To summarise:

- We do not believe that it is possible to be completely 'objective' in assessing disability.
- We have serious concerns as to how moves towards 'objectivity' will translate in practice for claimants with Severe ME, as the NHS carries out no specialist biomedical testing, hence there is no 'objective' record of biomarkers. It is worth emphasising that over 5,000 published research studies, going back to 1934, have demonstrated a range of biomedical abnormalities in a proportion of the patients studied.⁴
- As a result of the NHS failure to conduct appropriate specialist testing, all too often the only evidence about how this illness is impacting on ability comes from the patients themselves. Indications are that such accounts hold little weight with assessors, and that this is already a considerable difficulty experienced by people with severe ME in accessing Disability Living Allowance. These PIP changes could well mean that successfully claiming benefit will become even more difficult for people with severe ME.
- A lot of the disabling symptoms of ME - *e.g.* noise sensitivity, chemical sensitivity - are not necessarily visible and cannot be objectively measured, even in a snap-shot way.

Similarly, the PIP system might transpire to be '*easier to understand*' - but that doesn't necessarily mean that it will be fair and rational.

Likewise '*transparent*': one may be given a clear explanation of why one has or has not qualified, without the criteria employed to reach the decision having been appropriate and fair.

³ For example, the Select Committee on Public Accounts Twelfth Report, HMSO, 2004 evaluated statistics on decision making and appeals (presented in a prior report by the Comptroller and Auditor General "*Getting it right, putting it right: Improving decision making and appeals in social security benefits*"), the poorest performance having been found to occur in benefits requiring the examination of medical evidence, such as DLA. The Select Committee concluded that "*Too few decisions are right first time*".

⁴ See letter to Sir Michael Rawlins from Malcolm Hooper: <http://www.meactionuk.org.uk/Hooper-signed-letter-to-Rawlins.htm>

Critique of Case for Change and PIP Approach

This question is prefaced by a short presentation of the government's case for abandoning the DLA system. This rests on a mixture of patently spurious and more opaque reasoning, including:

- *'The definitions currently used are subjective....'* What are these 'subjective' definitions? In what sense are they 'subjective'? In so far as they are 'subjective', is this a flaw that could and should be remedied, or an intrinsic reflection of the enormous variety of ways in which different disabling disorders impact on different people's lives?
- *'...and reflect views of disability from the 1990s, not the modern day.'* The notion that the case for change is manifestly apparent through a clear distinction between 'the 1990s' and 'the modern day' is risible.
- It is asserted that 'care' and 'mobility' *"do not necessarily remain the best proxies for cost."* This is a fundamental issue in the present context, and some specifics of the *'conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st century'* and implications of same require to be indicated. On what points does the evidence differ? Also, we note that one of the DWP working papers to which this statement is referenced relates to *international* evidence on the cost of disability, and suggest that it is specifically the extra cost of disability experienced by people living in the UK that is pertinent to shaping the UK benefits system.

Also problematic is the case repeated mantra of focussing *'on those who face the greatest challenges to leading an active and independent life' / 'individuals whose impairments have the most impact on their lives'* - and similar, throughout the Consultation Paper.

- What does this imply? The present system operates on the basis that varying levels of DLA award are appropriate, with higher payments awarded to people with greater care and mobility needs. In Chapter 1 of the consultation paper this very feature of DLA is acknowledged - and used as 'evidence' of the need for change on the basis that DLA *'is too complex'*.
- Against this background, we envisage that concurrent moves towards 'simplification' and 'focus on individuals whose impairments have most impact' implies the removal of benefit from people whose disabilities, while not the greatest, nonetheless bring additional support needs and barriers and have a very real impact on cost of living.

1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

People with Severe ME: Problems and Barriers

A major barrier that people with severe M.E. face to leading independent, full, and active lives is having an illness with symptoms that severely limit their capacities. These symptoms are exacerbated by activity, rendering this barrier particularly thorny. We also face barriers of prejudice, barriers deliberately created by endorsing a deeply flawed psychosocial model of causation, barriers resulting from the associated pursuit of totally inappropriate and counter productive service models, and the barrier of denial of how severely physically ill we are. Also, as with many other disabling illnesses, the physical environment is hostile to our needs, due to a profound hypersensitivity to all stimuli that has massively debilitating consequences. People with Severe ME experience multiple disabilities within the environment that may appear initially invisible such as multiple chemical sensitivity and acute noise sensitivity.

The mindset that any and all barriers can necessarily be overcome and that disability benefits should be solely geared towards this purpose is potentially toxic for very sick and debilitated people, and quite simply wrong. With severe M.E. it is impossible to live a full and active life. The intensity and complexity of symptoms, including acute hypersensitivity to all forms of environmental stimuli, makes physical independence - in the sense of living freely in the world - almost impossible.

It has been officially recognised that there is no known cure for M.E.⁵ At the same time, approaches to activity intervention that have been trialled for 'fatigue' are being misapplied, much to the detriment of people with M.E. For example, in a survey of 25% ME Group members⁶ the vast majority of those who had undergone graded exercise - 82% - reported that it had made them worse. Furthermore *some patients were not severely affected before trying 'Graded Exercise Therapy*. So an intervention that is commonly considered - both in the NHS and on the part of DWP assessors - to be helpful to overcome the barrier of disability for people with M.E. is in fact greatly exacerbating the problem.

⁵ *No management approach to CFS/ME has been found universally beneficial, and none can be considered a "cure"*. Department of Health (2002): Report of the CFS/ME working Group: Report to the Chief Medical Officer of an Independent Working Group, London, The Stationery Office; section 4.1.2; page 34.

⁶ *Severely Affected ME (Myalgic Encephalomyelitis) analysis report on questionnaire; 25% ME Group 1st March 2004*. See page 8.

2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?

We agree with the aspects that will remain unchanged under PIP, as set out in paras 8-11 of Chapter 2. It is particularly welcome that '*The new benefit will not be means tested or taxable, and payment will not depend on having paid National Insurance contributions*'.

However, we argue that few if any of the changes that the move to PIP *does* entail are necessary or even desirable. We address the case for and against specific changes throughout this response, alongside the relevant Consultation Questions. Some key points include:

- It is essential that people are able to continue to provide evidence from their own GPs or other medical professionals, and - crucially - from carers. This is particularly important for people with severe M.E. in view of their cognitive disabilities and profound physical difficulties, and the consideration that there is a strong possibility that a person with severe M.E. will deteriorate as a result of the effort required to participate in face-to-face assessments.
- Where there is no cure or treatment that substantially ameliorates the person's disorder and a poor prognosis, then DLA awards for life should have been granted and such awards should be maintained under the new system. The person should automatically be awarded PIP without having to go through more interrogation, forms and exhausting procedures and having to prove their disability yet again, when they have already proved it to the satisfaction of the DWP for DLA.
- People who have already been awarded DLA should not lose out financially by the transition to a new allowance at a lower rate of benefit, or none at all.

There are also some important issues relating to entitlement that appear to have been decided already. Some other matters that will have far reaching impact on disabled people's lives are still under consideration but not through the Public Consultation. These include:

Longer Qualifying Period and 'Prospective Test'

It is planned to increase the present three month qualifying period to six months and introduce a new prognosis requirement. These are problematic for people with M.E. because of poor cognisance of likely duration (long) and prognosis (poor), alongside difficulty in providing a case specific *definitive* prognosis in respect of an individual person with M.E.

DWP medical examiners should be made aware that ME is included in the NHS National Service Framework (DH 2004⁷) as a long-term neurological condition, "*Substantial improvement in ME is uncommon and is less than 6%*" (Anderson et al. 2004⁸); and, "*Full recovery... is rare*" (Cairns & Hotopf, 2005⁹) anyone severely affected for more than 5 years has a poor prognosis of recovery (DH 2002¹⁰)

- Six months is a terribly long time to live with a disabling disorder and no financial support to help with what may be very significant costs arising as a result, costs which are often accompanied by reduced income.
- The concurrent introduction of a 'Prospective Test' in the form of a requirement that a person be expected to continue to satisfy the entitlement conditions for at least a further six months means that those who are impacted by disability for anything up to a year will not be granted any financial assistance to help with the additional costs. This is unacceptable.
- It is likely that these changes will impact adversely on people with Severe ME, not because it isn't a long term disorder - many patients experience decades of ill health and related high levels of disability¹¹ - but because this possibility isn't necessarily officially recognised.

⁷ Department of Health (2004) Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) exemplar. National service framework for children, young people and maternity services http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4098119

⁸ Andersen MM et al. *Illness and disability in Danish CFS patients at diagnosis and 5-year follow-up.* J Psychosomatic Research 2004; 56: 217-229.

⁹ Cairns, R. and Hotopf, M. (2005) *Prognosis of chronic fatigue syndrome: a systematic review.* Occupational Medicine 2005 55 20-31

¹⁰ Department of Health (2002), *A Report of the CFS/ME Working Group. Report to the Chief Medical Officer of an Independent Working Group*, London, The Stationary Office

¹¹ A survey of people with Severe ME (25% ME Group members) found that 85/99 respondents had been ill for 10 years or more, including 29/99 who had been ill for 20+ years. 38/98 respondents indicated that they were bedbound for most or all of the time. (25% ME Group Adult Social Services Survey, analysis report available to download at: www.25megroup.org).

Substantive Changes to the Components

The mobility component is to be reframed in terms of '*ability to get around*'; and a second component will cease to relate directly to 'care' but instead will concern '*ability to carry out key activities necessary to be able to participate in daily life*' and is to be known as '*the daily living component*'. It is notable that the public consultation paper does not seek views on this change. This is but one example of a very fundamental change that is not the subject of a Consultation Question. – it would appear to be a *fait accompli* without any form of public consultation.

We are very concerned about this government's focus upon what people can do, rather than what they can't, and the associated focus on the social model and exclusion of any consideration of medical model of disability.

3. What are the main extra costs that disabled people face?

Extra costs faced by people with Severe ME: some examples

Diet. In Severe ME there are often complex dietary needs due to ongoing gastric issues. Special dietary needs can include, for example, a requirement for gluten-free food, dairy-free food, and/or organic food.

Nutritional Medicine Supplements. For the most part the NHS will not pay for nutritional medicine supplements. These can help greatly in addressing problems relating to mitochondrial and other basic body functions. For a person with severe ME these are often taken at higher than average dosages (or recommended daily amounts) because a therapeutic dosage is required. Such preparations tend to be expensive and specialized and cannot just be brought cheaply across the counter. For many people with severe ME they are a huge and regular expense.

Household. Many people with severe ME experience allergies and chemical sensitivities, necessitating the purchase of specialised cleaning products, washing powders, soaps *etc.* Every single chemical can have a devastating impact in Severe ME, such that people have to source very expensive, very pure organic products. Specialist furniture, chemical free paints and decorating materials may also be needed.

Personal Hygiene Products. In severe ME there is acute hypersensitivity of the nervous system, commonly with associated multiple chemical sensitivity. This means that things like toilet rolls, tampons, cotton wool pads, need to be bleach free and organic. This is another high, regular cost.

Clothing and other Textiles. Due to hypersensitivity/allergy and resulting skin rashes, expensive organic clothing or particularly expensive makes of clothing and types of cloth may be all that is tolerated by people with Severe ME. This is also the case with bed linen and towels. Cheap everyday alternatives are not a viable option for people so affected. Duvets, pillows, and seating may need extra padding, extra soft textures and organic quality (due to chemical sensitivity) which all mean extra costs, costs that are necessary for the person to try to achieve a tolerable level of physical comfort.

Utility Costs. Heating bills may be higher because it's important to maintain a warm environment. Frequent baths are often needed to cope with the pain. The amount of cooking from scratch required to create special diets significantly increases fuel costs. Experiencing frequent profuse sweats means that clothes and bedlinen need washing more often. Some people with severe ME have incontinence, increasing washing needs and adding to higher electricity, gas and water bills. Severe ME can be very socially isolating and many people find that access to social contacts via e-mail and other on-line opportunities is a welcome lifeline. Computing costs to try and maintain access to the outside world are an ongoing expense.

Aids, Equipment, and Adaptations. Purchasing and maintaining aids and other equipment is an ongoing cost. The person's home may require to be adapted.

Domiciliary Services People may need to pay for providers of services such as hairdressing, chiropody, osteopathy to come to the home, which incurs extra costs. They may require to employ a gardener.

Carers There are direct and indirect costs of employing carers or having the help of family, friends, and neighbours.

4. The new benefit will have two rates for each component:

- **Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?**
- **What, if any, disadvantages or problems could having two rates per component cause?**

It is proposed that two rates of benefit will be payable in respect of each of two PIP component. Apparently *'this will simplify the overall structure, making it easier to understand, and reflect the range of individual needs'*.

Easier to Understand and Administer?

We do not agree that there is an issue of complexity that requires to be addressed as a result of having three levels in respect of DLA 'care' component and two for 'mobility'. Yes indeed, by the laws of arithmetic, that gives rise to 11 possible combinations of award. This is utterly irrelevant to complexity for claimants though – it isn't as though claimants are expected to perform this calculation. Each recipient will receive one of these combinations and one only, intended to reflect their level of need. This is so not rocket science and scarcely 'complex' nor in any way difficult to understand.

Neither would we have thought that having three rates for care component represents an onerous burden to administer. Nor that moving reducing this to two rates will provide greatly enhanced ease of administration.

Ensuring Appropriate Levels of Support?

We are extremely sceptical that the change to a two rate structure for one of the components will be competent in *'ensuring appropriate levels of support'*. On the contrary, there will be less flexibility to appropriately reflect the varying degrees and impacts of long term impairments and resulting extra costs, and almost certainly an associated loss of income for many claimant (this emerges from subsequent sections of the consultation paper).

Disadvantages and Problems

We note that the consultation paper gives no indication as to how PIP rates will compare to the present levels of DLA payments. We are of the view that there should be the equivalent rates of payment as there are now – or better - and also that no one should lose out because the number of rates at which benefit can be awarded have reduced.

There will be loss of much needed and highly valued income to sick and disabled people if the new PIP system results in a poorer level of payment than the same person would have received or had been receiving through DLA. There is a lack of detail in the public consultation paper as to how the qualifying thresholds in terms of degree of impairment and need will differ. However, we note with concern that *"It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support..."*

5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

The proposal is to end automatic entitlements to all but people who are terminally ill.

The case *for* change as presented in the consultation paper – that *'This will deliver a more personalised service that ensures resources are targeted where they are most needed'* – is highly contentious.

No attempt is made to identify factors mitigating *against* this change - notably, the potential for adverse impact on health of going through the mechanics of the assessment process itself, and the associated stress; and the cost to the public purse of assessing people who would previously have been automatically entitled.

In our view this Consultation Question implies a false dichotomy. Automatic entitlement presently applies only to certain severe disorders, such that a person with the relevant disorder can reasonably be expected to qualify for the relevant component at the rate specified *in view of need and regardless of any variation in personal circumstances*.

Not only is the list of conditions / impairments to which automatic entitlement applies extremely short, but *no* disorder confers automatic entitlement to an award of both care and mobility components of DLA. So it is highly misleading to imply that automatic entitlements are a major feature of DLA. We find this aspect of the consultation paper particularly galling, as the reaction to well nigh any and all attempts by people with M.E. to have the DWP address difficulties that people with M.E. experience in claiming DLA has been to ignore the specific points raised and simply reply that entitlement is *not* based on suffering a particular disorder, but on how the disorder affects the person.¹²

We would like to see the range of automatic entitlements increased rather than reduced. We would also like to see a 'semi-automatic' entitlement for people who are severely ill and disabled. In such cases, completing the forms and having supporting reports from people such as the persons doctors and carers should be sufficient. Severely ill and disabled people should not have to worry about having to undergo assessment procedures which can be very taxing for them to the detriment of their health. This would apply to people with Severe ME. (More on this at Questions 9 and 12.)

¹² There have been *many* such attempts and associated responses over the years. For example: *"Entitlement to Disability Living Allowance and Attendance Allowance depends on the effects that severe disability has on a person's life and not on a particular disability or diagnosis."* Letter from Anne McGuire MP, then Minister for Disabled People at the Department of Work and Pensions, to Tom Harris MP, 24th June 2007, ref: POS(6)10137/44. Mr Harris had written to the DWP after concerns were raised with him by a constituent with M.E.

6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

Prioritising support 'to those people less able to live full and active lives'

Those who are most ill and most disabled should be a huge priority, in order to ensure the least stress on their life and the maximising of opportunity to manage even the simplest of things. The appropriate way to prioritise support to those people who are least able to live full and active lives is to accord them the highest rate of the relevant benefit. It is *not* to remove or reduce benefit that is already paid to people who have a lower level of need, who likewise require assistance to meet the additional costs resulting from having a disabling disorder, albeit that the additional costs are likely to be lower than for a severely disabled person.

That, however, is *exactly* what is envisaged:

"It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support, but this has been justified by the policy aim to focus support on those with greatest needs." (Overview of Potential Equality Impacts, p28)

The 'justification' presented here is no justification at all. Not only is there is no suggestion that people who have highest needs will actually be better off under PIP than DLA but, even if this were the case, such a policy aim would not 'justify' removing assistance from others. It would appear that many will be denied the benefit of financial assistance by implication that their need is not great enough, whilst the current system acknowledges that it is. This is both illogical and damaging to people's lives.

At the same time, the perspective that steps to be introduced PIP – or any other system of changes, for that matter – "*should ensure that priority is given to those individuals who need to overcome the greatest barriers to living full and active lives*" fails to recognise that people who are very ill and very disabled *cannot* live full and active lives in the normal sense of these words.

Activities that will be Assessed

As with 'prioritising support' there would appear to be a loaded aspect to this question. Of course activities that are 'most essential' for daily life have to be taken into account. But this is *not* to say that *only* the most essential activities should have a bearing in determining eligibility for PIP.

There is a real difficulty if the PIP assessment is to look in a rigid and blinkered fashion at the capacity to conduct only certain pre-determined activities "*for example, planning and making a journey, and understanding and communicating with others*". There really is no getting away from the need for a rounded appraisal of the disabling impact of the person's impairment and their related support needs. This will inevitably involve qualitative judgements. As, indeed, will any system of assessment. On the basis of the DWP's track record in approaches to assessment, we suspect that the government is veering away from taking this on board by importing the spurious notion of 'objectivity' – which will take the form of a tightly delineated and mechanistic attempt at fitting the reality of disabled people's lives into some form of predetermined template. This should not be confused with 'objectivity'. It is a rigid and fundamentally unsatisfactory approach, quite unfit for purpose in the present context.

We note also that this question is framed in terms of activities rather than needs. People who are very sick and disabled often simply cannot undertake activities that are necessary to meet basic needs. Due cognisance requires to be taken of this in framing disability benefits legislation.

7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

Disability is unpredictable and every day is a day that a disabled person can be, is, or will be disabled. The potential for disability is ever-present, even if it is not manifesting in its fullest form. The assessment should not be a 'snapshot' of a single point in time. People with fluctuating conditions must be treated as if it is constant in terms of assessing them because to do otherwise is to deny the reality of the disabled person's life. People will go neglected unless they are respected fully. You are in effect disabled all the time, for the purpose of assessment.

Even at best, with a fluctuating condition, the person may still be very disabled. Due cognisance must be taken of this. A relative remission with less intensity of symptoms should not be treated as temporary recovery. Nor should such a remission be considered permanent.

The assessment of people with complex chronic fluctuating conditions requires sensitive engagement from a knowledgeable expert. There should always be scope to consider medical testimony from a physician who is acquainted with the person's case, where available. However, it is often the case with fluctuating or variable conditions that claimants' own testimony and/or the testimony of any family carers is the only 'proof' of impact of the disorder on health and functioning. Suitable steps should be taken so that this can be duly considered and does not count against them in assessment.

In addressing this question the PIP team could and should learn from the shortcomings of the WCA assessment, as evidenced to the Harrington review. WCA assessment looks at specific, clearly defined tasks, and considers single actions taken in isolation. This static 'functional' assessment fails claimants. It is irrelevant to the ostensible objective (deciding on capacity to enter and sustain employment). The prior existence of this terribly flawed and unfair but perhaps ostensibly 'objective' system has worrying implications given the stated intention to strive for 'objectivity' in the PIP assessment process. A valid assessment process cannot and should not just look at what a person might be able to achieve without considering the context and the regularity of that ability.

People with Severe M.E.

Myalgic encephalomyelitis is characteristically a long term disease with fluctuating symptoms and a relapsing / *relatively* remitting course. However, many experience a consistent and unremitting severity of symptoms, and sadly this tends to be the case for those who are most severely affected. As testimony from person with severe M.E. illustrates:

The only 'remission' in Severe ME is from being tormented to being less tormented, from being profoundly ill to extremely ill. There are so many symptoms all the time. The Severely Affected person is never going to feel 'well'. The only difference in experiencing Severe ME is maybe a slight variation in symptoms. How do you describe being in agony and then feeling worse and then returning to being in agony. This is the level on which symptoms may vary.

With M.E. there is an exacerbation on activity and this is highly relevant to assessing capacity to engage with activities of daily living. Due cognisance must be taken of the impact of planning and carrying out basic activities, and consequences in the form of debilitating symptom flare ups. Lack of stamina is a hallmark of this disorder: the cumulative effect of repeated activity and combinations of activity must be duly considered. The impact of adverse after effects is characteristically delayed and prolonged.

It should also be noted that many people with ME, and particularly people who are severely affected, find that undergoing the existing process of assessment for benefits is beyond their capacity, as evidenced by adverse after effects that can be both prolonged and severe.¹³ It is particularly important that sick people are able to reply upon the system to respect their vulnerable health and any negative impact that a particular form of assessment process might have upon it.

¹³ In a related context – the community care assessment – a survey of people with severe ME found that:

- Only a few of those who had been present while being assessed felt that they had been well enough to cope *during* the assessment [12/66 patients; 18%].
- Responses indicate that *all* of those who had participated in the assessment had been exhausted *afterwards*.
- Very few recovered from the adverse impact of participating in the assessment in a day or two. The vast majority had taken 3 days or longer to recover from the adverse impact of the assessment process, with around a quarter taking over a month.
- Several had been too ill to be involved in the assessment any way, and had been represented by family or an advocate.

SOURCE: 25% ME Group Adult Social Services Survey Report, available to download from the Group's website at www.25megroup.org

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

- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?**

Even in the present climate the government's views on this issue are quite stunning. In a smoke and mirrors attempt to negate the duty to assist with the very considerable extra costs encountered by disabled people in meeting their care and mobility needs *"We believe we should take greater account of the successful use of aids and adaptations as part of the Personal Independence Payment assessment..."* For example, where the mobility test used to be based on ability to walk, the mobility test will now be based on being able to get around – *"This might mean, for example, considering an individual's ability to get about in a wheelchair, rather than ignoring the wheelchair, as we do currently."*

The question as to whether not it is legal to change the focus from disability to ability, thus potentially excluding people already being provided for, must be considered. Does this approach infringe human rights or other legislation? Even if legal - is it moral?

The flawed notion of independence as having aids and therefore not being disabled is a nonsense and a shocking and shameful assault on the rights of disabled people. The fact that you need an aid should count *in favour* of qualification for assistance with disability costs – not against. At the same time, a person may not be awarded the PIP allowance because there might be some aid that might make a difference that they haven't yet got. This is breathtaking.

- Aids and adaptations cost, and it is only fair that disabled people be provided with some assistance towards these extra costs. This aspect of PIP appears to involve a move away from the fundamental premise of the DLA system – to provide additional support funds to help people who face additional costs of living due to having a disability – and would be extremely unfair.
- In any case, no aid makes life as easy to live as easy a fully physically or mentally functioning person. People with Very Severe Myalgic Encephalomyelitis (ME) are severely limited in their ability to participate in the world, despite aids and equipment, because of their severe neurological disease, the symptoms of which are a daily torment.
- People who need aids and equipment to function should receive PIP because no aid is a replacement for physical ability and no ability using an aid is equivalent to physical ability. Even at best aids are not totally adequate, and even if you have them it doesn't necessarily mean you well enough to use them.

While the observation that *"some aids and adaptations are provided by government while others might be paid for* out of an individual's DLA itself"* is valid, we note with concern that the DWP are *"considering the best way to prioritise support in this situation"*. Any attempt to withhold or claw back benefits payments to take account of, say, NHS wheelchair provision would take mean spiritedness on the part of the DWP – already a brand leader in the mean spirited stakes - to new heights. Aids can always go wrong, wear out, break. And the standard of equipment provided from public funds may fall short of what is best for the disabled person. This is particularly so of wheelchair provision.

* more correctly, others *are* paid for in this way

It would appear that PIP holds the potential to effectively negate recognition of needs across vast swathes of the disabled population: those who are achieving 'independence' through arrangements to access suitable assistance will not be entitled, those who may possibly achieve 'independence' through arrangements to access suitable assistance will not be entitled and – as highlighted in previous Consultation Question responses - those who cannot achieve 'independence' will not be entitled.

SO– no; none; and neither

9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:

- **How could we make the claim form easier to fill in?**
- **How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?**

This question is placed in connection with a paragraph on 'Gathering evidence'. And, as with many of the consultation questions, it neatly side steps some of the very salient issues that require consideration under the relevant heading. In this context, for example, we welcome the recognition that "*Disabled people are experts in their own lives*" but to simply continue "*and information they provide will continue to be vital*" is a facile misrepresentation of the way the system currently operates, in that claimants' accounts are routinely disbelieved and disrespected.

A major way in which the experience of claiming benefits could be improved is to cease to harass people regularly through constantly recurring assessment while disbelieving them on each occasion when they state the truth of their illness.

The Claim Form

There is a degree to which length and detail are required in order to sensitively capture the person's experience of disability and related support needs. We are conscious that difficulties to the claimant arising from length and detail have to be weighed against the need for sufficient appropriate information on which to base a decision. We are concerned that steps to make the form easier to fill in, combined with focus on "*best and most appropriate evidence... essential to ensuring that the Personal Independence Payment assessment is objective*" will mean a stripped down assessment process with even more riding on the availability – or otherwise – of patent evidence of impairment from an 'independent' source.

There are sound reasons why "*the claim form for DLA ... can require them [i.e. disabled people] to talk about their disability in a negative way, focusing on what they cannot do rather than what they can do.*" Disability is just that – a lack of ability– and the extra costs of living that disabilities bring is the bedrock of rationale for payment under the DLA system. If the PIP application form is to move away from this, towards recording abilities, this will *not* provide a more 'positive' experience of claiming for the claimant, but *will* provide a platform for disallowing payment on the grounds that the person has apparent capacity. It is very concerning to have to participate in a simplistic system that negates your reality, which PIP is likely to do, especially if it is linked to some computer model.

There are many specific ways in which the existing DLA claim form could be modified to facilitate recording of the impact of impairments and assistance required. A number of organisations representing people with M.E. have repeatedly made representations to the DWP on this subject¹⁴. We would be pleased to work with the DWP on reviewing the DLA application form to help resolve specific problems in relation to facilitating people with Severe ME to clearly express their care and mobility needs and restrictions, without compromising their health in the process.

Improving Information

As well as clear information about the purpose of benefit and qualifying criteria, urgent steps are required to improve the reach of such information. We are strongly of the view that the 'joined up thinking' that is much in evidence in terms of vesting responsibility for engagement with 'back to work' programmes beyond DWP and into the NHS and local authority services, is just as sadly lacking when it comes to spreading the word about the existence of disability benefits and how to access them. Immediate and comprehensive steps should be taken to remedy this.

Claiming Disability Benefits with M.E. - problems requiring to be addressed

Consistent testimony from claimants with Severe ME clearly demonstrates that they find that the process of claiming benefits to which they are entitled is an overwhelmingly stressful and unpleasant process, and furthermore potentially dangerous as it can markedly exacerbate symptoms and push the person into an even greater severity of illness.

As a very severely affected person explains:

Filling in the forms and having doctors /carers etc supporting reports should be enough for the genuinely sick and very disabled person with Severe ME. I have

¹⁴ To which we have consistently received the stock response that qualification for DLA depends on how an impairment impacts and is not automatic on the basis of having said impairment, a response that is irrelevant to the concerns raised

had to go through reapplications every 2 or 3 years for many years and been told at the Benefit Integrity Project that I was lying and generally felt harassed for years and it contributed to extreme deterioration of my health that I consider unacceptable. The DWP and associated privately contracted companies do not have unbiased properly aware officials and people with ME are always at risk more than other groups of being wrongly dismissed as having a psychosocial - or simply needing less help than they say so I don't feel it is safe for people who are dreadfully ill to have to be exposed to this. I believe having an incurable very severe disease with severe disability and torment I should have had the respect of a permanent award when first ill and would wish this for others like me because in 17 years all I have done is deteriorate and been afraid for many of them, as with ME you are so at risk of deterioration if exposed to these people and their tests and disbelief and intention to take money away from you. They are not humane! I also know people who have been wrongly assessed and awarded generally less than they should be entitled to and others who are just too ill to apply even though they need it. Automatic in these cases is the only way to show us respect and understanding.

All too often the only evidence about how this illness is impacting on ability comes from the patients themselves, or from the patient and their family carer. Indications are that such accounts hold little weight with assessors, and that this is already a considerable difficulty experienced by people with Severe ME in accessing Disability Living Allowance. Claimants' accounts are routinely disbelieved and disrespected. It would be hard to overstate the very damaging impact of this on a sick and vulnerable person in terms of sheer misery, dismay, and humiliation - a situation that requires to be rectified as a matter of urgency.

Difficulties attaining due entitlement under the existing system are attested to by the findings of 25% ME Group membership surveys. A survey canvass in 2004 found that *half* of awards had been granted only on appeal.¹⁵ And while most - 89/100 - were receiving DLA only 30 of the 89 (1 in 3) had been awarded DLA Care Component at the high rate, commensurate with the care needs that would be expected for a person who is severely affected by M.E. Also there was an inconsistent relationship between the level of severity reported by respondents and the level at which DLA care component had been awarded. For example, seven people who were mainly bedbound were among those who had been awarded the lowest rate of DLA care component.¹⁶

Research conducted by the Centre for Longitudinal Studies (CLS)¹⁷ has looked at this area. Relevant considerations included:

- *"individuals with poorly understood disabling conditions experience difficulties in accessing health and other services and face a lack of sympathy and stigmatization, which can affect claiming behaviour;"*

One factor contributing to these difficulties is the poor quality of the briefing material on this disorder that is provided to DWP assessors. It is a matter of record that the existing guidance provided to DLA assessors regarding 'CFS/ME' has been the subject of concerted criticism by patients and patient groups, including a joint campaign by the main UK charities in 2007. The content of this guidance requires to be reviewed and improved as a matter of urgency, and the necessary improvements imported into any new system such as PIP.

¹⁵ This has been reflected consistently in feedback to us from 25% ME Group members, including [*Severely Affected ME (Myalgic Encephalomyelitis) Analysis Report on Questionnaire Issued January 2004*, Report by 25% ME Group, 1st March 2004].

¹⁶ Analysis report available at 25% ME Group website:
<http://www.25megroup.org/Group%20Leaflets/Group%20Leaflets.htm>

¹⁷ *A Poorly Understood Condition: Disability Living Allowance and People with CFS/ME*; Cathie Hammond Social Policy and Administration Vol.36, No.3, June 2002 pp254-274.

10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

Re 'assessment of ability' Once again, if the agenda is to focus purely on what people *can* do and then deny their *disability*, you are not respecting the whole person.

Re 'what supporting evidence will help provide a clear assessment'

The greatest potential for provision of clear and comprehensive information on which to base assessment lies in an applicant's own account of their situation, where appropriate supplemented by information from a carer, and with access to suitable advocacy services to facilitate submission of claims as required.

Information from professionals involved with the person's care can also be helpful. Unfortunately, the reality for most people with M.E. is that they do not have access to the sort of specialist biomedical tests that might provide objective evidence of dysfunction.

What's more, people with severe M.E. may be invisible to the NHS, despite being among the sickest members of society, partly due to GPs' reluctance to make home visits and a well grounded desire not to be forced to undergo the pernicious 'rehabilitative' (sic) interventions currently in vogue for management..¹⁸ As this is a key issue in terms of obstacles to just and fair benefits' decisions, we believe that it is pertinent to spell out the underlying context in more detail:

Despite the classification of ME as a neurological illness by the WHO (ICD-10 G93.3) since 1969, the official UK attitudes as demonstrated by the MRC, DWP, Department of Health, and to some extent NICE:

- *ignores the neurological and other biomedical evidence*
- *shows an ideological commitment to a psychosomatic/behavioural model of the illness which is no longer tenable*
- *recommends only cognitive restructuring techniques (CBT and GET) that are "not remotely curative"¹⁹ and have been shown to be of no lasting value and in the case of GET to be positively harmful*
- *proscribes any investigative tests to identify the disorder, leading to missed diagnoses and misdiagnosis*
- *support cruel, even vicious, actions that lead to patients being wrongly sectioned and parents, particularly mothers, accused of Munchausens'-Syndrome-by-Proxy*
- *the result is that essential benefits and insurance payments to support patients and their families have not been paid or have been granted only after protracted and expensive legal action. All this adds to the burden of the illness for patients and for those who care for them.²⁰*

Re ' who is best placed to provide this':

Normally this will be the applicant, also each should be facilitated to identify who knows them and their situation best. Allowances must be made for very ill and very disabled people to have evidence provided from other sources such as carers, GPs, Consultants, Physiotherapists, Osteopaths and any medical tests, and assessment of their ill health and level of disability should be obvious from this [see above]. This includes people with Severe M.E., who must be treated with the respect their disease deserves and alternative information sought from medical and other sources, who know and understand their illness, in cases where this is available. Sadly, some sick and disabled people are isolated and struggling with survival and do not have another person in regular contact with them. This causes problems for them in accessing DLA Benefits that they are entitled to and greater consideration needs to be given as to how to treat them fairly and respect their illness/disability.

¹⁸ A total of 437 people took part in a survey conducted by the 25% M.E. Group in 2004. Over half (253 patients; 58%) stated that they were completely unable to attend their GP's surgery. Just over half of these patients (134 patients; 53%) *never* received a visit from their GP. The remaining patients did attend their GP's surgery. However, the vast majority of this group were completely reliant on others for transport to the surgery. Most felt obliged to struggle attend if they wished to see their GP, because the practitioner would not carry out home visits to address M.E. related health needs. SOURCE; Report by 25% ME Group 'Severely Affected ME (Myalgic Encephalomyelitis) Analysis Report on Questionnaire (1st March 2004).

Action for ME (AfME) surveyed members in 2001 and looked specifically at those who were very severely affected. This was defined as '*bedridden - totally reliant on others for care*' and 110 respondents met this description. Just over half of the *very* severely affected patients who participated in the AfME survey (55%) were not being monitored by a medical practitioner. And the vast majority of very severely affected respondents - eight out of ten - had been refused a home visit by their general practitioner at some time. SOURCE: Report by Action For ME 'Severely Neglected: ME in the UK' (Membership Survey March 2001).

¹⁹ Editorial, JAMA 19th September 2001:268:11

²⁰ Extract from letter to Sir Michael Rawlins from Malcolm Hooper: <http://www.meactionuk.org.uk/Hooper-signed-letter-to-Rawlins.htm>

Certainly not biased medical and other professionals who have a financial stake in removing people from benefits; who will just look at ability and deny the reality of the person and the profound impact their disability has upon them [as is planned - see next question].

11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- **What benefits or difficulties might this bring?**
- **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?**

We note with concern that the envisaged reforms introduce 'conditionality' into the system.

Face-to-face discussion with a healthcare professional: benefits and difficulties

Another gold plated example of 'doublespeak' occurs here with the description of such healthcare professionals as 'independent'. What this means is a healthcare professional who is *not* involved in the claimant's care and who knows nothing in advance of the assessment process about their case. While such a person would be 'independent' of the claimant, this does not necessarily imply that they would be 'independent' in the sense of being unbiased. It is likely that financial disincentives would apply to the agencies employing these 'independent' professionals in respect of granting claims. While the DWP uses ATOS to carry out assessments it is introducing a biased, non-independent, financially motivated factor into the equation.

Even at best, it is unrealistic to expect that an 'independent' assessor – *i.e.* an assessor who is quite ignorant of the claimant and their circumstances, will be able to obtain a suitable picture of the claimant's situation in an hour of questioning. The likely requirement for the assessor to input responses to a computer programme further compromises the capacity of this scenario to deliver an appropriate outcome. This is both a distraction from direct focus on recording what the person is saying, and a fundamental breach of basic accuracy if the requirement is to 'force' responses into a set list of pre-existing categories. We fear that such a distortion may be implied in the guise of 'objectivity'.

Another difficulty is that a claimant may require to provide their information in their own time and space – for a sick and disabled person to try to convey the necessary information over the course of an hour is unfeasible in terms of capacity to convey the necessary info comprehensively and succinctly. Indeed, this would be impossible for a Severe ME sufferer who:

- has difficulties with receiving and processing information;
- experiences concentration and memory difficulties and difficulties in thinking;
- experiences mental fatigue and brain fog;
- suffers from hyperacusis;
- cannot listen and speak to people on the phone;
- cannot listen to or converse with people on a 1:1 basis;
- is not able to physically hold a phone;
- does not have the breath to speak or become breathless when they do speak;
- does not have the energy to engage in ongoing conversation with others;
- is light sensitive;
- needs low lighting and a darkened room;
- has difficulties reading;
- has cognitive/processing problems understanding and make sense of questions, forms, letters;
- needs help to read their post, deal with bills, application forms;
- needs someone to answer the telephone, answer the door, make telephone calls for them, speak on their behalf;
- is unable to hold a pen;
- suffers from pain, paralysis, numbness, poor motor control and coordination, muscle fatigue and lack of energy and ability.²¹

In common with many other claimants, people with severe M.E. can only sustain attention for a small amount at a time. When completing form, many do so over a long period, giving the opportunity to focus on this task when circumstances permit. Indeed, many people with ME report that completion of their DLA applications takes up most of their available resources of activity over a period of weeks.

²¹ cf Stonebird A Severe ME Guide to Part 3 of the DLA Form: <http://www.stonebird.co.uk/dla.html>

Re circumstances in which it may be inappropriate to require a face-to-face meeting

We welcome the recognition that *"there may need to be some exceptions – for example ... Those disabled people who face the most complex barriers"*. There are indeed circumstances where a face to face interview would be inappropriate.

People who are severely ill and disabled should not have to endure these interrogations and should never have to put their health at risk to gain access to essential funding they are entitled to, to live. Who, when they are ill and feel overwhelmingly physically ill all the time, day and night, is able to function effectively in an interview?

Inappropriate for People with Severe M.E.

The requirement of a face-to-face discussion is not appropriate for someone with Severe ME, who will be made more ill due to complex symptoms and hypersensitivity to the environment and anyone in it.

- The mental and physical energy required to participate in an interaction like this is way beyond the ability of a Severe ME sufferer and could lead to a massive and prolonged deterioration of health as a consequence if enforced. Post-exertional fatigue and malaise and the sheer effort of trying to cope with an in-depth interview is likely to lead to a deterioration of symptoms and which could result in a worsening disability that could last for weeks, months, - even years.
- People with Severe ME should not be exposed to people who not only do not understand their disability but have the hidden agenda of reducing government spending, as opposed to meeting need and understanding genuine disability.
- It would be abusive to insist that people who are very ill, who do not live normal lives in the normal world, who would be made more ill by the demands exacted upon them, be required to meet with a government assessor.
- For people who have Severe ME there are massive barriers to communication, cognitive dysfunction; difficulties receiving information, processing information, comprehending questions, accessing information, remembering things, physically speaking. There is extremely limited energy available for communication, there are a massive number of symptoms to endure, which can act as a further barrier such as spasms, paralysis, severe body pain, hypersensitivity: light, noise, touch and sound sensitivity, multiple chemical sensitivity and extreme post-exertional fatigue and malaise. The person with Severe ME always experiences feeling ill.
- These factors must be understood by the DWP with acceptance as standard that is inappropriate to insist that people who are so severely disabled should have to undergo face-to-face interviews.

12. How should the reviews be carried out? For example:

- **What evidence and/or criteria should be used to set the frequency of reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

The matter of reviews is yet another area where the case for change is built on a near complete misrepresentation of the existing system. People who are in receipt of DLA are subject to review requirements - unless granted an award for life. It is the removal of the possibility of award for life that is being proposed - not the introduction of a review process (the impression that an uninitiated reader would glean from the relevant section of the consultation paper).

We totally repudiate the validity of potentially taking into account "*the successful use of aids and adaptations*" to trigger a lower level of PIP award, or removal of award, on review.

If the DWP changes the meaning of 'disability' to 'ability' and denies the physical reality of disabled people, with the intention of denying them the income they need to live with their disabilities, then the motive for constantly reviewing their case is suspicious.

All the time the DWP uses ATOS to carry out its reviews it is introducing a biased, non-independent, financially motivated factor into the equation. Furthermore, in a political climate where cutting the deficit has become the focus then surely increasing reviews and the amount of money paid to ATOS to conduct same is not the way to save money.

Implying that people need checking up on because they are falsely claiming money for a permanent disability is cruel and the motive is dubious, because it is so clearly hitched to deficit reduction, rather than meeting genuine disabled need.

In current practice the review system is a major source of stress to claimants in general and people with Severe ME in particular. We are of the view that anyone who is very ill and severely disabled should be entitled to high rate benefit, for both components, and where there is no treatment or cure available for their disease/disability they should be entitled to it for life. Severely ill and disabled people should not have to worry about having to endure through repeated long and arduous assessment procedures. This would include people with Severe ME, who should qualify for both components of DLA / PIP at the highest level. As a very severely affected person explains:

Filling in the forms and having doctors /carers etc supporting reports should be enough for the genuinely sick and very disabled person with Severe ME. I have had to go through reapplications every 2 or 3 years for many years and been told at the Benefit Integrity Project that I was lying and generally felt harassed for years and it contributed to extreme deterioration of my health that I consider unacceptable. The DWP and associated privately contracted companies do not have unbiased properly aware officials and people with ME are always at risk more than other groups of being wrongly dismissed as having a psychosocial condition - or simply needing less help than they say so I don't feel it is safe for people who are dreadfully ill to have to be exposed to this. I believe having an incurable very severe disease with severe disability and torment I should have had the respect of a permanent award when first ill and would wish this for others like me because in 17 years all I have done is deteriorate and been afraid for many of them, as with ME you are so at risk of deterioration if exposed to these people and their tests and disbelief and intention to take money away from you. They are not humane! I also know people who have been wrongly assessed and awarded generally less than they should be entitled to and others who are just too ill to apply even though they need it. Automatic in these cases is the only way to show us respect and understanding.

What is the agenda behind repeatedly requiring people with disabilities to prove they are still disabled? The severely ill and disabled should not have to worry about having to endure through repeated long and arduous assessment procedures. They should not feel insecure because they have only been awarded a very short-term allowance before reassessment. People who have long term disability, who have been already been thoroughly assessed and are unlikely to recover from their disability should not have to be forced to keep going through reviews again and again. It needs to be agreed that all people with permanent disability should not be re-reviewed regularly unless their disability worsens and they request it.

There is no cure, very little palliative treatment, and no biomedical investigations currently on the NHS for people with M.E. Continual reviews will cause greater physical suffering to the person with Severe ME and will almost certainly lead to a deterioration of their health and a worsening of their condition. (M.E. is characterised by a profound post-exertional impact.) Carers should not have the additional stress and worry of having to help people go through this

process again and again and see their loved ones almost certainly deteriorate from the stress and pressure that this entails. This is particularly so in respect of people with Severe In the case of someone with Severe ME, who has limited energy and is severely functionally impaired (less than 20% functional ability), to have to continually prove that you are ill and disabled is unfair and illogical.

It is a foolish waste of time, energy and taxpayers' money to frequently and repeatedly assess people who are physically disabled and severely ill and who will not get better. This issue must be taken seriously by the government and the DWP.

13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

This question is linked to two paragraphs headed ***Penalties for not reporting changes in circumstances*** where it is stated that *"If an individual is found to have knowingly withheld information about a change in circumstance which would have resulted in a reduction in benefit, they will have to repay the amount claimed. In addition, a penalty or a prosecution may result."*

Alongside the stress on the putative capacity of the PIP system to make it patently clear to claimants what changes require to be identified and reported, this punitive aspect of the PIP system seems designed to ensure that anyone who is found on review to have 'improved' to the point where they no longer qualify for PIP or qualify at a lower level will not only have benefit clawed back, but will quite possibly face an additional financial penalty or a prosecution. This represents a *very* major additional source of stress for sick people and a *substantial* deterrent to claiming PIP.

With M.E. there is a particular danger of misinterpretation and wrong removal from benefits. If someone is wrongly removed from benefits who has severe M.E. they are going to be less likely to be able to appeal, because they are so very ill in the first place and are in danger of their health deteriorating by engaging in the process.

Alongside the other measures outlined here – notably assessing on the basis of ability rather than disability, discounting need for financial help if use of an aid or adaptation is providing said help, discounting need for financial assistance if such an aid or adaptation could be procured and used in future – this stroke of administrative fiat appears destined to rule out any remaining potential claimants through sheer fear and anxiety as to what might lie in store for them further down the claiming road.

Some further points:

- The fraud rate for DLA, we understand, is 0.5% - a rate significantly lower than Income Support (2.9% fraud rate), Incapacity Benefit (1%) and Jobseekers Allowance (2.8%). Indeed, it's lower than the office error rate for the DWP, which stands at 0.6.
- We note the dubious equation of a person being 'able to identify and report changes in their needs' with understanding of the PIP system and the parameters used to gauge said needs under this system. It is as though (i) a person requires some external checklist in order to know if their needs have changed (ii) PIP will be an appropriate, thorough and sensitive yardstick for identifying personal needs.

14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

This question represents is a prime example of where taking the question in isolation from the related text in consultation paper would most probably lead to a failure to grasp what the government are planning – and asking about.

On the face of this looks like a question about advice and information for claimants regarding the PIP – such as how to apply, where to get help to apply, and what the qualifying criteria are. It isn't about this at all.

Instead: *"We are exploring ways to help inform individuals of the positive steps they might take to better manage or improve their situation if appropriate – for example, by accessing other forms of support in the health and social care systems. ... We could potentially explore making elements of this part of the requirements of the benefit, where appropriate."*

On the face of it, this may look like a helpful step. There are few, if any, people who have an impairment due to illness or other disability and who do not wish to know about any steps they may be able to take to help manage their disorder or otherwise improve their situation.

If only it were that straightforward. Two basic general points here:

- Much hinges on what is made of the term 'appropriate' -who decides what is 'appropriate' for an individual, and on what basis?
- In the context of the DWP's plans to remove / reduce PIP to people who may be able to access assistance such as aids and adaptations (see Consultation Questions 8 above and 16 below) this looks like – yet another – barrier to qualification.

For claimants with M.E. this suggestion is toxic. We have a well-grounded desire to avoid the pernicious 'rehabilitative' (sic) interventions that are currently in vogue for management. Such approaches to activity intervention have been trialled for 'fatigue' and are now being misapplied, much to the detriment of people with ME. For example, in a survey of 25% ME Group members²² the vast majority of those who had undergone graded exercise - 82% - reported that it had made them worse. Furthermore *some patients were **not** severely affected before trying 'Graded Exercise Therapy.* (For further explication on this see response to Consultation Question 10 above).

There should be no expectation that links any advice given to an obligation to comply, in order to remain in receipt of benefits. It would be ultimately dangerous for all people with M.E. if the advice given was for graded exercise and CBT aimed at graded exercise/activity.

²² *Severely Affected ME (Myalgic Encephalomyelitis) analysis report on questionnaire; 25% ME Group 1st March 2004. See page 8.*

15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?

Sick and disabled people know best what works for them and what does not. There is no reason why suitable information and signposting regarding sources of support should not be made available. However, no recommendation should be a *requirement* of receiving benefit, for anyone.

It is particularly unacceptable to make this a requirement for people with Severe M.E. There is little understanding and knowledge of M.E. in the NHS and DWP and a great deal of misunderstanding. As a result, advice is likely to be biased, ignorant, and downright dangerous, given that the current position on suitable intervention for this serious and profound neurological disease is blatantly to ignore biomedical needs and focus upon Graded Exercise and Cognitive Behaviour Therapy, the latter aimed at encouraging behaviour in the form of graded exercise or graded activity. Feedback from patient consistently indicates that such approaches may be at best ineffective and at worst harmful. Many, many patients report having deteriorated following exercise and indeed there are numerous, internationally documented, contra-indications for exercise emerging from published research papers.²³

The severely affected should absolutely not be at the mercy of advisors who are not involved in their medical care. This is a dangerous and wrong path to go down and is likely to endanger people's health, especially people with M.E.

If this were to be the sort of recommendation that an advisor would make, tied to the payment of PIP, as an expectation or as a requirement, then it is predictable that many people with M.E. will be seriously abused by this process and will end up in an impossible situation where they need the money but they cannot participate in the recommendations ('strings') attached.

²³ Re patient reposts of deterioration: in a survey of 25% ME Group members²³ the vast majority of those who had undergone graded exercise - 82% - reported that it had made them worse. Furthermore *some patients were **not** severely affected **before** trying 'Graded Exercise Therapy.*

What these numbers do not convey is the sheer human misery behind the statistics. The 25% ME Group knows of many individual cases. Including the experience of Lynn Gilderdale, a very severely affected young woman who with assistance took her own life in December 2009 because of her long term intolerable suffering. Back in 2001, Lynn's mother went public regarding her daughter's experience: *The family followed their GP's advice and encouraged Lynn to take as much exercise as possible. But that proved to be the worst course of action, says [Lynn's mother] Kay. "We would walk her down the road and she would get back to the house and collapse. It got to the point where she was totally bed-ridden and she couldn't sit up without going unconscious. She couldn't swallow anything at all. She was in terrible pain, with muscle spasms and she had swollen glands and lymph nodes."* SOURCE: *ME has taken over my daughter's life* <http://news.bbc.co.uk/1/hi/health/1234297.stm> Wednesday, 21 March, 2001.

Numerous examples of research findings challenging the wisdom of exercise can be found in ***Is Graded Exercise Safe for People with ME?*** - ScotME submission to the Gibson Parliamentary Inquiry, January 2006.

16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

This first question is a simple factual question – and one to which the government already know the answer. As indicated in the Consultation Paper, there are a number of ways in which aids and adaptations are funded, including people using part or all of their Disability Living Allowance award to pay for same, either on a one-off or ongoing basis (the latter applying particularly to car leasing through the motability scheme).

Of course recipients should be able to use PIP to meet the cost of aids and adaptations. They should be empowered to use PIP in any way that they see fit in order to help with the additional costs that having their long term impairment brings.

So, what is the relevance of these questions?

"We will explore the funding sources available at a national and local level for one-off aids and adaptations, and consider the role of DLA in meeting one-off costs..." – if this implies that DLA / PIP may be channelled in such a way that the NHS/Social services need not provide funding for any aids and equipment this would be a travesty.

In any event, use of aids and equipment entails more than the 'one-off' cost of purchase, because aids and equipment break over time, require servicing and the amount that benefits provide is unlikely to pay for quality aids, particularly for the most severely affected for whom basic aids are insufficient. This is amply illustrated in the motability car leasing scheme – where payments towards the cost of the vehicle re made on a monthly basis – to spread the high cost – and continuously, in that the vehicle is replace by a newer one (to get round wear and tear and additional servicing costs) before the monthly payments are sufficient to pay off the cost of the car in full.

(The likely relationship between qualifying criteria for awards of PIP and use of / ability to use aids and to gain benefit from adaptations is covered in more detail at Consultation Question 8.)

17. What are the key differences that we should take into account when assessing children?

Two things are clear from this section of the consultation paper:

- that the fundamentals of how the new system will apply to children are being decided behind closed doors – again an element in common with PIP for adults; and
- that a similar mean spirited outlook is at work in respect of child qualification for PIP as is evident in the proposals with regard to adults.

Re the first, the government *"are considering whether to apply these new eligibility and assessment criteria to children to ensure they are also assessed in an objective and consistent manner."* Given the very considerable shortcomings of the PIP eligibility and assessment system – as discussed above – we would counsel against applying this to children (or adults, for that matter). However, *we aren't being asked about this*. Instead this is being considered, behind closed doors, *"in discussion with specialists in this area"*.

Re the second: *"We are also considering ... whether or not we should take into account a child's support needs if they are being met from public funds by another institution, such as a school."* This points towards reduction or even complete cessation of the financial assistance currently provided to the families of disabled children via DLA if their disabled child has support needs that are being met at school. The provision of a suitable educational environment to meet a child's special support needs in no way negates the very real additional costs faced by the families of sick and disabled children. *However, this public consultation is not seeking views about this.*

We suggest that the Consultation Question as framed simply provides a platform for yet further hurdles to qualification – in addition to those already articulated vis-à-vis adults - to be placed in the way of access to PIP on behalf of disabled children.

18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?

The passport does reduce the stress in accessing other benefits and must be protected. We are pleased that the intention is to *"take into account DLA's role as a passport to other support as we design the new benefit"*.

A major foreseeable difficulty in this connection, however, is that if the DWP insist going ahead with PIP in the form suggested in the consultation, it will be much more difficult to obtain an award of PIP than is presently the case with DLA, and so a lot of people stand to lose out not only on the benefit itself but also all the other entitlements to which DLA is presently the passport. Those people won't have an automatic passport and it will make their life harder or they may have no access to those services at all.

We are particularly concerned that carers will lose Carer's Allowance if the person they care for loses their benefits under PIP, making it impossible to pay basic bills and to carry on caring. (Relatedly, we believe that Carer's Allowance must remain outside of the Universal Credit.) Carers save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would make making ends meet while caring all but impossible for some family carers.

The passport idea has advantages in terms of ease of access and streamlined administration. However, a downside is that people who are deemed not to meet the criteria for the 'passport' benefit fall through the cracks and get nothing. Qualification for the 'passport' benefit must be vested in a fair and rational system of assessment. PIP falls short in this regard.

We suggest that PIP should maintain the status of DLA as a 'passport' benefit, it should not necessarily be the only gateway to other benefits.

19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

Implications for disabled people would be the additional strain of a multiplicity of assessment procedures. This will be detrimental to health in some cases, including for people with severe M.E. Also the requirement to know about all the different benefits in the first place and how to apply for them.

Likewise for service providers, who would require to introduce and administer application procedures, with significant additional costs through requirement for additional labour and other resources.

In any event – we cannot see circumstances in which using PIP as a passport *"was not possible"*. Surely the government of the day has executive decision making powers in this matter?

20. 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?

We will tackle the two parts of this question separately, starting with the issue of sharing information.

This question arises from the likely role of PIP as a 'passport' benefit. It relates to the desirability of easy access – via an electronic link - to DWP data "*so that other authorities could automatically check entitlement on the basis of a Personal Independence Payment award.*" We note that the individual's permission would be required for such data sharing (necessary in consequence of the Data Protection Act?).

If the person is given sufficient unbiased independent information about the pros and cons of their data being shared, we are of the view, with this proviso, that the capacity for such data sharing could be appropriate, depending upon the DWP's agenda; is it to make life easier for people with disabilities, is it to make inter-departmental efficiencies, or is it a covert way of limiting access to essential allowances? If there was a just and fair assessment procedure where people were going to be accurately and rightly assessed for benefits, then people might want to choose that their information be made available to other organizations from whom they need to get benefit. But with the high likelihood that people will be wrongly assessed and dropped from receiving PIP, who were entitled to DLA, then there is great potential for misinterpretation of this information. In this circumstance data sharing would not be appropriate.

We also note that it would appear that the responsibility for pursuing provision of other benefits and services for which PIP would confer entitlement would lie with the disabled person and the authorities providing these services. We suggest that an award of PIP or other passport benefit PIP should *automatically* mean that the DWP seek the recipient's permission to link to other benefits and services, alerting them to the person's *automatic* entitlement to same.

Turning to the question regarding shared assessments: this is discussed under the heading "*Integrating with other provision*" and many of the considerations that are pertinent to the discussion on passporting arrangements (see questions 18 and 19 above) have some relevance here.

While there are some advantages to both the disabled person and the service provider of shared assessments in terms of simplification and fewer demands on the person and the system, the downside of a single assessment may be an 'all or nothing' situation, whereby a person in need of, say, care services and financial support to meet additional special needs arising from disability would either be approved for both or for neither.

We note that with shared assessment there is in principle the possibility of sharing information without the various service providers who have this information necessarily making the same decision regarding provision of their respective services (unlike 'passporting' arrangements). However, we believe that the downside of amalgamating these assessment processes would considerably outweigh any advantage. If the whole process of assessment is flawed, through misinterpreting disability in the first place, for PIP, then there is no congruent basis upon which departments could accurately assess claimants; the strong possibility that the PIP information will be skewed, partial, mechanistic *etc.* would mitigate against its use in other contexts. (Relying on medically unaware assessors, who furthermore have a financial motive for not providing benefit, is unlikely to produce a sensitive, rounded, and reasonably comprehensive picture of a person's needs.)

NB: This section of the consultation paper also covers the issue of overlap between funding streams (cited example of care component of DLA and adult social care services). We note with concern that the government "*will explore whether it is possible to ... eliminate areas of overlap*", and that the present Consultation Paper makes no attempt to gauge views on this subject.

21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?

We consider that changing from DLA to PIP may discriminate against people with disability. Focusing on ability denies the impact and importance of disability and the motive behind PIP is skewed, for it is financially driven rather than needs driven. Focusing on independence, without clearly defining what is meant by it and without using its broadest interpretation *i.e.* including facilitators will also potentially lead to discrimination and inequality.

People with M.E. are discriminated against already by the application of a misplaced psychosocial perspective on their illness, which denies their biomedical needs and their physical reality and recommends wholly inappropriate therapies charading as treatments. If PIP is introduced it will further discriminate against people with M.E. – as well as other disorders - because focusing upon ability disregards the very real illness and disability experienced.

It is ironic in the extreme to introduce a new system that will impact adversely on sick and disabled people, and to accompany it with an initial Equality Impact Assessment that trumpets the 'benefits' to this group. (This is attitude is, however, consistent with the rest of the Consultation Paper.)

We note that the DWP's initial Equality Impact Assessment vests the right to freedom from discrimination in a sub group of disabled people: "*Proposals to replace DLA ... provide an opportunity to promote equality of opportunity to those least likely to live full and active lives.*"

This represents a sly attempt to justify removing benefit from some disabled people:

"It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support..." (Overview of Potential Equality Impacts, p28)

The Impact Assessment continues: , "*but this has been justified by the policy aim to focus support on those with greatest needs.*" (Yet at the same time, the consultation paper refers, elsewhere in the document, to a 'broader focus on disability' in connection with moving perspective from 'disability' to 'ability'.)

This is no justification at all here in terms of morality or plain logic: not only is there is no suggestion that people who have highest needs will actually be better off under PIP than DLA but, even if this were the case, such a policy aim would not 'justify' removing assistance from others. We would ask whether or not this could be 'justified' in the eyes of the law *i.e.* is it compatible with the Disability Discrimination Act?

Perversely, in the very next breath the proposal to remove any and all automatic entitlements on the basis of diagnosis is touted as a step forward in terms of equality (as it "*should help remove differences in treatment which can currently arise*").

It is also asserted that the change from DLA to PIP will help avoid people mistakenly concluding that it is not possible to obtain the benefit if working, and that this will result in "*promoting equality of opportunity*". *Please*. In the first place, this misunderstanding re DLA operates to deter claiming – not to deter work. In the second place, how changing from DLA to PIP will succeed in making any difference in this regard is quite beyond us. Unless suitable steps are taken to clarify, it will simply mean having a benefit called PIP that some people misunderstand as can't be claimed if in work instead of a benefit called DLA that some people misunderstand as can't be claimed if in work.

Really, one could *not* make this up.

22. Is there anything else you would like to tell us about the proposals in this public consultation?

Regarding the proposals' impact on people with severe M.E.

M.E. is a serious neurological disease with multi-system dysfunction and needs to be treated as such by the DWP; it is not just a bit of tiredness that can be overcome by changing your thoughts and trying harder to exercise, which is the popular myth.

People with Severe ME have huge costs to bear, have total care needs and require endless help just to survive. They are profoundly disabled and in need of high level funding to manage their lives. Government departments and their staff – both directly employed and sub-contracted – can best help people with Severe ME to live as fully an independent a life as possible, as meaningful a life as possible, by respecting their level of illness and disability and responding appropriately. This requires understanding of the complexity of their needs and how extremely difficult communication is for them, so that the system enables them to get what they are entitled to in the least stressful way.

It is a matter of record that the existing guidance provided to DLA assessors regarding 'CFS/ME' has been subject to concerted criticism by patients and patient groups, including a joint campaign by the main UK charities in 2007. This requires to be reviewed and improved as a matter of urgency, and the necessary improvements imported into any new system such as PIP.

Regarding how the proposals will impact on all disabled people

We strongly believe that the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and carers

It is not, in our opinion, a fair, unbiased system that is being proposed under PIP. Rather it is akin to a circus, with hoops that the disabled person will have to keep jumping through in a never-ending performance cycle, from which there will be no escape, no hope of getting better, only the constant anxiety of having their money removed unjustly. It is dishonest to pretend that PIP will genuinely meet the needs of disabled people. PIP will not meet their needs. Instead, the introduction of PIP is likely to result in greater poverty, suicide, depression and worsening disability.

PIP is likely to lead to disabled people being unjustly failed by the Benefit System. It is likely to negate the reality of Chronic Illness and disability – from an administrative perspective - and it will not serve those who are currently receiving DLA, or those who have yet to claim it.

By focusing upon ability, being chronically ill and disabled is in great danger, under PIP, of becoming a negative label - leading to inequality, harassment and a denial of need.

People with ME have already experienced the denial of their physical reality, through the promotion of the psychosocial model of disability and it would be a travesty if the Government widens this injustice to include the whole of disability, which may result, if it introduces PIP.

We strongly urge the government to think again and leave DLA in place.