



GRŴP MYNEDIAD **ARFON** ACCESS GROUP
Equal Access for All - Hygyrchedd Cyfartal i Bawb



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Sunday, 4th August 2013

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**Response to Consultation on
Personal Independence Payment Assessment
Moving Around Activity**

Introduction

Arfon Access Group represents disabled people in the Arfon area of Gwynedd. However it holds much wider representative significance. As Chair of the Group I am also:
Chair of the Coalition of Access Groups in Wales
Secretary of the Wales Access Association
Co-Chair of the Wales Alliance for Citizen-Directed Support
Member of Gwynedd Service Improvement Group
Member of the Coalition on Charging Cymru
Member of every Welsh Government Working Group on Fair Charging for Community Care and Paying for Care since 2000
Member of the Welsh Government Blue Badge Modernisation Steering Group
and a Member of Disability Wales

Executive Summary

Notwithstanding the pending judicial review on this matter, the opportunity to debate this crucial policy shift is very much appreciated, not least because it has given disability organisations and disabled people another chance to remind Ministers and officials of the Social Model of Disability within which all policy is now required to be framed.

Against a background of an unsavoury media hate campaign targeting disabled people, stirred up by senior Conservative Members of Parliament, we have found the staff of the Department of Work and Pensions thoughtful,

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considerate and well-meaning. However, the policy intention of this process, namely to remove even the modest amounts of support and thereby access to limited but valued independence from many thousands of disabled people, is despicable and has already and will continue to have a death toll and a misery toll that Ministers must bear on their consciences for the rest of their lives.

What makes this all the more despicable is that no-one at any level of government can be unaware that the cumulative **cost** to government of denying these people their independence will by far outweigh the short term cost saving in the reduced benefit bill. For a government of any political persuasion to go out of its way to spend taxpayers' money on deliberately harming disabled people is beyond belief and has shocked even the most hardened and cynical disability equality campaigners.

Specifically, the arbitrary reduction of the distance criterion from 50 metres to 20 metres is rejected by all disabled people and every disability organisation as unfair and discriminatory and should be removed from the assessment process.

Lastly, I urge officials and Ministers to take full note of the response to this consultation from Disability Wales who are the umbrella organisation for disabled people and their organisations across the whole of Wales and speak with great authority.

The Consultation

1. Para 1.4 Background

- a. The established wisdom from British Standards, Building Regulations, Blue Badge Eligibility Criteria and the Department for Work and Pensions itself is that, to quote DWP:

"50 metres is considered to be the distance that an individual is required to be able to walk in order to achieve a basic level of independence...".

 - i. No evidence has been presented by Ministers or officials to counter this long-standing and widely-held consensus that has been agreed as fair and equitable by disabled people and disability organisations for many years.
 - ii. Also, the policy change was not the result of engagement with stakeholders.
 - iii. A simple distance parameter is not consistent with a Social Model approach to assessment but within the Medical Model context of the Personal Independence Payment assessment 50 metres has broad agreement as a fair threshold.

- b. If evidence can be found to suggest that 20 metres is a reasonable distance to substitute for the established 50 metres guide then this should be included in a further consultation to seek stakeholder views. If not then the assessment should revert to the 50 metres parameter.
- c. The stated objective of reducing the criterion:
“to focus the enhanced rate on those with the greatest barriers to mobility”
 is a very transparent code for **removing** support from a substantial number of people who have long been recognised as needing that support, without which they cannot access independent living¹ to which they are entitled under Article 19 of the United Nations Convention on the Rights of People with Disabilities [sic].

2. Para 4.2 How the assessment works

- a. In the consultation document ‘Disability Living Allowance Reform’ in December 2010 the following assertion is made at paragraph 13:
“We are committed to further breaking down the barriers in society that prevent disabled people from exercising choice and control, and living active and independent lives. Just as society is changing and advancing, so too must our benefits system to reflect those changes. The new benefit, Personal Independence Payment, and the guidance used to award it, will reflect this and be fit for the 21st Century.”
 For this statement to be anything more than empty rhetoric it is necessary to study the impact that will be felt by those disabled people who will lose their independence if the 20 metre criterion is allowed to stand.
- b. The 2010 consultation made the claim that:
“The benefit will continue to take account of the social model of disability. The assessment will be objective, reflect the impact of the barriers disabled people may experience, and make sure they are treated as individuals.”
 This was an unsubstantiated claim: the assessment is purely functional and far from a Social Model paradigm is set squarely within the Bio-psycho-social Model, which in effect is a flimsy cover for the continuation of the Medical Model. The 12 activities are purely functional tests and no attempt is made to enquire into the barriers that people face because no part of government has

¹ “Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves.”

Definition of Independent Living adopted by Welsh Government in 2012 as part of the Framework for Action on Independent Living

<http://wales.gov.uk/consultations/equality/frameworkforactionconsultation/?lang=en>

made a genuine attempt to understand the Social Model and put it into practice.

- c. The failure to honestly adopt a Social Model approach has numerous consequences on the direction of public policy and the effect on disabled people.
 - i. A Social Model approach would take into account the implications to the quality of life and complexity of life for individuals who need to use aids or equipment to support their functioning.
 - ii. Both the cost and complexity of getting, using, maintaining and repairing equipment has major quality of life limiting implications for individuals that may impact radically upon their ability to carry out daily tasks to the extent that is not recognised in these tests and assessments.
 - iii. The effects of pain are clearly not understood or accounted for in the assessment process. This has been summed up by one disabled person as 'present, referred and deferred pain', where deferred pain is that put off by medication in order to accomplish an important task but is nevertheless experienced at a later stage and probably more intensely, and referred pain is that experienced in a different part of the body when the brain can no longer process pain from the usual source but still has the imperative to inform the person that damage is being done.
 - iv. Also, the effects of conditions such as ME need to be considered, whereby a person may well be able to move 50 or even more metres unaided **today** and possibly repeat the task tomorrow but then may find that the effort has sapped their energy and they then are forced to rest for the following day or two. This obviously impacts on their ability to seek employment because they know that even if they are fully competent for the position on one day they will not be able to work on a number of days in any given time period so will be deemed unsuitable for employment by most employers who would view them effectively as unreliable.
 - v. I know this from the experience of family members and friends who have faced and continue to face harassment and bullying in the workplace because they have conditions that fluctuate and leave them dizzy or weak for short periods or who experience exhaustion and short term memory difficulty. In several of these cases their employers refuse to understand that these effects are symptoms of health conditions and on several occasions these individuals have lost considerable

chunks of their wages because they have been sent home as unfit to work when all they needed was to rest for a few minutes.

- vi. Any changes in support for disabled people must take into account the real world situations they face when attempting to get into or stay in employment if it is to stand the test of a Social Model approach.

3. True costs

- a. The impact of being reduced from enhanced rate to standard rate will be absolutely devastating for those affected because they will lose access to independent mobility with all of the attendant health and wellbeing effects and loss of access both to social interaction and to employment and education that would bring.
- b. Therefore, alongside this is needed an Equality Impact Assessment to determine the degree and type of effects on those people who will find their level of award reduced.
- c. This would need to look both at the effects upon the life and quality of life of those individuals but also consider the degree to which these negative effects impact negatively upon their health and wellbeing to the extent that they need to, [and do successfully], reapply for the higher rate of PIP.
- d. The combined effect would therefore show in many cases both that the individual's life has been negatively affected but also that the administrative costs involved in repeatedly assessing individuals far outweighs the apparent initial saving in reducing their original award.
- e. Therefore a Risk Assessment needs to be carried out to determine if, as is strongly suspected, the real administrative cost to central government of the introduction of a 20 metre rule would be much greater than any short term cost savings.
- f. Further, the combination of human suffering for those who lose independence and have to battle through appeals to regain it along with the overall administrative cost should be assessed in order to calculate if this proposal is in fact both cruel **and** expensive.
- g. Administrative costs would of course be compounded by the costs to local authorities who have to respond to increased need for support of those who have lost independence and whose health and wellbeing deteriorates as a result of reduction from enhanced to standard rate of PIP.

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- h. There would be further stresses also on the third sector who would be called upon to replace independent mobility with community transport.
 - i. Similarly, for those who could make use of public transport to any extent there would be the extra cost to central government of reimbursing public transport operators under the Concessionary Bus Fares Scheme for disabled and older people **and** their Carers or Support Workers.
 - j. Again, loss of access to social connections would have health and wellbeing implications, while loss of access to education and employment would have much wider social and economic repercussions including:
 - i. loss to central government of income tax for those who can no longer work and
 - ii. increases in benefits take-up for those thrown out of work by this change.
 - k. However, it must be clearly understood that whatever the additional costs of appeals; extra social support; community transport; a poorer educated population; loss of income tax take combined with an increase in benefits payments; increased stress on health service etc. the cost in human suffering is by definition incalculable but will be enormous and will include both a death toll and the shortening of many people's lives, on top of the loss of quality of life for many thousands and an increase in stress for Carers². This fact alone should be sufficient for **any** government to withdraw such a proposal but the fact that the very people affected are those who any government would acknowledge most need society's support should make this consultation redundant.

4. Transition Protection

- a. If UK Government presses ahead with this proposal then a number of protections need to be put in place to at least reduce the damage experienced by disabled people:
 - i. The extreme nature of the reduction in quality of life associated with a drop from enhanced to standard rate should be recognised by a period of protection to allow people to find ways to mitigate the harm done.

² A separate study will be needed to assess the effects on Carers of loss of enhanced rate for the person they support. Many Carers live on a knife edge of coping from day to day and you may have to anticipate a suicide spike in response to the traumatic effect of loss of independence this proposal will cause, plus all of the attendant increases in demand for GP and Social Services support. I declare my interest as a Carer for 25 years and counting.

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- ii. This should be measured in years to reflect the devastating nature of the loss of independence this change will bring. We strongly urge a five year period.

5. Training

- a. The training of assessors will be absolutely crucial in harm prevention.
 - 1. Genuine Disability Equality Training must be the foundation for any other training for these assessors³
 - 2. The caveats of 'repeatable, in a reasonable time period and to an acceptable standard' applied to the distance criterion must be drummed in to assessors as qualifiers that they must apply consciously at all times and the computer software should be adjusted so that assessors are reminded of this at random periods to reduce the tendency to see the words so often that they are ignored.

6. Notes on use of language and terminology within the document

- a. Disabled people have chosen to be referred to as 'disabled people'. This term is in keeping with the Social Model of Disability, which since 2005 has been the required paradigm within which all government policy must be framed. The term 'people with disabilities' is a Medical Model term and implies that the barriers that disabled people face are due to their impairments rather than social barriers: the law says that this is not true and that disabled people are people who have impairments and it is social barriers inflicted on top of those impairments that disable them. To deny this is to practice institutional disability discrimination.
- b. Similarly, people with mental health issues have chosen to be referred to as 'people with mental health issues'. Referring to "mental impairment" is just rude.
- c. References in the text to "people who suffer from" are unacceptable: the phrase "suffers from" is subjective – only the person who experiences the pain or impairment is in a position to determine if they consider that experience as "suffering". It is inappropriate for others to apply this term arbitrarily.

³ Disability Equality Training must not be confused with Disability Awareness Training. Disability Equality Training is offered only by appropriately trained and qualified disabled people.

On a personal note: it has been suggested to me that a sound political stance would be to stand back and let this shameful Coalition Government do its worst to poor people and disabled people in the expectation that the British public will be so shocked by their government's callous and inhuman behaviour that in 2015 the Conservative party will be relegated to permanent opposition and the Liberals wiped off the political landscape. While I think this is probably politically true it is unconscionable to allow the human despair and destruction that would occur in just two years without resisting.

Until recently I believed that Britain was moving, albeit painfully slowly, towards a level of civilization and that the new century was really something to look forward to. This Coalition Government has soured that hope and will go down in history as the disgrace it is. When a Secretary of State unashamedly quotes from the gates of Auschwitz that "work makes you free" while stripping away every vestige of human dignity from those least able to defend themselves it is time to hope that we have gone as low as we can in British politics and to aspire to a healthier future.

Under normal circumstances I tend to believe that government policies, however misguided I believe them to be, are drawn up with the best of intentions and within a Judeo-Christian ethic. The 'Welfare Reform' strategy has however thrown that belief aside and it is quite clear that this Coalition Government, in protecting those with the greatest wealth and watching the death toll of its policies on the poorest in society rise, has abandoned any pretence of principle or moral authority.

It is also tempting to suspect however that the 20 metre threat was thrown in as a calculated attempt to distract attention from the wider damage this government is inflicting upon disabled people and will be withdrawn, as always intended, at the last minute.

Shame on you!

Vin West
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Sunday 4th August 2013