Briefing on ESA Regulations

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Regarding *The* *Employment and Support Allowance (Amendment) Regulations 2012*, reference 2012 No. 3096

1. These regulations are presented as minor clarifications, but **in fact represent fundamental changes in how capability for work is to be assessed**.
2. There are positive changes to allow more cases to be placed in the Support Group without full assessment. However, these are overshadowed by changes that will clearly reduce entitlement overall.
3. The problems fall into two areas, likely to lead to claimants' capability being overestimated:
    a. The assumptions that can be made by an assessor
    b. What symptoms can be considered in which parts of the assessment

Assumptions Made By Assessors

4. **At present, an assessor can assume that a claimant could use some aids that they do not use**, and determine what the claimant's capability would be using that aid. **Many people have experienced problems with the "imaginary wheelchair test"**, in which the assessor decides they would be mobile with a manual wheelchair without discussion, and despite guidance from the DWP, sometimes without regard to the appropriateness or availability of a wheelchair for that claimant[1].
5. **Following these amendments, regulations would extend this to include imaginary prostheses and guide dogs**[2], extending "could reasonably be used" criteria to most parts of the assessment. In what circumstances a guide dog or prosthesis "could reasonably be used" when not used at present is unclear. If it is clear that a guide dog, for example, may be appropriate, availability is limited. **Obtaining and adjusting to an assistance dog takes considerable time and effort**[3]**. Concerns of adjustment apply to many aids.**
6. **The amendments would also allow any potential risk resulting from being found fit for work to be ignored** if a reasonable adjustment, or taking prescribed medication, would significantly reduce that risk. This may include cases where the risk is still considerable - if it is significantly reduced by hypothetical adjustments, it can be ignored[4]. **There is no stated requirement to take into account side effects of such medication.**
7. This also raises the question of **assuming a claimant will take any medication** they have been prescribed, calling into question **issues of medical consent**.

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[1] Recordings made for Channel 4's *Dispatches* show assessors instructed to give very broad interpretation to "could reasonably use" in the case of the 'imaginary wheelchair'. Quote may be found in Amelia Gentleman's write-up for The Guardian: http://www.guardian.co.uk/society/2012/jul/27/disability-benefit-assessors-film

[2] S.I. 2012/3096 Regulation 5 (1) (f)

[3] Guide Dogs information on training includes description of the training required by the user: http://www.guidedogs.org.uk/services/guide-dogs/applyforaguidedog/faqs/training/

[4] Further information may be found in part 3 of the appendix to this briefing

What Can Be Considered

8. The activities considered in the WCA have always been divided into two groups, Part 1 (labeled 'Physical Disabilities') and Part 2 ('Mental, cognitive and intellectual function assessment'). Part 1 concerns physical and sensory impacts, while part 2 considers emotional, cognitive and intellectual impacts.
9. However, **it was always clear in the regulations that any condition** ("a specific bodily disease or disablement" or "a specific mental illness or disablement") **could be considered in causing difficulty in any activity**. Furthermore, the side effects of any medical treatment, including medication, could be considered in any activity[5].
10. **The amendments propose to strictly separate the two parts**. Part 1 activities will only consider the effects of "a specific bodily disease or disablement", while Part 2 activities will only consider the effects of "a specific mental illness or disablement".
11. **Similarly, only side effects of treatment for physical conditions will be considered in Part 1, and side effects of treatment for mental illnesses only in Part 2**[6].
12. **This is inappropriate** for several reasons:
    a. **It is not possible to cleanly separate illnesses into the physical and the mental**; many conditions still have no clear aetiology, and many people are clearly ill but medicine has determined no appropriate diagnosis. In some cases, people have clear physical and mental illness, but the two interact in complex ways.[7]
    b. **Many diseases that are not yet well-understood have both physical, mental and cognitive effects**, and have been argued to have both physical and mental causes. Examples include ME and fibromyalgia.
    c. **Even where a disease is well-understood, it can have impacts that are both 'physical' and 'cognitive'**. A well-understood example is that of multiple sclerosis, that can cause paralysis, loss of sensation, vision, or any number of physical effects, but can also cause mood instability and loss of cognitive capability.[8]
    d. **Many medications for mental health problems produce physical side effects, and vice-versa**. A person who suffers severe chronic pain from a purely physical cause may take strong painkillers that severely compromise their cognitive ability, but the amended regulations would require that this effect be disregarded.[9]
13. **The Government may claim that this is clarifying policy intent, but the stated policy of this Government has been that the effects of impairment be considered without reference to the condition causing them**[10]. Indeed, this is also the stated policy intent of the Government that introduced ESA and the WCA[11].

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[7] Examples and references are given in part 2 of the appendix to this briefing

[8] NHS Information on MS symptoms: http://www.nhs.uk/Conditions/Multiple-sclerosis/Pages/Symptoms.aspx; MS Society information on symptoms: http://www.mssociety.org.uk/what-is-ms/signs-and-symptoms

[9] A collection of examples and references are given in part 1 of the appendix to this briefing.

[5] S.I. 2008/794 Regulation 19 (5)

[6] S.I. 2012/3096 Regulation 3 (2) (b)

[10] Hansard references are given in part 4 of the appendix to this briefing.

[11] Hansard references are given in part 5 of the appendix to this briefing.

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Appendix: Additional Information and References

1 - Treatments for Mental Conditions Causing Physical Side Effects, & vice-versa

Parkinson's UK have produced a guide to different types of parkinsonism[12], including drug-induced parkinsonism. Parkinsonism is a set of physical symptoms, but may be induced by neuroleptic treatments generally used to treat psychiatric conditions such as schizophrenia.

Similarly, information on adverse effects of levodopa[13], used to treat Parkinson's disease, shows that in treating a physical condition with physical manifestations, serious mental and cognitive side effects can result. These range from anxiety, elation or depression to the more alarming aggression, paranoid delusions or hallucinations.

Gabapentin is used to treat a range of conditions involving pain (particularly neuropathic pain) as well as epilepsy, for which it was developed. However, adverse effects[14] include drowsiness, dizziness, and impaired mental alertness. These can lead to difficulties in the the mental, cognitive and intellectual part of the assessment (part 2).

Baclofen is used to treat physical symptoms related to muscles in a range of conditions, including cerebral palsy, motor neuron disease, and multiple sclerosis[15]. Common side effects include depression, confusion and hallucinations.

In a Primary Psychiatry article exploring psychiatric issues in heart disease[16], we can see a concise summary of common psychiatric side effects to drugs used to treat cardiovascular disease.

A study by Fava *et al*[17] found that over 40% of participants taking antidepressants long term, all in full or partial remission of major depressive disorder, experienced significant physical symptoms including fatigue and sedation.

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[12] http://www.parkinsons.org.uk/about_parkinsons/what_is_parkinsons/types_of_parkinsons.aspx

[13] http://toxnet.nlm.nih.gov/cgi-bin/sis/search/r?dbs+hsdb:@term+@na+levodopa

[14] http://toxnet.nlm.nih.gov/cgi-bin/sis/search/r?dbs+hsdb:@term+@na+gabapentin

[15] http://www.nhs.uk/medicine-guides/pages/MedicineAbout.aspx?condition=Motor%20neurone%20disease&medicine=baclofen&preparation=; http://www.nhs.uk/medicine-guides/pages/MedicineAbout.aspx?condition=Multiple%20sclerosis%20and%20other%20demyelinating%20conditions&medicine=baclofen&preparation=

[16] http://www.primarypsychiatry.com/aspx/articledetail.aspx?articleid=493

[17] J Clin Psychiatry 2006:67:1754-1759

2 - Interconnectedness of Physical and Mental Health

The amendment regulations are predicated on the separation of illnesses into the physical and the mental. An immediate problem of terminology occurs, as Part 2 activities look at mental, cognitive and intellectual factors, not just mental health factors. In order, for example, for dementia to be considered in this section, conditions such as early-onset Alzheimer's would have to be considered "mental illness".

Beyond the question of terminology, however, is the simple fact that medicine cannot clearly separate conditions in this way. We have given the example of multiple sclerosis, a disease of physical aetiology, yet exhibiting symptoms in a broad range of areas - sensory deficiency, paralysis, weakness and fatigue would be considered physical, but cognitive dysfunction, confusion and mood disturbances could not be considered physical. For references, see footnote 7 in the main part of the briefing.

A further example of difficulty in the proposed classifications is presented by autism. Autism Spectrum Diagnoses/Disorders (ASDs) occupy an obscure diagnostic category, referred to as Pervasive Development Disorders (PDDs), distinct from mental health, psychiatric illness, learning disability or brain injury. ASDs are characterised by ritualistic behaviours linked to a need to manage and make sense of sensory input. The inability to perceive what an Autistic person perceives often leads to misunderstanding by people around them. Sensory issues are common in ASD and PDDs but go unnoticed, as most people (including those with ASD-PDD) take it for granted that they are processing information differently. Sensory input can affect cognition, which in turn prompts typically 'Autistic behaviour' that replaces or alters undesirable sensations with more preferable ones. The primary literature reveals mixed views on sensory issues, but dissenting papers such as Rogers and Ozonoff[18] tend to look mainly at children and historical research that did not seek out Autism-specific features that are self-reported by Autistic adults[19]. Currently ESA regulations can be interpreted to account for these complex features of Autism, but not under the intended changes.

Nor is it sufficient to classify some conditions as being both physical and mental. Firstly, this would be a massive task, as there are a great many conditions known to medicine, and the growth of medical knowledge only increases that number. Physical and mental health are now understood to be so interconnected that any illness could have effects crossing this seemingly convenient barrier. For example:

- Pain, particularly chronic pain, can have a direct impact on cognition. Dick *et al*[20], studying sufferers of chronic intractable pain, found that "high levels of pain disrupt cognition during the performance of demanding tasks". However, these changes to ESA rules would ignore out of hand any effect of pain on cognition.

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[18] Rogers, S. J. and Ozonoff, S. (2005), Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence. Journal of Child Psychology and Psychiatry, 46: 1255–1268. doi: 10.1111/j.1469-7610.2005.01431.x

[19] *Sensory Issues in Autism*, Autism and Practice Group, East Sussex Council 2007 https://czone.eastsussex.gov.uk/specialneeds/autism/Documents/sensory%20issues%20in%20autism.pdf

[20] B.D Dick; J.F Connolly, P.J McGrath, G.A Finley, G Stroink, M.E Houlihan, A.J Clark, 2003, The disruptive effect of chronic pain on mismatch negativity. Clinical Neurophysiology, 114(8): 1497-1506 doi: 10.1016/S1388-2457(03)00133-0

- Chronic pain is also a predictor of mental health conditions. In a large study, Demyttenaere *et al*[21] found that “mental disorders were more common among persons with back/neck pain than among persons without”, and “association of mental disorders with back/neck pain showed a consistent pattern across both developed and developing countries.” The National Pain Audit (2012)[22] is also clear about the link between chronic pain and mental health conditions, citing the Chief Medical Officer's 2008 claim that “in 49% of those with chronic pain there is depression, and this can result in suicide.”
- Physical illnesses can easily lead to profound mental health complications, such as described by Shalev *et al*[23]. They found that “a possible occurrence of post-traumatic stress disorder (PTSD)[24] should be considered among patients who have undergone a medical event associated with a feeling of intense and inescapable distress, lack of control, and perceived or actual threat to life.” Indeed, it is not difficult to find many reports of such experiences online. Van der Kolk *et al*[25] explore the issues of PTSD, demonstrating repeatedly that the mind and body cannot be clearly separated.
- There is an entire category of conditions that are psychiatric in origin but manifest principally physical symptoms, known as somatoform disorders[26]. A claimant with a somatoform diagnosis may receive no support under these changes, as their diagnosis is of a mental health condition, yet the symptoms are physical, in many cases giving severe functional limitations. Löwe *et al*[27] found “substantial associations of somatoform disorders with functional impairment and elevated health care costs”, so declining to support these claimants cannot be justified.

Finally, where a person has both physical and mental health problems, the synergy between them produces greater effects than either would in isolation. If it is painful to get up and walk 50 metres, a person who is significantly depressed will find a given degree of pain a greater barrier than a person who is not, as they will face greater barriers in motivating themselves in spite of the pain. In cases of mental illness comorbid with physical illness, it can be impossible to determine which is responsible for a given functional limitation.

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[21] K. Demyttenaere, R. Bruffaerts, S. Lee, 2007, Mental disorders among persons with chronic back or neck pain: Results from the world mental health surveys, Pain, 129(3): 332-342 DOI:10.1016/j.pain.2007.01.022

[22] http://www.nationalpainaudit.org/media/files/NationalPainAudit-2012.pdf, p. 11

[23] A.Y.Shalev, S. Schreiber, T. Galai, R.N. Melmed, 1993, Post-traumatic stress disorder following medical events. British Journal of Clinical Psychology, 32(2): 247-253 doi:10.1111/j.2044-8260.1993.tb01052.x

[24] The DSM-IV description of PTSD can be found online at http://www.mental-health-today.com/ptsd/dsm.htm

[25] Van der Kolk, B.A., McFarlane, A.C., Weisaeth, L. 'Traumatic stress: the effects of overwhelming experience on mind, body and society.' ISBN 1-57230-088-4

[26] DWP A-Z of medical conditions: http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/somatoform-disorders/

[27] B. Löwe, C. Mundt, W. Herzog, R. Brunner, M. Backenstrass, K. Kronmüller, P. Henningsen, 2008, Validity of Current Somatoform Disorder Diagnoses: Perspectives for Classification in DSM-V and ICD-11 Psychopathology 41:4-9 doi: 10.1159/000109949

3 - Assumption of Reduced Risk

The Black Triangle Campaign's medical advisor, Dr Stephen M Carty MB ChB MRCGP DRCOG, has commented on the proposal to disregard risk where it can be significantly reduced.

> "I have grave concerns about this guidance to decision makers, though I understand the principle that may underpin some of the thinking.
>
> The examples given are rather simplistic.
>
> A common reason for having LCW is due to severe and intractable pain.
>
> For a decision maker to get involved in decisions/judgments about chronic pain management is totally inappropriate.
>
> The commonest drugs used for chronic pain are opiates, neuropathic agents(such as gabapentin) and tricyclic antidepressants (such as amitriptyline).
> They individually and collectively have very significant side effect profiles and interactions.
>
> It must not be the place of an unqualified unskilled administrator with very limited knowledge of the claimants past medical history or medication history
> to make inferences that a chronic pain problem could be simply remedied by a trip to the GP for some tablets.
>
> These medications taken on their own or together frequently cause significant drowsiness or confusion. Lightheadedness, clumsiness and an increased risk of falls.This may represent a substantial risk to the claimant and potentially anyone they work with.
>
> They are amongst the commonest drugs responsible for avoidable hospital admissions and their prescribing is a delicate balance of risk between Doctor and patient.
>
> For an unqualified decision maker to presume to have a role in Chronic Pain management or for that matter any other element of health care provision, represents
>
> **"An ill informed leap of faith into the abyss of complex risk management"**
>
> In my experience it is precisely these medications - whilst sometimes necessary to control symptoms of pain - that present the sort of "substantial risk" that regulation 29 and 35 should be applied to.
>
> Theses statutory instruments are a very serious development and need to be fully considered and their potential application risk assessed immediately"

We may assume that such a decision to disregard will be taken on the advice of a Medical Services Health Care Professional (HCP), a service currently provided by Atos, it is not clear that the risk will be determined anew given any assumptions, and determined to be not sufficient to warrant a finding of Limited Capability for Work. Furthermore, just because a doctor has prescribed a medication for a patient, it does not follow that either the doctor or patient would

consider it appropriate in any given context.

4 - Government Statements on Effect vs Nature of Condition

Ministers have, on several occasions, made statements regarding the principle that assessments take account of the effect of conditions, not the nature of those conditions; this is a logical position with widespread support. However, the proposed separation of physical and mental conditions in the WCA seems to be in opposition to this principle. A selection of Government and ministerial statements supporting this principle in relation to ESA and the Work Capability Assessment are given below:

Maria Miller, Parliamentary Under Secretary of State (Disabled People) (HC Deb, 24 November 2011, c567W):

> "We do not believe it right that we should judge people purely on the type of health condition or impairment that they may have. As such neither the work capability assessment nor the assessment for personal independence payment which we are currently developing, focus on the health condition or impairment a claimant has, neither do they require a specific diagnosis. Instead they look at the impact of these and their symptoms, such as pain, on individuals. The work capability assessment focuses on the impact of health conditions or impairments on capability for work, while the assessment for personal independence payment will focus on their impact on ability to carry out a series of key everyday activities."

Chris Grayling, Minister of State (Employment) (HC Deb, 10 January 2011, c119W):

> "However, the WCA is a functional assessment. Eligibility is not based on having a particular condition but on the impact that condition has on an individual's functional ability. This is why it is important for us to assess each claimant individually, and why no particular conditions are 'exempted' from the WCA."

Chris Grayling, Minister of State (Employment) (HC Deb, 18 October 2011, c935W):

> "Entitlement to employment and support allowance is determined using the work capability assessment which is based on the premise that eligibility should not be based on the diagnosis of a specific condition, but rather on the way that the condition limits an individual's functional, capability."

Mark Hoban, Minister of State, Department for Work and Pensions (HC Deb, 5 November 2012, c589):

> "What the work capability assessment does is assess people's ability to work. It is a review of their capability and functionality, not a diagnostic assessment."

A recent House of Commons Library briefing paper regarding ESA and the WCA (www.parliament.uk/briefing-papers/SN05850.pdf) quotes a DWP memo submitted to the SSAC:

> "It is a functional assessment which focuses not on an individual's condition but on the functional effects on that particular individual."

5 - Statements of the last Government on ESA/WCA Policy Intent

Statements from the previous Government clarify the original policy intent of ESA and the WCA, as regards the relevance of diagnosis, or the type of condition.

Jonathan R Shaw, Minister of State (Disabled People) (HC Deb, 21 July 2009, c1331W):

> "The number of people claiming incapacity benefit has fallen in recent years. The number of people claiming for physical conditions has fallen significantly as a result of Government programmes to get more people who are able to work back into suitable employment. The number of people claiming incapacity benefit for mental health conditions has remained broadly unchanged over the last few years.
>
> …
>
> We have replaced the old system of incapacity benefits with the more work-focused employment and support allowance to engage with people more actively and to ensure they are aware of opportunities available.
>
> The essential rule for entitlement to either incapacity benefit or employment and support allowance does not depend on an individual's diagnosis or condition, but on the effect that condition, or a combination of conditions, has on each individual's mental and physical function."

Jim Murphy, Minister of State (Employment and Welfare Reform) (HC Deb, 20 June 2006, c1783W):

> "We are still developing details of the criteria that will decide whether a person's physical or mental functions are so severely limited that it would be unreasonable to require them to engage in work-related activity. We want to ensure that the criteria are based on functional ability, not on diagnosis, and that they will correctly identify those who should receive benefit without having to take part in work-related activity, without dismissing those for whom engagement is possible."