

Disability Rights UK



Professor Harrington's 3rd WCA Review

Disability Rights UK Response – September 2012

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Introduction and background

Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012. We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK's objectives are:

- To mobilise disabled people's leadership and control;
- To achieve independent living in practice;
- To break the link between disability and poverty; and
- To put disability equality and human rights into practice across society.

With half working age disabled people out of work, we see an effective Work Capability Assessment (WCA), as a key means of ensuring disabled people can access appropriate out of work support, including income. Sadly, the current test is unfit for purpose and fails disabled people at a considerable human and financial cost to the UK taxpayer.

We believe the wasted resources would be better spent supporting disabled people through training, skills and real work opportunities. Over £50 million was spent on the appeals for WCA/ESA decisions last year. This funding would support thousands of disabled people under the Access to Work scheme and it is bitterly disappointing that the recommendations of the former Harrington reviews have not been implemented to prevent this tragic waste of funding and opportunities.

We are also a member of the Disability Benefits Consortium (DBC) and support the response and recommendations the DBC is also submitting.

Our response

The following information represents our report of the responses to our online survey relating to disabled people's experiences of the WCA. The questions we used to form our survey are attached as an Appendix.

We then include further examples of how the WCA affects specific groups of disabled people – most of which have been provided by some of our member organisations. We are grateful to the Greenwich Welfare Rights Unit, the Dystonia Society and the Camberwell ME Support Group – and their disabled member and/or clients – for sharing their further experiences of the WCA.

The results of our WCA survey

We are an inclusive organisation, run and controlled by disabled people. We try to engage individual disabled people in all our work, but especially our policy and campaigns activities.

We ran a survey using the formal Review questions as well as some of our own to generate this response. This ran online and was advertised to members in our newsletter and Updates – including post copies as an accessible means of communicating. Almost 800 people responded.

We are very grateful for member organisations and individuals who responded to our survey on this issue. Thank you for your input.

The people who helped shape our response

Almost 800 people responded to our survey.

Almost three quarters (74.2%) self-identified as disabled people, 16% were a family/friend/carer/advisor of disabled people and 9.8% were non-disabled people.

Two thirds of our respondents were aged 45-64 (66.3%). Exactly one quarter were 25-44 with 6.3% being over 65 and just 2.4% being 16-24.

59.8% of our respondents were women, 39.4% were men and 0.8% declared transgender status.

More than a third (34.2%) had undergone a WCA personally with many others advising and/or otherwise supporting people who had (19.7%).

Almost a third of our respondents (31%) received ESA with just 2.1% receiving Jobseeker's Allowance. 64.2% of respondents received neither.

The WCA and its role in supporting disabled people into work

Disability organisations and many disabled people believed the WCA would act as a new gateway to accessing either appropriate benefit levels or the support to get and keep work never formerly provided – including skills, training and work experience. Some disability organisations welcomed the introduction of Employment and Support Allowance from 2008 with this belief.

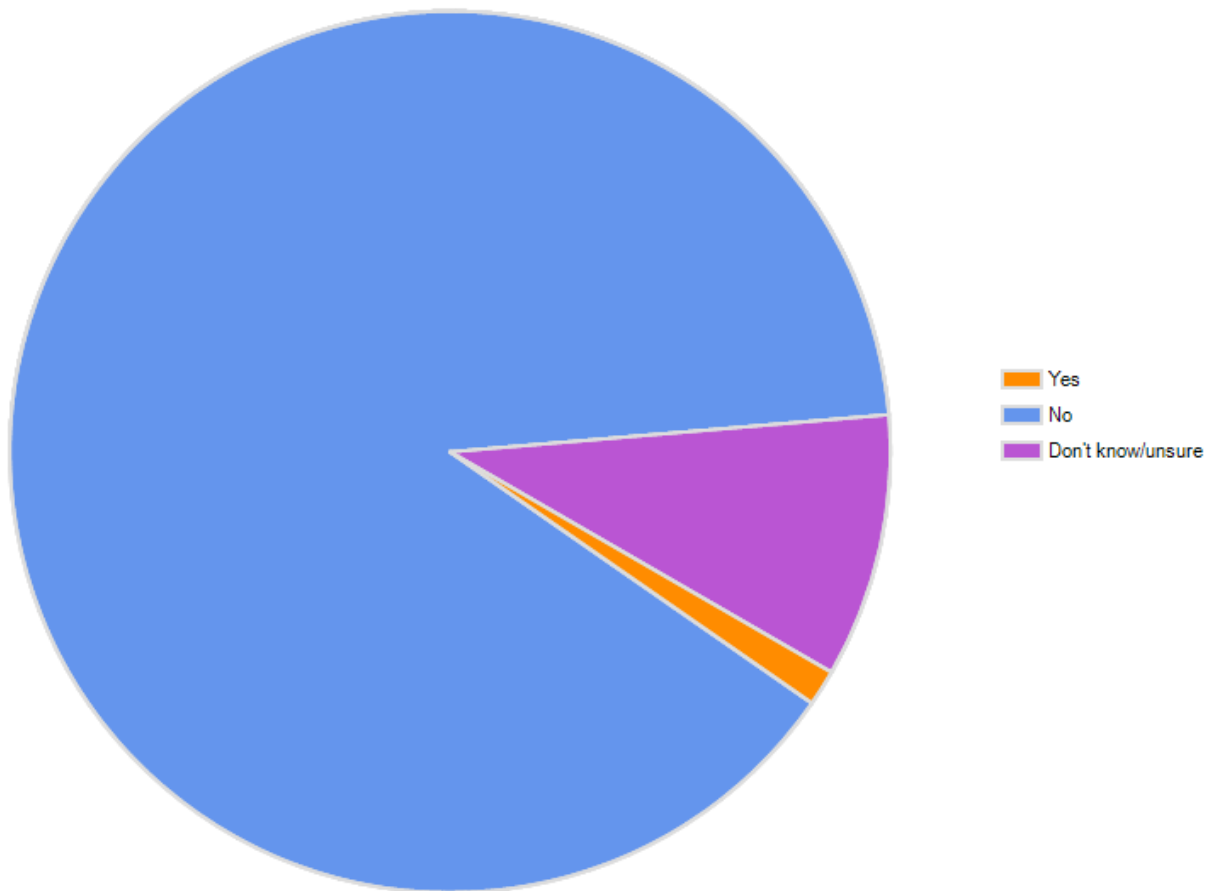
Sadly, we cannot conclude the introduction of ESA has had the positive effects intended by 'no one written off' rhetoric – with too many disabled people failed by the system, forced onto inappropriate benefits and lacking sufficient help to enter work.

The future appears bleak for many more disabled people given the new 365 day time limit imposed since April 2012 even for disabled people in the Work Related Activity Group (WRAG) – and competition for available work at a very high level.

The findings of our survey demonstrate a clear crisis of confidence in the testing system and urgent improvements are required now to prevent further damage to disabled people's lives, the lives of disabled people's families – and to prevent further waste of public funding on a system that remains unfit for purpose.

We asked if people felt that the WCA was an adequate test of fitness for work. The results were resounding:

Do you think the WCA provides an adequate test of ability to work?

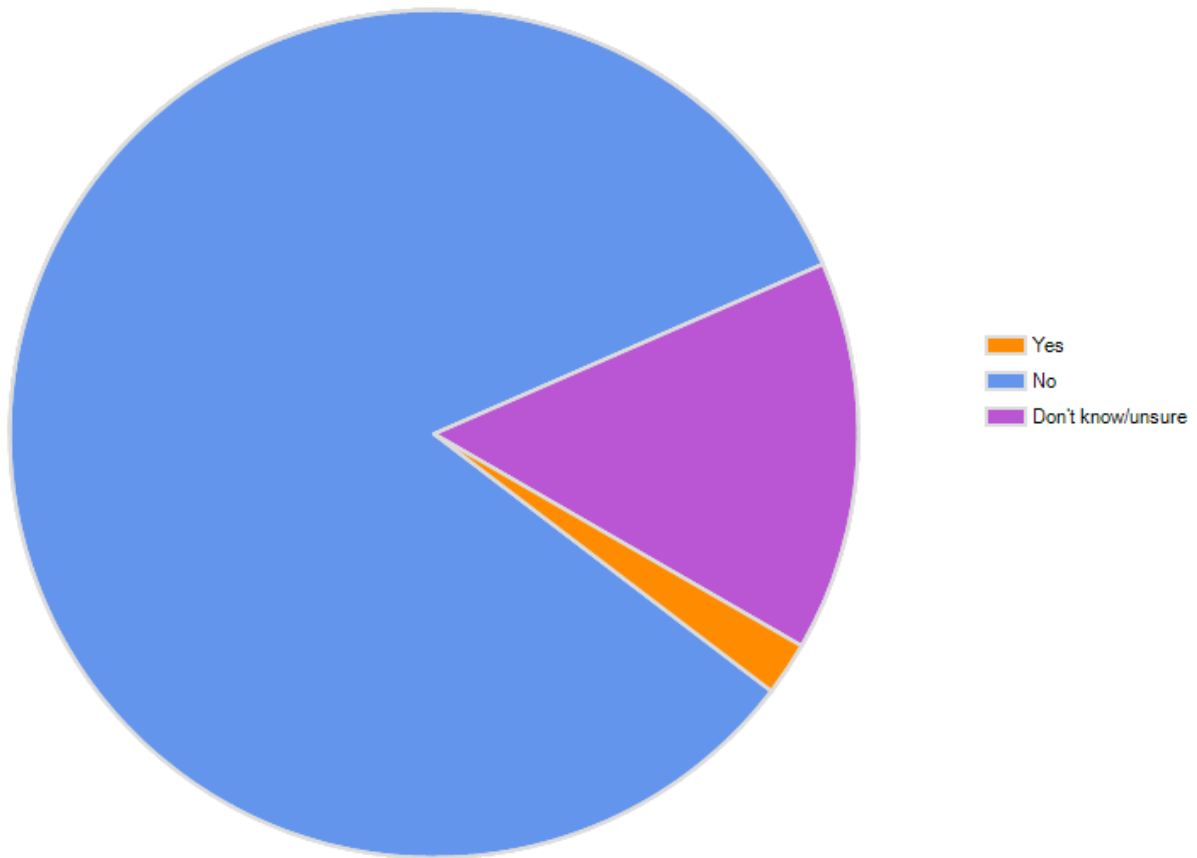


An overwhelming 88.7% of respondents did not believe the WCA is fit for purpose. Just 1.4% concluded that it was an adequate test of ability to work. 9.9% didn't know or were unsure.

We have worked with the Government to try and improve the WCA and design a better system. We asked if people felt the Government should work with disability organisations and employers to ensure the WCA was developed into an appropriate test of work ability and 98% thought this was a sensible approach, 1.1% disagreed and 0.9% were unsure or didn't know.

We asked respondents about whether the WCA helped disabled people access sufficient support. The results are clear:

Do you think the WCA ensures disabled people can access sufficient support?



Just 2.1% of our respondents thought the WCA was helping disabled people access sufficient support. 83% believed the WCA was not helping disabled people access sufficient support and 14.9% either didn't know or were unsure.

We also asked people if the WCA was helping get disabled people into work. The results were equally astonishingly resounding:

- 83.4% said the WCA did not help more people into work;
- Just 4% suggested the WCA did help more people into work; and
- 12.7% didn't know or were unsure.

Harrington Review responses

We asked the specific questions from the Review. A breakdown of these responses is available to the Harrington Review team if required.

Q1a: We asked if respondents had undergone more than one WCA:

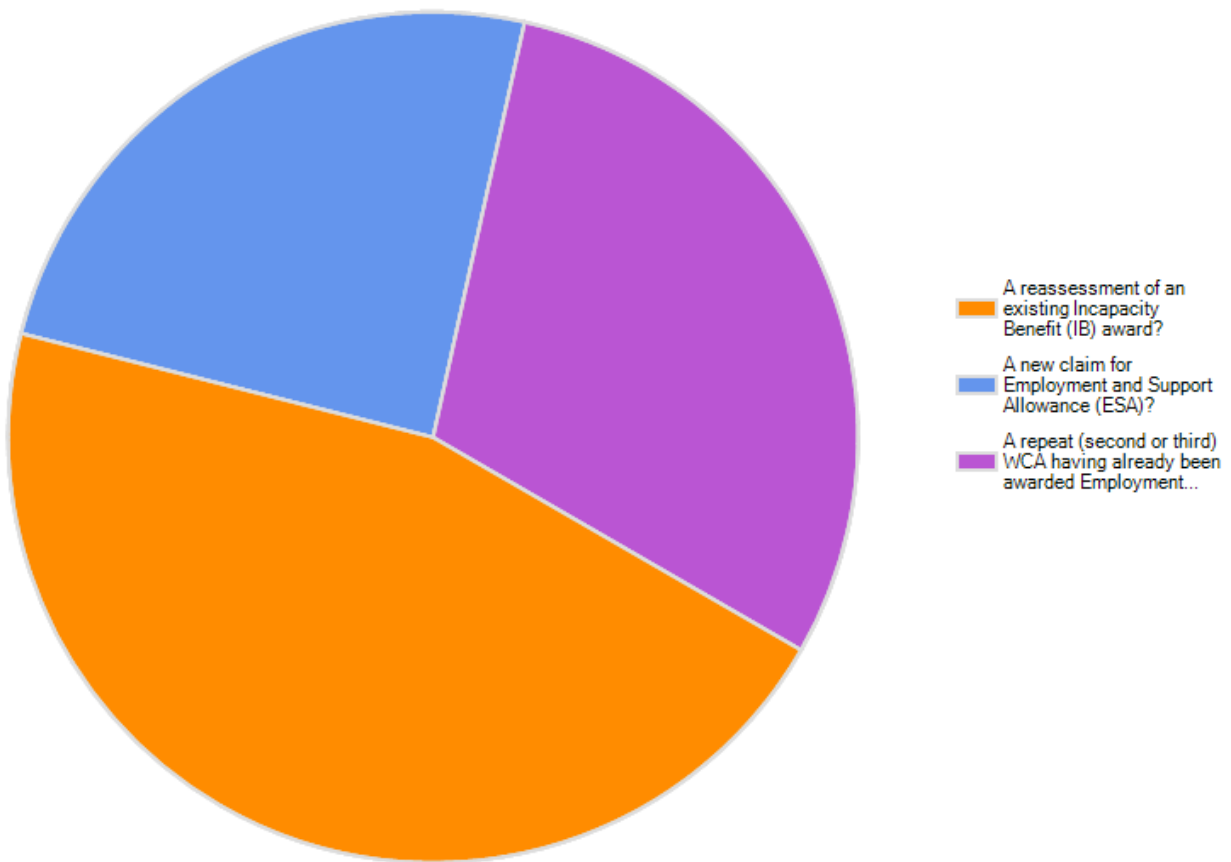
- 31.4% had undergone more than one WCA; and

- 68.6% had not.

Q1b: We asked what the reason for the most recent WCA was:

- 45.6% were for a reassessment of an existing Incapacity Benefit award;
- 24.5% were a new claim for Employment and Support Allowance; and
- 29.9% were a repeat WCA after an ESA award.

Harrington Question 1b: Was your most recent WCA: (Please select only one)



Q2: We asked where people underwent their WCA and:

- 33.1% were in South East England;
- 12.5% were in South West England;
- 11.1% were in North East England;
- 14.1% were in North West England;
- 19% were in the Midlands;
- 6.3% were in Scotland; and
- 3.9% were in Wales.

Q3: We asked what people were assessed for, and:

- 18.4% were for a mental, intellectual or cognitive condition or disability;
- 40.1% were for a physical health condition or disability; and
- 41.5% said both.

Q4: The outcome of awards were:

- 30.3% were found fully fit for work (JSA);
- 41.2% entered the ESA WRAG; and
- 28.6% entered the ESA Support Group.

Q5a: Thinking about the start of the claim, we asked if there were any changes in the telephone contact between the respondent and DWP between the first and most recent WCA:

- 5.9% said there had been an improvement;
- 26.2% said it was not as good; and
- 67.9% said there was no change.

Q5b: We asked if respondents noticed any changes to the written communications from DWP between the first and last WCA:

- 4.7% said there was an improvement;
- 62.5% said there was no change; and
- 32.8% said it was not as good.

Q5c: The DWP ESA50 limited capability for work questionnaire form has been amended. We asked if this had improved:

- 8.8% said it had improved;
- 37.4% said it was not as good; and
- 53.9% said there was no change.

Q6: We asked if there was there a notable difference between the first and most recent face to face WCA:

- 22% said the first was better;
- 65.6% said there was no difference; and
- 12.4% said the last was better.

Q7a: We asked if respondents, since the last WCA, had noticed a difference in the way in which the outcome was communicated by a DWP decision maker:

- 7.5% said there had been an improvement;
- 56.3% said there had been no change; and
- 36.2% said it was not as good.

Q7b: We asked if additional evidence provided in support of a claim (eg from a GP, consultant or support worker) was taken fully into account by the DWP decision maker:

- 11.5% said evidence was considered and changed the initial decision;
- 24.3% said evidence was considered but didn't change the decision;
- 35.5% said evidence was supplied but not considered; and
- 28.6% said this was not applicable.

Improving confidence in the system

We also asked if the Government should publish annual statistics for the number of disabled people supported into work. This was a central aim of the welfare reforms begun by the last Government in response to 'The Missing Million'¹ and other reports which highlighted disabled people's aspirations and desire to work, but lack of opportunities in a disincentivising benefit system.

We believe demonstrating that the abolition of incapacity benefits was about delivering real support to get and keep work requires this kind of data – and publishing it would significantly boost confidence in the system (if disabled people are attaining/retaining work). Of our respondents:

- 92.6% agreed the Government should publish results;
- 2.6% thought this was not necessary; and
- 4.9% didn't know or were unsure.

We believe if disabled people are to be confident reform is about developing skills and opportunities for work, then DWP and Government more generally should provide information on the success rate of supporting disabled people into employment.

We asked if people wanted to work. Just 13% said no, 67.5% were keen to work and a further 19.5% were unsure. Only half working age disabled people in work and we believe employment is a route out of poverty for many disabled people – with appropriate support as required.

Currently, the belief is that the original WCA and the adjustments under the Coalition Government have been driven by cost-savings. Only full data and a

¹ See: <http://www.ippr.org/publication/55/1341/the-missing-million-supporting-disabled-people-into-work>

concerted employment effort will change that negative perception of welfare reform.

Examples of WCA experiences from member organisations

Below we include some further information from our member organisations. Our members are delivering frontline support to disabled people and many are led/controlled by disabled people. Some of the examples have been made anonymous.

We are particularly grateful to the Greenwich Welfare Rights Unit, Dystonia Society² and Camberwell ME Support Group for some of the examples provided in this section of our response.

Communication and administration

There appear to be failures of communication and administration that in many cases are compounded by punitive responses to perceived non-compliance.

March 2012 – Z contacted the DWP having received a letter dated 17th March reminding her that she needed to complete her ESA50. Z had not received an ESA50 to complete. Z received this letter on the 20th and it stated DWP must receive the form on the 21st March. Z was advised a note would be placed on the system and an ESA50 would be issued. Z returned the ESA50 along with medical evidence a week later (it could not be completed sooner due to requiring support to fill the form). A few days later Z discovered ESA payments had been stopped. The JCP team refused to accept that Z had good cause for not returning the ESA50. After three weeks without an ESA payment (the time it took for the ESA50 to be received in the office) the JCP team finally accepted Z had good cause for not returning the initial ESA50, reinstated the benefit and paid backdated ESA. In the meantime Z, who is disabled and has a child of school age, was forced to rely on crisis loans for living expenses.

A lack of flexibility in the system or in DWP staff and contractors' decisions is unsuitable considering the serious health problems experienced by many customers. Many customers have problems attending appointments due to physical and mental health problems. Instead of trying to facilitate attendance, the first response is often to stop an award of benefit.

² The Dystonia Society is the national organisation providing information and support to everyone affected by dystonia in the UK. Information on the Society and on dystonia can be found at: <http://www.dystonia.org.uk/>

May 2012 – W was due to attend a medical assessment on a Sunday but was unable to attend due to illness. W rang the helpline but discovered it was only open Monday-Saturday. W rang on Monday morning to explain the non-attendance but was informed papers had already been sent to DWP stating he had failed to attend. JCP told W that they would not reconsider the decision without a letter from W's GP stating that he had been unable to travel on the Sunday. The GP would not provide a certificate as the GP had not seen W in the short period of illness. JCP upheld the decision to stop benefit.

Failure to issue letters regarding important decisions relating to benefit claims also seems to be a common occurrence. This is very problematic due to the conditions and impairments of the disabled people seeking ESA.

March 2012 – N has ME and lives alone. N contacted an advisor five months after having ESA and Housing Benefit stopped after failing to attend a WCA. N had not received a letter about the initial WCA. N made a new claim for ESA but would not be paid until undergoing a medical examination, though N was not well enough to leave home. As a result of the lack of income N's condition worsened and there were concerns over the deterioration of physical and mental health. There were concerns about N's ability to eat in this period. The Belfast BDC refused to accept non-receipt of an appointment letter as good cause for non-attendance despite the existence of an ongoing police investigation into N's landlord intercepting post. Following an appeal it was accepted that N had good cause for not attending the WCA and N received 7 months' backdated payments. Refusing to accept good cause needlessly penalised N in very vulnerable circumstances.

Decisions must be made more sensitively and routinely assuming the claimant is at fault is unhelpful and inaccurate.

Camberwell ME Support Group³ also questioned the poor communication of ESA50 information – suggesting that claimants should be informed of the context of questions – and especially the need to ensure tasks can be performed 'reliably, repeatedly, safely and without the exacerbation of symptoms'. If assessors and claimants were better aware of and better used this terminology it is believed many more disabled people – and including people with fluctuating conditions – would receive more appropriate WCAs.

³ Camberwell ME Support Group has also responded directly to the Harrington Review.

The Support Group also highlighted the need for more time for completing ESA50s – which was cut by the Government and may affect the ability of previous Harrington recommendations to have had the desired effect.

Assessment

There are significant problems with the quality of assessment when determining whether a customer has limited capability for work.

February 2012 – D is limited to the house and incontinent. D was a home carer for 23 years until stopping due to poor health. Following a domiciliary medical assessment D was placed in the Work Related Activity Group. The doctor undertaking the assessment was due to attend on a Wednesday but did not turn up and did not contact D. The doctor attended the following day and spent about 20 minutes on the assessment. D has no warning regarding incontinence. D experiences complete evacuation of the bladder about eight times a day and complete evacuation of the bowel sometimes daily. However, D didn't give details to the visiting doctor due to embarrassment and the doctor didn't ask about incontinence. D assumed the doctor would realise as the commode and incontinence pads were visible at the home. D was later placed in the support group after receiving support from advisors.

The quality of the assessment can also be compounded by staff being too rigid in completing assessments.

S has chronic fatigue syndrome, anxiety, and suicidal depression. But S believes the health care professional undertaking the assessment seemed inexperienced and was only interested in the 'yes/no' questions on the computer screen. When S tried to discuss health problems and their impact, the assessor said they were out of time. S was found fit for work but felt that the ESA85 misrepresented responses to the questions and appealed.

DWP, JCP and Atos staff can also exhibit a culture focused on trying to catch clients misreporting illnesses. This can be a problem in assessing people that are especially vulnerable due to language barriers.

L speaks Albanian and limited English. On arrival for assessment L was asked the mode of transport used to get to the appointment. L answered in limited English but accidentally gave the impression of having driven to the appointment. L's son had driven the car. L was awarded nine points for sitting and standing, but these were all removed by the DWP decision maker on the grounds L had driven to the assessment.

Such important decisions should not be based on information gained in response to questions that may not have been properly understood and/or recorded.

Reviews can be scheduled too regularly. An extreme example is G, who has extreme mobility and mental health problems. After receiving a domiciliary medical assessment and transferring to the WRAG from incapacity benefit G came up for reassessment. G received a new ESA50 almost exactly one month later. Such a quick reassessment period should only occur if the customer has a temporary condition. This is an issue repeatedly raised by advisors. There are concerns that despite missing targets for facilitating 15,000 WCAs per week, many disabled people are over-regularly recalled for assessments. In line with the recent National Audit Office report, there are concerns that Atos may be receiving payments for over-assessing some disabled people whilst being under-fined for not reaching DWP contract targets.

Some disabled people are also being asked to attend appointments that are unsuitable and place them under avoidable stress. Commonly, people are asked to make journeys that are overly long given the tiredness and lack of strength due to health conditions. This can mean people forced to make journeys that cause extreme discomfort. Services can also be overloaded and there is a lack of consideration about the way this can impact on customers. One person, L, told our member organisations of having to attend an assessment three times before being seen due to over-booking. L has mental health issues and was incredibly anxious about attending but was forced to prepare and make the journey three times – twice without being seen.

The failure to properly take into account the impact of mental health problems in the assessment process – or understand duty of care rules – is also worrying.

K has a mental health problem but ESA was stopped (and consequently Housing Benefit resulting in an eviction notice from the landlord). K is unable to leave home alone. K's mother was unable to take K to the WCA appointment due to a domestic emergency. K rang Atos to let them know and asked for another appointment. K was told Atos would have to inform JCP of the failure to attend. K suffered severe hardship for over four months which was compounded by causing a deterioration in mental health.

Atos should ensure JCP is aware of the cause of missing an assessment (where known) rather than just notify 'failure to attend'. This would meet Atos and DWP (as Atos' paymaster) meet duty of care responsibilities and ensure no further costs are caused by avoidable appeals, as well as (in K's instance) higher NHS use.

Further concerns of our members surround the under-use of exceptional circumstances rules. F can live independently and look after personal health and wellbeing, but has behaviour challenges which mean not accessing community services without the company of two council staff. F has lashed out without warning or apparent trigger. F was placed in the WRAG after assessment but is appealing and hopes exceptional circumstances will be taken into account. This could have been considered during the initial assessment.

Assessors and fluctuating conditions

The Dystonia Society and Camberwell ME Support Group raised concerns about experience of medical professionals undertaking the WCA. The belief is that awareness is low amongst the general medical profession of dystonia and ME and this is reflected in Atos staff. This fits the pattern of the WCA not being able to identify the needs (or even conditions) of many of the disabled people it is designed to test – and of the WCA being particularly problematic for people who experience fluctuating conditions.

Dystonia Society members provided the following experiences of assessments where the doctor clearly had no experience or knowledge of dystonia nor had made any attempt to educate themselves about the condition prior to the assessment visit (despite medical information being supplied):

I had to attend a 'medical test' which was done by a so-called doctor who did the most basic of physical tests.

I asked this doctor...if he had heard of Dystonia. He hadn't. He asked me if I had used the stairs to get to his office, which I had. This was marked against me as I was clearly able-bodied enough to walk. I tried to explain to him that Dystonia causes so much 'unseen' pain that walking can be very painful and near-on impossible at times. He didn't understand. The whole test took only a few minutes and needless to say the outcome was that I was not entitled to ESA.

I found this very stressful and it had a huge impact on my health. Even writing about it now nearly 5 years later still makes me angry.

Camberwell ME Support Group also raised the training of assessors in ensuring appropriate awareness of the pain involved in asking some disabled people to perform tasks – and a need for assessors to be more sensitive to pain levels.

Other people underwent rudimentary tests which led to inaccurate conclusions about work ability:

The [assessor] had never heard of blepharospasm and appeared unfamiliar with dystonia – he couldn't find it on his computer 'pick list'.

He conducted a simple eye test with me facing a brightly lit window (I'm photophobic) and again instructed me to keep my eyes open. My visual ability to read was tested by being asked to read a very short line from a form – which I was able to do – but I am unable to read more than a couple of lines of writing without my eyes closing and losing my place. I was asked closed questions and not allowed to explain how my condition affects my... daily living.

I also asked him to read the Dystonia Society leaflets and a list I had compiled of my symptom's and triggers – he briefly scanned over these and declined to include them in my file.

Concluding comments

Disability Rights UK cannot conclude that the WCA is fit for purpose. The faith in the system is lost and our survey results suggest very few people believe the WCA is improving. Some of the examples provided by our respondents

and members (including Greenwich WRU and the Dystonia Society) help demonstrate why disabled people believe this is the case.

This is deeply distressing for the thousands of disabled people being seen each week. This should also be a considerable concern to DWP given the level of waste in the current system – with about £17million of initial WCA test costs being misspent and a further £54million appeals costs in the last year.

We acknowledge that some of the findings of our survey are not suited to the narrow remit of this third and final Harrington review. But we believe it is important for the terms of reference and remit of the next two reviews that our concerns – and those of the disabled people going through WCAs and their families, friends and advisors – are taken into account.

With such tragic consequences for some individuals and their families of the WCA failings to date, and the under-performance of the ESA system at ensuring disabled people are supported into work, it is essential that the next review focuses on the full aims of the WCA and welfare to work agenda.

Contact/further information

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Appendix A

The questions we asked in our WCA survey

Professor Harrington is undertaking his third and final independent Review of the WCA and we would like your help to shape our response. We have drafted a short survey and your answers and input could help improve the WCA. The questions from the Harrington Review form part of our survey. We also provide some extra questions to ensure we provide a response based on disabled people's experiences.

First; about you

Although this survey is anonymous we would like to know a little bit about you. Please select all which apply to you

Which age group are you in?

- Under 16
- 16-24
- 24-44
- 45-64
- Over 65

What gender are you?

- Male
- Female
- Transgender

Do you consider yourself to be:

- A disabled person?
- A non-disabled person?
- Family/friend/carer/advisor of disabled person?
- Other: (please specify)

Second; about the WCA and 'work ability'

Have you had a Work Capability Assessment?

- Yes
- No
- Know someone who has
- Don't know/unsure

Do you receive ESA or JSA?

- Yes
- No

Don't know

Do you think the WCA ensures disabled people can access sufficient support?

Yes

No

Don't know/unsure

Do you think the WCA is helping the DWP aim of supporting more disabled people into work?

Yes

No

Don't know/unsure

Do you think the Government should publish statistics on how many disabled people it supports into work from welfare reform per year?

Yes

No

Don't know/unsure

Do you think the WCA provides an adequate test of ability to work?

Yes

No

Don't know/unsure

Do you think the Government should work with disability organisations and employers to ensure the WCA is an appropriate test of work ability?

Yes

No

Don't know/unsure

Do you want to work?

Yes

No

Don't know/unsure

Next; the Harrington Review questions

We have provided the questions for individuals below based on the Harrington Review questions.

Please complete this survey if you're an individual or supporting an individual (eg as a friend, carer or welfare rights advisor).

Question 1

a) Have you had more than one WCA?

YES

NO

b) Was your most recent WCA:

(Please select only one)

- A reassessment of an existing Incapacity Benefit (IB) award?
- A new claim for Employment and Support Allowance (ESA)?
- A repeat (second or third) WCA having already been awarded Employment and Support Allowance?

If you answered YES to Question 1a), please go to Question 2

If you answered NO to Question 1a), please go to Question 9

Question 2

Please tell us where you live in Great Britain

(Please select only one)

1. South East England
2. South West England
3. North East England
4. North West England
5. Midlands
6. Scotland
7. Wales

Question 3

Were you assessed for:

(Please select only one)

1. A mental, intellectual or cognitive condition or disability
2. A physical health condition or disability
3. Both

Question 4

What was the outcome of your award?

1. Found fit for work (JSA)
2. Work related activity group (ESA WRAG)
3. Support group (ESA)

Question 5 (communications)

a) Thinking about the start of your claim, were there any changes in the telephone contact between you and DWP between your first and your most recent WCA?

(Please select only one)

- There has been an improvement
- It was not as good
- There was no change

b) Between your first and your last WCA, did you notice any changes to the written communications which DWP sent you?

(Please select only one)

- There has been an improvement
- There was no change
- It was not as good

c) The DWP ESA50 limited capability for work questionnaire form which covers health issues has been amended; please can you tell us if you think:

(Please select only one)

- There has been an improvement
- It was not as good

There was no change