

Shaping future support:

Survey by the Disability Benefits Consortium carried out for the Health and Disability Green Paper consultation

October 2021

Introduction

This report provides new evidence and lived experience from a survey of 694 people claiming health and disability benefits on what navigating the system is like, and importantly what changes and improvements they would like to see made to the support and services they receive from the Department for Work and Pensions (DWP).

It is a companion document to the DBC's submission based on member organisations' evidence and experience: **Shaping future support: submission by the Disability Benefits Consortium to the Health and Disability Green Paper consultation**, DBC, October 2021.

Methodology

The survey was carried out by Leonard Cheshire on behalf of the DBC and ran from 14th September to 1st October, receiving a total of 694 responses. The survey was distributed by members of the DBC via social media channels and email networks. 74% of respondents are receiving either Employment and Support Allowance or Universal Credit, and 90% are receiving either Personal Independence Payment or Disability Living Allowance.

To allow respondents to skip questions and topics that might prove distressing to discuss, all questions were optional once the initial screening questions for the survey had been passed. This means that the sample size for the statistics quoted in this report varies, but details on the sample and descriptions of the base are provided.

Findings

1. Providing the Right Support

Improving reasonable adjustments

When asked about reasonable adjustments that had been requested from the DWP, the most common requests were around making meetings more accessible (changing the time and/or date of a meeting- **49%** and changing the location of a meeting- **46%**), followed by changing the channels through which the DWP communicated with them (communicating via email instead of by phone- **27%**)

Table 1. Reasonable adjustments requested from the DWP

Providing information in an alternative format	7%
British Sign Language (BSL) interpreting	2%
Providing audio recording of interview	16%
Communicating via email instead of by phone	27%
Changing location of meeting	46%
Changing the time and or date of a meeting	49%
Holding meeting in a private room	16%
Arranging car parking	16%
Access to toilet facilities	4%

In only a third (**33%**) of all cases did respondents indicate that the requested adjustment had been made by DWP, for a further third (**33%**) only some of the adjustments were provided some of the time.

When those who had not made any requests were asked why this was, a quarter (**25%**) said this was because none were needed to meet their accessibility needs. Worryingly **37%** of respondents said that they didn't know that they could, while **18%** said that though they were aware they could make requests for adjustments they didn't feel comfortable enough to do so.

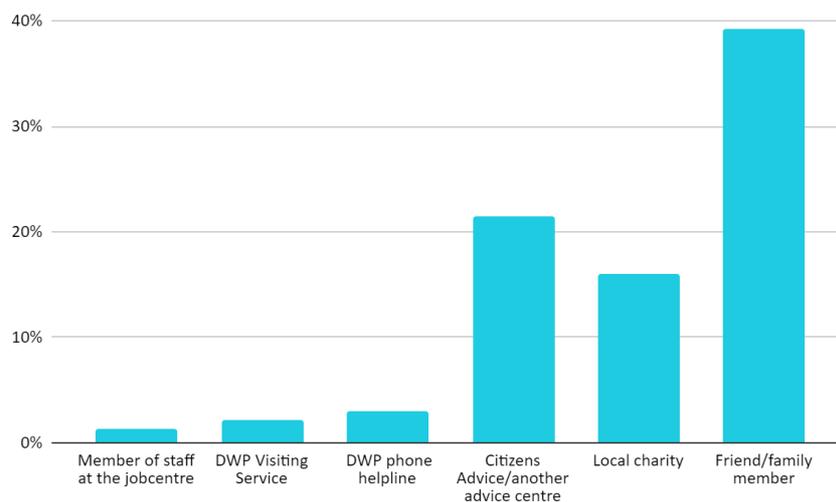
Advocacy Support

The Green Paper suggests that, among the principles advocacy support could be based on, were: 'It would only be offered to the people who need it most; It could be for people who do not already have the support of charities and other organisations; and It should be flexible enough to support people whenever they need help.'

Based on this, respondents were asked whether they have received support previously, where from and what kinds of support would be most helpful to receive as part of an advocacy support offer.

The majority of respondents (**82%**) have received some form of help or support for their benefit applications, though among those that did not receive any help most said they would have liked to have some. Help and support most commonly came from friends and family (**39%**), closely followed by advice centres or local charities (**38%**). Only **5%** of respondents said they received any help or support through services provided by the DWP such as the Visiting Service and Universal Credit or Jobcentre Plus helplines.

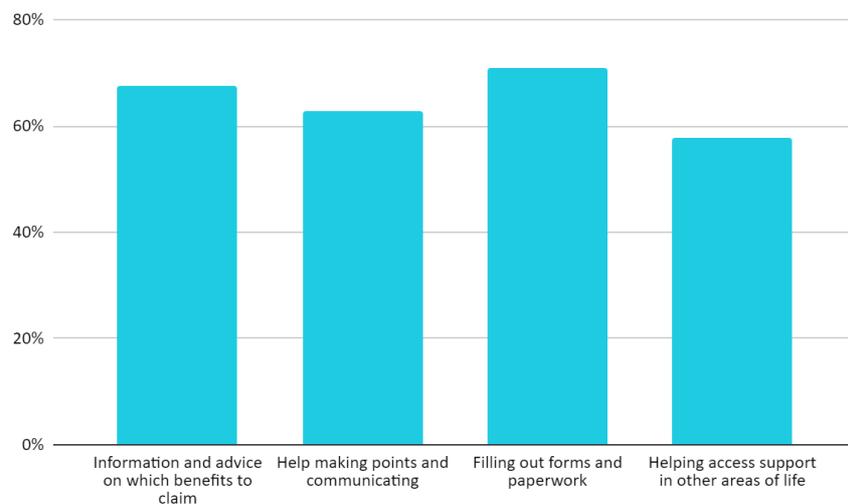
Figure 1. Where disabled people receive help with benefits from



The kind of support respondents were most interested in receiving was help with filling out forms and paperwork (71%), closely followed by receiving more information and advice on which benefits they should claim (68%): see figure 2. A number of respondents also mentioned that

it would be important for any independent advocacy support offer to provide assistance across all parts of their benefits journey rather than just applications and assessments, such as when challenging decisions via mandatory reconsideration.

Figure 2. What help disabled people would like from advocacy support



Almost all (**92%**) of respondents said that an independent advocacy service that provided any of this support would be helpful for them, which did not vary significantly across disability or health conditions or based on whether respondents had previously received help or not (but would have liked to) with managing their claims.

“It’s about trust, reliability, and access. I need an independent advocacy service that is on my side”

Almost all respondents would benefit from advocacy support, yet only a third have received similar help from advice agencies or charities. An important part of any offer will be identifying those entitled to this support. This might be those new to the system or equally those who have received disability benefits for a long time, even without a deterioration in their disability or health condition. Some respondents indicated they felt worn down by assessment processes and thought they were now less able to advocate for themselves than previously.

“Attending medical appointments with me and other DWP appointments because I can't speak because it's too stressful now. I wasn't like this before six years ago. System has made me worse and I'm very isolated”

2. Improving employment support

Providing more support before the Work Capability Assessment

When asked to think back to the period before their WCA and consider if receiving support to look at appropriate employment opportunities and learn more about what in-work support is available would have been helpful to them, respondents were likely to feel it wouldn't. **46%** said it would not have helped, a further **15%** said it would have been unlikely to help.

A common theme that emerged in the reasons why respondents wouldn't have found this helpful, was that managing their health condition or disability (particularly mental health problems) was of greater importance and needed to be carried out before they could consider looking for any alternative employment.

“I was struggling with my mental health. It took me changing to a new GP and getting specialist help. I think I really needed to get the right help first before thinking about returning to work.”

“I had always put my mental health on the back burner & been on auto-pilot, my mental health has to come first, so it is unlikely I would have looked at alternative employment as my underlying significant mental issues would have remained unresolved.”

Employment support provided digitally

Following learning from the pandemic, the Green Paper suggests that more could be done to provide employment support digitally.

Respondents were more likely to be uncertain about (**33%**) or opposed to (**26%**) employment support being provided digitally than in favour of it. This lack of certainty may be due to concerns such support might become the default or lead to a more generalised, rather than individualised, support offer being provided.

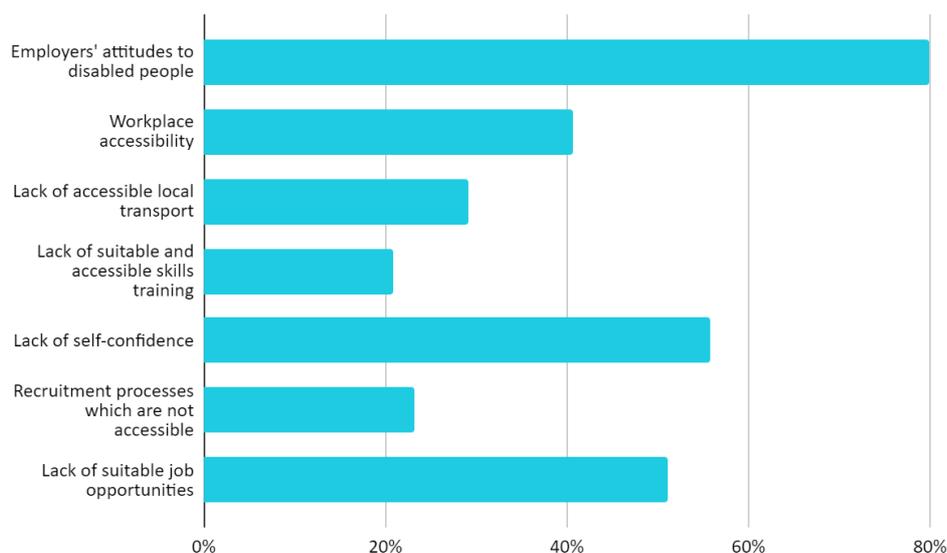
Among some of the options suggested, **14%** of respondents felt that being able to speak to a work coach via video call would be helpful for them, while **23%** felt that being able to access some form of training or learning material digitally as part of this employment support would be most helpful.

Employment support for people in the ESA Support Group or with LCWRA

Research from the DWP suggests that one in five of those in these groups would like work and think they would be able to work at some point in the future. A similar proportion of respondents in these groups said they would like to work in the future (**19%**), however were much less optimistic about the likelihood of this (**3%**).

As Figure 3. shows, many of the barriers to employment identified by those who would like to work were structural, such as employer attitudes to disabled people (**80%**), problems with workplace accessibility (**51%**) and accessible transport in their local area to travel to potential workplaces (**29%**). The main personal barrier that respondents identified was a lack of self-confidence in being able to carry out paid employment (**56%**).

Figure 3. Barriers to employment for disabled people in Support Group or with LCWRA who would like to work



3. Improving the DWP's current services

Different ways of conducting assessments

Since the pandemic, in many cases it has not been possible to conduct face-to-face assessments, meaning the DWP has been carrying out assessments by telephone. Respondents were asked what forms of assessment they had gone through and how they felt about the experience of them being carried out via that channel (separate from their satisfaction at the outcome).

As Figure 4. shows, irrespective of the channel, respondents to the survey do not find going through assessments an overall positive experience. Only **12%** said they felt positive about face-to-face assessments, and while phone was the channel that respondents were most positive about, this was only the case for slightly over a quarter (**27%**). Assessments carried out on papers was the only channel which more than half did not have a negative experience of (**59%**).

Figure 4. Experiences of assessments through different channels

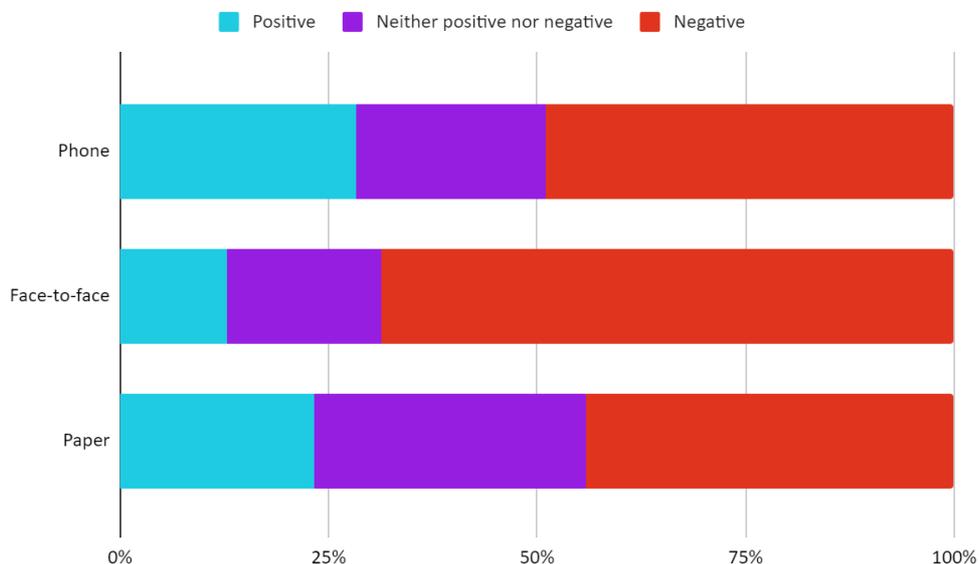
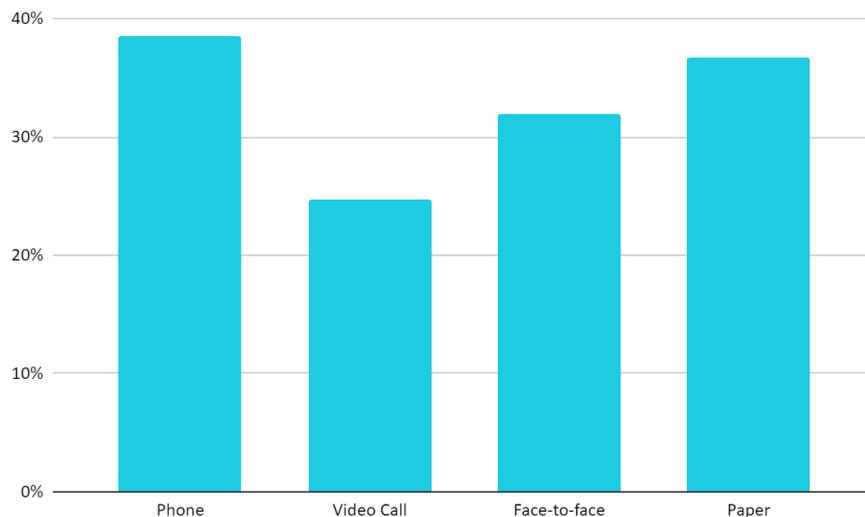


Figure 5. Preferred choices of channels for assessments



Importantly, despite the overall experience across all assessment channels tending towards negative, when asked what their preferred assessment channel would be if given the choice, opinion was almost evenly split. Phone was the most popular option (**39%**), closely followed by paper (**37%**). Despite the apparent negative experiences of the format, a third (**32%**) chose face-to-face, with a quarter (**25%**) saying they would like video calls if given a choice.

A reason underlying the negative experiences captured from respondents may be that, regardless of the channel, the majority are dissatisfied with the report that comes from the assessment. When asked if they had seen a copy of the report for any of their previous assessments, among those that had **85%** were dissatisfied with its accuracy.

4. Re-thinking Future Assessments

Work Capability Assessments

The DBC has developed proposals containing key recommendations to improve the Work Capability Assessment (WCA). The aims of these recommendations are two-fold: focusing on practical improvements that could be made to the WCA process here and now; whilst also exploring longer-term structural changes to assessing people for work-related disability benefits.

Some of the key principles for immediate and the longer-term structural changes to the WCA were tested in this survey to assess their support from disabled people with experience of the WCA. Among immediate changes, by far the most popular principle was that assessments take into account fluctuating conditions, rather than trying to capture a ‘snapshot’ or ‘typical day’ (**88%**). Three quarters of respondents (**76%**) wanted evidence other than medical evidence to be equally considered during an assessment.

When considering longer term structural changes, a majority (**62%**) of respondents agreed that there should be a focus on supporting people instead of any work-related conditionality or sanctions. However, there was not substantial support for the two other principles for longer term change: access to a support coordinator after the assessment, to help draw up a support plan, on a voluntary basis (**20%**) and providing a holistic assessment of barriers to work that focuses more on external barriers (**16%**).

Table 2. Support for DBC principles for change to the WCA

Principles for immediate change	
Taking into account fluctuating conditions	88%
Ensuring evidence other than medical evidence is equally considered	76%
Principles for longer-term change	
Receiving access to a support coordinator after the assessment to help draw up a support plan	20%
Providing a holistic assessment of barriers to work that focuses more on external barriers	16%
Focusing on supporting people instead of any work-related conditions or sanctions	62%

5. Exploring ways to improve the design of the benefits system

Support people with their extra costs

One proposal in the Green Paper on better supporting disabled people to live independent lives was through improving awareness and/or access to aids, appliances and services. It was suggested that the DWP explore the potential to allow people to voluntarily swap all or part of

their benefit payment for such aids, appliances, or services, with this offer operating in a similar way to the Motability Scheme.

The responses to this proposal from survey respondents to such a scheme being made available to them were considerably mixed. **43%** said they would be interested in trading part or all of their award, while a quarter (**25%**) said this wouldn't be of interest to them, and a third (**32%**) said they weren't sure or would need more information about how this would work in practice.

“[I would be worried that] things such as hearing aids which you are entitled to on the NHS would have to be paid for out of PIP which isn't right. A lot of people need PIP for heating etc as the other money isn't enough aids should be free”

Some of the key concerns raised underlying this uncertainty or opposition to the proposal were around affordability and choice – that inadequate options could be available and would be expensive relative to the wider market. Many respondents also highlighted the current inadequacy of benefit levels, meaning that if they were to trade some of their award, they would be unable to afford food or heating. In principle some respondents opposed this proposal as they believed aids, appliances and services they need should be provided free of charge rather than being required to trade some of their PIP award to pay for them.

6. Conclusion

As noted in the introduction to this report, these findings help to illustrate some of the themes explored in the companion document, also submitted to the Green Paper consultation, based on DBC member organisations' evidence and experience.

Taken together, we trust that they will prove helpful to continuing discussions in the coming months.

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