

## Written evidence from Sense (HAB0069)

### About Sense

Sense is a national disability charity that supports people with complex disabilities to be understood, connected and valued. Sense supports children, young people and adults in their home and in the community. Sense campaigns passionately for the rights of the people it serves, and offers practical help and support to families and carers, including information and advice, short breaks and family events.

At Sense Centre Touchbase Pears we run an employment support service. This service provides advice on welfare and benefits, employability skills workshops, assistance with applications and support learning about accessible technology.

Sense regularly employs disabled people in a range of different roles across our workforce. In the People Count - Third Sector 2019 survey,<sup>1</sup> Sense confirmed that 7.2% of our employees were disabled, compared to a median rate of 4% across our chosen peer group, and a median rate of 3.1% across all participants.

### Who does Sense support?

Sense supports people with complex disabilities including people who are deafblind, as well as those with learning disabilities, autism, sensory impairments and complex health conditions. The individuals with complex disabilities we represent often require significant or constant care and support from family members or social care, including support with personal care. Many of the people we support are also deafblind, including individuals with congenital deafblindness and also those who are visually impaired or Deaf or Hard of Hearing who then acquire an additional sensory impairment. While those who have acquired deafblindness tend to have less complex care needs, they are still likely to have communication needs which require the right support.

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<sup>1</sup> Agenda Consulting, August 2019, People Count- Third Sector Survey. Third Sector Human Resource Benchmarking. Vol. 1.

## Supporting individuals with complex disabilities

The welfare, benefits and employment support system needs to take a more holistic approach to supporting disabled people. Many of the disabled people Sense supports are reliant on welfare benefits, either to support them because they are unable to work, or because they face additional living costs as a result of their conditions. We need a welfare system that recognises the long-term financial support needs of those with complex disabilities who are furthest from the workforce. It is essential that services and support can empower individuals with complex disabilities to live independent lives as active citizens in their community, and where appropriate support disabled people into work.

For those disabled people who want to work, it is key that government schemes provide the necessary funding, resources and support for those with more complex needs. Individuals Sense supports report that often Jobcentre Plus services, training or schemes for disabled people are inadequate for those with more complex disabilities and communication needs. The Government needs to focus on creating a more meaningful journey towards work for those with complex disabilities. This journey needs to recognise, support and develop skills including communication, independent living, using accessible travel support, technology and most importantly enable the confidence to apply for work. By investing in these vital skills and ensuring the right support is available, those with complex disabilities will be more likely to access employment and stay in work.

Currently, welfare and employment services do not fully recognise or appropriately support those people with complex disabilities for whom work is not an appropriate outcome. For those disabled people with the most complex care and medical needs, we need welfare services that celebrate essential skills and outcomes, including communication skills, wellbeing and health. These are outcomes that need to be achieved through joined up working between Local Authorities, Jobcentre Plus, social care services, VCSEs and most importantly co-produced with the disabled person and their family. By supporting individuals with complex disabilities to develop independent living skills, participate in the community and volunteer, the DWP can reduce the impact of health inequalities, social isolation and also reduce the need for complex care and medical interventions. This is also a vital step in taking a more holistic and cross-government approach to disabled people and their support needs.

## How we have developed this response

As an organisation representing people with complex disabilities, it is vital to us that our response to policy proposals is informed by the experiences of the people we support.

This submission is based on both our existing evidence and consultation exercises carried out while preparing our response to the Health and Disability Green Paper.

## Summary of Recommendations

### **The Department for Work and Pensions should:**

- Offer applicants the option of telephone, video and in-person assessments, with all types of assessments being treated equally during the assessment process.
- Ensure that communication support is always available in assessments of every format, such as through building in the ability for communication professionals to join video assessments.
- Require assessment providers to automatically postpone assessments where communication support is needed but not available, such as when there is a poor connection, without the claimant being negatively impacted.
- Introduce a Severe Disability Group, the criteria for which should be mainly focused on the impact of a condition or impairment on someone's life.
- Not restrict eligibility for the Severe Disability Group to those who will 'never' work.
- Attach the same weight to evidence from support organisations, social care staff and other allied professionals as it does to medical evidence.
- Ensure that assessors have received training that covers complex disabilities as well as more general disability equality training.
- Provide assessors with access to expertise on an applicant's condition or impairment prior to their assessment.
- Ensure that communication support is always available to those who need it during assessments.

## Challenges faced by people with complex disabilities accessing employment

The employment rate for disabled people is almost 29 percentage points lower than it is for those who are not disabled. This gap has only slightly narrowed in recent years, falling from 30.8 percentage points in 2016.<sup>2</sup> The barriers to employment facing disabled people are complex, including societal attitudes to disability, unfair recruiting practices, a lack of suitable job opportunities and a failure to provide employees with the support they need to work effectively.

For people with complex disabilities, whose support needs tend to be higher, these challenges are often more acute. And while some people with complex disabilities would be able to work if they were given the right support, work is not always an appropriate outcome for other people with complex disabilities.

## Challenges faced by people with complex disabilities accessing benefits

“Unemployed people on benefits with complex disabilities have enough daily barriers and challenges in life”

Sense Employment Support Group Member

Even though they are one of the groups the welfare system is designed to support, people with complex disabilities often find the system inaccessible. People with complex disabilities often receive information and forms in formats that are inappropriate for their information and communication needs, leaving them reliant on friends, family or support services while applying for and managing their benefits claim.

Similarly, people with complex disabilities sometimes find that their assessments are inaccessible, and assessors can be unsympathetic and lacking in their understanding of disability. This can result in decisions based on inaccurate or misrepresentative information, leading applicants to challenge the decision through Mandatory

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<sup>2</sup> <https://researchbriefings.files.parliament.uk/documents/CBP-7540/CBP-7540.pdf>

Reconsideration or Tribunals. Unsurprisingly, people with complex disabilities often find the process of applying for benefits distressing.

## Responses to questions

### 1. How could DWP improve the quality of assessments for health-related benefits?

The people we support often feel frustrated by the fact that the assessors often do not know anything about their condition or impairment during the assessment. They tend to have a more positive experience when their assessor has an understanding of their condition.

For example, someone we support reported that the assessor at one assessment knew nothing about his condition (Usher's Syndrome). As a result, he found the process more complicated and distressing. In contrast, he later went to an assessment which was less distressing because the assessor had clearly carried out background research on his condition beforehand.

Assessors without even a basic knowledge of the applicant's condition or impairment would also be less able to evaluate someone's support needs.

While we understand that it would not be feasible to have specialist assessors for every condition or impairment, every assessor should have received disability equality training that covers complex disabilities. Bringing in experts to provide assessors with briefings about an applicant's condition or impairment before an assessment could also improve the quality of the decision. It would also make it more likely that an assessor would accommodate an applicant's accessibility requirements and communication needs.

## Recommendations

### **The Department for Work and Pensions should:**

- Ensure that assessors have received training that covers complex disabilities as well as more general disability equality training.
- Provide assessors with access to expertise on an applicant's condition or impairment prior to their assessment.

- Ensure that communication support is always available to those who need it during assessments.

## **6. How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?**

Where it is feasible and does not disadvantage an applicant, we believe that applications should be decided without the use of an assessment. Particularly in cases where someone has an unchanging condition, the people we support tell us that they do not understand why they have to go through repeated assessments.

We therefore welcome the proposal set out in the Health and Disability Green Paper to test the DWP's introduction of a Severe Disability Group, which would fast-track applications for UC and PIP for disabled people who meet the eligibility criteria.

However, we are concerned that the proposed criteria that we have seen includes a requirement that a medical professional assesses whether an applicant will 'ever' be able to work. Given the complexity of the barriers facing disabled people, from societal attitudes to the availability of assistive technology, we do not believe that medical professionals would necessarily have the expertise to make such a judgement.

As eligibility for PIP is not related to whether or not someone can work, we are concerned that this criterion may unnecessarily restrict eligibility for the Severe Disability Group. There are people with complex disabilities in employment who would meet all of the criteria for the Severe Disability Group except for the fact that they are in work or looking for work. This would mean that some people with unchanging conditions would miss out on the automatic eligibility for PIP conferred by being in the Severe Disability Group.

More generally, we believe that any application using solely written evidence should also consider supplementary evidence from those who support the applicant on a day-to-day basis. While a clinician would be able to use their clinical expertise and a patient's medical records to assess someone's symptoms are likely to improve, they would not necessarily understand the full impact of those symptoms on person's day-to-day life.

There is no guarantee that a clinician's experience of the patient in a clinical setting would be representative of a patient's day to day life. For example, a clinician who sees a patient for relatively short appointments on an infrequent basis may not see the patient experiencing the symptoms at their worst. Neither would they see the cumulative impact of repeatedly carrying out day-to-day tasks. As a result, they could unknowingly under- or overestimate the impact of a person's condition on their life.

In contrast, a support worker, unpaid carer or care worker would be more likely to understand a patient's support needs on a day-to-day basis in the context of their own home.

For example, a Sense employee supporting disabled people with accessing both work and the benefits system would likely be better placed than a medical professional to comment on whether the applicant is able to work and the assistive technology they would need to do so.

When used alongside medical evidence, evidence from support organisations working with the applicant on a day-to-day basis could help create a fuller picture of the barriers applicants face and the support they need to overcome them.

## Recommendations

### **The Department for Work and Pensions should:**

- Introduce a Severe Disability Group, the criteria for which should be mainly focused on the impact of a condition or impairment on someone's life.
- Not restrict eligibility for this group to those who will 'never' work.
- Attach the same weight to evidence from support organisations, social care staff and other allied professionals as it does to medical evidence.

### **9. Is there a case for combining the assessment processes for different benefits? If not, how else could the Department streamline the application processes for people claiming more than one benefit (eg. PIP and ESA)?**

While increased sharing of data and evidence between benefit applications could make the application and assessment process simpler and less distressing for people with

complex disabilities, we would be concerned about any moves towards merging PIP and UC/ES into benefit or introducing a single assessment.

While many people go through both the PIP assessment and the WCA, UC/ESA and PIP are fundamentally different in nature, with PIP being designed to pay for extra costs while the WCA assesses a person's ability to work. Merging these benefits could risk confusing the purpose of the benefit, making it less likely to address the needs of those receiving it. It could risk creating an 'all-or-nothing' system where inaccurate assessments or unfair decisions could mean that people with complex disabilities lose out on all their support at once.

**10. What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments? Is there a case for making some of the changes permanent?**

As the communication needs of people with complex disabilities vary, it is important that there are a range of different formats of assessment, allowing applicants to choose the format that is most appropriate for them.

Some people that we support have told us that they preferred their assessment when it was carried out by telephone, as travelling to an assessment in an unfamiliar location can be difficult for some people with complex disabilities.

Many people with complex disabilities will need communication support such as interpreters in assessments. As the DWP expands the range of formats for assessments, it is vital that it builds in ways for people with complex disabilities to access this support, such as through ensuring that communication professionals are able to join video calls.

If communication support is not available, then people with complex disabilities will be put at an unfair and potentially discriminatory disadvantage. The DWP should therefore automatically postpone an assessment if this support is not available, such as when there

is a poor connection or a communication professional is unable to join a video call, without the claimant being negatively impacted.

It is also worth remembering that some people with complex disabilities require specialist IT equipment that they may not have at home, meaning it is not always practical to be assessed by video call.

## Recommendations

### **The Department for Work and Pensions should:**

- Offer applicants the option of telephone, video and in-person assessments, with all types of assessments being treated equally during the assessment process.
- Ensure that communication support is always available in assessments of every format, such as through building in the ability for communication professionals to join video assessments.
- Require assessment providers to automatically postpone assessments where communication support is needed but not available, such as when there is a poor connection, without the claimant being negatively impacted.

**12. DWP believes that applications for some benefits dropped sharply at the start of the pandemic because claimants weren't able to access support (for example, from third sector organisations) to complete their applications. What are the implications of this for how the Department ensures people are able to access health-related benefits consistently? How can the Department best help the third sector to support claimants in their applications?**

**13. DWP recently published research on the impact of applying for PIP or ESA on claimants' mental and physical health. What would be the best way of addressing this?**

Given that independent living for disabled people is one of the objectives of the benefits system, people with complex disabilities should be able to make and manage their claims

independently if appropriate. The fact that so many people applying for benefits have to use external support to fill in their applications forms suggests that the Department for Work and Pensions could do more to make the process as accessible and as straightforward as possible.

The people we support often tell that us that the application forms for PIP and Universal Credit are not only long and complicated, but often inaccessible. For example, while some people we support preferred to apply for their benefits online, others told us that the DWP's online application forms did not work with their assistive technology.

A number of people we consulted said that the complexity, length and inaccessibility of the forms meant that they needed support from charities, family members or professionals such as social workers while filling in their application forms. Given that one of the objectives of disability benefits is to increase independence, it is vital that the application process itself is designed to enable complex disabilities to make and manage their own claims with as little support from others as possible. The current application processes for PIP and UC fail to do this.

## Recommendations

### **The Department of Work and Pensions should:**

- Simplify the application forms for PIP and UC.
- Adopt accessibility standards across DWP.
- Give applicants a range of options for applying for both PIP and UC, including through online, phone and paper forms.
- Keep an accurate and up-to-date record of an applicant's information and communication needs, ensuring these are met.
- Ensure that all its staff understand the importance of accessibility, including the communication needs of people with complex disabilities.

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