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# The Activity Trap: **Disabled people's fear of being active**

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October 2018

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Based on a study commissioned by the Dwarf Sports Association UK and undertaken by Flex<sup>MR</sup>.

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and Emma Spring, Activity Alliance.



**Activity Alliance** (the operating name for the English Federation of Disability Sport) is an organisation that brings its members, partners and disabled people together to make active lives possible. Collectively, it seeks to challenge perceptions and change the reality of disability, inclusion and sport.



**The Dwarf Sports Association UK** is the leading National Disability Sports Organisation providing sport and activity for people with a restricted growth condition. It aims to promote and develop sport for persons of restricted growth regardless of their location, ability, or financial support.

# Foreword

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**Disabled people deserve the same right to be active as everybody else, no matter whether they want to make use of their local gym or become an elite athlete. But the reality is that disabled people are still twice as likely to be inactive as non-disabled people.**

The Activity Trap opens the debate into how disability discrimination impacts physical activity. It is rigorous, well evidenced and has an important role to play in changing the reality of disability, inclusion and sport. It is the first time that the sport and activity sector has delved knowingly into the wider systemic barriers that affect disabled people's ability to be active.

Being active and reaping the benefits from activity does not happen in isolation. We cannot continue to assume that becoming active is a simple process of moving from inactive to active. There are many stages and considerations in between that we may not even associate with taking part in sport and active recreation.

To many disabled people, finding appropriate transport, getting personal support or even having the confidence to leave the house can affect our motivations to be more active. We need to understand the challenges and barriers that disabled people face on a daily basis, including how we are represented in the media. It is not simply because we do not want to take part or cannot be bothered.

The numbers within the report, although shocking, give us a starting point for change. Undeniably, they show that unless we provide robust, effective support to disabled people in all aspects of their lives, we are not going to see a meaningful increase in the number of people being active.

It will take work with and across government to make active lives possible and we hope this report helps to widen the discussion beyond sport and health. Whilst some actions are long-term and will not happen overnight, there are things we can fix within the system at local and national level. These changes will make society better for everyone, including disabled people.

**Kamran Mallick, Chief Executive  
Disability Rights UK**

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# 1.0 Executive summary

We believe that all people deserve the right to be as physically active as they want to be. Disabled people are twice as likely to be inactive as their non-disabled peers (43% vs 21%) and account for a fifth of the population but just one in 10 volunteers <sup>1</sup>. This means that they are missing out on the positive social, economic and health outcomes of being active, as identified by the Government's Sporting Future strategy. The benefits system and other forms of government and NHS financial assistance\* are designed to enable disabled people to be active in all aspects of their lives. However, evidence suggests that disabled people fear losing such support as a result of being seen to be active.

Commissioned by the Dwarf Sports Association UK (DSAUK), this study focused primarily on participants with physical impairments <sup>†</sup> and sought to determine the prevalence and extent of this fear, with a particular emphasis on the processes of Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Employment and Support Allowance (ESA).

## Being active is important to disabled people.

- Four in five people in the study would like to be more active (**83%**) and think it's important to be active (**84%**).
- Activity helps them to manage impairments and pain, keep fit, improve mental health, gain autonomy over their own health and facilitate social opportunities.

## Disability benefits are critical in enabling disabled people to be active.

- Almost two thirds (**65%**) of people in the study said they rely on benefits to be active.
- Without such support, they say they would be unable to afford travel, paid-for exercise and specialist equipment. They also anticipate that as a result they would become more reclusive and housebound due to their conditions and pain worsening.

## However, a fear of losing benefits is preventing disabled people from being more active.

- Almost half (**47%**) are fearful of losing their benefits if they are seen to be more active.

'I don't take part in [any] form of physical activity at this moment in time as I am scared that it would have an impact on my disability benefit' <sup>‡</sup> - **Participant with dwarfism or restricted growth**

- Almost half (**48%**) fear being seen as 'too independent' for a disabled person.

\* In this study, 'benefits' refers to both state benefits and other forms of government and NHS financial support associated with disability and health conditions.

† All 26 participants in the qualitative section of the study had physical impairments and were recruited on this basis from the quantitative survey of 206. Many are likely to have also had non-physical impairments. The quantitative survey also included those with solely non-physical impairments (**11%**).

‡ Quotations come from answers to a number of questions and have been proofread, abridged and had minor edits made to them where needed to aid readability.

- More than half (**55%**) said they were likely to be more active if benefits weren't at risk of being taken away.

'I have a lot of concerns when it comes to benefits and the constant fear of them being taken away or worry of being reassessed. It then impacts my life and any involvement in sport and physical activity which is none at the moment due to the concerns I have and not wanting my benefits to be taken off me.'

- **Participant with limb impairment**

**Fears of being active are driven by perceptions of government agencies as well as personal experience and knowledge of benefits not being awarded or being removed later.**

- More than a third (**34%**) have had or know someone who has had benefits sanctioned or removed as a result of being physically active.

'I'm always afraid of doing too much as it could have a negative impact on my disability benefits entitlement. This is partly from the forms, but also because I had a friend who tried doing a little more than I do now, to try and help with her pain management, and they took away half her benefits and told her she was capable of going to work as she was capable of doing so much exercise - despite her having regular fits etc.! She was told that to stand any chance of getting them back she'd have to give up all but one class and maintain that level for six months. You'd think we'd be encouraged to reduce pain using non-medication routes, but apparently not!' - **Participant who is a manual wheelchair user**

**Disabled people were at the heart of this research with results coming directly from them. Although looking at the fear of benefits being taken away, the research also highlighted the challenges that disabled people face through the application system. It showed that the process is a stressful experience for many and something they are hesitant to have to revisit if their benefit eligibility is questioned.**

- Almost half (**46%**) found it difficult to find information about the availability of benefits.
- The most commonly used sources of information were those that may be open to misinformation and misinterpretation, including online searches (**34%**) and friends or family (**28%**). Citizens Advice (**10%**) and jobcentres (**8%**) were used by just one in 10.
- Almost three in five (**57%**) find the application process difficult.

**Many participants faced difficulties in securing the financial support they needed initially. The resulting appeals caused worry, stress, frustration and negative impacts on conditions.**

- A common experience is a lack of opportunity to explain adequately the impact of impairments and social / financial barriers, especially when applying for PIP mobility component. For example, if an applicant with a solely physical impairment can walk more than 20 metres 'reliably' they are not eligible for the enhanced rate (and Motability). This is the case even if public transport is further away and its removal would significantly reduce independence. Under DLA, the distance was 50 metres.

**There is confusion as to what restrictions, if any, apply to how benefits can be spent. While there are restrictions on some forms of financial assistance, there are none for the main forms of disability benefit - PIP, DLA and ESA. A clearer understanding may enable more disabled people to use their benefit payments to be active.**

- One in five (**19%**) didn't know if there are any spending conditions associated with their benefits or financial assistance. A further one in five (**21%**) said there are restrictions.

## **1.1 Recommendations and discussion points**

Four key recommendations and four significant discussion points emerged from the study to address some of the fears, ambiguity and difficulty involved in being physically active when receiving benefits and financial assistance, especially with regard to PIP. Activity Alliance and DSAuk are working with expert partners, including Disability Rights UK, to move forward those discussion points that focus on a range of improvements to the benefits system itself. More detail on each area is included in the main body of this report.

Activity Alliance will work collaboratively to:

1. Drive stronger alignment between public health agencies, the NHS, DCMS, DWP and local government. This should aim to foster a social welfare system that encourages disabled people and people with long-term health conditions to be active without fear of losing benefits and financial assistance.
2. Produce advice and guidance on being physically active and how it relates to benefits assessments. Ensure that disabled people are signposted to information that already exists from expert sources such as Citizens Advice and Disability Rights UK.

3. Increase positive media stories about disabled people being active and the positive impact it has on their lives to help relieve the fear factor.
4. Provide clarity about how benefits and other forms of government and NHS financial assistance can be used to support access to sport and physical activity.

Work with expert partners including Disability Rights UK and Government should aim to discuss the following points:

5. How to ensure that guidance from official agencies is accurate, recorded and binding.
6. How to make application forms more accessible. This should include ensuring that applicants can answer in a way that fully reflects their experience and providing clear guidance on the level of detail expected, such as by using the diary system advocated by Citizens Advice <sup>2</sup> and Disability Rights UK <sup>3</sup>.
7. How to support the assessment process to help assessors to take into account individuals' conditions and the impact they have on day-to-day living, including social and financial barriers, in a more bespoke manner. This should cover debate of the '20-metre rule' that determines eligibility in PIP for enhanced-rate mobility component and ensure that mental health, especially as related to a person's physical health, is given equal importance.
8. Whether PIP reassessment for those with conditions that will not improve can be removed except when initiated by the applicant.



## 2.0 Introduction

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There are almost 14 million disabled people in the UK, accounting for **22%** of the population <sup>4</sup>. Around 3.5 million disabled people of working age receive the main disability and health-related benefits, including Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Employment and Support Allowance (ESA) <sup>5</sup>. This financial support enables disabled people to meet day-to-day practical challenges as well as participate more fully in society, including physical activity and sport.

Activity levels among disabled people are critically low. Disabled people aged 16+ are twice as likely to be inactive (**43%**) as non-disabled people (**21%**) <sup>6</sup> and three times more likely (**31% vs 10%**) to take part in no physical activity at all <sup>7</sup>. Additionally, **75%** of disabled people have more than one impairment <sup>8</sup> and Sport England's Active Lives Survey has revealed that the more impairments someone has, the more inactive they are. More than half (**51%**) of people with three or more impairments are inactive compared with one in five (**21%**) people with none <sup>9</sup>.

In spite of all this, previous Activity Alliance research has shown that at least seven in 10 disabled people would like to do more sport and physical activity <sup>10</sup>.

Evidence from the membership of the Dwarf Sports Association UK (DSAuk), other National Disability Sports Organisations (NDSOs) - including LimbPower, Cerebral Palsy Sport and WheelPower - and Activity Alliance suggests that disabled people have significant concerns that being seen to be active may negatively affect their entitlement to benefits. This could be a barrier preventing them from being more active.

This concern is not unfounded given that half (**50%**) of those receiving DLA higher-rate mobility component were denied the equivalent level when moving to Personal Independence Payment (PIP) - losing access to the Motability scheme <sup>11</sup>. 629,000 disabled people relied on the Motability Scheme to support their independence in 2017 <sup>12</sup>, down from 648,000 a year earlier <sup>13</sup>. This significantly reduces those disabled people's ability to access new activity or remain physically active, undermining Public Health England's strategy of 'getting every adult active every day' <sup>14</sup> and potentially increasing the financial requirement of the NHS <sup>15</sup>.

### 2.1 Method

In order to investigate and properly quantify this concern among disabled people, DSAuk - with support from Activity Alliance and other physical impairment NDSOs - commissioned Flex<sup>MR</sup> to undertake research with disabled people using online surveys and discussion groups. From 26 June to 17 July 2017, Flex<sup>MR</sup> undertook an online quantitative survey of 206 disabled people recruited through DSAuk, WheelPower, Cerebral Palsy Sport and Activity Alliance's social media channels and contact / membership lists. Participants were either currently (**96%**) or previously (**4%**) in receipt of disability benefits and the survey was designed to secure some basic information about their activity levels and experience of benefits and financial assistance as well as to recruit participants for a second, qualitative stage. From 24 July to 2 August, 26 participants took part in this second stage and answered questions about their experiences of disability benefits and physical activity in an online private 'diary' section and a question board in which answers were visible to other participants.



## 3.0 Demographics

The recruitment survey obtained a good split between female (52%) and male (48%) participants. Figure 3.1 shows that there was a good age spread of respondents, although there were fewer aged 65+ than would be expected in a sample of disabled people. This might be due to recruitment taking place through NDSOs and Activity Alliance, which may attract a younger audience interested in sport. As an online survey, it may have appealed less to older people who are less likely to use the internet <sup>16</sup>.

**Figure 3.1: Proportion of participants by age group**

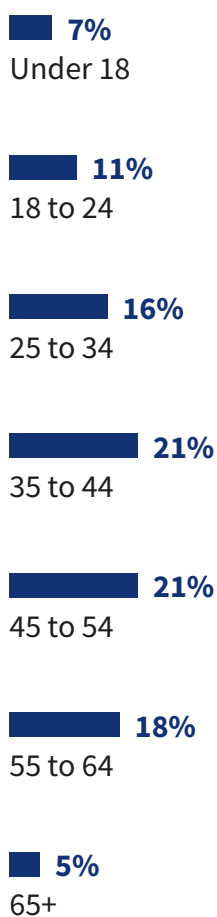
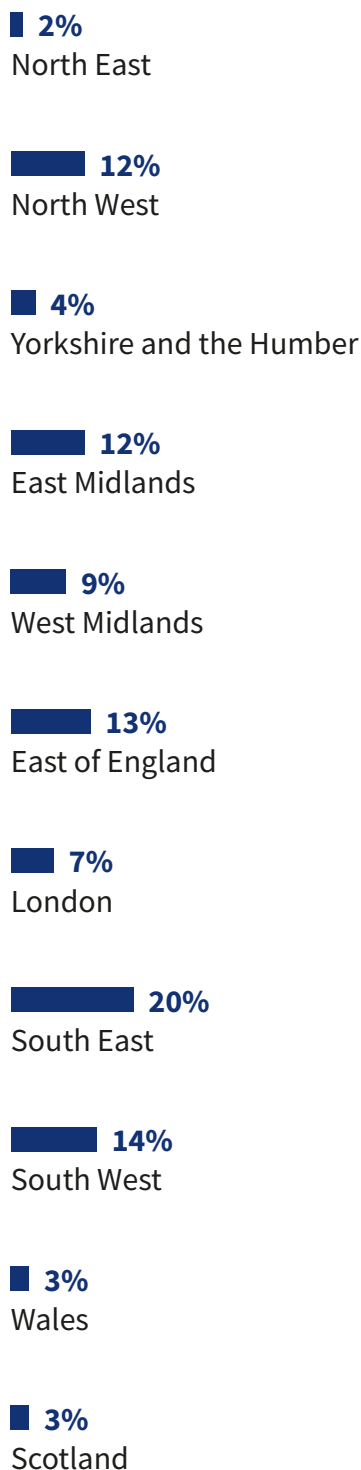


Figure 3.2 shows the proportion of participants from each devolved nation and English region with representation from each except Northern Ireland.

**Figure 3.2: Proportion of participants by devolved nation and English region**



More than a fifth (**22%**) of respondents were not working and not looking for work with a further **16%** retired and **8%** not working but looking for work (figure 3.3). Almost a fifth (**18%**) were employed full time with a further **14%** employed part time and **7%** self-employed.

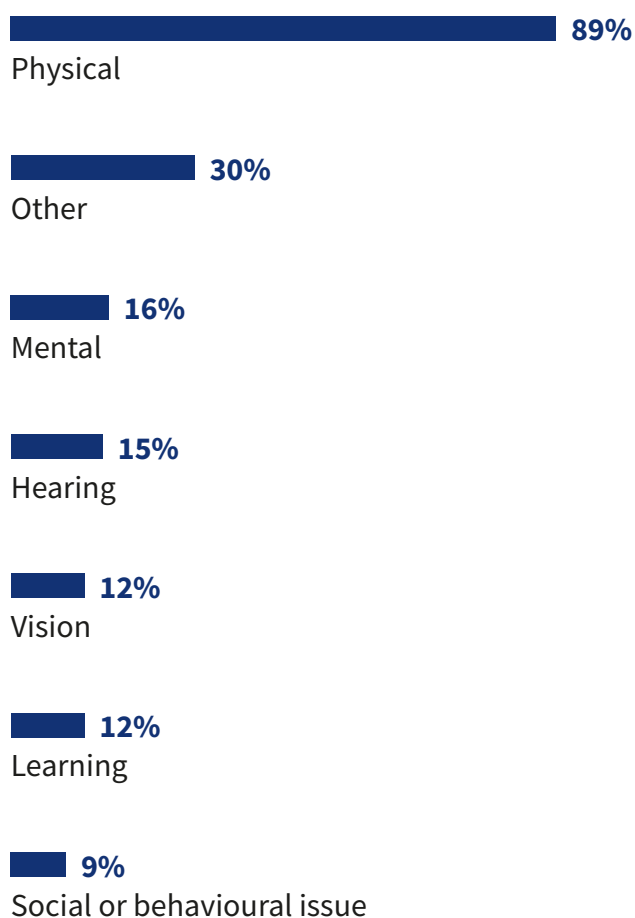
**Figure 3.3: Proportion of participants by employment status**



Around four in five (**83%**) participants responded about themselves with **17%** responding on behalf of someone else, likely those they care for.

Around nine in 10 (**89%**) participants had a physical impairment, with 'other' - which includes stamina or breathing difficulty, difficulty speaking or making yourself understood, dexterity difficulties, long term pain - second in prevalence (**30%**) (figure 3.4).

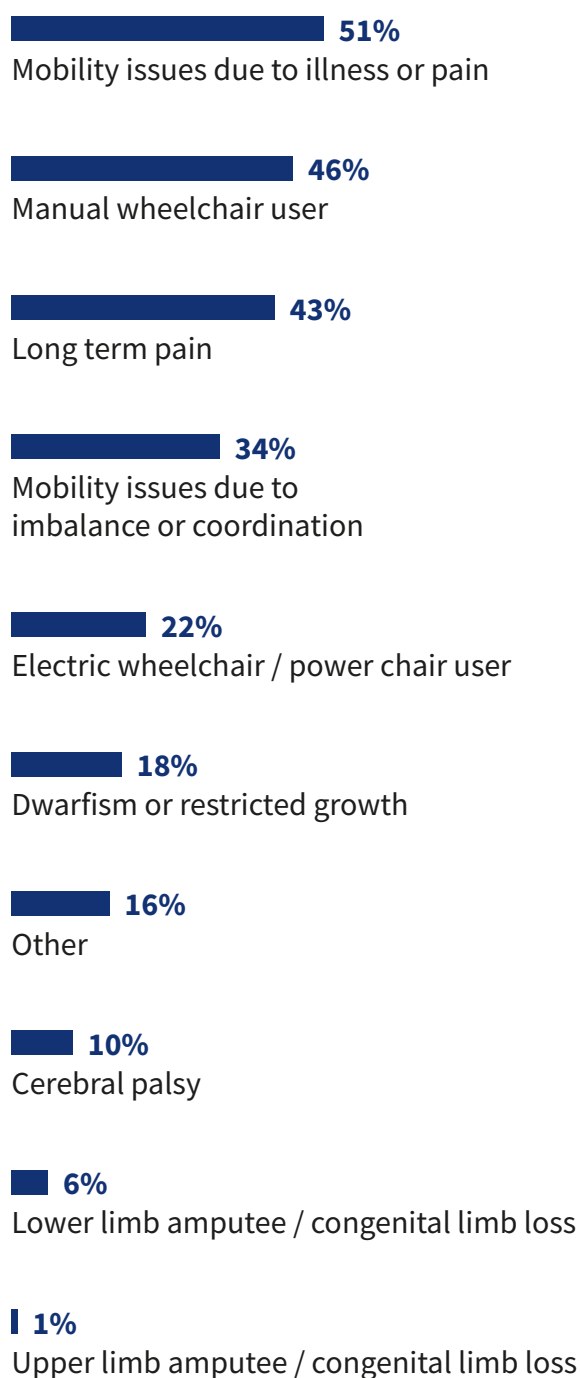
**Figure 3.4: Proportion of participants by impairment type \* †**



\* Social or behavioural issues include, for example, those due to neurological diverse conditions such as Autism, Attention Deficit or Asperger's Syndrome.

† 'Other' includes stamina or breathing difficulty, difficulty speaking or making yourself understood, dexterity difficulties, long term pain.

**Figure 3.5: Proportion of participants by physical impairment type and / or condition**

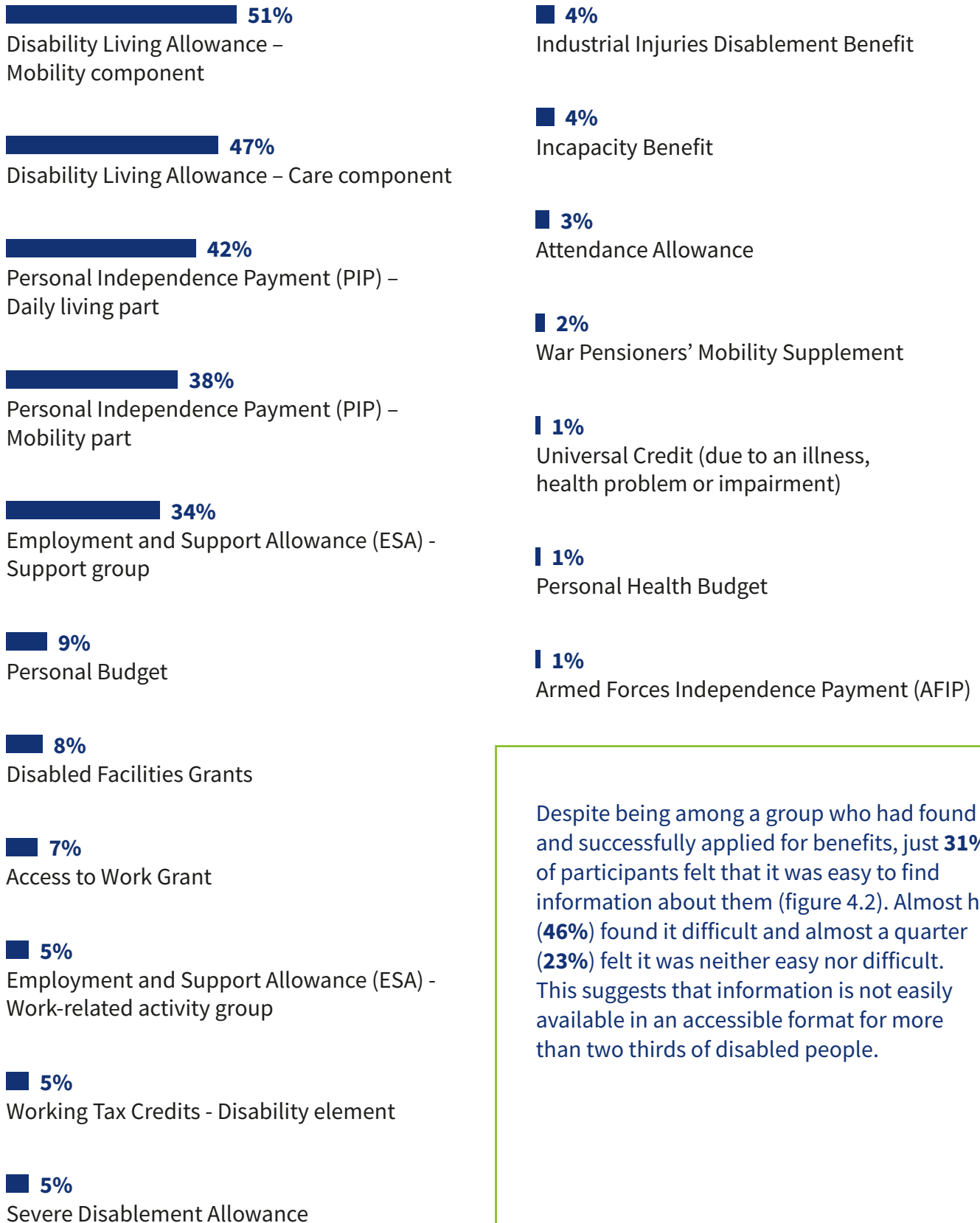


Of participants who had a physical impairment, more than half (**51%**) had mobility issues due to illness or pain, almost half (**46%**) were manual wheelchair users, more than two in five (**43%**) had long-term pain and a third (**34%**) had mobility issues due to imbalance or coordination (figure 3.5). This sub-question was included to facilitate analysis of data by, and monitor participation among, those impairment groups covered by physical National Disability Sport Organisations (NDSOs). The two-thirds (**67%**) who were manual wheelchair or electric wheelchair / power chair aligned with the core member base of WheelPower; Cerebral Palsy Sport supports people with cerebral palsy (**10%** of respondents); the Dwarf Sports Association UK covers those with dwarfism or restricted growth (**18%**); and those with limb amputations or congenital limb loss (**7%**) are the target audience of LimbPower.

## 4.0 Benefits and activity

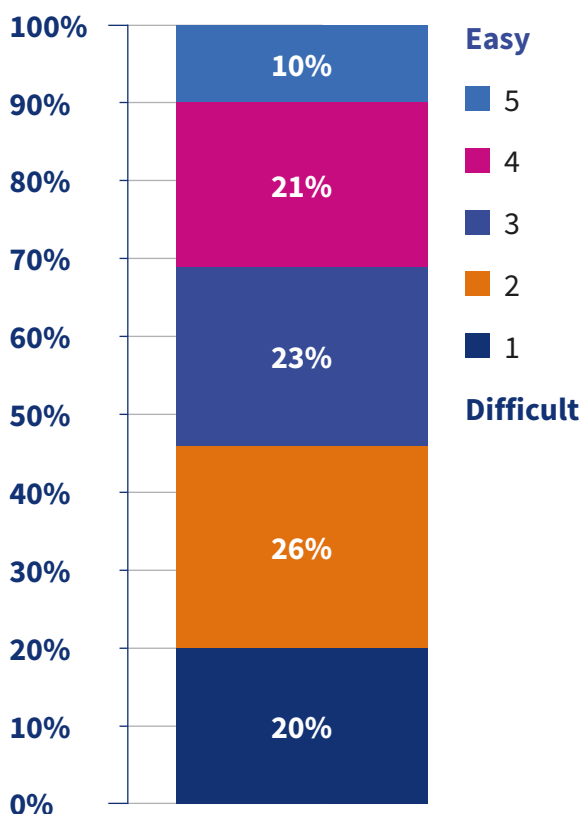
Participants reported being in receipt of a full range of disability and illness-related benefits and financial assistance (figure 4.1). Nine in 10 (**89%**) respondents to the quantitative survey were in receipt of the mobility components of Disability Living Allowance (DLA) or its replacement, Personal Independence Payment (PIP). This is the primary form of state financial support aimed at enabling disabled people to retain mobility. Indeed, if the higher rate DLA or enhanced award PIP mobility components are awarded, they can be exchanged for access to the Motability Scheme to lease a car, scooter or powered wheelchair. While a greater proportion of participants claiming DLA received some rate of mobility component (**51%**) than care component (**47%**), the reverse was true for those on PIP (**38%** vs **42%**).

**Figure 4.1: Proportion of participants in receipt of each disability benefit**



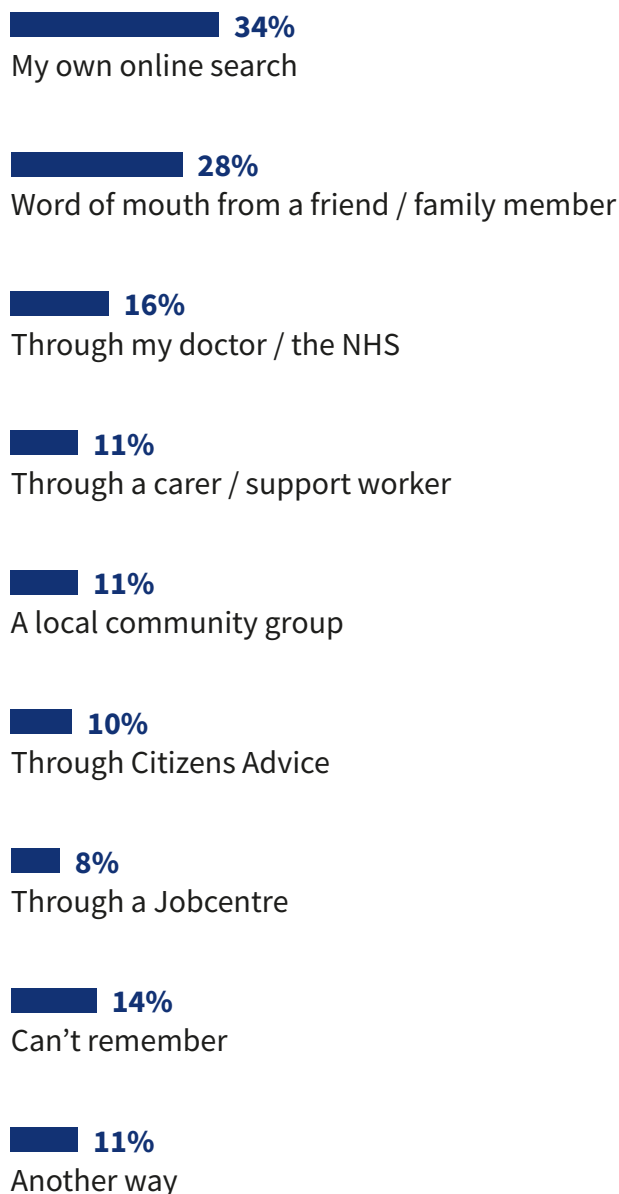
Despite being among a group who had found and successfully applied for benefits, just **31%** of participants felt that it was easy to find information about them (figure 4.2). Almost half (**46%**) found it difficult and almost a quarter (**23%**) felt it was neither easy nor difficult. This suggests that information is not easily available in an accessible format for more than two thirds of disabled people.

**Figure 4.2: Proportion of participants by ease or difficulty of finding information about availability of benefits and financial assistance**



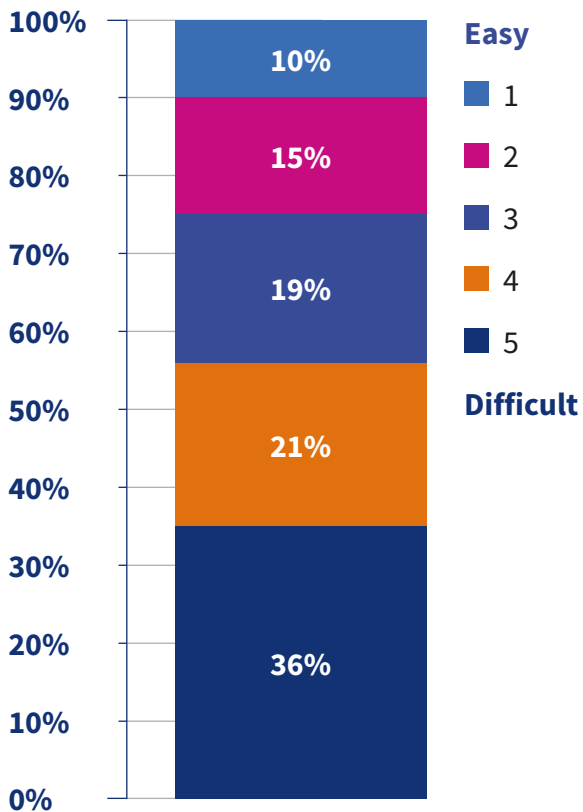
Participants said that they had used the sources shown in figure 4.3 to find out about available benefits and financial assistance. Online searches (34%) and word of mouth from a friend or family member (28%) were by far the most important sources, with more formal advice from Citizens Advice (10%) and Jobcentres (8%) the least used source. This suggests that government sources are either not available or not trusted by those looking to apply for benefits and leaves them at risk of receiving incorrect or unhelpful information. Those receiving Employment and Support Allowance (ESA) were more likely to have sought information from a carer or support worker (24%). Jobcentres, with their emphasis on work-related benefits and activities, may not be seen as a relevant brand for those seeking information about disability benefits.

**Figure 4.3: Proportion of participants by sources of information about benefits and financial assistance used**



Participants suggested that the actual process of applying for benefits is even more difficult than sourcing information about their availability, with almost three in five (57%) finding it difficult and just a quarter (24%) saying it's easy (figure 4.4).

**Figure 4.4: Proportion of participants by ease or difficulty of applying for benefits and financial assistance**



In the qualitative stage of the study, most participants reported having to seek assistance from someone else to complete the application forms. These comments mainly refer to PIP, but also DLA and ESA among others. These forms were perceived by some to be too long and laborious, physically challenging and particularly difficult for those with an impairment affecting writing, for example, those with multiple sclerosis. The forms were also felt to be confusing in how much detail is required - often being too broad in covering disability rather than individual conditions. They were described as ‘depressing’ and ‘soul destroying’, particularly for those with lifelong impairments.

Many participants believed that the forms don’t account for day-to-day differences in how impairments affect them, with an ‘average’ day - as requested by the form - not fully accounting for the impact. Many were not aware of the importance of accounting for their worst days in their statements, or were concerned that they could underestimate their impairments when completing forms on a good day. Some also felt there was insufficient opportunity to explain the impact of their impairments on their mental health. It was also noted that the timeframe given is insufficient to obtain required medical evidence. Specific concerns included:

1. Inaccessibility of forms (Including, for example, having to handwrite answers and a lack of plain English in questions.):

‘It would be great if it could be completed online - writing is difficult for me. I would like the forms to be shorter.’  
- **Participant who is an electric wheelchair / power chair user**

‘Use proper English, not form English, and don’t keep asking the same questions over and over again as its very confusing for people, especially people with brain injuries or lower comprehension!’  
- **Participant who is a manual wheelchair user**

2. Length of time to complete the application:

‘Mostly the worst thing was how time consuming it was to fill in the form and how depressing it felt to have to explain all my difficulties.’ - **Participant who is an electric wheelchair / power chair user**

3. Confusion about what detail to include and how to do so:

‘The form is generally a very lengthy process to fill out, with a lot of questions that can get very confusing at times. [It is also hard in] knowing how to word day to day life and to know how much detail to put in as they don’t make it very clear. And also it is not made very clear on what evidence to supply with the application form.’

- **Participant with upper limb impairment**

4. Inability to explain fully how the condition affects the person:

‘The only issues I have had is making myself clear and being able to express myself fully on the form. The only time I could get my full story across is when I was able to see a doctor.’ - **Participant with dwarfism or restricted growth**

5. Not accounting for day-to-day differences:

‘Depressing to fill in. [...] It didn’t account for differences in day to day ability, e.g. effects of tiredness, illness etc.’ -

**Participant with cerebral palsy**

‘It was difficult to articulate the full effect of my condition and its effects on my daily living. I found it easier to talk to my immediate family to help me think about what narrative was needed.’ - **Participant who is a manual wheelchair user**

6. Not accounting for lifelong conditions:

‘There should be a form for people with incurable conditions so that you can tell them if there have been any changes (positive and negative) and what they are.’

- **Participant who is an electric wheelchair / power chair user**

7. Concern about specific questions and answer options that don’t reflect their experience:

‘The eligibility criteria for certain components is not clear and can be ambiguous. Certain questions which ask you to make a judgement on “yes”, “no” or “sometimes” are not always quantifiable. It would be far easier if the form just simply listed a condition and from this, symptoms with their impacts could be matched avoiding unnecessary form filling.’ - **Participant who is a manual wheelchair user**

These issues resulted in many participants facing difficulties in securing the relevant level of support they needed when initially applying, with long delays in obtaining assessments also a significant problem. This often resulted in appeals which created feelings of worry, stress, anger and frustration, all impacting existing conditions. A common difficulty is the lack of opportunity in the application to adequately explain the impact of impairments and the social / financial barriers faced.



'I started off by completing an application form I then had a response saying that I could not receive any support. I then had to ask for a medical assessment as I don't think I was able to clearly give all the information on the form. It was after this that I was found to be eligible for support. Overall the process was very stressful it would have been good if I could have just easily given all the information I needed on the application form so I could have been clear and not have required the stress of a doctor's visit. I think it was hard to describe exactly how my disability affected me physically. The form wanted my day to day life but made it hard to talk about good days and bad days. This made it hard to clearly describe what I am like when I am at my worst. This made me worried when I was told in my original decision notice I was not eligible for support. I was angry as I knew I was not able to give the full picture in the original application.' - **Participant with dwarfism or restricted growth**

The Department for Work and Pensions announced in October 2016 that it 'intended to exempt ESA claimants with the most severe health conditions and disabilities from future reassessments'<sup>17</sup>. The changes were introduced for those in the ESA support group and Universal Credit claimants with limited capability for work and work-related activity (LCWRA) who attend a Work Capability Assessment from 29 September 2017 and are found to have a severe, lifelong disability, illness or health condition and are unlikely to ever be able to move into work. The Department for Work and Pensions' position is that 'for the most severely disabled PIP claimants however, the interval before their claim is reviewed may be up to 10 years, and may involve a "light touch" process not requiring a further face to face assessment.'<sup>18</sup>

It would be beneficial to understand the reasons behind the decision to exempt those with the most profound health conditions and impairments in receipt of ESA from reassessment but not those in receipt of PIP. This is inconsistent as in February 2016, more than half (**52%**), some 1.3 million, of the 3.5 million people in receipt of ESA were also in receipt of DLA / PIP<sup>19</sup>. This means that a significant proportion of those exempted from reassessment for ESA are still likely to be reassessed for PIP. Exemptions from reassessment should apply equally to both ESA and other disability and illness benefits. Removing this perceived 'threat' of reassessment could resolve a number of issues raised by participants with lifelong conditions.

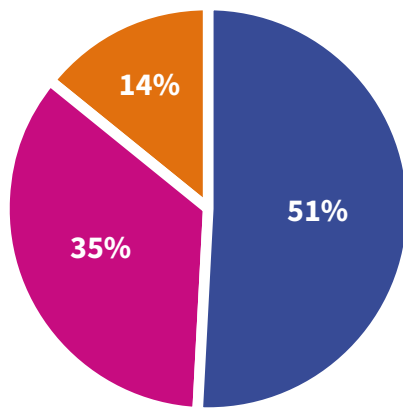
The context within which assessment and reassessment is taking place is crucial. In the quantitative stage of the study, almost three in five (**58%**) of those in receipt of DLA or PIP mobility components, Armed Forces Independence Payment (AFIP) or War Pensioners' mobility supplement exchange it for access to the Motability Scheme. An additional **7%** formerly accessed the scheme but no longer do so. For those exchanging DLA or PIP, this means that they are in receipt of the higher rate or enhanced award mobility component. Indeed, while around three quarters (**73%**) of respondents in receipt of DLA mobility component exchanged it for access to Motability, this proportion fell to just over half (**55%**) of those receiving PIP. Government statistics show that half (**50%**) of DLA claimants who were in receipt of its higher mobility rate were assessed as being eligible for a lower rate when moving to PIP - losing access to the Motability scheme<sup>20</sup>. The effect of this is shown by the fact that 629,000 disabled people relied on the Motability Scheme to support their independence in 2017<sup>21</sup>, down from 648,000 a year earlier<sup>22</sup>.

Confirming this, figures from the Department for Work and Pensions in figure 4.5 show that just **14%** of those claiming DLA receive a 'nil rate' mobility component, compared with almost a third (**31%**) of those claiming PIP.

Additionally, while the proportion receiving the ‘lower’ DLA rate (35%) or ‘standard’ PIP award (29%) is similar, there is a substantial difference between the ‘higher’ DLA rate (51%) and ‘enhanced’ PIP award (40%), which are required to access the Motability Scheme.

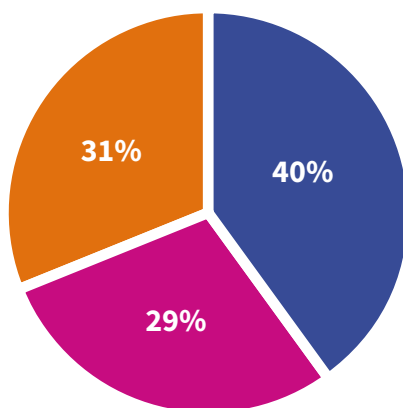
**Figure 4.5: Proportion of those claiming DLA<sup>23</sup> and PIP<sup>24</sup> who are in receipt of each mobility component rate (August 2017) - United Kingdom**

**DLA recipients**



- Higher - 1,088,684 (51%)
- Lower - 733,038 (35%)
- Nil - 303,824 (14%)

**PIP recipients**



- Enhanced - 609,637 (40%)
- Standard - 448,618 (29%)
- Nil - 469,744 (31%)

The difficulties in applying for, in particular, PIP and the reduction in those found eligible for enhanced rate mobility component is, in part, due to the ‘moving around activity’ qualifying ‘descriptor’ criterion for enhanced-rate mobility component in PIP requiring that applicants cannot walk without severe difficulty for more than 20 metres, down from 50 metres under DLA<sup>25</sup> \*. This descriptor was implemented despite substantial opposition to the move during the consultation on PIP mobility eligibility rules<sup>26</sup>. While the Department for Work and Pensions acknowledged that the introduction of a social model approach taking into account specific barriers faced by each individual had ‘considerable support’<sup>27</sup>, it rejected such a system on the basis of it being ‘lengthy’, ‘complicated’, ‘subjective’ and ‘inconsistent’<sup>28</sup>. It also stated that it felt that:

‘the use of 20 metres is the best way of identifying those whose physical mobility is most limited. We think it is justified to focus support in this way given the policy intent to target support on those with the greatest need and create a more financially sustainable benefit.’<sup>29</sup>

This is counter to much of the evidence provided by stakeholders. The Disability Benefits Consortium (DBC) argued that there is evidence that those who can walk for more than 20 metres, but less than the DLA benchmark of 50 metres, face the same additional costs as those unable to walk 20 metres.

\* It is possible for a physically-disabled claimant who can walk more than 20 metres to receive enhanced rate mobility component in PIP if they receive sufficient points from the ‘planning and following a journey’ activity. However, they would only potentially be eligible for descriptors in this activity if they also had a mental health, cognitive or sensory impairment.

Examples given include someone unable to walk 50 metres no longer having access to a Motability car despite public transport being more than 20 metres away <sup>30</sup>.

In addition, the DBC highlighted that the 20 metres rule is inconsistent with Government guidelines in other areas. It states that a '50 metre benchmark distance is a well-established and research based measure of significant mobility impairment - notably in relation to other disability benefits including DLA, the blue (disabled) parking badge and in official guidance on creating an accessible built environment' <sup>31</sup>. Indeed, as the DBC also notes, the second draft of assessment criteria for PIP published in November 2011 based its 'moving around activity' criteria on the 50 metres benchmark, stating that '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 such as the ability to get from a car park to the supermarket' <sup>32</sup>. Despite this, the Department for Work and Pensions' response to the consultation on the moving around activity criteria states that 'whilst there is no clear evidence for one particular distance, the 20 metre distance was introduced to distinguish those whose mobility is significantly more limited than others and who face even greater barriers on a day-to-day basis - those who have the highest need' <sup>33</sup>.

Illustrating the issue, there have been high-profile cases of athletes who have been negatively affected by the transfer from DLA to PIP and the new assessment criteria.

For example, Carly Tait, a European silver medallist wheelchair racer was moved from higher rate mobility DLA with a lifetime award to a standard-rate component under PIP months before trials for the 2016 Summer Paralympics.

Coverage in The Guardian claims that:

Tait says when she was called for her PIP interview she was sure she would still qualify for her car. "[I thought,] I'm going to my assessment in a wheelchair. What more evidence do they need?" But within a few minutes of the test, Tait says she began to feel the examiner wasn't there to support her but rather "to catch me out". This only increased, she says, when she told him she was training for the Paralympics. "He alluded to the fact someone like me - who can go wheelchair racing - shouldn't get the same support as someone who can't... It was like 'you can do sport, you don't need help,'" she recalls <sup>34</sup>.

Other Paralympians, including European silver medallist runner Ben Rowlings and Paralympic gold medallist wheelchair racer Hannah Cockroft, voiced concerns in the run up to the 2016 Paralympics about losing their access to the Motability Scheme following reassessment for PIP <sup>35</sup>.

The impact of long-term conditions and the impairments they cause, by their nature, often fluctuate <sup>36</sup>. As such, it is essential that those administering systems of benefits acknowledge fluctuation as somewhat of a default position. The Department for Work and Pensions' guidance around fluctuating conditions in relation to PIP applications is currently relatively vague, stating only that 'if your needs vary, tell us in what way and how often - for example, telling us about good and bad days or how your needs vary throughout the day.' <sup>37</sup>

The Department for Work and Pensions' official guidance to organisations and individuals supporting applicants for PIP is similarly lacking in detail, stating that 'the claimant can use this form [How your disability affects you] to describe how their health condition or disability affects their daily life, on both good and bad days and over a range of activities.' <sup>38</sup>

Although detailed guidance for assessment exists in technical documents, ‘descriptors’ of difficulties faced by applicants are used on the basis that they are likely to apply for more than 50% of a reference time period <sup>39</sup>. Should a fluctuating condition result in an applicant being bedbound for three days per week but able to walk more than 50 metres ‘reliably’ \* for the other four, for example, their condition would not be described as severely limiting their mobility, despite them requiring substantial additional support for much of their week. This guidance, or a simplified version thereof, is not provided directly to applicants despite being key in determining eligibility.

Citizens Advice provides much more detail directly to applicants on how to account for day-to-day differences, with the following guidance:

Explain how you cope on both good days and bad and how you manage over a longer period of time (like a week). This gives the DWP a better picture of how you cope most of the time.

Make it clear:

- If you have good days and bad days.
- How often you have bad days.
- If you have bad days more often than not.
- How your difficulties and symptoms differ on good days and bad - for example, you can't finish preparing a meal or you only use pre-chopped vegetables.

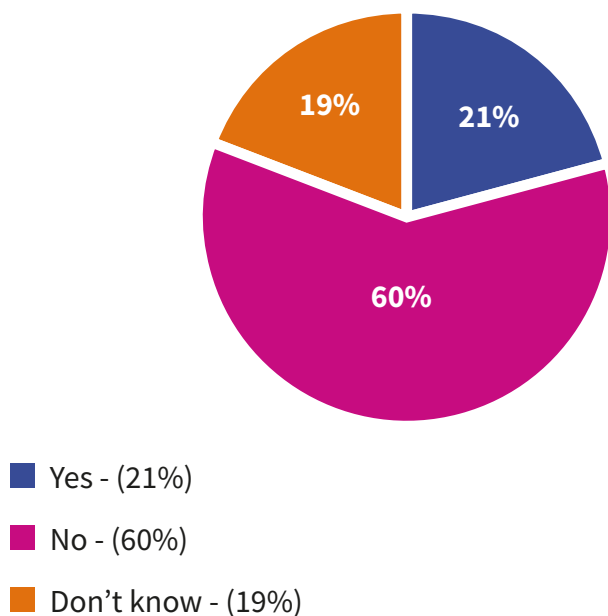
It's OK to estimate your bad days but say if you are. If it's too difficult to estimate - explain why. For example, because your condition fluctuates.<sup>40</sup>

It also has comprehensive, step-by-step written guidance for completing the PIP application form as well as support from an advisor using an online chat system <sup>41</sup>. Unfortunately, our study found that just one in 10 participants had used Citizens Advice to find information about benefits.

Disability Rights UK's <sup>42</sup> and Citizens Advice's <sup>43</sup> guidance provides detailed examples of how a diary system can be used to evidence the fluctuating effect of some impairments. This system facilitates a much more detailed explanation of the impact and additional costs of an applicant's disability but is in addition to, rather than in place of, questions around, for example, a concrete figure about how far an individual can walk.

Ambiguity in the system and a resulting lack of understanding extends after the application process. Figure 4.6 shows that there is a lack of clarity around benefit restrictions among claimants. One in five (19%) don't know if there are any spending conditions associated with their benefits or financial assistance and a further one in five (21%) say there are. At least a third of those who said there are conditions were referring to Personal Budgets and Access to Work, which do have conditions.

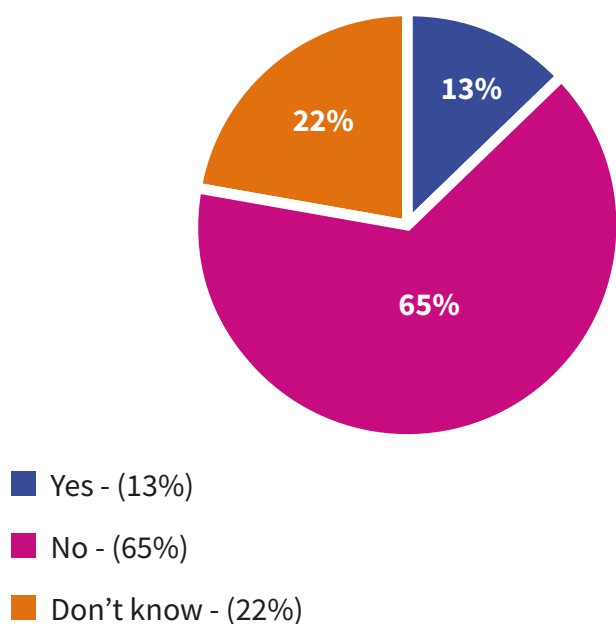
**Figure 4.6: Proportion of all participants by whether they believe their benefits have spending restrictions**



\* See [pipinfo.net/issues/reliably](http://pipinfo.net/issues/reliably) :  
'To be assessed as able to carry out an activity to the level described in a descriptor, a claimant must satisfy the descriptor "reliably", that is: safely, to an acceptable standard, repeatedly and in reasonable time.'

A similar result emerges when discounting benefits and financial assistance that do have conditions attached (Access to Work grants, Disabled Facilities Grants, Personal Budget and Personal Health Budget) and limiting it to participants in receipt of DLA, PIP or ESA, which are unrestricted. One in five (22%) still didn't know if there were spending conditions and one in eight (13.3%) believed there are (figure 4.7).

**Figure 4.7: Proportion of participants in receipt of unrestricted benefits by whether they believe their benefits have spending restrictions**



Age UK states that there are no spending restrictions for either component of PIP <sup>44</sup> or DLA <sup>45</sup>, despite their award being based on needing additional assistance in these two areas. However, this information is not easily available from an online central government source. For example, there is no clear reference to restrictions on the official Gov.uk PIP <sup>46</sup> or DLA <sup>47</sup> webpages. Instead, there is reference to eligibility based on requiring help with daily life, care or mobility.

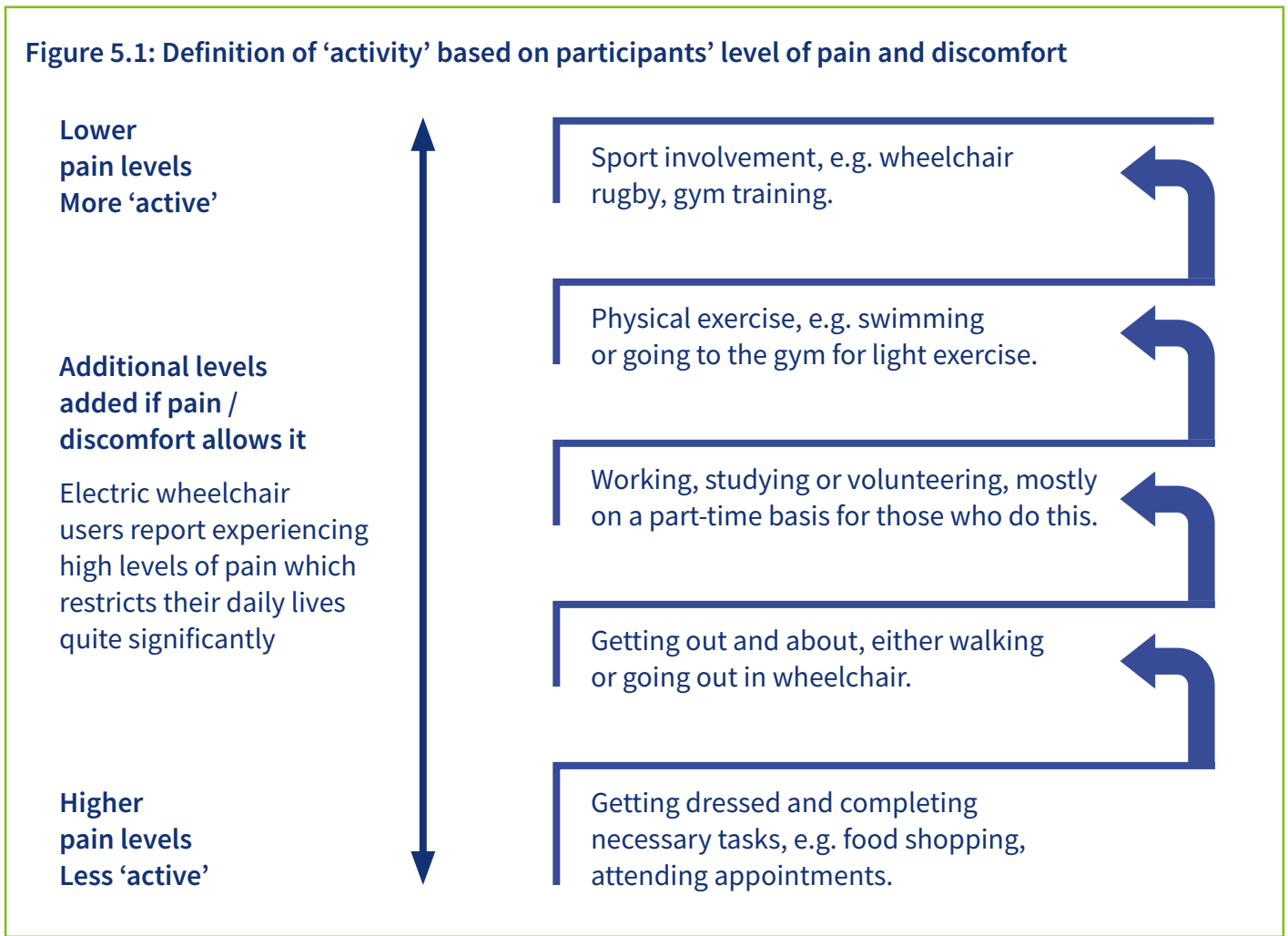
This ambiguity, combined with the labels for each component, has clearly instilled in some that there are greater restrictions on some disabled people's benefits than exist. One participant with dwarfism or restricted growth said that 'DLA Care and mobility, so it has to be spent on mobility (a car in my case) and my care needs' while a respondent with cerebral palsy felt that 'PIP money is for mobility needs and getting around.' Others believed that the mobility component had to be spent on Motability or another form of transport, and, similarly, a few believed that the care / daily living component could only be spent on personal care.

## 5.0 Fear of benefit removal and its impact on activity

Day-to-day activities that come naturally to non-disabled people can pose significant challenges to disabled people. Most participants in the qualitative portion of the study felt that a structured daily routine, with stretching and a balance between being active and getting enough rest, is crucial. The pain and discomfort experienced by participants had a substantial effect on their definition of what constitutes 'activity'. Those experiencing lower comparable pain levels might describe participation in organised sport as activity, while for those with much higher levels, essential tasks such as getting dressed, making food, shopping and attending appointments might be both the most relevant form of activity and what they most believe activity to be, as shown in figure 5.1.



**Figure 5.1: Definition of 'activity' based on participants' level of pain and discomfort**



Respondents felt that benefits supported daily life in three core ways:

1. Independence: being able to pay household bills, treatment, special equipment and medications.
2. Security: being able to have a social life and getting from A to B (e.g. travel to appointments).
3. Staying active: paying for leisure activities, gym membership and maintaining a social life.

In terms of 'independence', it's clear that many have to use their benefits for basic needs - utilities, treatments and medications. This has the potential to detract from their ability to pursue additional rehabilitation and physical activity services that may reduce the impact of their impairments. For instance, one respondent - who is an electric wheelchair / power chair user - stated that 'as far as I know I'm able to spend any benefits in a way I decide, usually this is helping to pay household bills etc. before I can think of luxuries that would actually benefit me!'

A respondent with upper and lower limb impairment reinforced this:

“They can give you independence and the chance to occasionally when I am feeling up to it be able to go the cinema or for a small day outing. It also enables me to know I can get all the therapy, physio and treatments I need and that I have the money that will allow me to be able to travel to all appointments, also a feeling of security with daily life and the cost of household bills, extra costs for equipment and the help of getting medications. Most of my financial support ends up on paying my bills, and travel costs to get to my appointments.”

Surfing the internet (63%) was the leisure activity currently enjoyed by the highest proportion of participants. However, this was closely followed by visiting friends and family (61%), visiting outdoor spaces (60%) and eating out (59%). Playing sport was still enjoyed by half (49%) of participants with other exercise or physical activity (33%) and visiting a gym or leisure centre (30%) enjoyed by approximately a third (figure 5.2).

**Figure 5.2: Proportion of participants by leisure activities currently enjoyed**

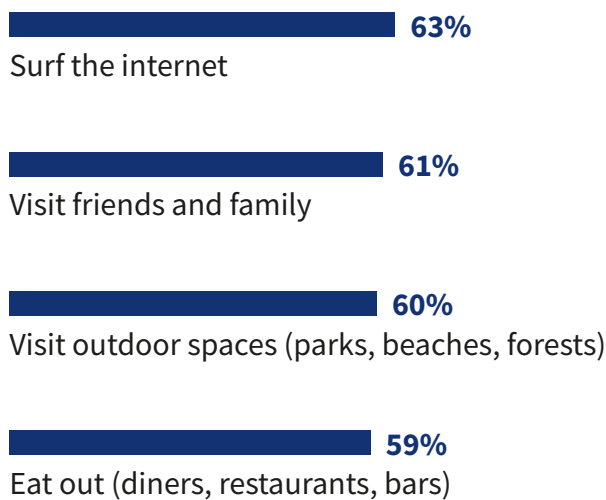




Figure 5.3 shows that participants were most likely to want to do more in terms of playing sport (54%), ahead of travelling (53%) and visiting outdoor spaces (51%), with taking part in other exercise or physical activity (38%) and visiting the gym or leisure centre (34%) in fourth and fifth places.

**Figure 5.3: Proportion of participants by leisure activities they would like to do more of**



This suggests a strong belief among disabled people participating in the study that being active is desirable. Indeed, while 70% agreed that they enjoy being physically active, an even greater proportion, 84%, agreed that it is important to be physically active.

One participant with dwarfism or restricted growth said that being physically active ‘means I am in charge of my health - it means I am not reliant on doctors (whose opinions are not really relevant to me) and I am keeping fit. It means I see people regularly who don’t question my ability.’

More than two thirds (69%) of participants take part in exercise or physical activity for at least 30 minutes twice per month. Almost four in five (79%) of these would like to do more physical activity, while more than nine in 10 (91%) of those currently less active would like to do more, as shown in Figure 5.4.

**Figure 5.4: Proportion of participants who would like to do more physical activity by current activity level**

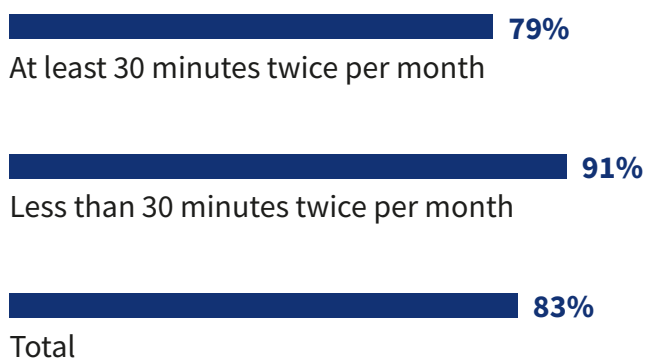
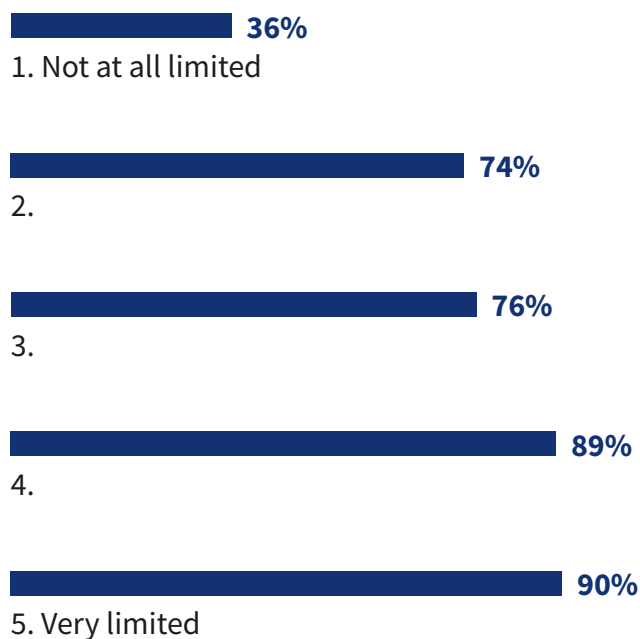


Figure 5.5, shows the proportion of participants who would like to be more physically active by the extent to which they are limited by their illness, health problem or impairment. Those who felt more limited were more likely to want to do more physical activity, including nine in 10 (**90%**) of those most limited compared with just over a third (**36%**) of those not at all limited.

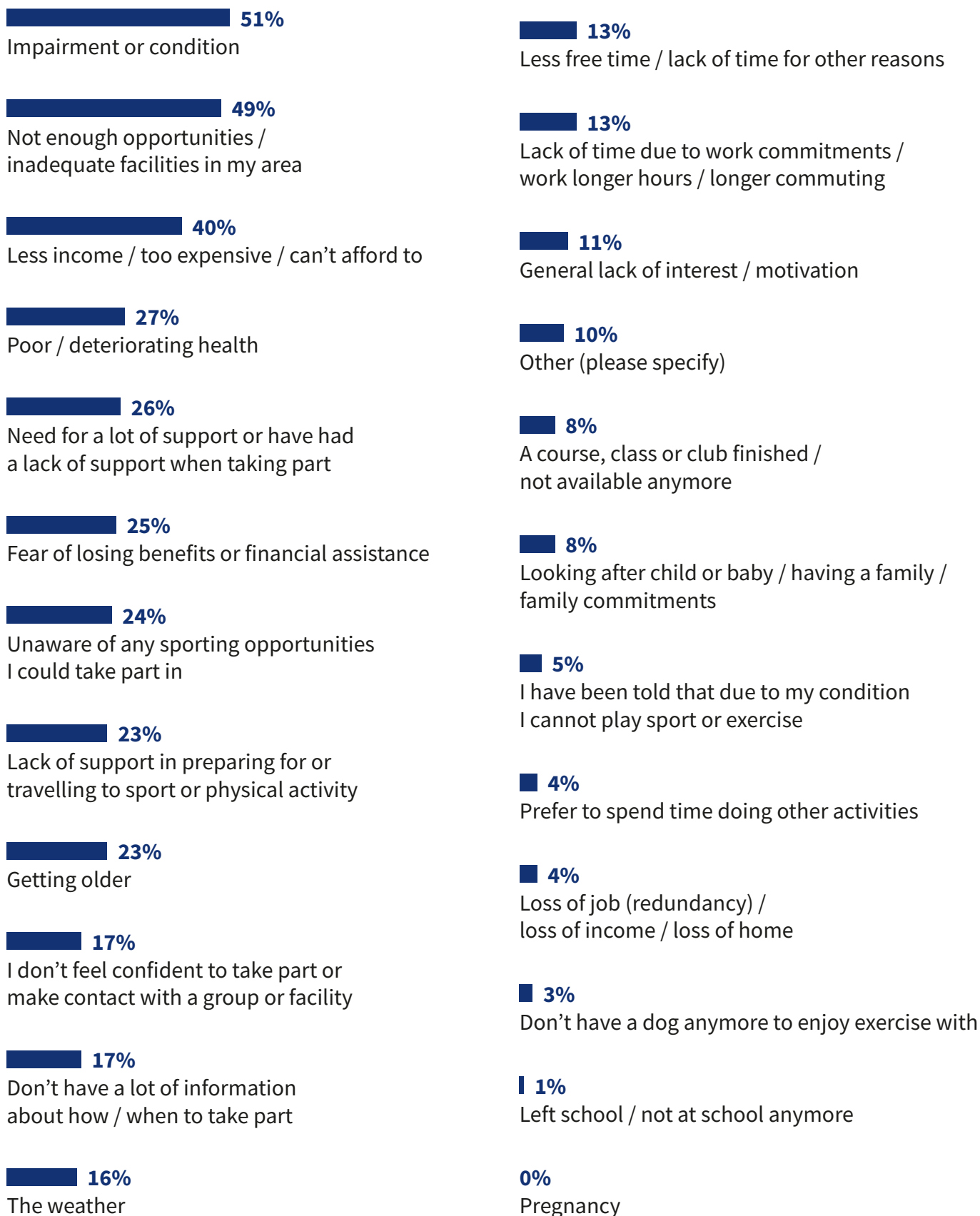
**Figure 5.5: Proportion of participants who would like to do more physical activity by the extent to which their activity is limited by their impairment**



When asked to choose from a list of barriers preventing them from participating in sport and physical activity in general, figure 5.6 shows that their impairment is the biggest barrier for disabled people. Not enough opportunities (**51%**) or inadequate facilities in their area (**49%**) are the next most prevalent barriers.

Finances and benefits weigh heavily, with **40%** unable to participate due to insufficient funds and a further quarter (**25%**) fearful of losing their benefits or financial assistance.

**Figure 5.6: Proportion of participants by factors preventing participation in sport or other physical activity**



When asked what prevents them from trying to be **more** active, figure 5.7 shows a lack of confidence around the practicalities of taking part and fears of not being capable (63%) or being supported by others (57%) were the biggest barriers. Concerns about the impact of benefits are twice as high among participants when considering being more active than when thinking about participating in general. Almost half (47%) of participants feared losing their benefits or financial assistance by trying to be **more** active while a similar proportion (48%) feared being seen as too independent for someone with a disability.

**Figure 5.7: Proportion of participants who are prevented from trying to be more active by each fear**

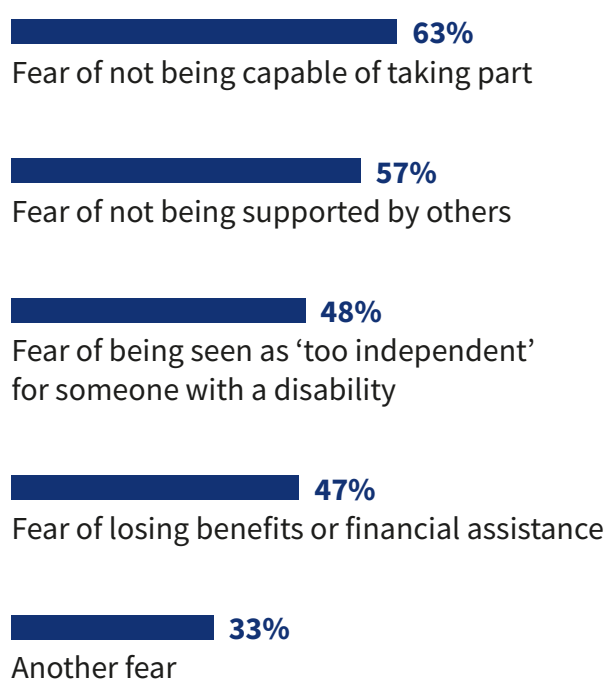
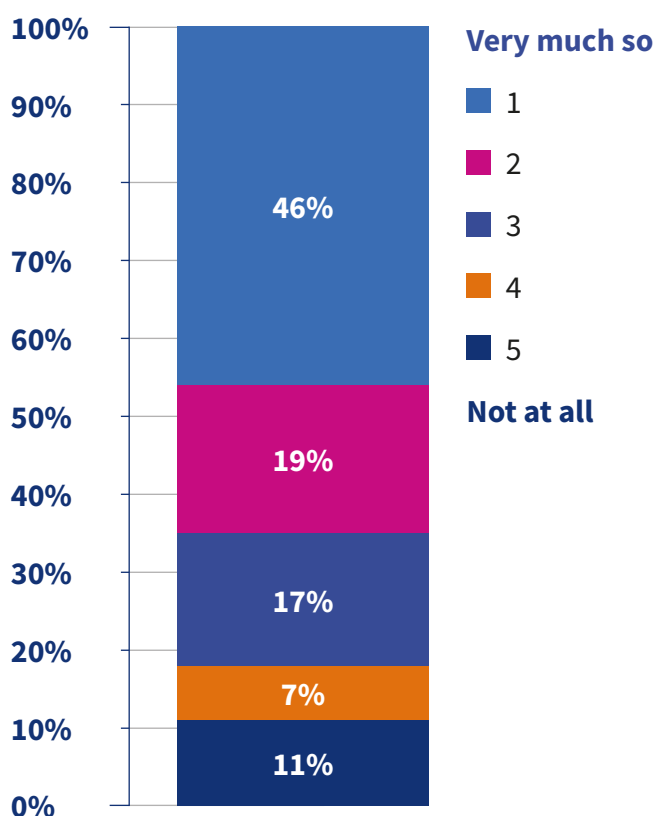


Figure 5.8 shows that almost two thirds (65%) felt they relied on their benefits to be active to a significant extent, with electric wheelchair / power chair users even more likely (80%) to say this. Those who said they were more reliant were also more fearful of losing them.

**Figure 5.8: Proportion of participants by how reliant they are on benefits or financial assistance to be active**



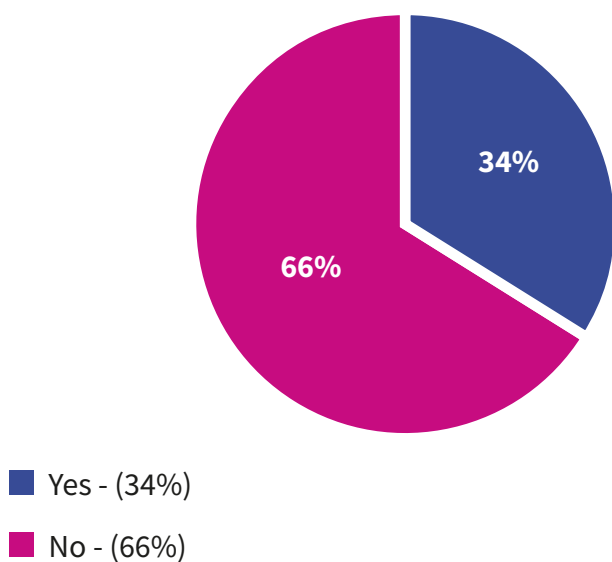
This fear of sanctioning and removal of benefits and a reliance on them to be active is significant as Public Health England's strategy of 'getting every adult active every day' states that 'low physical activity is one of the top 10 causes of disease and disability in England' <sup>48</sup>. It also highlights that:

Disabled people are half as likely as non-disabled people to be active. Only 1 in 4 people with learning difficulties take part in physical activity each month compared to over half of those without a disability.

The CMO physical activity guidelines can be applied to disabled adults, and should be adjusted for each individual, based on that person's exercise capacity and any special health or risk issues.

The fear of benefits being sanctioned or removed is by no means unfounded. More than a third (34%) of participants had experience of their benefits, or those of someone they know, being sanctioned or removed as a result of being physically active, either by being reported by someone else or through self-reporting during an assessment / reassessment (figure 5.9). This indicates a substantial driver of fear among participants.

**Figure 5.9: Proportion of respondents who had experience of their benefits or financial assistance or those of someone they know being sanctioned or removed as a result of being physically active**



The qualitative stage confirmed and unpicked these fears, with participants concerned by:

- The reputation of government agencies including the Department for Work and Pensions.
- The reputation of PIP being stricter than DLA.
- Stories in the press about people losing benefits.

- Difficult experiences with the application process.
- Personal experiences of support being withheld.

A participant who is a manual wheelchair user said:

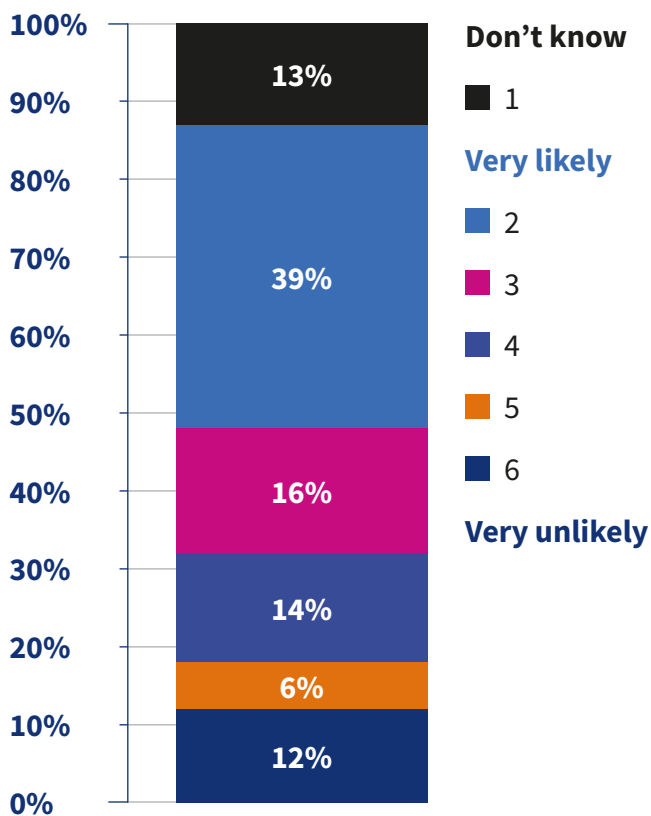
‘I’m always afraid of doing too much as it could have a negative impact on my disability benefits entitlement. This is partly from the forms, but also because I had a friend who tried doing a little more than I do now, to try and help with her pain management, and they took away half her benefits and told her she was capable of going to work as she was capable of doing so much exercise - despite her having regular fits etc.! She was told that to stand any chance of getting them back she’d have to give up all but one class and maintain that level for six months. You’d think we’d be encouraged to reduce pain using non-medication routes, but apparently not!’

While another who is an electric wheelchair / power chair user related their experience of losing benefits:

‘I lost my benefits for 4 years because I was given the wrong information on the phone. It took years to sort out but I eventually got it back - I had to go to court and it was like all the evidence I had given suddenly came to light - even though I had been sending it to them for 4 years. The problem was that I phoned to ask if I tried a job to see if I could manage it and they said that I could and if it failed I would get my benefits back as they were. They were wrong. So I just lost everything. (I had been advised not to try getting work but I hated being on benefits and was really trying hard).’

Potential solutions were indicated by the fact that more than half (**55%**) of participants felt that they would likely try to be more active if their benefits or financial assistance were unconditional; that is, they couldn't be taken away (figure 5.10).

**Figure 5.10: Proportion of participants by their likelihood of trying to be more active if benefits and financial assistance were unconditional**



A participant with upper and lower limb impairment:

'I have a lot of concerns when it comes to benefits and the constant fear of them being taken away or worry of being reassessed. It then impacts my life and any involvement in sport and physical activity which is none at the moment due to the concerns I have and not wanting my benefits to be taken off me, as DWP are not known for being understanding or nice and will try and find any reason to remove someone's disability benefits.'

I would also like to see change in the attitudes of the assessors but everyone within DWP who deals with disability benefits and for them to be more understanding and to see that disabled people can still do things if it is adapted and we have good days as well as bad days, and for them not to feel the need to find anything to put against someone on benefits just so they can take disability benefits. I know this would encourage me to get involved more if I felt like they understood that we are still people and should still be able to have lives, as there are things that we of course want to be able to do just like everyone else, even if that means having to adjust or adapt the way we exercise.'

In the qualitative stage of the study, participants cited paid-for exercise, travel, specialist equipment (e.g. wheelchair maintenance) and a social life as aspects of their lives that they wouldn't be able to afford without support. They expected that their conditions would worsen due to a lack of physical activity and that they would become more housebound and reclusive as a result. Most also expected that they would experience more pain and difficulty.

Where possible, the removal of reassessment for those in receipt of ESA should be extended to those receiving PIP. For those with conditions that are lifelong, reassessment, except when initiated by the applicant or their supporters due to deterioration, seems both unnecessary and has a counterproductive effect of deterring recipients from engaging in physical activity that may help to manage the impact of their impairments.

## 6.0 Case studies\*

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The following case studies of individual participants in the qualitative stage of the study help to illustrate the challenges faced by disabled people in their day-to-day lives, their engagement with the benefits system and their efforts to remain physically active.

### 6.1 Case study one:

21-year-old participant with dwarfism or restricted growth working regularly

#### Challenges in applying for Disability Living Allowance (DLA)

I have not received any communication from the DWP for some time. The last time I had to apply for DLA was when I was 16 and this was mostly done by my parents.

I can remember the form being very complicated with lots of different sections to fill in it looked very boring and not very inspiring.

I started off by completing an application form I then had a response saying that I could not receive any support. I then had to ask for a medical assessment as I don't think I was able to clearly give all the information on the form. It was after this that I was found to be eligible for support.

Overall the process was very stressful it would have been good if I could just have easily given all the information I needed on the application form so I could have been clear and not have required the stress of a doctor's visit.

I think it was hard to describe exactly how my disability affected me physically. The form wanted my day to day life but made it hard to talk about good days and bad days. This made it hard to clearly describe what I am like when I am at my worst. This made me worried when I was told in my original decision notice I was not eligible for support. I was angry as I knew I was not able to give the full picture in the original application. I was annoyed at first about having to attend the medical assessment but then in the end I was happy that it gave me the opportunity to fully describe all of my issues.

The only issues I have had is making myself clear and being able to express myself fully on the form. The only time I could get my full story across is when I was able to see a doctor.

I would like to have a form which was colourful and looked interesting to complete. I want it to make it easy to give all the information that I can.

\* Quotations come from answers to a number of questions and have been proofread, abridged and had minor edits made to them where needed to aid readability.



## **What benefits provide and what would happen in a world without benefits**

The main disability benefit I receive is my Motability car without this I would be very stuck. The fact that I have access to an adapted car makes sure I am able to keep a regular commitment to my job. If I wasn't able to drive on some days, I would have to take those days off sick. This would obviously have serious consequences. I also receive some money to help towards my care, I try to save this money and put it towards buying things which I need to help me live an independent life. Without this support I would think that I would require extra help from either friends or family.

Without [the car] I think I would find it very hard to live a normal life. I require several adaptations to be made and I don't think I would be able to afford to have these on top of the cost of the car. Not only would I may not be able to get to work some days I would also find it hard to get to my local swimming pool. If I was not able to take part in swimming it would be most likely that my physical condition would get worse. This would then lead to a downwards spiral especially if I wasn't able to get to work either this would then most likely begin to have an effect on my mental health.

## **Physical activity and its expected impact on entitlement to disability benefits**

I like to take part in swimming, this is sometimes three times a week but I try to always go at least twice a week. I find it hard to take part in other physical activity as it puts a lot of strain on my joints and this eventually leads to pain.

I like taking part in sport as I feel that it keeps me healthy and stops my condition from getting worse. It also allows me to keep social as I have a good group of friends which I like to talk to at the swimming pool. There isn't really anything which would discourage me from taking part in sport apart from the fact that I maybe tired at the end of a long day. In this case I find it more important to stay at home and have a good rest otherwise I am unlikely to be able to survive the next day. I would also be less likely to do physical activity if I thought I was going to get bullied where ever I was going to or have people make fun of me.

I would be scared in taking part in lots of physical activity as I feel it would have a negative effect on my health. I would also be concerned that if I was seen to be taking part in lots of physical activity even if I was pushing myself to my upper limit that I may be seen by some to not be eligible to claim any benefits. This obviously doesn't mean that I am in that condition all the time and in the most likely situation if I had push myself to the limit I would probably find that I was in a very bad way the next day.

## **What physical activity means to them**

I like being involved in sport as it gives me a sense of belonging to something as I have my friends at the swimming pool. It gives me motivation and it is something to look forward to at the end of the day. An active lifestyle is important to me as I feel that it keeps me fit and healthy. I would like to have more of an active lifestyle although I would have to balance this with making sure I can still do all of my other day to day activities.

## 6.2 Case study two:

45-year-old participant who is an electric wheelchair / power chair user working part time

### Challenges in applying for Personal Independence Payment (PIP) and Employment and Support Allowance (ESA)

I made sure I could answer as fully as possible - but I had to ask for a reassessment for PIP because they didn't take into account my mental health, even when they did they actually made it seem like I had lied and completely discounted some aspects.

The form causes such stress and I had to spend several days thinking about my answers to ensure I gave a full picture. I also made sure I filled it in on or near a bad day because when I feel well I tend to underestimate the effect my illness has.

It is very difficult and stressful. Focussing on the bad days is the opposite of what is good for my mental well-being and the forms make me feel depressed.

I also think that the [small] amount of people who succeed after a reassessment is an outrage. They don't seem to be trying to make people's lives easier and it is a punitive exercise.

It would be great if they sent a summary or a copy of the form... it's so long that it's difficult to copy... I always do because I feel I need to because they forget things you've put. I think I mean the questions are just such broad questions. It would be easier if they were tick boxes such as: Can you use the hob? Yes / varies. Can you press a button? Yes / no / varies. The question about walking starts at 50 metres. I can't walk 50 metres but I can walk a bit. I feel like they are trying to trick people here into ticking the 50 metre box. I think the ability to complete it online would help. Or if they could send it so you can type the answers in.

[In the PIP form] they could say - how far can you walk - or have more choices i.e. 5m or less, 10m or less - etc.

If you can walk 50 metres they will probably say you aren't disabled, so why are they putting that as the first option. It's complicated because they have to cover so many different abilities / disabilities. It would be nice if they could ascertain the type of disability and then send a more appropriate form. I'm sure that would be achievable.

It is so difficult because you don't quite know what they are looking for. That is why there are lots of crossings out.

It would be great if it could be completed online - writing is difficult for me. I would like the forms to be shorter.

### How benefits affect participation in physical activity

I get very tired and find sitting for long periods painful so after I do Flyball at the weekends it takes me a couple of days to recover, which means I then have to catch up with work and don't get a chance to exercise. I really need to exercise because I have arthritis, I'm overweight and have a big risk of diabetes. I have been advised to give up Flyball to focus on my health.

I am lucky that at one pool in Harrow I can swim for free and I get dial a ride but I do sometimes need to get a taxi - so benefits help to pay for that. Also for the wheelchair that allows me to go out. I do save for gym membership but I have been so unwell lately that I haven't been able to go - I'm still hopeful that I will in the near future. I think having a regular massage would help me but that is out of my reach even with benefits.

I lost my benefits for 4 years because I was given the wrong information on the phone. It took years to sort out but I eventually got it back - I had to go to court and it was like all the evidence I had given suddenly came to light - even though I had been sending it to them for 4 years. The problem was that I phoned to ask if I tried a job to see if I could manage it and they said that I could and if it failed I would get my benefits back as they were. They were wrong. So I just lost everything. (I had been advised not to try getting work but I hated being on benefits and was really trying hard).

I had to appeal my PIP because they completely discounted my mental health difficulties, the person who visited my house said I had no problems despite me telling in detail what they were. The assessor clearly had no idea about my condition and didn't even bother to look it up.

### **What benefits provide and what would happen in a world without benefits**

I have been able to get a cleaner every other week and I was able to buy a more comfortable wheelchair (than the NHS one which didn't really enable me to go out anymore). The wheelchair has given me a life, I am able to go out and join in with activities and before I wasn't able to go out at all because walking was too much for me. In fact, I walk more now I use a wheelchair than I did before. I use my benefits to help me buy things I need for using the wheelchair - like gloves because my hands don't grip well.

[Without benefits] I think I would still be sitting in the corner hoping to feel better and not actually being able to have a life which involves other people. I have been able to travel independently and visit my children because of my wheelchair. I am able to attend events with my husband and dogs and even help the team out by sorting out the dog training. That level of contribution would not happen if I didn't have a wheelchair. I also really need a cleaner because my husband works full time and we struggle to keep up with the housework and have a life outside of the home, which we really need.

I wouldn't be able to travel to the leisure centre because I couldn't afford a taxi and in the long run, I wouldn't even be able to afford an appropriate wheelchair so would barely go out at all. This would mean I couldn't visit my children as well. I would be very miserable again because I would just be sitting in my house.

### **Physical activity and its expected impact on entitlement to disability benefits**

I think [physical activity] would help my weight, help my joints and help me feel well mentally. I really like sport. I used to run and weight train and I since becoming disabled I learned to swim so that I can still exercise as it doesn't cause pain. The only thing that discourages me is difficulty getting dressed after swimming and if I am in a lot of pain to start with it makes it even more difficult. I also get tired so it's hard to commit to a membership because my illness makes it impossible.

I try to do some seated exercise and gentle yoga at home - it depends how tired or achy I am. I also try to swim but it has been about 3 months since I was able to go. I would like to go back to weight training but I need to start very gently so at the moment I just rejoice at what I can manage.

I would hope that [more physical activity] wouldn't [affect entitlement to benefits] because it is so important to my health. I am prediabetic so exercise would be so good for me but I do worry that 'they' would rather I went to work than exercised even if it gives me even more health problems.

### **What physical activity means to them**

I find exercise helps me feel better. It lifts my mood and swimming can be really mindful. I also love the feeling of moving my body in the water because it's not as painful. I try to walk in the water too to try and keep my mobility as good as possible. I also would really like to be slimmer, that would also help my mood. If I only focussed on exercise at the moment, I wouldn't be able to do the 4 hours of work a week I do - and it's a really difficult choice because I also need to feel valued.

### **6.3 Case study three:**

18 to 24-year-old participant with dwarfism or restricted growth working full time

#### **Challenges in applying for benefits**

When I applied for PIP 3 years ago, I was worried that I would not receive what I needed to become independent. I had heard from people transferring to PIP that it was a lot tougher than the old DLA. I wasn't very mobile at the time due to back issues. However, I would have like to have done some sport e.g. swimming to help the pain, but I felt restricted in case I didn't get my benefits.

Took a very long time to get the assessment appointment. Then a further delay in getting the decision. Got local MP involved to speed up. Then delay in waiting for the car. Reducing mobility and independence.

#### **What benefits provide and what would happen in a world without benefits**

My benefits provide me with an adapted car which without I would not be able to afford myself. This gives me independence, not having to rely on others to get around. I am able to travel around with my wheelchair and participate in normal day to day activities. My care benefits are then used to fund the cost of fuel to get me around, any specialist equipment or resources that I need.

Without benefits I would not be able to leave the house. I cannot go out and use public transport. I would not be able to transport my wheelchair around.

I would probably feel less restricted in the different physical activities that I take part in. E.g. become more involved in other sports offered at Dwarf Sports Association games.

#### **Physical activity and its expected impact on entitlement to disability benefits**

Physical activity shows people that I'm not letting my disability affect what I can do. It has built my confidence and self-esteem and allows me to just think of me when I'm in the pool and no one else.

I am reluctant to take part in more physical activity as I worry it will affect my entitlement to my benefit. Therefore, I feel restricted in what sports I can take part in.

[Benefits restrict] the amount of physical activity that I do, I am probably capable of doing more, but don't like doing too much in case my benefits get taken away.

#### **What physical activity means to them**

I love sport, particularly swimming. It's the one thing that has always been a strength of mine. I love being in the water and competing gives me a real thrill. I would like to be involved in more day to day sports but am sometimes restricted due to pains and mobility issues.

### **6.4 Case study four:**

45 to 54-year-old participant who is an electric wheelchair / power chair user studying part time

#### **Challenges in applying for Personal Independence Payment (PIP)**

I looked online to see if it seemed that I meet the criteria then I rang for an application form. They sent it to me. I didn't have problems finding medical letters as I keep it all together already. It was embarrassing asking my doctor and my physiotherapist to give me letters as well though as I felt not 'bad enough' to be asking for the benefit. I filled in the form over a few days as it made me miserable to do. I then got lower rate PIP so asked for a mandatory reconsideration as it seemed I met the higher criteria which I then got awarded. I was very happy to get the final letter through the post and as it included some backdated money I was able to buy an electric wheelchair second hand.

The form was very long winded and detailed. I found it quite depressing to complete it as I had to explain all the things I couldn't do.

I understand why they want so much information but I would have found it less depressing to tick boxes instead of describe my problems.

The forms are so laborious. They take a very long time and are depressing to have to explain all my difficulties of everything I do. On a day to day basis I just get on with things the best I can, but having to write down all the difficulties I have makes me think about them more and makes me sad. The face-to-face assessments are stressful as well although I've always found the assessors very nice and friendly to me.

I was concerned I might not get any benefits I have applied for (PIP, ESA and blue badge) as I wasn't sure I would meet the criteria fully enough. This did not affect any activities but was stressful.

### **What benefits provide and what would happen in a world without benefits**

I use my enhanced part of mobility PIP for a van which I am waiting for at the moment. It will really help me get out easier, including being able to go for walks (wheeling) as I can't get my electric wheelchair in the car. I also had to give up work due to my condition so ESA really helps make ends meet. I had to buy an electric wheelchair through eBay as I don't meet the criteria for an electric chair even though I can't walk or self-propel due to my condition (EDS). I bought crutches (lighter than the NHS ones I was given) and splints and a TENS machine with my PIP.

[Without benefits] I would be stuck using a manual wheelchair that I got from the NHS which would further damage my neck, shoulders and hands. I would not be able to drive as I couldn't pay for the adaptations I need. I would not be able to buy splints I need (the NHS has given me some but not more when they wear out).

If I did not have PIP I would not have a Motability vehicle so it would be very hard to go out. I could not have bought my electric wheelchair so would have further wrecked my hands, shoulder and neck using the manual chair so needing more surgery than I have already had (and costing the NHS more) and caused more pain and disability. If I did not get ESA I would also not have been able to buy lighter crutches or splints so causing more damage to my body.

### **What physical activity means to them**

More swimming would be beneficial to my pain levels and strength and fatigue. But I have to be careful not to overdo it too. I would like to be fitter. I miss going for walks in the countryside, and I hate the fatigue which stops me from doing things.

## **6.5 Case study five: 35 to 44-year-old participant who is a manual wheelchair user not working**

### **Challenges in applying for Disability Living Allowance (DLA) and Employment and Support Allowance (ESA)**

The initial form for applying for Disability Benefits (both DLA and ESA) was given to me when I was still a patient in the spinal injuries unit.

I found the questions on the forms confusing, especially as many seemed to ask the same things, and you had to answer some and not others. I was very lucky as we had a visitor come in to the spinal unit from the local CAB who helped fill in the forms if we needed it, and they gave us advice (including the advice that you should always answer as your very very worst day if you wanted to get anything!), then told us to keep a copy of our forms before sending them off, so we could refer to them when filling in any later copies of the same forms.



This all helped immensely, as I don't think I would be managed to do these forms alone - especially as I have a brain injury as well as a physical injury, which can make it tricky for me to understand what's being asked of me - and I'd highly recommend getting help from the CAB the first time you have to fill in these forms and keeping a copy for later referrals!

Always have to fill in forms for your very very worst day, or you don't get appropriate money. However, this then leaves you more vulnerable to being called a benefits cheat. Swings and roundabouts!! The forms aren't very clear sometimes, and as a hard of hearing person with no access to a textphone I've found it very difficult to get hold of anyone at the benefits office for help. However, I've found the CAB very helpful, and have always kept copies of the forms so I know what to write next time!!

[To improve the forms] use proper English, not form English, and don't keep asking the same questions over and over again as its very confusing for people, especially people with brain injuries or lower comprehension!

Also, have a clear mention in the cover letter that the CAB can help fill in the forms.

### **What benefits provide and what would happen in a world without benefits**

My benefits are mostly used to pay my bills, as I have no other source of income. What little is left over does go into savings for rare trips out though. My tennis classes are paid for by benefits money - £5 per week. But most importantly, my benefits give me my Motability car, which I would be lost without. This is how I get out and about, and without it I would be stranded home all the time.

Without my benefits, my daily routine would be like on my worst day - get out of bed, get on sofa, go back to bed. However, because I use benefits money to pay for my housing I'd be homeless, and because I have no other source of income, I'd literally have no money. People can say that I could attempt to work, but I know I wouldn't last long, even part-time, so I'd still be in the same position. Thank goodness for benefits, even if they make us jump (or roll!) through hoops for them!

If I didn't have benefits, I wouldn't be able to be involved in any activities as I wouldn't have any money to pay for them, or a car to travel there. The only thing I'd be able to do is exercise at home.

### **Physical activity and its expected impact on entitlement to disability benefits**

I definitely notice a benefit to the physical activity I take part in - it makes me feel better mentally, and also helps with stretching and exercising the muscles that get stiff and sore from wheeling myself around all the time.

When I don't go to activity sessions I notice a decline in my mental health and more physical stress too. There are three main things that discourage me getting involved in things:

- Fears that benefits might find out and decide I no longer need assistance, so I lose money.
- The cost and accessibility of sessions.
- Body image problems, especially if the rest of the group are all slim, able-bodied gym bunnies!

I currently do wheelchair tennis once a week, which I really enjoy. When I can manage it I also go to an accessible dance and exercise class once a week too. I would like to be able to use the gym but the local one isn't accessible, and I can't afford any of the other local classes either. I'm also really conscious about not doing too much activity outside my house in case the benefits people decide I'm too able-bodied and take my money away!

I'm always afraid of doing too much as it could have a negative impact on my disability benefits entitlement. This is partly from the forms, but also because I had a friend who tried doing a little more than I do now, to try and help with her pain management, and they took away half her benefits and told her she was capable of going to work as she was capable of doing so much exercise - despite her having regular fits etc.! She was told that to stand any chance of getting them back she'd have to give up all but one class and maintain that level for six months. You'd think we'd be encouraged to reduce pain using non-medication routes, but apparently not!

### **Perceived restrictions on benefit spending or activity**

In literal terms, [the only restriction is] that my mobility payment goes to pay for my car. However, it's very clear that if you do more than you put on your forms and are caught, then you'll lose it all - which can be a problem when you have to fill in the forms for your very very worst day to get any money at all!!

### **What physical activity means to them**

For me, taking part in sport and exercise isn't about winning competitions, it's about getting some confidence and fitness back, and improving my mental health. It's about socialisation - something I don't get anywhere else - and working toward achieving something, even if that's just being able to hit a backhand successfully, or remembering a dance routine, then celebrating that success with my friends. All of that is something really important, and not something I'm getting elsewhere, and to lose it would be bad for my health, both mental and physical. Having the choice to have a more active lifestyle would mean the chance to increase those benefits - a wider circle of friends, more fitness, more mental health benefits, more goals to achieve - but on my terms. If I want to do it, I can. If I don't, I don't have to. But removing the barrier to it would mean a great deal.

## **6.6 Case study six:**

35 to 44-year-old participant who is an electric wheelchair / power chair user studying part time

### **Challenges in applying for Employment and Support Allowance (ESA)**

The form takes so long to write and is emotionally exhausting. It is fairly clear in terms of language. It's invasive but I guess it has to be. It's a complete waste of time. My condition is genetic and will only get worse. Filling them in is depressing and soul destroying, especially when it comes to the mental health section.

There should be a form for people with incurable conditions so that you can tell them if there have been any changes (positive and negative) and what they are. Perhaps a signature from your GP to verify the information would help. This would take a lot of stress away from people with permanent conditions.

I was extremely relieved that I wasn't asked to attend a face to face meeting. I think this was because I sent reams of medical evidence.

My main difficulty is anxiety. For both ESA and PIP, I dread letters appearing. I often have to get other people to open them or I put them to the bottom of a huge pile and forget about them. That doesn't usually end well. My anxiety is borne of the frequent horror stories in the press and social media of people being denied benefits and dying a few weeks later.

I hate the idea of filling the forms in. It's never as bad as I think it will be but it's so depressing. The focus has to be on all the things you can't do. If I was designing the forms, I'd add a section about something you can do. I always put something like that in the 'any other info' box. I'm not just a list of things I can't do. I'm really good at drawing on a good day. I generally don't have to have face-to-face interviews for benefits as I send so much medical evidence the envelope barely closes.



My most recent DLA to PIP transfer necessitated a visit from ATOS (or similar). I was terrified. I thought they'd try and trip me up. I hadn't taken a copy of the form so there was a chance I'd estimate how many days a week I could do something and get it slightly wrong. The person who came was nice but I kept thinking it was an act. She was there for 2 hours by which time I was exhausted and couldn't think straight. Fortunately, she recognised this. She used to be a physio specialising in chronic conditions and pain. I made a point of asking what she did so I knew how technical to get, medically speaking. An Occupational Therapist wasn't going to necessarily understand a CT scan. I got a positive outcome about a week later, although I was told it may take 6 weeks.

I've never had any concerns about my entitlement, legally. I have been concerned about the competence of the person assessing the form, since it was privatised. I've been worried I'd end up having to appeal etc. because there isn't a box to tick if you can't walk at all, for example.

I have a drive-from-wheelchair car from Motability but can't use it much as I won't drive on certain medications. When my kids were younger and I was fitter I used it daily. I've had it for 9 years. I'll lose it in March and won't get another grant as they changed their rules for drive from wheelchair drivers. (You have to be working or volunteering for 16 hours a week - I'm not well enough to do that. I spend quite a lot of time in hospital.

There's not much money left for leisure activities at the moment. If benefit levels were higher, I would be more likely to get involved.

The demonisation of disabled people in the media has led to a situation in which many are afraid to participate in sport because they are worried about getting reported for fraud, even if it really isn't. I also read about the Paralympian who lost her PIP despite having severe Cerebral Palsy. I think these stories prey on the minds of disabled people.

I'm about to lose my mobility car due to a change in the rules about 'drive from wheelchair' vehicles. This will severely limit my ability to participate in everything. I tried to take Motability to court over the change in rules but it was unsuccessful.

I know someone who is in trouble with ESA for not reporting being in part time education (a 4 hours a week taught masters).

### **What benefits provide and what would happen in a world without benefits**

I have no other source of income, so benefits allow me to stay in my own home, eat, keep my animals, and enjoy a few hobbies. They pay for my Internet which is so important. They pay for my vehicle through Motability and diesel. They pay for coffee and cake when I meet friends. They pay for my mortgage minus the £80 a month paid for by the DWP. If I hadn't owned my home when I became too unwell to work, I'd be a lot better off. Most of my rent would be paid. There isn't much left after mortgage payment and the extra money involved in home ownership (building insurance, maintenance etc.). I'm still grateful for what I get though. I know others who have had to go through appeals etc. I used to have to contribute to the Independent Living Fund payment I received to pay my personal assistants but I don't have that outlay since it was closed. That is one bill I miss paying. Benefits mean I can have some ready meals in the freezer in case a PA phones in sick.

[Without benefits] as I have no other source of income, I guess I'd be made to sell my house and rent something many miles away because rents are ridiculous where I live. I'd lose friends, support and my medical team from having to move away. There would be no money for anything beyond the absolute basics of living. My health would, no doubt, suffer. I provide things like splints and other small pieces of equipment (e.g. transfer boards) out of my benefit money. When I ran out of money from selling my house, I'd be homeless and destitute. It doesn't bear thinking about.

Physical activity would become an unaffordable luxury if benefits were no longer available. My nutrition would suffer if food needed to be cheap and unhealthy. My level of hygiene would suffer if care was reduced, making my participation in physical activity much less likely.

### **Physical activity and its expected impact on entitlement to disability benefits**

When I was in better health, I used to co-run a boccia club. It was successful and I benefited from the exercise and social side. Soon after, I did a taster for wheelchair tennis at a multisport session and was asked to join a club. I was really bad at it but I loved it. I genuinely dreamt of hitting perfect shots. I had injuries from playing but mostly the effect on my physical health was positive. These days I'd be a bit scared of doing too much. I could probably manage boccia but would be in a lot of pain afterwards. I need to use extra oxygen when I move so my O2 requirements from a canister would go up. I would struggle financially to get involved in sport again.

I don't currently do any physical activity apart from bed-based physio exercises. The most physically demanding thing I do is holding and entertaining my 5-month old granddaughter for half an hour. I find that exhausting! My arms don't work afterwards. I'd love to be able to play wheelchair tennis again but I think that's never going to happen. I'd love to be able to swim. I need to find a pool that's warm enough and doesn't mind someone walking up and down next to the pool with an oxygen canister. I'd have to start really slowly - 10 minutes in the pool. I guess a bit of apathy stops me looking into it too much.

I don't think my participation in sport would affect my benefit entitlement personally. I think I'd still be classed as having high needs of care if I swam with oxygen and flotation aids, for example.

I have a friend with multiple sclerosis who won't mention any trips to the gym on Facebook in case she loses her PIP. I understand her fears completely. There are media reports of the DWP catching out fraudsters by looking at their social media. It makes legitimate benefit recipients afraid to own up to having a good day and doing stuff. This is especially true of people who only talk about their good days on social media and not the 2 days in bed with unbearable pain after they've done the activity.

### **What physical activity means to them**

I'd love to participate in sport again. I really miss it. I slept better because I was tired for the right reasons. I enjoyed being with friends. I'm sure doing something would improve my health a little bit.

## **6.7 Case study seven: 45 to 54-year-old participant who is a lower limb amputee and manual wheelchair user, working and studying part time**

As reported in the national press <sup>49</sup>, due to ineffective communication between the NHS and a Local Authority and a disagreement about how much funding each should provide, this participant had to fight for more than 14 months for their personal budget to include necessary care elements as well as a budget for physical exercise to ease their pain.

### **Challenges in applying for a Personal Budget (funded jointly by the NHS and Local Authority)**

I am waiting for a review of my personal budget, which is meant to take place in August. I don't know why it hasn't been done sooner as the budget started in November and reviews are meant to be yearly but I never got a review last year. I'm not complaining, it's just another example of incompetent council social workers / useless adult social care system.

I'm also in the midst of trying to sort out my council tax support. I've been trying to sort this out since about January this year. I keep sending them info they ask for (proof of income etc.) and they keep working it out wrong and sending me council tax bills for money I don't owe. Again, their incompetence is ridiculous. I have even worked it out for them and sent them all the stuff and now I don't even get a reply from them.

[The council and NHS] initially refused to fund gym / swimming membership of £300 / year. I had to threaten them again with complaints and continually harass them into giving it to me, even though both ombudsmen stated that gym membership was common in personal budgets. It is now in my budget... My concern is that I know the system and am able to argue my case, others are not...

The ombudsmen (health and local government - I had to work with two) gave various recommendations in their full report regarding delays in the process, better communication, better working together between the organisations, etc. I agree with their recommendations.

Impact in general was worsening of health (emotional and physical), couldn't get out of the house easily, care was lousy with private carers (I was sleeping downstairs on a borrowed hospital bed using an OT provided commode for the first 9 months, for example!), my savings were all used up with forking out money for numerous different care related things, so things like getting out swimming were the bottom of the list, when I was struggling with other more basic stuff.

Then when the personal budget was finally agreed they still dug their heels in over things like the swimming / gym membership and me being able to adapt my garden so I could get to things and so it wasn't so dangerous. I persisted and finally got agreement on both these things. I got about £700 for one off payment to adapt garden and £300 / year ongoing for swimming. Their thinking is all about short term stuff, there's no acknowledgement that actually if I was to swim / exercise regularly then my health (emotional and physical) would be improved, I would be using less of other services, saving them money in the long run... the Care Act is meant to include preventative stuff but they don't implement this properly.

[In relation to disability benefits like DLA, PIP and ESA] the forms are long, biased towards physical health conditions as oppose to mental health, support for help in filling them in is dwindling...

### **What benefits provide and what would happen in a world without benefits**

It's really hard to itemise what pays for what exactly as all the money I get goes into a pot (apart from my personal budget) and I don't really allocate what gets used for what. However, some would be used for travel (I don't have a car nor any family who can give me lifts to places) and some goes on things like additional costs that my disability costs me, such as clothes, or deliveries, or additional costs associated with my wheelchair, or things that I used to be able to do but can't now (DIY, shopping, gardening / household related things etc).

As I said previously, it is hard to itemise what pays for what. However, it is clear that I wouldn't be able to lead the life I do now, in the sense that non-essential things I do wouldn't get done, so I guess my physical activity of swimming wouldn't get done, I wouldn't get out and about as much, wouldn't go away on holiday, etc... just the sort of things that are usual and that everyone takes for granted really...

It would have an impact across the board for me, including in physical activity. Things like physical activity would be near the bottom of the list in priorities - have to pay the bills first, feed myself, etc., so those would get priority over leisure / physical activities.

### **Physical activity and its expected impact on entitlement to disability benefits**

There are particular advantages for me - I'm a wheelchair user, so it's hard to get enough physical activity. Also I'm a bilateral above knee amputee (BAKA) so that makes it even harder. Things that discourage me are the cost and hassle of travelling to get to where I need to go, any cost of special equipment I may need, lack of local facilities. The fact that I would undoubtedly be the only person there who is a BAKA - I get used to the stares etc. but I'm quite competitive so it's nice to get an even competition with others also!

I swim three or four times a week. I'd like to do sitting volleyball also and approached my local club regarding this. They set up a sitting volleyball season, which was great, but it's hard for me to get to and held early evening, not a good time for me. I went a couple of times but couldn't manage it much after...

### **What does sport and physical activity mean to them**

I use exercise to keep fit, build up muscles, maintain weight... it would be hard for me to do more, I'm already pretty busy as it is (work, student, etc.). I'd like to do sitting volleyball also but it would take it out on me physically (I'm over 50!) and I guess it would make me tired / too much in pain to get my other stuff done that I need to do. The fact I live by myself, have no family support, little other support, etc. makes it harder to do much more...

## 7.0 Conclusion and recommendations

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This study has identified a significant degree of fear among disabled people in receipt of disability benefits and other forms of financial assistance. This fear centres around the ambiguity in eligibility conditions for, in particular, Personal Independence Payment and Disability Living Allowance as well as personal experience and knowledge of sanctioning and removal of such support due to attempting to remain physically active.

This is, in part, due to insufficient guidance in the application processes and an apparent disconnect between advice offered by those providing information and decision makers. There also seems to be inconsistency in decision making between those administering benefits, who appear focused on the bureaucratic process, and appeals tribunals that seem to have the capacity to take into account personal circumstances in a more bespoke manner.

For those in receipt of benefits, ambiguity remains a problem in terms of what level of physical activity is acceptable and what might lead to removal of support. The '20 metre rule', which has a substantial impact on whether applicants receive an enhanced rate of the mobility component of PIP - which is necessary for access to the Motability Scheme - appears to have placed recipients in a Catch-22 situation. Those who are unable to maintain independence without the enhanced rate - the equivalent of which they would have received if they couldn't walk more than 50 metres under DLA - are subject to a strong disincentive to attempt to improve their mobility. Ability to walk a certain distance, particularly less than the established 50-metre mark, is not an effective measure of the costs faced by applicants<sup>50</sup>.

## 7.1 Recommendations and discussion points

Four key recommendations and four significant discussion points emerged from the study to address some of the fears, ambiguity and difficulty involved in being physically active when receiving benefits and financial assistance, especially with regard to PIP. Activity Alliance and DSAuk are working with expert partners, including Disability Rights UK, to move forward those discussion points that focus on a range of improvements to the benefits system itself.

Activity Alliance will work collaboratively to:

1. Drive stronger alignment between public health agencies, the NHS, DCMS, DWP and local government. This should aim to foster a social welfare system that encourages disabled people and people with long-term health conditions to be active without fear of losing benefits and financial assistance.
2. Produce advice and guidance on being physically active and how it relates to benefits assessments. Ensure that disabled people are signposted to information that already exists from expert sources such as Citizens Advice and Disability Rights UK.
3. Increase positive media stories about disabled people being active and the positive impact it has on their lives to help relieve the fear factor.
4. Provide clarity about how benefits and other forms of government and NHS financial assistance can be used to support access to sport and physical activity.

Work with expert partners including Disability Rights UK and Government should aim to discuss the following points:

5. How to ensure that guidance from official agencies is accurate, recorded and binding.
6. How to make application forms more accessible. This should include ensuring that applicants can answer in a way that fully reflects their experience and providing clear guidance on the level of detail expected, such as by using the diary system advocated by Citizens Advice <sup>51</sup> and Disability Rights UK <sup>52</sup>.
7. How to support the assessment process to help assessors to take into account individuals' conditions and the impact they have on day-to-day living, including social and financial barriers, in a more bespoke manner. This should cover debate of the '20-metre rule' that determines eligibility in PIP for enhanced-rate mobility component and ensure that mental health, especially as related to a person's physical health, is given equal importance.
8. Whether PIP reassessment for those with conditions that will not improve can be removed except when initiated by the applicant.



## 8.0 Notes

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