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



With support from:
WheelPower, Cerebral Palsy
Sport and LimbPower

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. 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 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%).



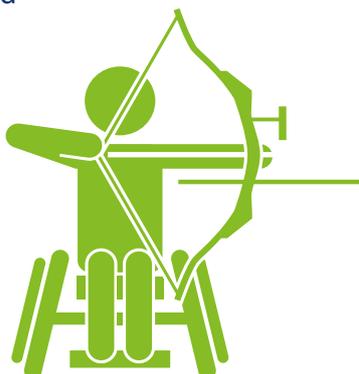
Activity helps them to manage impairments and pain, keep fit, improve mental health, gain autonomy over their own health and facilitate social opportunities.

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.'

- Participant with dwarfism or restricted growth

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

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.



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 the benefits system itself. More detail on each area is included in the full 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 and Disability Rights UK.

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.

The full research report can be found at:

www.activityalliance.org.uk/research

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