Key community issue: financial security

Note: this document primarily applies to England, but has relevance for our work throughout the UK more broadly.

Background

Our community of over 110,000 people in the UK living with one of over 60 muscle wasting and weakening conditions have been hit particularly hard by the cost-of-living crisis. They face additional costs for things such as care, housing adaptations, wheelchairs and electricity, for charging and running the equipment and assistive technology they need. These additional daily costs are common within the disabled community – leading disability equality charity Scope estimates that on average the additional costs faced by disabled households amount to £1,010 per month.[1]

We know that having the right financial support is crucial for our community. It helps provide them with financial security, independence and a reasonable quality of life. Our latest *Financial Insecurity* report (2024) found that over half of people living with a muscle wasting and weakening condition feel financially insecure.[2]

People living with a muscle wasting and weakening condition are entitled to a range of benefits. Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) are two commonly used disability benefits.[3] However, our community often come up against barriers to accessing this support, both in the application and assessment process, as well as in decisions made about benefit categories or award levels.

As well as challenges accessing benefits, our community can also face limited employment opportunities. One in four (24%) of the respondents in our *Community Survey* said they did not have the opportunity to work or study should they want to.[4]

This combination of growing daily living costs, decreasing income from benefits and barriers to employment, is a struggle to live with.

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[1] Scope UK, "*Disability Price Tag 2024*".

[2] Muscular Dystrophy UK, "*Financial Insecurity*", November 2024.

[3] Muscular Dystrophy UK, "*Below standard: MDUK's assessment of the benefits system*".

[4] Muscular Dystrophy UK, "*Community survey findings*", May 2024.

Benefits

What are the challenges?

People can apply for ESA benefit if they have a disability or health condition that affects how much they can work.[5] To assess their eligibility, a Work Capability Assessment (WCA) is used to find out how much their illness or disability affects their ability to work.[6] In March 2023, the Department for Work and Pensions released a White Paper, *Transforming Support: The Health and Disability White Paper*, in which they announced getting rid of the WCA.[7] The WCA has always been seen as a controversial assessment in assessing ESA eligibility, particularly within the disabled and rare disease communities.[8] Some of the concerns raised include its tick-box structure, lack of input from healthcare professionals, and questions unrelated to specific conditions.[9] There is the risk that when our community is assessed by the WCA it may result in them being put into the work-related activity group (they cannot work now, but can prepare to work in the future) instead of the support group (they cannot work now and they're not expected to prepare for it in the future).[10] The former offers a lower payment as it's for people who may be able to work in the future.[11]

PIP is a disability benefit claimed by 53% of our community.[12] It helps with extra living costs by providing a daily living award for everyday tasks and a mobility award for getting around - of varying amounts according to the assessment.[13] For many of our community, PIP is their lifeline.[14]

But concerns have also been raised about PIP. Our 2020 *Below standard: MDUK's assessment of the benefits system* report found that almost half of the respondents had to wait three months or more for their application to be processed and to get a face-to-face assessment.[15] The face-to-face assessment stage of PIP can also be problematic. Previous evidence has shown that assessors can lack the condition-specific knowledge and expertise needed to assess rare conditions.[16] This can lead to people in our community being found ineligible for a higher award, resulting in a decrease of the

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[5] UK Government, "*Employment and Support Allowance (ESA)*".
[6] UK Government, "*Employment and Support Allowance (ESA)*".
[7] UK Government, "*Transforming Support: The Health and Disability White Paper*".
[8] House of Commons, "*Proposals to abolish the Work Capability Assessment*".
[9] Department of Work and Pensions, "*Unsuccessful Employment and Support Allowance claims – qualitative research*", 2011.
[10] UK Government, "*Employment and Support Allowance (ESA)*".
[11] UK Government, "*Employment and Support Allowance (ESA)*".
[12] Muscular Dystrophy UK, "*Below standard: MDUK's assessment of the benefits system*".
[13] UK Government, "*Personal Independence Payment (PIP)*".
[14] Muscular Dystrophy UK, "*Financial Insecurity*", November 2024.
[15] Muscular Dystrophy UK, "*Below standard: MDUK's assessment of the benefits system*".
[16] Muscular Dystrophy UK, "*Below standard: MDUK's assessment of the benefits system*".

financial support they need to sustain their livelihood. It can also increase the chances of a person having to go through a stressful mandatory reconsideration and reappeal process, if they're unhappy with the original award status given to them.

In April 2024, the previous government unveiled plans to overhaul benefit payments, including PIP.[17] We are still waiting to hear about the current government's plans for welfare reform. More details are expected in Spring 2025.[18]

What we're calling for and what we're doing

A massive overhaul of the welfare system is needed. This is because our findings demonstrate how a wider approach to work and welfare is needed to improve a sense of financial security for people living with muscle wasting and weakening conditions.

In the meantime, we're calling on the UK Government to:

- Increase the available income of people with muscle wasting and weakening conditions (for example by raising the level of financial and disability-related benefit allowances, or additional one-off payments).
- In the longer term, the UK government, in consultation with disabled people and patient organisations like us, should implement wider changes to the social security system to better meet the needs of people living with muscle wasting and weakening conditions.
- In the shorter-term, the UK government should limit the number of benefit reviews for people who have progressive, long-term muscle wasting and weakening conditions.[19]

What we're doing:

- We're influencing national policy by responding to consultations, promoting messaging through coalitions or by meeting directly with parliamentarians. We've recently responded to the former Government's Green Paper on reforming the current PIP system. Their proposals caused confusion and raised concerns that these changes may end up taking away any independence people currently have.[20] However, it's important to note these are only proposals, no decisions have been made yet on how PIP may be reformed. We hope the consultation is a vehicle to improving the currently stressful experience of PIP that our community experience. It's essential that benefits are better suited to the nature of muscle wasting and weakening conditions.

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[17] Muscular Dystrophy UK, "*Government planning changes to disability benefit system",* April 2024.
[18] UK Government, "*Biggest employment reforms in a generation unveiled to Get Britain Working again*". November 2024.
[19] Muscular Dystrophy UK, "*Financial insecurity*", November 2024.
[20] Disability Rights UK, "*DR UK Responds To Proposed Changes To Personal Independence Payment (PIP)*".

- Our Helpline and Advocacy Support Service provides support to anyone affected by a muscle wasting and weakening condition, providing guidance on benefits and supporting in challenging welfare decisions.

Accessing employment

What are the challenges?

People living with a muscle wasting and weakening condition should have the support and opportunity to work if they're able to. Yet our community can face limited opportunities and many barriers to doing so, which can create financial insecurity.

A House of Commons briefing from March 2024 reported that more disabled people of working age were out of employment in the last quarter of 2023 than the year before. The disability employment gap currently is 27.9%, which is higher than in previous years.[21] The disability employment gap is also predicted to grow among people living with neurological conditions.[22]

We know people living with muscle wasting and weakening conditions face a range of challenges in accessing employment and remaining in work.[23] Employers do not always make application and interview processes fully accessible. Interviewers are often not adequately trained to support disabled candidates. Once successful in securing a role, many disabled people may have to leave employment due to the sick leave they must take to cover their specialised healthcare needs or due to some exclusionary working conditions.[24]

We welcome the new Government's approach to both improve people's health and provide tailored employment support, including facilitating a more localised approach.[25] We also welcome the launch of an independent review of how employers could better support disabled people get in and stay in work.[26] But our financial insecurity report was clear. Employers need a better understanding of the needs of people living with muscle wasting conditions. There also needs to be more opportunities for disabled people.

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[21] House of Commons, "*Disabled people in employment*", March 2024.

[22] Neurological Alliance, "*Written evidence submitted by the Neurological Alliance (MRS0465)*", May 2020.

[23] Muscular Dystrophy UK, "*We're calling for people with a muscle wasting and weakening condition to be able to feel financially secure*".

[24] UK Government Disability Unit, "*Exploring the everyday lives of disabled people*", September 2021.

[25] Muscular Dystrophy UK, "*What do the work and pensions secretary's priorities tell us about the new UK government's plans for supporting people into work?*", July 2024.

[26] Department for Work and Pensions, "*Biggest employment reforms in a generation unveiled to Get Britain Working again*", November 2024.

What we're calling for and what we're doing

Our findings demonstrate how a wider approach to work and welfare is needed to improve a sense of financial security for people living with muscle wasting and weakening conditions. To this end, we urge the UK Government to engage with organisations like ours to deliver their manifesto commitment to publish "a proper plan to support disabled people to work."[27]

We're calling on government and employers to:

- The UK government should ensure that people living with muscle wasting and weakening conditions, and other disabled people, do not feel at risk of losing their benefits.
- The UK government and employers should work with expert organisations to improve employer understanding of the needs of disabled people. This should also look at how to develop more opportunities for disabled people.
- Employers should implement flexible working practices, in particular the ability to work from home on some days.[28]

In addition to influencing national policy here like we do for benefits above, we also:

- Provide an employability service to support anyone living with a muscle wasting and weakening condition to find the right employment opportunities.[29]

Any questions about this key community issue or advocacy, email campaigns@musculardystrophyuk.org.

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[27] Labour UK, "*Kickstart economic growth*".
[28] Muscular Dystrophy UK, "*Financial insecurity*", November 2024.
[29] Muscular Dystrophy UK, "*Employability service*".