

**Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Cydraddoldeb a Chyfiawnder Cymdeithasol ar Anabledd a Chyflogaeth**

**This response was submitted to the Equality and Social Justice Committee consultation on Disability and Employment**


**DE26**

**Ymateb gan: Cymdeithas Clefyd Niwronau Motor | Response from: Motor Neurone Disease (MND) Association**

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## **MND Association Response – Disability and Employment Consultation**

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These are the views of:	The MND Association – the leading charity in England, Wales and Northern Ireland focused on funding research, improving access to care and campaigning for people living with or affected by MND.

### **About Motor Neurone Disease (MND)**

Motor neurone disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It leaves people locked in a failing body, unable to walk, talk and eventually, breathe.

MND affects around 5,000 people in the UK and around 1 in 300 people in their lifetime. Here in Wales, approximately 250 people are living with MND at any one time. One third of people die within a year of diagnosis and over half die within two years. At present, there is no cure.

### **Overview**

We welcome this inquiry into the disability employment and payment gap in Wales. We acknowledge the progress made to date, but there is more to be done to provide equal opportunities for employment for disabled people in Wales.

We preface our response to this consultation by stating that for many people living with MND in Wales, their health and care needs means they are unable to work and all recommendations set out within this response must be complemented by a fully funded, fair, and fit-for-purpose welfare system which provides those that cannot work with the resources and funding they need to live safely and independently.

We must move away from narratives that force people back into work when this is not an option for many people. We urge Welsh Government to lobby their UK Government colleagues to ensure this narrative does not impact those living with MND in Wales and that they are sufficiently supported and protected from sanction.

However, many people living with MND wait a long time while pursuing a diagnosis, during which time they often need to continue working. Further, continuing employment post-diagnosis is a desirable option for the health and wellbeing of some people living with MND. For them, it is crucial that employers and workplaces are accessible and flexible to allow people with MND to live independently for as long as possible.

On the importance of continued working, one person living with MND in North Wales said

*“My boss and I have a verbal agreement that I’ll either work until I die, or until I feel like I’m not contributing positively to the organisation anymore. It takes away another layer of worry to feel that I’m not going to be thrown on the scrapheap because of my MND.”*

Efforts to reduce the employment gap have been hampered by a lack of evidence and slow progress in implementing the necessary policies. Access to financial support is slow or non-existent and the increased use of work conditionality within the welfare-benefits system is shifting the focus away from progressive policymaking. There is a need for better financial support, easier access to workplace adaptations, and improved intersectional policymaking. Guidance for employers on flexible working and remote work as reasonable adjustments as well as improved communication about the available support may help reduce the employment gap.

**What progress has been made to deliver the recommendations set out in the ‘Locked Out’ report and to reduce and remove barriers faced by disabled people who want to access Wales’s labour market. Why progress to reduce the employment and pay disability gap has been so difficult to achieve.**

Despite the progressive policy proposals outlined in the ‘Locked Out’ report, we believe the progress to reduce and remove the barriers faced by disabled people who want to access Wales’ labour market has been too slow.

We believe this progress has been difficult to achieve due to several factors which we will outline below.

**How the social model of disability is being used to underpin employment and recruitment practices, and what barriers continue to exist throughout society that impact on access to work (i.e. transport, attitudes).**

We welcome the Welsh Government's commitment to the social model of disability. However, many societal barriers remain which prevent people from accessing employment.

One of the main barriers that persists is employer attitudes. The 'Locked Out' report highlighted that there is a persistent problem with employer understanding of legal responsibilities to provide workplace adjustments and we consider this to remain an issue. The report suggests Welsh Government should invest in public and employer education and workplace dispute resolution and these are recommendations we endorse.

Many disabled people require adapted facilities and the lack of provision in this area often acts as a barrier to employment. The Equality Act requires organisations to make changes so disabled people are not disadvantaged, this is the duty to make reasonable adjustments. These include physical adjustments such as changing a workspace to make it accessible or alternative ways of working such as changing working patterns, flexible working, or altered responsibilities. However, a recent report by Disability Wales highlighted continued reluctance by employers in Wales to implement reasonable adjustments<sup>1</sup>. We believe this is a crucial barrier that must be addressed to support disabled people to remain in work.

To highlight how crucial reasonable adjustments are, one person living with MND in North Wales said:

*"Having a supportive employer is absolutely brilliant. When I had the provisional diagnosis of MND, I decided to send out an all-staff email to explain what was going on and why I might be grumpy at times, or why it might sound like I'm slurring in the afternoons. It had an amazing response across the organisation and they're now all aware of MND.*

*By telling my workplace about the condition, it has enabled them to put things into place to help. The desk I'm sitting at has a button that adjusts the height of it, so I can use it with my wheelchair when I need to. They've given me a very supportive chair to sit in, and are prepared to invest in things that will help me to contribute to the organisation's future rather than writing me off. They're also making adaptations to the role I'm doing so that I can continue to contribute in a positive way."*

Though much progress has been made, accessibility of public transport in Wales varies widely depending on the region, the type of transport, and the specific needs of the individual. There is very limited data on disabled peoples' experiences of public transport in

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<sup>1</sup> [0637-PS DW-Report.pdf \(disabilitywales.org\)](#)

Wales but particularly in rural parts of Wales, the availability of accessible buses remains low and many train and bus stations do not have step-free access<sup>2</sup>. Further, there are inconsistencies about the accessibility of the information and availability of assistive staff which make using public services extremely difficult for disabled people<sup>3</sup>. As MND is a progressive condition affecting the brain and spinal cord, most people living with MND will be unable to drive and a functional public transport system is vital to their independence and to accessing employment.

**How effective Welsh Government actions (e.g. the network of Disability Employment Champions and apprenticeships) have been in reducing barriers to employment and reducing the employment gap between disabled and non-disabled people, including the extent to which Welsh Government policies complement/ duplicate/ undermine those set by the UK Government.**

As outlined above, we believe that despite concerted effort from the Welsh Government, progress against the core areas set out in Locked Out Report to reduce the barriers to employment and the employment gap between disabled and non-disabled people has been slow.

A key driver of this is the lack of available evidence. We welcome the establishment of the Equality, Race and Disability Evidence Units but their role in driving policy remains unclear. We urge Welsh Government to clarify the purpose and output of these Evidence Units, to progress on publishing more granular data more rapidly to support high-quality, evidence-based policy making. In their recent report<sup>4</sup>, the Equality and Social Justice Committee recommended the Welsh Government provide the Evidence Units with clarity regard their priorities and timescales and we endorse this recommendation.

Relatedly, we believe Welsh Government should continue to push for mandatory Disability Pay Gap reporting to support policy change in this area. The Trade Unions Council (TUC), a federation of the main Trade Unions in England and Wales, has suggested that mandatory

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<sup>2</sup> [https://d3cez36w5wymxj.cloudfront.net/wp-content/uploads/2024/04/29135634/TF\\_Information-and-infrastructure-barriers-to-bus-use-in-Wales\\_V4.pdf](https://d3cez36w5wymxj.cloudfront.net/wp-content/uploads/2024/04/29135634/TF_Information-and-infrastructure-barriers-to-bus-use-in-Wales_V4.pdf)

<sup>3</sup> [https://d3cez36w5wymxj.cloudfront.net/wp-content/uploads/2024/04/29135634/TF\\_Information-and-infrastructure-barriers-to-bus-use-in-Wales\\_V4.pdf](https://d3cez36w5wymxj.cloudfront.net/wp-content/uploads/2024/04/29135634/TF_Information-and-infrastructure-barriers-to-bus-use-in-Wales_V4.pdf)

<sup>4</sup> [How we must all play our part: a public health approach to halting the epidemic in gender-based violence \(senedd.wales\)](https://www.senedd.wales/How-we-must-all-play-our-part-a-public-health-approach-to-halting-the-epidemic-in-gender-based-violence)

disability pay gap reporting would help highlight the barriers faced by disabled people in the workplace and improve inclusion<sup>5</sup>.

There are continued issues around funds that are available, particularly around the Access to Work scheme. Many do not know the scheme exists and the scheme itself is renowned for payment delays. Many organisations supporting disabled people have reported lengthy delays which undermine their ability to find and retain jobs<sup>6,7</sup>. Welsh Government should continue to lobby the UK Government to increase funds for Access to Work to speed up the processing and implementation of solutions.

In addition to the above, we are concerned that the impact of Welsh Government policy is hampered by issues within the UK Government's welfare-benefits system overall. The MND Association supports changes to the welfare system which allow people with MND to access the support they need more easily. Specifically, we support changes to simplify the number of assessments needing to be undertaken by people applying for benefits. Far too often people with MND must have to contend with multiple layers of bureaucracy to receive financial assistance. This leads to a poor experience of engaging with the Department for Work and Pensions (DWP) and unnecessarily delays timely access to financial support.

We are also concerned about the blurring of the lines between work conditionality and access to benefits. The space between the Work Capability Assessment (WCA) and Personal Independence Payments (PIP) has existed for a reason. The former assesses someone's ability to work and the latter the impact of a disability on a person. Therefore, using only PIP as a passport to additional disability-related benefits within Universal Credit risks placing work conditionality requirements on those with a disability. Similarly, if there are work-related requirements within PIP, then people may risk being denied PIP because they are judged fit to work. The Labour Party manifesto committed to reforming or replacing the Work Capability Assessment and we urge Welsh Government to work with UK Labour colleagues to drive this change

Further, the earnings limit on carer's allowance often forces people to give up work when they do not necessarily need or want to, forcing many carers out of the workplace and into substantial levels of debt. Welsh Government should work with UK Government to reform the carer's allowance system and consider supplementary funding for both this and paid carer's leave.

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<sup>5</sup> [TUC Calls For Mandatory Disability Pay Gap Reporting | Disability Rights UK](#)

<sup>6</sup> [Access to Work delays report PDF Version.pdf \(rnib.org.uk\)](#)

<sup>7</sup> [Access to Work delays - RNID](#)

**What further policy measures are needed to support disabled people, young disabled people and employers to increase participation rates and what can be learned from elsewhere.**

There is little targeted support for financial support for disabled people which complements their ability to work flexibly in a way that works for them. Welsh Government should consider establishing a dedicated, ring-fenced fund to support workplace adaptations for employers who cannot reasonably cover them.

The disability employment gap intersects with other protected characteristics including both ethnicity<sup>8</sup> and gender<sup>9</sup> so Welsh Government must consider developing a strategy to encourage more intersectional, inclusive practices and policies driven by Welsh-specific data from the Equality, Race and Disability Evidence Units.

Welsh Government should publish guidance for employers on the benefits of and implementation support for flexible and remote working. We believe this would help employers understand how and why to improve accessibility within the workplace and thereby bring down the employment gap in Wales.

To complement the above, Welsh Government should consider commissioning and delivering training on employment rights and reasonable adjustments for disabled people in the workplace.

As recommended in the Locked Out report, Welsh Government should consider the benefits of a change in the law to legally recognize home working as a reasonable adjustment. We strongly believe this would allow people living with MND and their carers to continue employment in a way that suits them for as long as possible or desirable.

Welsh Government should consider publishing guidance around and establishing better reporting mechanisms for discrimination in the workplace. Employment discrimination is disproportionately faced by disabled people and adequate reporting tools may prevent employers from engaging in discriminatory practices and thereby may help disabled people remain in the workplace.

There is a need for better communications about the support available for disabled people in the workplace. For example, we previously outlined the low take-up of the Access to Work

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<sup>8</sup> <https://www.disabilityrightsuk.org/news/understanding-intersection-unemployment-disparities-among-disabled-individuals-crossroads>

<sup>9</sup> [https://www.tuc.org.uk/research-analysis/reports/jobs-and-pay-monitor-disabled-workers-23#:~:text=The%20pay%20gap%20has%20narrowed,per%20cent\)%5B3%5D.](https://www.tuc.org.uk/research-analysis/reports/jobs-and-pay-monitor-disabled-workers-23#:~:text=The%20pay%20gap%20has%20narrowed,per%20cent)%5B3%5D.)

scheme. Welsh Government should, alongside counterparts in UK Government, consider a public campaign to increase awareness of the funding available. We note the continuation of the Single Advice Fund<sup>10</sup> and we hope Welsh Government will ensure the service(s) commissioned prioritise the promotion of employment support available for disabled people.

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<sup>10</sup> [Apply for the Single Advice Fund grant | GOV.WALES](#)