

Access to Work Is Missing the Point for People With M.E./C.F.S.

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UK-based Community Interest Company, Stripy Lightbulb CIC is raising serious concerns about the suitability of support currently being offered to people living with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (M.E./CFS) through the Department for Work and Pensions' Access to Work scheme.

Recent reporting by The Canary, to which Stripy Lightbulb CIC contributed, highlighted how people with M.E./C.F.S. are being directed towards coaching services that categorise the illness as a form of "acquired neurodivergence". These services typically focus on cognitive, behavioural or workplace coaching approaches.

Our concern is straightforward: this type of support does not address the fundamental barriers to employment experienced by people with M.E./CFS and other energy?impairing conditions.

M.E./CFS is a serious, multisystem disease characterised by post?exertional malaise, where physical or cognitive exertion can cause significant and prolonged worsening of symptoms. For many people, the primary barrier to work is not confidence, organisation or mindset, but a severe and unpredictable lack of usable energy. No amount or style of coaching can resolve this.

As we stated in our contribution to The Canary investigation, *"there is currently no requirement for organisations providing workplace support through Access to Work to have any training or understanding of M.E./CFS."* This gap leaves people being offered generic interventions that are not designed for, and may be inappropriate for, their condition.

Stripy Lightbulb CIC is particularly concerned that responsibility is being placed on the individual with M.E./C.F.S. to adapt or improve their capacity, rather than on systems and employers to understand the illness and make safe, realistic adjustments. This reflects a longstanding pattern in which M.E./C.F.S. is misunderstood, leading to well?intentioned but unsuitable support.

It is also important to be realistic about employment outcomes. Many people with M.E./CFS are unlikely to be physically able to return to work in the absence of effective treatments. At present, there are no approved disease?modifying treatments available. Without substantial investment in biomedical M.E./CFS research and the development of therapies, attempts to move people back into employment through coaching alone are unlikely to succeed and may cause harm.

From our work supporting employers and professionals, Stripy Lightbulb CIC believes that Access to Work funding would be better directed towards training employers, HR teams and Occupational Health providers to understand energy?limiting conditions. Employers need accurate, condition?specific information about M.E./CFS, post?exertional malaise, fluctuating capacity and risk management, not outsourced coaching aimed at the employee.

We are therefore raising these concerns formally with the Department for Work and Pensions, as well as with other relevant government departments whose work intersects with employment, disability and health policy.

Stripy Lightbulb CIC supports genuinely inclusive employment where it is safe and appropriate. However, inclusion must be grounded in biological reality, not redefined through frameworks that do not reflect the lived experience or medical evidence associated with M.E./CFS. People with energy?limiting conditions need understanding, appropriate adjustments, and long?term investment in research, not interventions that place the burden of change on them.

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