

We Warned You”: Welfare Reform Debate Ignores Evidence Submitted Years Ago

Friday 19 June, 2026

As Westminster intensifies its rhetoric on welfare reform, Stripy Lightbulb CIC is highlighting a simple but uncomfortable truth: the crisis now dominating political debate was predicted in detail, and in writing, years before it reached the front pages.

Across parties, MPs are expressing alarm about rising economic inactivity and the growing welfare bill, framing the situation as a sudden and urgent challenge. Yet in 2023, Stripy Lightbulb CIC submitted written evidence to the Plan for Jobs and Employment Inquiry that outlined precisely why this moment was coming. We warned that Long COVID and M.E/C.F.S were driving a surge in long-term sickness, that the conditions were chronically misunderstood, and that the government’s own data systems were failing to capture the scale of the problem.

Our evidence made clear that half of Long COVID cases meet M.E/C.F.S diagnostic criteria, that three-quarters of people with M.E/C.F.S are physically unable to work, and that recovery rates remain extremely low. These are not marginal conditions. They are central to understanding why so many people are too sick to work, yet they remain almost entirely absent from the political narrative.

Sally Callow, Managing Director of Stripy Lightbulb CIC stated -
“Politicians are acting shocked by rising welfare costs, but we warned them years ago. You can’t ignore a public health crisis and then feign surprise when it shows up in the welfare bill.”

The current debate often implies that economic inactivity is a matter of personal choice or insufficient motivation. This framing ignores the biomedical reality of chronic illness and risks pushing sick people into deeper hardship. Tightening assessments will not change the fact that the system still cannot accurately identify, code, or support the conditions driving long-term sickness.

We also highlighted the enormous role played by carers, most of whom are spouses or partners of working age, whose employment is affected by the demands of caring for someone with M.E/C.F.S. Their contribution remains almost entirely invisible in the welfare debate, despite its profound economic impact.

The welfare bill is rising because millions of people are sick, not because millions of people have suddenly chosen not to work. Until policymakers address the diagnostic gaps, coding failures, and lack of biomedical understanding at the heart of this issue, welfare reform will continue to misfire.

Stripy Lightbulb CIC Calls for Evidence-Led Policy, Not Rhetoric

We urge policymakers to revisit the evidence already provided. Reducing welfare costs requires accurate diagnosis, proper coding, investment in biomedical research, and policy grounded in the lived reality of chronic illness. Without this, the welfare debate will continue to revolve around the absence of the very evidence we placed in front of decision-makers years ago.

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Stripy Lightbulb CIC

T. 07725658199

E. info@stripylightbulb.com

W. <http://www.stripylightbulb.com>

Additional Contact(s):

Sally Callow - Founder/Managing Director

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