

## Improving the Life Chances of Disabled People

I am glad the government is thinking and consulting about ways to improve disabled people's lives. I would like to respond to the employment section of your report.

I am a disabled person with ME (myalgic encephalomyelitis), a condition from which most people do not recover, although many improve. A minority deteriorate, and those who do not recover fully must always guard against this danger. I have had ME for 15 years and was extremely ill for the first 2 years. I then made a partial recovery, but in the last 5 years started getting worse again, although I am not as ill as I was at first. But I have to be extremely careful to stop this deterioration progressing.

The risk of deterioration means ME must always be taken seriously when considering employment. I have (very slowly because of my illness) been undertaking some small research into ME and employment as part of a Masters degree. My investigation shows that most people with ME, like people with other impairments, are keen to work if they possibly can, although many are of course far too ill to do so. There is nothing I personally would like better than to have satisfying and sustainable employment, but there is no way I could even manage a half-time job. The government has tended to assume that if disabled people are able to work at all they can do full-time hours, or at least move towards that with support. But for a lot of us that is not the case. Although some people with ME and other conditions may slowly be able to increase our hours there are many who will not.

If the government is serious about making work possible for more disabled people a number of issues need to be tackled. As well as ensuring physical access to work places and making Access to Work support available prior to employment, there needs to be much more acceptance of very part time working. Even with full environmental access many disabled people will not be able to work many hours. As few as 3 hours per week might be needed in some cases and a diverse range of jobs should be available in a low hours format. People with fluctuating conditions like ME could benefit from working monthly as opposed to weekly hours, doing more work during weeks when they were reasonably well and less or none when ill. The government would need to undertake a major strategy to convince employers that the benefits of having very part-time employees can outweigh the disadvantages, or it must offer incentives.

Then there must be greatly increased flexibility and support from the benefits system. I recognise the government has been taking steps in this direction, but there is still a long way to go. Although there have been moves to help disabled people into full-time work, appropriate support is also needed for those who will never be able do more than a few hours a week. Supported permitted employment is a positive move, but few organisations so far offer the appropriate support, and poorer disabled people can still only earn £20 pw without losing benefit. Combine this with the extra expense and exertion of working and it is often simply not worth trying, even if we could find a suitable job.

Those disabled people with high care costs will often be worse off working than on benefits. DAI recently came across a disabled single mother who wanted to combine part-time working with caring for her daughter. This was a very competent young woman, but she is now no longer contributing her talents to the labour market as she could only make more money than her benefit levels if she worked full-time. The answer

to this ridiculous situation is absolutely not to cut benefit levels, given disabled people are already one of the poorest groupings in society. Instead disabled people must be able to keep more of the income they earn on top of total benefit. This would encourage us to work as much as we are able, improve our income and quality of life, whilst also increasing the government's revenues.

However, many disabled people will never be able to work, and it is vital not to pressurise us towards employment when it is not appropriate. Benefit levels for disabled people should be increased, not reduced, so that no disabled person is penalised for their inability to work, nor for society's inability to make work accessible.

Yours sincerely

Julia Cameron

Founder member North London ME Network

Committee member, Disability Action in Islington (DAI) (both in personal capacity)