mnda
motor neurone disease
association

RESPONSE TO THE COMMAND PAPER '21ST CENTURY WELFARE'

INTRODUCTION

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, it is always fatal and it kills five people every day in the UK. It can leave people locked into a failing body, unable to move, speak or eat normally. Cognitive impairment and / or behavioural changes of varying severity can occur in up to 50% of cases. There are around 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no effective curative treatment.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

MND can occur in any adult, but is more common in older people. This has implications for the take-up of benefits among people with MND: approximately half of people with MND are of working age and so make use of out of work benefits. In respect of other benefits, MND claimants are also split between Attendance Allowance and Disability Living Allowance. It should also be noted that their requirements for specialist equipment and high levels of care and support often require people with MND to live in housing that might otherwise be considered oversized for their household.

The path out of the workforce followed by people with MND must be recognised: for many people with MND, remaining in work for as long as possible is very important, and it is fair to assume that by the time a person with MND gets to the point of claiming Employment Support Allowance their ability to work has been profoundly and irreversibly compromised.

We state this here in light of recent comments made by the minister of state for employment on national television, to the effect that people with MND might regularly be expected and challenged to re-enter the workforce. We do not accept this: for people with MND who have reached the point of claiming out-of-work benefits, the only appropriate and compassionate response is to recognise their inability to work, and to support them accordingly.

RESPONSES TO CONSULTATION QUESTIONS

1. What steps should the Government consider to reduce the cost of the welfare system and reduce welfare dependency and poverty?

In respect of reducing poverty, the Government must acknowledge that severe disability and terminal illness can cause poverty, and must pledge to protect people thus afflicted from poverty. We note the identification in the command paper's foreword of the, “the root causes of poverty,” as, “family breakdown; educational failure; drug and alcohol addiction; severe personal indebtedness; and economic dependency.” The Government must add long-term illness and disability to this list, and pledge to support those who are at risk of falling into poverty for these reasons: nobody should be forced into poverty by the onset of illness.

2. Which aspects of the current benefits and Tax Credits system in particular lead to the widely held view that work does not pay for benefit recipients?

The main thrust of the command paper is clearly to find ways in which the benefits system can be used to reduce unemployment (or ‘worklessness’ as the command paper refers to it). We will not address this at length, as it is not an area on which we wish to comment: people with MND who have reached the point where their illness forces them out of work will not be able to return, and should never be expected to do so.

That said, it may be of concern to people with MND and their carers that there is not a clearer recognition in the command paper of groups who can never be expected to work again, and who must be supported; phrases such as, “target support more efficiently, supporting and protecting those in vulnerable circumstances,“ fall short of a frank acknowledgement that there are groups who cannot work and who must, in a civilised society, be supported by the state.

This point applies both to people with MND, and to their loved ones who are forced out of work to become carers: of the latter group, those still of working age will be able to return to work after their caring role has ended, and should be supported to do so; but it must be recognised that for many people with a loved one who has developed MND, leaving work to care for them is the only option available, for reasons both of practicality and conscience.

Ministers have made such acknowledgements much more frankly in speeches and discussion at stakeholder events; more candid statements to this effect would be welcome in future documents.

3. To what extent is the complexity of the system deterring some people from moving into work?

For people with MND, the complexity of the system relating to terminal conditions can see them threatened with an enforced return to work, as the current arrangements around Employment Support Allowance and the work capability assessment are not wholly adequate for identifying those who cannot work and placing them in the support group. Greater simplicity and clarity in the system would have the benefit of allowing vulnerable people to navigate it more confidently and thereby reduce errors made as a result of both claimant mistakes and DWP error.

4. To what extent is structural reform needed to deliver customer service improvements, drive down administration costs and cut the levels of error, overpayments and fraud?

The benefits system certainly needs to be made easier to understand and use, although the picture here is not uniformly negative. Understanding of different benefits varies greatly among people with MND. Of respondents in our 2010 Tracking Survey:

- C.50% did not understand Disabled Facilities Grant, Continuing Care and Direct Payments.
- 93% and 82% respectively felt confident that they understood DLA and Attendance Allowance
- 68% of those who were eligible and who understood the benefits found them easy to access
- 17% of those who were eligible and who understood the benefits found them difficult to access.

We would therefore be interested in seeing structural reform options explored that will make it easier for people with MND to use the system and obtain the support they need.

We note with some concern, however, the examples used in Chapter Two of the command paper of countries reducing spending on welfare: they are extreme and unbalanced examples, as both Ireland and Iceland suffered enormously in the recent economic crisis, both much more so than the UK.

Question 5 Has the Government identified the right set of principles to use to guide reform?

These principles are not adequate. They do not sufficiently address the needs of those who cannot work and should never be expected to. They are obliquely referred to in the fourth principle ('continue to support those most in need') but even this then goes on to talk in terms of reducing unemployment. A separate principle is needed, stating explicitly that there are groups that are so vulnerable they will always be supported by the state, such as those who cannot work owing to serious illness or disability.

The stated intention to reinforce conditionality must also be amended in light of this: for the cohorts that cannot work, reinforcing conditionality is inappropriate. Conditionality must only be raised, even as a principle, in respect of customer groups who might ultimately return to work.

Commitments to ensure that communication with claimants is as clear as possible, and that take-up of benefits is maximised, are also notably absent, and we recommend that they be included.

We also note with concern the link made between Disability Living Allowance and employment under the heading 'Affordability':

“Demographic changes mean that the cost of the welfare system is predicted to rise at a time when we can least afford it. We started to address this through the measures announced in the Budget, in particular the changes to the uprating of benefits, Disability Living Allowance and Housing Benefit. These reforms, along with reforms to obligations placed on out-of-work lone parents, build on a wealth of evidence that highlights the role of a strong system of conditionality in helping those dependent on benefits move into paid work.”

This link between DLA and work is extremely alarming and wholly incorrect. DLA is not an out of work or income replacement benefit and we would oppose any attempt to turn it into one.

We also note that these principles will not apply to other government departments, and that the consequences of decisions taken elsewhere, particularly by or in agreement with the Treasury in the recent Budget and forthcoming Comprehensive Spending Review, may run against these principles.

It is hard to see how, for instance, decisions in the Budget on Housing Benefit (HB) are consistent with a pledge to, “support those in most need.” These changes include:

- up-rating the Local Housing Allowance (LHA), which determines the maximum housing benefits that can be paid, in line with the consumer price index rather than local rents
- reducing LHA rates to the 30th percentile of local private rents from October 2011, rather than the median as at present – this means HB claimants will be able to receive up to the maximum value of the lower 30% of rents in an area as their benefit, rather than up to the local median average; the lack of transition arrangements will mean that some people suddenly find their rent is completely unaffordable
- reducing HB by 10% for job-seeker’s allowance claimants after twelve months – in principle this ought not to affect people with MND, but those wrongly denied ESA, whose appeals can take a year or more to be completed, could fall into this group
- increasing non-dependant deductions (NDDs) to the levels they would have been at had they not been frozen since 2001, which could seriously hit a person with MND with grown-up offspring living at home
- limiting HB entitlement to reflect household size in the social sector, as well as the private, which could embroil some people with MND in a battle to show that they are not ‘under-occupying’, in light of the increased space requirements due to their illness, relative to other households.

As can clearly be seen from these examples, while these proposed principles may apply to the current process of reform, they might not be respected by decision-making elsewhere, which risks undermining or outweighing any potentially beneficial effects of the reform programme.

Question 6 Would an approach along the lines of the models set out in chapter 3 improve work incentives and hence help the Government to reduce costs and tackle welfare dependency and poverty? Which elements would be most successful? What other approaches should the Government consider?

We cannot comment on which models would be most likely to improve work incentives. We would welcome further clarity on the effects of some of the models on benefits for those who cannot work owing to illness; in most cases, these appear to be marginal considerations. This may be appropriate if the main benefits for this cohort are to be reviewed separately. With all those caveats, we would express a tentative preference for the simpler approaches such as Universal Credit. Brief comments on each option are below.

'A Universal credit'

What impacts would this have on the ill and disabled? DLA would presumably be left untouched (it is not mentioned in the proposals) while there would be an element of universal credit for those unable to work through illness or disability, replacing ESA – is this correct? If so, we would be interested to see this idea explored further.

We are pleased with the reassurance that, “We would in any case separately consider the role of additional income-related payments for disability as we develop ideas on disability benefit reform. It would not, however, be our intention to use Universal Credit reform to reduce the levels of support for people in the most vulnerable circumstances.“

'A single unified taper'

As this reform would relate entirely to those people who are able to return to work, we offer no comment on it.

'Single working age benefit'

We would be deeply concerned at any system that did not recognise the particular needs of the ill and disabled relative to the able-bodied: disability and terminal illness bring considerable costs with them, and a failure to acknowledge this would do enormous harm to the most vulnerable people in society.

'The Mirrlees model' / 'Single benefit / negative income tax model'

As these proposals appear to have no bearing on benefits for the ill and disabled, we can offer no comment.

Question 7 Do you think we should increase the obligations on benefit claimants who can work to take the steps necessary to seek and enter work?

And

Question 8 Do you think that we should have a system of conditionality which aims to maximise the amount of work a person does, consistent with their personal circumstances?

Reliable identification of those who can work and those who cannot is essential before further pressure can be placed on those capable of work. Failings in this regard will lead to grave difficulties for vulnerable groups such as people with MND, who will find themselves subject to these new mechanisms inappropriately.

We welcome the clear statement that no conditionality will attach to those who cannot seek work, such as those in the ESA support group (which is where we believe all claimants with MND should be placed automatically; although the current processes do not allow this to happen reliably, it is typically where people with MND are currently placed, when the system works). This should be reflected clearly in the principles for reform as well.

We are alarmed, however, by this proposal:

"Benefit claimants who currently have no work search conditionality applied (for example because of ill health or caring responsibilities). We could apply conditionality to match financial incentives for working even relatively short hours where appropriate – requiring some people to look for or prepare for work of a few hours a week in line with their capability and circumstances – and extend conditionality as an individual's circumstances change (for example, when their health improves)."

While its logic is in principle clear and fair, this approach would in practice create problems for vulnerable groups such as people with MND, as a new mechanism would be created for trying to get people off benefits. It seems sadly inevitable, based on past experience of the WCA, and the Special Rules regime, that misunderstandings among DWP staff and contractors would lead to people with MND being harassed to return to work under the misapprehension that their health might improve or be improving. Careful system design and thorough training will be essential if this is to be avoided – the track record to date of the DWP and its contractors does not inspire confidence that it is likely to be able to deliver this, but we will if necessary work with the Department to assist in this work.

Question 9 If you agree that there should be greater localism what local flexibility would be required to deliver this?

We are sceptical of the value of greater localism in the benefits system to vulnerable groups such as people with MND: these individuals need to have confidence that their needs will be met, and not be at the mercy of local variations and a post code lottery. Benefits that are currently administered locally are among the worst-performing: the Disabled Facilities Grant (albeit administered by local authorities rather than local DWP agencies) in particular is among the least well-understood benefits among people with MND, is hard to access and is notoriously slow – with cases of modifications not being made until the individual's needs have changed and they are unable to use them, or even not being made before the individual dies, are not uncommon. Well-publicised variations between different local authorities in standards of social care provision also suggest that greater localism produces inequalities.

It may be that the devolution of greater autonomy to local DWP bodies, rather than local authorities, will produce better results, but based on the extremely poor record of LAs, we cannot support greater localism for benefit delivery.

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