The Muscular Dystrophy Campaign response to the 21st Century Welfare Consultation:

The Muscular Dystrophy Campaign represents the estimated 71,000 children and adults in the UK affected by one of more than 60 different types of muscular dystrophy and related neuromuscular conditions affecting adults and children. These are rare and very rare conditions which weaken and/or waste muscles. They can cause lifelong disability and/or premature death.

There are currently no cures or treatment and without multi-disciplinary care most patients and their families experience a further reduction in quality of life and for some conditions, shortened life expectancy.

Muscular dystrophy and related neuromuscular conditions can be severely disabling, and many people affected by these conditions are unable to carry out any work-related activity. For others, work-related activity and employment is possible through adapted workplaces, part-time and flexible working, and supportive employers.

Trailblazers is a nationwide organisation of more than 250 young disabled campaigners. Trailblazers is part of the Muscular Dystrophy Campaign, the leading UK charity on muscular dystrophy and related neuromuscular conditions, and aim to fight the social injustices experienced by young people living with muscle conditions, and to ensure we can gain access to essential services.

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

With disabled people twice as likely to live in poverty as non-disabled people¹, we believe the government must ensure that any reforms of the welfare system not only protect current levels of disability benefits, but go further to ensure that every person with a muscle disease has both dignity and a decent quality of life. Neuromuscular conditions are complex, progressive and often severely disabling conditions, and the support required can fluctuate on a day to day basis.

For this reason we believe that Disability Living Allowance must be retained in a reformed welfare system, as it goes some of the way to reflecting the extra costs of disability. For people whose disability does not allow them to take part in employment, the level of Employment and Support Allowance (ESA) paid to those in the support group must be paid at a sufficient level to stop people who
are unable to work through no fault of their own from falling beneath the poverty line.

In addition, while we fully endorse the commitment of the government to provide more support for people on Incapacity Benefit who wish to move into employment through the migration onto ESA, this must also be matched by the understanding that many people with severely disabling muscle wasting conditions are unable to take on employment. Reforms to the welfare system must not, in the government’s striving not to “write people off” by keeping them on disability-related out of work benefits, inappropriately place people as ready for work, cutting off their benefits and support. Indeed on this point, we endorse the view of the Citizens Advice Bureau who stated: “There is an urgent need for recognition that – contrary to the Government’s intentions – some people are being ‘written off’ by being found capable of work, and therefore being removed both from benefit support and from the help and support they need to find work.”

**Question 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?**

It is important to stress that the main disincentive for people with muscle disease to take up employment, where possible, is the lack of accessible, available and suitable job opportunities.

However, it is also important to note that for people with disabilities who require home adaptations, being in paid work means that, following means testing, they are very likely to be judged to have to make a very substantial contribution to the cost of these adaptations (through the Disabled Facilities Grant). There is a very strong sense among families that it makes no financial sense to work, as they then have to pay much more for essential adaptations (only undertaking due to necessity) than if they were not working.

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

We welcome the intention in the consultation paper to simplify the complex benefits system, and to make the process more efficient.

Our members report confusion over what will happen if they move from benefits into employment, and due to their medical condition, they are unable to remain in their job. For example, one member with a progressive and disabling neuromuscular condition is an Incapacity Benefit claimant. He has reported that he is reluctant to move into employment in case the job does not work out. He would then have to wait six months before being able to be assessed for ESA, and would then have to undertake the Work Capability Assessment, which he does not believe will assess his condition fairly.

In addition the complexity and limited budget of Access to Work also acts as a disincentive to those who would like to work but have significant care needs. Research by *Trailblazers* – The Muscular Dystrophy Campaign’s Young Campaigners Network - earlier this year highlighted a number of further concerns with how Access to Work works in practice:
• A candidate must have already been offered a job before an Access to Work assessment is carried out.

• When starting a new job there is an initial delay in funding while assessments are carried out thus increasing anxiety during the first few weeks.

• If adaptations are required for the building, theoretically the funding is available, but the time delay between applying for a job and starting a job could be months if major alterations are required which reduces the likelihood of securing the job.

• A disabled employee must have the money in advance to pay for added cost. Reimbursement may take weeks to arrive, compromising cash flow.

The consultation paper states that reforms should: “support our wider goal of … enabling disabled people to have an equal role in society.” We recommend that Access to Work is made more efficient and responsive to the needs of disabled people in employment, and crucially, sufficiently funded to meet the access needs of every disabled person who is able to carry out paid and unpaid work.

In addition, the closure of the Independent Living Fund to new claimants further cuts of a lifeline of support to people with severe disabilities and complex care needs who are moving into work.

Question 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?

We recommend structural reform of the Work Capability Assessment (WCA) following the review by Professor Harrington. Further welfare reform cannot be based on the results of a test with such a high rate of failure, and has been found to be dangerously inaccurate for people with complex and long-term disabling conditions.

Under the Incapacity Benefit system, if you were receiving Disability Living Allowance Care Component (higher rate), or you had medical evidence to show that you were affected by a severe and progressive neurological or muscle wasting disease you were exempt from the Personal Capacity Assessment. These are not exemptions under the Employment and Support Allowance rules.

This can mean that very severely disabled people are subject to an assessment by health professionals who do not understand their condition: the health professionals who carry out the WCA are not trained in muscular dystrophy and related neuromuscular conditions – rare and complex conditions, with over 200 genetic loci. Many GPs may only see one patient in their whole career affected by a neuromuscular condition, and it is therefore unlikely that the ATOS health professionals will have experience in these conditions.

We recommend that during the assessment process, additional information is requested and taken into consideration from medical professionals who have
Expertise in rare conditions so that the assessor can fully understand the impact of these complex, multi-system disorders on a claimant’s capacity for work. This would work in a similar way to claims for Disability Living Allowance, which do not compromise the doctor’s relationship with their patient.

The WCA further fails in to take into consideration real-life context – it does not measure the availability of accessible and appropriate work, only functionality. The failure to assess real-life context when assessing ESA claimants points to a wider issue with the proposed reforms: for many disabled people who are able to work, it can be almost impossible to find, obtain and retain employment, due to inaccessible workplaces, transport and employer attitudes.

For example, research by Trailblazers – The Muscular Dystrophy Campaign’s Young Campaigners Network - earlier this year found that:

- almost three out of four young disabled people believe the job application process puts disabled people at a disadvantage;
- seventy per cent of young disabled people believe their job applications have been rejected due to the perception of disability;
- almost three out of four young disabled people feel physical access to the workplace is a major obstacle to getting into employment;
- more than half of respondents cite an employer’s aversion to risk as a major obstacle in finding work;
- almost half of young disabled people think inaccessible public transport is a major factor in finding work;

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

We welcome the principle to “continue to support those most in need”. However, we believe that the first and overall principle for welfare policy is to provide dignity and a decent quality of life for people who are unable to work due to severe disability.

We would further include a principle that the welfare system should support people with disabilities who want to work – for example, by providing sufficient funding for Access to Work and the Independent Living Fund.

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 believe that it is crucial to retain Disability Living Allowance as a separate non-work related benefit, to be paid to both children and adults in work and out of work, to cover the extra cost of disability.

We are also concerned that one of the proposals for reform highlighted in the consultation paper is the Single Working Age Benefit, which would be paid at the same level for jobseekers and those who are classed as unable to work due to a disability. Currently the most severely disabled person claiming Employment and
Support Allowance may receive £91.40 per week, with the maximum a person may receive on Jobseekers Allowance only £65.45 per week. We would oppose such a system being adopted without this shortfall being met through alternative disability benefits or a disability premium being paid on the benefit.

We have similar concerns regarding the proposal of a Universal Credit, with regards to the level of disability premium. We welcome the commitment in the consultation paper that: “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.” However, further details are urgently required, ahead of further promotion of this policy as to how a disability premium would be provided and work in practice to meet the levels of DLA and ESA.

**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?**

Any increase in obligation on benefit claimants who are judged to be able to work must only follow structural reforms to the Work Capability Assessment, and the levels of support provided to people with disabilities and high-level support needs who are able to, and wish to take up employment, as outlined in the answers to questions 3 and 4.

In addition any increase in obligation should also be matched by increased pressure to increase the number of employment opportunities available to people with physical difficulties, and in particular wheelchair users, and those who require the support of a personal assistant.

**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?**

Any increase in conditionality on benefit claimants who are judged to be able to work must only follow structural reforms to the Work Capability Assessment, and the levels of support provided to people with disabilities and high-level support needs who are able to, and wish to take up employment, as outlined in the answers to questions 3 and 4. This is particularly necessary for people with neuromuscular conditions, who find that their support needs fluctuate from day to day, due to the complex and progressive nature of their condition.

In addition any increase in obligation should also be matched by increased pressure to increase the number of employment opportunities available to people with physical difficulties, and in particular wheelchair users, and those who require the support of a personal assistant.

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

We would remain concerned that greater localism could lead to a postcode lottery in the financial support received by people with disabilities who were unable to work.
Question 10: The Government is committed to delivering more affordable homes. How could reform best be implemented to ensure providers can continue to deliver the new homes we need and maintain the existing affordable homes?

Many families with disability struggle to find accessible and affordable housing, and many battle for years for home adaptations. Any reform to increase the supply of affordable housing must include a focus on affordable and accessible housing. We support the adoption of the Lifetime Homes standard for all new housing developments, and indeed urge the government to go further to ensure that housing is developed to promote a decent quality of life for people with disabilities.

Question 11: What would be the best way to organise delivery of a reformed system to achieve improvements in outcomes, customer service and efficiency?

We would support the move towards a reformed delivery system, with a single application point.

Question 12: Is there anything else you would like to tell us about the proposals in this document?

We are deeply concerned that on repeated occasions since the May election, both in the 21\textsuperscript{st} Century Welfare paper, and more widely, Disability Living Allowance (DLA) has been referred to as an “out of work benefit” or that this has been implied. This is clearly incorrect – DLA is intended to go some way towards meeting the extra costs people living with a disability face. These include for example, adapted vehicles and higher transport costs, paying for their own wheelchairs, higher heating and electricity bills, and often being forced to spend thousands of pounds to make their homes accessible. We strongly urge the government to ensure clarity in future statements on this matter.

We would further be concerned if such misstatements were being used to reduce the credibility of the DLA and blur in people’s minds the purpose of the benefit, ahead of a move to a universal credit system. Any reform to the Disability Living Allowance must be carried out with the intention of promoting independence and quality of life for people with a disability, and not as a cost cutting measure.

We are further concerned that the Consultation Paper states that Jobseeker’s Allowance (JSA) and Employment and Support Allowance (ESA) are “often providing the same level of financial support.” This neglects to mention that the highest level of ESA is in fact 50\% higher than the standard rate of ESA. As many forms of muscular dystrophy and related neuromuscular conditions are severely disabling, our members are often receiving this level of support, and we would be extremely concerned if this important differential was not reflected in any proposed reforms.

30\textsuperscript{th} September 2010

1 Leonard Cheshire Disability Poverty in the UK (June 2008)
2 CAB: Not working: CAB evidence on the ESA work capability assessment March 2010