Muscular Dystrophy Campaign submission to the Work and Pensions Select Committee’s inquiry into the Proposal to replace DLA with Personal Independence Payment
August 2011

Executive summary

• We welcome the Committee’s inquiry into the proposal to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP). We have significant concerns about how a new assessment will work for people with neuromuscular conditions and about the proposal to remove the mobility component from people living in residential care and residential colleges.

• Neuromuscular conditions are a set of rare and very rare conditions affecting 71,000 people across the UK. Because neuromuscular conditions are so rare, healthcare professionals carrying out a face-to-face assessment, as seems likely to be proposed for PIP, are therefore unlikely to have come into contact with more than a handful of such patients in their careers and will have little knowledge of the conditions.

• We therefore propose a tiered assessment process, with evidence from experts, such as an individual’s consultant neurologist or neuromuscular care advisor, being given due weight and face-to-face assessments only being carried out where there is insufficient information to make a decision on eligibility for PIP.

• Similarly, as the majority of neuromuscular conditions are progressive, and in some cases life-limiting, we do not believe that regular reassessment is necessary for this group of people.

• We strongly disagree with the proposal to remove the mobility component from people in residential care and are concerned that this could have a significant impact on people in residential homes or residential colleges.

• We welcome the fact that the proposed changes do not currently apply to children and would urge full consultation on any future proposals to reform child DLA.

• We believe that the Government should reconsider how PIP applies to adults over the state pension age. Current arrangements mean that older adults with late-onset conditions often miss out on vital support.
Introduction
1. The Muscular Dystrophy Campaign represents the 71,000 people in the UK with muscular dystrophy or a related neuromuscular condition. There are more than 60 different types of muscular dystrophy and related neuromuscular conditions, many of which are low incidence, orphan conditions and indeed some are very rare and are regarded as ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the exception of a couple of acquired conditions, there are no known effective treatments or cures.

2. Disability Living Allowance (DLA) is a vital benefit intended to help people meet the extra costs of their disability and, as such, is fundamental to supporting disabled people fulfil their potential and giving them the same opportunities as others in society.

3. In our 2010 report, *The Cost of Living with Muscle Disease*¹, we found that, of the people we surveyed, over two-thirds had experienced financial difficulties as a result of living with their condition; two out of five families struggled to pay their bills due to their neuromuscular condition and four out of five families did not think that the benefits system adequately covers these costs.

4. Extra costs can arise for people with neuromuscular conditions for a number of reasons, for example through having to rely on wheelchair-accessible taxis in areas where public transport is not accessible, or because of the higher electricity bills which can result from specialist equipment such as such as powered wheelchairs, ceiling hoists and through-floor lifts.

5. Whilst reviewing DLA is welcomed, the Personal Independence Payment (PIP) which currently is proposed as the replacement benefit, must continue to allow people with neuromuscular conditions to meet these extra costs and enable them to live the lives they want to. With the Government aiming for a ‘reduction target’ of 20% in DLA payments, as set out in the Budget report in June 2010², we are concerned that some people’s needs may not be recognised, meaning some may miss out on the vital support they need to live an independent life.

---

Indra has a form of muscular dystrophy and due to her progressive muscle wasting condition, she has considerable mobility issues. She has good and bad days; some days she can manage her needs but on other days, due to her muscle strength and fatigue, she requires assistance with almost everything – walking, getting up from a sitting position, cooking, washing and personal care. During bad periods, she can go for four weeks without being able to leave the house. She has recently been reassessed for DLA and has been told she is no longer entitled to the care component and will have her mobility component downgraded.

The newly proposed assessment process must have a level of flexibility to allow for people like Indra whose needs may not always be immediately apparent. Indra desperately requires this assistance to meet the extra cost of living with her disability; the thought of losing this support has put her under severe stress and consequently she was recently taken to hospital with panic attacks.

The Muscular Dystrophy Campaign is now working with Indra to get the support to which she is entitled, allowing her to live a full, independent life.

---

The design of the PIP assessment
6. At the moment, potential claimants are required to fill in a comprehensive form outlining the impact of their disability on their day-to-day life in order to apply for DLA. Some people may also be required to undergo a face-to-face assessment with a healthcare professional if further clarity is required before making a decision regarding eligibility for the benefit.

7. Claimants are also able to ask someone who knows them to complete the section on the DLA claim form confirming their statements – most often their doctor or another healthcare professional – although they are not required to do this.3

8. Because of the range of neuromuscular conditions, the severity of conditions and how they affect individuals varies greatly from person to person. However, the majority are progressive, causing the muscles to gradually weaken and waste over time, affecting mobility and leading to some sort of disability. Some conditions, such as Duchenne muscular dystrophy, are severe and life-limiting; those affected will generally require a wheelchair by the age of twelve and will often not live beyond early adulthood.

9. In their response to the public consultation on DLA reform, the Government state that they intend the assessment for the daily living component of PIP will focus on “those key everyday activities which are essential to enabling participation and independence”4.

10. It is currently proposed that this part of the assessment will focus on activities such as feeding, toileting and dressing. Whilst these activities are vital to daily living, we believe that looking at these activities in isolation will not enable PIP to achieve its stated intention of targeting supporting “at individuals who require the most assistance to live full, active and independent lives”5. People with complex needs arising from their neuromuscular condition may well require different types of support, for example to access education or to get involved in their local community.

11. It has been proposed that some aids and adaptations should be taken into account when assessing eligibility for PIP. We would have concerns about this approach as the provision of equipment, such as a wheelchair, does not remove all of the barriers to accessing mainstream society or the additional costs of a disability. Wheelchair users, for example, will still often be reliant on taxis as much public transport remains inaccessible and 50% of the UK’s trains and stations’ facilities for disabled people were not up to scratch when investigated as part of the End of the Line transport report in 20096.

12. We would be highly concerned if the criteria for PIP were to mirror those currently being used to assess eligibility for Employment and Support Allowance. The 2011 descriptors now assess whether an individual is able to mobilise 50 metres, as opposed being able to walk 50 metres. In practice, this means that if an individual can self propel a manual wheelchair for 50 metres on level ground and none of the other descriptors apply they will be found fit for work, which fails to take into account many of the practical barriers to work faced by a manual wheelchair user.

---

5 Ibid, p. 23
6 http://www.muscular-dystrophy.org/assets/0001/4049/Trailblazers_-_End_of_the_Line.pdf

Muscular Dystrophy Campaign
August 2011
13. We would strongly recommend that issues such as these are given careful consideration and would suggest that aids such as wheelchairs should not be taken into account in the PIP assessment.

The delivery of the PIP assessment

14. The public consultation on DLA reform talks about introducing a new objective assessment, most likely a face-to-face assessment carried out by a healthcare professional. Whilst this may be appropriate in some cases, many people with muscle disease will be severely disabled by their condition and it may not be the most effective use of limited financial resource to require them to attend a face-to-face assessment.

15. Instead, we propose that there be a tiered assessment process. For many individuals with neuromuscular conditions, completing a comprehensive form similar to that used at the moment and submitting supporting evidence from a healthcare professional who knows them well – for example a consultant neurologist or neuromuscular care advisor – should be sufficient to adequately assess their entitlement to the benefit. Only when this approach does not provide enough information to assess entitlement should someone be invited for a face-to-face assessment.

16. Similarly, for individuals with severe, progressive and life-limiting conditions such as Duchenne muscular dystrophy, it makes little sense for them to be given the benefit for a fixed period of time as their condition will only worsen. In these cases, indefinite entitlement should be retained.

17. Finally, any new assessment for PIP must take into account the lessons learnt from Professor Harrington’s first annual review of the Work Capability Assessment (WCA) and the second review which is currently being carried out. The first review highlighted a number of problems with the WCA, including the fact that Jobcentre Plus Decision Makers “typically ‘rubber stamp’ the advice provided through the Atos assessment”. For rare conditions such as muscular dystrophy, the assessor is very unlikely to have sufficient knowledge to adequately assess the full range of an individual’s needs: it is therefore vital that evidence from experts, such as a neuromuscular care advisor, is given due weight during the assessment process.

Elliot and his twin brother have limb girdle muscular dystrophy - a progressive muscle wasting condition for which there is no cure and which can be severely disabling. Both experience extensive mobility impairments and require similar levels of support. However when assessed for DLA, Eliot’s specialist needs were misunderstood and he was denied this support whilst his brother had no issue in receiving this benefit.

Elliot needs were a clear fit for the DLA criteria: he struggles to walk, dress, wash, cook or undertake his personal care independently. Because those assessing him did not understand the implications of his condition, he struggled for many months without this financial assistance. The Muscular Dystrophy Campaign has since worked with Elliot and he now receives the higher rate of both the mobility and care components of DLA.

---

Muscular Dystrophy Campaign
August 2011
The mobility component of PIP for people in residential care and colleges

18. The Welfare Reform Bill 2011 currently gives the power to enact regulations removing the mobility component of PIP from people living in residential care. We strongly disagree with this proposal and are concerned that this could have a significant impact on people in residential homes or residential colleges.

19. Residential colleges may only provide transport for the start and end of term, with no extra provision for visits at weekends, or for the young person when they’re at home during the holidays. Without the mobility component, families will be left without this vital support to help meet transport costs, and furthermore, be ineligible for an adapted vehicle through the Motability scheme.

20. Many families will not be able to fund their own adapted vehicle, leaving them unable to visit their child at school, and take them out for visits, or even back to the family home. During the holidays, young people may end up stuck as a prisoner in their own home, unable to get out and take part in leisure activities, or even attend essential hospital appointments.

21. This proposal will also affect adults of all ages with severe disabilities who are supported by the state to live in residential care – including many young adults living independently for the first time who rightly expect to live full and independent lives.

22. Restricting their access to Motability or financial support for paying for public transport, many disabled adults will be unable to retain voluntary employment (which is not covered by the Access to Work scheme), or simply to visit family and friends.

23. By arguing that disabled people in care homes should just make do with the transport provided by the home (where it exists) the government is acting in contradiction of the objectives behind the personalisation of social care, Direct Payments and Personal Budgets, where disabled people are given the choice and resources to manage their own lives. It is hard to see how this proposal can co-exist with the principle stated in A Vision for Adult Social Care: Capable Communities and Active Citizens: “Personalisation: individuals not institutions take control of their care.”

How DLA/PIP should apply to children and people over the state pension age

24. During the second reading of the Welfare Reform Bill 2011, when asked about the impact of DLA reform on children, Iain Duncan Smith said: “We are consulting on that. However, this is going to be done later on, so we will have plenty of time.
to hear many more representations concerning children before we make any decisions.46.

25. We welcome the fact that these changes do not currently apply to children. We would have concerns about subjecting young people and their families to face-to-face assessments, particularly when they may be dealing with the impact of receiving a diagnosis of a life-limiting condition and struggling to access the specialist health care they need.

26. We would urge the Government to consult fully before making any changes to child DLA.

27. As current proposals stand, only adults of working age will be able to make a new claim for PIP. This is also true of DLA and can have a significant impact on the lives of older adults with neuromuscular conditions, particularly those who develop one of the conditions which typically manifests itself in later life; for example Inclusion Body Myositis.

28. These rules can deny older adults the opportunity to continue to live an independent and active life. For example, Doug Sibley from Eastbourne is affected by FSH muscular dystrophy, and told us that not being able to claim DLA is: “Like kicking you when you’re down. The rules do not consider the fact that you want to remain active.”48

29. We therefore strongly believe that adults over the state pension age should be able to make a new claim for PIP.

Submitted on behalf of the Muscular Dystrophy Campaign by:

Lisa James
Senior Policy and Campaigns Officer

Muscular Dystrophy Campaign, 61 Southwark Street, London SE1 OHL
t: 020 7803 2865   e: l.james@muscular-dystrophy.org

9 http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110309/debtext/110309-0002.htm

Muscular Dystrophy Campaign
August 2011