

**Government Green Paper (England):
*Shaping the future of care together***

Policy briefing

On 14 July 2009 the Government released its Green Paper, *Shaping the future of care together*, outlining proposals for state provision of care and support for people in England, including disabled people and those in later life. The public has been invited to respond to the Paper by 13 November 2009.

Action for M.E. has launched a consultation survey, in association with the Disability Alliance, to see how people with M.E. think the Green Paper may affect them. The survey is available online at www.afme.org.uk. A print out is available from Alex or Michelle on 0117 930 7286.

Introduction

This document gives an overview of M.E.-related aspects of the Paper. It does not represent a formalised statement of Action for M.E.'s stance. Since the Green Paper is not entirely clear as to the proposed reforms, commentary has been drawn from several sources.

Proposals include:

- a standardised national assessment which means that if a person moves from one part of the country to another, they will not have to do a new assessment
- a commitment to giving users of social services better choice and control over the way their care needs are met.
- a system of “joined-up” working, a wider range of care and support services and better quality and innovation.

It goes on to state: “We should consider integrating some elements of disability benefits, for example Attendance Allowance, to create a new offer for individuals with care and support needs...”¹

Action for M.E. is concerned about what this means for people with M.E., what exactly would replace disability benefits, and how this would be shared out.

Uncertainty over allowances

There is some concern about Attendance Allowance (AA) and Disability Living Allowance (DLA). A recent article in *Community Care* says the Green Paper “states that ‘some elements of disability benefits, for example Attendance Allowance’ might no longer be paid to people and instead integrated into a new social care budget and there are those in the social care world who support this, thinking that such benefits are to ‘pay for care.’”

“It goes on: ‘Because Attendance Allowance /Disability Living Allowance are paid through the social security system they are underpinned by standard, national, transparent and legally enforceable criteria and can be challenged by formal appeal processes - something which doesn't apply to the postcode lottery of care service ‘rights’.”²

Whether the Paper represents a possible move towards streamlining the assessment of social care and benefits into one process is not clear.

The emphasis of the Green Paper appears to be on care and support services specifically. Historically, DLA and AA were intended to cover the extra costs associated with disability such as higher fuel and housing costs. Many of those on DLA/AA do not need/receive a care package. It is unclear what provision will be made to support these additional costs under the new proposal.

Withdrawal of the funding may also have a knock-on effect. In a recent article in *The Guardian*, Michelle Mitchell, charity director for Age Concern and Help the Aged, said: “That extra bit of help may help prevent, or delay the need for more formal care.” The same might be said of people with M.E., for whom extra pressures could result in a relapse which requires a higher level of support.³

The Institute of Social & Economic Research has said that the plans “may increase the amount of social care available to some severely disabled people but that it will reduce the income available to meet the weekly costs faced by many more elderly and disabled people living at home.”⁴

Online information provider, Benefits and Work, has initiated a campaign which aims to overturn plans which it interprets as stopping disability benefits and diverting funds to social services instead.⁵ It notes that the Child Poverty Action Group (CPAG) have “had an assurance from the DWP that DLA will not be involved in any reforms” but adds: “However, few disabled campaigners are likely to be satisfied with a private assurance from unnamed officials rather than a government minister. And that still leaves the issue of AA unresolved.”

The Disability Alliance amongst others has adopted a more collaborative approach to the Green Paper, but it still has concerns.⁶

Implications for people with M.E.

Based on the commentary above and statistical data from our Welfare Reform Survey 2008⁷, we would like to highlight the following:

- Many people who receive DLA/AA do not receive care through social services as well. The Green Paper does not make clear what would happen to these people. Would they become eligible for funding through Social Services; lose their benefit with nothing to replace it, or continue to receive DLA/AA.?

411 out of 2760 respondents to Action for M.E.'s Welfare Reform Survey 2008 said that they receive DLA. 40% of the general population receiving DLA/AA would be below the Government's indicative poverty line if this benefit was removed.⁸ This gives some impression of the number of people with M.E. this could effect, and how severely.

- According to our Welfare Reform Survey, 15% of respondents had to appeal against decisions made in relation to their DLA. At the moment it is unclear what right of reply people with M.E. will have under the new system, if they are assessed unfairly by people who do not fully understand M.E.
- DLA/AA is not currently means tested, so those who need it are entitled to it even if they have access to other funds such as savings, or the proceeds of selling their home e.g. to move into a care home. If DLA/AA funding is transferred to social services, where eligibility is currently means tested, this may not continue to be the case
- The Green Paper does not make clear whether the way needs are assessed will change radically. Disability Alliance says, "DLA and AA were intended to help with the higher costs of living disabled people and their families experience." This might mean using it to pay for help with gardening, or to buy chemical free products, for example. These goods and services may make a great deal of difference to a person with M.E., but they may not exist within the social services system.

Will the new assessment system take these types of needs into account? Will the money be apportioned in the same way? Will the assessors understand M.E.? Will the questions be appropriate for those with a chronic, fluctuating illness?

- Some local authorities have put restrictions on how direct payments are spent, whereas DLA can be spent however the recipient wishes. This means that if the local authority became responsible for administering the money, people may not have the same freedom to use it as they see best.

What do you think?

Action for M.E. would like to encourage people with M.E. to comment on any issues relating to the Green Paper which they are concerned about, either by:

- accessing our Future of Care consultation survey at www.afme.org.uk, so that we can represent your views in a formal response to Parliament
- responding to Government direct at <http://careandsupport.direct.gov.uk/greenpaper/>

Action for M.E.
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1 Department of Work and Pensions, Department of Health (2009) *Shaping the Future of Care Together*. London, Stationery Office.

2 <http://www.communitycare.co.uk/blogs/social-care-experts-blog/2009/07/adult-green-paper-could-be-cat.html>

3 <http://www.guardian.co.uk/society/2009/jul/29/attendance-allowance-support>

4 <http://www.iser.essex.ac.uk/news/2009/07/21/threat-to-disability-benefits>

5 <http://www.benefitsandwork.co.uk/news/latest-news/1092-dla-and-aa-fight-back-begins>

6 <http://disabilityalliance.myzen.co.uk/care6.htm>

7 <http://www.afme.org.uk/res/img/resources/No%20one%20written%20off%20consultation%20report%202008%20FINAL.pdf>

8 <http://www.guardian.co.uk/society/2008/feb/06/longtermcare.socialcare1>