

Response to 'Self-sufficient local government: 100% Business Rates Retention', Department for Communities and Local Government consultation

About MND and the MND Association

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.
- iii. There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. 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 groups, and 3,000 volunteers. The MND Association's vision is of a world free from 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.

Introduction

- i. This response addresses question one only, and focusses on the inclusion of Attendance Allowance on the list of proposed responsibilities to be devolved.
- ii. We do not believe that the devolution of this benefit meets the criteria set out by the Department of Communities and Local Government (DCLG) in the same consultation document. We also believe that it seriously risks leaving older people with MND without any kind of government support.
- iii. Our concerns about this proposal are shared by organisations such as the Joseph Rowntree Foundation, the Strategic Society Centre, a range of health and disability charities and the Local Government Association (LGA), with whom the Government has been working in partnership to design this new system of 100% business rates retention. We would like to take this opportunity to add our concerns about the practicality of devolving Attendance Allowance, and the

serious impact it will have on older disabled people. We strongly recommend that the benefit is not devolved.

Devolving responsibilities: Attendance Allowance

- i. In its consultation, DCLG sets out four criteria against which to assess candidates for devolution. The consultation is clear that responsibilities do not need to meet all of these criteria, but that they should act as 'guiding principles to shape discussions' regarding the responsibilities.¹
- ii. We have assessed Attendance Allowance against this criteria and we do not believe that it meets any one of them. Our reasons are outlined in detail below.
- iii. We have assessed the proposal based on the information available, which is limited. We have also offered comments on some of the practical problems that government departments and local councils may face, or some key issues that would need to be addressed, during the process of devolution. We understand from a statement made by Justin Tomlinson MP when he was Minister for Disabled People that there will be a further consultation on the policy details if this proposal proceeds;² we would like to seek additional assurances from the DCLG that this is the case. However, ultimately we believe this proposal should not proceed for the reasons outlined below.

Measuring Attendance Allowance against the guiding principles for devolution

- i. Below we have taken each principle in turn and discussed the extent to which it does or does not meet the criteria set out by the DCLG.

1) Devolution of a responsibility should build on the strengths of local government

- i. This first criterion includes questions around whether there is appetite from local government to devolve the responsibility, whether there is capacity at a local level to deliver services, whether it would remove barriers to other innovative service delivery models and whether it would provide opportunities for integration across services. While local government is capable of delivering innovative, integrated and user-centred services, we do not believe that there is either the capacity or the appetite for delivering Attendance Allowance locally.
- ii. The LGA has been clear that councils do not want responsibility for Attendance Allowance. In its press release in response to the launch of this consultation it said:

*Councils do not want responsibility for administering the Attendance Allowance benefit for older people. Responsibility for administering it would create significant cost pressures for councils whose budgets are already under significant strain.*³

This is an unambiguous statement regarding the lack of appetite for this reform from local government. The Welsh Government has added its own objection to the

¹ DCLG, [Self-sufficient local government: 100% Business Rates Retention](#) (2016), p.16

² Justin Tomlinson MP, [Answer to written question 42341](#) (14/07/2016)

³ LGA, [LGA responds to DCLG consultation on business rates retention](#) (2016)

proposals as well, which would necessitate the devolution of Attendance Allowance to Wales. First Minister Carwyn Jones stated that for the foreseeable future 'it was better to maintain a "unified welfare state for the whole of the United Kingdom".'⁴ We encourage the Government to listen to these objections and the reasons behind them, and follow the advice of local authorities and nations.

- iii. In addition, we do not believe that councils have the capacity to deliver these services to the level required for older disabled people. Nationally administered benefits have been devolved in the past, and there are lessons to be learnt from this process about the impact on local services and local people. The independent review of local council tax support (LCTS) schemes, three years after Council Tax Benefit was devolved to local authority level in England, revealed there were still major barriers to delivery.⁵ It cites financial constraints and local variation in numbers of people eligible as primary problems. It also highlights that the cost of creating systems to manage the associated processes has been significant for many councils, and that because most councils are designing and implementing systems independently, savings from economies of scale are not realised. The report went so far as to say that the barriers faced meant that the benefits of localism were not being realised; 'Councils feel restricted in what they can do; there is the sense that Government has provided localism only where it suits wider Government policy.'⁶
- iv. If the Government's ambition is to create a local-level system of financial support for older people with care needs, who would previously have qualified for Attendance Allowance, then local authorities are likely to face similar problems as were seen with LCTS. Devolving Attendance Allowance would necessitate another round of local spending on new systems and processes. Local councils would have to re-create systems that already work well on a national level at a local one. This could include establishing eligibility criteria and mechanisms for the benefit, recruiting and training new staff teams to ensure there is the right level of expertise available, gathering medical and other evidence, creating fast-tracking systems for people with terminal illnesses such as MND and a means by which carers would still be passported to eligibility for Carer's Allowance and other forms of support. This is a substantial package of work for any local authority, and one which many will find difficult to implement on top of existing pressures. With the experience of LCTS in mind, we do not believe it is sensible, realistic or indeed necessary to ask councils to create these systems and we are concerned about the impact of problems, delays and regional variations on the financial stability of people with MND and their carers. If, however, the Government's ambition is to scrap Attendance Allowance and instead simply pass on the funding to social care, this comes with a separate set of problems, described in more detail later in this document.
- v. Finally, in letters seen by the MND Association from MPs to their constituents, MPs have stated that the decision to devolve Attendance Allowance would mean that 'decisions on precisely how to spend that money to support older people with

⁴ BBC News, '[Wales would 'lose out' if more welfare is devolved, says Jones](#)' (21/01/16)

⁵ Eric Ollerenshaw OBE, '[Three Years On: An Independent Review of Local Council Tax Support Schemes](#)' (2016)

⁶ *Ibid.*, p. 84

care needs would be taken at a local level', which chimes with the ambition expressed under this criterion around opportunities for greater local service integration. However, this does not match with the evidence about who is in receipt of Attendance Allowance, and how they interact with local social care systems. Research by the Joseph Rowntree Foundation demonstrates that over a third (35%) of older people in receipt of local authority-funded social care receive no disability benefit. In addition, only 13% of those in receipt of higher rate awards actually receive local authority social care.⁷ The two systems do not overlap in a way that allows them to be integrated to the benefit of people who need support. The two separate streams increase the reach of support to older people who face significant extra costs as a result of ill health or disability. Cutting one of these streams simply runs the risk of cutting a significant group of older people out of any kind of support. The potential negative outcomes of this are significant, and will be discussed in more detail below.

2) Devolution of a responsibility should support the drive for economic growth

- i. The devolution of Attendance Allowance would clearly have little or no relationship with driving economic growth or meeting local policy targets relating to employment, skills or infrastructure. The proposal does not meet this criteria in any way.
- ii. Indeed, we are concerned that the lack of link between economic growth and changing demands on support systems for older disabled people would put that support at risk. The ageing population and increased life expectancy will most likely see higher levels of demand on Attendance Allowance, although it is difficult to predict demand in part because benefits for older people are so widely underclaimed at present.⁸ The advantage of the current funding of Attendance Allowance as part of Annually Managed Expenditure (AME), administered through the Department for Work and Pensions (DWP), is that this funding can increase flexibly as demand changes. Business rate income, however, will fluctuate depending on the health of local economies. It will be extremely difficult to ensure that budgets for a local version of Attendance Allowance are consistently based on actual need, rather than levels of rates collected, which risks leaving people with eligible needs without support. As the LGA has stated:

[C]ost pressures and applications for demand-led services like Attendance Allowance can go up very quickly whereas it can take much longer for local areas to generate business rates income.⁹

- iii. The Government seems to acknowledge this risk posed by the mismatch between developing patterns of need and resources available from business rates. In the consultation paper, it states that:

If the value of new responsibilities exceeds the increased retained rates receipts, Government would continue to make grant payments to fund the difference[.]

⁷ Joseph Rowntree Foundation, *Disability and poverty in later life* (2016)

⁸ Age UK, *How we can end pensioner poverty* (2016)

⁹ LGA, '[LGA responds to DCLG consultation on business rates retention](#)' (2016)

While it is not yet clear how this would operate in practice, it is clear that it would be difficult to administer accurately. Some local authorities, those with older populations overall, will face significantly higher levels of demand than others, and this demand is likely to change over time. Financial pressures and uncertainty over this form of ‘compensation’ would likely result in local authorities rationing the support available, which will again see people who need support missing out.

3) Devolution of a responsibility should support improved outcomes for service users or local people

- i. As has been touched on earlier, devolving Attendance Allowance would not meet this criterion, and indeed risks leading to worse outcomes for older disabled people and their carers, who may not be eligible for any support under a new system.
- ii. Attendance Allowance is vital to helping people with MND to maintain their independence and enjoy as good a quality of life as possible as they battle a progressive and terminal illness. Indeed, people with MND tell us that they use their benefit to pay for extra clothing, specialist equipment to let them keep up their hobbies and the extra costs of getting out and about with a disability. It is not, and was never, designed to finance social care. It was made clear at the time of its introduction that it was ‘never suggested that [Attendance Allowance] would be enough to provide professional help’, but rather it would be a ‘valuable additional cash resource for the long haul of chronic severe disability for households which... bear the financial burden’.¹⁰ So far, while evidence suggests that it falls short of meeting the needs and significant extra costs faced by older people,¹¹ it does broadly fulfil this policy ambition.
- iii. Social care is in crisis as a result of chronic underfunding; this is a concern that we hope Government will devote substantial parliamentary time to over the coming years in order to find a resolution. However, scrapping Attendance Allowance as a national disability benefit and passing on the responsibility to local government is not a solution. It will not lead to integrated, user-centric, outcomes-focussed approaches to supporting older disabled people, because there will not be the resources to redesign the system in such a way that is able to merge what are two very separate avenues of support. It will simply leave older people worse off.
- iv. We do not believe that service provision can reflect the distribution of need across the country, as the consultation says it should. As already stated, many areas with higher numbers of older people, as well as worse health and wellbeing outcomes, will face higher levels of demand for Attendance Allowance. These areas may also face higher pressures on social care systems, especially where there are also higher levels of deprivation. If Attendance Allowance were devolved locally and simply merged into social care spending, as seems likely given the complexity of creating new systems, there would be considerable geographical variation in demand. It would create a situation where older people were no longer able to

¹⁰ Sir Keith Joseph, House of Commons Hansard, 10/7/70, col. 1013.

¹¹ Joseph Rowntree Foundation, [*Disability and poverty in later life*](#) (2016) pp.15 - 16

seek financial support from the nationally-funded benefit, and would have to turn to social care instead. As the Strategic Society Centre has stated:

Demand for local authority [adult social care (ASC)] may increase as more individuals who would have received [Attendance Allowance] but never applied for council support come into contact with the ASC system. If the transfer of responsibility for Attendance Allowance reduces the reach of support of the Attendance Allowance system, this could reduce the provision of other forms of support, such as unpaid care, that may depend on the availability of Attendance Allowance, and could lead to an increase in demand for local authority ASC.¹²

Whether older people are eligible for local authority-funded care or are self-funders, this will place extra demand on social care systems, which will have to manage an increase in care assessments, advocacy requirements and either funding or arranging social care. If people do not get the care they need when they need it, this has the potential to increase the burden on local health services. Extra demand will be greatest in areas where services are already struggling, and where there is the most limited potential for earnings from business rates.

- v. We believe that there is a significant risk of creating a post-code lottery for people with MND, carers and other older people as a result of this proposal, and because of the geographical variation referred to above. The consultation document states that ‘it is important that local authorities should have as much flexibility as possible to tailor local services.’¹³ This would strongly suggest that local authorities could be left to devise their own scheme for administering Attendance Allowance locally. The current system represents a single, standardised offer to every older person in England, Wales and, for now, Scotland. If the benefit is devolved along these lines, this will no longer be the case. Older people may have access to different levels of support in different parts of the country, be expected to complete different assessments and meet different eligibility criteria, and face different waiting times from one authority to the next. We are particularly concerned about what this will mean for older people with a terminal illness such as MND. There is currently a system in place, called ‘special rules for terminal illness’ (SRTI), which ensures that those with the shortest expected survival time, including those with the fastest progressing forms of MND, are able to access the right level of benefits as quickly as possible. This is vital when a person is managing a swift decline with developing needs that change day-by-day. We are not confident that it is possible for local authorities to replicate this relatively effective, uniform system for people with a terminal illness, especially if every local authority is managing its case load in a different way, and given the high levels of demand many local authorities will face.
- vi. This change would have a direct impact on older people with disabilities, a group with protected characteristics under the Equality Act 2010. It would take away one avenue for accessing support and would in all likelihood leave them struggling to access the second avenue, due to local rationing and restrictive eligibility criteria.

¹² Strategic Society Centre, [Attendance Allowance and local government: examining the evidence and the options](#) (2016)

¹³ DCLG, [Self-sufficient local government: 100% Business Rates Retention](#) (2016), p. 17

This could in turn reduce their independence, have a considerable impact on their health and wellbeing and make it much more likely that they reach a crisis point or move into hospital or residential care. Unless local authorities work with the DWP to resolve the complex issue of passporting for Carer's Allowance, carers will also see their health, wellbeing and independence restricted. Taking away Attendance Allowance from potential future claimants reduces their choice and control, which has a negative impact on their own health and wellbeing, and is likely to cost the system significantly more. Without financial support to maintain independence, engage with communities and social networks and to pay for care in the home, people may experience worse health outcomes or may be forced to move into more expensive residential care, regardless of their wishes.

4) Devolution of responsibilities should be made with consideration for the medium-term financial impact on local government.

- i. Without detail of how the new system would operate, it is difficult to assess the financial impact on local authorities. However, as stated earlier, we believe that the cost of administering and delivering a system of financial support to those who would otherwise have claimed Attendance Allowance, and those carers who would have been passported into receipt of Carer's Allowance as well, will be prohibitive. We have already outlined our concerns regarding the unpredictability of demand, the geographical variation and the potential for creating post-code lotteries and pockets of extremely limited support. Ultimately, we do not believe that local authorities will be able to afford to provide an adequate level of support to older people without imposing severe rationing, and thus cutting people out of the support they need. In fact, it could end up costing local and national government more if more people need to access residential or acute care as a result of missing out on the preventative benefits of Attendance Allowance.
- iv. This year, total spend on Attendance Allowance is estimated by the Office for Budget Responsibility (OBR) to be £5.5 billion. By 2020/21, it is projected to be £6.4 billion.¹⁴ Total projected income from locally collected rates and central list income will be £14 billion, according to the consultation document, although this figure may change according to economic performance.¹⁵ This means that to deliver the same level of financial support to older people as is currently available, local authorities would have to spend up to 45% of their business rates income on a local Attendance Allowance. In reality, the percentage is likely to be a little lower as some of this expenditure will be for people who started their claims before this change comes into force. However, many people who were in receipt of the benefit will have died, while new potential claimants will continue to need support, so it is conceivable that the cost of providing a benefit that offers the same support to older people as Attendance Allowance could quickly reach this proportion of spend.
- v. In addition, total spend for Carer's Allowance is projected as £3.5 billion by 2020/21, an increase of around 35% on this year's figure (£2.6 billion). 295,000 people in receipt of Carer's Allowance are currently in receipt of it because they care for someone who is entitled to Attendance Allowance. Assuming a similar

¹⁴ OBR, [Economic and fiscal outlook](#) (Cm 9212) (2016) p. 144

¹⁵ DCLG, [Self-sufficient local government: 100% Business Rates Retention](#) (2016), p. 12

percentage increase to the increase in total spend, this number could rise to 398,250 in 2020/21. The number in receipt of Carer's Allowance today would be protected from any loss, as the Government has made it clear that no one currently in receipt of Attendance Allowance will lose their entitlement, and so no passported carers will lose theirs. However, that still leaves 103,250 additional carers by 2020/21 who would not be entitled to financial support. Unless councils either create separate systems of support for carers, or are able to establish a robust mechanism by which these carers can still demonstrate they are entitled to the benefit, this is highly likely to place a significant extra burden on adult social care departments which will have to pick up the tab. Departments may need to create alternative forms of financial support for these carers, may face onerous demands on their time to confirm to central Government that someone meets qualification criteria or, in the worst case scenario, it might mean that the unpaid carer is no longer able to provide care, and so the local authority has to arrange care itself.

- vi. Given the extent of the funding challenges that currently exist, we do not expect a devolved system will offer anything like the current level of support, already far less than the actual extra costs associated with disability and ill health as stated earlier, to older people. It simply will not be possible to deliver anything other than a cut in support for older people if this proposal goes ahead. Social care systems are already under significant cost and demand pressures. They are already under-delivering for carers of people with MND, as recent research by the MND Association has found.¹⁶ Cutting Attendance Allowance and removing entitlement to Carer's Allowance will mean the preventative benefits of both are lost, risking in turn further pressure on health and social care services. While Attendance Allowance at the higher rate for one person costs the Government £4,279.60 per year, the average cost of home care for two hours a week is around £11,000, for full-time care during the day may be around £30,000 and for residential care is £28,500.¹⁷ The potential cost of providing alternative social care to people who will not have needed to access it before, for the sole reason of removing Attendance Allowance from the Treasury's books, is huge. This proposal does not offer value for money to the taxpayer, nor does it contribute to the medium-term financial sustainability of local authorities.

Conclusion

- i. As outlined above, we do not believe that this proposal meets any of the criteria agreed upon by Government and the LGA, and as such we do not believe this proposal should be taken any further.
- ii. This proposal could leave a significant number of older disabled people without any kind of support from the state. This should be reason alone to preserve Attendance Allowance as a nationally administered, non-means tested extra costs benefit.
- iii. We urge the Government to listen to charities, the people they represent, the Welsh Government, the LGA and councils themselves, who do not want

¹⁶ MND Association, [Caring for carers of people with MND: how Government can help](#) (2016)

¹⁷ The Money Advice Service, [Care home or home care?](#) (accessed 22/08/16)

Attendance Allowance to be devolved. We urge the Government to leave this proposal out of future planning and development for 100% business rates retention.

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