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# Quality of life and independence 2017 -why Attendance Allowance is so important to blind and partially sighted people

**Final report**

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## Key findings and messages

* Attendance Allowance (AA) is a benefit available to disabled people aged 65 and above to help with the additional costs of disability. It plays an important role in promoting independent living.
* There were 52 respondents to our survey from across England, with greatest representation in the South East, West Midlands and London.
* The gender split of respondents was roughly equal and the majority were in their eighties.
* Around half of respondents lived alone and half lived with a partner.
* 62 per cent of respondents (32 people) received the lower rate of AA and 38 per cent (20 people) received the higher rate.
* Nearly all respondents received help from someone. Most commonly, they received help from a carer who did not live with them (44 per cent of respondents; 23 people). Only three respondents said that someone received Carer’s Allowance for helping them.
* 88 per cent (46 people) received help from a carer/ other person with travel to and from the hospital; 86 per cent (45 people) with housework; and 83 per cent (43 people) with cleaning.
* Levels of support from social services were low, with the majority of respondents (94 per cent; 49 people) saying they received no help from social services.
* Respondents used their AA in a variety of ways. The most common use was for travel to and from the hospital and to and from the doctor (94 per cent; 49 people), suggesting that the payment is particularly important for accessing medical care. Other uses included taxis, the hairdresser, window cleaning, gardening, accessing support in the home and visiting the chiropodist.
* All respondents said that losing AA would make a difference to their lives. The most common example of the impact the loss would have was difficulty of paying for travel and leaving the house, as well as struggling more financially.

## 1. Introduction

1.1 In its December 2015 consultation paper on the local government financial settlement [see note 1][[1]](#footnote-1), the Government announced that it was developing a proposal for the funding for AA to be transferred from the Department for Work and Pensions to the Department for Communities and Local Government, for onward transmission to local authorities in England and to the Welsh Government. (The proposals do not extend to Scotland and Northern Ireland, where different arrangements apply).

1.2 A similar proposal reappeared in the July consultative paper on the projected new business rates regime in England [note 2]. The suggested transfer of AA funding would, under these proposals, form part of these new arrangements for local government finance. Any payments made locally, replacing AA in some form, would become a call on business rates rather than a demand-led social security benefit.

1.3 In other words, the former AA funding would be distributed locally, very likely subsumed into the local authority social care rationing system. But recent research published by the Strategic Society Centre presents evidence suggesting that among AA recipients living at home with some degree of mobility, only about 15 per cent receive any help from local authority social care [note 3].

1.4 The clear implication was that the former AA would be rationed, very likely means-tested and potentially very difficult to obtain for all but the most severely disabled people. This would remove its role in promoting independent living and keeping disabled people out of the more intensive forms of social care.

1.5 Certainly, something needs to be done about social care funding, which is wholly inadequate to cope with existing demand, let alone the challenges posed by an ageing population in the coming years. But this should not be at the expense of AA.

1.6 AA is intended not as an alternative funding mechanism for social care, but to help compensate for the additional costs of disability. As such, it plays a key role in underpinning independent living. There are two rates, depending on degree of disability – £83.10 and £55.65 per week (as of April 2017). There was no realistic hope, especially given local authorities’ very limited powers to raise additional revenue, that business rates would be able to replicate this support.

1.7 Existing AA claimants would have been protected in some unspecified way, but this had no relevance to long-term structure and to independent living in the future.

1.8 There had been a similar attempt to dissolve AA into social care funding previously, in the later stages of the last Labour Government, but the idea was dropped in the run-up to the 2010 General Election, following a vigorous campaign by disability organisations and a Conservative promise not to implement the policy if elected.

1.9 As part of that campaign, the Royal National Institute of Blind People (RNIB) conducted research, in 2009, based on 116 case studies of blind or partially sighted AA recipients [note 4]. A striking feature was the sheer practicality of the use that claimants made of their benefit: “getting out and about” for both daily living and leisure purposes; help with shopping, cleaning, gardening – activities crucial to an independent existence and a decent quality of life.

1.10 Once again, we have found ourselves campaigning, along with other disability and older people’s organisations and disabled people themselves, to ensure that AA remains a national social security benefit, based on clear entitlements [note 5]. And again, our 2009 research has helped us to make the case – it remains just as relevant today.

1.11 However, we also thought it useful to revisit this area of inquiry in 2016, to see if the experiences of current AA recipients seemed any different or if they confirmed the powerful messages of the original research – hence this present report, an interim version of which was used during the recent campaign to supplement and reinforce its predecessor in feeding into the debate.

1.12 In January 2017, the Government responded to the business rates consultation and among other things made the very welcome announcement that the proposal to transfer to local government responsibility for the funds currently intended for AA would not proceed. Local government itself had been clear, through evidence submitted by its representative bodies, that AA should continue as a national benefit, in concurrence with the overwhelming consensus among organisations concerned with disability, social care and independent living. It is good that Ministers were prepared to listen.

1.13 Meanwhile, our recent research findings, supplementing those of the earlier study, remain of interest in illustrating the immensely positive role of AA in promoting independent living among older blind and partially sighted people.

## 2. Methodology of the research

2.1 We invited blind and partially sighted AA claimants, who live in England, to complete a survey regarding their circumstances and their use of this benefit during a telephone interview or via a web-based survey (using the questionnaire website, SurveyMonkey). Potential participants were invited via RNIB networks. A total of 45 respondents expressed their interest to take part in a telephone survey and were subsequently interviewed between 23 May and 23 August 2016. An additional seven respondents completed the web-based survey.

2.2 Respondents were not selected to be statistically representative of the general population of blind and partially sighted AA claimants, but their evidence nevertheless provides instructive insights.

## 3. Characteristics of claimants in the survey

3.1 A total of 52 AA claimants were surveyed (of these, six were carers answering on behalf of a blind or partially sighted person). In this section, we set out introductory information about our respondents.

3.2 Please note that the percentages in these tables are rounded to the nearest whole per cent and may not total 100 per cent.

**Table 1: Gender**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Male | 24 | 46 |
| Female | 28 | 54 |

The gender split of respondents was roughly equal.

**Table 2: Age**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| 65-69 | 1 | 2 |
| 70s | 14 | 27 |
| 80s | 30 | 58 |
| 90s | 7 | 13 |

The majority of respondents were in their 80s, and just over a quarter of respondents were in their seventies.

**Table 3: Location**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| South East | 15 | 29 |
| West Midlands | 9 | 17 |
| London | 8 | 15 |
| Yorkshire and the Humber | 5 | 10 |
| South West | 4 | 8 |
| North East | 4 | 8 |
| East of England | 4 | 7 |
| North West | 2 | 4 |
| East Midlands | 1 | 2 |

All respondents lived in England and were spread across the country. However, the South East, West Midlands and London were more heavily represented, with just over half of respondents living in these areas.

**Table 4: Living situation**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| With a partner/spouse | 24 | 46 |
| Alone | 23 | 44 |
| With adult child/children | 5 | 10 |

About half of respondents lived with a partner or spouse, and nearly as many lived alone.

**Table 5: Rate of AA currently received**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Lower AA | 32 | 62 |
| Higher AA | 20 | 38 |

The majority of respondents received the lower rate of AA (at the time, £55.10 per week).

## 4. Help received by claimants

4.1 We asked about help from various sources.

**Table 6: What help does the respondent receive?**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Help from people/carer(s) who don't live with you | 23 | 44 |
| Help from both people/carer(s) who live with you and who don't live with you | 14 | 27 |
| Help from people/carer(s) you live with | 12 | 23 |
| No extra help | 3 | 6 |

Nearly all respondents received help from someone, most commonly from a carer/ people who did not live with them. This reflects the high proportion of respondents who lived alone (see Table 4).

Although three people responded that they had no extra help, this figure dropped to 1 when specific types of help were prompted (see Table 7.)

**Table 7: Type of help received**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Travel to and from the hospital | 46 | 88 |
| Help with housework | 45 | 86 |
| Cleaning | 43 | 83 |
| Help with shopping | 43 | 83 |
| Driving you to places | 43 | 83 |
| Secretarial help (reading mail etc.) | 36 | 69 |
| Help with collecting/help with taking medication | 28 | 54 |
| Washing/ironing clothes | 27 | 52 |
| Cooking/preparing food | 27 | 52 |
| With appearance or dressing/undressing | 23 | 44 |
| Gardening | 1 | 2 |
| No extra help | 1 | 2 |
|  |  |  |

A high proportion received help with being driven to places, and travel to and from hospital. Nearly all respondents received help with cleaning, housework, and shopping.

4.2 Very few respondents said someone received Carer’s Allowance for providing them with help.

**Table 8: Receipt of Carer’s Allowance**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Yes | 3 | 6 |
| No | 49 | 94 |

4.3 The overlap – or lack of it – between social services support and AA has been an important feature of this debate.

**Table 9: Help received from social services**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Receives help | 12 | 23 |
| Receives no help | 40 | 77 |

In contrast to the help received from carers, the overall level of support from social services was low. Approximately, four fifths of respondents said they received no help.

Help for the remaining eight respondents included hand rails, aids and equipment to help make things more visible (for example, painted stripes to provide more contrast) or more tactile (for example, “bumpons” or raised stickers), mobility aids such as a white cane, low vision aids, liquid level indicators, anti-glare sunglasses, talking aids, emotional support and chiropody.

## 5. The uses claimants make of AA

5.1 Respondents were asked to indicate from a list of pre-set options what they used their AA for. They were also given the option to add further uses if not already listed.

**Table 10: What do people use AA for?**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents | |
| Travel to and from the hospital/clinic | 49 | 94 | |
| Travel to and from the doctor | 44 | 85 | |
| The hairdresser | 42 | 81 | |
| Taxis | 42 | 81 | |
| A window cleaner | 38 | 73 | |
| The chiropodist | 35 | 67 | |
| A gardener | 29 | 56 | |
| Housework/home help | 29 | 56 | |
| A cleaner | 28 | 54 | |
| Social outings/leisure activities | 27 | 52 | |
| Aids and equipment | 26 | 50 | |
| Reading and writing aids | 23 | 44 | |
| Helper's costs for a car | 16 | 31 | |
| Laundry/ironing | 15 | 29 | |
| Help with shopping | 15 | 29 | |
| Gutter cleaning | 1 | 2 | |
|  |  |  |

5.2 The most common use of AA was for travel to and from the hospital, and to and from the doctor, suggesting that the payment is particularly important for accessing medical care. Additionally, the use of taxis for reasons other than medical appointments was also high, indicating that many participants particularly rely on this means of transport (as public transport may not be accessible to them).

5.3 Personal care (such as visits to the hairdresser) was also frequently mentioned, as was the use of domestic help and home maintenance support – such as a window cleaner, gardener or help with the housework.

5.4 Social activities (which help to combat loneliness) were mentioned by about half of participants, suggesting that some claimants are more able to take part in leisure activities as a result of receiving AA.

## 6. Would it make a difference to claimants’ lives if they didn’t get AA?

6.1 The 52 respondents reported unanimously that yes, it would make a difference to their lives not to receive AA. Key themes identified were:

**Not being able to travel**: Just under a third of respondents (n=16) said they would not be able to pay for travel or that it would make it hard to leave the house. For example:

“I would be confined to my house”. Male, 70s.

“The difference would be there would be restrictions on travel”. Male, 70s.

“Yes it would. I wouldn’t be able to go out. I would be stuck at home”. Female, 80s.

**Struggling financially:** Just under a quarter of respondents (n=10) said that they would find life difficult, struggle financially or not be able to pay the bills. For example:

“It would make a difference. I would struggle financially to stay where I am”. Female, 80s.

“We wouldn’t be able to manage”. Female, 90+.

“We would struggle. It helps no end”. Male, 70s.

**Not being able to afford support in the home**: Seven respondents said that they would not be able to afford help in the home, such as a cleaner or gardener:

“I wouldn’t be able to pay for people to help me”. Male, 80s.

“Without the extra support I could not shower, prepare food, and would be at increased danger of falling”. Male, 90+.

6.2 Respondents also mentioned paying for shopping delivery, aids, talking books, and services such as hairdressers. Some also made a more general comment on how they would be affected if they did not have AA, indicating that they would find it difficult to manage, especially due to limited other income :

“It would be awful. It would be like losing an arm. I would miss it enormously”. Male, 80s.

“An enormous difference. Independence, making your own decisions”. Female, 70s.

“A great deal, as I do not have a large pension”. Female, 70s.

6.3 Just under a fifth of respondents still struggled to make ends

meet, even with the receipt of AA.

**Table 11: Even with the receipt of AA, do you struggle to make ends meet?**

|  |  |  |
| --- | --- | --- |
|  | Number of respondents (n=52) | Percentage of respondents |
| Yes | 10 | 19 |
| No | 39 | 75 |
| Prefer not to answer | 1 | 2 |
| Don’t know | 2 | 4 |

## 7. Conclusions and comments

7.1 This report points strongly towards similar conclusions to those reached by the 2009 research. AA is used by blind and partially sighted people for practical purposes that promote independent living in the community.

7.2 For example, if people cannot participate in leisure activities then they may be at risk of isolation, which in turn potentially increases the risk of depression.

7.3 Similarly, if people are unable to travel to their hospital or doctor’s appointments, then they may be unnecessarily placing their health or treatment at risk.

7.4 Or inability to afford home maintenance may create or hasten the need for residential care.

7.5 Many participants also indicated that would struggle to pay their bills without AA.

7.6 Correspondingly, the loss of AA for future claimants and the substitution of cash-limited, rationed options through social care would not be expected to lead to an effective alternative system, given the limited social services role found both in our research and the wider evidence [note 6]. Social care spending has increasingly focused on the most severe disabilities, not upon the wider role of supporting independent living in the community and (given the pressures on local authority finances) there is no reason to suppose that this would change.

7.7 The proposed change would therefore have amounted to a major setback for independent living on the part of older disabled people, would probably affect those with visual impairments disproportionately (as they tend to be particularly marginalised by social care rationing) [note 7] and could only have exacerbated the overload on more intensive forms of social care support and on the National Health Service.

7.8 As noted in section 1 above, the decision not to proceed with that proposal has consequently been widely welcomed.

## Notes

1. **The provisional Local Government Finance Settlement 2016-17 and an offer to councils for future years – consultation**, Department for Communities & Local Government, December 2015, para.1.4.

2. **Self-sufficient local government: 100% business rates retention**, Department for Communities & Local Government, July 2016, p.19.

3. J. Lloyd, **Attendance Allowance and local government: examining the evidence and the options**, Strategic Society Centre, July 2016, p.13.

4. G. Fimister, **Quality of life and independence**, RNIB and Visionary, 2011.

5. G. Fimister, **Submission by organisations of and for visually impaired people to the Department for Communities and Local Government consultation on 100% business rates retention**, September 2016.

6. See table 9 and note 3 above.

7. C. Byron, M. Blake & S. Bridges, **Secondary analysis of adult social care data: what can the data tell us about blind and partially sighted care users?** RNIB/ NatCen Social Research, 2013.

## Acknowledgements and further information

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1. Notes are at p.17 below. [↑](#footnote-ref-1)