

Summary of findings from Age UK's survey of disabled older people who receive Attendance Allowance

September 2016

Introduction

The Government is asking for views on transferring support currently provided to disabled older people through Attendance Allowance (AA) to councils in England, as part of a consultation on business rates. Currently 1.23 million people age 65+ in England receive AA, so although the consultation says current recipients would be protected any change could have major implications for disabled older people who need support in the future.

So far, the Government has not provided any information about the likely impact of any change. However, academic analysis shows that AA is currently well targeted on the poorest and most disabled older people¹ and other reports and anecdotal evidence demonstrate the important role it plays. For example, qualitative research commissioned by the Department for Work and Pensions (DWP) and published in 2010 looked at AA and Disability Living Allowance (DLA), and concluded:

Findings showed a wide range of ways in which DLA and AA are currently enabling elderly and disabled people to afford to pay for services and items they need (Section 7.1.3). The benefits have preventive roles in helping people avoid moves into residential care or nursing homes, and maintaining or avoiding deterioration in health.²

Age UK has previously asked older people about the impact that claiming AA and other benefits have on their life³ and in the light of possible reforms we decided to look at this again. We wanted people to tell us how they spent their AA and explain, in their own words, what impact it has.

¹ *Disability and poverty in later life*, Ruth Hancock, Marcello Morciano, and Stephen Pudney, 2016.

<https://www.jrf.org.uk/report/disability-and-poverty-later-life>.

² <https://www.gov.uk/government/publications/the-impact-of-disability-living-allowance-and-attendance-allowance-findings-from-exploratory-qualitative-research-rr649>.

³ For example *Transforming Lives - tackling Poverty and Promoting Independence and Dignity through Information and Advice* Age Concern, 2008.

Overview and key points

We received over 550 responses to our survey of disabled older people who receive AA. People told us they used it for a wide range of expenses linked to their disabilities. These include: practical help and support at home, transport for essential trips, higher every day costs such as extra heating, and disability equipment.

Some people used the allowance to help with their care needs. This can be through formal payments to carers or by meeting the costs of family and friends to enable them to provide care and support.

Many people told us that AA made a very big difference to their lives, enabling them to stay independent at home, easing financial worries, and improving general wellbeing and peace of mind.

These findings need to be seen in the context of Age UK and other analysis and our professional experience on the ground all pointing to it becoming more difficult for older people to access care and low level support services. This is not surprising, given the well documented gap between the rising demand for such services from an ageing population, and levels of investment that have failed to keep pace.⁴

In addition, local Age UKs report that in many localities low level support services like lunch clubs and day centres have either had to raise their prices considerably, scale back or quite often close altogether.

Most AA recipients do not receive council care services and only around one in seven of those who responded to our survey were receiving this type of support. Most of the comments we received from those who had approached their council for help were negative about the process and/or the outcome.

Most people did not support the idea of contacting their council for help instead of applying for AA. Many were happy with the system as it is, while others had negative views or felt funding pressures would mean there would be less support available.

Overall, the findings emphasise how important AA is in providing choice and control that helps older people to stay independent and Age UK is firmly of the view that transferring resources to councils instead of retaining a centrally-maintained cash benefit would deny future disabled older people vital support. More information about Age UK's views is set out in our response to the Department for Communities and Local Government's consultation.⁵

⁴ http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Briefing-The_Health_and_Care_of_Older_People_in_England-2015-UPDATED_JAN2016.pdf?dtrk=true

⁵ *Age UK's response to the DCLG consultation - Self-sufficient local government: 100% Business Rates Retentions*, Age UK, 2016.

About our survey

To gather information, we produced a questionnaire aimed at disabled older people receiving AA which was mainly distributed through local Age UK Information and Advice services in England. This asked a range of questions covering areas such as: benefits received, what people spend their AA on, the impact it has on their lives, the difference it would make if they no longer received it, their contact with council services, and their views about approaching their local council for help. This paper summarises the main findings and views using verbatim quotes to illustrate typical responses.

We are extremely grateful to the older people who took part in the survey and to the local Age UKs which distributed it for us.

About the people who responded

We received over 550 responses. While we cannot say whether the responses are typical of all AA claimants, we can compare our respondents with national data on gender, age, receipt of care services and entitlement to benefits. Some of the main points are given below and there is further information in the appendix.

- Nearly half of the people in our survey were aged 80-89. This is in line with national AA data. However, more of our respondents were aged under 70 than in the national data, and fewer over 90, so we have a somewhat younger age distribution. This is unsurprising as the oldest and most severely disabled older people, including those with dementia, may be less able to respond to a survey.
- Nearly three-fifths of those completing our survey who gave their gender were female compared to nearly two-thirds of AA claimants nationally in England.⁶
- Around one in eight (14 per cent) of our participants told us they received council care services, a figure broadly similar to analysis of national data which has found that between 11 and 13 per cent of people 65+ receiving disability benefits also have social care services.⁷
- Around two-fifths (39 per cent) of our respondents said they were receiving means-tested support (Pension Credit, Housing Benefit and/or Council Tax Support). This is higher than the proportion in the total UK pensioner population which is just over a quarter (26 per cent).⁸ However, we would expect the percentage of AA claimants receiving means-tested benefits to be higher than among the general pensioner population as AA claimants tend to be older, and receipt of AA can increase the likelihood of qualifying for additional support.

⁶ DWP tabulation tool, Feb 2016 data.

⁷ *Disability and poverty in later life*, Ruth Hancock, Marcello Morciano, and Stephen Pudney, 2016. <https://www.jrf.org.uk/report/disability-and-poverty-later-life> and *Public support for older disabled people: evidence from the English Longitudinal Study of Ageing on receipt of disability benefits and social care subsidy*, Ruth Hancock, Marcello Morciano and Stephen Pudney, Health Economics Group, University of East Anglia, 2016.

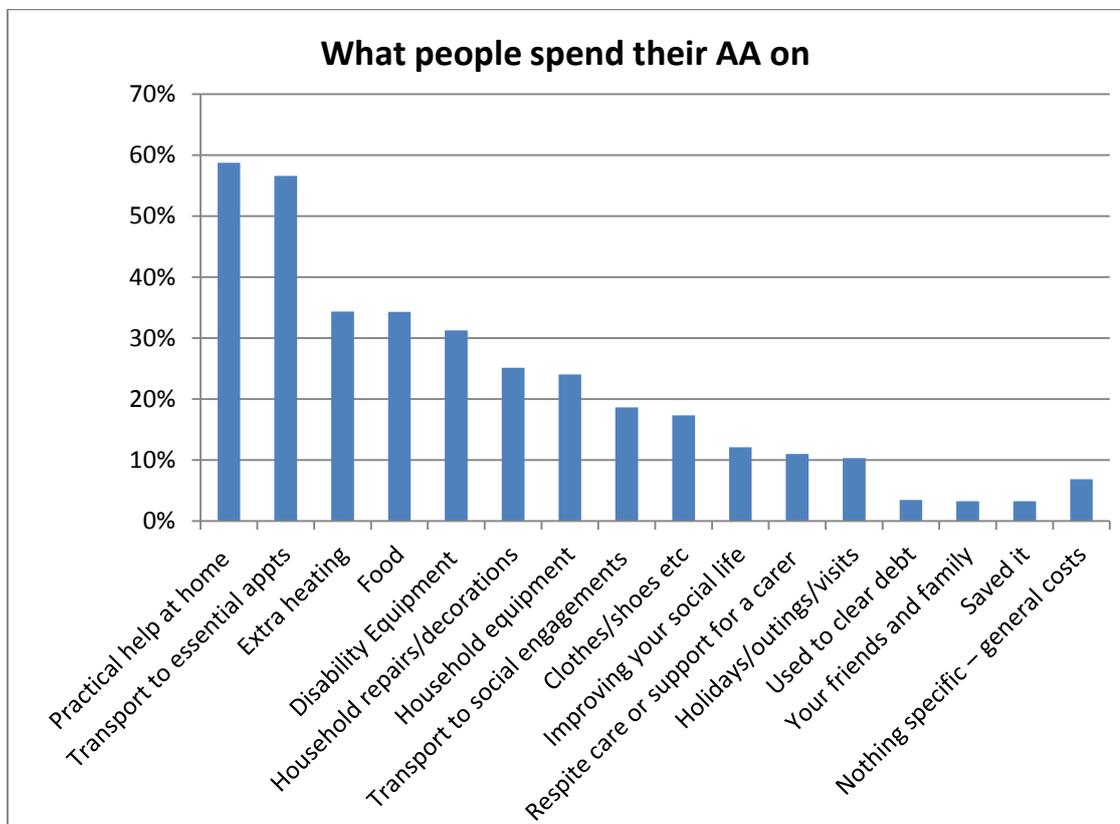
⁸ *Pensioners' Incomes Series 1994/95-2014/15* DWP, 2016.

In conclusion, while our survey mainly covers people who have been in contact with Age UK Information and Advice services, based on the information that we can compare with national data, we have no reason to believe our respondents are particularly unusual.

How do people spend their AA?

Our questionnaire asked people how they spent their AA. As can be seen from the chart below, only a small proportion said it was used for general costs, with everyone else giving one or more specific items. Even when people were spending their allowance on everyday costs such as food and clothing there were often reasons linked to their health and disabilities that resulted in the need for additional spending. The most common items of spending, each cited by over 30 per cent of respondents, were:

- Practical help at home
- Transport to essential appointments
- Heating
- Food
- Disability equipment.



Age UK survey 2016 – 553 respondents

In addition to indicating the categories of spending from the list we provided, over 100 people added a comment about what they spent their money on, and 460 people responded to an open question on the difference that receiving AA makes to them (see below). From these we gathered more information about how people use their allowance on a day-to-day basis.

Practical help at home

Nearly three-fifths of people said they put their AA towards practical help at home. Many described paying for someone to help with tasks such as cleaning, shopping, and gardening. It was clear that people see this support as essential to enabling them to continue to cope at home, as well as for their general well-being.

As I have fallen over several times I cannot tidy my garden, cut the lawn etc. and it makes me miserable, not being able to look out and see it tidy. Same with my housework. I am afraid of falling and don't want to go into hospital. I haven't much puff! But I want to be independent. (Female 80-89)

Keeps me independent in my own home. I couldn't afford the extra heating costs, prepared meal service, or have my house cleaned and gardening done. (Female 60-69)

I wouldn't be able to afford to pay for a cleaner or gardener as we're only on basic pensions. We are able to eat better food; I get too tired looking around for bargains. (Female 80-89)

A few people mentioned the need for help with additional laundry being a particular concern due to incontinence. People may also need to pay others to do work in the house such as decorating and carrying out repairs, which previously they would have done themselves.

A big difference as I am not able to do housework and I pay my cleaner with this. I am incontinent and go through a lot of clothing and bedding due to washing so much. (Female 70-79)

I would find it difficult to be able to pay a cleaner or gardener or handyman/decorator to do the things I used to be able to do myself, because of my disabilities, I am unable to do them myself. (Female 80-89)

Care services and other health-related services

Many of those completing our survey will be receiving informal support from friends and relatives and some will be paying for services. Around 40 people gave comments about

the care services they paid for. This was mainly for carers who came to their home, although two respondents mentioned going to a day centre, and four said their AA helped them with their care home fees.

I employ a carer every day to help with the shower and dressing and housework. (Female 80-89)

One day per week at a day centre. (Female 70-79)

It helps me to pay for my carers, as I live independently. Have carers 3 hours a day and my family care for me 21 hours a day, 7 days a week. (Female 80-89)

Several referred to non-NHS health-related services – mainly paying for physiotherapy or chiropody, although others were also mentioned including acupuncture and osteopathy.

Private physiotherapist as NHS give up on you after 12 months, [without AA] I wouldn't get the physiotherapist I need to help me improve after my stroke. (Male 70-79)

A visiting chiropodist. (Female 80-89)

Enabling informal care

Moving to a local system of support would have implications for carers' benefits as eligibility for these benefits depends on the person they care for receiving AA (or other benefits in the case of younger disabled people). This wasn't something we explored in this study as our focus was on the use of AA by older people themselves. However, comments show that in some cases AA is used to enable informal care. The first quote below demonstrates how AA can help people to make their own arrangements, in this case paying a neighbour for support. Other people told us it enabled them to meet the costs that their friends and family incur, or to show their appreciation for support.

Pay my neighbour for help washing/showering and dressing etc. Can't manage without and would need to go into care. (Male 70-79)

My daughter and sons - they care for me and I pay their expenses in caring for me. (Female 80-89)

Also to pay some fuel money to my daughter as she helps me with personal care and takes my heavy washing to do at her home. (Female 70-79)

Transport

Unlike benefits for people disabled before the age of 65 (Personal Independence Payment and its predecessor Disability Living Allowance) AA does not have a component for mobility needs. Our questionnaire shows how important AA is today to help people get out and about, with nearly three-fifths putting it towards transport - most saying they used it for essential travel for appointments. People mentioned visiting their GP, attending hospital appointments or getting to the shops. A few said it helped them run a car but the majority talked about using taxis.

I would find it difficult to get to GP and hospital appointments by public transport - I can get taxis now. (Male 70-79)

I have to get taxis to appointments, couldn't afford this without the extra money I receive. (Female, 60-69).

Helps me to maintain my own car to get to appointments (Male 70-79)

I have difficulty walking and can't carry shopping; the AA pays for taxis to the supermarket. (Female 80-89)

Heating, eating and other everyday costs

Many people receiving AA have restrictions in their mobility or other impairments which mean they need additional heating, while some require special diets or have to use expensive convenience foods because these are easier to prepare. It is therefore unsurprising that around a third of respondents put some of their money towards extra heating and a similar proportion towards food. People may also have less energy or ability to go from shop to shop looking for the best deals – something we know many older people on low incomes who are physically able are very adept at doing.⁹

I am incontinent and need to have the central heating on all day and night. (Male 90-100)

[Without AA] A drastic difference with a much lower standard of living as extra heating would be beyond my means. I am in constant pain and greatly reduced mobility. (Male 80-89)

I would feel sad as the payment helps me to purchase better food which helps with my health. (Male 70-79)

⁹ *Living on a low income* Age UK, 2012. http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Living_on_a_low_income_full_report.pdf?dtrk=true

I would not be able to pay for my morning Care Worker or the special pureed meals that make life easier for myself and my wife. (Male 70-79)

Disabled people may also have to spend more on other everyday items – for example, additional clothing and footwear due to increased wear and tear or specific needs.

It would make it harder for me to buy extra clothing due to having a stoma bag for a hernia. (Male 70-79)

I need special shoes and my condition means I need to have extra heating. (Age 80-89)

Specialist equipment

Nearly a third of people told us they had put their allowance towards equipment to help with their disability. People mentioned help with the cost of an alarm system, aids for daily living and adaptations to the home.

Would no longer be able to buy safety aids, things that would help in everyday living, things that would make day to day living more manageable. (Female 70-79)

Deaf aids, orthopaedic chair. (Male 80-89)

Assistance to fix external rails and building steps to front and rear doors. (Male 80-89)

Only a small number of people completing our questionnaire told us they saved any of their AA but of those who did a couple explained that this was to buy expensive items linked to their disability.

Partially saved towards a stair-lift/mobility scooter. (Male 70-79)

I am saving for extra expensive equipment I will need in the near future e.g. electric scooter to get around more. (Female 70-79)

Social activities and combating isolation

A limited number of people put part of their allowance towards outings and holidays (11 per cent), improving social life (12 per cent) and transport to get to social engagements (18 per cent). Research now clearly shows how loneliness and isolation undermine health and resilience in later life so there are likely to have been positive health benefits

to these older people of them continuing to stay socially connected and enabled to get out and about.¹⁰

[Without AA] I would go out much less often, meet fewer people and become depressed again. (Female 70-79)

It enables me to get out of the house more often, and to visit my wife in the care home. (Male 80-89)

I am not mobile. I can get a taxi to town. I don't feel so isolated. I can have the odd meal out. (Age 70-79)

The impact of receiving AA

We asked some general questions about whether AA had affected different aspects of people's lives, giving them the option to say things had 'improved', or 'not changed'. The biggest positive impact was on their 'ability to live independently' with around seven out of ten saying this had improved.

Unsurprisingly, for the majority, the allowance meant it was easier to pay bills and meet essential costs, while just over half said it had improved their mental wellbeing.

We also asked how receiving AA made them feel. Only 7 per cent said it made no difference, with around three-fifths saying AA made them 'happier/more content' and a similar proportion felt that 'someone is on your side to help'.

What difference would it make if you did not receive AA?

In order to get a picture of the impact AA makes in its current form we asked recipients what difference it would make if they no longer received it (while making clear that the Government has said that existing AA claimants would be protected so they themselves would not lose the allowance).

Over four-fifths (460 respondents) answered this open question. Many referred to the loss of independence with some fearful they would need to move into a home.

Things would be very different and harder. I think I would end up in a home. (Female 80-89)

¹⁰ See, for example, the academic research on loneliness and health referred to in *Later life in the UK*, http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

I have to get taxis to appointments, couldn't afford this without the extra money I receive. I would be imprisoned in my own home, in poverty and vulnerable. I manage to look after myself happily without help from statutory help and being more of a burden. (Female 60-69)

Would struggle to live independent. Be more reliant on family and friends for help to take me to appointments. Need help with cleaning and personal care. (Female 70-79)

Many talked about the items and services they would not be able to afford and the adverse impact on their quality of life. Others explained they would worry a great deal about money and told us about how it would undermine their finances.

Life would be unbearable. I would mentally and physically be unable to cope. It would stop me from getting to healthcare for my problems - I have severe back problems, also hips and knee issues. My family do not live nearby so I have many problems to cope with which the attendance allowance allows me to cope the best way I can as I live alone. (Female 70-79)

I would be devastated. This allowance has changed my life. I no longer lie in bed at night worrying about money and how to cope. I am able to get help in the garden which has been wonderful. I feel more confident about being able to cope with everyday problems. (Female 90-100)

I would have to do without extra food and heating and find it hard to keep my doctors and hospital appointments. (Female 70-79)

Many simply said things such as 'a big difference' or 'miss it very much' while others told us about the overall impact on their life, or how it would make them feel.

More worry, more stress. (Male 70-79)

I would get very depressed about my situation. (Male 70-79)

AA eases the mind. (Male 70-79)

Of all the hundreds of comments we had, just two people said it would have little or no affect.

Age UK's comments on how people spend their AA and the difference it makes

AA is a benefit to help with the extra costs that disability brings. It is up to individuals to decide how to use it, but the feedback we have had through our survey shows how extra costs can fall into three main categories:

- The need to pay others for care, support and practical help at home. This can be paying for formal care services, help with expenses of friends and families or paying for jobs in the home that people are no longer able to do themselves.
- Specific disability-related items such as non-NHS medical items, and disability equipment.
- The need to spend more on some normal everyday costs. Paying more for transport and extra warmth are common concerns and, depending on people's disabilities, they may have higher laundry costs, need special diets or have to spend more on items such as clothing.

Needs vary between individuals, and from week to week, but life is likely to be more expensive for everyone with the level of disability that qualifies them for AA. The feedback we received emphasises how important the allowance is and how some people feel it makes all the difference to whether they can continue to manage living independently. Comments show it is valued because it provides choice and control. It is difficult to see how any system involving a council assessment of need could provide support in a way that is as flexible or gives individuals the same sense of control over their lives.

When we compare our current findings with a similar survey we carried out in 2007-08 we find many similarities.¹¹ For example, practical help at home again was the top item with extra heating and food also high on the list. However, the 2016 survey found a much higher proportion of respondents spent some of their benefit on transport. Over half (56 per cent) said they used it to get to essential appointments, compared to just 13 per cent who used it for any kind of travel in our earlier survey. Using the allowance to buy disability equipment was also higher in the current survey – 31 per cent compared to 21 per cent previously. This may reflect the fact that some support, such as transport to hospital, is now harder to access in many areas because of funding constraints, placing more onus on the individual to make their own travel arrangements.

Approaching the council for help

We were interested to know if the people who completed our survey had been in contact with their council for care support. Around a fifth said they had, and about one

¹¹ Unpublished data on what AA recipients spent their money on in 2007-08. Collected as part of survey covered in *Transforming Lives - tackling Poverty and Promoting Independence and Dignity through Information and Advice* Age Concern, 2008.

in seven (14 per cent) said they received services – the most frequently mentioned being home care. These figures are very similar to the national information we have and show that the large majority of older disabled people receiving AA manage without any formal care or support services.

We used an open question to ask about people's experiences. Most of those who had applied for help added a comment so we have feedback from around 100 people.

The majority, of the comments were mixed or negative. Many criticised the process, saying it took a long time or it was difficult to navigate, even if they ultimately received support.

Long, drawn out process by people who do not fully understand a disabled person's care needs. (Female 60-69)

Not good. Long wait, inefficiency, confusion. (Female 90-100)

Successful, but a long and complicated process because of all the different agencies involved. (Age 70-79)

Others said they had been refused help or had been told that they should arrange it privately, while a few had received a service but had not found it satisfactory. The comments below are typical of those we received illustrating these points.

They do not have enough carers and have too many clients - they could not help. (Female 80-89)

They sent me a list of commercial companies/organisations, several of which were condemned by old/disabled friends. I am still examining the market. (Male 80-89)

OK, however the carers don't come at the times I would like. They have too many people to see. I asked for a lunch-time visit but they are unable to accommodate this. (Female 80-89)

Around a third of comments made were positive. Many were quite general, for example just saying things such as 'good' or 'very helpful' while others described the services they received. Some examples are given below.

We had good care for six weeks after my husband was in hospital. (Female 80-89)

We have been helped with carer's costs since leaving hospital. This was arranged by the social worker. (Male 70-79)

An assessment for a handrail by the front door and back garden door - a good service from the council. (Female 80-89)

Approaching the council instead of the current system

The Government has said that those already in receipt of AA will be protected, so even if there are changes these would not apply to people who completed our survey. However, we were interested to know how they would feel if the system was different so we asked if people would be happy to contact their council for support such as AA. Many said they were 'not sure' - (perhaps unsurprisingly as they were already receiving AA) but of the others, around a third said 'no' compared to about a fifth who said 'yes'.

Nearly 250 respondents added a comment. Even including comments made by those who said they would be happy to contact the council, fewer than ten were entirely positive. Many said they were happy with the system as it was. Others said they would contact the council 'if it was necessary' and a few said it would be alright only as long as they got the same amount of support.

Nicer to keep it the way it is because I have more control over this. (Male 80-89)

I am very happy without my council being involved with anything to do with my care. (Female 60-69)

When I get my AA I can decide which is the most important and essential things I want to do with it and some weeks it varies. If I had it from the council they would decide how it was spent. (Male 80-89)

However, over half of the comments showed concerns about approaching the council for support. Some were linked to poor experiences in the past when asking for help, while others reflected more generally negative views about their local council.

They are reluctant to put services in place and are always trying to save money and cut corners. (Male, 70-79)

They are bad enough getting a blue badge and bus pass. Please don't inflict this on us. Life is hard enough as it is! (Male, 70-79)

Once the council get hold of things they tend to go pear-shaped. (Female, 70-79)

I am not sure how helpful they would be as I trust the present system much more than the council. (Male, 70-79)

Quite a few people expressed a general reluctance to contact their council for reasons including pride and concerns about privacy.

I would be too embarrassed [to go the council]. Incontinence is not a subject one can discuss easily. A lovely nurse from Age UK originally came to see me. I was very fortunate. The nurse explained why I needed Attendance Allowance and helped me to apply for it. (Female, 70-79)

I don't want them knowing all my business. (Female 80-89)

There would be no point as the benefit would be means tested as soon as it would be transferred to the council. I would prefer to die proud than a beggar to the council. (Female, 70-79)

Others were concerned about the ability of councils to manage with the additional responsibilities, and over 30 people specifically referred to the funding pressures on councils. Some people felt support would be harder to get, would become means-tested, be less fair or result in people having less control.

The local council is so overwhelmed with the needs of the increasing amount of people needing help. (Female, 70-79)

I would prefer it if it could stay with DWP [my] council has made so many cut backs with ever more threatened. I do not feel they would be able to afford to make AA payments which I need to keep my independence. I believe it is the responsibility of the DWP to provide this support. Our council have had to cut back on services due to cuts in funding from the Government. (Female, 90-100)

I have the greatest respect for the council but they do struggle each year against funding cuts. These obviously have to be passed on - please, not to the elderly and infirm! (Female, 80-89)

It would be means-tested and as usual I would miss out. (Male 70-79)

Conclusion

Age UK has long believed that AA makes a big difference to the lives of older disabled people and this has been reinforced by our survey. The feedback we received shows how important it is to maintain the benefit in its current form and in our view, transferring resources to councils instead of maintaining a centrally-maintained cash benefit would deny future disabled older people vital support.

Appendix: Age UK survey respondents

We received 553 responses to our survey, mainly from disabled older people who had received help from local Age UK Information and Advice services. Some of the main demographic information we collected is provided below, along with the national data on age and gender.

Gender and age (and comparison with national AA data)

	% in Age UK AA survey*	% of AA claimants in England**
Female	59	65
Male	41	35
Under 70	10	4
70-79	33	27
80-89	46	48
90+	11	21

* Age data based on full sample of 553 respondents, gender data on 530 respondents as 23 did not give their gender

**DWP tabulation tool, Feb 2016 data

Ethnicity: 93% of respondents described themselves as White British. We also had responses from people from eight other ethnic groups, the most common being: White Irish, Caribbean and Indian.

Region: We had responses from all English regions although we do not have a full breakdown.