

Attendance Allowance receipt and evidence of disability in ELSA

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1 A contentious finding: the low measured rate of disability among AA recipients

The English Longitudinal Study of Ageing (ELSA) is a nationally representative panel collecting data on health and disability and the financial circumstances of people aged 50 and over and their partners living in private households in England. Surviving sample members living in residential addresses in England were re-contacted every two years, tracking changes in their health and economic circumstances over time through face-to-face interviews, self-completion questionnaires and nurse visits (available in waves 2,4 and 6).

The analysis in this note relates to the set of respondents in the core ELSA wave 6 sample of over-65s, who report receiving Attendance Allowance (AA). A (weighted) proportion of 40.7% (95% confidence interval: 35.8% - 45.7%) of these 391 cases report no difficulties with “activities of daily living” (ADLs). The relevant question in ELSA covers both ADLs and “instrumental activities of daily living” (IADLs). The ADL/IADL question is worded as follows and uses a showcard to elicit responses.

Here are a few more everyday activities. Please tell me if [^you have / [^name] has] any difficulty with these because of a physical, mental, emotional or memory problem. Again exclude any difficulties you expect to last less than three months. Because of a health or memory problem, [^do you / does he / does she] have difficulty doing any of the activities on this card?

INTERVIEWER: PROBE - 'What others?'...Code all that apply.

- 01 Dressing, including putting on shoes and socks
- 02 Walking across a room
- 03 Bathing or showering
- 04 Eating, such as cutting up [^your / his / her] food
- 05 Getting in or out of bed
- 06 Using the toilet, including getting up or down
- 07 Using a map to figure out how to get around in a strange place
- 08 Recognising when you are in physical danger
- 09 Preparing a hot meal
- 10 Shopping for groceries
- 11 Making telephone calls
- 12 Communication (speech, hearing or eyesight)
- 13 Taking medications
- 14 Doing work around the house or garden
- 15 Managing money, such as paying bills and keeping track of expenses
- 96 None of these

(Responses 1-6 are regarded as ADLs, while 7-15 are IADLs.)

If we interpret this finding as meaning that over 40% of AA recipients have no significant disability, then it suggests remarkable degree of inefficiency in the targeting of AA on people in need. We would strongly disagree with such an interpretation.

2 Sample selection issues in calculating the rate

Calculations of this kind can be affected significantly by apparently minor changes in the rule used for selecting the sample for analysis, and there is usually no single “correct” sample selection. We investigated some variants of the sample selection.

Some of the ELSA members who entered an institution or moved outside England agreed to be interviewed in wave 6 but they should be excluded from the analysis if the goal is to draw inferences on the population living in private dwellings in England. Among respondents aged 65 and over (5,685), 71 were in an institution at the time the interview took place and 20 had moved out of England. A further 17 respondents responded “*Don't Know*” to the question asking about receipt of Attendance Allowance and 4 responded with a “*Refusal*” or “*Don't Know*” in the ADL limitation questions. In our view, these cases would preferably be excluded from the analysis.

A further 329 sample members aged 65 and over were interviewed by proxy. This often happens for health or disability reasons, so there is a risk of bias if they are excluded. On the other hand, measurement error might be more serious than among respondents who provided a full or partial interview in person. So there are also some grounds for exclusion of proxy interviews. If we exclude all of these cases, we end up with a sample of 351 rather than 391 AA recipients. The “false” AA claim rate observed in the ELSA is then even higher than the one observed in the whole 65+ sample, at 43.8%.

Thus, sample selection does not appear to be the explanation for the surprisingly high proportion of ELSA AA recipients reporting no ADL difficulties.

3 Comparison with FRS data

The Family Resource Surveys (FRS) is a continuous cross-sectional survey, designed to be representative of UK private households. Covering a large national population sample of around over 20,000 households each year, the FRS collects detailed information on the personal characteristics, incomes and living circumstances of all adults in the sampled households, together with detailed information on their receipt of public support. The survey also includes questions covering functional difficulties with domains of life. The appendix gives the question structure used in the FRS questionnaire.

Figure 1(a) shows the empirical proportion of cases of reported AA receipt where there is a valid response to HEALTH (or HEALTH1, post 2012/13) but where no disability is reported in the question DISDIF (DIS1, post 2012/13), by survey year. This shows a “false AA claim” rate of around 6%, with an outlier of over 10% in the 2005/6 survey¹ and a minimum of 3.4% for 2011/12.

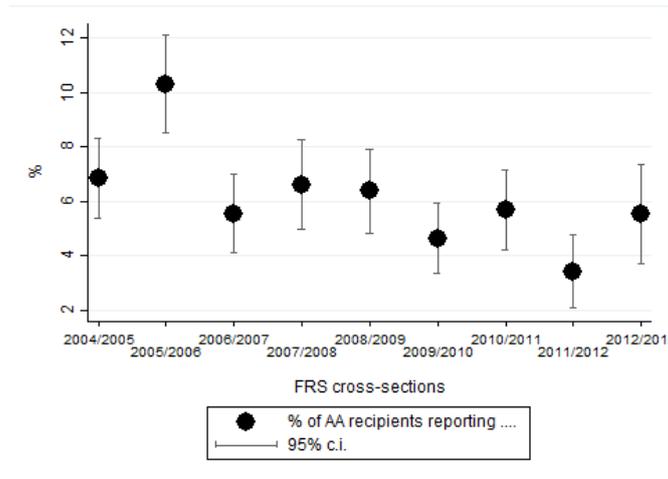
¹ The peak observed in the 2005/2006 cross-section is mainly due to the very high percentages of “false” recipients for the North-East (13%) and North West (21%). In 2004/5, the weighted rates observed among the two regions were respectively 3.6% and 7.6%.

Figure 1(b) shows the empirical proportion of cases of reported AA receipt where a long-standing condition is reported in the response to HEALTH (or HEALTH1) but with no indication of any limitation in the response to HPROB (or CONDITION, post 2012/13). This measure suggests a “false AA claim rate” of around 3%.

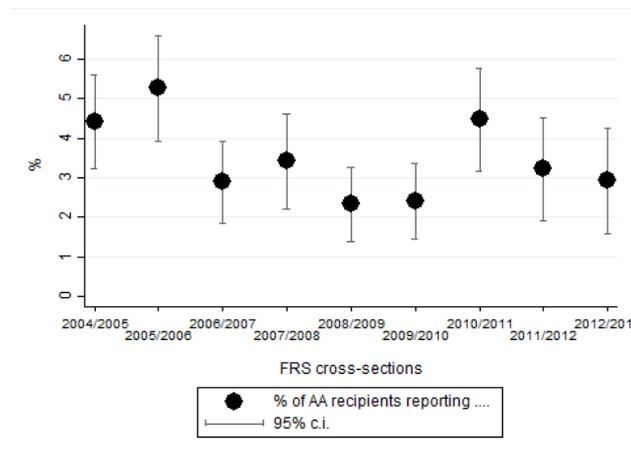
Figure 1(c) instead defines the cases of interest as those where *either* no disability is reported in the question DISDIF (or DIS1) *or* a difficulty is specified in DISDIF (DIS1) but it is reported as non-limiting in HPROB (or CONDITION). This gives a higher estimated “false AA claim” rate of around 8%, with the 2005/6 outlier at 14% and the 2011/12 minimum at roughly 6%.

These rates for the FRS are very much lower than the rate for ELSA wave 6.

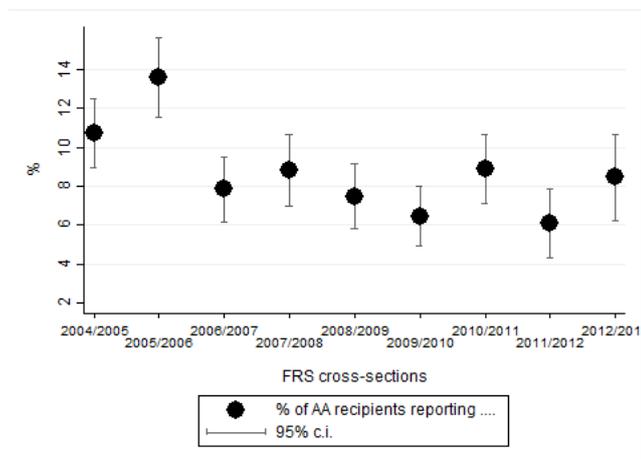
Figure 1 Prevalence of “false” AA recipients in the FRS data (2004/5-2012/13)



a) % AA recipients with no reported difficulties in daily activities¹



b) % AA recipients reporting non-limiting long standing illness²



c) % AA recipients with no reported difficulties in daily activities or some non-limiting difficulties³

Notes: weighted estimates computed over the sample of 65+ living in private dwellings in the UK. ¹ No difficulty reported in DISDIF (DIS1) ² HEALTH (or HEALTH1) = yes and HPROB = no (CONDITION = 3). ³ No difficulty reported in DISDIF (DIS1) or difficulty reported but HPROB = no (or CONDITION = 3)

4 Survey response behaviour and the interpretation of self-reported disability indicators

The sequence of health/disability questions in ELSA wave 6 is very long – when printed out, the CAPI script for the health module runs to 98 printed pages. This module is also likely to be seen as repetitive by many respondents who will not be aware of the subtle distinctions some researchers will make between difficulties with mobility, ADLs, IADLs, etc. Picking out question groups which might reasonably be seen as relevant to measurement of disability, the question sequence used in the wave 6 questionnaire is broadly as follows:

1. Existence of long-standing illness/disability/infirmity
2. Ability to walk a quarter mile
3. Use of equipment/aids
4. Health conditions diagnosed in last 2 years and treatment/medication
5. Falls in last 2 years
6. Joint replacements in last 2 years
7. Pain
8. General mobility question, followed immediately by:
9. ADL/IADL question (see section 1 above)
10. Social care module

The ADL questions come late in the sequence, and may be seen by respondents as repetitive of earlier questions. In particular, the general mobility question which immediately precedes ADL/IADL covers remarkably similar ground:

Because of a health problem, [^do you / does he / does she] have difficulty doing any of the activities on this card? Exclude any difficulties that you expect to last less than three months

INTERVIEWER: PROBE - 'What others?'...Code all that apply.

01 Walking 100 yards

02 Sitting for about two hours

03 Getting up from a chair after sitting for long periods

04 Climbing several flights of stairs without resting

05 Climbing one flight of stairs without resting

06 Stooping, kneeling, or crouching

07 Reaching or extending [^your / his / her] arms above shoulder level (either arm)

08 Pulling or pushing large objects like a living room chair

09 Lifting or carrying weights over 10 pounds, like a heavy bag of groceries

10 Picking up a 5p coin from a table

96 None of these

There are three general issues relating to respondent behaviour. One is that responses to such questions are inherently noisy, perhaps because of the lack of precision in the concept of “difficulty”. Evidence from a randomised experiment and reactive dependent interviewing in the *Understanding Society Innovation Panel* (Jäckle and Pudney 2015) suggests a degree of inconsistency in responses and spurious “churning” of reported health states over time.

A second possible problem relates to respondent burden and the behavioural response that some respondents make to limit that burden. Evidence in the general survey methods literature suggests that this can generate systematic downwards bias in reporting. For example Eckman et al (2014) and Kreuter et al (2011) find evidence that some respondents give strategic responses to filter questions to avoid the burden of follow-on questions. Although the ELSA ADL/IADL

question is not filtered (unlike the FRS disability question), it is preceded by a great deal of similar questionnaire content and respondents may feel that they have already given the required information and take the easiest option of answering “no” rather than concentrating attention on yet another showcard.

A third concern highlighted by the Jäckle and Pudney (2015) experiment is that the reporting of difficulties caused by health problems is influenced by treatment or other kinds of support. For example, if someone has significant care needs but receives help from the local authority or an informal carer to address that need, he or she may not report a difficulty. The ADL/IADL questions do not ask what state the respondent would be in without publicly-provided assistance

In our view, there are important conclusions to be drawn about the way that the concept of disability should be implemented in empirical work. First, any survey indicator of disability should be regarded as noisy, and suitable methods (such as latent variable modelling) that allow for this are to be preferred. Second, it is important to make measurement as robust as possible by looking at a wide range of indicators, rather than responses to a single survey question – again, latent variable methods are a good way of combining multiple indicators. Third, the receipt of support, such as social care or medical treatment, may be a good indicator of disability and also an explanation of some degree of under-reporting of ADL difficulties.

5 Exploiting other disability information in ELSA

ELSA wave 6 contains a very large amount of other information relevant to health and disability. We have pointed out how this might interact with respondents’ behaviour to produce downward bias in reported ADL difficulties, so there is a case for using a much wider range of ELSA information.

Table 1 shows the outcome of a sequential procedure of eliminating from the group of cases with an apparent false AA claim those for whom there is evidence of ill-health or disability from other parts of the ELSA health module. We begin with the 159 cases that, on the basis of ADL information, appear to be “false” AA claims. If we then successively introduce additional evidence of health or disability problems from other parts of the ELSA questionnaire, this number reduces dramatically – the biggest contributors to the reduction being indications of problems from the IADL options for the ADL/IADL question, and the general mobility question that immediately precedes it. We also find that the remaining group of unresolved respondents give relatively low quality responses to the question on AA receipt – for example, two-thirds of the 15 remaining at the penultimate stage of Table 1 were unable give an amount for the AA award, compared to 24% for all AA recipients.

Table 1 Analysis of health indicators for AA recipients who report no ADL difficulties (ELSA, wave 6)

Additional evidence of disability	No. cases dropped (unweighted)	No. remaining (unweighted)
Number of AA recipients	-	391
ADL difficulties	222	159
Difficulty in recognising danger or taking medication	7	152
Blind/impaired vision *	9	143
Deaf/impaired hearing *	8	135
Illness/physical impairment*	4	131
Impaired concentration/anxiety/other mental health problem *	4	127
Cancer in last 2 years	8	119
Stroke in last 2 years or problem from stroke over 2 years ago	10	109
Chronic diagnosed psychiatric condition	6	103
Hip replacement	4	99
Injury from fall	12	87
Reported mobility problem or other IADL	65	22
Reported work-limiting condition/ long-standing illness/hypertension/fall	7	15
Has adaptations in home (e.g. ramps, stair lift, etc)	6	9

* Reported by interviewer rather than respondent

The receipt of social care services is also a potential indicator of disability. In ELSA, the questions on receipt of care are only asked of respondents who report some ADL or IADL difficulty. Of the 159 respondents who report AA receipt but no ADL difficulties, there are 69 (43%) who report at least one IADL difficulty and were therefore asked the social care questions. Table 2 shows how many of them reported receiving formal or informal care of various kinds. Among AA recipients generally, other evidence (Hancock et al 2015, Table 2) suggests that approximately 11-13% of AA recipients also receive formal social care. In ELSA, the rate of social care receipt among AA-recipient respondents reporting IADL but not ADL difficulties is 4%, but a further 14% receive privately-funded care services. A very high proportion (55%) receive informal care from someone outside the household. Although this is based on very small sample numbers, it does suggest that IADL responses are informative of care needs and should not be ignored.

Table 2 Receipt of care among the anomalous group

Additional evidence of disability	No. cases (unweighted)	%
No. AA recipients reporting no ADL but some IADL difficulties	69	-
Receives formal care at home	13	20.3%
<i>LA-funded care</i>	3	5.8%
<i>no LA-funded care but pays privately for formal care</i>	10	14.5%
Receives care from an informal carer	45	65.2%
<i>co-resident (husband/ wife)</i>	7	10.1%
<i>care only from someone outside the household</i>	38	55.1%

There is also information on ADL difficulties from earlier ELSA waves. Table 3 tracks responses on ADLs (IADLs and all other disability indicators are ignored) provided by the group of 159 respondents who reported AA receipt but no ADL difficulties at wave 6. In each past wave, 19%-26% of the people reported at least one ADL difficulty in each past wave. Overall, we found that almost half (77 out of 159) have reported at least one ADL limitations in at least one previous wave. This cast further doubt on the reliability of self-reported ADL measures at a single point in time.

Table 3 ADLs responses in previous ELSA waves for the anomalous group

wave	Number of respondents	Number of ADL limitations reported	
		none	1+
6	159	159	
5	146	108	38
4	133	108	35
3	121	89	32
2	125	100	25
1	140	113	27

6 Credibility of the finding: the AA application process

Over 40% of the respondents to ELSA wave 6 reporting receipt of AA do not report any form of ADL difficulty. If we interpret this as evidence of poor targeting we are assuming that the response to the ADL question is a fully reliable indicator of disability, while receipt of AA does not necessarily imply anything about disability. The credibility of that assumption requires an evaluation of the AA application process as an assessment of care needs.

The application process for AA currently involves a 31-page form which must be completed, signed and submitted by post. The form asks for a great deal of detail on the nature of the health condition(s) involved; their duration; treatment/medication; reports and test results; past (and future scheduled) spells in hospital or care homes; and any aids or adaptations that are used. The applicant is asked to give contact details for his or her GP, any other medical staff consulted, and any carers or other relevant social or family contacts, who may then be contacted by DWP. The form has questions on the nature of the dwelling and location of sleeping/toilet facilities, followed by a very detailed 15-page section on the exact nature and timing of care needs. A supporting statement is invited from a person who is “most involved with your treatment or care”.

The AA and DLA programmes have a formal system for challenging entitlement decisions made by the Department for Work and Pensions (DWP). There are two stages in the process of challenge. Claimants can request from DWP a mandatory reconsideration which, if successful, may replace or supersede the initial decision. If reconsideration is unsuccessful, claimants can

then appeal to a tribunal, which operates independently of DWP under the auspices of HM Courts and Tribunals Service.

Table 3 gives a quantitative indication of the way these work in practice, for the most recent year for which we have complete data, 2011/12. All claims for DLA are made before the age of 65 and it is perhaps unsurprising that the rejection rate on new DLA claims is considerably higher than that on new claims to AA. There is a much higher rate of challenge to DLA decisions than to AA decisions, but the success rate in those challenges is only slightly higher than the AA success rate. The evidence suggests a tougher regime by DWP for mandatory reconsideration of DLA, with that difference being reversed by tribunals at appeal.

Table 3 Rates of challenge to decisions on new AA and DLA claims, 2011/12¹

	AA	DLA (all ages)
Rejection rate for new claims	20%	56%
<i>Proportion of new claims sent for reconsideration</i>	6%	32%
Success rate in reconsiderations	50%	43%
<i>Proportion of unsuccessful reconsiderations referred to appeal tribunal</i>	39%	86%
Success rate on appeals	26%	39%
Overall success rate on challenges ²	55%	62%
Successful challenges / new claims rejected ³	16%	35%

¹ Source: Hansard written answer HC Deb, 17 January 2012, c644W. ² Successful reconsiderations and appeals as % of number of reconsiderations. ³ This ratio is an upper bound on the success rate in challenges to rejections of initial claims, since some challenges are to the award of a lower rate of benefit rather than the rejection of a claim.

The demanding nature of the application process and high rates of successful challenge (much higher than conventional rates of type I error in statistical testing) suggest a rather rigorous system of claims assessment by DWP – which seems inconsistent with the idea that 40% or more of AA claims in payment are unfounded.

7 Conclusions

In our view, this analysis serves to underline an important proposition: that survey measures of ill-health and disability are inherently noisy signals of “true” disability, for two reasons: the inevitable imprecision in the design of survey questions; and the behavioural response of people faced with long, repetitive questionnaire modules.

Our preferred response to this is to take a broad view over a wide range of disability indicators, and preferably using analytical techniques (such as latent variable methods) that allow for statistical noise in the observed indicators of health or disability.

We do not regard the ADL evidence from ELSA wave 6 as a sound basis for making judgements about the efficiency of disability-targeting by the AA benefit programme.

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Appendix: FRS disability questions

For 2011/12 and earlier:

HEALTH Do you have any long-standing illness, disability or infirmity? By 'long-standing' I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months.

If 'yes' to HEALTH:

HPROB Does this physical or mental illness or disability (Do any of these physical or mental illnesses or disabilities) limit your activities in any way?

DISDIF SHOW CARD E1

Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life? Please read out the numbers from the card next to the ones which apply to you.

PROBE: Which others?

- 1: Mobility (moving about)
- 2: Lifting, carrying or moving objects
- 3: Manual dexterity (using your hands to carry out everyday tasks)
- 4: Continence (bladder and bowel control)
- 5: Communication (speech, hearing or eyesight)
- 6: Memory or ability to concentrate, learn or understand
- 7: Recognising when you are in physical danger
- 8: Your physical co-ordination (eg: balance)
- 9: Other health problem or disability
- 10: None of these

Probe and code at this question all substantial difficulties the illness causes the respondent. This is important to allow DWP to capture and analyse the extent to which disabilities/health problems affect the areas of respondents' lives.

For 2012/13 onwards:

HEALTH1 Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?

1. Yes
2. No
3. Don't know (spontaneous)
4. Refusal (spontaneous)

If 'yes' to HEALTH1:

DIS1 SHOW CARD E1

Do any of these conditions or illnesses affect you in any of the following areas?

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting and carrying objects, using a keyboard)
5. Learning or understanding or concentrating

6. Memory
7. Mental Health
8. Stamina or breathing or fatigue
9. Socially or behaviourally (for example associated with autism, attention deficit disorder or Asperger's syndrome)
10. Other
11. Refusal (spontaneous)

Probe and code at this question all substantial difficulties the illness causes the respondent. This is important to allow DWP to capture and analyse the extent to which disabilities/health problems affect the areas of respondents' lives.

CONDITION Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?

1. Yes, a lot
2. Yes, a little
3. Not at all