



Disability Living Allowance Advisory Board

SPECIAL RULES STUDY

1 INTRODUCTION

1.1 In January 2004 Maria Eagle, the then Minister for Disabled People, asked the Board to undertake a confidential study of the special rules arrangements for Attendance Allowance (AA) and Disability Living Allowance (DLA).

The terms of reference of the study were:-

To examine the current arrangements for processing special rules AA and DLA claims, with particular reference to the adequacy of the current guidance for Medical Services doctors and decision makers, and make proposals, if necessary, for changes to the arrangements and guidance: to investigate the extent to which, if at all, (a) special rules awards of DLA and AA have been made in inappropriate cases (and the proportion of such cases which might qualify for the benefits under the normal entitlement rules), and (b) special rules awards which were appropriate at the time they were made but which might no longer be appropriate (and the proportion of such cases which might qualify for the benefits under the normal entitlement rules) and: to provide advice on:-

- *The circumstances in which it would be generally appropriate to reconsider special rules awards and the criteria to be used in selecting awards for reconsideration: and*
- *Which current special rules awards should be reconsidered.*

1.2 The request explained that such a study was necessary:-

- To consider whether and how the administration of special rules might be improved;
- To throw light on why some special rules awards remain in payment for longer than would appear reasonable;
- To establish whether a need exists for new guidance to be framed for decision makers and medical advisers to enable consistency in deciding and reviewing special rules cases.

2 BACKGROUND TO SPECIAL RULES

2.1 Special rules provisions were introduced for AA in October 1990. The provisions were carried forward without change into DLA upon its introduction in April 1992, and are currently set out in sections 66(AA) and 72(DLA) of the Social Security Contributions and Benefits Act 1992. The objective of the special rules is to enable people with a short time to live to receive immediate help with their disability-related extra costs. The special rules achieve this objective by giving people who are terminally ill:-

- Automatic access to higher rate AA or highest rate of the DLA care component without having to satisfy either the normal “personal care requirements”, the qualifying period (6 months for AA and 3 months for DLA) and in the case of DLA the 6 months prospective test.

- Access to the DLA mobility component (providing they satisfy the normal entitlement conditions and a modified “prospective test”) without having to satisfy the qualifying period.

2.2 For the purpose of the special rules the legislation provides that a person is “terminally ill” at any time if at that time they have a progressive disease and their death in consequence of that disease can be reasonably expected within 6 months.

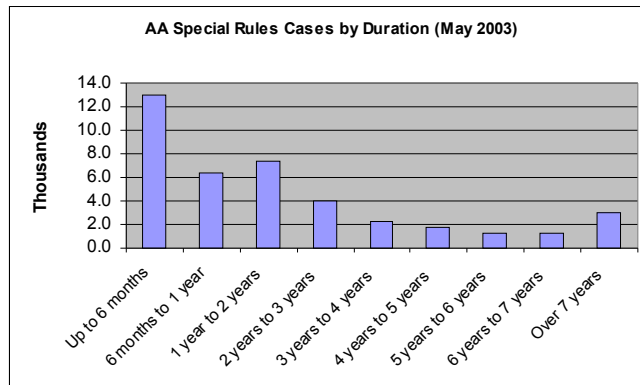
2.3 Claims made under special rules are subject to the normal age limits on entitlement to DLA/AA and to satisfaction of the normal rules as to residence and presence in Great Britain.

3 CURRENT POSITION

3.1 DWP statistical data provided to the Board at the start of the Study showed that at 30 May 2003 over 85,000 special rules awards (of which 45,000 were DLA and 40,000 were AA) were currently in payment. The data also showed that:-

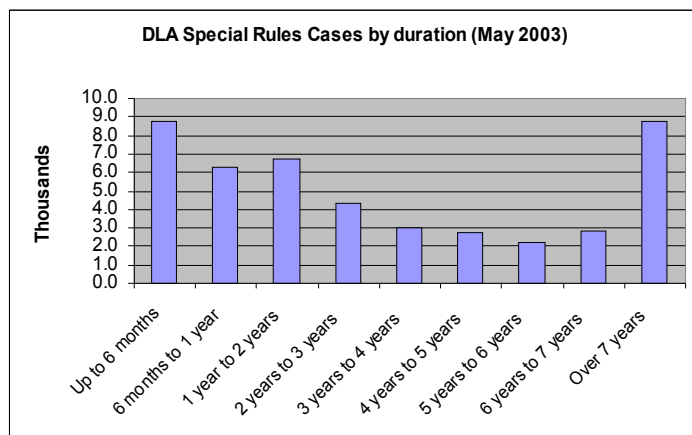
AA SR Cases (thousands) by Duration at May 2003

All	40.0
Up to 6 months	13.0
6 months to 1 year	6.4
1 year to 2 years	7.4
2 years to 3 years	4.0
3 years to 4 years	2.3
4 years to 5 years	1.7
5 years to 6 years	1.2
6 years to 7 years	1.2
Over 7 years	3.0



DLA SR Cases (thousands) by Duration at May 2003

All	45.5
Up to 6 months	8.8
6 months to 1 year	6.3
1 year to 2 years	6.7
2 years to 3 years	4.3
3 years to 4 years	3.0
4 years to 5 years	2.7
5 years to 6 years	2.2
6 years to 7 years	2.8
Over 7 years	8.8



(i) Taking the total special rules awards together (DLA and AA), over 40 per cent (34,000)¹ have been in payment for between 6 months and 1 year, and over 20 per cent (32,000) for between 1 and 5 years.

- **DLA** - 33 per cent (15,000) of DLA awards were in payment between 6 months and one year and 38 per cent (16,000) between one and five years.
- **AA** - 48 per cent (19,000) of AA awards were in payment between 6 months and one year and 38 per cent (15,000) for between one and five years.

(ii) In addition some 30 per cent (14,000) of DLA special rules awards have been in payment for more than five years, of which 64 per cent (9,000) have been in payment for more than seven years. Some 13 per cent (5,000) of AA special rules awards have been in payment for more than five years of which 7 per cent (3,000) have been in payment for more than seven years; and

(iii) “Malignant disease” and “unspecified terminal illness” have always been recorded as the main reasons why people are awarded benefit under the special rules.

3.2 Estimated Annual Managed Expenditure (AME) on special rules awards is over £300 million at current benefit rates.

3.3 Special rules claims are made by the customer (or their representative) indicating in the relevant tick box on the DLA or AA claim form that they wish to claim benefit under the special rules provision. The customer (or their representative) is asked to obtain form DS1500 from their GP or hospital / hospice specialist and send it to the Disability and Carers Service (DCS) together with their claim pack. Form DS1500 is a concise medical report in which the customer’s doctor is asked to provide factual clinical information about the medical condition. Doctors completing form DS1500 are provided with guidance on issuing these reports see Annex 3. In the claim pack the customer (or their representative) is advised that if they are claiming DLA or AA under the special rules provisions there is no need for them to complete the section detailing their care needs. However, if they wish to claim the mobility component (DLA), they are advised that they should complete the relevant mobility section of the claim pack.

3.4 On receipt of the claim form and DS1500, the decision maker seeks advice from a Medical Services doctor as to whether the customer is terminally ill, (i.e. is suffering from a progressive disease and that their life expectancy is likely to be less than 6 months as defined in the legislation). This advice is provided to DCS within one working day. It is usually the case that the decision maker accepts this advice and awards the higher rate care of AA or highest rate care of DLA **for an indefinite period**. In DLA cases the medical adviser may also provide advice as to whether the clinical condition described is consistent with a severe limitation of walking ability. In some cases the medical adviser may be unable to advise on walking ability

¹ All amounts rounded to nearest thousand

because of a paucity of information. If the decision maker is unable to determine eligibility to the higher rate mobility component of DLA on the basis of the information in the claim pack, the DS1500, and medical advice, they will seek further evidence. This is usually a telephone enquiry to the customer, carer or healthcare professional.

3.5 The Disability and Carers Service currently meets its specific target to clear special rules claims in 8 days – DLA special rules claims are being cleared in just over 6 days and AA special rules claims in just under 5 days.

3.6 The Welfare Reform and Pensions Act 1999, removed the statutory wording that allowed a special rules claimant to receive the benefit for the rest of his life, and substituted wording that allowed benefit to be paid only so long as the claimant was regarded as being terminally ill. However, although the powers now exist to review such awards there are **no structured review arrangements** in place or guidance on how decision makers should handle cases which remain in payment for longer than might be reasonably expected from the “death....within 6 months” qualifying criterion.

4 METHODOLOGY

4.1 Following a Board discussion, and by seeking and using the advice and expertise of experienced Board members with research skills combined with the Department’s statisticians, a statistically significant number of cases to be studied were agreed together with a questionnaire designed to collate the relevant information. A small preliminary sample of special rules cases was examined to familiarise Board members with the evidence available including the form DS1500 and to explain the administrative processes. Details of the methodology were submitted to the Minister prior to the commencement of the study.

4.2 The Board considered a total of 200 cases in which the benefit was awarded under the special rules provisions. The files were obtained in the summer of 2004, after the quarterly statistic enquiry at the end of May 2004, when all of the customers concerned were in receipt of benefit. Of the 200 files in the study, 104 claim files were for DLA and 96 were for AA (see Table 1). Also approximately 100 were recent claims (*within the last year and referred to subsequently in this document as recent cases*) and approximately 100 were claims where benefit had been awarded under the special rules provisions over 5 years ago (*referred to subsequently as older cases*).

Table 1

Type of claim at 31 May 2004	
AA claims	96
DLA claims (under age 65)	84
DLA claims (over age 65)	20
TOTAL	200

Table 2 shows a breakdown of the length of time that the award had been in payment for the older cases.

Table 2

Length of time on benefit of the older cases at 31 May 2004	
5-6 years	23
6-8 years	37
8-10 years	36
10 years or more	10
TOTAL	106

For a detailed analysis of the results see Annex 1.

5 DISCUSSION

5.1 The main reasons for the special rules provisions are the speed of assessment, the fact that they enable benefit to be paid immediately, and without the need to serve a qualifying period or to have to demonstrate care or supervision needs. Prior to the introduction of the special rules provisions in 1990, the qualifying period for Attendance Allowance of 6 months meant that very often terminally ill people had died before the end of the period and did not receive the benefit.

5.2 Despite advances in medicine, predicting life expectancy can never be an exact science and this is recognised in the legislation which states “reasonably expected”. Some people will always live longer than anticipated, since the basis of the decision is made on the balance of probabilities. For example the effects of treatment in an advanced medical condition may be uncertain, but if it is more likely than not that treatment will be unsuccessful, the special rules provisions are satisfied, as the person could be reasonably expected to die within the next six months. There will always be a proportion of cases where the decision to award under special rules could be questioned.

5.3 For those who have survived and been in receipt of benefit under special rules for several years, there is a possibility that the initial diagnosis or prognosis was not correct, or the prognosis had improved considerably due to treatment. A person may be in long-term remission or cured; even in some

conditions where it would be expected that they would normally have a very limited life expectancy.

5.4 The Board's study found that some conditions giving rise to special rules claims are very rare and/or an accurate assessment of the prognosis is difficult to determine, particularly some heart conditions, certain neurological conditions, chronic rare conditions in children and uncommon malignant conditions. A breakdown of diagnostic conditions in this study is shown at Annex 2.

5.5. In some of the older claims the decision to award benefit under special rules may have been appropriate at the time, particularly in certain types of condition. However, advances in treatment, particularly chemotherapy for some leukaemias and lymphomas, and other common cancers like breast and large bowel; and highly active anti-retroviral treatment (HAART) for those who are HIV+, has improved considerably the short to medium term outlook.

5.6 With a small sample of cases it was not possible for the Board to draw firm conclusions as to whether the majority of customers would be eligible for care under normal rules at the time of award, or, if eligible, the level of care. (See Annex 1 paragraphs 1.8 -1.10). The major bar to making this evaluation was lack of evidence. Nor is it possible to assume that seriously ill customers will require a given level of care, since there is much variation between individuals and between medical conditions.

5.7 The Board observed during the course of the study that the revised version of form DS1500 (issued early in 2004) is a great improvement on its predecessor. The new form asks for more information than previous versions, is far better focussed, and should lead to more germane information being provided in support of special rules claims. The latest version of form DS1500 and the accompanying notes for doctor's completing the form are shown at Annex 3.

5.8 Where no form DS1500 is provided in support of the special rules claim, the Board believe it is important that some type of recent robust clinical supporting evidence should be required for consideration of the claim.

6 COMMENTS AND RECOMMENDATIONS

6.1 The Board was asked:-

- *To consider whether and how the administration of special rules might be improved;*
- *To throw light on why some special rules awards remain in payment for longer than would appear reasonable;*
- *To establish whether a need exists for new guidance to be framed for decision makers and medical advisers to enable consistency in deciding and reviewing special rules cases.*

6.2 The Board fully supports the principle of special rules, and believes that the current procedures generally work well. The provisions play an important part in ensuring that the benefit gets to people at a time of their greatest need in a prompt and efficient way.

6.3 The Board understands that Medical Services produce evidence based guidance for their doctors, which includes advice about the prognosis of various conditions. Whilst such guidance is welcomed, it is necessary to ensure that it is up to date in a rapidly developing field of medicine, particularly in some of the very specialised areas.

The Board recommends that, for the purpose of addressing the key criteria for entitlement in special rules claims, doctors need access to up to date information about these conditions. If it is not already happening the Medical Services doctors should be encouraged to contact the claimants' oncologist or specialist to obtain advice particularly in the rarer conditions.

6.4 This is important in that the Board concluded that in older cases, sufficient information to accurately determine whether a claim might be considered under special rules was often lacking. The latest version of form DS1500 gathers details of clinical features and treatment but, where this information is absent, the Board consider it important, that it should be obtained, preferably by telephone from the clinician, and recorded.

6.5 The form DS1500 in support of a claim under special rules is usually completed by a registered medical practitioner, i.e. the patient's GP or a hospital specialist and this is the Board's preferred option. However, the Board accepts that nurse practitioners, palliative care nurses and specialist nurses may know a patient very well and can often give valuable information about a patient's condition and treatment to support a special rules claim.

6.6 The special rules provisions have now been in place for over 14 years and the figures produced by the Department (for May 2004) show that some 31,500 people have been in receipt of benefit under special rules for more than 3 years (10,500 on AA and 21,000 on DLA). As explained above, this may be for a variety of reasons including an original misdiagnosis, remission, or people living longer than expected. However, the evidence gathered by the Board does suggest that some mechanism is required to ensure that a

claim that was fast tracked on to the benefit, perhaps some years earlier, continues to satisfy the normal rules for continued receipt of the benefit.

The Board recommends that consideration should be given to reviewing the existing older cases, on a rolling programme, starting with those who were awarded benefit earliest under the special rules provisions. However, the Board recognises that the Department might want to give consideration to exempting certain cases, for example, those of people of extreme age.

6.7 In the future, the Board is mindful that survival rates will vary with conditions and from individual to individual. However, the Board believes action should be taken after a reasonable period of time has elapsed to ascertain whether the normal rules for the receipt of benefit continue to be satisfied.

The Board recommends that where benefit is claimed and awarded under the special rules provisions, the award should be for a fixed period of three (3) years. Towards the end of this period, but not earlier than 2½ years from the original claim made under special rules, a renewal claim under normal rules should be invited. Taken together with the recommendation for the re-examination of the older cases, this should ensure that those receiving benefit under special rules for less than 3 years would not be reviewed.

6.8 In conclusion the Board wishes to reiterate that it fully supports the principle of special rules. These provisions play an important part in ensuring that benefit gets to people at a time of their greatest need in a prompt and efficient way.

ANALYSIS OF RESULTS

1.1 Of the 200 cases, the Board considered that 145 cases (73%) met the special rules provisions on the basis of the evidence available to the Board. Of the remaining 55 cases (27%) where the Board considered the customer would not have qualified under special rules, 49 were cases where benefit had been in payment for 5 years or longer, and 6 were recent cases. In the recent cases the Board expressed the view that there was insufficient evidence to make a judgement.

1.2 In the study the evidence included a DS 1500 report in 166 cases. In 34 (17%) cases no form DS1500 had been submitted with the claim. Alternative medical evidence was available in these cases, from a range of sources including a supporting statement on the claim pack completed by a doctor or healthcare professional, medical reports (including EMP reports), reports from other professionals and records of telephone calls to professionals involved in the customer's care.

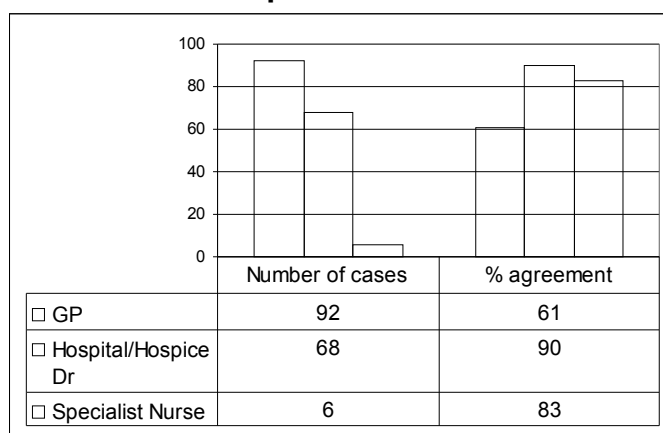
1.3 Although these figures are not statistically significant there is a likelihood that a correct decision in respect of Special Rules (73% agreement) is made if a DS1500 is submitted with the claim. This reflects the fact that doctors are advised to issue a form DS1500 to their patient who they consider is terminally ill. In cases without a form DS1500 alternative evidence requires careful scrutiny to arrive at this judgement. The Board disagreed with the special rules provision in a greater number of cases where there was no DS1500.

Table 3 Availability of Form DS1500

	Board agrees Special Rules	Board disagrees Special Rules	Total
No of cases	145	55	
DS 1500 available	122 (73%)	44 (27%)	166
No DS1500	23 (67%)	11 (33%)	34

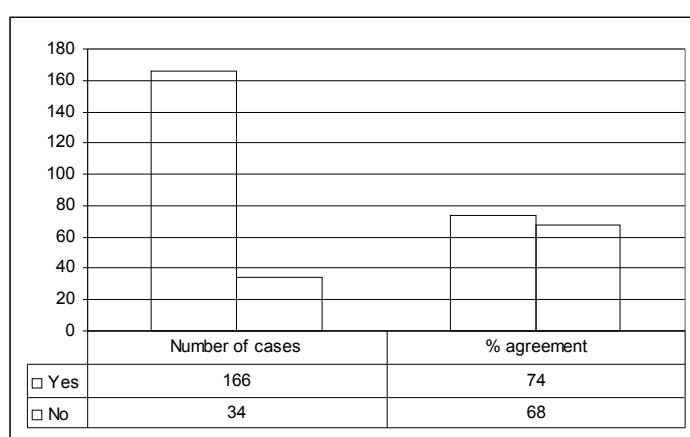
1.4 In those cases where there was a form DS1500 for the Board's consideration, the source of the form DS1500 was recorded. Results as follows:-

Table 4 Who completed Form DS1500?



1.5 These figures indicate that the Board appeared to give greater weight to the evidence where the form DS1500 was completed by a hospital doctor rather than a general practitioner, when considering the appropriateness of the special rules award. No formal evaluation was made in the study of the amount or quality of the information given on the form DS1500, as this was not within the remit. However, the overall impression was that hospital doctors provided fuller information in the report or that it was more up to date. This is not to underestimate the comprehensive relevant information that general practitioners provide in many cases.

Table 5 Further Treatment planned?



1.6 The study shows that in 53 (26.5%) of cases further treatment for the condition was planned. In these cases the Board considered that only 49% of claims were appropriate under the special rules provisions. In contrast in 146 (73%) of cases palliative treatment only was planned. In these cases the Board considered that 82% of the cases would meet the special rules provisions. In one case it was not possible to determine whether any further treatment was to be undertaken.

1.7 One explanation for this is that in cases where further active treatment is planned, the prognosis is less predictable and more variable than in cases where only palliative care is planned. This would suggest that where a claim indicates that further active treatment is planned, an argument could be made for limiting the award and reassessing the case.

Consideration of the sample cases under normal rules

1.8 *The commission asked the Board to consider whether the cases might have been entitled to an award under normal rules at the time of the award.*

In many cases it is not possible to make this judgement since there is no evidence on which to assess the customer's likely care needs. As explained in paragraph 3.3, customers claiming under special rules are not expected to complete the section of the claim pack detailing their care needs. Although it might seem sensible to assume that people who are seriously ill will require a considerable amount of care from another person, it is not possible to judge how much help an individual will require. Indeed modern palliative care techniques are designed to help patients with advanced malignancies, for example, to retain activities and independence for as long as possible. In 106 cases (53%) little or no indication of care needs was available. In the remaining 94 cases (47%) completion of the claim pack was as follows:-

• Care and mobility sections	29	(31%)
• Care section only	24	(26%)
	<u>53</u>	<u>(57%)</u>
• Mobility section only	41	(43%)

1.9 Of the 53 cases where the care section of the claim form was completed, the Board could make a judgement on entitlement for care under normal rules:-

- 15 cases (28%) might have received care at the highest rate (3 AA and 12 DLA)
- 19 cases (36%) might have received care at the middle rate (12 AA at lower rate and 7 at DLA middle rate)
- 6 cases (11%) might have received care at the lowest rate of DLA
- 13 cases (25%) might not have been entitled to any care component.

1.10 Of the 106 cases with little or no indication of care needs, the Board could venture an opinion on care in 54 cases (51%) on the basis of the minimal amount evidence available. In the remaining 52 (49%) cases there was insufficient evidence to make any judgement.

Cases where benefit has been in payment for 5 years or longer

1.11 Of these 49 cases (Annex para 1.1 refers), where the Board thought that the award under special rules was inappropriate, they considered that at the time of the original award a decision on care could be given in 27 cases (55%) but not in the remaining 22 cases (45%). This was because

insufficient evidence was available in the latter group i.e. care section of the claim pack was not completed.

Mobility component of DLA and special rules

1.12 There were 104 claims to DLA in the sample. In 24 of these claims the higher rate of mobility component (HRM) was already in payment prior to the special rules claim, often for a different medical condition, for example, arthritis.

1.13 Of the remaining 80 cases, in 65 cases HRM was awarded at the same time as the special rules claim; in 3 cases HRM was awarded at a later date; and in 12 cases no mobility component award was made.

1.14 Of the 65 cases where there was sufficient evidence to make a judgement on mobility, the Board considered that there might have been entitlement to HRM in 51 cases.

BREAKDOWN OF DISABILITIES IN SR STUDY

1. There were as is to be expected a range of different medical conditions, the majority of which were some form of malignant disease. In the malignant diseases diagnoses, these are shown as the site of the primary tumour.

Malignant conditions		Non-malignant conditions	
Lung cancer	26	Heart disease	10
Breast cancer	18	HIV+ infection	5
Large bowel cancer	18	Rare children's conditions (non-malignant)	5
Brain tumours	15	Motor Neurone disease	2
Prostate cancer	13	Liver disease	2
Ovarian cancer	10	Other non-malignant conditions	3
Lymphomas Including Hodgkins disease	8		
Oesophageal cancer	7		
Stomach cancer	7		
Malignant melanoma	6		
Gynaecological tumours (excluding ovarian)	6		
Renal cancer	5		
Leukaemia	5		
Bladder cancer	5		
Mesothelioma	4		
Laryngeal cancer	3		
Other malignant conditions	17		

Total 200

Doctor's Report for Disability Living Allowance, Attendance Allowance or Incapacity Benefit to accompany your patient's claim under Special Rules

Surname	<input type="text"/>	Address	<input type="text"/>
Other names	<input type="text"/>		<input type="text"/>
Date of birth	<input type="text"/> / <input type="text"/> / <input type="text"/>		<input type="text"/>

Part 1 – Condition

Is the patient aware of their condition and/or prognosis?

What is the diagnosis?

Other relevant diagnoses?

YES NO

If not, please tell us the name and address of their representative

Date of diagnosis?

 / /

Part 2 – Clinical Features which indicate a severe progressive condition. (For example: rate of progression, recurrence, staging, tumour markers, CD4 count and viral load, bulbar involvement, respiratory and/or heart failure, etc.)

Part 3 – Treatment

Is any other intervention or treatment planned which may significantly alter progression of the condition?

Please give details of relevant past or current treatment with

dates including response (if none or palliative please state)

Declaration: the person named above is my patient. This is a full report of their condition and treatment. I have read and understand the notes on the completion of this form and I am satisfied that the form is appropriate. I am the patient's:

Registered General Practitioner

Address or FHSA stamp

Hospital or hospice consultant

Signature

Your name

Phone number

Date

DS1500 (KT/SB)