Knowing and understanding Disability and Carers Service customers

Dr. Janine Hawkins, Dr. Carol Goldstone and Meena Bhagat
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### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AA</td>
<td>Attendance Allowance</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>BME</td>
<td>Black and minority ethnic</td>
</tr>
<tr>
<td>CA</td>
<td>Carer’s Allowance</td>
</tr>
<tr>
<td>CAB</td>
<td>Citizens Advice Bureau</td>
</tr>
<tr>
<td>CTB</td>
<td>Council Tax Benefit</td>
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<tr>
<td>DCS</td>
<td>Disability and Carers Service</td>
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<tr>
<td>DIAL</td>
<td>Disability Information and Advice Line</td>
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<tr>
<td>DLA</td>
<td>Disability Living Allowance</td>
</tr>
<tr>
<td>DWP</td>
<td>Department of Work and Pensions</td>
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<tr>
<td>EMP</td>
<td>Examining Medical Practitioner</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HB</td>
<td>Housing Benefit</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IB</td>
<td>Incapacity Benefit</td>
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<tr>
<td>IBS</td>
<td>Irritable Bowel Syndrome</td>
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<tr>
<td>IS</td>
<td>Income Support</td>
</tr>
<tr>
<td>JSA</td>
<td>Jobseeker’s Allowance</td>
</tr>
<tr>
<td>LD*</td>
<td>Learning difficulty</td>
</tr>
<tr>
<td>ME</td>
<td>Myalgic Encephalopathy (also known as Chronic Fatigue Syndrome)</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>MH*</td>
<td>Mental health</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>MS</td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>Phys*</td>
<td>Physical disability</td>
</tr>
<tr>
<td>Sens*</td>
<td>Sensory disability</td>
</tr>
<tr>
<td>TS</td>
<td>Tribunals Service</td>
</tr>
<tr>
<td>U16*</td>
<td>Under 16</td>
</tr>
<tr>
<td>WFI</td>
<td>Work Focused Interview</td>
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*Used after verbatim quotations to identify customer disability/illness type/age
Summary

Research aim, objectives and method

The aim of the research was to undertake an exploration of experiences of Disability and Carers Service (DCS) customers; those applying for Attendance Allowance (AA), Carer’s Allowance (CA) or Disability Living Allowance (DLA). This exploration included customer journeys before they approach DCS (including benefits’ awareness and information access), and also their experiences of DCS as customers, including claiming, receiving and using the benefits. More specifically, objectives of the research were to:

• determine how disabled people and carers hear about benefits and DCS services, and ascertain the processes by which people decide to make a claim;

• understand how customers actually make the claim and their understanding of whether or not they may be entitled to benefit;

• examine the actual contact process with DCS, and explore customers’ experience of contact with DCS and with other parts of the Department for Work and Pensions (DWP);

• understand the expectations that customers have of DCS and their familiarity with the service and examine experiences of DCS services;

• examine the circumstances surrounding the appeal procedures and understand the experiences of customers using these procedures;

• investigate longer-term issues including what steps recipients should take if their condition changes or if there are changes in their own circumstances or those of the person they care for; and,

• examine recipients’ attitudes towards benefits and how these are used in the context of other services, e.g. social care;

• monitor differences between different client groups (e.g. benefit type, age, gender, ethnicity, impairment type, etc.).
A further aim of the research, to be achieved through delivery of the objectives listed, was to establish if and how customers with different types of disability or health condition differ from each other in their experience of DCS and the claiming journey. The research included recipients of all three disability benefits:

- **AA**, which is payable to those aged over 65 with severe disabilities and personal care needs. AA is paid at two levels relating to the level of personal care required for assistance with bodily functions and the avoidance of danger;

- **CA**, which is the benefit for those aged over 16 who look after someone (for more than 35 hours per week) who is disabled and in receipt of AA or DLA;

- **DLA**, which is payable to people aged under 65 who are so severely disabled that they require personal care and/or have walking difficulties.

A qualitative approach was taken to the inquiry. Qualitative research is inherently different from its quantitative partner; it is not about statistical representation, rather it is about the detailed exploration of experiences and the meanings that participants attach to those experiences. The research findings we present are not based on quantitative statistical evidence, and cannot, therefore, be generalised to all DCS disability benefits customers. Qualitative research was deemed most appropriate by the Department to provide and capture detailed descriptions of customers’ experiences.

One hundred depth interviews were carried out with benefit applicants. These interviews were carried out in person, often in the customers’ homes, and followed an ‘interview’ or ‘topic’ guide to make sure that all issues were explored fully with all interviewees. In order to represent a wide range of the characteristics found in the claimant population, targets for a minimum number of interviews were set for:

- benefit type (i.e., AA/CA/DLA);

- illness/disability type (physical/sensory/mental health and learning difficulty);

- successful and non-successful claims (including award on first application, award after reconsideration/appeal/reapplication, and those who had chosen not to pursue a rejected claim);

- length of award.

The interview guide allowed for the coverage of more than one experience where appropriate: for example, interviewing a mother about both the application for DLA for her child, as well as her own (related) CA claim.

Customer ages ranged from under two to over 90, and the interviewees were selected to include a good selection of other characteristics including gender, ethnicity and geography (interviewing was carried out in 20 locations across England, Scotland and Wales). Interviews were carried out by experienced interviewers from an independent social research agency over a 16 week period between May and September 2006.
As a precursor to the main interview phase, four ‘discussion’ or ‘focus’ groups were carried out with professional advisers who work with benefit customers, to allow insight into the topic and to shape the structure of the interview guide. In the region of eight professional advisers attended each group and were asked to discuss customers’ awareness of benefits, and their experiences of the claims process.

Research findings

Experiences of professional advisers

The professional advisers interviewed as part of this research, had a very good understanding of the claims process and customers’ experience of DCS. Further, professional advisers tended to be positive about their dealings with DCS, and the widely used advisers’ line was considered useful and to be staffed by knowledgeable personnel.

Professional advisers reported their contact with customers coming about in a number of ways: people approaching with either a general enquiry about health or finances, or at onset/worsening of illness or disability, which leads to a benefits claim; customers seeking advice when they have submitted a claim alone which has been turned down; or are themselves approached by professional advisers as part of a proactive campaign because they belong to the organisation’s customer group (e.g. elderly people being contacted through a local community group by Age Concern). On first contact with advisers, customer awareness and understanding of benefits was reported to be poor.

We suggest that as a consequence of their wide experience assisting DCS customers with their claim, professional advisers were well placed to provide an overview of the service they encountered. In our research, advisers reported many positive aspects of the service but also a number of criticisms. In particular, the problems they highlighted related to the inconsistencies in the quality of advice provided by DCS staff, the complexity of claim forms and apparent repetition of questions, the inappropriate use of standard rejection letters and the perception that inconsistent decision making resulted in the rejection of legitimate claims and extended delays before appeals. Professional advisers also believed that customers claiming without professional help would find the process very difficult. These perceptions were consistent amongst all the professional advisers who took part in the group discussions, and the findings of the customer element of this research largely endorse these experiences.

An area in which professional adviser perceptions differed from customers was in relation to the role of the General Practitioner (GP). Whereas customers believed that their GP was the most appropriate medical spokesperson to provide information about their condition and how it affected them, professional advisers felt that a minority of GPs provided inappropriate or ill-considered information to DCS.
Customer awareness

Claimants became aware of AA, CA and DLA from both professional sources (e.g. professional advisers as described already, medical practitioners and government agencies) and non-professional sources (primarily friends and acquaintances).

For some, awareness was brought about at a time of accident or diagnosis, for others, by a change in financial circumstances which facilitated a need to look into sources of benefit assistance.

It was unusual for claimants to be aware of disability benefits before the onset of their illness or disability. Even where such awareness existed, this was of little consequence, there was no trigger that made claimants suddenly think ‘this applies to me now’.

The claims process

There were many factors at play in deciding whether to make a claim, including perceived eligibility, which in itself required claimants to acknowledge their status as ‘disabled’ or ‘carer’. Financial stability had an impact, in terms of how much claimants needed the additional income.

Depending on the source of awareness, the influence of third parties is deemed to play a very large role in the decision to claim, particularly when a professional was involved and could reassure on eligibility, and assist with the application process. This professional involvement tended to increase customers’ confidence that the application would be successful. Whilst it was beyond the scope of this research to investigate whether or not professional involvement was more likely to lead to a successful claim, we suggest that it did have a positive impact on the customers’ perceptions that claiming was the right thing to do, and would result in a benefit award.

In deciding whether to proceed with an application, customers also considered the extent to which they wanted to ‘be on benefits’. This was not always as easy as simply needing the additional income, there was a stigma attached for some with the idea of becoming ‘claimants’.

Customers either made the application almost immediately on finding out that they may be eligible for the benefit, or experienced some form of delay. The source of awareness of benefits and the amount of detail (for example, eligibility criteria) provided at that time had some influence on how quickly claimants made their application.

Delays were caused by concern on the part of the potential customer, including eligibility, pride, whether they thought they deserved the benefit, knowledge, (lack of) confidence and/or a need for reassurance (‘am I doing the right thing?’) Those who waited often needed a subsequent nudge to make the application, which could be anything from weeks to months later.
Impact of a professional

Where customers first heard about a disability benefit from a professional adviser, such as a social worker or voluntary agency adviser, that professional often assisted in the claims process, including form filling and any subsequent stages. We found that such customers tended to ‘trust’ the professional advice that they were eligible, and enjoyed reduced involvement with the application process, as the professional engaged with forms on their behalf.

In contrast, customers completing forms unassisted, had to engage more fully with their application, and many found forms to be complicated and repetitive, which prompted some to seek the assistance of professional bodies. In the absence of professional help, the support of family and/or friends was often found to be useful.

The claims forms

Of the three groups of benefit customers, those applying for DLA appeared to find the claim forms the most daunting. However, we report this within the caveat that other customers had advantages here, namely that AA customers were more likely to have assistance in form filling, and CA customers tended to have been involved in the related DLA or AA claim, and thus enjoyed both the benefit of experience, and also the shorter (in contrast to DLA in particular) CA application form.

Whether applications were carried out alone or with assistance, we noticed that customers found forms to be lengthy and confusing to varying degrees. Some struggled, in particular, with the need to be transparent about the nature of their illness/disability/caring duties, and described how detailing the daily impact of the situation with brutal honesty could feel very negative. This went against the usual mindset of ‘looking on the bright side’. This was particularly difficult for parents completing forms on behalf of children.

Some DLA and AA customers found it difficult to provide a typical example of the impact of their condition, as to focus on a good day may have reduced the likelihood of a successful application, but to focus on a bad day may have been seen as exaggerating.

Those customers with non-physical illnesses/disabilities were more likely than those with mobility issues to have found the forms not relevant in places.

Customer expectations

Customer expectations varied. Once applications had been made, customers often ‘didn’t know’ whether or not they would receive the award. Confidence tended to be lowest amongst those applying for DLA but relatively higher amongst potential AA customers. We believe that AA applicants were more positive as a result of their greater tendency to be advised to apply for the benefit by a third party, and more often than not, be assisted in the application process by someone they had confidence in. Customers of all three benefit types who had professional assistance
in form filling showed the greatest tendency to believe that their claim would be automatic – this was often an inherited attitude from a confident professional who believed in the strength of the claim.

Amongst all three customer types, of those that had the view that ‘I probably won’t be successful’, concerns included accuracy of form filling, uncertainty of eligibility, and a conviction that others were more deserving. As suggested above, when customers were more optimistic that their claim would be successful, this was often down to:

- confidence because a professional helped with the form filling;
- belief that they fulfilled the award criteria; and/or
- knowing a person in similar circumstances who had been successful.

**Award on first application**

Successful customers recalled being informed of their award via a notification letter, usually within the stated time frame after application, indeed, for some customers this was significantly sooner than anticipated. It often came as a surprise to customers that awards were on variable rates, which we suggest is due to their sparse understanding of benefits at time of application. AA and DLA customers who had submitted their claim with professional assistance were more likely to contest an award perceived as ‘too low’ than those submitting claims alone.

Customers not in receipt of a lifetime award tended to appreciate the rationale behind needing to reapply periodically in order to capture any changes in circumstances impacting on their eligibility. However, those with a condition, or caring for someone with a condition, which whilst not terminal, had no potential for improvement, saw periodic reapplication as a waste of time.

**Unsuccessful applications**

With unsuccessful applications we have identified a number of stages that we believe impacted on a customer’s decision on whether to engage in a disputes process, including:

- the customer’s mindset when they first made the claim;
- their reaction to the award outcome; and
- the influence of other people, including friends, family and professionals.

We suggest that it is the blend of customer personality and the impact of these stages that resulted in a customer either accepting the claim rejection, or deciding to appeal.

Some unsuccessful customers who did not appeal simply accepted that they were not eligible. Others, who underwent a more complex process of decision making, ultimately found that the desire not to take the process any further outweighed the desire to have the benefit.
This was a more complex process than it sounds, as it was often not a simple
decision (i.e. ‘I want the benefit, so I’ll go through the next stage’), rather a
process of weighing up complicated and often emotional pros and cons resulting
in a ‘Yes I will, no I won’t’ spiral, until they decided that the process of appealing
outweighed the need for the benefit.

In almost all cases, unsuccessful applicants who chose not to dispute the
decision, completed their original application either alone, or with the help of a
non-professional. Most of these customers simply accepted their ineligibility, and
assumed that this negated any dispute as ‘there’s nothing new to say to prove
eligibility’. Some, however, chose not to proceed to appeal as they did not want to
pursue an application process that had already proved complicated and intrusive.

**The disputes process**

Letters from DCS which inform customers that their application has been
unsuccessful also outline the process of appeal. Where a customer is not satisfied
with the decision, their first port of call is with the original decision-making office,
potentially with additional evidence, at which point the office may have sufficient
information to reconsider and make the award (or increase the rate, if that is the
dispute).

If the award is not reconsidered and awarded, the decision-making office prepares
a ‘submission’ (case summary) that is then sent to both the customer and the
Tribunals Service (TS), for a tribunal hearing to be scheduled. This can be an oral
or paper hearing, and can involve the submission of further evidence from either
the customer or the decision-making office, and either party can attend with
representatives. The process of a tribunal hearing is explained to customers in
several ways: the pre-hearing enquiry form, which the customer submits to the TS
at an early stage, a series of leaflets produced by the TS for appellants, and further,
a clerk greets appellants on the day of oral hearings (if that format is chosen) and
explains the process to them.

In actuality, customers rarely distinguished between reconsiderations and ‘written
appeals’ (i.e. paper hearings via the TS). They described processes that could be
either (reconsideration or an appeal), but invariably referred to both as ‘appeals’.
The lack of mentions of ‘reconsiderations’ suggested that at least some challenges
described as appeals were in fact reassessments by the original decision-making
office. This lack of awareness of the ‘reconsiderations’ stage is unsurprising as, in
an effort to inform customers using Plain English, precise terminology is not used,
and customers are instead informed simply of their ‘right to appeal’.

We found that claimants who did not attend tribunal hearings described the process
as less harrowing than those who went to the tribunal in person. We suggest that
attendance at tribunal was vastly eased when co-ordinated and attended with
professional assistance, and it appeared that the help of a professional at the
initial claim impacted heavily on the decision to take an unsuccessful claim to the
appeal stage.
It was common for tribunals to result in an overturned decision, either the granting of a previously unsuccessful claim, or award at a higher level than previously given. Regardless of the outcome of the appeal, the process was described negatively by appellants.

Customers attending tribunals (in the research sample, largely DLA applicants) rarely felt that this was an independent review, feeling instead that it was an opportunity for the original decision to be upheld. Appellants who attended tribunal hearings reported feeling as if they were on trial and describe being made to feel small or guilty, commonly finding the process humiliating and/or degrading.

### Change in circumstances

We suggest that there is a lack of clarity over which changes in circumstances recipients would report to DCS. Customers on DLA/AA consistently cited a worsening condition (and the possibility of higher benefit) as a necessary change to be reported. A less common view was the need to report an improvement in condition (and potential loss of award). In our opinion this is not due to an intention to defraud, but an assumption (especially if the recipient has a fixed period award) that the change will be noted at the next application, so there is no urgency to report change in the meantime.

It was a common finding amongst customers on DLA/CA that work was not perceived as a feasible activity and therefore, not actively considered. For those on DLA and CA who may be in a position to contemplate paid work, there was some evidence of confusion over hours/income allowed.

### Use of benefits

There are recipients who are very aware of what their benefit is spent on and others for whom it falls within the general household income. This tended to reflect personal budgeting style (and for some, level of income). We suggest that the more a customer struggles financially, the more likely they are to put their benefit into a ‘general pot’ that pays for rent, bills, food and so on.

Amongst those who allocate their benefit for specific items, AA and DLA claimants tend to use these either for taxis (particularly AA claimants) or for disability/illness related items including medicines, treatments and aids. It is not common for customers to use the money to pay for a professional ‘carer’ (although some instances of this were found), and some give a proportion to friends and family who help out with shopping and household chores.

### Awareness of DCS

We found that there was limited recognition of DCS as an entity. ‘They’ are variously described as DSS/benefits office/social services. There was no spontaneous mention of ‘the Tribunals Service’, although this is unsurprising as the Service was only created in April 2006.
Expectations of DCS were limited, and customer ability to evaluate the service was negligible, we suggest this was partially because it was uncommon for customers to know what ‘DCS’ is. Information received from DCS (letters of notification, advice provided) was evaluated as better than contact where claimants were seeking progress updates on their claims.

The most frequently cited communication problems experienced by customers related to the difficulty in getting through on the telephone at all and, once the call was taken, having problems finding the relevant department to respond to the query. Some suggest that staff, although commonly described as polite, were not always as well trained or knowledgeable as customers wanted or expected.

Conclusions and recommendations

This study focused on the experiences and perceptions of DCS customers as they make the journey through the AA, CA and/or DLA application processes and beyond to become benefit recipients. We propose six key conclusions and recommendations, developed from the interview analysis and our subsequent interpretations:

• The disability claims process is dramatically eased with the intervention of a professional adviser. We suggest that this should be acknowledged formally and guidance provided for customers as to which bodies can be approached for assistance.

• The application forms are found by customers to be lengthy and complicated; this is more noticeable for DLA forms when compared with those for CA (with carers often involved in the associated DLA claim having the dual advantages of both ‘practice at form filling’ and noting the comparatively shorter CA application). We propose that guidance on the best approach to completing applications (i.e. that most likely to secure a successful outcome) should be developed.

• Our third key conclusion concerns the disputes process; customers need more information about appealing, which may involve wider distribution of the fact sheets already prepared by the TS (which capture many of the queries appellants raised in the interviews). Further, we propose that customers would appreciate a less stressful experience when they attend oral tribunal hearings; we suggest an extension of the DCS/TS work already underway, to incorporate review of the appeals structure and give further consideration to how the experience can be made less traumatic.¹

¹ Indeed, work is underway to explore the possibility of piloting an early evaluation of claims by the TS prior to formal submission, to help inform the decision DCS makes at the ‘reconsideration’ point.
• Our fourth conclusion relates to DCS staff and the difficulty customers experienced where they have to contact agency staff more than once on the same issue. We recommend that DCS decides upon a threshold volume of communication, past which an individual is assigned a single contact who deals with all subsequent communication.

• The penultimate conclusion we draw from the study is that the quality of information provided by DCS contact centre staff varies in quality. We suggest this is related to two issues: customers calling with inappropriate expectations/queries, and secondly, inconsistencies in DCS contact centre staff’s ability to deal with queries. We suggest that customers should be provided with information outlining pertinent uses of the contact centre, including the type of enquiry that cannot be dealt with in this way. DCS may also need to pay some attention to measuring contact staff knowledge/competence, and increase training (and monitoring of performance) where appropriate.

• Finally, as we have learned that it is common for applicants to have learned of relevant disability benefits only by chance, it is inevitable that eligible individuals exist who are as yet unaware of benefits to which they are entitled. We suggest that additional ways of alerting potential customers of the benefits should be sought, both by DCS itself and in partnership with relevant bodies.

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2 To note, at the time of reporting, the Department had commissioned a study to explore the feasibility of measuring and estimating take-up.
1 Introduction

1.1 Background

Disability and Carers Service (DCS) aims to help disabled people and carers to lead independent lives by administering and delivering disability and carers’ benefits, providing advice on benefits, and supporting the Government’s commitment to increasing the inclusion of disabled people in society. The benefits it administers are Disability Living Allowance (DLA), Attendance Allowance (AA) and Carer’s Allowance (CA).

**DLA** is payable to people aged under 65 who are so severely disabled that they require personal care and/or have walking difficulties. DLA has two components: care, relating to the amount of attention required in relation to bodily functions and the avoidance of danger, and mobility, concerned with the ability to walk, or the level of assistance needed when outside. Care and mobility components are paid at different rates, depending on level of need.

To be eligible for DLA, a person must have satisfied the entitlement conditions for a ‘qualifying period’ of at least three months, and be likely to satisfy them for at least a further six months (the ‘prospective test’). There are special rules for people with a progressive disease who are likely to die within six months.

**AA** is also payable to those with severe disabilities, specifically, those aged over 65 with personal care needs. AA does not have a mobility element, but is paid at two levels relating to the level of personal care required for assistance with bodily functions and the avoidance of danger. Whilst applicants must satisfy a six month qualifying period, there is no prospective test. As with DLA applicants, there are special rules for those likely to die from progressive disease within six months.

Finally, **CA** is a benefit for people who look after someone who is disabled; carers do not have to live with, or be related to the person they care for to be eligible for the benefit. Applicants for CA must be aged over 16, and spend at least 35 hours per week caring for a person getting AA or DLA (at the middle or highest rate for personal care). Carers cannot claim if they are in full-time education involving more than 21 hours per week supervised study, or earn more than a certain amount per week (£84 at the time of writing).
If carers receive another of a range of specific benefits (including the State Pension), that is the same or more than CA, they may not receive CA, and instead have an ‘underlying entitlement’. This means that instead of receiving CA, they will get the ‘carer premium’ added to their Pension Credit, Income Support (IS) or other appropriate benefit.

All ‘claimants’ and ‘recipients’ of these benefits are ‘customers’ of DCS, and we use these three terms to describe various stages of the journey, although primarily refer to ‘customers’. Some customers subsequently become recipients, but others submit claims that are turned down by DCS, and customers may later dispute that decision. Where appropriate, customers are, therefore, also referred to by the term ‘appellants’. This latter term is used where a customer has received a notification from a DCS office that their application for a benefit has been unsuccessful, and they choose to dispute this. From here, we refer to that customer as an appellant. This covers all elements of the disputes process, from a customer asking the decision-making office for a reconsideration, through to the Tribunals Service (TS) becoming involved when the appeal goes on to a tribunal hearing.

At present, there is little information about the experience of DCS customers and no research has directly explored the experience of accessing and claiming the benefits. As part of its programme to improve its service to disabled people and their carers, the Department for Work and Pensions (DWP) commissioned a qualitative study to investigate the experience of all DCS customers – both claimants and recipients – starting from their route to accessing the benefit through to long-term receipt. This report details the findings of this research.

1.2 Research objectives

The key purpose of the research was to underpin DCS service delivery and support development of departmental policy and strategy on disability benefits. The overarching objective was to examine the experiences and perceptions of DCS customers as they go through the process of applying for disability/carer benefits. This main objective can be elaborated upon by separating it into a number of secondary objectives. In summary, these were identified as follows:

- to determine how disabled people and carers hear about benefits and DCS services;
- to ascertain the processes by which people decide to make a claim;
- to understand how customers actually make the claim, and their understanding of whether or not they may be entitled to benefit;
- to examine the actual contact process with DCS;
- to explore customers’ experience of contact with DCS and other parts of DWP;
- to understand the expectations that customers have of DCS and their familiarity with the service;
• to examine experiences of DCS services;
• to examine the circumstances surrounding the appeal procedures and understand the experiences of customers using this procedure;
• to investigate longer-term issues including what steps recipients should take if their condition changes or if there are changes in their own circumstances or those of the person they care for;
• to examine recipients’ attitudes towards benefits and how these are used in the context of other services, e.g. social care;
• to monitor differences between different client groups (e.g. benefit type, age, gender, ethnicity, impairment type, etc.).

To ensure that each objective was covered in the research interviews, the interview guide was developed using these topics as key points of discussion to be covered with interviewees.

1.3 Research methodology

A qualitative methodology, in two phases, was used for the research:

1.3.1 Phase 1: Introductory phase

Four focus groups were undertaken with professional advisers who deal directly with the DCS customer group.

The main purpose of these groups was to inform the topic guide for the customer research. Group discussion with staff with direct experience of dealing with customers and the claims process allowed us an insight into relevant topics and issues. This in turn helped to shape the interview topic guide by highlighting key areas for discussion. However, whilst these groups had a key role in the development

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3 All research tools and a number of technical tables are appended to this report. These include: organisations participating in the professional focus groups; selected areas for depth interviews; opt out letter sent to all contacts; achievement versus quota for the main phase of fieldwork; and topic guides for both the professional focus groups and the customer depth interviews.

4 A focus group is a research group in which participants discuss and debate questions and issues brought up by the person leading the group (the group moderator). Focus groups typically involve eight to ten people, and last for one-and-a-half to two hours. A key feature of focus groups is that participants are able to interact with, and react to, each other in order to fully discuss the questions and issues that arise. It is important, therefore, to ensure that participants are broadly ‘compatible’, in this case, all having a common professional purpose. The group moderator works from a ‘topic guide’ which is a list of topics and questions to be discussed by the group.
of the interview guide, we feel that they also have value to DCS in their own right in order to understand the attitudes to DCS of these key stakeholders.

Eligible respondents for each group were professional advisers working with disabled and/or elderly people and who have dealings with DCS on behalf of their own customer groups. Respondents came from a wide variety of organisations and included both generalists (primarily from Citizens’ Advice and welfare rights organisations) and specialists who mostly dealt with specific groups such as older people or those with specific illnesses or disabilities.

Focus groups were held in March 2006; two groups were held in London and one each in Leeds and Reading.

Findings from the focus groups are reported separately from the main interviews (Chapter 2) and Chapter 8 includes a discussion comparing the expectations of professional advisers with the experiences of customers.

1.3.2 Phase 2: Main phase

The main phase of fieldwork was the completion of 100 in-depth face-to-face interviews with DCS customers. Twenty locations were selected across England, Scotland and Wales to cover urban, suburban and rural locations; to include areas with high and low density of benefit applications; and wealthy and more deprived areas.

For each area, a sample of customers for each of the three relevant benefits was drawn from DCS administrative records. All contacts were sent a letter advising them of the research and providing them with the opportunity to opt out if they wished. Where applicable, the database included representatives of customers who were too infirm to complete their benefit application unassisted, and thus allowed for the inclusion of all applicants regardless of communication difficulties. All interviews were booked by telephone and were generally held in the respondent’s home. The number of interviews per area ranged from three to seven.

In order to ensure that those interviewed would cover as wide a range of experience as possible, a large number of minimum ‘quotas’ were set, ensuring that we interviewed a minimum number of each type of customer, a minimum number of people with different types of disabilities and illnesses and so on. In practice, we found that it was common for respondents to have had wider experience than was evident from the sampling information. For example, with ‘customer type’, on several occasions respondents selected for the CA sample had also been involved in the DLA or AA application by the person they were caring for and in such cases, their interview would cover both benefits.

Similarly, some longer-term customers had needed to make several applications over time and could have experienced both successful and unsuccessful applications and have appealed on one occasion and not on another. For this reason, it was common for interviewees to ‘tick more than one box’, and be able
to discuss a variety of experiences (more than one type of form, both successful and unsuccessful claims and so on).

Interviews were held between May and September 2006.

1.3.3 A note on qualitative research

This qualitative study involved depth interviews and group discussions, as detailed already. For both the groups and the interviews, interviewers used a topic guide (essentially a detailed list of topics to be covered) to lead the discussion. This meant that the discussion was flexible and could focus on issues particularly important to those taking part, whilst maintaining enough structure to ensure that key research topics were covered.

Qualitative research methods were chosen as a way of obtaining detailed information in an informal setting. It must be noted that qualitative research is inherently different from its quantitative partner. Qualitative research derives data from observation, interviews or verbal interactions and focuses on the meanings and interpretations of the participants. It is not about numbers, percentages or frequencies, but about understanding and exploring motivations and behaviour – typically, the ‘why’ and ‘how’ type research questions.

It must be remembered when interpreting qualitative research findings that the results are not based on quantitative statistical evidence. The findings are based on a relatively small sample, which has been designed to cover a cross-section of professional advisers and benefits customers, to ensure that a range of characteristics and experience are captured, but this should not be confused with statistical representativeness. Qualitative research was deemed most appropriate by the Department to provide and capture detailed descriptions of customers’ experiences.

1.3.4 A further note on reporting

Throughout this report we discuss the experiences of AA, CA and DLA customers on their journeys from first discovering that they may be entitled to the relevant benefit, through to award (or indeed, non-award), including a small number of cases going through to a tribunal hearing.

Where we refer to ‘customers’, it should be taken that discussion is equally applicable to all three customer types. Where we found an experience or viewpoint to generally hold true for just one or two customer types (e.g. AA and DLA customers, but not those in receipt of CA) we make this explicitly clear, either in the outset of the chapter/section, or in the relevant paragraphs where the relevance of discussion to all is limited only momentarily. Where there is no specification of which customer type we are referring to, it should, therefore, be taken that comments refer to all.

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2 Professional advisers

Prior to the main phase of research, four focus groups were held with professional advisers who work with the Disability and Carers Service (DCS) customer groups. Although the main purpose of the groups was to inform the topic guide for the customer interviews, group respondents also discussed their personal experiences as customers of DCS. This chapter looks at the main findings of the focus groups and discusses the expectations and experiences of the participating professional advisers. In Chapter 8, views of professional advisers are compared with the experiences of the main customer groups, as derived from the depth interviews.

2.1 Respondent background

The participating professional advisers came from a wide variety of backgrounds and therefore had varying perspectives and experiences. They included both generalists, who had an extensive range of customers (including those who were not DCS customers), and specialists who worked with a specific customer group such as old people or children, people with specific illnesses or disabilities or distinct parts of the community such as those in specified ethnic groups. Most had been in their current post and/or similar posts for a number of years but some had worked in the benefits arena for only a year or two. It was usual for the professional advisers to be involved in helping Carer’s Allowance (CA) applicants in addition to Disability Living Allowance (DLA) and/or Attendance Allowance (AA).

The geographic locality covered by respondents varied too. Most had responsibilities within a confined geographic area but a small number (mostly working out of their organisation’s head office and almost exclusively based in London) would take cases on a national basis. Although some of the professional advisers provided advice only, it was more common for participants to report that they undertake advocacy work and will contact DCS (or other benefit providers) on behalf of their customers. The frequency of contact varied from once every couple of weeks to five or six times per day. Several of those participating in the groups specialised within their organisation in dealing with cases involving DCS benefits and a number had attended DCS tribunal hearings with customers.
2.2 Dealing with Disability Carers Service

In general, professional advisers were positive about their dealings with DCS – it was generally regarded as one of the best of the Department of Work and Pensions (DWP) agencies – although some difficulties were highlighted.

Virtually all professional advisers participating in the focus groups had used the professional advisers’ line when phoning DCS. This was generally well regarded and compared very favourably with the experience reported to them by customers who tried to contact DCS directly. Unlike the customer line, advisers felt that the advisers’ line was staffed by well trained and sympathetic personnel (see Section 6.3 for customer perceptions). In addition, the professional advisers noted and appreciated that they were treated as fellow professionals by the DCS staff handling the advisers’ line.

‘You can ask specific questions, and the people at DCS know that they’re speaking to somebody who knows a little bit more than Joe Public. …and therefore they can give more relevant information.’

(Group 4, London)

One respondent noticed a difference in the reaction she got from the staff on the advisers’ line when she changed organisations and was dealing with a more ‘deserving’ clientele.

‘I noticed a big difference when I moved from Citizen’s Advice Bureaux to Cancer Support and it was much easier. When I worked in the CAB you used to feel the barriers coming up when you rang. When I moved to Cancer Support you could feel the barriers coming down. …That’s about perceptions of deserving and undeserving cases.’

(Group 1, Leeds)

Others in the group agreed with this comment.

Although they did not necessarily agree with the policy, it was clear to the professional advisers that DCS staff were limited in what they could tell either customers or the professional advisers over the telephone. However, they were always grateful for any ‘hints’ that might be dropped by individual DCS advisers as to the expected ruling on a particular case. A positive hint could end the period of anxiety for customers resulting from the wait whereas advance knowledge of a negative outcome gave the professional adviser additional time to consider whether or not to take this further. DCS staff varied in their willingness to bend the rules in this way.

‘I think it depends on who you get. Some people who work there are lovely and will do what they can to help you. And you get others who say no, sorry, can’t have that, these are the rules.’

(Group 1, Leeds)
The biggest problem for professional advisers was the variability in knowledge of DCS staff about disability benefits, in particular because of the regular increase in case law which impacted on how the regulations should be interpreted.

‘I think the standard of service generally is pretty good, but in terms of can you rely on the information that you’re given, I think very often there are question marks over that. When you apply to DLA you get a standard explanation. If you were to try to get into ins and outs of the benefits rules, you don’t get very far. …They don’t have the knowledge of the benefit law, the case law, the entitlement conditions to be able to give good accurate information that relates directly to the client’s personal circumstances.’

(Group 3, Reading)

In addition, only a minority of DCS staff (generally, but not exclusively, more senior DCS advisers) had a firm grasp on the interaction between disability and other benefits and most professional advisers felt that they tended to have a better overview of the benefits system than DCS staff.

One group was critical of the fact that, unlike within other parts of DWP, DCS would not provide them with the names of individual decision makers so that they could discuss problematic cases with them.

2.3 Why professional advisers are used

Professional advisers reported that they might be approached by the customer at any stage in the journey into benefits. However, matching subsequent reports by the customers themselves (Section 3.1), there were a number of routes that were particularly common:

Firstly, the professional adviser might become involved in benefits as part of a general assessment of the individual’s social and/or financial situation. Typically, this might be at the onset of the illness or disability or at a time of crisis. The crisis might be financial (due to increasing debt), medical (declining health) or social (individuals no longer able to cope without assistance). It was common for professional advisers to include a financial check even when the individual was most in need of a social assessment.

The second common trigger was when a benefit application was turned down. The rejection was sufficient for the customer to approach the professional adviser, either for help with pursuing the claim or to see what else they could do.

Commonly, customers found out about the advisory organisation by hearing about it from somebody else, for example, a friend or relative would have been alerted to or awarded a particular benefit or found the relevant organisation to be helpful.
‘People have heard somebody say, oh there's such and such a benefit available. They don’t always have the right name for the benefit. All these carer’s amounts or carer’s pensions, sometimes as they call them.’

(Group 3, Reading)

Other people with the same illness or disability (or who had family members with that illness or disability) frequently recommended professional advisers with particular familiarity with that condition.

Some organisations were proactive in visiting relevant institutions to provide information on benefits or other advice. In some cases such visits were made regularly but other organisations undertook periodic campaigns. Amongst the types of institutions mentioned were schools, doctors’ surgeries or clinics and self-help groups.

‘We visit tenants associations, we visit church groups. By invitation I might add, we don’t just barge in. But we visit them with leaflets, we hold little surgeries for them.’

(Group 2, London)

The visiting professional adviser might leave leaflets, give a talk about help accessible to customers (including benefits) or be available to talk to individual customers. Although not a common theme, some organisations ‘advertised’, to seek out people they thought might be eligible for benefit.

‘For instance with our Attendance Allowance campaign we wrote to 1,000 people over 75 recently who were getting help with rent and council tax, but weren’t getting the Attendance Allowance and invited them to phone us for a benefit check.’

(Group 2, London)

It follows from this that although some customers were aware of the existence of disability benefits before they talked to the professional adviser, most either knew nothing of the benefits or knew very little. Furthermore, even those who were aware of the disability benefits often had inaccurate information, even at the most basic level. For example, it was not common for customers to know the benefit names, and professional advisers reported particular confusion between AA and CA although there was occasionally awareness that a benefit for carers did exist.

‘We get about 50 per cent of people coming in asking to help them with Carer’s Allowance when actually they don’t, they want Attendance Allowance.’

(Group 1, Leeds)

Generally, for those who went to a professional adviser at an early stage, such confusion was of no consequence as the professional adviser was on hand to deal with the situation. However, in exceptional cases, lack of knowledge had led to incorrect applications such as a person over 65 years sending off a DLA claim instead of an AA claim.
Overall, the initial approach to the professional adviser was far more likely to be in connection with a DLA or AA claim than for CA. However, once the adviser was involved with the family, advice and assistance in relation to a CA claim would often follow.

2.4 Applications

Professional advisers participating in the focus groups were sure that it was extremely difficult for individuals to successfully complete the disability application forms without professional help, especially those for DLA and AA (as discussed from a customer perspective in Section 4.1). This was, in part, because of the length and complexity of the forms but was also because applicants would have little understanding of what is required. A number of different points were raised in relation to this.

The professional advisers noted that form completion requires a very ‘negative’ attitude, so that disabled people were forced to think about what they could not do rather than what they were able to do. This was the exact reverse of the general encouragement for people to think positively about their disability, and was known to cause distress, something again reiterated from the applicants’ point of view in Section 4.1. In addition, people were reluctant to say they were unable to do something if they could do it, even with great difficulty.

‘There’s an issue about how the questions are answered… Say for example somebody with osteoarthritis in their spine, well, OK, there’s a question here about getting in and out of bed. How’s that for you? Do you have any problems? Yeah, well it takes me about ten minutes. Right, how do you do it? …So they explain it to you. You put that down. Somebody else is just going to go no, not really, so they tick no. Just move on. So you’ve got a form with no’s on it, which obviously is going to get refused, isn’t it?’

(Group 4, London)

Professional advisers were also aware that their customers perceived the form as being very repetitive. When people brought them copies of what they submitted, it was evident that sections were omitted because the applicant thought that they were being asked for information that they had already provided. Amongst professional advisers, it was believed that incomplete forms were often the reason why applications had been rejected.

Another problem cited with forms was that parts call for very personal information and it was common for applicants – particularly, but not exclusively, older people applying for AA – to suffer from acute embarrassment, sometimes to the point of omitting information.

It was understood that the forms needed to gather complex information and could not be too simple. One professional adviser suggested that the attempts to simplify the AA form had reduced the form’s usefulness.
‘Given that it is a difficult set of criteria I think you have to have a difficult form [but] I think the Attendance Allowance form is completely useless and I’m amazed anyone ever gets Attendance Allowance based on those, because it doesn’t actually ask you to say anything relevant. The Disability Living Allowance form is difficult to fill in but one of the things I would say to care managers is, that if you actually do one of those properly you will know a lot about the person.’

(Group 2, London)

This view was supported by others in the group. Professional advisers commonly believed that they were quickly able to ascertain whether or not an individual was likely to be eligible for benefit. This enabled them to provide appropriate guidance, especially when claimants were turned down. Where such applicants were willing to engage in a disputes process, professional advisers estimated that they would be able to judge the final outcome to a high accuracy level.

‘I personally think I’m usually about 90 per cent right. Whether that’s a positive or a negative, I’m seldom surprised, but it happens.’

(Group 1, Leeds)

This adviser expected to be wrong only where the case was marginal or where he believed that the final outcome was wrong.

Whereas the DLA and AA forms were considered to be too complex for customers to complete, professional advisers perceived the CA form differently. Not only was the form itself less difficult but since it was common for applicants to apply for CA at a later date, earlier problems had already been resolved.

2.5 Awards

There were considerable concerns about the apparent inconsistency in who gets the benefit awarded on submission of the original application. This was despite a conviction that application forms (where completed by the professional adviser) were completed in a consistent way.

‘Two forms in the same week, for almost identical cases of profoundly deaf children, with no other issues, one got it, one didn’t. And they were both filled in almost identical.’

(Group 1, Leeds)

Examples were given of DCS case officers who would have different approaches to a given set of circumstances and this was put down to insufficient training. Furthermore, there were complaints that case officers would have a standard approach depending on the illness or disability rather than examining the merits of the particular case.
'The decision maker may not be experienced enough to know the background to a certain illness and actually think outside the box, because what’s written down is one thing, but what’s not written down is another. Somebody’s put they suffer from osteoarthritis, and they’ve put that they can walk 50 metres before stopping or feeling severe discomfort, and then they put I don’t have any problems getting out of bed, I don’t have any problems cooking my meal, I don’t have any problems dressing and bathing. I’d be questioning that, and sometimes people don’t.”

(Group 4, London)

Some professional advisers believed that undue weight was given to the medical section of the form, often completed by the applicants’ General Practitioner (GP). Some professional advisers argued that some GPs were unaware of the full extent of how the disability affected their patients and others provided only scant information, sometimes to the point of negligence.

‘Sometimes GPs do not understand the sort of living needs. They understand their medical needs. ‘cos I had client who got cross with me, he lost a claim for severe asthma. His asthma was dreadful and he’s had a heart attack. And his doctor said he could manage at home. It was an absolute load of nonsense. He could just about get to his front door to let me in. And when I left I had to shut the door myself and put the keys back for him. And the doctor was saying he can move. It was nonsense.’

(Group 3, Reading)

As will be seen later in this report (Section 4.5), the attitudes of professional advisers in this regard were in stark contrast to those of customers who felt strongly that their own GP was the person who best understood their condition and that his/her views should be taken, particularly in preference to that of an independent medical adviser.

A particular source of anger amongst the professional advisers was the ‘standard letter’ used for rejecting customers. From their perspective, this was often highly inappropriate and could leave the customer frustrated and/or misinformed, as well as upset about their rejection.

2.6 Disputes

Professional advisers were very aware of the high number of cases that were initially rejected and then had the decision overturned after a dispute from the customer – a figure of 50 per cent of rejected claims being subsequently awarded was commonly quoted. They believed that this was indicative of the poor procedures and insufficient training that they had already identified. It was also suggested that more cases should be reconsidered in-house. This would increase natural justice, reduce claimant anxiety and save a large amount of money spent on the tribunals process.
The tribunals process was recognised as being generally fair and several professional advisers cited improvements that they had seen over the recent past. In particular, tribunal chairs were praised as providing the best possible service under the circumstances.

*I think in the main tribunals do try and be fair, and are fair. Within the DCS itself, reviews, discussions, reconsiderations, they’re very hit and miss.*

(Group 4, London)

Nonetheless, the actual process was the subject of some criticism. The first cause for concern was the actual time taken to reach a tribunal hearing. Even allowing for the initial stages including the reconsideration of the claim, the period in which claimants were left anxious and uncertain was considered to be far too long. Advisers did not differentiate between time taken by DCS (for reconsideration and submission preparation) or the Tribunals Service (TS) (arranging a hearing) but felt that the allowed time parameters were too long. Another complaint was that if the customer had applied for a paper hearing, there was often no notification of when this was to be held, with professional advisers occasionally notified only after the event.

The oral tribunal hearing itself was considered by professional advisers to be often undignified and embarrassing. In all groups, professional advisers noted the frequent need for appellants to discuss intimate information, in front of total strangers.

*[Appellants] don’t even imagine that they would have to get to that sort of detail. Or that they’ll have to sit next to somebody at a tribunal and she would have to sit in front of three men and tell them how she wets herself. It’s that bad and she’s sitting there in tears. And you have to go to those levels to get something.*

(Group 3, Reading)

While the independence of the tribunal was valued, the personal issues raised were discomforting and upsetting for the appellant and the professional advisers all felt that it should be possible to deal with this by an alternative route: see Section 5.5.1 for further discussion of these issues.

Professional advisers were not surprised that it was common for customers who were considered to have a good case not to countenance going to tribunal.

Some professional advisers were critical of the importance placed on Examining Medical Practitioner (EMP) visits since they considered these to be of variable quality and not always providing an adequate assessment of the claimant's needs.
‘[The tribunal] would weight the evidence from an EMP maybe higher than they would from anybody else, including the claimant, and somebody that’s in your house for like 20 minutes, who might have been rushing to get to the next one because he’s already running late. … Generally the complaints are that they don’t spend enough time assessing that person, and the 20 minute snapshot of how this person is. The fact that somebody might go to the door to let you in doesn’t mean that they’re not virtually unable to walk if they end up collapsed back in the sofa again for an hour afterwards.’

(Group 4 (London))

There were also some specific criticisms of local facilities which suggests a range of localised problems which need to be addressed. One group cited the use of an inappropriate building – generally used for employment tribunals – which was not easy for people with mobility problems to access. Another discussed the refusal by one tribunal to let the professional adequately represent the appellant.

‘At the tribunals now, I have been the last couple of times, and I’ve been there as a representative, and they’ve actually told me to shut up and wait until they ask me any questions. And I say I’m here to… “Just be quiet or we’ll ask you to leave.” I’m here to represent this person, I’m allowed to speak aren’t I? But they’ve actually told me no, and it’s not only to me, it’s happened to other colleagues as well.’

(Group 1, Leeds)

2.7 Customer satisfaction

The professional advisers did not think that there was a great deal of interaction between customers and DCS, something reiterated by customers themselves (Section 6.2). Occasions of personal contact were particularly likely to be uncommon if the professional adviser was acting on behalf of customers.

‘I mean the contact isn’t that frequent. Even if they order their own claim form, they ring them up, they order the claim form, they fill it out, or we fill out on their behalf, they send it back. They get a letter and it says we’re dealing with it, see you in ten weeks. Ten weeks, they get a letter, if they’re lucky. And that’s pretty much the contact unless it goes wrong. You write for a reconsideration; if that goes wrong you write for an appeal. But outside of that there’s no interaction.’

(Group 1, Leeds)

Basing their opinions on comments from their customers, the professional advisers believed that DCS staff dealing with the public are generally polite but often insufficiently knowledgeable, especially as regards other benefits and the interaction between benefits. They also believed that there was too much variability in staff, both in their approach and style. This meant that the professional adviser could not be sure how customers would be dealt with.
There were also a small number of specific problems that were raised which suggested that some disabilities or other special requirements were not always dealt with satisfactorily. Within the groups, examples of such problems included the lack of availability of a minicom for deaf customers, difficulty in accessing language services for non-English speakers and the lack of special provision for some groups such as those with mental health problems or speech impairments. Professional advisers believed that not only did such problems reduce customer satisfaction but also (because customers were unable to resolve their queries) resulted in low benefit take up.

The amount of time that callers were left waiting for a response was criticised, again reiterated by customers later in this report (Section 6.2). Professional advisers suggested that the availability of an email address might be helpful – especially for deaf people for whom this is the favoured method of communication.
3 Before the application

The remainder of this report examines the findings of the main stage of fieldwork – the depth interviews with Disability and Carers Service (DCS) customers. This chapter looks at how claimants learned about the benefits and the process by which they decided to make a claim. This provides an overview of customer awareness and motivation for claiming, leading into Chapter 4, which presents experiences of the claiming process.

3.1 Sources of awareness

With regards to Attendance Allowance (AA) and Disability Living Allowance (DLA), it was uncommon for customers to be aware of the disability benefits prior to falling ill. Where there was previous awareness, this tended to come either through work or because another member of the family or a close friend was on the relevant benefit. For example, one respondent had a profoundly deaf daughter for whom she had previously claimed DLA. Although her daughter had long been adult and claimed the benefit on her own account, when the respondent herself became ill, she remembered the benefit and made enquiries to see whether she might be eligible.

’It was all found [originally] through the Deaf Society. We got it from the home, from my daughter first ‘cos she’s severely deaf. We got it when she was at school. ….When the doctor told me I couldn’t go to work again, and I thought I would apply to see whether I was eligible for it.’

(DLA, 60+, physical disability (Phys), Bury St Edmunds)

However, some individuals who had previous knowledge of DLA and/or AA did not think of it in terms of their own circumstances. A retired geriatric nurse, who had advised patients and their families about AA, had not thought of getting her ailing mother to claim the benefit, despite her previous experience, until she was reminded about it by a former work colleague.
'I went out with a friend, I said something about my mother, and she said do you get, and she's a retired nurse and she does appeals actually for people that are turned down. And so I'm just talking, out for a meal and everything and she said well, and I said I hadn’t thought of it, and I hadn’t, even though I was working as a nurse. …I used to visit elderly people [and tell them about benefits]…If I was going to your house and you had your mum there, and I would probably say, because it was my mum [I didn’t think of it].’

(Carer’s Allowance (CA) and AA, 45-64, Phys, Llanelli)

Other than in exceptional cases, claimants had no existing knowledge of disability benefits (as described in Section 2.3). We suggest that the source of awareness is an important factor affecting subsequent attitudes and actions.

A common route of awareness was through professional sources. The first of these were medical practitioners; some customers had been told that they might be eligible for DLA or AA by people involved in their treatment including General Practitioners (GPs), consultants and nurses. In such cases, there was generally no further information provided other than that the benefit existed and should be investigated. Medical staff (especially doctors) were unlikely to provide further information (for example, about eligibility criteria or any other details about the benefits) and individuals were left to make their own enquiries.

‘We didn’t really think that [DLA] was something we’d qualify for and I think his paediatrician said, well actually, you know, based on this, this and this and you would qualify for it. [And who told you about CA?] I’ve got a friend who’s got a child with special needs as well and I think she probably mentioned it to me.’

(DLA and CA, 25-44, learning difficulty (LD) and mental health (MH), Bristol)

Medical professionals were less commonly the source of awareness for CA and, where medical staff had mentioned the benefit, it was generally nurses rather than doctors.

The second group of professional sources were people working for statutory bodies such as Jobcentre Plus or the local authority. Some claimants had approached these bodies because they needed to claim some other benefit such as Incapacity Benefit (IB) or Jobseeker’s Allowance (JSA) from Jobcentre Plus, or Housing Benefit (HB) or Council Tax Benefit (CTB) from the local authority.

Commonly, individuals would see a benefits adviser who would undertake an overall financial check to examine their income and look at what benefits they may be eligible for. In these cases, the claimant would not only be told that they may be eligible for benefit but they were also more likely to be provided with the claim pack, given relevant advice (e.g. about eligibility criteria and levels of benefit) and, usually but not always, would have the assistance of the benefits adviser in completing the form.
Not all professional advisers undertook a complete check. In particular, some DLA and CA customers complained that Jobcentre Plus advisers had not informed them of the existence of disability benefits, appearing unaware of what was available.

‘You’ve got to make an appointment and then you’re still passed from pillar to post because they don’t, they haven’t got people there that know about what you can get and what you can’t get and how to go about it.’

(DLA, Phys and sensory disability (Sens), 45-64, Reading)

‘[Jobcentre Plus] are supposed to encompass all these kind of benefits really. I thought they might have made it a bit clearer and told me about [CA], because I could have been on it a lot sooner, instead of looking for jobs.’

(CA, Phys and MH, 45-64, Perth)

Home visits by social workers or charity advisers, although they may not be initiated for financial reasons, were also a common route through which AA and DLA claimants would be made aware of disability benefits. This was particularly likely to be true for AA claimants as they were more likely than DLA claimants to receive home visits. Discussion of benefits would generally occur only after more immediate concerns (e.g. arranging home help, meals on wheels, etc.) had been dealt with.

‘The hospital got Social Services to come to assess me about the shower. It just went from there and she got all the forms and came back the next day and filled them all in for me.’

(AA, 65-74, Phys, Aylesbury)

Voluntary bodies such as Age Concern, Citizens’ Advice or Mencap were usually approached by claimants or their families at a time of crisis – either financial or medical. As with visits to social services, the financial check was a part of the help provided and, where appropriate, an adviser would help complete the form.

There were some examples of respondents who had learned of DLA through support groups or self-help groups they attended. In one case, the local parent/toddler group for autistic children had arranged for a benefits adviser to speak to the parents and to meet with each of them after the talk.

Where claimants had heard no mention of benefits from professional sources, they would commonly have been alerted about the benefit by word-of-mouth. This included friends, family or fellow members of support groups.

Another less common experience was of individuals who had actively looked for information on benefits to see if there was anything that was available for themselves or a sick or disabled family member. The internet was the usual route for this search and it was generally reported by younger individuals – especially parents with sick children, thus tending to be CA and DLA claims.
'No one told me what benefits or anything I was entitled to. My mum found it out on the internet.'

(DLA and CA, 25-44, Phys and LD, Reading)

There were variations in the time that carers became aware of CA. Some were told of it at the same time as they learned of DLA or AA for the person they cared for, but others had discovered that an allowance existed for carers only some time after the DLA or AA claim had been made.

Overall, with rare exceptions, claimants of all three benefits were unlikely to have prior knowledge of disability benefits and learned of them only by chance.

While some were advised of the benefit at the onset of their illness or soon after, others had worked out that they could have put in a claim some time before they became aware of the benefit. Whilst some may not have been eligible at an earlier date, others were sure of the longevity of their condition and thus, longevity of their entitlement. Undoubtedly, such individuals regretted that they had not known of the benefit earlier because, having successfully claimed, it provided a much appreciated financial cushion which would have been useful sooner.

'I was really surprised, I was really pleased and quite shocked that I'd got that money coming in and also a bit cross that I hadn't applied for it earlier, so I missed out on nearly a year's benefit.'

(DLA, 45-64, Phys, Leamington Spa)

The fact that some individuals had been unwell for some time before learning of DLA or AA suggests that there may be some potential customers who do not know of the benefits. This is commented on further as one of the key conclusions of this research (Chapter 9).

Based on our case histories, we conclude that some of the professionals working with sick, disabled and elderly people do not see it as part of their role to alert their patients/customers to benefits. One respondent suggested that where this is true, it may be because medical professionals do not want to raise their patients’ hopes of benefits when these may not be awarded.

3.2 Timing of application

Customers participating in this study fell into two separate categories – those who applied as soon as they learned of the benefit and those who procrastinated. Although we believe that individual personality played a big part in determining which of those two groups a claimant belonged to, additional criteria affected the time lapse between becoming aware of and applying for the benefit.

We suggest that the way in which an individual had learned of the benefit was critical in affecting the speed of application. Where the message was strong, there was a far greater likelihood of people applying quickly. For example, if a medical professional had just mentioned the benefit in passing, with no further input or
discussion of what it was, the overall familiarity was generally low and application was unlikely to follow quickly.

Conversely, where someone had learned of the benefit through a benefits adviser, social worker or voluntary worker, we found that the message was likely to be strong. The discussion about the benefit was often extensive, with the professional describing eligibility criteria, exploring the likelihood of the sick/caring person meeting those criteria and considering their possible level of award (where applicable). In such circumstances, the application was more likely to be completed with no significant delay. Indeed, the professional advisers included in this research tended to believe that they are able to ascertain likelihood of a success soon after meeting a potential claimant (Section 2.4).

In these latter cases, individuals were more likely to be ‘swept along’ by the third party involved in the discussions with forms completed for them. We suggest that there was no time for anxiety or concern about the form or about obtaining state benefits, and the application might be completed on the first or second meeting with the adviser. Sometimes, especially if AA/DLA claimants were very unwell, the customer was hardly aware that the application was being made. By the time their medical crisis was over, benefit had been awarded (see also Section 4.6).

‘It was brought to my mum’s attention first of all. I think they discussed it with my mum because I was unwell. That I would be entitled to get some sort of benefit while I was ill. The lady who came in, she was a community psychiatric nurse. And she sat me down and went through the form with me. And I really don’t remember too much about it because of various things while I was in hospital.’

(DLA, 25-44, MH, Knutsford)

However, it is our opinion that other factors also affected whether or not the application was made very soon after learning of the benefit. The stage of the illness or the caring role and how this linked with the individual’s acceptance of it appeared to be an important factor for some applicants. Lack of acceptance of the condition was commonly found where a parent was applying for DLA on behalf of their sick child, although this was found to some extent with other customer types. The need for the parent to accept that the child was ‘different’ from other children of similar age was often a major emotional barrier (further discussed in Section 4.1). Where DLA and CA were applied for at separate times, this barrier had usually been broken down by the time the parent applied for CA. The decision to apply for this benefit in addition to DLA was, therefore, generally considered to be less traumatic.

Emotional issues also affected some older people applying for AA. A common explanation was that they considered themselves ‘old’ rather than ‘disabled’ and therefore, did not believe that any disability benefit could apply to them. Similarly, and applicable also to DLA applicants, was the belief that the individual was not sufficiently incapacitated or that others were more deserving. Where such feelings existed, the applicant would be less willing to apply.
‘My daughter says that we really could claim Mobility Allowance, but [my husband], he’s just independent, like people are, but he was really wanting to send back the Attendance Allowance. I said, well as long as we spend it on taxis and things that. …I mean we’re not needing the money and some people really do need it desperately to cope with everyday life.’

(AA, 75+, Phys, Aylesbury)

A near universal finding was that older people were reluctant to apply as they perceived a stigma in receiving benefit or considered it charity. This trait was generally less common amongst those of working age (i.e., DLA and some CA customers).

‘I never tell anybody. To this day nobody knows. I just feel very embarrassed. I haven’t told anyone I’m on attendance and I jolly well won’t.’

(AA, 75+, Phys, Ipswich)

We propose that a major factor determining whether or not an individual would apply for benefit immediately on learning of it was their level of financial need. Indeed, the way in which benefits are spent by successful claimants indicates that for some the award allows ‘the little extras in life’, for others, the income becomes a fundamental part of the household income (see Chapter 7). Bringing this back into the present context, potential DLA and CA customers forced to give up work as a result of their/the person they were caring for’s condition, were particularly likely to need the additional income and this could be sufficient impetus to overcome any doubts or reluctance they may have.

There were a number of other reasons given by all three claimant types for not applying for the benefit immediately. These included the individual being uncertain as to whether they would be eligible, lack of knowledge about the benefit (including, for example, eligibility criteria and understanding about how the benefit ‘works’), and a general lack of confidence which for DLA and AA customers would sometimes be an effect of becoming unwell.

‘I left it for a little while, ‘cos I wasn’t sure, because I was on incapacity, I was worried about whether I’d be entitled or not. When you’re a worker, it’s difficult to get into knowing all these things, because I thought, well is this a scam? Is this what people are doing to try and get more money, you know like, being illegal, and I thought no, so I left it. But when I spoke to my doctor again, my doctor said, have you applied? And I said well I’m a worrier, ‘cos I do suffer badly with my nerves, [so] would I be entitled to it? And he said yes, you do need to apply.’

(CA and DLA, 45-64, Phys and MH, Coventry)

As noted previously, we believe that a strong initial message about the benefit (and readily available information on it) reduced the strength of such attitudes and made speedy application more probable.
Applications for CA were not always made at the same time as that for DLA or AA, even when those concerned were aware of the separate benefit for carers. Reasons for delaying CA applications were that it was too much effort to complete both forms at the same time or a preference to see the outcome of the DLA or AA claim before progressing on to the next one. It was common for CA applicants to be involved in the DLA or AA application but where this was not the case, the CA application was usually made at a later date.

Some applicants for CA had particular guilt about applying for benefit because they believed that they were being paid for undertaking caring duties which were part of their general responsibility for the family – spouses and parents were most likely to feel this way although some carers felt the same about their care for ageing parents.

‘From my point of view I’m being paid for something that I feel is my duty anyway.’

(CA, 25-44, Burnley)

3.3 The final nudge to application

People who had failed to apply for a benefit as soon as they learned about it would often take a considerable time before they finally made a decision to apply. Typically, the waiting period was several months. It should also be noted that our respondents were all individuals who had made an application – there will be other sick and disabled people who learned of the benefit but have not overcome their personal barriers to application.

If the application process had been delayed, for whatever reason, there would usually be a subsequent identifiable event that pushed customers to make the application.

‘At first my husband said, no, we’re not doing that,…we don’t need that, we’ll leave that and so we left it for a long time, but then I said, well, I want to send him privately for speech therapy, ‘cos that’s where his main problem is with the communication and the speech and I said it’s £55 an hour for this speech therapist.’

(CA and DLA, 25-44, Knutsford (for under 16 (U16) MH son))

The two most common events were an adverse change in their medical or financial situation, or a subsequent reminder – typically by a friend or family member – that the benefit was available and that they may be eligible. The latter situation was most frequently experienced where the original source of awareness had not provided a strong message. One AA applicant was finally persuaded by an advertisement.

‘Well I think it was a television advert. I said, oh we’ve got to go and ask them about it and then I went to [the council] and asked them like.’

(AA, 75+, Phys, Bristol)
3.4 Certainty of eligibility

Applicants ranged from those who were certain that they were eligible for benefit to those who were equally certain that they were not. Overall, of the three disability benefits, we found that confidence tended to be lowest for those applying for DLA. It is our opinion that the higher confidence of AA applicants was a consequence of the increased tendency to receive advice and assistance in completing the documentation; they were, therefore, more convinced both about their eligibility and the accuracy of their form filling. This is further supported by professional advisers’ beliefs that they can predict with a high level of accuracy whether claims will be successful (Chapter 2).

For all benefits, those receiving professional help with filling in forms were much more likely to be confident that they were eligible for benefit.

From respondent descriptions of their benefits application journey, it is clear that those who had received advice to apply from a trusted professional source were much more confident about their eligibility. Both medical and social professionals were expected to know everything about the relevant benefit and customers assumed that professionals would not suggest an application lightly. The level of confidence was particularly strong where an AA application had been suggested by the doctor.

Those applying for CA tended to be reasonably confident; we suggest that this is because the criteria for CA are more clear cut than those for AA and DLA. Provided they were giving the requisite amount of care and their earnings were below the stated amount, CA applicants considered that they were eligible. Moreover, as the claim was linked to a DLA or AA claim, they had less difficulty in perceiving their claim as credible.

Some applicants (of all three types), or applicants’ families, made a point of seeking further information either through the relevant helpline or through the DWP website. They described how this would help them to resolve specific queries they had about their case and about their likely eligibility for benefit.

‘[The clinic], where he goes for psychiatric treatment told us he should be eligible for DLA. [What else did they tell you about DLA?] Nothing really, not how much it was or under what circumstances. Just that we ought to explore it. So I went on website didn’t I?’

(DLA and CA, 25-44, Ipswich (for U16 MH son))

Those using the CA helpline had found this a very good source for confirming if they were likely to meet the benefit criteria. One respondent was particularly disappointed that her earnings exceeded the threshold by only about £3 per week, thereby completely excluding her from benefit. She had hoped that a sliding scale might apply so that she could receive partial benefit since she met all the caring criteria.
Inevitably, confidence was sometimes misplaced. For example, some CA applicants recalled how they had confidently sent off their application only to be rejected because they had failed to read the documentation thoroughly and note that there was an earnings threshold.

There was little understanding of the relationship between disability benefits and work. It was common for DLA recipients to be too ill to work and, therefore, it was not an issue; similarly, it was usual for CA recipients to be spending too much time in their caring capacity to be able to work at all. However, there were some individuals who were currently working or who had aspirations to do so in the future.

It was common for those who were not yet working to assume that they would no longer receive their DLA once they started work. The correctness of the assumption was unlikely to be explored until work became a real possibility. A similar situation pertained for CA claimants. It was not common for non-working CA recipients to be familiar with work criteria for the benefit unless they had explored this prior to applying – for example, if they had given up work in order to be eligible for benefit. As with DLA recipients, criteria were seldom investigated except where circumstances were changing so that work was possible. These issues are further discussed in Section 4.7.
4 The claim

Having examined sources of awareness of disability benefits amongst potential Disability and Carers Service (DCS) customers, we now examine the next stage in the process, that of applying. Key points for discussion in this chapter include the reaction to the application forms, the differences in experience when applying alone or with professional help, and then expectations once the forms are completed and the application is made. The chapter culminates with the positive experiences of those who are successful in their application, and receive their award on this first attempt.

4.1 Perception of the application form

As suggested by professional advisers (Chapter 2), claimants tended to describe finding the benefit application forms daunting, initially reacting to their length. Indeed, the length of the form and fear of tackling it was occasionally a reason for delaying the benefit application. The questions added to that negative reaction, as they were found to be repetitive at best, inapplicable at worst, for some Attendance Allowance (AA) and Disability Living Allowance (DLA) customers.

The issue of repetition was mentioned frequently, with some claimants feeling this was a deliberate attempt to ‘catch them out’, to check whether there was any exaggeration behind their claim. Some DLA and AA customers recognised that questions are designed to capture a variety of information around the same theme (nature of disability, impact of disability, need for assistance due to disability and so on). Similarly for those applying for Carer’s Allowance (CA), there were customers who recognised the purpose behind the apparent duplication, i.e., capturing both nature and extent of caring duties.

Some customers mentioned the logic behind ‘giving in’ part way through, simply referring the reader to a question answered previously, suggesting that ‘See Qx above’ appeared to be an obvious answer in some places. We recall the findings of the groups here (Chapter 2), with professional advisers suggesting that this can be a cause for failed claims.
We suggest that a further issue is the length of the claim forms, with several claimants citing the need to tackle the form over a period of time, attempting separate sections at different sittings, completing a version in draft first, or indeed, a combination of the two.

The benefit of customers completing an electronic version was mentioned here, with some enjoying the luxury of saving the form on computer and returning to it when they felt ready. Whilst this appears a positive approach, we suggest that it is very much a ‘coping mechanism’; for example, AA and DLA applicants are not in the best of health, which for some impacts on levels of energy and attention span whilst in pain.

‘And the biggest problem is you’re answering the questions is one, it’s upsetting because it makes it real, something you’ve just learnt to deal with from day to day makes it suddenly real and two you get so sick of talking about it, and actually I’ve forgotten what ‘normal’ is…but then I thought well, if you can do it online, I could do it bit by bit, so I started doing it bit by bit and you can save it and then do another bit. It actually took us about four weeks at least to do the form.’

(DLA, 45-64, physical disability (Phys), Newcastle)

With regards the type of information sought by claim forms, we propose that there are three key issues arising: negativity, (in)applicability, and for DLA and AA claimants, (im)measurability. The first issue, negativity, was also cited by professional advisers (Section 2.4), namely the need for DLA and AA claimants to focus on the adverse impact of their illness or disability, what they cannot do, how their lives are hindered by their situation.

Parents with sick or disabled children were particularly likely to find this difficult, as adopting a negative mindset reminded them of the very real limitations faced by their offspring. For some, completing the DLA benefit claim form on behalf of their child was the first time they had acknowledged the situation in stark black and white, especially for those applying for the benefit as a result of a recent accident or diagnosis.

Whilst more common amongst parents, this reaction to negativity was by no means limited to those applying on behalf of their children, with some AA and DLA customers claiming for themselves also describing the difficulty in presenting the limitations they face. A woman with Multiple Sclerosis (MS) described finding the experience of engaging with the debilitations of her illness a very difficult one.
‘…with MS it was a very difficult form to fill in. Because, there was, if you know anything about MS, you can get remit and relapse, and then it can go into like secondary progressive. Well, at the time I had applied for the Disability Living Allowance I hadn’t myself accepted that it had gone onto a secondary progressive stage, so filling the forms in, I was in a bit of denial myself, and people were saying “but how do you do this, do you do that” and I was having to come to terms while I was filling this form in exactly how bad I was. So I found it very difficult.’

(DLA, 45-64, Phys, Durham)

The impact of focusing on the negative was evidenced, to a lesser extent, amongst older claimants (i.e., those completing AA forms), as they were often more accepting of their deteriorating eyesight or reduced mobility as a result of simply ‘getting old’, and more likely to have settled into this as a facet of their twilight years.

It was most common for AA and DLA customers with a sensory, mental health or learning disability to mention the issue of inapplicability; an elderly AA claimant with macular degeneration said that the forms reiterated for her that those with sensory disabilities are second-class to those with an element of ‘physical impediment’. A woman with Myalgic Encephalopathy (ME) explained how the information requested on the form did not provide the opportunity to explain the impact of ME to the full, another showed concern over the combination of relevance of questions combined with having a little known mental health diagnosis.

‘…a lot of the questions are irrelevant and so it’s quite hard to justify to people, people who are assessing these forms probably have less understanding or experience of what it’s like to have mental health problems perhaps than, it’s easier to relate to someone who’s got a dodgy hip and they can’t get about than somebody that’s maybe got a condition that they’ve maybe got no idea what it actually is.’

(DLA, 16-24, Phys and mental health (MH), Perth)

This brings us to the issue of the phrasing of questions on the form, and the ‘measurable’ evidence needed to prove the effects of the illness or disability on claimants everyday lives. This was mentioned by all three customer types (AA, CA and DLA) with equal vigour, having to, in some way, quantify or typify their everyday experiences. For AA and DLA customers this included frequency of night disturbances, of distances they are able to walk, of length of time taken to get up in the morning, or to bathe and go to bed.

Main concerns here were whether to focus on a good day or a bad day, whether to cite what is possible despite being in excruciating pain, and/or whether to consider the circumstances with support (be that a physical aid or another person) or without. For some AA and DLA claimants, trying to decide what type of evidence to provide was simply frustrating, for others it brought about a debate as to whether focusing on the negative was lying (‘But some days I can walk 20m
without stopping to sit down’) or whether being positive negated the severity of
the condition and would reduce the likelihood of a successful claim (‘I can get
downstairs without my husband’s support, yes, but that’s me done then for the
rest of the day’).

‘See if I put down nought yards, there’s some days that I can walk it, am I
lying? And then you think, well, if I put 15 to 20 yards down, other days I
can’t walk even one yard, and are they going to penalise me ‘cos I can walk
15 to 20 yards? It is difficult.’

(DLA, 25-44, Phys, York)

According to respondent accounts, of the three forms (AA, CLA, DLA) it was the
DLA form that appeared to be the most daunting, although there are a number
of potential caveats here:

• DLA claimants were more likely than AA claimants to attempt the forms alone;

• DLA claimants did not have the prior ‘experience’ of CA claimants (who were
very often involved in the associated DLA claim);

• relatively few claimants had completed both the DLA and AA forms and were,
therefore, unable to make comparisons between the two; and

• a number of DLA claimants were parents claiming on behalf of their children,
and thus engaging with the illness or disability from a negative point of view,
for some, for the first time.

At the other extreme, claimants pursuing CA report the least difficulties with
the application process, this often stated in comparison with the forms for the
associated DLA claim. Whilst CA forms are indeed shorter, it is also common for
CA claimants to have co-ordinated the parallel DLA application, and we suggest
that this in itself provides a familiarity with the process and documentation.

The issue of ‘jargon’ was mentioned by all three types of customer (AA, CA and
DLA), not in relation to the questions on the form but rather to the terminology they
should use in completing it. Several AA and DLA customers were not familiar with
the medical definitions used to describe their condition, others worried whether a
diagnosis perceived to lack medical kudos (‘foot drop’, ME, the ‘highs’ and ‘lows’
associated with diabetes, or ‘simply having old bones’) would be sufficient to
warrant a successful claim.

Some customers with past experience of DCS claim forms, and some having
professional people or bodies help with their form filling, described how there
is a very precise use of terminology and phrasing involved in a successful claim
and knowing this is the key to success or failure. Again, see Section 2.4 for the
professional adviser reiteration of this point.

For example, a claimant explained how his hospice day centre carer had filled in
his DLA application, stressing that he needed to think about how his life would be
without any aids or coping strategies, to think of the impact of his illness without
any of the controls in place.
‘Don’t tell them what would help you to do it, think that you’ve got no help, you’ve nothing there, you’re just laid on the settee or sat in a wheelchair in some cases whatever, you cannot do anything for yourself as you’ve been given no assistance, and work it from there…the questioning can be a little ambiguous, like “do you have trouble walking?” To me, yeah I do, but I don’t because I walk with sticks, so to me I don’t have trouble walking, because I’ve got round them, I’ve got rails at home, so I no longer have problems standing up any more. That was the problem, I should have been putting yes’s to problems, not no’s that are only no’s because I’ve learnt how to cope with them.’

(DLA, 25-44, Phys, York)

Whilst the claim forms associated with both disability benefits and carers allowance were acknowledged as lengthy, for some this was an observation as opposed to a criticism, as was any comment on repetition or providing examples of the typical impact of their illness or disability.

When probed on their attitude to the forms, claimants who experienced form-filling as straightforward typically cited their educational background, or being in (or retired from) professional employment as reason enough to be able to complete claim forms without undue concern. When combining this attitude with the form-filling process described, these claimants tended to adopt a structured approach, including: reading the form through before filling it in, having relevant letters and notes to hand and/or approaching it as an exercise to be completed over a number of sittings as opposed to expecting completion when first engaging with the application pack.

4.2 Applying with help

Where we saw earlier that initial sources of awareness of disability-related benefits were professional and non-professional, so too were the types of help sought by claimants completing AA, CA and DLA forms. But how was the decision to seek help made in the first instance? We suggest that this is particularly important, given the view of the professional advisers (Chapter 2) that completion without help is extremely difficult.

For some claimants (of all three benefits) who received professional help in form filling, this was simply the next stage in the process of discovering that the benefit may be available to them; those who were advised by a benefits adviser or advisory organisation that they should apply were then taken through the form, and the application was made. Similarly, where the initial source of awareness was a medical professional or body, there were a number of DLA and AA claimants who were then taken through the application form as the next step in the process; there was little or no consideration that they would ever have completed the forms alone.
For other claimants, where the initial source of awareness was a non-professional (i.e., friend or family member) there was a pragmatic acceptance that assistance would be required. This was most notable amongst AA claimants since it was common for these to have a relative or acquaintance looking out for their interests. Help was then found by either word of mouth (i.e., recommendation from other people) or existing knowledge of support and advisory bodies. A wide range of agencies and bodies were used for assistance (by all three recipient types; be that the original source of awareness, or selected as part of a later decision). A sample of those mentioned within this study is listed below to provide an indication of the types of organisation providing such help.

- Citizens Advice Bureau (CAB);
- Alzheimer’s Society;
- War Veterans Service;
- social worker;
- Third Eye Project;
- nurse;
- health visitor;
- Catch Up;
- Age Concern;
- benefits adviser;
- community nurse;
- ward staff;
- ‘help on the phone’;
- (medical) consultant;
- hospital crib sheet (diabetes clinic).

It is universal that those who did not have professional assistance from the outset, but by the time of claim submission had带来的 professional on board, began by believing that they would complete the forms themselves. For some, this assumption was made before seeing the application pack and the initial reaction to the length and perceived complexity prompted them to seek professional input. Exceptional cases made their approach to the professional adviser after having an initial claim turned down (see Chapter 5).

More claimants however, attempted at least an element of completion before deciding to seek assistance. We suggest that precisely how much was achieved before this happened was down to a combination of the individual’s tenacity, their attitude to independence and belief in the privacy of financial and medical matters.
In some cases, notably for DLA and AA customers, applicants decided when they received the forms that simple facts such as contact details and medical history could be completed unassisted, with the remainder of the form left for a professional person. As with those seeking assistance from the outset, the decision on which professional (body) to approach for help was very much a product of existing knowledge or advice from friends or family.

There were two main types of assistance that customers described professionals as supplying: The first, and by far more common, was form-filling. This largely involved the claimant sitting with the professional, with the latter reading out the questions and then prompting for appropriate information and detail. We believe that this is the crux of assisted applications, where the professional clarified the precise nature and level of information sought. On several occasions, claimants described how this prompting and elaboration led them to provide a different account than they would have done if interpreting the questions alone.

‘She asked questions, things I wouldn’t have mentioned that I would’ve put down to old age. If she hadn’t suggested it a lot of them would’ve gone unknown because I wouldn’t have considered it as an ailment, more of old age.’

(AA, 65–74, Phys, Bristol)

The other, less common benefit of liaising with professionals over completing claim forms, was where a body provided notes or a crib sheet explaining how to complete the forms, almost a non-personal equivalent of the above. Again, respondents described how this altered their approach to the information given.

There were a small number of claimants for whom literacy was an issue, either because English is not their first language or because of low educational attainment, who would not have considered completing forms unaided as this would have proved impossible. For some of these, especially those of black and minority ethnic (BME) origin, the CAB is a tried, tested and valued source of support for many matters, of which the disability benefit was simply the next on the list (discussed further in Section 8.3.1).

Finally on the matter of professional help, we note that this was far more likely to be sought from non-central government sources such as local authority benefits advisers, voluntary, information/advice/guidance and charity organisations. Whilst some customers telephoned the given helpline, or approached benefits advisers, most saved such contact for chasing the progress of their claim. Where benefits advisers or the helpline or website were used, this was often in the initial stages, to clarify eligibility.

Some claimants expressed a reluctance to engage with the Department for Work and Pensions (DWP) any sooner because of their nature as holder of the purse strings, being the very body that awards or refuses the claim. For some claimants, going to DWP with queries was seen as having it ‘on the record’ and they preferred the perceived neutrality offered by non-connected voluntary or charity organisations.
The other type of assistance was non-professional, this being a friend or family member. This was again more likely amongst AA claimants who have relatives or acquaintances caring for them in some capacity anyway, and it was taken as read that with time, assistance would either be requested by the elderly person, or offered by their helper. It was common in DLA cases, and to a lesser extent CA, that a partner or spouse of the claimant would be heavily involved. On several occasions this was described as simply part of the process of being married or having a long-term partner, as the claim was an issue that affected both parties. We suggest that this was less common amongst AA claimants because of the greater likelihood of a third party (professional or friend/family member) assisting in the claim, reducing the involvement of both the elderly customer and their spouse.

The assistance received from family and friends was described differently to that received from professionals; the former was very much concerned with support and reassurance as opposed to seeking the views of someone who was more likely to complete the form correctly. The one exception to this is the more elderly AA customers who were sure of the younger generation’s ability to deal with bureaucracy better than they could.

Without exception, those who received professional help were grateful for this, and were sure (to varying degrees) that they would have found it far more difficult (if not impossible) to complete the forms alone. They also felt that this increased their confidence relating to eligibility and likelihood of success. In the frequent cases where the initial source of benefit awareness was the same professional adviser who subsequently assisted in completing forms, customers felt a sense of inevitability that claiming was the right thing to do, and that the claim had been submitted accurately and evidence phrased appropriately (see Section 4.4 for further discussion of customer expectations).

It is interesting to note however, that one apparent impact of an assisted claim (by a professional), compared with a non-assisted claim, can be an element of loss of control of the process; some claimants not being overly sure of how they were eligible for the benefit, or how likely their claim was to be successful. This lack of knowledge does not appear to concern assisted customers. They tend to focus on the belief that the professional will complete forms appropriately and only if the claim is viable, rather than concern themselves with the fact that some elements of the application have been taken out of their hands. A similar process is described in Chapter 5, which focuses on the disputes process, in Section 5.5.1 with regards to attending oral tribunal hearings alone or with professional representation.

4.3 Applying alone

As described earlier, some of those applying unassisted only ever considered applying ‘solo’ – this appears to have been linked to a fundamental belief in their own powers of literacy and comprehension, or their experience in professional employment.
For a number of claimants (most notably for AA claimants who applied unassisted) there was a stoical belief that the nature of a benefit application as financial and requiring detail of a personal and medical nature, rendered it private and, therefore, a process that could only be undertaken independently.

For some cases, regardless of how they evaluated the process of completing the claim form, customers reacted to the concept of having help as ‘that would have been nice’ but this was not stated with any urgency or regret. Others had used professionals for their initial application but felt that they had enough information to attempt the renewal application themselves (discussed further in Section 4.6).

On the whole, there was little recollection of the application pack making available any sources of assistance, although some mused that there may have been a phone number. When pursued on what they would have done if difficulties were encountered, claimants were sure that they would have been able to find help if they needed it. When asked to elaborate on where they would have looked if they had needed assistance, customers cited a ‘common sense’ approach, including for example, the telephone directory, the internet, their General Practitioner (GP) surgery or friends and family.

### 4.4 Expectations

We propose that there is a perceived difference between ‘eligible’ and ‘entitled’; whilst all three customer types could often make the connection that they were eligible for a benefits claim because of their illness, disability or status as a carer, there was a subsequent consideration as to whether they were entitled to the benefit based on whether their lives were affected ‘enough’. Adding to this was the question of whether there was an element of the resource being finite – would someone else in more adverse circumstances be seen as more deserving and therefore, be more likely to claim with success?

Commonly, however, claimants simply reported having ‘no idea’ as to whether they would receive the benefit, indeed, once the claim form had been submitted, the process was often perceived as being in the lap of the gods. For those who described feeling uncertain as to whether their application for benefit would be successful, this could be either positive or negative uncertainty.

The distinctions are drawn out in Table 4.1. Where expectations were negative, reasons included aspects of the application process itself, such as whether they fulfilled unknown ‘criteria’, and if the form was completed correctly. There were also customers who believed the award process to be a lottery with unknown rules behind success and rejection, even if this was because other customers were ‘more’ eligible in some way.
Table 4.1  Reasons why customers think their claim will/will not be successful

<table>
<thead>
<tr>
<th>‘Not sure’ (negative)/ ‘Probably not’</th>
<th>‘Not sure’ (positive)/ ‘Probably’</th>
</tr>
</thead>
<tbody>
<tr>
<td>I might have filled the form in wrong</td>
<td>(A professional who knows about these things) told me to apply</td>
</tr>
<tr>
<td>I don’t know if I fulfil the criteria</td>
<td>I think I fulfil the criteria</td>
</tr>
<tr>
<td>I daren’t get my hopes up</td>
<td>I’ve paid in all my life</td>
</tr>
<tr>
<td>It’s a bit of a lottery</td>
<td>I need it</td>
</tr>
<tr>
<td>There are people a lot more deserving than me</td>
<td>(Friend/acquaintance etc.) gets it and we’re in the same boat</td>
</tr>
</tbody>
</table>

In a rare occurrence, falling outside the common themes listed in Table 4.1, a woman applying for CA described how it did occur to her that she may not be successful due to the ‘believability’ of her story.

‘It was never the doubt that I care for my mother, it was more of the fact that I had a work history. How can somebody have a job for all those years and suddenly say ‘I can’t work now, I’ve got to look after my mother’ ‘cos I suppose people might look at that and think ‘well surely you could get an hour in somewhere’ and I’d say to them, ‘well if I could I would, but that’s the position I’m in and I can’t’.’

(DLA, 45-64, Phys, sensory disability (Sens) and learning difficulty (LD), Knutsford)

There was evidence amongst some of those applying that the money was quite vital to them as potentially a replaced or only source of income, and this resulted in an emphasis on ‘thinking the unthinkable’ in preparation for being turned down, as to think positively was tantamount to tempting fate.

Amongst claimants who felt at least an element of confidence that their claim would result in benefit award, there was a sense of inevitability, usually from one of three sources:

- professional opinion (that they are eligible to claim);
- professional assistance (in submitting an appropriately completed claim form); or
- just knowing that they were entitled (based on the severity of their situation, understanding the criteria for award or the knowledge that other people in the same situation receive the benefit they were applying for).

For some there was confidence which we felt emanated from the sense of justice behind the fact that they need the benefit to remain solvent, or indeed, the sense of indignation that they have paid for their benefit through a lifetime of tax and national insurance, so why wouldn’t they be successful?
‘Well I just thought that because I had mobility problems that would have been it that I would have been given the allowance.’

(DLA, 45-64, Phys, Durham)

As discussed in Section 4.2, where claimants were advised or assisted by a professional, they were less likely to recall being doubtful or nervous that the claim would be successful. Whilst that did not necessarily translate into complete confidence, there was a very real belief in their eligibility and also that the forms had been completed appropriately. These convictions served to eliminate (at least partially) expectations that their claim may be rejected.

4.5 Medicals

A minority of DLA and AA applicants had a medical from an Examining Medical Practitioner (EMP). This was generally perceived as being a rushed affair with few doctors spending much time with the applicant. Views of the medical visit varied and were more likely to be negative if the benefit award had been turned down.

‘They sent somebody out to the house…I came in and he was sitting here and he asked me to walk from there to here, and I did. I can’t remember what I said at that point, but anyway, I walked from there to here trying as best I could to do it and I sat down and then he asked me various questions and he seemed fine when he was here. Everything was fine with the doctor, he was very pleasant, nothing about him, but I was denied the DLA because he said I could walk 100m in so many minutes, and I thought, well, how did he come to that decision, because I can’t walk hardly any distance.’

(DLA, 45-64, Phys, Durham)

There is no doubt that claimants felt that their own GP had a much better view of their situation than the visiting stranger. On the whole, claimants had no problem about a doctor visiting them – indeed, several who had not received such a visit expressed surprise about this – but resentment tended to be expressed amongst those blaming the EMP for the fact that their application was rejected, especially if they felt that this was a misrepresentation of the situation (as in the case cited above).

4.6 Award on first application

Customers of all three benefit types who completed their application with professional help, tended to describe the award as simply the next step, focusing not on the reaction to being successful, but instead on the length of time between application and award. Often this was discussed positively, as taking in the region of eight to 12 weeks (in agreement with the period stated on the acknowledgement letter). This letter in itself was greeted favourably, and claimants were generally satisfied with that element of the claims process (see Section 6.2 for further evaluation of customer satisfaction with DCS communication).
Of those completing forms with non-professional help, i.e. family or friends, the reaction to the award was more variable. It was common for AA applicants whose ‘helpers’ completed the forms on their behalf, to perceive the process almost as those with professional help; an assumption made that forms were completed accurately, removing some of the uncertainty about eventual award success.

A similar reaction was found amongst those (not just AA claimants) whose friends or family intervened due to literacy issues, with the forms completed on their behalf to a large degree, and again, the removal of uncertainty due to the lack of involvement in the process and the assumption that the helper completed forms appropriately.

Where applicants received the help of a spouse or partner, this tended to be an approach not of being assisted but of deciding to tackle the application together, and there was evidence of more uncertainty here.

Similarly, of the several claimants who completed the forms entirely alone, there was less assuredness that the award was guaranteed, although levels of real ‘uncertainty’ were less well-evidenced. These claimants tended to be less emotive about the process and would not have gone through the open brain storming and discussion about the more complex parts of the form that was described by those who completed the forms as a two-person effort. There was more pragmatism amongst those applying completely unassisted, and a similarly less-emotional attitude to the award notification.

In terms of the award itself, claimants recalled letters of notification explaining how far the award would be backdated, and for which amount/level. Given that awareness of benefit level and eligibility was often sparse on application, it tended to be at award stage that claimants discovered that there are indeed variable ‘rates’ of award. Reaction to this showed no particular pattern, although those in contact with professional assistance were more likely to contest a level perceived as ‘too low’, more often than not at the instigation of the third party. This issue is examined in more detail in Chapter 5.

For claimants not in receipt of a lifetime award, the reaction to the need to reapply after a stated period of time was appreciated, based on the logic that their condition, that of the person they are caring for or changes in employment/income may instigate an alteration to their benefit.

However, there was also resentment from some recipients about the need to reapply for benefit on a regular basis when the disability was one which was not going to improve. This was considered to be a waste of everyone’s time.

‘While some disabilities might become kind of transient, if that’s the right word and people might out grow them, some of them aren’t…Having to refill that out every three to five years is just a waste of time and it’s depressing. You’ve got so much to do anyway when you’ve got a child with extra needs that it’s really the last straw.’

(DLA and CA, 35-44, MH and LD, Bristol)
Whilst for some this process of reapplication was met with trepidation, customers who received professional help were less daunted, largely because they anticipated returning to the professional for assistance again. Similarly, applicants completing forms alone or with non-professional help tended to have their concerns alleviated by having ‘done it before’. Indeed, several customers whose initial application had been completed with professional help did not return to the professional for the reapplication, feeling sufficiently confident to tackle the form alone or with just family assistance.

In addition to concerns about form-filling, some applicants were worried about how they would cope financially if their reapplication was unsuccessful. Reliance on the benefit ranged from simply ‘having got used to the extra money’ to total dependence, so for some, an unsuccessful application would mean the loss of a large part of their household income. This is examined in much greater detail in Chapter 7.

It is interesting to note that customers were often able to recall how severe their (or their dependent’s) condition was when they first applied, and therefore, able to comment on whether circumstances have changed in any way, which logically would allow them to judge whether or not their reapplication would be successful. In practice however, customers who were involved in claims with no change or negative change showed as much trepidation as those who had experienced positive change (i.e., improved health/reduced caring duties and potential loss of benefit).

### 4.7 Change in circumstances

Claimants were probed on which circumstance changes they need to spontaneously report, and to whom they would report them, as a separate issue to the reapplication process associated with time-bound awards. Across all three benefit types, recipients were vague on this issue.

Claimants often reacted as if they had not considered or been informed of this eventuality before, and responded with an ‘off the top of the head’ reaction that of course, any change in contact details would be communicated to DCS. A second relatively common issue that would be reported was a sudden windfall, this often stated, tongue in cheek, as a lottery win or the death of a (non-existent) millionaire relative and the inheritance that would follow.

For some of those on AA or DLA who engaged with the idea of changed circumstance in a health context, this was seen as a non-issue, as they did not expect their condition to improve. Indeed, it was quite common for customers within our sample to be in a position whereby their condition would deteriorate over time, proving terminal at worst.

These issues highlight how reporting a change in circumstances was understood as potentially leading to an alteration in benefits. There was an assumption amongst claimants with regards ill-health and caring circumstances that if their condition...
(AA and DLA) or circumstances (CA) satisfied original criteria for award, then they would still be entitled to it if they or their circumstances worsened in any way. From respondent reactions, we suggest that it is not common for the idea of improved health (of them or the person they care for) to be a realistic outlook, and thus, the hypothetical need to communicate this was not considered in any real terms.

‘If I think these people need to know about it then I’ll phone them and tell them. And I’ve been as honest as I can with them, it’s like I said, as soon as the doctor told me I had 93% arthritis in the knee, that it’s not going to get any better, he said ‘as you get older it will get worse’. I disclose those things and I tell them, I let them know what they need to know.’

(DLA, 25-44, Phys and MH, Ipswich)

There was some evidence that claimants were more likely to communicate a negative change (and potentially increased or longer award) than a positive one (and the threat of reduced or halted benefit).

Where claimants are in a situation that has the potential to improve, it is near universal that they would not spontaneously report this but rather wait for the eventual reapplication process, and ‘see what happens’. Largely, this is not seen by customers as in any way fraudulent. DLA and AA customers tend to rationalise that they have been awarded a benefit for a period of time, so if their health improves in the meantime, that will be picked up on when the award is due for re-assessment. There was never an indication that claimants would not report such improvement, rather that they could justify the time delay in reporting this to DCS.

For those in receipt of CA there was evidence of a different set of potential changes, with regards to the health of the person in receipt of DLA or AA and the existence of that award per se. Further, there was the issue of the carer either altering their employment status in some way or experiencing a change in their own benefits (the most common of which is the underlying entitlement issue when they become of pensionable age).

However, it must be noted that with regards to the CA customers’ own circumstances, there was little consideration of employment (either seeking or increasing hours) as caring was often described as a ‘24/7’ responsibility that leaves no time for paid work. In the (rare) cases where this was a potential reality, there was little understanding of the precise rules governing working hours and income and maintaining the CA allowance. There was more likelihood of CA claimants acknowledging the need to report a change in circumstance when this was related to the DLA or AA award, with a perception that ‘the system will already know of the change’ which will ultimately, and inevitably, impact on the connected CA award.
5 Disputing a decision

In this chapter we review the benefit claims processes for those who are not successful with their initial application. This includes those who go through a process of disputing the decision, as well as customers who decide not to challenge this, applying again at a (sometimes much) later date. The final group, those who choose not to challenge at all, and remain ‘non-recipients’ are also examined.

Immediately, however, we present an overview of the disputes process, including the roles of the deciding office and the Tribunals Service (TS) and the various stages involved when a customer disputes an outcome. This is followed in Section 5.2 by our proposed model of the decision-making process customers go through when they are advised of an unsuccessful application and consider whether to dispute this. We have developed this model from the individual processes described by customers.

5.1 The disputes process

In the first instance, where a customer is not satisfied with the result of their application (for example, due to non-award, or award at a lower rate than felt appropriate), they begin their dispute with Disability and Carers Service (DCS), via the office responsible for the decision. The right to dispute and the process for doing so is outlined in the decision letter that the office sends to the customer. The opportunity to dispute is, therefore, available to all automatically.

Customers have a month from receipt of the decision letter within which to dispute; or six weeks if they request a written statement of the reasons for the decision. As the first stage of the dispute, the customer writes to the decision-making office, specifying the decision they are disputing, including the reasons (i.e. why they believe the decision to be incorrect) and potentially what they think the correct decision should be. This may include additional evidence (e.g. further medical information).

The office can change the decision at any time during the disputes process; if this goes in the customer’s favour, the dispute ends there and the decision is referred to as a reconsideration. If the decision is not in the customer’s favour, the dispute
continues as an appeal against the decision in its revised form. Similarly, if the office does not reconsider the decision, the dispute becomes an appeal and goes on to a full tribunal hearing, which, either way, is where TS become involved. The TS guidance recommends that if professional help is to be sought, that the customer does this as soon as possible.

On receiving the customer’s second communication (i.e., the appeal) the decision-making office prepares a ‘submission’ (including reasons for the decision, the evidence and relevant points of law supporting that decision). This, along with a ‘pre-hearing enquiry form’ (TAS1) is then sent to the customer and a copy of the submission sent to the TS.

The customer has 14 days within which to send their completed enquiry form to TS. This form provides the customer with the details of the tribunal hearing process and subsequently, TS with information necessary to organise a tribunal hearing, including whether the customer would like an oral or paper hearing, and details of representatives and/or interpreters, if applicable. In an oral hearing, the customer attends the tribunal to present their case in person. Where a paper hearing is chosen, the appeal is decided on the basis of written evidence only. Where no party (customer/DCS/TS) requests an oral hearing, the tribunal defaults to a paper format.

Most oral hearings are arranged as soon as the Enquiry Form is received by TS, usually within six weeks. Whilst in some cases, the tribunal Chair will specifically request additional information from either the customer or deciding office, in all cases, customers have the opportunity to provide evidence, be that additional documentation in advance, or verbal or witness evidence at an oral hearing. Moreover, if the customer feels that the decision-making office submission (i.e., case summary) is inaccurate, they can prepare their own version of facts and relevant law, also to be submitted in advance of the hearing.

On the day of the oral hearing, the customer is led through the tribunal hearing by a clerk, who greets them and explains the processes involved, from claiming expenses to the hearing itself. The tribunal is drawn from a judicial panel and both the customer and office can have representatives participate in the process, with the customer also entitled to take someone ‘for moral support’. This is fundamentally different from a customer representative, whom TS guidance advises should be a trained professional able to advise and assist in all matters relating to the tribunal, from points of law, to communication with the decision-making office, to preparing the customer submission.

The format of the tribunal hearing can vary from case to case, but will usually include opening submissions, evidence (where the tribunal takes the lead in asking questions), closing submissions (an opportunity for both sides to summarise their

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5 If the appellant does not respond to the TAS1, the appeal is likely to be struck out in accordance with the relevant legislation.
position) and the decision. This is usually made on the same day. Other outcomes include the decision being sent to the customer by post (where a decision cannot be made that quickly) or in extreme cases, adjournment to another hearing.

The remainder of this chapter describes the experiences of DCS customers who have failed claims, both those who choose to accept the negative outcome and those who dispute the decision and go through the above processes.

### 5.1.1 Customers experiencing the disputes process

It is important to specify the types of customer in our sample who had entered a disputes process with DCS (and potentially TS). This included a total of 17 customers whose dispute went through to an oral tribunal hearing, the vast majority of which (15 of the 17) were Disability Living Allowance (DLA) claimants. None of the Attendance Allowance (AA) claimants we interviewed had attended a tribunal, and as described below, some confusion remains as to whether their disputes (and those of some Carer's Allowance (CA) and DLA customers) involved reconsiderations on the part of the decision-making office, or paper tribunal hearings.

Indeed, with regards awareness of the disputes process, appellants who had experienced a tribunal hearing in person had good recollection of this and know that that was what they had participated in.

However, where customers did not attend a hearing, we found that there is very little awareness of the disputes process with regards to whether their dispute ended after a reconsideration (via the decision-making office) or following a paper tribunal hearing (thus, involving TS). Whilst these customers were sure they had ‘appealed’ they were unable to say whether a changed decision was as a result of a reconsideration or a tribunal. Whilst it was common for appellants to describe ‘sending forms’ or ‘documents’, it was unclear whether these were additional evidence in support of a request for their application to be considered by a second decision-maker, or as part of a fuller submission to be considered by TS. This discussion is revisited in Section 5.4.

Where appellants had their dispute co-ordinated by a professional, this muddied the water further, as often that professional would take charge of the process without fully explaining to the customer what was going on (see Section 5.6.1). Before examining these issues further, we present our model of the decision-making process that customers go through on hearing that their initial claim has been unsuccessful.

### 5.2 Unsuccessful claimants decision-making process

The eight stages we propose below describe the various impacts on a claimant’s decisions when informed that their benefit claim has been unsuccessful. Not all customers go through all eight stages, rather the model shows the wide range of impacts that may be experienced. We suggest that the exact route depends very much on the individual customer and their circumstances.
**Stage One** *Mindset at original claim.* This first stage refers to the expectations of claimants when they first apply, including their understanding of the claim and its value to them. This mindset provides an indication of the extent to which a customer may pursue a claim if the application is turned down.

**Stages Two to Four** *Being informed of the negative outcome, Reasons given/suspected for the outcome and Reaction to the refusal.* Where some customers accept that they are simply not eligible for the benefit claimed, others seek additional information. We suggest that the reaction of customers here is very much concerned with how ‘justifiable’ they feel the rejection is, and is met with acceptance (‘I’m not sick enough’/‘I work more than the prescribed hours’) or indignation (‘I deserve this’).

Where customers accept the failed claim because they appreciate that they may not have met the eligibility criteria, we suggest that they are also less likely to challenge that decision because they feel that ‘if I wasn’t eligible then, I won’t be eligible now’ and therefore, believe that any dispute on their part will not result in a different decision. We propose that the reaction to the rejection dictates whether customers accept the unsuccessful claim, go on to dispute or indeed, reapply.

**Stages Five to Seven** *Preparedness to engage further, Influence of others and Awareness of help sources.* For some customers (where rejection is met with anger or indignation) there is no possibility that they will accept a failed claim, and the decision is then very much around ‘what do I do next?’.
We have seen that the influence of other people is a major factor in whether customers decide to dispute a failed application. This is considerable where a professional assisted in the initial claim as that professional will often react to a failed claim with an assumption that the next stage is to dispute the decision. The influence of others is not always positive, as in some cases friends or family will simply agree with the customer that there is little to be gained in disputing a failed application.

Not all those who make an unsuccessful claim recall being made aware of the opportunity for dispute, despite it being standard practice for customers to be sent a decision notice explaining their rights. Customers are far more likely to pursue a claim where a professional is involved, carried along with the professional’s understanding of the process and their view that an initial rejection by no means has to be the final outcome.

Stage Eight *Understanding of next steps*. Whilst we have seen that the existence of a third party influence (professional in particular) will impact here, we suggest that so too will the reasons given (or suspected) for the rejection, and the reaction to that outcome. Customers who accept that their application failed because their situation does not fit the criteria for award, are less likely to dispute the decision on the basis that ‘nothing’s changed’ or they feel that they stated their case with sufficient clarity in the original application.

We propose that customers also react differently according to their understanding of what a disputes process is trying to ascertain, whether they will be submitting more information to clarify the initial claim, or whether they are about to go through a process of *proving* their eligibility from a basis where their situation is perfectly clear and understood, just not considered ‘enough’ to warrant an award.

We propose that it is when departing from any one of these eight stages, customers make a decision whether to accept the failed claim or to dispute this with the decision-making office. The remainder of this chapter presents the various options on hearing that a benefits claim has been unsuccessful, beginning with those who decide not to challenge the rejection, and become non-recipients.

### 5.3 Decision unchallenged

In almost all cases, claimants who experienced an unsuccessful claim and chose not to challenge this, completed the initial application either alone or with the help of a non-professional friend or family member. These included claimants of all three disability benefits (AA, CA and DLA). Just two claimants who had professional assistance with their initial application had their claim refused and chose not to dispute this with the decision-making office.

The most frequently given reason for AA and DLA rejections was simply that at time of application they were not sufficiently ill/disabled/immobile/dependent.
For the CA claimants, one was working too long hours, one had not provided sufficient evidence in support of the claim and one was turned down as his wife was not on AA.

Amongst AA and DLA claimants who remained non-recipients, the most common reaction to the decision was simple acceptance; that they were ineligible. For those who considered disputing the decision, this was swiftly decided against on the basis that their condition had not deteriorated in the interim and a belief, therefore, that nothing had changed. As described in the discussion of the decision-making model, these (non) claimants accepted that they do not meet the criteria for award, and fail to see how or why a dispute would be successful.

‘[Why didn’t you appeal?] Well, I thought I wouldn’t be successful ‘cos they’d just ask for the same information that I’d already put on that form, and it’d be the same again and they’d say “there’s been no change in your circumstances or anything, that’s the decision”.’

(DLA, 25-44, physical disability (Phys), York)

‘I got a letter back to say that I hadn’t got the Carer’s Allowance because I was working. But what I said was, that wasn’t made clear at the time I applied, because if it had been then there wouldn’t have been a point in putting a form in. I’m still working, so nothing’s different.’

(CA, 45-64, Phys, Llanelli)

A feeling of not wishing to repeat an application experience was cited by customers (on all three benefit types), who chose not to dispute on the basis that the original process was too difficult, humbling or intrusive. Further, there were a number of claimants who cited a simple change of heart as the reason for not pursuing a failed claim, with comments such as ‘I can’t be bothered’, ‘Other people are more deserving’, ‘On reflection I don’t need it that much’ and ‘Why should I take it further, they’ve already said no?’

For some of these claimants, this comes across as a very real reaction to their situation, we suggest impacted upon by their mindset at the original claim, and the reaction to the refusal (particularly where they were told that they were ineligible). However, there are cases where the change of heart as to the importance of their claim was combined with a negative reaction to the application itself, suggesting more to the change of heart than meets the eye.

‘[Did you not consider appealing?] No thanks, no thank you. The form is too official, there’s no empathy there, no sort of we’re sorry about this but we have to ask this, there’s no empathy there whatsoever, just this Nazi interrogation stuff, black and white. It’s too much trouble, I’m not rich, I’m not poor, but I’ve, I can only debase myself so many times. It’s not only that, there’s a lot more people in the world that need the money more than I do. All right, it’s a struggle with the bills and everything else like that, but I wouldn’t do it again.’

(DLA, 45-64, Phys, Coventry (non-recipient))
5.4 Decision challenged

For unsuccessful AA, CA and DLA claimants who decided to pursue their claim, there were two paths taken: dispute and/or reapplication. As presented in Section 5.1, at the request of a customer, a disputed decision can be re-evaluated by the decision-making office (i.e., a DCS reconsideration) or if this does not result in a satisfactory decision for the customer, through a tribunal hearing, as co-ordinated by the TS.

Awareness of the specific term ‘reconsideration’ is poor, indeed, just two claimants specified that they had been through reconsiderations. Appropriately, information and literature distributed by DCS and TS are produced according to Plain English guidelines, and further, are written to provide detail in a user-friendly manner and thus, it is not surprising that customers are not au fait with agency terminology.

Whilst this is perhaps not important from a customer point of view, it makes analysis and interpretation difficult, as appellant tended to describe ‘written appeals’ which, from the definitions provided by customers, could equally have been reconsiderations or paper tribunal hearings.

As mentioned in the discussion of the disputes process in Section 5.1, this is further complicated when professionals are involved, partly because of the customers’ loss of control (and awareness) of what steps are being taken. Further, some professionals co-ordinating disputes on behalf of customers, will write to DCS requesting a reconsideration, and know to include additional documentation in support of the challenge. The volume of paperwork and documentation described, and the processes involving much to-ing and fro-ing between the appellant and the DCS (and potentially TS) makes it difficult to ascertain which stage the ‘written appeal’ went to.

The discussion in subsequent sub-sections should be read with this in mind, that what is understood to be, and described as, ‘a written appeal’ by the customer could equally have been a paper tribunal hearing or a reconsideration.

Before turning to discuss claimants who pursued their initial failed application, we turn to those who decided not to challenge the rejection, but instead submitted a fresh application some time later.

5.4 Reapplications

Just three claimants with failed initial applications described reapplying some time later, one AA claimant after an interim three-year period and a notable deterioration in his health. Another, a CA claimant had her mother’s claim for AA declined as she was in hospital, resulting in a parallel failed CA claim. Once the mother was out of hospital, both benefits were reapplied for, both successfully.
The third case was of a young man suffering the after effects of an industrial accident, who had a failed claim in December 2004, and did not challenge the decision on the basis that he accepted the decision of ineligibility (‘not sick enough’). A further operation resulted in worsened mobility, and so the claimant decided to reapply on the basis that his eligibility may be increased, but he also recalled being more detailed in the second application.

‘[With the first application] I was very positive, because the hospital had said that I had done well to be out of hospital and not in a wheelchair and stuff. But second time I thought, well this is how I’m going to be forever now, I’m not going to be able to run or that sort of thing. So I put in all things like that, tried to do it more detailed. I think first time I’d have put the sentence “I can walk this far” but this time I said “I can only walk this distance but struggle with bags” and all that kind of stuff.’

(DLA, 25-44, Phys, York)

5.5 Reconsiderations and ‘appeals’

As mentioned above, there is an element of confusion over whether some claimants reporting ‘written appeals’ had disputed their outcome with DCS alone, or whether this had gone on to involve TS. The two instances where reconsiderations were specifically described (one AA, one DLA) were facilitated through a professional and resulted in successful awards of previously rejected claims.

‘Yes, it [the letter] said thank you for your communication asking us to look at your claim again. We have looked at the facts and evidence we used to make our decision and as a result we have changed the decision, and then they said that they would back date it to 4th May, my original application date.’

(AA, 75+, Phys, York)

This man’s wife had had a claim (also for AA) facilitated by a benefits adviser who was made aware of the husband’s rejection on her first visit to the couple, and explained the reconsideration process and assisted in writing the letter of request. The other case of assured reconsideration was with a young woman applying for DLA on behalf of her autistic son, who described a very difficult process of form-filling (alone) and subsequent clarification phone calls. There were issues over whether her son’s behaviour was atypical of a ‘normal’ two year old, which left her nervous over whether her child would be eligible, despite the medical diagnosis. On receiving the rejection letter, she called the office and was specifically advised to seek a reconsideration prior to appealing.
'It said on the refusal letter, it said on the bottom that I could appeal. I rang the office and asked them what was the best thing to do, and I was advised to go for a reconsideration first and if that didn’t work, then to appeal. She did give me the impression that it’s not uncommon to get a refusal letter and if you ask for a reconsideration it’s likely you could get it, which surprised me as it made it sound like they refuse a lot of people, not just me, and if they ask for it to be reconsidered, then they’re proving that they actually need it, so they’d get it then. I didn’t hesitate then in doing the reconsideration with the Health Visitor, and within two weeks it was like, here it is.'

(DLA, 25-44, Aylesbury (for under 16 (U16) Phys son))

This quotation provides an insight into the conundrum of written appeals/paper hearings/reconsiderations, in that whilst DCS sees a disputes process that involves a decision-making office ‘reconsideration’, or an ‘appeal’ which results in TS involvement and a tribunal hearing, customers simply know that they have ‘appealed’ their decision. As documentation is involved in both processes (especially when co-ordinated by a professional adviser), the distinction between reconsideration and (paper) tribunal is lost when we ask the customer to differentiate between the two.

Universally, ‘written appeals’ were co-ordinated by a professional, and involved the submission of further information in support of the initial application. This tended to be sought from medical professionals. As mentioned in Chapter 4, where a professional assists with the initial benefits application, some claimants lose track of the process, but this appears to be a positive factor, in that whilst they do not fully understand the processes, having a professional co-ordinate their claim allows an element of relief.

The same is common amongst those having a professional co-ordinate their dispute, one man with terminal cancer described how much he knew about the process of disputing the decision when his social worker first stressed to him that he should take his rejected DLA application further.

’[Social worker] did explain that she was writing a letter in to appeal against the decision, and that she would get the doctor to write a letter to go with it, of why I should get the money, and things like that, but that was all, and she said it would go to a review board of different people that originally done it. [So did you have to do anything?] No, no, [social worker] did everything.’

(DLA, 25-44, Phys, Coventry)

The remainder of this section largely refers to the experiences of DLA claimants, with tribunals appearing to be a relatively uncommon experience for our AA and CA claimants.

As described earlier in the chapter, we propose that the initial stages in the process of deciding whether to dispute an unsuccessful benefit application are concerned with the attitude of the claimant at the original application, the reaction to the negative outcome and propensity to engage further. Claimants opting to proceed
with a dispute are likely to have decided that the claim is important enough to them, that the outcome is potentially open to challenge and that they are prepared to go through a disputes process.

With regards to reactions to the notification that an application has been unsuccessful, a failed claimant from Swansea cited the indignation she felt when her DLA application was turned down, comparing her experience with a successful claim made by an acquaintance whose disability she perceived to be less severe.

‘It made me feel annoyed more than anything, because at the same time I knew a lady who’s got arthritis in one of her fingers from working on a till, and she’s on £250 or whatever it is a month through hers. I’ve had a serious accident, held all over the place with screws and pins, the doctors told me that I was very lucky not to lose my leg, and they told me they couldn’t help me, they weren’t prepared to help me.’

(CA and DLA, 25-44, Phys, Swansea)

As was true for other customers, this claimant based her attitude on the perceived level of disability rather than the extent to which the disability affects day-to-day living, which is actually the basis of award.

Another failed DLA claimant described how such indignation fuelled her decision to appeal, taking the pursuit of the application past a simple benefits claim after she was challenged by the DCS on the extent to which her Myalgic Encephalopathy (ME) was a physical manifestation, or ‘all in the mind’. This was a rare reaction to a failed claim.

‘So whilst it does affect your mind, it’s not a mental thing, it’s a physical thing and I just saw this and I thought, there’s absolutely no way I’m living with this and it didn’t even boil down to DLA money after that, it boiled down to the principle… I thought how dare they? My life’s been taken away from me, how dare they? And they haven’t even got any reasons behind it, so I’m not doing this on me own, but because we couldn’t get legal help we had to employ a solicitor, so far, my solicitor’s cost me £800.’

(DLA, 45-64, Phys, Newcastle)

Also of importance in deciding whether to proceed to dispute a decision are:

• the influence of others;
• awareness of help sources; and
• understanding of next steps.

Indeed, these three factors were present in the single most common approach to disputes, where a professional stepped in and took the process forward as the next step in the claim. Often, but not exclusively, this was the person who assisted in the original application. Here, an external (expert) influence encouraged the claimant to appeal, provided a source of help and was able to take the claimant through the process involved (sometimes doing this with little claimant involvement), providing that vital understanding of next steps.
'To be honest, I felt really dejected and I thought, well I'm not taking this any further, but people were saying to me, “you’re crazy, you’ve got to keep going with this”, so I thought I’d see about appeal, so I went to the CAB and this fella there said to me “well, if you take it to appeal, I think you’ve got a good case”.'

(DLA, 45-64, Phys, Durham)

'[Did you spend any time deciding whether to appeal or not to appeal?] It was automatic. [Social worker who assisted with the original claim] said, you’ve just got to appeal. Do it. She, well [social worker’s] words were, they quite often do this the first time, so appeal and you’ll probably get it.’

(DLA, 25-44, Phys, York)

Alternatively, those not in contact with a professional tended to cite the letter as informing them of the right to dispute the initial decision. It was common for these few appellants to be convinced that the unsuccessful claim was a mistake or injustice, so the decision would be overturned and this provided the impetus to challenge the non-award. The presence of a professional here appears instrumental to the manner in which the dispute is approached, with more conviction potentially required of customers deciding to challenge DCS without help.

5.5.1 Oral tribunal hearings

In general, the more common experience of the disputes process was an oral tribunal hearing, with the appellant attending in person. Appellants who pursued an oral tribunal hearing with professional support tended not to engage in a ‘decision-making’ process as to whether to challenge the rejection, rather, this was seen as an automatic next step, very much led by the professional. Whilst leading up to, and on the day of the hearing, appellants with professional representation/assistance seemed less knowledgeable about all elements of the process, this appeared to go some way to alleviate worrying, with the assumption that ‘all was in hand’.

'[Do you feel that the process was explained to you sufficiently before you went to the appeal?] Yes, I did, because this lady came with me, I can’t remember where she came from, it’s something to do with human rights, but I can’t explain which one it was…and when she came in with me, she did a part of the talking. She had to produce a doctor’s letter and various papers. I hadn’t seen them so I couldn’t, well, I wasn’t allowed to see them. [And now that time has passed, how do you feel about the appeals process?] I think it’s a good thing, it was appropriate, yeh.’

(DLA, 65+, Phys, Durham)

It was near universal (amongst our sample of customers disputing a DCS decision) for these to be hearings in pursuit of DLA, with claimants tending to have assistance from a professional, often the person who assisted with the initial application as suggested already.
‘Yes, she did [Disability Advice Bureau Adviser]. I didn’t even know you could appeal, she advised me to. She said it can be a little bit nerve racking, because it’s a panel of people sitting in front of you, and it’s true, you know, you’re facing them and it’s very intimidating, it’s really not a nice thing at all, you feel like you’re on trial, you feel like you’re a criminal, and you also feel like you’re a mental health patient with all these people observing you. That was nasty, that was degrading.’

(DLA, 25-44, Phys and mental health (MH), Ipswich)

‘We should have been given the chance to appeal, so that’s what he did [DIAL Adviser], he took it to tribunal, he explained about it, that it wouldn’t cost us anything because the DIAL centre is a charity so they would pay for it.’

(DLA, 60+, Phys, Bury St Edmonds)

The purpose of the hearing is to decide whether a customer is legally entitled to the benefit applied for, and Section 5.1 outlines the process, including that the tribunal takes the lead in asking questions, gathering ‘evidence’. Whilst this is a fundamental element of the hearing, we suggest this is responsible for appellants describing the tribunals process negatively, with claimants describing feeling on trial and as if sitting before judge and jury.

‘At the tribunal itself, understandably, they are trying to trip you up, and I do understand it, there are people out there who should never be on it. So I have every sympathy with the tribunal for trying to trip people up, but when you’re on this side, it doesn’t feel, I’m not going to say it feels good, put it that way.’

(DLA, 45-64, Phys, Perth)

‘With hindsight, you can’t blame them, because they want to sort out genuine people. And it is a difficult, I mean we know of people that are getting DLA money, and you think, well what’s wrong with them? And you can understand that the criteria of questions, that they’ve got to ask, they need to. But to me, and I don’t say this lightly, if you’ve got all these medical records in front of you, I don’t think that you should really stress people out to the level that I, to be honest, I was in a terrible state. I was in an absolute awful state.’

(DLA, 45-64, Phys and MH, Coventry)

Amongst customers experiencing oral tribunal hearings, there was little belief that the disputes process exists to review a benefit claim independently and little understanding of the difference between DCS and the TS, indeed, of the fact that another agency became involved at all. There was a widely held perception that the hearing was held to reaffirm that the claim was not valid, an opportunity for the tribunal to uphold the original DCS decision.
As an example of this, a man appealing a failed DLA claim was told on entering the tribunal that the decision to uphold the rejection had already been made on the basis of evidence from a care assistant, who had proposed that the problem of not being able to stand in the kitchen to chop vegetables could be solved by carrying items through to the living room and preparing food sitting down.

‘They asked “what problems do you have at home” and then they’d give me an answer to what I should be doing. Like, I can’t stand and peel potatoes, “well put them in a pan, walk through and use the coffee table”. I can’t lift heavy pans out of the oven, “well microwave it”. “How far can you walk? Well walk a bit less and sit down more often”. It sounded like it had all been pre-planned to what, off the form, what I’d already put down, and what the answers were going to be.’

(DLA, 25-44, Phys, York)

Whilst information about the tribunals process is available to all in hard copy and from the tribunal clerk on the day, appellants tended to be quite vague about the format the tribunal had taken, and the reason behind the day’s proceedings. Whilst uncommon, for some this resulted in a straightforward process of ‘panel-questions-answers-decision’. In all cases where appellants were not phased by their tribunal hearing, a professional assisted in the preparation and eased the hearing itself by providing both expert and emotional support.

‘Well, I just sat, I sat before a panel of three people, three men, and one of them was a doctor, and he’d gone through my notes, they asked me questions and then I had to leave the room and go and sit in the waiting room and wait till they’d discussed it, and the young woman that was representing me [from the Association for People with Physical Disabilities] went into the, back into the interview room to get the decision, and the answer was yes.’

(DLA, 45-64, Phys and sensory disability (Sens), Hull)

It was, however, common for claimants to experience a lack of understanding over who was present at the tribunal hearing. Despite the pre-hearing information describing this, and introductions being made on the day, appellants rarely seemed to capture precisely who was present, what their role was and how they came to be involved.

‘It’s very stressful when you don’t understand the legal system. Sometimes I think they make it complicated just on purpose, but it seems that it could be done a lot easier, a lot easier to understand for a layman, if they just put a little more effort into it.’

(DLA, 65+, Phys, Bury St Edmunds)

Claimants who took a professional representative described a less harrowing experience than those who went alone or with a family member. However, appellants did not always recall being informed that they were allowed to take someone with them.
‘They tell you that there’ll be three people on the appeals panel, and they tell you who the doctor’s going to be in case you know them, there’s a letter that comes out with that on it. They don’t tell you anything else, like you can take somebody with you, they don’t advise you to have a representative or anything like that, you have to find out all these things for yourself. You’re ill anyway, and you’re got to go and face three people, it’s like, honestly, I feel that I’ve answered more questions than somebody who is up for murder.’

(DLA, 45-64, Phys, Newcastle)

Whilst it is common for those with representation to experience the tribunal more positively than those attending alone/with non-professionals, and for the relative lack of comprehension to prove less of an issue, this is not exclusively the case. One man described his wife’s DLA tribunal hearing as halted and hindered in various ways because of lack of evidence co-ordinated by the professional representation (a Citizens Advice Bureau (CAB) worker), resulting in a postponed tribunal.

‘This will be the second appeal see because the first one, she [CAB adviser] hadn’t done any proof. She hadn’t gone to the hospitals and got any paperwork to come to show them.’

(CA, 65-74, Phys, Newcastle)

For failed claimants who attended their tribunal hearing without a professional (either alone or with a family member), such accompaniment appears to do little to ease either the experience or assist the outcome, despite its initial appearance as ‘moral support’. Further, as evidenced by the two quotations that follow, appeals tribunals can be largely negative experiences despite the nature of the support (the first customer having professional support, the second being accompanied by a family member).

‘…they are very personal, for instance, can I take myself to the toilet? They asked if I need help in that respect. It feels demeaning, but like I say, they have to know the truth. But sometimes I do think a bit, that’s a bit too much.’

(DLA, 45-64, Phys and Sens, Hull)

‘I had my two daughters with me actually, the eldest did say something small, but they came out in tears with me, ‘cos they said mum that was awful, I don’t ever want you to have to go through that again.’

(DLA, 25-44, Phys, Hull)

On the whole, appellants attending an oral tribunal hearing alone or with a non-professional associate were far more likely to describe being ‘on trial’. Whether this was a true reflection of the behaviour of panels when in a hearing with an unrepresented appellant, or simply an interpretation of the customer due to feeling insecure, is unknown. Further, for those attending without a professional, the process is described as less well co-ordinated, although we conjecture that this may be an impression gained of a tribunals process that is little understood rather than a realistic interpretation of events.
5.6 Dispute outcomes and evaluations

By far the most common experience amongst claimants whose claims went through a disputes process was one of success; either receiving a benefit previously not awarded or succeeding in pursuing a higher level award. These claimants tended to go through the disputes process with the assistance of a professional. Indeed, upheld claim rejections were more common amongst those who entered a disputes process alone or with the support of a friend or family member.

Given that the process of attending an oral tribunal hearing tends to be experienced negatively, appellants were asked how the process could be improved for them. Some focused on the distance to the hearing and whilst there may be little the TS can do about this, there is an associated issue of whether appellants can afford to pay travel costs to have these reimbursed at a later date or whether they need the monies before travelling because of cash flow issues.

‘Not really, because it was all dealt with by the DIAL centre. We weren’t actually dealing with them, I think if we’d have to had dealt with it ourselves, I think it would have been horrendous…I’d probably have made sure it was nearer.’

(DLA, 65-74, Phys, Bury St Edmunds)

‘[Is there anything you think should be changed about the appeals process?] I think it would be a lot easier if you could get to the appeal. They say that they will reimburse you, but you’ve got to have the money in the first place to get there...if you’re on a set amount of income support you haven’t got that spare money to pay to get there.’

(DLA, 45-64, Phys and Sens, Reading)

It is more common for appellants to suggest changes needed with regards to provision of information ‘pre-tribunal’ so that they fully understand the processes, procedures and format of the session. Despite the fact that the TAS1 (pre-hearing enquiry form) outlines what is involved in a tribunal hearing and suggests that customers ask for the information leaflet, it was common for appellants to comment on not feeling fully aware of what the processes were. Given the stresses discussed earlier, it is feasible that this would go a long way to easing the experience for claimants. One appellant described how this lack of understanding was the root of her feeling like a guilty party on trial.

‘[Did anybody say to you “this is what’s going to happen today“?] No, I don’t think so, no. To be honest, you go in there and you feel guilty before you start, because you don’t know what’s going to happen, and a lot of the time you don’t always understand what they’re on about, and you, I felt that it was my fault, it was, it’s like going to trial for something you haven’t done.’

(DLA, 45-64, Phys, Coventry)
For claimants who attend their oral tribunal with professional representation, this eases the process and as a result, hearings are evaluated more favourably. We suggest that this is due to increased comprehension of the process, as well as the expert and emotional support provided.

It is common for appellants to evaluate attendance at an oral tribunal hearing by saying how they did not feel heard or felt that they were not given an adequate chance to state their case. Perceiving the proceedings as a ‘trial’, appellants expect to be able to ‘defend themselves’. Initially, this suggests that more information from the TS before tribunal would be usefully received by appellants, as it may serve to dampen their expectations about the extent to which they are able to present their argument over and above the formal documentation and proceedings.

However, this is a need that has already been partially met, as the TS have a series of leaflets which are available to customers, referenced on the pre-hearing enquiry form. We suggest that referencing these is not enough for appellants, that the leaflets need to be distributed with the form rather than relying on customers making the effort to source the leaflets under their own steam. This point is resumed in Chapter 9.
6 Experience of Disability and Carers Service/the Tribunals Service

This chapter, which starts by looking at familiarity with the brand names of Department for Work and Pensions (DWP) and its agencies, primarily focuses on the experience that customers have in dealing with Disability and Carers Service (DCS). It outlines some key points at which contact between applicants and DCS may occur and then looks at levels of satisfaction with those contacts. The chapter closes with a comparison of the DCS experience with that of The Pension Service and Jobcentre Plus.

6.1 Familiarity with brand names

With certain combinations of customer and agency, it is understandable that there would be low levels of familiarity with brand names, as those of working age have little reason to engage with The Pension Service, and the services offered by Jobcentre Plus have little relevance to retired people (although there may have been contact pre-retirement). However, even with these caveats, across the board there was low awareness of both the name of the DWP and its constituent agencies – DCS and The Pension Service. Familiarity with the Jobcentre Plus name was higher, particularly amongst those who had claimed other benefits such as Jobseeker’s Allowance (JSA) or Incapacity Benefit (IB) (often Disability Living Allowance (DLA) customers as opposed to Carer’s Allowance (CA)).

Customers tended to talk about the Benefits Office, Social Security, DSS, social services or just ‘the Social’. This lack of awareness appeared to make no practical difference to claimants, none of whom had experienced any difficulty in obtaining claims packs or finding contact details if they needed to phone to chase claims or get queries answered. For those unable to make contact in any other way, Jobcentre Plus, the most visible face of DWP, would be the default contact route.
It should also be noted that it was very common for claimants to fail to differentiate between local and central government assistance. They had no clear understanding that Council Tax Benefit (CTB) and Housing Benefit (HB) were dealt with by the local authority, whereas disability benefits and employment-related benefits were the responsibility of central government. Instead, there was often a vague notion that ‘somewhere official and to do with government’ deals with benefits, and that they were responsible for all payments.

Where customers had been involved in a tribunal hearing, there was no obvious familiarity with ‘the Tribunals Service (TS)’, simply that a tribunal is attended by a number of people in an official capacity. As mentioned in the summary, whilst this is unsurprising seeing as the service was only developed in April 2006, there were no spontaneous mentions of the Appeals Service either. Indeed, for some customers, the distinction is purely a ‘them and us’, with little thought given to whether the appeals tribunal is managed as part of DCS or by a separate agency/service.

It was notable that a number of older people (AA or CA claimants) assumed that their claim was dealt with by The Pension Service, because their benefit (or entitlement) was incorporated in the pension statement that they received through that agency. Again, such incorrect assumptions made no material difference to customers, especially if their benefit needs had been met.

Although there was a general lack of understanding about where responsibility for particular benefits lay, claimants who had claimed CA in addition to DLA or AA tended to be aware that there was a different office dealing with this and they were able to make comparisons of the service and contact they had had with each.

However, it appears that an overall lack of clarity meant that customers were unable to consistently discuss their experience with DCS in any meaningful way since they were themselves unaware of which agency they were dealing with. There was particular confusion between claims relating to IB and DLA. There were rare occasions where customers discussed their DLA appeal, which, on careful questioning, turned out to be an IB appeal. Where experiences were negative, dissatisfaction would often be generally directed at the overall system rather than at DCS specifically. The following discussion of satisfaction should be read with these points in mind.

### 6.2 Points of contact

Customers tended to describe minimal contact with DCS, something noted by professional advisers working with claimants (Chapter 2). There were a number of potential contact points that were experienced universally by claimants, and others (especially those initiated by the claimant) that were less common. We note that contact could be made at any of the following points during and subsequent to a claim.
• **Initial contact** was possible prior to obtaining or submitting a claim form. Claimants commonly contacted the relevant helpline or Benefits Enquiry Line if they had no professional adviser acting for them. Typical queries were to ascertain eligibility criteria generally, to discuss their own case, or to clarify points on the form/accompanying documentation.

• **Acknowledgement letters** were received following submission of the application form. This was generally rated as clear and providing a time frame within which the decision would be reached. Dissatisfaction therefore would only be voiced by those who had waited for a decision for longer than the specified period.

• **Telephone queries** were sometimes initiated by customers to enquire about the progress of their claim.

• **Additional queries** were sometimes initiated by DCS (by phone or in writing) to clarify aspects of the claims form.

• **The decision letter** was often the final contact for those whose claim had been accepted (and at an acceptable level for the recipient). Those rejected could then be involved in the disputes process (see Section 5.6 for customer evaluation).

### 6.3 Satisfaction with contact

The satisfaction experienced by DCS customers in relation to their dealings with the agency depended on a number of different factors. Most important was the outcome of their claim – invariably, those whose claim was successful and especially those who were successful on their first application, consistently had positive things to say about the process and their contact with staff. Conversely, those with unsuccessful claims – and especially those who had been turned down on reapplication after receiving benefit for some time previously – negatively reported their experience.

For all telephone contact, one of the main areas of criticism was the difficulty in getting through to a person who was able to adequately deal with the query. There were common complaints about being left waiting on the telephone for excessively long periods. It was possible to be left holding for 20 – 30 minutes and then to be cut off without ever having spoken to anyone. Others recalled being passed from one department to another in a vain attempt to speak to an appropriate staff member. For people who were already ill and/or anxious, this was often the last straw.

‘They keep on passing you around, that’s what winds me up. You phone them and... then you’ve got to wait for someone, then they’ve got to pass you on to someone else. In the end my patience just snapped and I said all right then, and you put the phone down and just forget about it.’

(DLA and CA (rejected), 25-44, physical disability (Phys), Knutsford)
Overall, DCS staff were seen as helpful by those who had contacted them for advice or information and some claimants had nothing but positive comments to make about staff.

‘I’m really pleased and satisfied at the service I’ve got. I am, I’m really, I can’t get over it, I can’t get over it, it’s all, I’ve been well looked after. If anybody says any other, well they’re very hard to please. But the service I’ve got, the people on the phone, I mean to say it doesn’t matter, anything at all, they’re very polite and they’re very helpful and I couldn’t put anything wrong.’

(AA, 75+, Phys, Newcastle)

Even where there were other complaints, staff were perceived as polite.

‘I don’t know whether you’d call it luck or what. I have been very fortunate in the people that have actually dealt with me. The service has been very considerate and bear in mind I’ve been very fragile and when you’re fragile you are very critical, you want everything to run smoothly and everybody to say exactly what you want to hear and want them to say it’s a very strange transition in your life and I have to say I was very fortunate. I don’t know whether it’s the norm but that’s how it was for me.’

(AA, 65-74, Phys, Coventry)

Negative perceptions of staff were exceptional but more commonly found amongst those trying to find out about the progress of their claim or, particularly, those trying to find out more about why their claim had failed. Amongst these groups, being exceptional cases, applicants had found staff rude, unsympathetic or uncaring.

‘They have no idea. They’re civil servants they push paper, they fill out forms, they do their job, but when it comes to speaking to people on the phone they haven’t got a clue, they don’t care, they don’t care about my circumstances, they don’t care about anybody’s circumstances, they’re very, I wouldn’t say rude, they just don’t care. There’s no sympathy.’

(CA and DLA, 25-44, Phys and sensory disability (Sens), Coventry)

Others queried staff expertise or training. A common complaint was that staff had no understanding of the particular condition that the disabled person had.

‘Some of them can be helpful, some of them just don’t want to know basically, “you’ve been told you’ll hear from us soon okay?”. Sometimes I put the phone down on them because of their attitude. You think when you phone and they say at the beginning “calls may be recorded for training purposes”, the one that just spoke to me ain’t blinking trained yet.’

(DLA, 25-44, Phys and MH, Ipswich)
'The chap that phoned me from the DLA, it did actually make me worry, he did make me anxious about what I was dealing with, because I thought then I’m up against a brick wall, do you know what I mean? I thought it’s hard enough understanding myself [my son’s] condition, let alone trying to explain it to someone else that hasn’t got a clue.’

(CA and DLA, 25-44, mental health (MH) and learning difficulty (LD), Aylesbury)

There was some criticism that the service had deteriorated since queries had been centralised to a call centre. The quality of call centre staff was experienced as variable and therefore customers could not be sure that their queries could be adequately dealt with.

‘Overall I think the service is not very good and the length of time you have to wait, sometimes it’s just really depressing. I remember one woman who… was more helpful, the fact I remember her specifically because she and she said to phone back. …She seemed to know what she was talking about which the others hadn’t really. …Considering the urgency some people need their benefits dealt with and it’s like say things getting lost or different departments not knowing which department is the right department to do the thing and that kind of thing it’s a bit complicated and could do with a bit, it probably needs a bit of an overhaul so that things are run a bit more efficiently.’

(DLA, 16–24, MH, Perth)

Several customers commented on the difficulty of speaking to different people each time they called. They would all have preferred to deal with one person to provide continuity and avoid having to start from scratch each time in explaining their situation. This was perceived as a waste of everyone’s time. Where applicants had been in contact with both DLA/AA staff and those dealing with CA, it was the latter who tended to be more positively perceived.

The benefits website is not widely used by customers; those who had done so tended to be (although were not exclusively) younger people who were exploring the possibility of claiming DLA and/or CA. The most common evaluation of the website was that it includes all relevant information in an accessible format.

In summary, whilst it was uncommon for customers to have had personal dealings with staff, those who did had mostly positive experiences to record. On the rare occasions where customers were not positive, staff were described as unhelpful or uncaring and with insufficient familiarity with the specific condition that was the subject of the application. The issue that staff can sometimes lack current benefits knowledge (raised by professional advisers, reported in Chapter 2), was not a concern for customers themselves, we suggest because even the sparsest staff knowledge will be more than that held by claimants.

Those who had experienced appeals tribunals, however, were largely negative about the (written or personal) contact experienced, regardless of whether their
appeal was successful or not. This was especially true where the appeal was attended by the appellant (as opposed to a paper hearing/reconsideration), and even more so where the customer went alone or with a non-professional. Even in cases where an appeal had successfully overturned a previous non-award, this success did little to ‘over-ride’ any negative perception of an oral tribunal hearing. When we look at the level of anxiety experienced by some appellants going to a benefit tribunal in person, a subsequent award is not significant enough to counter how much stress was caused by the hearing itself.

This is in contrast to the way customers immediately successful with their first application tend to ‘forget’ the difficulties faced when completing application forms, once they receive notification that their application has been approved; they appear much more ‘forgiving’ of DCS and the claims process. In interpreting this finding, we propose that where immediately successful customers found form-filling arduous but subsequently received the benefit, the success went some way to cancelling any bad feeling about the claims process. We suggest that this is because of the relatively low significance of form-filling compared with the comparatively high significance of going through an oral tribunal hearing. Form-filling is a part of life for many people; application forms for jobs, learning programmes, financial matters and the like, mean that, even where literacy is poor, forms are part and parcel of many activities.

However, attending a tribunal, no matter how far the TS goes to explain, assist and ease the experience for customers, is not a common life experience, and has the associated links with ‘court’, ‘law’ and ‘trials’ for many; something that generally law-abiding citizens do not experience frequently. This makes a tribunal a significant event in the life of the customer, one which is not easily forgotten or lessened through being successful in a benefits claim.

6.4 Comparison with other Department for Work and Pensions agencies

Only a small number of individuals had experience of other DWP agencies which they were able to compare with DCS. Even where people were customers of The Pension Service and/or Jobcentre Plus in addition to DCS, they were often unable to distinguish between them. As noted earlier (Section 6.1), there was little understanding of the various DWP brands or of the split in responsibilities across DWP or, indeed, across all public sector organisations providing benefits and related guidance.

Where customers were aware of having made contact with The Pension Service – normally to enquire about their pensions or a letter that they had received – they were generally very happy with the service. Some (generally AA applicants) had also applied for Pensions Credit.
Commonly, customers (especially AA recipients) had received letters from The Pension Service. Details of the benefit were included in pension statements and it was this that was the most commonly cited cause of confusion between the two services in the minds of customers.

There were seldom any complaints about the letters or financial statements received from The Pension Service, although one AA recipient had become anxious because she had received several apparently contradictory statements in close succession. The differences between the letters were small and needed careful perusal to understand any changes.

‘I read through the letter and think oh well, I’ve said oh look this is just a repetition, I can’t understand why they’ve sent it and I forget all about it. But with all respect to you Mum, you get a little bit upset don’t you? You did get a little bit upset oh there’s another letter what am I going to do with this? For Mum’s generation it’s difficult to understand why she’s had it. I just look at it and I think you know it’s just a repetition letter.’

(CA and AA, 60+, Phys, Bury St Edmunds)

Some CA and DLA customers of working age had experienced contact with Jobcentre Plus. As noted earlier, a number of individuals had very muddled perceptions of DCS and Jobcentre Plus staff since both were concerned with their benefits – such vagueness was particularly common amongst those claiming IB in addition to DLA.

Where customers were more clearly able to differentiate between the service they had received from the two DWP agencies, contact with Jobcentre Plus had most commonly occurred before their claim for disability benefits. Occasionally, it was an adviser at Jobcentre Plus who had suggested that the person should apply for disability benefits. However, there was an expectation that all Jobcentre Plus staff would be familiar with disability benefits and would discuss the full range of benefits available to disabled customers. On occasion, customers were (with hindsight) surprised that Jobcentre Plus staff had not mentioned the benefits to them and assumed that this meant that staff were not familiar with DLA and/or CA.

Amongst those interviewed it was highly unusual for people to have spoken to a specialist Disability Employment Adviser. In general, where customers had the opportunity to compare DCS and Jobcentre Plus staff, the latter were considered less helpful and less knowledgeable.
Another point of contact found between disability benefits and Jobcentre Plus was CA recipients called in to their local Jobcentre Plus office for Work Focused Interviews, something felt to be totally inappropriate.⁶

‘The Jobcentre sent me a letter saying that after your child is two they start getting you back into work. I phoned them up and I said, you should know the situation, it should be on the computer. And he turned round and said to me, if you don’t turn up to the interview they’ll be taking some more money off my benefit. So I turn up and [as I expected] he did turn round and say, you can’t, there is no point going back to college until [your child] is at school because they’ll only fork out money for another carer to look after him when I’m doing it.’

(CA, 16-24, Phys and LD, Reading)

⁶ It must be noted that; as from October 2005, CA customers no longer have to attend for WFIs. Whilst we mention the issue here as a valid experience for some of the customers interviewed, we highlight that policy changes mean that this situation would no longer arise.
7 Receiving and using the benefit

Recipients of Attendance Allowance (AA) and Disability Living Allowance (DLA) tended to describe the purpose of their benefit as some form of compensation for being ill or disabled, allowing them to ‘do the things that other people can do’. Those in receipt of Carer’s Allowance (CA) largely described their benefit as replacement income as they cannot work and fulfil their caring role at the same time. It was common for there to be a sense of justice behind these viewpoints, that claimants are entitled to the extra income as it provides them with a chance of equality with people whose lives are not adversely affected by disability or ill health.

The single most common use of disability benefit income, across all three customer types, was ‘nothing in particular/general income’, although this was elaborated upon in two ways: Firstly, and as raised in Section 4.4, there were claimants who relied on the income to simply make ends meet, often merging their benefit with all other household income to pay for rent, bills, food, clothes and transport; basic everyday living expenditure. A family dependent entirely on a combination of CA (father), DLA (mother and son) and Income Support (IS) (father) and Child Tax Credits described how the benefits income is largely taken up by general household expenditure, although with the occasional treat to boost the diabetic son.

‘It just makes every week, the money that goes out to pay for bills, it makes that a bit easier to pay for them. It’s £47, it’s not blinding, not a lot of money, but it certainly helps, and we can help buy [son] the odd present and that, to cheer him up when he’s down.’

(CA, 25-44, physical disability (Phys), Aylesbury)

Secondly (also equally common amongst all three benefit types), there were claimants who could not specify how they spend their benefit; this was not related to a lack of income (as they felt that they had sufficient income to have ‘the little extras in life’) but rather they chose to merge all of their personal income, knowing that both necessities and luxuries would be paid for at the end of the month.
Amongst those who can cite a specific use of their benefits, some are very deliberate in that ‘it pays for xxxx’, whilst others are aware that the additional allowance enables them to do certain things, simply as the benefit expands the general household income. Two examples of this follow; firstly with a woman budgeting her husband’s Alzheimer’s-related AA claim described some of the expenditure she can account for given the benefit, also reiterating that the allowance provided a general cushioning in the overall household income.

‘It’s an advantage because now he has to go to the chiropodist every six weeks, so that pays for that. It also pays for the cab if we have to take it because the two of us don’t drive and never have. So you know, you think to yourself, well alright, I’ve got that money there, or again during the winter, even though you get the heating allowance, you haven’t got to worry, because you know again, you’ve got that balance.’

(AA, 65-74, mental health (MH), South Woodford)

The second example of benefits ‘allowing the little extras’ is an elderly couple, both AA claimants, knowing that the AA contributes towards the household income, but by no means being dependent on the benefit.

‘I’ve told myself that it’s not a waste of money to have somebody to come and clean twice a week for an hour, and we have somebody to help in the garden and because that money’s there, I’m happier to do it, but if it wasn’t there, we could still do it, we could still afford it.’

(AA, 75+, Phys, Aylesbury)

Whilst cleaners/gardeners were amongst the most common specific uses of AA, the most common specific uses of both AA and DLA – outside of those DLA recipients who had a Motability vehicle – were transport (namely taxis) and disability/illness-related items including medicines, treatments, foods and aids. Adult DLA claimants with mobility limitations were often in a relationship where their partner dealt with day-to-day chores relying on transport (mainly shopping), so where a car was not available to the household, public transport was required. When the claimant needed to venture outside, this was often for hospital or day centre visits, and the requirement for a taxi arose. Similarly, where the DLA claimant was a child, and public transport was not appropriate in a car-less household, parents would often make hospital and related journeys by taxi.

It was more common for AA claimants to either live alone or with an equally infirm partner and the likelihood of either having access to a car or feeling confident of using public transport, was much reduced. These claimants tended to display a more general reliance on non-public transport, including to attend social events and to do their food shopping, as well as the previously discussed trips to see their General Practitioner (GP), or to attend hospital appointments.

‘The Attendance Allowance helps me to pay for minicabs as well, as because if ever I go out, I know I’ve got to have a car. Every time I go shopping it costs me £8, that’s £4 each way.’

(AA, 75+, Phys, South Woodford)
It is common for claimants to have requirements pertaining to their illness or disability and for these needs to absorb the additional income from the allowance. A young woman described her dietary needs as a diabetic, and how she budgeted for this whilst at university as ‘the student diet isn’t generally, you can’t live on beans and pot noodle in my situation so I found (the benefit) really helpful’. A pension-age woman caring for Human Immunodeficiency Virus (HIV) positive son cited a wide variety of medical needs that his DLA (and her CA) catered for.

‘…muscle building foods and vitamins and stuff like that, anti oxins and foods from Herbal Life that are quite expensive…special shampoos and things like that for his scalp ‘cos he gets a very dry scalp…special bedding and his own towels.’

(CA, 45-64, Phys, Aylesbury)

However, whilst it was common for AA and DLA claimants to cite disability-specific uses for their benefits, this was rarely for care, rather for food, medicines and aids to assist in mobility as opposed to any assistance from a third party. In exceptional cases there were examples of setting aside the benefits for carers such as: an AA recipient setting aside her allowance for a cleaner and special foods for her Irritable Bowel Syndrome (IBS), with the remainder allowing her to employ a carer for an hour a week (at £14 per visit); and a DLA claimant described how his benefits allow for an external carer for both him and his wife.

‘Like, for them baths I get, she comes Tuesdays and Thursdays to bath me. Now it’s £10 a bath, that’s what I’m paying Lancashire County Council. I get a bill every month for £80. Now that comes out of that [AA]. Same as if I wanted more help, I’d have to pay for that, but there’s money there now to pay. Like I say, if [wife] is poorly, I’d have to get somebody else in.’

(AA, 65-74, Phys, Burnley)

Other claimants described how they use their disability benefit for ‘the little luxuries’, although precisely what constitutes a luxury differed from person to person. At one extreme, a DLA recipient from Leamington Spa mused as to which aspects of her life would change were she not to receive the allowance, suggesting that she would no longer use taxis, have massages or buy pre-prepared vegetables. At the other end of the scale, an AA recipient from Coventry explained how whilst the benefit contributed to everyday expenditure, it allowed her to have her milk and papers delivered.

‘It does get swallowed up in day-to-day living, like I have a milkman which sounds silly but it is quite a luxury, and I have a paper delivery which are extras I wouldn’t dream of having without it. I don’t want to trivialise myself in any way, and they seem simple things don’t they? But they’re things that you learn to cut down on when you’re on a budget…I find it very beneficial because it takes, it’s very difficult to talk to someone about, but it takes the fear away that you can’t meet a few bills and you can’t keep your roof over your head and you need extra things or extra care or extra hygiene things, things like that.’

(AA, 65-74, Phys, Coventry)
Other specific DLA and AA benefit uses included employing a cleaner/gardener (as mentioned previously, this more commonly amongst AA recipients) and various ‘social’ aspects, including the odd flutter, the occasional pint and nice clothes to go out in on rare excursions outside the home. A young man with schizophrenia living in supported accommodation summarised such outgoings as simply his ‘independence’, that without the pocket money provided by the DLA, he would be far more dependent on his parents, this described as a very negative eventuality for him.

Older claimants (at the top end of the DLA age range and recipients of AA) had an almost generational attitude to money and budgeting, believing that their disability benefit was only appropriately used if spent on specific items related to their condition and its effects. Commenting on this, a 90-year old man with asthma and oedema described how both he and his sister saved their benefits until they had an amount substantial enough to pay for the various items of furniture they both need to ease the effects of their disabilities.

‘I wouldn’t like to feel that people getting Attendance Allowance are using it, like it was just a kitty they put in and use for going out drinking or something like that. I said to my sister, we will use the Attendance Allowance (for the furniture) they are very good to give us that, so that’s what we did.’

(AA, 75+, Phys, South Woodford)

As with recipients of AA and DLA, those receiving CA tended to be most likely to use their benefit for ‘nothing in particular’ or ‘just general income’, although to a greater extent than those on other benefits, as they do not have the additional expenditure arising from disability or ill-health. An exception to this was a young mother from Ipswich in receipt of CA, and also the associated DLA claim for her son with Attention Deficit Hyperactivity Disorder (ADHD), who described how the combined income is used to repair damage in the family home caused by the periodically destructive son.

Returning to all recipients, we can look at use of benefit according to how financially ‘comfortable’ recipients are. Claimants were asked not only to describe their sources of income but also to summarise ‘how things are’ financially, which allows us a non-judgemental picture of financial stability and security. Obviously, this is a subjective assessment by customers, encompassing a variety of interpretations of what it means to be solvent; for some this means knowing how the next month’s rent will be paid, for others this equates to having bills paid and being able to put savings aside. There were no clear distinctions between customers by claimant type; no evidence that any one group are more or less likely than others to consider themselves financially comfortable.

When we compare AA, CA and DLA claimants who described themselves as struggling financially with those who said that they were ‘comfortable’, those who were in difficulty in some way were more likely to say that the benefit ‘goes into the household pot’ as opposed to allocating it to specific (disability-related)
items. A York man on DLA for occupational asthma described how having his son temporarily living back at home had reduced the amount of his pension, insurance policy and DLA that he could think of as ‘expendable’, given the additional food costs alongside an increase in poll tax (sic), having lost his single person’s reduction.

‘It just goes out, like, rent, poll tax, that’s £450 … then paying electric, gas, water, insurance for the property, and I mean it’s £37 for the insurance for me car, and petrol in there too. It’s really hard.’

(DLA, 45-64, Phys, York)

Those who had a more fluid cash flow were more readily able to specify where ‘that extra’ goes, on the basis that existing income pays for everyday expenditure such as accommodation, food and bills. This was not exclusively the case; one young woman on a tight budget of IS and DLA explained how that income is carved up for general household expenditure, with any remaining disability allowance used for her disabled son.

‘Well the Income Support I put half of it up a week, and that is for water bills and TV licence and stuff like that. The rest of it is for nappies and wipes, bibs and stuff. And then the money I get every month, the Disability Living Allowance, well some of it I use for the rest of the bills. And then the rest is for the taxi fare and stuff like that to get him to hospital.’

(CA, 16-44, MH, Reading)
8 Overview by customer type

This chapter draws together specific features of sub-samples of customers in order to identify patterns of behaviour and to explore how each group tends to differ from others.

The first section looks at each of the three disability benefits – Disability Living Allowance (DLA), Attendance Allowance (AA) and Carer’s Allowance (CA); the second at customers by disability type – physical illness or disability, sensory problems, mental health and learning difficulties; the final section examines specific groups of customers including people from black and minority ethnic (BME) groups, parents of young children and young adults in order to identify particular issues that they face. The chapter concludes with a brief discussion about differences in the perceptions of professional advisers and Disability and Carers Service (DCS) customers.

8.1 Type of benefit claimed

Although the experience of customers was generally common across all three of the disability benefits examined, there were a number of differences that distinguished one from another. In general, differences either distinguished CA claimants from DLA and AA customers or reflected differences between those claiming DLA and AA.

On balance, the experience of claiming DLA was probably the most difficult, with a higher number of individuals reporting negative aspects of their path to benefit. There were a number of reasons for this: Firstly, people of working age, especially those who had developed an illness or disability rather than coping with a lifelong condition, had more positive expectations of good health so that they needed to come to terms with the fact that they had a debilitating condition, often at the same time as they were submitting their DLA application. In comparison, it tended to be the case that AA applicants were experiencing a gradual decline in health with age with more time to adjust. Thus, DLA claimants were less likely to have any positive feeling about the benefit application.
Another difference had its origins in the fact that the involvement of a professional adviser was a major factor influencing the path to benefits, providing guidance and, in particular, being on hand to help with the application. Although widespread amongst both groups, AA applicants were more likely than DLA customers to be involved with professional advisers (see Section 4.2). This made their whole experience less fraught and, generally, more positive. A number of AA applicants had only minimal involvement in their application, much of the effort being undertaken by professional advisers or family members on their behalf. This, too, reduced the anxiety experienced and resulted in higher levels of overall satisfaction.

It is worth recalling (again, further discussed in Section 4.2) that the involvement of family was important to many older people. They had implicit faith in the ability of their children (or other family members) to act for them. They expected their efforts – in form filling, for example – to lead to a positive result, in this case, a successful benefits claim. Equally, the involvement of a professional adviser was particularly likely to be welcomed if this was at the recommendation of family.

In comparison, younger people, while still welcoming the help and support of family, were less likely to expect such individuals to have a better ability to work through the claims process than themselves. For AA customers, all dealings with the benefit claim were frequently passed across to family whereas DLA customers were less inclined to have no involvement. For example, form filling was more commonly a joint venture between husband and wife or (for adult children) parent and child.

Other differences were generational, reflecting expectations and experiences in the wider community. For example, the current generation of AA recipients tend to have a higher trust in ‘authority’ figures such as doctors and social workers than is prevalent amongst younger people and, therefore, they were generally more willing to follow recommendations to apply for benefit or, where necessary, to appeal against a rejection. However, older applicants were also more likely to have concerns about privacy and therefore found it particularly intrusive to record details relating to their personal care.

After making allowance for the fact that AA claim forms were less likely to be completed by the claimant alone than was the case for DLA, comments in relation to the actual forms were similar. There is no evidence from claimants that the AA form was easier to complete than the DLA form, although it should be recalled (see Section 4.1) that it was rare for individuals to have been involved in claims for both AA and DLA.

In general, the experience of claiming CA was a more satisfactory experience than for DLA or AA claimants. The form was smaller, less difficult to complete and more straightforward overall. In addition, those using the CA helpline were especially likely to have had a positive experience and this had increased their confidence about the process. As noted elsewhere, it was also common for CA claimants to
have been involved in the corresponding claim for DLA or AA. Although, of the
three disability claim forms, the CA form received least criticism overall, negative
comment was particularly unlikely to be voiced by those who had completed or
helped to complete a DLA or AA claim.

However, for some older carers, the concept of underlying entitlement was very
poorly understood and constituted a specific problem. There were some professional
advisers who explained the entitlement to their customers and encouraged them to
apply because of the other advantages that would accrue, but even in these cases,
claimants were hazy about what they had been told and some were evidently
disappointed that they were receiving nothing (or, occasionally, very little) in the
way of actual benefit.

‘It doesn’t matter how much you explain it to them they, well it doesn’t
say they’re not entitled because they are entitled. It says you’re entitled but
we’re not going to pay you it, which is right, and you’ve tried to explain that
to them, because you’ve done it for the premium. It doesn’t matter how
many times you explain it, they get that letter and they’re upset.’

(Group 1, Leeds)

Where no professional adviser had provided such advice, there was seldom any
understanding of what had resulted following the application. Several customers
described themselves as having been turned down for CA although the financial
summary statement they received from The Pension Service clearly showed that
they were eligible for underlying entitlement.

It was notable that none of our AA customers had experience of an oral tribunal
hearing. In part, this is because of the higher involvement of professional advisers
in the claims process. Moreover, where AA claims were turned down, there was
a higher tendency for professional advisers to try to resolve the situation without
involving the elderly person in a personal tribunal.

Overall, older people (whether AA or CA claimants) tended to have slightly higher
levels of satisfaction than their younger counterparts. We believe that this is not
because of any difference in the way that such customers are treated but rather a
combination of generational differences and greater involvement of professional
advisers.

8.2 Disability type

In line with the profile of DLA and AA recipients, those included in the research
were most commonly people who had a physical illness and/or disability. However,
the study deliberately included a number with sensory problems, mental health
issues and/or learning disabilities. Some individuals fell into more than one category
of disability.

In terms of their experience in applying for and receiving benefits, there were few
differences which related to the actual condition. Where differences arose, these
were almost exclusively in relation to completion of the application form (see Chapter 4). Firstly, some customers with non-physical disabilities – and particularly with mental health problems – felt that the application form was primarily written with physical problems in mind so that it was more difficult for them to adequately reflect their own problems. This view was not universal – for example, others with mental health conditions thought that their problems were as easy (or as difficult) to get across as those with physical disabilities. Some noted that there was an open section at the end of the form which allowed them to provide additional information if they did not think that they had provided an adequate picture earlier.

Furthermore, inability to reflect the effect of their condition was not restricted to those with mental health problems. In exceptional cases, individuals with physical disabilities – for example, as discussed in Section 4.2, one woman with Myalgic Encephalopathy (ME) and another with Multiple Sclerosis (MS) – also felt the form inadequate for their needs.

Of those with learning difficulties included in the sample, none had had any part in completing the forms. This was undertaken by their usual carer – most frequently a parent – and often with the help of a professional. Schools were very important for carers in this situation as the initial source of awareness of benefits and, often, in providing guidance about the application. Since those with learning difficulties had little input in obtaining or spending the benefits, attitudes and awareness were very similar to those with other problems.

Hardly any customers with mental health problems had filled in the form alone – especially where the application had been made when they were in a crisis point in their illness. Inevitably, where anxiety was a part of their illness, the application form was a considerable cause for concern and confidence about the application or its eventual success were very low. However, relief at the success of an application was especially strong with this group. Inadequacies in the claim form (preventing adequate description of how the customer’s claimant’s care or mobility needs were affected) were more common amongst those with mental health issues than other types of impairment.

Within our sample, successful claimants with sensory difficulties all had physical disabilities also. The sole claimant with visual impairment only had been turned down for AA twice despite the fact that she felt that she needed a high level of help from family to enable her to live independently. There was no suggestion that the application form failed to allow the impact of sensory disabilities to be recorded or explained.

Overall, therefore, the most commonly mentioned issue across the types of disability and impairment is the perception of some customers with mental health issues that the application form fails to provide them with the opportunity to describe their condition adequately.
8.3 Specific groups

8.3.1 Black and minority ethnic groups

The study included only a small number of customers from Black and minority ethnic (BME) groups and, therefore, although some issues were apparent, it is possible that others were not covered by the research. Allowing for interviews where more than one benefit was discussed, the sample covered five individuals claiming DLA, two AA and four CA.

Those included in the study came from a variety of places including Kosovo, Jamaica and the Indian sub-continent. Some of the group were living in London while others were interviewed in other parts of the country. Four of the interviews were conducted through family interpreters.

The only notable difference between those from black and minority ethnic groups and other claimants arose when the claimant had little or no English. The relevant forms are available in English (and Welsh) only and this meant that individuals with a major language barrier had to try to complete a complex form which was found difficult by native speakers.

‘Sometimes my friend says even for English people it’s hard to fill this form not just for you in your second language, you know.’

(CA, 25-44, physical disability (Phys) and mental health (MH), Burnley)

In every case, family members had rallied round, initially finding out about the benefit and then either completing the form or arranging for a suitable professional adviser to provide help and advice with this task.

‘My older sister filled it in for him. I know a few times she actually rang up while she was doing the form. She found them very helpful.’

(DLA, 65-74, Phys, Shepherds Bush)

One Bengali family, part of a small Bengali community in Swansea, felt that their difficulties in finding help were greater than would have been the case in a larger community such as London where more support groups existed.

‘Well, [even] if it is in more than English, it is difficult to fill up, because you have to know the details. My mother tongue is Bengali but the situation because we’re living here, a small minor community, for my family, is not very good. We need help in Bengali, some of the words to understand.’

(AA and CA, 65-74, Phys, Swansea)

BME customers in this study commonly learnt of the benefit through medical professionals. Although social workers were sometimes involved in providing advice and completing forms, only one had learned of the benefit from this source. None of the small number of BMEs interviewed in this study had used specialist benefits advisers fluent in their own language, although such advisers are available in some areas. For example, one of the professional advisers participating in the groups was himself from an ethnic minority and fluent in several Asian languages.
Perhaps because of the language difficulties they experienced, this group tended to be particularly unclear about the benefits that they were on and how they related to other benefits such as Income Support (IS), Council Tax Benefit (CTB) and Housing Benefit (HB).

### 8.3.2 Influence of locality

We visited 20 locations across England, Scotland and Wales. Although there was no evidence of differences across regions, the area of residence did impact on claimants, especially insofar as available professional help was concerned. Some areas were better endowed with support than others – one respondent was keen to receive DLA as this would give him access to the local Dial-a-Ride service. However, there was no evidence of any link between the density of claimants and the number or quality of professional services available.

In some areas, there appeared to be numerous sources of advice mentioned by different customers but elsewhere, there seemed to be only a small number of places where benefits advice could be obtained and all other organisations in that area would signpost people to the appropriate organisation. This pattern was confirmed by the professional advisers in the groups.

One specific issue was evident in Wales: All applicants with a Welsh postcode are sent a version of the relevant claim form which is in both languages. This means that a document that is already large is even bigger and more daunting, even though only half of it needs to be completed.

One suggestion was that two documents could be sent out rather than one dual language form. Applicants could then select which they preferred to complete. A customer from Llanelli described how she had debated for a while which way up the form was supposed to be before working out that one end was Welsh, the other English, also commenting on how having two forms would halve the width of the booklet; a positive thing in her opinion.

‘I think it’s important they have one in English and Welsh. Wouldn’t it be easier if there were two forms rather than, I think it’s, turn it round and it’s the other way, is it? So to have two, oh this is the English one, I’m going to fill this in, this is the Welsh one, it wouldn’t be that double thickness then, would it?’

(CA and AA, 45-64, Phys, Llanelli)

### 8.3.3 Parents of young children

Where the sick or disabled person was a young child, it was common for professional advisers to be involved. One scenario was that diagnosis would be followed by visits from local authority advisers to assess the family’s needs and so parents of young children were generally advised of benefits by medical or social work professionals.
'It was the health visitor that told me about it, first of all, and also, [child] went to a group called Portage, which is for autistic children and they mentioned it as well.'

(CA and DLA, Bury St Edmunds (for under 16 (U16) MH son))

However, although they may be quickly advised about DLA, knowledge of CA was not always given at the same time. In several cases, parents had learned of DLA through the medical consultant and CA through another route such as a benefits adviser.

Another route was through support groups or through the child’s school. A typical example was of a woman who learned of relevant benefits through the specialist centre that her autistic son attended.

’It was after him being there for a year that someone said to me, are you claiming DLA, and I said, well, no, ‘cos I didn’t hear anything about it before then. I think it was one person coming in and just checking that people knew about it. …This would be like a year after [child] joined, so I could have been claiming this for a year and I didn’t even know about it and she suggested it to me. And then I didn’t know about the Carer’s Allowance, neither, until I got the pack and I thought that I wouldn’t be entitled to that with my husband working and then they said, no, it’s nothing to do with that, it’s to do with what you do for your child and that’s when I decided to claim for that as well.’

(CA and DLA, Knutsford (for U16 MH son))

For parents of children on DLA, the biggest barrier to claiming benefit was acceptance of the child’s illness or disability.

’We sat down and got stressed out by filling it in. …I think it’s the stigma of actually admitting that you’ve got a child that is different, and he has got a disability. It took a long time, really heart rendering and you think well, yeah, well why is he different? Then having to fill in the piece of paper just saying all that to someone you don’t even know.’

(DLA and CA, Ipswich (for U16 MH son))

These emotions were often increased when completing the form because of the need to think about all the ways in which the child was different from others of the same age. As noted earlier (see Section 4.1 and also Chapter 2), the form required focus on negative features whereas in all other contexts the parents were encouraged to think positively about their child’s abilities.

’You have to think of the worst state that your child’s in. I think it’s very difficult to fill in a form like that, ‘cos you want to make out that your child’s OK and he’s getting better and everything, but really you have to look at him, right, OK, what is his problems and as a parent it is very difficult to do that because you always want to tell people, well, now he’s doing this. You don’t want to say, well, actually he doesn’t do that, you want to think of all the positive things.’

(CA and DLA, Knutsford (for U16 Sens and learning disability (LD) son))
Where one or both parents worked, there was often an initial reluctance to claim benefit through pride and/or a belief that others needed the money more than they did. However, parents were particularly likely to ring-fence benefit income to spend specifically on the child and several parents observed that it was the need to spend additional money on treatment that finally decided them to apply.

‘Being autistic, you need to get them out socialising with other people, communicating. And it can be very expensive. So I knew I had to do it for him.’

(CA and DLA, Bury St Edmunds (for U16 MH son))

Among the uses that money was put to were special outings, speech therapy, after school activities such as drama classes and replacement of household items regularly broken by a child with Attention Deficit Hyperactivity Disorder (ADHD).

### 8.3.4 Transition at 16

For those who were involved in a DLA and/or CA award for a child aged under 16, there was sparse awareness of what (if anything) would happen when the child got older, especially if the child was not yet of secondary school age. Some hoped that the child’s problems would have diminished to the point that no DLA was required but those with ongoing problems such as Down’s syndrome were more concerned as they realised the child would have ongoing care needs.

None of those interviewed had made firm enquiries but there was an assumption that parents will be informed of any alteration to the benefit or need to re-apply in any way.

Where parents or carers had a child aged 15 or younger, the notion of change at 16 was met with understanding from a legal point of view, in terms of societal definitions of children making the transition to adulthood.

‘[Do you know what happens when he’s 16?] It stops doesn’t it? No I don’t know. I don’t know. Is it 16 or 18?’

(DLA, Cheltenham (for U16 Phys son))

Within the sample, it was uncommon for customers (or their parents/carers) to have experienced an award that continued from pre-16. This was largely perceived as a non-event, in that recollection of any specific changes or processes at this stage was vague, if it existed at all.

For example, one young man recalled how his mother had received help from his school to guide them through the transition period. The most significant feature for him was that this was a recognition that he was officially able to handle the money himself.
‘I do remember that transition period, aye, I was at still at school. My mum went to the school. It’s a special school, it’s actually a secondary school for people with disabilities. And my mum had no clue about the benefits I could be entitled to. …That was probably first benefit I actually claimed myself.’

(DLA, 16–24, Phys and LD, Glasgow)

However, the perception of the legal situation was often accompanied with some surprise in that actual changes with regards independence and level of care required or dependency shown was said to occur much earlier. Combining these issues we present the case of a 23 year old diabetic woman who had been in receipt of DLA since the age of four. She described how her benefit was reviewed at age 13, with the award reduced from medium to low level as she became able to monitor her own condition and thus, required less additional supervision.

‘I think there was time when I was 13 perhaps that I was reassessed and put down into a lower payment but I think that was from 13 being the age where I didn’t need so much supervision from my parents. I was starting to understand my condition and how it worked. …But I don’t remember a particular time, even when I was 16 and taking it over, it’s always just goes into the bank account. It’s always been a direct debit or whatever it’s called, I don’t remember that ever altering.’

(DLA, 16-24, Phys, Knutsford)

8.3.5 Differences in perception of professional advisers and customers

Views of the professional advisers participating in the focus groups and DCS customers did not generally differ a great deal for the majority of topics discussed. It is also true that, for the main part, the professional advisers do have a very good understanding of claimants’ experiences, even though their personal role may be unduly biased as they spend a disproportionate amount of time dealing with complex cases which are difficult to resolve.

Claimants’ perceptions varied from those of professional advisers in one major way. Professional advisers were scathing about the minority of General Practitioners (GPs) who were perceived to be careless or even negligent in completing the relevant sections of the DLA or AA claim form (discussed fully in Chapter 2). Although some were very helpful and diligent, others were reluctant to input the requisite time to adequately check their records and provide up to date information about the applicant. Cases were cited where a doctor was asked to complete information about a condition despite not having seen the individual for several years.

The claimants themselves, however, clearly believed their own GP (if not their consultant) to be by far the best person to approach as regards their medical condition and how this affected their day to day lives. Comparison was made with the Examining Medical Practitioner (EMP) whose visit was very short and generally thought to be highly superficial. None of the customers interviewed had anything negative to say about their doctor or their part in their application, even when the application had been rejected.
Only professional advisers discussed the rejection letter in any detail. This was because customers who received such a letter were unaware that this was a standard document and they tended to assume that it had been composed for them and their circumstances. However, use of standard letters angered professional advisers who considered them misleading.

‘They believe it is tailored to them, and you’re then having to say to them no, actually it’s just a general standard letter that’s got nothing to do with you personally, and they’ve just decided that you don’t qualify, but you’re getting the same letter that everybody else does.’

(Over 4, London)

Other differences also reflected the professional advisers’ deeper understanding of the benefits system. For example, their attitudes to appeals were shaped by knowledge of the system and awareness of the high level of success. They were, therefore, much more willing to move to appeal, especially since they were confident that they could identify those cases which were most likely to succeed. Professional advisers believed that DCS staff had a lesser understanding of eligibility criteria and the relationship between the full range of available benefits than they did themselves. Customers, however, expected staff to be able to respond to all their queries and to provide them with all relevant information – negative views were voiced when this expectation was not met.

Professional advisers correctly anticipated that there would be notable differences between those who used their services and those who did not avail themselves of professional advice. Indeed, the availability of professional advisers is a most important factor in smoothing the path to benefits of those with long-term illness or disability. Customers trying to fight their way through the complex path to benefits alone tended to have a more difficult and more traumatic experience which was more likely to end in failure.
Conclusions and recommendations

This study has focused on the experiences and perceptions of Disability and Carers Service (DCS) customers as they make the journey through the Attendance Allowance (AA), Carer’s Allowance (CA) and/or Disability Living Allowance (DLA) application processes and beyond to become benefit recipients. As mentioned in other chapters, it is vital that the reader recalls that this is qualitative research, concerned with exploring experiences and perceptions amongst a group of customers in order to provide insight, as opposed to being a statistically representative piece of research.

As a primary conclusion, we have found that the disability claims process and any subsequent experience of any disputes process is dramatically eased with the intervention of a professional adviser. We, therefore, suggest that this should be acknowledged formally and guidance provided for customers as to which bodies can be approached for assistance.

We also suggest the Department for Work and Pensions (DWP) should specify the level and type of information they wish to see provided by third party agencies, and to work with its partners to hone this into a standard format, which could then be disseminated amongst all relevant organisations and bodies. This might make it easier to recommend DCS customers to others for assistance, as it would be clear that the information provided by such third parties had been ‘verified’. Such an element of formalisation would ensure a ‘no wrong door’ approach, with customers receiving the same type of information regardless of which agency they approached.

Linked to this, our second conclusion is to recommend that DCS formalises, in customer guidance, the approach to application forms that professionals tend to adopt, outlining the method of completing applications that is most likely to result in customers providing the required information in the appropriate way. This is because the application forms are found by customers to be lengthy and complicated, with a key issue appearing to be the need to typify or quantify everyday experiences, when it is common for different disabilities and illnesses
to result in variable impacts. This is particularly difficult for those with sensory or mental health problems, who largely find the forms inapplicable. For those who do not have professional help, this is notably problematic.

The experience of customers participating in this research suggests that the key to a successful claim is providing evidence according to a bad day, without aid or intervention. On the one hand this will mean telling claimants the ‘secret’ to a successful claim, and potentially increasing their chances of making a successful claim. On the other, if information from claimants is more standardised when submitted to DCS, the proportion of claims going through the disputes process should be significantly reduced as a result of better decision making from the first application.

At present, while such guidance is not formalised and provided, we suggest that an unsuccessful claim may not always be a result of fundamental ineligibility, rather, on occasion, an inability to complete the form ‘appropriately’.

It must be acknowledged that this conclusion, that guidance would make the form-filling process easier for customers, is made as a response to the fact that customers largely find the form-filling arduous and confusing; most notably those applying for DLA – which could be linked to the finding that DLA recipients less commonly cited the use of professional help than AA recipients. An alternative conclusion would be that the forms need to be re-designed in order to eradicate the complexity altogether. It may be that a combination of the two is an appropriate way forward, with forms redesigned to rationalise parts of the documents, most notably:

- sections that appear to repeat themselves by asking for information that has already been provided in a previous question;
- parts of the forms that may be inapplicable for those with non-physical disabilities/illnesses;
- questions that ask for quantification of impact of illness (distance walked, frequency of night-time disturbances, etc.) when these can vary from day to day.

Whilst we believe that this would go some way to reducing the need for separate guidance for specific elements of the form (how to approach complex sections) we suggest there is still a need to clarify, for customers, how to answer questions on the impact on their illness/disability (or those of the person they care for) when they have a condition that is variable. This is borne from the level of concern from customers when describing ‘an average day’, and how this may impact on their award if they are not perceived to be affected enough to get a level of award that may be appropriate on ‘a bad day’. Whilst we appreciate that scope for redesign of application forms is limited (as standard information on illness and impact is needed in order to ascertain eligibility), we suggest that guidance on how to answer questions will standardise the responses that DWP receive.
The third key conclusion we propose has regard to the disputes process, and we put forward a model of decision making that summarises the many impacts on a customer when considering whether to pursue or to accept a failed claim. We hope that this is useful for DCS and the Tribunals Service (TS) to consider at which stages further interventions could be made to ease the process for customers in understanding whether they wish to appeal, how to go about it, and crucially, what that appeal will involve.

This is the vital element of the third conclusion, that the customers we interviewed would have benefited from more information about the process of appealing and what those stages involve, particularly if their dispute reaches an oral tribunal hearing. Again, we suggest that recommendation of professional assistance and where to source that from would greatly alleviate the stresses and pressures often experienced by customers.

Positively, this may be as simple as increasing awareness and distribution of the information leaflets produced by the TS. In their present form, they include the vast majority of information that customers mentioned needing, either at the time of lodging the dispute, or information that with hindsight would have been useful, including:

- the advantage of having professional advice and assistance and where to get this from;
- general tribunal hearing timings;
- what constitutes grounds for appeal;
- the details of the tribunals process, including options for oral/paper hearings, how the venue is selected, the difference between representation and moral support, detail of the proceedings on the day, preparation needed by the appellant;
- what happens after the appeal.

Given how common it was for appellants to have a negative experience of tribunal hearings, we applaud the work that the TS is undertaking (along with DCS) to review the disputes process and examine the possibility of alternative approaches, and also to look at ways of speeding up decision making by undertaking early evaluation of cases before formal submission.

We suggest the key here is to review ways in which the impact of the experience can be made less traumatic for unsuccessful customers. We feel that the two elements most strongly contributing to the negative experience are the trial-like nature of the oral tribunal hearing and the need to discuss highly personal care information in front of a group of total strangers. We propose that any ways of alleviating these would reduce the element of trauma currently common amongst appellants.
Our fourth conclusion relates to DCS staff, and the difficulty customers experienced where they have to contact Department staff more than once on the same issue. This is described variously as frustrating and time-wasting, when circumstances and cases need to be repeated to bring a telephone operative up to speed on last communications in order to proceed with the query. We recommend that there should be a threshold of volume of individual communication, past which an individual is assigned a single contact who deals with all subsequent communication.

Linked to this, the fifth conclusion we draw has regard to the competence and knowledge of DCS call centre/contact staff. Professional advisers and DCS customers variously comment on the frustrations of not being able to secure the required information from the first contact and being passed from one adviser to another until a person with the requisite knowledge is found. There is a related issue with regards precisely which information is available to customers once their application is underway (details on, and progress of, individual cases appearing difficult to get hold of).

We suggest a two-pronged approach to this issue; firstly that customers may need further information on precisely which parts of the agency can deal with which types of query, including for example, the extent to which call centre staff can engage in medical discussion or timelines of individual cases. From the other angle, we propose that it will be beneficial for DCS to undertake a skills/knowledge audit of contact centre staff and increase training if there are skills/knowledge gaps found. Alternatively, a mystery shopping exercise may be a quicker way of ascertaining a rough measure of staff knowledge of common, foreseeable customer queries.

Finally, as we have learned that it is common for customers to only have learned of relevant disability benefits by chance, it is inevitable that eligible individuals exist who are unaware of benefits. We propose that additional ways of alerting potential claimants of the benefits should be sought, both by DCS itself and in partnership with relevant bodies.

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7 Mystery shopping is the evaluation, measurement and reporting of customer service standards by use of agents acting as if they were customers, and is one of the fastest and most effective methods of obtaining objective management data about customer service levels.
Appendix A
Organisations participating in the professional focus groups

Several organisations provided participants in more than one group:

• Age Concern;
• Bradford Cancer Support;
• Carers UK;
• Citizens Advice Bureau (CAB);
• Community Action for Roundhay Elderly;
• Contact A Family;
• Dial UK;
• Ebor Gardens Advice Centre;
• Greenwich Council;
• Hertford CAB;
• Holbeck Elderly Aid;
• Lambeth Carers;
• Mind;
• RNIB;
• RNID.
Appendix B
Selected areas for depth interviews

East – Bury St Edmunds
East – Ipswich
London – South Woodford
London – Shepherds Bush
Midlands – Coventry
Midlands – Leamington Spa
North East – Newcastle
North East – Durham
North West – Burnley
North West – Knutsford
South East – Aylesbury
South East – Reading
South West – Bristol
South West – Cheltenham
Yorks/Humber – York
Yorks/Humber – Hull
Wales – Swansea
Wales – Llanelli
Scotland – Glasgow
Scotland – Perth
Appendix C
Opt out letter sent to all contacts

(Name)
(address)
(address)
(address)
(address)

April / May 2006

Dear (Name)

We are writing to ask for your help with an important study looking at peoples’ experiences of applying for and being on [benefit]. We have asked Carol Goldstone Associates (CGA) to carry it out on our behalf. CGA is an independent research agency, specialising in studies like this. All of the company’s interviewers are fully trained and have to operate according to the Market Research Society’s (MRS) Code of Conduct.

Someone from CGA may call you in the next few weeks to arrange to visit you, at a time and place which suits you. CGA will give you a gift of £25 at the end of the interview as a thank you for your time and help with this study.

If you need additional help to take part in the interview, please let us know so that we can arrange this. For example, if you do not speak English or if you use British Sign Language (BSL) we can arrange for a suitable interpreter to be present at the interview. To arrange this, please fill in the form at the end of this letter and send it back to us.

The answers you give to this study will be kept private and will only be available to the research team. We are interested in your honest opinions and would like to stress that, in accordance with the Data protection Act, your name will not be
linked with any of the information you supply. If you have any queries about any aspect of this research please contact Carol Goldstone at CGA on 020 7375 3577. If you would like to confirm the validity of the study then please contact myself, Pauline Heather on 0114 2098 205.

We are keen to hear your views and would value your participation. However, if you would prefer not to take part then please fill in and return the page 3 of this letter (using the freepost envelope provided) by [date] 2006, and we will not contact you again. Whatever you decide, taking part in this study will not affect any benefits you receive either now or in the future.

We would like to thank you in advance for your time in helping us with this study.

Yours sincerely

Pauline Heather  
Senior Research Officer  
Office for Disability Issues

You can obtain a large print copy of this letter by phoning 020 7375 3577.
Appendix D
Achievement versus quota for the main phase of fieldwork

The two tables that follow show the sample structure (1) as amended shortly after the onset of interviewing, and (2) as achieved. Sometimes interviewees were able to discuss in detail more than one type of claim (a parent completing the process for their child’s Disability Living Allowance (DLA) and their own Carer’s Allowance (CA), or similarly with an elderly couple and a CA/Attendance Allowance (AA) claim couplet). The final sample structure (Table D.2) includes all claims covered, and therefore totals 131 claims as opposed to the 100 interviews. Points to note:

• Overall, a very satisfactory spread of customer types and experiences was achieved.

• A quota for black and minority ethnic (BME) customers was set (target of ten), with seven achieved in the final sample. BME customers were more likely to have unobtainable/discontinued phone numbers, and to refuse participation when contacted.

• The 16-24 age group were also more difficult to secure participation from, having higher than usual proportion of unobtainable phone numbers and a greater tendency to refuse participation when contacted.

• CA claimants caring for people with sensory disabilities were also slightly short of target. This may be due to the fact that none of our customers had dual sensory disabilities (e.g., deaf-blind) which are more likely to require third party assistance.

• We did not manage to secure any interviews with AA claimants (a) with learning disabilities (b) who had appealed a decision.

• Whilst no quota was set for customers not in receipt – nine were achieved.
• The original quotas included recipients and non-successful claimants who had and had not appealed, all of which were originally to be ‘recent’ customers’ (on the basis that recency of experience would allow for an accurate recall of the process). Positively, we found that longer-term claimants had very good recollection of appeals processes they had experienced, so the quotas were widened to include these claimants, and changed in definition to simply ‘unsuccessful’ and ‘appeal’. This allowed capture of those who had ever had an unsuccessful claim, but had gone on to be successful (e.g., after appeal), which accounts for there being 31 unsuccessful claims, yet just nine non-recipients.

Table D.1 Revised quotas June 2006, after initial interviews completed (alterations highlighted)

<table>
<thead>
<tr>
<th>Benefit</th>
<th>DLA</th>
<th>AA</th>
<th>CA</th>
<th>Total</th>
</tr>
</thead>
<tbody>
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<td>Total</td>
<td>40</td>
<td>30</td>
<td>30</td>
<td>100</td>
</tr>
<tr>
<td><strong>Customer age</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 16</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>16 – 24</td>
<td>6</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25 – 44</td>
<td>6</td>
<td>10</td>
<td></td>
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</tr>
<tr>
<td>45 – 64</td>
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<td></td>
</tr>
<tr>
<td>65 – 74</td>
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<td>12</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td>3</td>
<td>4</td>
<td></td>
<td>Max 4</td>
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<tr>
<td><strong>Disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>20+</td>
<td>15+</td>
<td>15+</td>
<td>50+</td>
</tr>
<tr>
<td>Sensory</td>
<td>Min 5</td>
<td>Min 4</td>
<td>Min 4</td>
<td>Min 13</td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>Min 5</td>
<td>Min 4</td>
<td>Min 4</td>
<td>Min 13</td>
</tr>
<tr>
<td>Mental illness</td>
<td>Min 5</td>
<td>Min 4</td>
<td>Min 4</td>
<td>Min 13</td>
</tr>
<tr>
<td><strong>Customer type</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Recipient – long-term</td>
<td>Min 4</td>
<td>Min 3</td>
<td>Min 3</td>
<td>Min 10</td>
</tr>
<tr>
<td>Recipient – medium-term+</td>
<td>Min 4</td>
<td>Min 3</td>
<td>Min 3</td>
<td>Min 10</td>
</tr>
<tr>
<td>Recipient – short-term</td>
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<td>Min 3</td>
<td>Min 3</td>
<td>Min 10</td>
</tr>
<tr>
<td>Been through appeal</td>
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<td>Min 3</td>
<td>N/A</td>
<td>Min 11</td>
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<tr>
<td>Has made unsuccessful claim</td>
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<td>Min 2</td>
<td>Min 2</td>
<td>Min 8</td>
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### Table D.2  Sample achieved – by total claims (notable shortfalls highlighted)

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<tr>
<th>Benefit</th>
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<th>AA</th>
<th>CA</th>
<th>Total</th>
</tr>
</thead>
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<td><strong>Total claims</strong></td>
<td>56</td>
<td>35</td>
<td>40</td>
<td>131</td>
</tr>
<tr>
<td>(total interviews)</td>
<td>(37)</td>
<td>(32)</td>
<td>(31)</td>
<td>(100)</td>
</tr>
<tr>
<td><strong>Customer age</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 16</td>
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<td>16 – 24</td>
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<td>–</td>
</tr>
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<td>45 – 64</td>
<td>22</td>
<td>–</td>
<td>15</td>
<td>–</td>
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<tr>
<td>65 – 74</td>
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<td>17</td>
<td>4</td>
<td>–</td>
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<td>75+</td>
<td>23</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>41</td>
<td>38</td>
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<td>107</td>
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<td>Sensory</td>
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<td>5</td>
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<td>12</td>
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<td>Learning difficulty</td>
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<td>0</td>
<td>9</td>
<td>18</td>
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<tr>
<td>Mental illness</td>
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<tr>
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<td>13</td>
<td>36 (29)</td>
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<tr>
<td>Recipient – medium-term+</td>
<td>10</td>
<td>5</td>
<td>4</td>
<td>19 (14)</td>
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<tr>
<td>Recipient – short-term</td>
<td>20</td>
<td>21</td>
<td>16</td>
<td>57 (48)</td>
</tr>
<tr>
<td>Been through appeal</td>
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<td>17</td>
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<tr>
<td>Has made unsuccessful claim</td>
<td>16</td>
<td>6</td>
<td>9</td>
<td>31 (27)</td>
</tr>
</tbody>
</table>
Appendix E
Topic guide for customer depth interviews

Knowing and understanding Disability and Carers Service customers
Customer topic guide Final

Introduction
Moderator to introduce herself and explain:

• Background to study

Disability and Carers Service (DCS) are part of the Department for Work and Pensions (DWP) and they are responsible for several government benefits including Disability Living Allowance (DLA), Attendance Allowance (AA) and Carer’s Allowance (CA).

DCS have commissioned Carol Goldstone Associates (CGA) to conduct a research study for them to explore the experiences of their clients. They are interested in details about how clients heard about benefits and decided to put in an application and then also their experiences as customers. This research will be used to help improve the way that the system operates so that, in future, contact will be more efficient and more effective for all DCS clients and to improve the overall experience of all concerned. We also want to understand the client’s journey from start to finish, identifying areas in most need of improvement. Respondent has been selected at random from the list of people who have applied for or who are receiving [benefit].
• **Reassure respondent**

Explain this is independent research. No one outside of the immediate project team knows who our respondents are and individual identified responses will not be fed back to anyone within DCS. All results will be combined together for analysis purposes. No individual or anything that they say can be identified as originating with them so all respondents can feel free to speak very openly. The research team is not part of DCS and nothing that is said during the interview will have any effect on applications for or receipt of benefits. The interview is expected to last for around 45 – 60 minutes.

• **Tape recorder**

Explain that the interview will be taped to assist with subsequent analysis and to ensure that moderator can concentrate on what is being said rather than on taking notes. Comments made by participants will not be identified with them by name.

Note: Moderator to vary individual interviews to meet specific circumstances e.g. whether or not ill/disabled from birth. Where appropriate, ensure that responses include both dealings with DLA/AA and with CA.

**Introduction and classification**

• Get respondent to describe self including:
  - Age
  - Family circumstances (e.g. size, structure of household)
  - Work status and brief work history
  - Sources of income including benefits currently received
  - Financial circumstances
  - *For parent/appointee: Above details to pertain to sick person. Obtain brief description of own circumstances also*

• For DLA/AA claimants:
  - Details of illness/disability
  - When illness/disability started
  - Nature of illness/disability (e.g. whether sudden or gradual onset, future prognosis)
  - Effects of illness/disability on day to day life
  - Care received (e.g. social services, meals on wheels etc.). **Probe for:**
    - Type of care received
    - Source of care (e.g. from friends, family, social services etc.)
• For CA claimants:
  – Details of person cared for:
    ~ Age, family circumstances, relationship to carer
    ~ Details of illness/disability (as for DLA/AA above)
  – Amount/nature of caring:
    ~ Time per week spent caring
    ~ Main caring duties
    ~ When started caring
    ~ Other help received (e.g. from friends, family, social services etc.)

History of claim
• Obtain potted history of claim:
  – If now receiving benefit
  – Whether initial application successful
  – Whether went through appeals procedure
  – Time taken from initial application to receipt of benefit/end of process
  – If awarded benefit: How long was the benefit awarded for? (indefinite period vs. time prescribed)
• If appointee: Who dealt with claim (e.g. self, sick/disabled person, both, other)
• Source of awareness of benefit:
  – Whether aware of benefit before onset of illness/disability
  – Source of awareness of benefit
    ~ Who suggested individual could claim?
    ~ What were the circumstances of learning about benefit (e.g. from professional adviser in course of dealing with other issues, visit to professional adviser to ask about financial assistance available, via friend or family, via other DWP agency)?
    ~ Initial reactions to learning of benefit
• What did they know about the benefit at this stage? Probe for:
  – Amount
  – Eligibility
  – Whether they thought it was means tested
  – What did they find out about the application process?
  – What did they think the benefit is for Probe on: financial help to lead their life vs. ‘compensation’ for disability?
– For DLA: Did they know that it is possible to work and get DLA
– For CA: Did they know it was linked to DLA/AA receipt
– Awareness of underlying entitlement
– Awareness that it is possible to do some work (with earnings limit) and still obtain benefit

**Before the application**

- What, if anything, did they do to try to find out more? **Probe for**:
  - What sources used (e.g. who spoke to, whether used internet, use of benefits helpline etc.)
  - Whether consulted with medical advisers, professional (benefits) advisers, friends and family
  - What advice did they receive?
- What time elapsed between learning of the benefit to submitting the claim?
- **If not immediate/quite fast**: What were the reasons for delay? **Probe for**:
  - Embarrassment/disinclination to claim benefit
  - Belief that benefit was means tested
  - Expectation of ineligibility (medical and/or financial)
  - Fear of being turned down
  - Fear of application process
  - Physical/emotional difficulties involved in claiming
  - **For CA, if appropriate**: Effect of being eligible for underlying entitlement only
- Feelings about applying
  - Three adjectives to describe feelings **Probe on** why adjectives selected are positive/negative
- What were the advantages of applying? **Probe for**: advantages other than just financial
- What were the disadvantages?
- Expectation of success/failure. Why?

**Making the claim**

- Reaction to application form
  - Initial reactions to form
  - Were initial reactions justified (e.g. length, complexity, bureaucracy etc.)
– How was it to complete (e.g. easy, repetitive, incomprehensible, embarrassing)?
– Describe application form as an animal. Reasons for choice
– What was the worst thing about the form?

• Did respondent complete form alone or with help?
  – Who helped?
  – Reasons for choice of helper. **Probe for:** professional vs. non-professional advice
  – Awareness and use of alternative forms of application (e.g. text phone, online, use of Benefits Enquiry Line etc.) Were these/would these have been of help? **Probe on:** Awareness that Disability Benefits Centres provide a service via telephone to help customers complete the DLA/AA form

• Level of understanding of what was being asked for/looked for.

• *If DLA/AA:* Was applicant required to attend a medical from department doctor?
  – *If yes:* Explore reactions to this

**Expectations and outcomes**

• What expectations of process claimant had after sending off application. **Probe for:**
  – Source of expectations
  – Amount of time expected to wait before getting response
  – Whether any interim communication was expected before decision notified
  – Awareness of the proportion of claims successful at first attempt

• How expectations were met by actual experience. **Probe for:**
  – How long from application to notification of decision (and to receipt of benefit)
  – Whether any interim communication experienced (either to or from claimant)
    – *If yes:* explore nature of communication – e.g. channel method, reason for communication, claimant attitude to and satisfaction with communication and its outcome
  – Outcome of claim. **Probe for:**
    – Whether awarded/not awarded, whether time linked and whether at higher/lower level
• Feeling about the outcome
  – Whether outcome was what was expected
  – *If awarded:* Was it awarded at the expected level
  – Emotions experienced. Probe for both positive and negative
    – *If time linked:* Did the time linking make sense in terms of respondent’s condition
  – *For CA claimants with underlying entitlement:* How did they feel about not getting any money despite being eligible for benefit?
    – Are they/have they applied for other benefits e.g. Pension Credit

If unsuccessful claim:
  – Attitude to rejection letter
    – Was it fair? Accurate? Appropriate to claimant? Sufficiently detailed?
    – Did recipient understand why claim had been turned down?
    – Did they note the possibility of appeal included in the letter?
  – What did claimant do then? *Probe for:*
    – Who was claim discussed with? (Professional adviser, family/friend etc.)
    – What did they decide to do next? Why?
    – How long did the decision take? Why?

Reconsiderations
• Did claim go through a reconsideration process?
  – What was claimant told about this?
  – Was it the result of a specific request to reconsider or part of the normal procedure prior to an appeal? *Probe for:* Understanding of what was done

Appeals procedure
*For all those whose *(first)* claim was rejected or who wanted the award at the higher level:*

• Awareness of appeals procedure
  – When did claimant first realise that an appeals procedure exists?
  – Source of awareness

• How was the decision made whether or not to appeal
  – How long did it take to decide to appeal/not to appeal?
  – Who was consulted? What advice did they give? How influential was the advice?
- Reasons for decision
  - *If consulted others:* How much claimant was told about the procedure. *(If appeal made):* Was the advice accurate?

- For those submitting an appeal:
  - Was the appeal in writing or in person?
  - Was additional information submitted as part of the appeal?
    - *If yes:*
      - How did they know that this was possible? What were they told would be useful?
      - What was the nature of the additional information?
      - Who helped claimant to prepare it?
    - *If no:*
      - Was claimant aware that additional information could be submitted?
      - *If yes:* How did they know? Why did they not submit anything further?
      - *If no:* Might it have been helpful to submit further information?
  - *For appeal in person:* Describe the appeal process. **Probe for:**
    - Practical details
    - Who accompanied appellant (professional/non-professional)?
    - Was anyone from DWP there to represent the department? **Probe for:** How did they feel about the department’s representation/lack of representation? Should someone have been there or did it not matter? Why?
    - Feelings (e.g. embarrassment, anger, bewilderment) during process and after
    - Was process adequately described to claimant by adjudicators?
    - How long did it take? And when was outcome notified?
    - What does appellant feel about process now (after some time)? **Probe for:** whether it was fair, appropriate procedure, lasting feelings
    - What could be done better about the appeal process?
    - And what should not be changed?
  - *If appeal turned down:* Would they or have they applied for benefit again? *If yes:* Details of why and when etc.
Experience of DCS staff

- Moderator to summarise points at process at which respondent had dealings with DCS staff (e.g. personal contact – face to face or phone – or by remote channels such as email and letter)

- Describe image of typical DCS member of staff

- Satisfaction with contacts. Reasons for satisfaction levels
  - What were examples of good/satisfactory contact during process
  - What were examples of poor/unsatisfactory contact

- What contact has respondent had with other parts of DWP (e.g. JCP and TPS)?
  **Probe for:**
  - How satisfactory have such contacts been?
  - How does contact with DCS staff compare with contact with other DWP staff?
  - Do JCP/TPS staff have any/sufficient knowledge about disability benefits?

Dealing with long-term issues

- Awareness of what to do if circumstances change. **Probe for:**
  - What type of circumstances need to be reported to DCS (e.g. changes in condition, work circumstances, other family circumstances, hospitalisation, caring duties)?
  - How would they report such changes?
  - What would they expect to happen?
  - **For CA recipients:** Cover both own circumstances and those of cared for person

- Have there been any changes of circumstances since award of benefit
  - Has benefit recipient got better/worse since they claimed? **If yes:** Have they notified the department?
  - Have any other circumstances changed? **Probe for:** changes that require notification such as hospitalisation, starting work etc.
  - Where these changes reported? **If yes:** What happened? **Probe fully:** How changes reported, attitude of DCS staff, outcome etc.
  - Would changes be reported in future? Why/not?
  - **For CA recipients:** Has benefit ever been stopped because of hospitalisation of self/cared for person? **If yes:** Impact on own circumstances. **Probe for:** temporary stopping of benefit due to hospitalisation – practical and emotional impact

- How long before need to put in next benefit application (if at all)?
– Attitudes towards the need to re-apply
– Feelings evoked by this. Why?

**Using the benefit**

*N.B. Tell respondent that there are no limits on how the money is used – this section is just so that DCS can understand how recipients do use it. For non-recipients, ask about how benefit might be used if awarded.*

- Is benefit money put towards specific uses (e.g. provision of taxis, purchase of aids or services) or is it just incorporated into general household income?
- What does benefit enable respondent to do that would not otherwise be possible?
- Are there any financial drawbacks to having the benefit?
- Are there any needs relating to the respondent/cared for’s disability that are not being met? What and why? **Probe for:** Financial vs. other needs.

**Wind up and close**

- Overall impressions of DCS and the service it supplies
  – What are the strengths of DCS?
  – And what are the weaknesses?
- Are there any aspects of the benefits process (application, appeal, receipt) that have not been previously discussed?
- One thing to change about DCS and its service

**THANK AND CLOSE**
Appendix F

Topic guide for professional adviser focus groups

Knowing and understanding DCS
Focus Groups with Professional Intermediaries
Final Topic Guide

Introduction

Moderator to introduce herself and explain:

• **Background to study**

Disability and Carers Service (DCS) have commissioned research to explore the experiences of their clients – both in terms of their journey before they approach DCS and their experiences as customers. This research will be used to underpin DCS service delivery and policy development to make future contact more efficient for all DCS clients and to improve the overall experience of all concerned. We also want to understand the client’s journey from start to finish, identifying areas in most need of improvement.

The work is to be undertaken in two phases. The first phase – which includes this group – is consultation with professional advisers through a series of focus groups and the second is depth interviews with recipients of and applicants for Disability Living Allowance (DLA), Attendance Allowance (AA) and Carer’s Allowance (CA).

A total of four groups are to be held. The groups will provide valuable information in their own right and will also inform the topic guide for the second phase of depth interviews. We are talking to a variety of front line staff with different responsibilities and possibly using different approaches.
• **Reassure respondent**

Explain this is independent research.

No one outside of the immediate project team know who our respondents are and individual identified responses will not be fed back to anyone within DCS. All results will be combined together for analysis purposes. No individual or anything that they say can be identified as originating with them so all respondents can feel free to speak very openly. The group will run for around 1½ to 2 hours.

• **Tape recorder**

Explain that the interview will be taped to assist with subsequent analysis and to ensure that moderator can concentrate on what is being said rather than on taking notes. Comments made by participants will not be identified with them by name.

• **NOTE TO MODERATORS:**
  
  – Conclude each section with brief summary
  
  – Wherever relevant, ensure that differences across the three benefits are explored in full

**Warm up and classification**

• Round table introduction – name, organisation.

• Explore respondents’ work history
  
  – Brief description of individual’s role and responsibilities
  
  – Range of clients dealt with.
    
    ~ **Probe for:** types of client, problems dealt with etc.
  
  – Type of role (e.g. generalist or specialist)
  
  – Which of the relevant benefits (DLA, AA and CA) they deal with/know about
  
  – Length of time in job

**Dealing with DCS**

Investigate experience of dealing with DCS

• Frequency of contacting DCS on behalf of clients

• Importance of DCS in work for clients compared with other DWP agencies/other agencies

• Importance of DLA/AA/CA in work compared with other benefits/other types of advice (e.g. housing, employment education needs etc.)

• How long has dealt with DWP (or predecessors)
• Perception of relationship between intermediary and DCS (e.g. co-operation, levels of trust etc.).

• Sources of information – how do intermediaries learn about changes to benefits/payments or rules etc.

**Dealing with clients**

• How do the clients learn about intermediary? E.g.
  – Via health or educational professionals,
  – through local social services,
  – intermediary organisation used for other purposes,
  – via friend or family etc.)

• What is the role of the doctor in the advisory process (e.g. advises clients that they should apply for benefit/payment? Anything else?)?

**Client journey to benefit**

• At what point in the process is the intermediary most likely to become involved? E.g.:
  – At onset of ill health/disability or later
  – At time of change (e.g. change in health, employment status, caring role etc.)
  – After benefit application rejected

  ~ **Probe for**: Extent of involvement for crisis point only (what proportion clients are seen only at crisis); what are the most common points for intermediary to become involved and to cease involvement

• To what extent is the approach to the intermediary made in relation to benefits?

• Why did the client go to an intermediary rather than dealing with DWP?

• What is the level of client knowledge about benefits at the time that they approach the intermediary?
  – Knowledge of benefits (explore familiarity with DLA/AA/CA and also other benefits such as IB, JSA etc.)
  – Knowledge of eligibility criteria
  – Extent to which inappropriate people apply for DLA/AA/CA prior to intermediary involvement (i.e. extent to which applications are made by those who are not eligible or applications not made by those who are eligible) Is it difficult to explain to customers why they may not get the benefit?
  – Knowledge of application procedures
– To what extent can you anticipate who is going to be eligible for DLA/AA and who is not?
– Do customers approach you when they’ve been claiming for a long time. If so, what do they approach you about?

• Factors affecting client behaviour
  – How does client’s attitude affect their actions (e.g. in denial of illness so won’t apply for benefits)?
  – Impact of age and relationship to disabled person on attitudes to benefits. E.g.
    ~ Do older people assume they are not eligible for benefit because they are old rather than ill?
    ~ Do spouses assume they are ineligible for benefit because they don’t see themselves as a ‘carer’)?
    ~ Do you have to encourage people to apply?
    ~ If people are apprehensive about applying, what worries them?

• Level of help required by clients in completing claim forms. Who else is involved?

Expectations and Experience of DCS

• What are intermediaries expectations and experience of DCS?
  – **Probe for:** Positive and negative experiences

• What do clients expect to happen when they approach DCS? What shapes these expectations?

• How do actual experiences match expectations? What is better/worse/different from expectations? Why?

• What expectations were not met? Why? Were the expectations realistic?

• What positive experiences of DCS do clients report? What negative experiences?

• For clients who have been dealing with DCS for a long time, have their experiences/expectations changed over this time?

• What are the key problems for clients in dealing with DCS? How can these best be resolved?
  – What are the major differences across different client groups (e.g. by age, disability type, educational level/social class, other)?
  – **Probe for:** problems by channel type; communication (keeping clients informed)
Appeals procedures

- Familiarity/knowledge of intermediary with appeals procedure
- Do clients know that appeals are possible? How does this awareness vary across benefit/client groups?
- What are the reasons why clients choose to appeal/not appeal?
- What is the intermediaries’ perception of the appeals procedure?
  - **Probe for**: fairness and necessity; methods used; what improvements should be implemented and why; what means could be used to reduce the number of appeals

Wind up and close

- Summarise issues raised.
- Invite other comments that should be passed on to DCS about routes to benefits and customer service that have not already been discussed.

THANK AND CLOSE