

Department for Work and Pensions

Research Report No 490

Disability Living Allowance: Disallowed claims

Andrew Thomas

A report of research carried out by Insite Research and Consulting on behalf of the Department for Work and Pensions

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The Author

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Abbreviations

AA	Attendance Allowance
ADHD	Attention Deficit Hyper-activity Disorder
BME	Black and Minority Ethnic
CA	Carers Allowance
CAB	Citizens Advice Bureau
DBC	Disability Benefits Centre
DCS	Disability and Carers Service
DEA	Disability Employment Adviser
DIAL	Disability Information and Advice Line
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HMRC	Her Majesty's Revenue & Customs
IB	Incapacity Benefit
IBS	Irritable Bowel Syndrome
IS	Income Support
JSA	Jobseeker's Allowance

ME	Myalgic Encephalopathy (also known as Chronic Fatigue Syndrome)
MP	Member of Parliament
MS	Multiple Sclerosis

Summary

Introduction

Disability Living Allowance (DLA) is a complex benefit designed to contribute towards the extra costs faced by disabled people. It is non-contributory and it is neither means tested nor taxable. Entitlement to DLA is based on the need for personal care and/or the need for help to increase mobility for those with walking difficulties arising from severe disability.

There is an overall DLA disallowance rate of 52 per cent. This high level of disallowances suggests that some claims are being made which have very little chance of succeeding. The result, over many years, has been a considerable waste of time, effort and resources. This research study looks at why some applications are made when it should be clear to the applicant that they do not meet the eligibility criteria.

Method

Qualitative, in-depth interviews were undertaken with 100 people who had made a claim for DLA which had been initially disallowed. Research was restricted to cases in which the applicants were adults of working age only (aged 16-64), and to cases where Disability and Carers Service (DCS) judged the disallowance to be obvious (clear disallowance) cases in which applicants had either failed to meet basic eligibility criteria or had failed to show in their applications that they had the care and mobility needs that would entitle them to the benefit. Only cases in which the allowed time for making an appeal had passed were included. All the applications were, therefore, 'closed' cases.

Purposive sampling of cases was undertaken to ensure adequate coverage of the range of circumstances and characteristics of applicants known or hypothesised to be significant to understanding the factors behind high disallowance rates. In particular, cases were over-sampled for: those ruled ineligible because they did not meet 'residence' and 'presence' requirements; electronically submitted claims (e-claims); those whose main disability was given as a sensory disability; and those whose main disability was learning difficulties.

Findings

Knowledge and perceptions of DLA

There was a generally low level of knowledge about DLA among applicants and widespread poor understanding of what the benefit is for and what the criteria are for entitlement. Most applicants knew little or nothing about DLA before making their application. For many, the suggestion by a third party to apply for DLA was the first time they had heard of it. Accurate knowledge about the benefit and how it is awarded was very rare. The great majority of applicants had only a vague idea of what it was they were applying for and relied essentially on 'hearsay' for the little understanding they did claim to have.

In general, applicants were found to place far greater store by word of mouth, than they did by formal written information sources. Few said they had seen the leaflet about DLA prior to making their claim, and among those who had recall of what was in it was weak, and in some cases non-existent. Starting to fill in the application form had a momentum that meant most were determined to carry it through, having started, even if the process generated doubts in their mind as to their entitlement.

There was widespread poor understanding of the aims, purposes and operational criteria for the awarding of DLA. The three specific areas in which many applicants had apparently failed to understand the particular criteria determining entitlement for DLA were:

- the requirement to demonstrate care and/or mobility needs;
- the requirement to have such needs at a sufficient level of severity;
- and the requirement for needs to have existed for at least three months and be expected to last for at least a further six months.

The most evident misunderstanding about DLA was its confusion with out-of-work benefits. A great many of the disallowed claimants were under the impression that, like Incapacity Benefit (IB) for example, being out of work was a sufficient condition for receiving it. There was often the implicit assumption that its main purpose financially was to act as a substitute for work, and to bridge the gap when work income was reduced or lost.

A pervasive and widespread perception of DLA among disallowed applicants was that entitlement to it was simply and straightforwardly consequent upon having a disability. The name of the benefit (Disability Living Allowance) may be playing some part in determining or maintaining people's perceptions of it as payable to those with a demonstrable disability, of whatever kind, rather than payable to those with care needs and severe mobility restrictions.

A further widely held view of DLA was that it was a difficult benefit to claim successfully and that it was getting even harder to do so. Also reported as 'common knowledge' was the view that applications for DLA were routinely rejected at the

first attempt and thus to be successful required one to apply several times and to keep on trying. This view was apparently being supported by several third-party organisations who were reported as giving the advice to customers to keep applying even if initially disallowed.

There were also those who felt disallowances to be inconsistently applied, from case to case, and even from one part of the country to another, and for some this perceived inconsistency was compounded by a sense that the whole application process lacked transparency and was 'unfair'. The key driver for this was claimed knowledge about other people who had made successful applications with similar or less severe disabling conditions than that for which they had themselves applied.

Reasons for making an application

The reasons given for making a claim were generally a mixture of four main elements, which in practice were often difficult to disentangle from one another:

- the onset or deterioration of a disabling condition;
- change (or anticipated change) in living circumstances;
- work difficulties or crises;
- financial problems.

Almost all the failed applications were occasioned by a specific 'trigger' event. Without knowledge of these triggers there was generally no very obvious reason why an application had been put in at the particular time that it was. The vast majority of applicants had been specifically advised or encouraged by a third party to make an application.

Informal encouragement from a familiar and trusted person was very important as a trigger to making applications, especially among those less inclined to read information literature for themselves. Several said that without such encouragement they doubted that they would have applied. However, the really crucial 'trigger' element for the majority of applicants was the more formal advice and support they received from health, welfare and benefits professionals. This 'official' view of their case, as applicants saw it, was absolutely decisive for many of them. It appeared that many claims were going in with the applicant still not entirely convinced of their case, but allowing advice from a professional source to override any personal doubts and uncertainty that they had. The authoritative nature of such professional opinion, as perceived by applicants, can scarcely be over-stated.

The professional opinions and advice that were reported as triggering applications for DLA came from a variety of sources ranging from government agencies to local authority departments and voluntary organisations. By far the most frequently mentioned professionals were advisers at Jobcentre Plus who were cited in almost half of the cases where advice from a professional had triggered a DLA claim.

Speculative claims

Among the clear disallowances there were, as might be expected, a high number of speculative applications. Some expressed the strong view that the entire process was essentially one of chance. For some, even though the chance of being awarded payment was very slim, the effort required to make the application was not great either (especially for those applying on-line) and so a speculative claim could be made with little expenditure of time or money.

There was evidence too of professional third parties advising customers on this basis, or of lending their authority to claims they knew to be speculative and to have little chance of success. In certain institutions, and with certain individual professionals, there may be contexts in which all customers that come into contact with them are encouraged to 'give it a go' with a DLA application.

The application process

The great majority sourced their forms either directly from Jobcentre Plus or indirectly from DCS, and in roughly equal numbers. Whereas, very often the professional advice and encouragement they received at these gateways was the key motivating factor for them going ahead with a claim, there was little in the way of information exchange about DLA or consideration of the advisability of the claim. In this way an opportunity to help filter out claims almost certain to fail was being missed, both in face-to-face situations and at points of telephone contact.

E-claimants were predominantly in the middle age range and more likely to be working than were other applicants. Submitting a claim electronically was attractive to them primarily because of the ease of instant access to the form and the time saved. Those applying on line were much less likely to have been through the gateways accessed by other applicants or to have come into contact with professionals regarding DLA. Few had had any professional help with their e-claim. They were even less likely than others to have seen or read the information leaflet about DLA, and were largely dependent upon the information available to them on screen and on the Department for work and Pensions (DWP) website. There is a prima facie case for saying that the higher rate of disallowances among this group are, at least in part, explained by this combination of circumstances. Instant (free) access to the application process meant that relatively little investment of effort was required, which in turn appeared to have encouraged more speculative claims.

Ineligible applicants

It might be assumed that ineligibility on residence/presence grounds would be easy to identify at the start of claims. Certainly most ineligible applicants had had some contact, support or encouragement from a third-party organisation, and some opportunities to filter claims on this basis must have been missed. However, it was easy to see why such apparently fundamental information could have been overlooked given the seriousness and urgency of some of their needs, the

language difficulties some of them had, and the somewhat disordered nature of some of their lives.

Experience of forms

For many applicants the common misapprehension that DLA was a disability entitlement rendered the form apparently 'perverse' in its emphasis on care and mobility needs. Applicants struggled with the fact that they seemed to have to answer 'no' to nearly all the questions. It is testimony to the power of those factors which led to obtaining an application form in the first place, such as the authority of professional advice and encouragement that these applicants still failed to interpret this experience as evidence that they should not go ahead with their claim.

Because the emphasis on mobility and care needs was so poorly understood, application forms were seen as 'unfair' and to have a 'bias' towards physical disability, in a way perceived to prejudice the cases of those with sensory disability, learning difficulties or mental health conditions.

Generally, the quality of form filling was poor and had sparse detail. Several applicants had failed to convey on the paper form all aspects of their disability or disabilities. Many felt that they would have benefited from more information and advice, particularly if they could access this face-to-face with an informed adviser.

Responses to disallowance

There was a general acceptance among the majority of applicants that their claims had been disallowed, with many acknowledging the reasons and explanations they had been given and accepting that they did not qualify. Several had reached the conclusion that they never should have made the application in the first place, and acknowledged their error.

Others accepted the explanation as to why they did not qualify according to the rules governing DLA, but still expressed dissatisfaction that the rules excluded their own circumstances, or that the threshold of severity for allowance was too high.

Despite all explanations, there were elements of basic misunderstandings about DLA that persisted throughout the application process and which informed people's responses to hearing they had been disallowed. In extreme cases the disallowance was interpreted as a denial of the applicant's disability itself.

Applicants receiving a fuller explanation of the reasons for their disallowance (under a pilot then running in the North West) were more likely than other applicants to say that they understood the decision after reading the notification letter. They were also more likely to say that they accepted the decision and as a consequence were less likely to have either considered an appeal or thought about re-claiming in the near future without a major change in their disabling condition.

Conclusions

Any action taken to attempt to reduce the number of DLA disallowances is likely to be of one of three general types:

- control of the quality, availability and effective transmission of information to potential applicants;
- influence over the behaviour of third parties involved in applications in various ways;
- and tightening of the application process itself to improve the 'filtering out' of claims that will not succeed before they are submitted.

General information materials, such as leaflets, may have some impact on perceptions, but it is probable that past practice in relation to awards will play a much greater role. Ensuring consistency and uniformity of awards practice over time and across all regional Disability Benefits Centres (DBC's) is likely to have beneficial effects over the longer term, even though it can not prevent other perceptions from being formed erroneously.

One possible way of influencing people's general perceptions about DLA might be to change its name so that it better reflects the intended purposes of the benefit and the criteria under which entitlement is assessed. The national roll-out from 24 September of the detailed decision letters piloted in the North West during the research should also help over time with promulgating a better understanding of the criteria for awarding DLA.

It is of great importance that accurate and appropriate messages about DLA reach the professional third parties, who will in turn pass them on to prospective applicants and ensure that 'no hope' applications are not encouraged. By far the most frequently cited third-party organisation involved in DLA applications was Jobcentre Plus. There are obvious opportunities for DCS to work more closely with this sister organisation to ensure consistency of approach and understanding.

The application process and administration provides the most direct points of contact with customers at which initiatives might be taken to filter out or deter 'no hope' claims. These currently comprise:

- the point of request for an application form;
- for those turning 16, the letter inviting re-application;
- the activity of completing the form;
- the point of seeking help with filling in the form;
- and the letter informing of the assessment decision (disallowance).

There is a case to be made for increasing the level of control that DCS has over these points of contact by bringing the provision of application forms entirely in-house, and dealing with third-party organisations only in relation to specific

cases. This would also ensure greater control over the provision of printed information, such as leaflets, which are not always provided, along with forms as things stand.

The opportunities raised by the remaining three points of contact with customers are essentially for including necessary and appropriately worded information and messages within printed materials, including potential filtering mechanisms. There appears to be a case for strengthening existing messages about eligibility and the appropriateness of claims, for taking the opportunity to highlight and repeat key information about the nature of the benefit and who should be applying for it, and for building-in explicit filters. Such filters could be genuinely automatic on e-claims and prevent the continuation of an application.

The letter sent out to DLA claimants who have received DLA in the past, when it was claimed for them as children by their parents, but who have now reached the age of 16, provides a point of contact with a sub-group of applicants. The purpose of the letter is to inform customers of the need to re-apply in their own right. Evidence from those interviewed who had recently been in this position suggests that a clear explanation of why this might not be an automatic continuation of benefit could be helpful.

Finally, the letter sent to applicants informing them of disallowance, and the reasons for it, provides a preventive opportunity. Although too late in the process to stop the first application, it may well head off further claims from being made. Some evidence exists that the piloted letters with fuller explanations may already have had such an effect. It is arguable that the inclusion of even more explicit and fundamental messages about the basis for criteria of eligibility for DLA could be effective for some applicants who continue to harbour misunderstandings about the benefit even at this stage in proceedings.

1 Introduction

1.1 Background to Disability Living Allowance

DLA is a complex benefit designed to contribute towards the extra costs faced by disabled people. It is available to people who claim help with these costs before the age of 65 and is non-contributory. It is usually paid in addition to other social security benefits and it is neither means tested nor taxable.

Entitlement to DLA is based on the need for personal care and/or the need for help to increase mobility for those with walking difficulties arising from severe disability. Entitlement is not based on the existence of disability, but on the way disability impacts upon the individual's daily living. Both the care and the mobility elements of DLA can be awarded on a graduated scale of rates according to assessed need.

Decisions about entitlement (and different award rates) require the exercise of a good deal of judgement. These decisions are made by DCS Decision Makers, working from a network of nine DBCs across the country. Decision Makers examine, follow up on and weigh up evidence submitted as part of the claim. The outcome of an application cannot be known until this process has been completed.

1.2 Disallowed claims for DLA

Currently, over half (57 per cent) of all new claims for DLA are initially disallowed. About one-third of these decisions are subsequently reconsidered and/or appealed against and six per cent of initial disallowances are overturned within a seven month period of the initial claim. This results in an overall disallowance rate of 52 per cent. (This is an upper bound for the disallowance rate as some claims will not have fully completed the dispute process within this time).

This high level of initial disallowances suggests that some claims are being made which have very little chance of succeeding – although it is very difficult for potential claimants to understand or assess before claiming the benefit whether or not they might be eligible. The result, over many years, has been a considerable

waste of time, effort and resource, both for claimants who have to complete a daunting application form, often without assistance, and for DCS staff who have to process many applications which subsequently turn out to be disallowed.

There appear to be considerable variations in disallowance rates across the country, by gender, age group and disability type. For example, adults between the ages of 25 and 45 are most likely to be disallowed, whilst children under the age of 16 are least likely to be. Also, women under the age of 35 have a higher disallowance rate than men of the equivalent age. The type of main disabling condition also makes a difference. For example, people with traumatic paraplegia are substantially more likely to be awarded benefit than those reporting inflammatory bowel diseases as their main disabling condition. Finally, those making electronic claims on line (e-claims) appear to have a higher rate of disallowances than those using the standard hand written application form.

All these various influencing factors have been investigated in this study, alongside the key finding from a previous piece of qualitative research (see Bibliography) which indicated that an important factor in the high rates of disallowance appeared to relate to the role of third party professional advisers who may help applicants with their claim. The input of third-parties was found to make a substantial difference to claim outcomes. A perception that required to be tested was that third-party intermediaries may not always be giving appropriate advice to potential and actual claimants.

1.3 Aims of the research project

DWP had already commissioned a separate feasibility study to look at possible ways of measuring DLA eligibility and addressing the barriers to take up from the claimant's point of view (see References). This research study, therefore, looks at the other aspect of the problem – why some applications are made when it should be clear to the applicant that they do not meet the eligibility criteria.

This report is designed to inform the better understanding of the respective role of DCS staff and that of intermediary advice organisations in shaping applicant awareness and behaviour with regards to the claiming and appeals process. The purpose of this study was to discover how well applicants themselves understand the benefit's purpose and entitlement conditions, in order to feed this into the design of appropriate operational strategies for improving the targeting and efficiency of the claims' process.

The study addressed the following key research questions:

- What are the drivers and/or influences on customer behaviour and understanding in relation to the existence of DLA, the eligibility conditions, the application and appeals' process?
- What happens when a customer decides to make a claim for DLA?
- Who takes the lead in completing the claim form? What evidence is used? How thoroughly is the claim completed etc?

- To what extent does knowledge and/or understanding about the benefit get inappropriately mediated by third-party organisations?
- What types of customers do/do not use third-party help, and are there any issues about claiming that are specific to particular customer groups (e.g. by type of disability or by type of channel used to claim)?
- In what ways could DCS target its marketing and partnership strategies to increase the proportion of successful claims and reduce the volume of disallowed claims?

1.4 Methodology

The basis of the methodology for carrying out the research and meeting its objectives was face-to-face, in-depth interviews with people who had made a claim for DLA which had been initially disallowed. Research was restricted to cases in which the applicants were adults of working age only (aged 16-64). It excluded applications that fall under the 'special rules' heading for automatic eligibility and was restricted to cases where DCS judged the disallowance to be obvious (clear disallowances) and for there to be no evident reason as to why the application was made. Only cases in which the allowed period of time for making an appeal had passed were included. All the applications were therefore 'closed' cases.

A 'long list' of cases was taken by DCS from a scan of disallowances made in the previous seven months at three of the regional DBCs: Bootle, Manchester and Wembley. Additional cases were selected from Sutton DBC. Sampling was undertaken from within this long list. Applicants were contacted by letter and offered the opportunity to opt out of the research. Those not choosing to opt out were then contacted by telephone for recruitment. Just over a quarter of those contacted agreed to take part in the research. Drop out from interviews after an appointment had been agreed was relatively infrequent. Fifteen people cancelled appointments. Those who did so were replaced from cases held in reserve.

Sampling was undertaken to ensure adequate coverage of the range of circumstances and characteristics of applicants known or thought to be significant to understanding the factors behind high disallowance rates. In particular, cases were over-sampled in the following key areas due to the small proportions present overall:

- cases ruled ineligible on grounds of 'residence' and 'presence' (less than one per cent of all disallowed claims);
- cases of electronically submitted claims (e-claims) ruled as 'clear disallowances' (approximately 1.5 per cent of all disallowed claims);
- cases in which the main disability given was a sensory disability (three per cent of all claims);
- cases in which the main disability given was learning difficulties (five per cent of all claims).

Full details of sampling and recruitment methodology can be found in Appendix A.

One hundred face-to-face interviews were carried out with DLA applicants, in their homes, during June and July 2007 using the interview topic guide included in Appendix B of this report. Interviews covered the following main groups of customer characteristics:

- age group of the applicant (16-24 years; 25-44years; 45-65 years)¹;
- type of main disability – grouped according to four broad categories (physical disability; mental illness; sensory disability; and learning difficulties)²;
- main different means of submitting claims (by post and by e-claim);
- claims ruled ineligible on grounds of failing to meet residency and presence requirements.

All interviews were tape recorded and transcribed for analysis.

1.5 Structure of the report

The structure of the rest of this report is as follows:

- Chapter 2: explores the levels of understanding and knowledge about the benefit among customers
- Chapter 3: looks at applicants' perceptions of the DLA benefit
- Chapter 4: presents customers' stated reasons for making an application for DLA and looks at the trigger factors leading to an application at the particular time that they had done so
- Chapter 5: examines customers' experiences of the process of making an application, including the initial decision to apply, any advice, help or persuasion they received, how they acquired and completed an application form, and received a decision
- Chapter 6: summarises the key messages to emerge from the research and sets out the report's conclusions.

¹ Broadly speaking the volume of disallowances increases with age, whereas the proportion of cases disallowed decreases.

² Of which sensory disability claims have the highest level of disallowance (63 per cent) and learning difficulties the lowest level of disallowance (28 per cent).

2 Knowledge and understanding of Disability Living Allowance

Throughout the following presentation of findings from the research, it is important to bear in mind the very specific context of the remit under which it was conducted. The disallowed applicants interviewed were all judged to be 'clear disallowances' by DCS assessors.³ As such, these disallowed cases were the most immediately obvious, most clearly evident, cases in which applicants had either failed to meet basic eligibility criteria or had failed to show in their applications that they had the care and mobility needs that would entitle them to the benefit.

Initial sampling by DCS suggested that approximately a quarter of disallowed applications and therefore approximately one-eighth of all applications could be considered to be 'clear disallowances,' for which there was no likelihood of disagreement between different assessors, and for which there was no indication that further investigation or additional supporting evidence would change the judgment.

³ A case is considered a clear disallowance if the customer claims little or no mobility or care needs and a consideration of 'understatement of needs' does not indicate that further investigation may be advised. The customer's stated impairment/condition, along with any listed medication, indicate whether or not 'understatement of needs' is likely. An applicant is considered **ineligible** if they fail Residence and Presence criteria, which means they are not eligible to claim DLA, and therefore mobility and care needs are not considered and no disability code is assigned to the case. Customers deemed eligible to claim can still be **disallowed** if they fail the Qualifying Period and Prospective Test criteria. This means mobility and care needs are considered, but the duration of needs is not expected to last long enough to satisfy the Qualifying Period and Prospective Test.

Respondents to the research, therefore, comprised those whom it appeared should never have made a claim for DLA. Had these applicants understood the nature of the benefit and the criteria for entitlement to it and acted accordingly, then on the basis of their application forms, they should have realized that their claims would be disallowed and that there was no point in making the application.

2.1 Little prior knowledge

Given the target group of clear disallowances, it was not surprising to find a generally low level of knowledge about DLA among applicants and widespread poor understanding of what the benefit is for and what the entitlement criteria are.

Most applicants knew little or nothing about DLA before making their application. Indeed, for many the suggestion by a third party to apply for DLA was the first time they had heard of it.

'I didn't even know what it was to be honest.'

(Interview 47: male aged 45-65 years)

'I didn't really understand much about it, no I didn't.'

(Interview 23: male aged 25-44 years)

Even those who were in receipt of other benefits such as Income Support (IS) or IB had frequently been unaware of the existence of DLA until it was brought to their attention by someone suggesting they should apply. Only a relatively small number of people among the clear disallowances were actually claiming other benefits, compared to the numbers known to be claiming IS, IB or Jobseeker's Allowance (JSA) among DLA recipients (around 80 per cent), and there was little or no evidence of applications being made in a calculated way from within what might be called 'a benefits culture.'

'I've never claimed anything in my life.'

(Interview 36: male aged 45-65 years)

'I really didn't know anything about benefits and...I didn't know what DLA was.'

(Interview 21: male aged 25-44 years)

Indeed, several people said they had been quite reluctant to apply because they didn't see themselves as benefits claimants:

'I actually felt really bad for applying for it in the first case because...I've always worked and been busy and I don't like being on benefits – and there seems to be a benefit culture [here] and like even when I go down the shops I hear people talking about "I'm going to get this benefit and that benefit" and it makes me feel bad in myself because I don't want to be associated with these kind of people.'

(Interview 21: male aged 25-44 years)

Several people admitted to feeling uneasy about claiming benefits:

'...I've never done that sort of thing, it's not in my nature.'

(Interview 47: male aged 45-65 years)

And a considerable number of their applications for DLA was the first time they had claimed benefit of any sort.

'...I've never in my life applied for anything [before].'

(Interview 57: female aged 45-65 years)

A lack of familiarity with disability related benefits may indeed have directly disadvantaged several applicants in that their applications for DLA were misguided and were undertaken in place of applying for IS and IB which appeared to be more appropriate to their circumstances. More than one person reported having been directed towards DLA by Jobcentre Plus staff at the point at which illness prevented them fulfilling the job search requirements of JSA.

2.2 The 'cream' of benefits

Because of the nature of DLA (non-means tested, unlinked to employment status and awardable indefinitely) there was an expectation that some people would be found to have applied because they viewed DLA as 'the cream of benefits' to get oneself onto for relatively little expenditure of effort. However, this was not the case. Most applicants were operating with very sparse information or understanding, with far more applications arising from misunderstanding than from calculated speculation. A small number saw DLA as a 'secure' benefit in the longer term, but always in the context of fears and concerns that their disabling condition would eventually get much worse than it currently was. As one applicant put it, referring to the low, medium and high levels of DLA awards:

'I know on the low one you don't get much – even if I get on that it wouldn't bother me at all – but one day I could end up on the big one if I am very ill.'

(Interview 49: male aged 25-44 years)

2.3 Informal sources of information

Accurate knowledge about the benefit and how it is awarded was very rare. The great majority of applicants had only a vague idea of what it was they were applying for and relied essentially on 'hearsay' for the little understanding they did claim to have. Often their information was gleaned from family members, some of whom had claimed DLA themselves.

'[I only knew] what my daughter had told me – she said that I perhaps could qualify because she got the money for my grand-daughter.'

(Interview 10: female aged 45-65 years)

'I only knew about it because my mum's family – a lot of them – have had to claim because like they've had cancer and other stuff like that and I've heard about mobility and all this, but I don't know too much about it.'

(Interview 3: female aged 25-44 years)

In other cases the experience of DLA was rather more distant from the applicant and any information about it came to them more indirectly.

'It's just people – 'oh my friend so and so' or 'my cousin this' you know.'

(Interview 57: female aged 45-65 years)

'I got talking to a client...he just said 'well you might be able to get it' – he did actually mention DLA – he says 'you might be able to,' he didn't go into any detail, it was just a general conversation.'

(Interview 45: male aged 25-44 years)

'I'd heard some of the folk at the blind club talking about the DVLA (sic) is it?'

(Interview 73: female aged 45-65 years)

At the extreme, even 'some people down the pub' (Interview 33: male aged 16-24 years) was cited as the main source of information.

2.4 Formal sources of information

In general, applicants were found to place far greater store by word of mouth, from friends, family or colleagues at work, than they did by formal written information sources such as the DWP leaflet on DLA or even the explanatory booklet that they received along with their application form if they made a postal application. Leaflets about DLA were clearly not always being routinely handed to customers when they made enquiries about DLA at Jobcentre Plus offices, or when an application was suggested by other third-party organisations. For several applicants the first time they got to see the leaflet was when a copy was sent to them along with their letter informing them their claim had been disallowed.

Few said they had seen the leaflet about DLA before (when shown a copy at interview) and not all of them had read it even if they did recognise it.

'Something like that...I don't usually read it, I just fill out the forms and send it off...'

(Interview 68: male aged 16-24 years)

Among those who had seen the leaflet prior to making their claim, recall of what was in it was weak, and in some cases non-existent. When asked what they thought to have been the key message the leaflet was trying to convey, applicants were vague, and in some instances had clearly come away with erroneous impressions, indicating partial readings perhaps undertaken to reinforce what was often a mistaken preconception. For example, the mother of one 21 year old applicant:

'[The main message was] if there's a disability of the sort where you have help, you know if she's not able to get full-time work then there is something – there's money there to help her out...'

(Interview 30: female aged 16-24 years)

And from a dyslexic applicant:

'I received the leaflet stating...that it can help you get back into work...I couldn't really understand it properly where it had to be read to me...and the print was quite small.'

(Interview 13: female aged 25-44 years)

A broadly similar situation was found in relation to the explanatory booklet of notes accompanying the application form. Although people were more likely to remember having seen it than the leaflet many had not felt a need to refer to it as they saw the form as being reasonably self-explanatory. For some, the size of the booklet was off-putting and they did not wish to engage with it at all if they could avoid doing so. When asked if he had read the booklet one young applicant said:

'No!...they're about that thick and about that big – I'm 18 years old, I'm not going to sit there and read every one.'

(Interview 33)

Similarly, applicants' interpretation of the material in the booklet where they had read it was often confused and partial with most looking for some kind of 'confirmation' of their eligibility but failing to grasp the full meaning: this from someone suffering severe eczema and erratic blood sugar levels:

'I read the part that it didn't matter if you were working or not working; if you were employed or unemployed you would still qualify for the benefit and if you have got certain medical problems you can apply...I'm sure it did state that [skin conditions qualified] yes. It said something about diabetes, I think diabetics can apply for it.'

(Interview 10: female aged 45-65 years)

And from someone deaf in one ear:

'There was leaflets in an information pack...and it more or less said I was eligible for it, the way it worded things...'

(Interview 3: female aged 25-44 years)

There was a strong sense that for many of the applicants by the time they came to fill in their application form they had already made a firm decision to apply and nothing by then was likely to put them off. In this sense they were not seeking clarification by this stage, or new information. Starting to fill in the application form had a momentum that meant most were determined to carry it through, having started, even if the process generated doubts in their mind as to whether they would be successful or not.

2.5 Difficulties with the written word

In a large proportion of the cases of clear disallowance the applicants displayed uneasiness when faced with formal written materials, whether these were leaflets, booklets of clarificatory notes, letters from DCS, or the application form itself. Many had some level of difficulty with reading or writing, or both, or with absorbing and retaining information. Three groups accounted for the majority, but not all, of the people in this position:

- recent immigrants and some of those from an ethnic minority background⁴ had difficulties understanding English which was not their first language;
- some of those applying by virtue of suffering from learning difficulties were functionally illiterate, and others struggled with conditions such as dyslexia, Asperger's Syndrome and Attention Deficit Disorder, requiring assistance from others with reading and writing tasks;
- several of those applicants with a mental health condition found the added stress of describing their condition in order to make a claim more or less debilitating.

It was not uncommon to find that applicants were much better able to describe their conditions and needs in the interview with a researcher than they were apparently able to do on paper. Application forms were frequently sparsely filled in, with obvious gaps, and omitting aspects of the impacts from disabilities on

⁴ There was a higher proportion of black and ethnic minority customers among the disallowed applicants interviewed (**excluding** ineligible applicants) than there are in the population of customers who are in receipt of DLA (and ethnicity was not a sampling criterion). The difficulties some had with understanding English will be one reason for this. Other difficulties understanding how the benefit applies may have had cultural factors behind them, and their experience of the application process may have differed from other applicants because of their ethnicity though there was no direct evidence of this.

applicants' daily lives which appeared to be relevant. Whether this information – not available to assessors from the application forms – would be sufficient to lift any of the cases into qualifying for DLA was doubtful, though in a few instances it might have successfully constituted reason for looking further into the case, or seeking additional information.

2.6 Poor understanding of entitlement

Over and above the specific problems noted in Section 2.5, was widespread poor understanding of the aims, purposes and operational criteria for the awarding of DLA. Many were forthright in admitting as much.

'I have no idea how it works...'

(Interview 42: male aged 25-44 years)

'I don't understand, but I just thought it would help – [be] extra help as I said.'

(Interview 62: female aged 25-44 years)

'I haven't got a main reason [for applying] just the pain, and I didn't know how it's working, so that's why...'

(Interview 69: female aged 16-24 years)

However, admitting to being largely in the dark about DLA had not prevented people from going ahead with their applications in any case. Particularly where a third party was taking responsibility for making the claim on their behalf, applicants were happy to take a secondary role and seemed unconcerned at their personal lack of understanding.

'The CAB filled it all in for me and I just signed the back of it...I don't know how it works – not even gone into that side of it. I never even asked...'

(Interview 64: male aged 45-65 years)

In several cases it was clear that applications for DLA had been made as part of a speculative trawl across a number of possible sources of benefit without any attempt to understand the specifics of any one in particular:

'I just told them [at Jobcentre Plus] my situation...enquired to see what I was entitled to...and they give me a few different forms and I just applied for all of them...'

(Interview 33: male aged 16-24 years)

On occasion simple misunderstandings were being made about the nature of DLA and the circumstances under which it was payable. These ranged from confusions with other disability related benefits through to rather vague and confused wishful thinking:

'I don't know [why people get this benefit]...maybe it will help them if they don't have money and medicine and stuff like that.'

(Interview 18: female aged 25-44 years)

There were three specific areas in which many applicants had apparently failed to understand the particular criteria determining entitlement for DLA. These were:

- the requirement to demonstrate care and/or mobility needs;
- the requirement to have such needs at a sufficient level of severity;
- and the requirement for needs to have existed for at least three months and be expected to last for at least a further six months.

2.6.1 Lack of care/mobility needs

A significant minority of disallowed applicants appeared to be entirely oblivious of the need to show that their disabling condition affected their day-to-day life in ways that entailed a need for care and for mobility support.

'No it doesn't [affect my daily life]...it's just I'm not very good with people.'

(Interview 7: male aged 16-24 years)

'It doesn't affect me getting around much...it's just generally...I can't play football and I couldn't run a marathon or do anything strenuous.'

(Interview 42: male aged 25-44 years)

'It's just my reading, my spelling, stuff like that.'

(Interview 74: female aged 16-24 years)

2.6.2 Severity of needs

Perhaps more understandably, many applicants were unsure of, or misunderstood, the level of severity of care and mobility needs that would be required for a claim to be allowed. As one sciatica sufferer put it:

'I didn't think I was that bad because there are a lot of people that are very bad, but then again I don't know...how serious is bad, you see what I mean?'

(Interview 51: female aged 45-65 years)

Most generally found it easier to describe and talk about the degree of severity of their disabling condition, than to focus on the severity of the needs arising from it:

'If I go blind, lose the use of my feet, you know, or I go completely and utterly doolally, then maybe they might think about [awarding me] something, I honestly don't know. I don't know what the assessors look for or don't look for.'

(Interview 43: male aged 25-44 years)

In particular, those who felt they had made determined efforts to minimize the impact of their disability, and to get on with their lives in spite of it, struggled to understand how this might make them less likely to be awarded DLA than someone who in their eyes had 'given in to it'.

Being faced with apparent examples of this, or urged by a third party to apply, or hearing of someone else in a similar situation applying successfully, some applicants clearly allowed their previous judgment that their own needs were not severe enough to be over-ridden and went ahead with an application anyway.

'Well...with moderate learning difficulties, from what I've heard, people don't tend to get it [DLA] anyway – it's only the people with more severe learning disabilities that tend to get it"... "[but] we just heard that someone had applied for DLA and got it, so we thought well we can try...'

(Interview 41: female aged 25-44 years)

In a number of applications the issue of how severe were their care and mobility needs was confused in the mind of the applicant by fears or expectations for the future.

'I think the only reason [I applied] was I thought I might get worse at the time – I thought I really might seriously be incapacitated...'

(Interview 47: male aged 45-65 years)

'I'm losing some sight and eventually...accordingly to the surgeons, I might go blind.'

(Interview 4: male aged 45-65 years)

'I'd say [my condition] was above mild, but it is worsening and it's worsening fast.'

(Interview 44: female aged 16-24 years)

In the latter two cases the applicants having been disallowed this time round, were envisaging making further applications as and when their conditions deteriorated.

2.6.3 Duration requirements

Despite the fact that allowance criteria for the duration of care/availability needs are relatively clear-cut (requiring needs to have been present at their current level for at least three months at the time of application, and expected to continue

for at least six months into the future) several applicants appeared not to have understood this basic requirement. A number of applications had been made in relation to short-term situations such as accidents and operations that could not qualify on these grounds. Some of these were due to delays in making a claim, others reflected confusion about the nature of DLA as a benefit:

'I didn't really think of it much at the time, I just thought that people who had an injury – I'd never heard of IB – I thought people with an injury were usually on DLA until they're better.'

(Interview 63: female aged 16-24 years)

Overall, most applicants were either unaware of the entitlement criteria for DLA, unsure about how to assess them, or allowed other factors and other people's judgments of their situation to override their own doubts (see Chapter 4).

2.7 Confusion with out-of-work benefits

The most evident misunderstanding about DLA was its widespread confusion with out-of-work benefits. A great many of the disallowed claimants were under the impression that, like IB for example, being out of work was a sufficient condition for receiving it.

'People just said about not working...[DLA is for] people who can't work.'

(Interview 33: male aged 16-24 years)

'I didn't find the information all that helpful...I just know that if you can't go out to work it [DLA] can help.'

(Interview 13: female aged 25-44 years)

'The Jobcentre said that...If you are ill and you cannot work, they said to fill in the form of the DLA...'

(Interview 18: female aged 25-44 years)

Specific parallels were drawn between DLA and IB by several of the applicants. Indeed at times respondents were not entirely clear as to which of these benefits they were referring, and there was a general tendency to refer collectively to disability related benefits simply as 'the disability'.

'For IB they allowed me [a medical] – so I thought, well if I can go in front of a board of doctors and get that, and then be turned down for DLA, I don't know how they work it.'

(Interview 58: female aged 45-65 years)

The confusion extended also to specific aspects of other benefits such as contributions-based IB.

'I think [the level of DLA awarded] depends on whether you're got any contributions.'

(Interview 34: male aged 45-65 years)

A small number of people thought DLA would be means tested.

'I didn't think I would have any chance at all – because I own my own house.'

(Interview 33: male aged 16-24 years)

The general confusion with out-of-work benefits appeared to have been compounded in many people's minds by the fact that they had either first heard of DLA in the context of other business with Jobcentre Plus, or had been referred there for information, application forms or the DCS telephone number. More than one of those interviewed had been advised to apply for DLA by a Jobcentre Plus adviser when their disability prevented them from fulfilling the jobsearch and work availability conditions associated with receipt of JSA.

2.7.1 DLA as a substitute for work

Even where DLA was not explicitly identified as an out-of-work benefit, there was often the implicit assumption that its main purpose financially was to act as a substitute for work, and to bridge the gap when work income was reduced or lost altogether.

'It's stopped me from working so I thought I must be entitled to something you know.'

(Interview 68: male aged 16-24 years)

'Having difficulty to work, it can substitute that...it would bring a substantial amount to work for the family.'

(Interview 19: male aged 45-65 years)

This view of DLA as a substitute for work meant that for most people it was a question of either work or DLA, rather than a question of a special benefit over and above anything they may or may not be earning.

'My husband was getting [DLA] when he had his first operation...and then he got a medical and the doctor said "no, you don't need it no more". But he still hasn't got a job...he can't go to work because he's always got this problem.'

(Interview 3: female aged 25-44 years)

'At the end of the day she is looking for help. If she can get a job she is happy to leave this stuff...she was desperate, because she can't get a job so applied for disability [DLA].'

(Interview 22: female aged 25-44 years)

3 Perceptions of Disability Living Allowance

A pervasive and widespread perception of DLA among disallowed applicants was that entitlement to it was simply and straightforwardly consequent upon having a disability. The question of allowance or disallowance that this perception typically raised in the minds of the applicants, therefore, was essentially what did they need to do to 'prove' they suffered from a disability. Their concerns in making an application were consequently to get as much detail across as they could about their condition, its symptoms and its diagnosis, but frequently to the detriment of information about the precise impacts it was having on everyday life.

By shifting the focus in this way, away from the specific mobility problems and day-to-day care needs crucial to entitlement, applicants jeopardised, rather than enhanced, their case. Many described more about their care/mobility needs in their research interview than they had put down on paper in their application forms. They had either put all their time and effort into trying to make a convincing case that they were 'disabled' and that this was medically verifiable, or, because they took the confirmation of a disabling condition by a doctor or other professional to constitute sufficient grounds in itself for DLA to be awarded, did not feel the need to provide lots of further information.

This view of DLA entitlement had persisted with some applicants right through to being informed of their disallowance, and fuelled a sense of unfairness that was not dispelled even by explanations given in letters of notification. For these applicants it appeared that such a view, once adopted, was extremely hard to change or to counter.

3.1 A disability entitlement

DLA is acknowledged to be a complicated benefit, the allowance of which requires the exercise of considerable, frequently subtle, professional judgment. This complexity is in turn difficult to convey to many potential applicants. The much simpler, and perhaps more immediately graspable, idea that DLA is an

entitlement for disability certainly informed the approach and actions of many of those subsequently deemed to be clear disallowances.

'I thought...so this is a disability, so there I applied.'

(Interview 11: female aged 25-44 years)

Indeed, the power of this perception appeared at times to determine the way that applicants read and (mis-) understood the DLA literature:

'...as it says "if you've got a disability" I understood that you might get help...'

(Interview 1: female aged 45-65 years)

Frequently it was allowed to override doubts arising from information leaflets or from experience of the questions on the application from itself.

'They ask you things like 'can you dress yourself? Do you need help getting out of bed?' Well obviously I don't, but it is a disability to be 100 per cent deaf in one ear – a great disability.'

(Interview 1: female aged 45-65 years)

Confirmation from a third party that a particular condition amounted to 'disability' and could be given this label, was reported as a deciding factor in some applications.

'I didn't think it [IBS] was a disability ... but then I got told I was entitled to Tax Credits because I've got a disability and [I'm] not leading a full life.'

(Interview 97: male aged 16-24 years)

'He was 99 per cent sure...they were going to get it because...one ear is now completely deaf and also he has been issued with a [disabled person's] free bus pass as well.'

(Interview 19: male aged 45-65 years)

The endorsement of a professional was seen as compelling evidence and official recognition of entitlement.

'I thought obviously I was [entitled to DLA] because I've got [a disability] with a document to prove it and everything.'

(Interview 50: female aged 25-44 years)

This focus on the 'symptoms' of a specific disability rather than its impact on everyday life in terms of care and mobility needs had the further effect of generating frustration in attempts to complete the application form, giving many the feeling that the form was not giving them the opportunity to present all the specific aspects of their own particular disability. Without this detail they felt they could not be receiving a fair assessment.

'I might be looking at this wrong, but it's not like there's a section on... visual ailments or especially [my condition] macular degeneration.'

(Interview 4: male aged 45-65 years)

When details were all felt to have been included, but still the claim had been disallowed, applicants were perplexed and indignant, and viewed the decision, through the distorting lens of the perception that DLA is a disability entitlement, as unfair or perverse.

'I found out that dyslexia is on the DLA and I phoned up and they said "oh yes, it is counted" and they sent me a claim pack...I sent in a full report... from the psychologist. It is an in-depth report on [my] disabilities and abilities, if you like, so they knew everything – and the reason I was turned down is because I can walk and make a meal for myself. So why is it considered a disability then? So why do they say "you can claim for dyspraxia" and then say "no you can't" for reasons that are nothing to do with dyspraxia?!'

(Interview 50: female aged 25-44 years)

The ultimate consequence of this perception was for applicants to see their disallowance as some kind of denial of their disability itself, or an indirect accusation of dishonesty.

'How can they sort of say that if you can cook meals for yourself and get around then you're not disabled? But I am disabled!'

(Interview 50: female aged 25-44 years)

'I volunteered to go for a medical examination because I'm not telling lies...'

(Interview 4: male aged 45-65 years)

3.1.1 Demonstrating disabled status

From the premise that DLA is an entitlement for people with a disability, the process of making an application became, for many, a matter of demonstrating or 'proving' their disabled status. Not surprisingly most struggled to do this in the way they felt was required, in the course of the questions on the application form. Some attempted to provide what they saw as crucial information in the form of an attached letter. Others tried to refer decision-makers to their doctor for medical, scientific evidence of their disabling condition, which they felt would be more compelling than their own account.

'I think he [a doctor] can explain to you better than I can...a doctor can explain exactly how serious the injury is.'

(Interview 4: male aged 45-65 years)

'I probably would [re-apply for DLA] but I think I'd just get knocked back again...unless the doctor says "here's a medical certificate for it". Because I think then you've got more of a chance to prove your actual, you know, disability.'

(Interview 3: female aged 25-44 years)

The perception that what was required was to prove or demonstrate disablement and that the best way to do this would be through some form of medical endorsement was widespread. Some expected their records and their doctor's opinion would be sufficient. Others wanted the opportunity to undergo a medical examination.

'They should take it through your doctor...that would avoid stress and everyone being disappointed – they know exactly what's wrong with people because they've got the medical notes.'

(Interview 25: female aged 16-24 years)

I even wrote them a letter – if there's any doubt about my claim for DLA I'll go to any doctor anywhere for a medical examination because it's a thing that you can't pretend; you can't cheat.'

(Interview 4: male aged 45-65 years)

Because of the assumed decisive weight that medical opinion would bring to bear on their claims for DLA, applicants were particularly unhappy where it appeared that no contact had been made with doctors and no additional information sought from medical sources. Many assumed that because they had had to provide contact details for their doctor that they would automatically be contacted.

3.1.2 The name 'Disability Living Allowance'

There were a number of indications that the name of the benefit (Disability Living Allowance) may be playing some part in determining or maintaining people's perceptions of it as payable to those with a demonstrable disability, of whatever kind, rather than payable to those with care needs and severe mobility restrictions. The very prominence of 'disability' as the first term in the name encourages a focus on this element and for some the direct equation 'DLA is disability' (46).

'Living Allowance' appeared much less immediately understood. Although it was not uncommon for applicants to interpret a living allowance as a benefit to help cover their extra costs, these were generally interpreted as any (or all) costs associated with their own disability. Thus applicants identified such items as flashing doorbells and special telephones (for the deaf) as costs they expected DLA to cover, in the same way that they identified the costs of a special diet or the cost of taxis if they could not drive.

With no reference in the benefit name to either care or mobility needs it appeared easier for some customers to develop and maintain misleading perceptions about

the purpose of DLA and the criteria for entitlement to it. There can, of course, be no absolute guarantees against such misinterpretations and false expectations. One applicant even argued a lengthy case for why he felt DLA should be paid to him because his disability was preventing him from working, on the grounds that work and earning an income was an essential part of 'living'. The most that can be said is that, as it stands, the name 'Disability Living Allowance' appears to be leading many people to unhelpful assumptions and reinforcing commonly held misconceptions. In the absence of any wording within it that might signpost the key aspects of care and mobility needs, it may be contributing to the numbers of applications that have to be disallowed.

3.2 A difficult and unpredictable benefit

A further widely held view of DLA was that it was a difficult benefit to claim successfully and that it was getting even harder to do so.

'I knew the chances were very, very slim because I know...you could be dying in your bed and you still wouldn't get it...it's a very hard benefit to apply for.'

(Interview 44: female aged 16-24 years)

The system seems to be designed to make sure that as few people as possible are paid – I can understand that of course!

(Interview 61: female aged 45-65 years)

No doubt the current very high disallowance rate has provided the backdrop to such perceptions, with people quite likely to know someone, or to have heard of someone who had been disallowed. There was a strong belief among some applicants that it had got much more difficult to claim in recent years than it had been in the past. Some were convinced that there was a conscious policy in place to reduce the number of successful claims.

'A long time ago...people if they fell over and broke their leg...they'd be able to get it. But now the systems have changed...they're very strict on things now.'

(Interview 48: male aged 25-44 years)

'I know they're trying to cut down on DLA certainly.'

(Interview 36: male aged 45-65 years)

Also reported as 'common knowledge' was the view that applications for DLA were routinely rejected at the first attempt and thus to be successful required one to apply several times and to keep on trying.

'Someone actually told me to apply again because they said most people that they know, they don't get it the first time they apply anyway...they always knock you back the first time.'

(Interview 42: male aged 25-44 years)

'We just thought that a lot of them DLA claims get turned down first time anyway for some reason.'

(Interview 41: female aged 25-44 years)

This view was apparently being supported by several third-party organisations who were reported as giving the advice to customers to keep applying even if initially disallowed.

'The training course [people] are saying normally they do turn you down on your first time but there again you've got to keep applying. It does take a little while but you've got to keep applying.'

(Interview 64: male aged 45-65 years)

The CAB – the man that did it – said that if you don't get it, come back and she could try again.'

(Interview 17: female aged 25-44 years)

Applicants reported cases they said they knew or had heard of in which people had persisted with applications over a long period until they had finally been awarded the benefit, though no account appeared to have been taken of the possibility that people's conditions might actually change considerably in that time.

'[I know of a] person who is claiming – I think apparently has been claiming the last, I think, the last twelve years for his disability...in the end he got it, but it took him twelve years...'

(Interview 64: male aged 45-65 years)

This insistence on the need to keep applying for DLA even following multiple rejections indicated a perception of the awarding process among some applicants as unpredictable and a matter of chance.

'It's the chance isn't it? Fifty-fifty?'

(Interview 70: female aged 16-24 years)

There were also those who felt disallowances to be inconsistently applied, from case to case, and even from one part of the country to another:

'It's sort of one rule for one and one rule for another, depending on where you live.'

(Interview 43: male aged 25-44 years)

'There are people that are going on it [DLA] that are not ill, and there is people that have got illness that can't get it – that's what annoys me, I think it's a bit unfair.'

(Interview 49: male aged 25-44 years)

And for some this perceived inconsistency was compounded by a sense that the whole application process lacked transparency:

'Some of the wording I found on the form like really sort of, not misleading but a bit...almost as if they weren't quite telling you what you were eligible for and how you would be eligible for it.'

(Interview 21: male aged 25-44 years)

3.2.1 Perceptions of others on DLA

While many of these perceptions arose from, or were informed by, feelings of grievance at having had a DLA application disallowed, they contributed to a wider, more general, feeling of unfairness that was seen to attach to the process of DLA awards. The key driver for this was claimed knowledge about other people who had made successful applications with similar or less severe disabling conditions than that for which they had themselves applied. Knowing a single such case can alone affect people's behaviour.

'[I would re-apply] if I heard of somebody that was receiving disability for similar reasons.'

(Interview 1: female aged 45-65 years)

Numerous cases were cited to support the view that DLA was awarded unfairly, even capriciously, among people with the same condition.

'I was very surprised that I got turned down actually because one of my friends has got exactly the same condition and she gets it.'

(Interview 13: female aged 25-44 years)

I don't see any difference between me and my uncle who has got very bad asthma. He needs help at home but he can care for himself – but he gets it.'

(Interview 97: male aged 16-24 years)

However, some of the comparisons appeared less justified, as with one applicant arguing that her friend should have been awarded a higher rate of DLA than she had been:

'My friend who applied for it – she's got a heart condition and has trouble walking, like walking distances...she got turned down...[on appeal] she still only got like middle rate care when people walk around [claiming] "Oh I've got a bad back" and you see them like doing the gardening and stuff like that – they get higher rate care.'

(Interview 41: female aged 25-44 years)

Similar views were expressed by applicants with all different categories of disability, including for example, mild learning difficulties and partial deafness.

'I know my brother gets it because he's dyslexic.'

(Interview 20: female aged 16-24 years)

'I know loads of people who are deaf and they claim it...I even know one person who has ... only got one hearing aid – he's got one good ear and one bad ear – he gets it!'

(Interview 36: male aged 45-65 years)

Of course, there is plenty of scope in these anecdotal accounts for customers to be mistaken, and to be seeing only what they want to believe. It is not possible to verify their perceptions nor to be sure that they were in full possession of the facts. In the two cases quoted above, for example, the brother of the applicant with learning difficulties was under the age of sixteen and likely therefore to have had different criteria applied to his need for care. Equally the partially deaf applicant may well have been unaware of additional disabilities (unrelated to deafness) which may have made the case cited different in kind to his own for assessment. Other cases cited as examples of unequal treatment also ranged widely, from examples taken from close family and partners, where it might be reasonable to assume that the full facts were known, through to hearsay about complete strangers. Nevertheless, the perception was common and widespread.

The further possibility exists that some of the cases people pointed to exist as the result of assessment mistakes – or, as some respondents believed, of more flexible rules – in the past, and now 'clog' the current system. As one applicant put it:

'I know they've tightened up a lot now so obviously there must have been a lot of people claimed [in the past] and...weren't entitled to it.'

(Interview 1: female aged 45-65 years)

Notwithstanding possible mistakes that may have been made by the assessment and allowance process, this view of inconsistent practice in relation to the awarding of DLA had inevitably led some applicants to conclude that others were benefiting from successful 'fraud'. People apparently successful in getting DLA, where they themselves had failed, were suspected of having done so through dishonesty.

'I just don't know how they work it because there's people I know that get it and there's nothing wrong with them...it really is annoying.'

(Interview 28: female aged 45-65 years)

'I've heard people get [DLA] for depression and, you know, different things – I don't know how they get it; they must falsify the forms or something...I really don't know.'

(Interview 1: female aged 45-65 years)

'One of my ex-boyfriends, he claimed...he had epilepsy that wasn't that bad really, to be honest – I think he were making it out to be a hell of a lot worse than what it were. I knew different!'

(Interview 44: female aged 16-24 years)

Closely related to this was the concept of 'the deserving disabled' which a few applicants articulated. The belief that some DLA recipients were responsible for their own disabling condition was, as in the case below, the main motivating force behind the speculative, and repeated, applications of their own.

'Me and my daughter is entitled to DLA, no matter how many times they refuse me – I don't know why they can't give it to people like [us] yet they can give it to people who have drinking problems [or] drug problems.'

(Interview 78: female aged 16-24 years)

4 Reasons for claiming

Applicants who had been adjudged to be 'clear disallowances' were asked what had led to their making a claim for DLA, why they had made a claim at the time that they had, and whether there were any particular 'trigger' factors involved that had prompted their application.

The reasons they gave were generally a mixture of four main elements, which in practice were often difficult to disentangle from one another, although for most individuals one factor was felt to have dominated the others. The four elements put forward were:

- the onset or deterioration of a disabling condition;
- change (or anticipated change) in living circumstances;
- work difficulties or crises;
- financial problems.

Applications were made for DLA in order to seek some extra resource to help address these problems which in some cases (but not all) had implications for care and mobility support needs that entailed additional costs to the applicant.

DLA was sought, for the most part, in its own right as a discrete source of possible financial help. There was little apparent awareness among applicants of the passported benefits that being in receipt of DLA could bring, though a small number were seeking indirect benefits of one kind or another. Some applicants had been led to making a claim for DLA in the (apparently mistaken) belief following advice from third parties such as Her Majesty's Revenue & Customs (HMRC) that without it they could not get Disabled Persons' Tax Credits. One applicant had similarly made a claim following an attempt to get a grant for a new central heating boiler. Three applicants were seeking DLA as a form of 'certification' of their disability (much like the former Green Card mentioned by two of them) from which they expected indirect benefits in the form of respectively: greater toleration from work colleagues for time off to attend hospital appointments; access to car parking close to the work-place; and extra student study support.

'It's never been about the money, it's about just the recognition – so I could go to work and say "well, there you are"...'

(Interview 23: male aged 25-44 years)

4.1 Financial motivation

In a sense there was a financial motivation to virtually all applications, given that they were seeking a benefit to help with costs related to a disability. For many, however, getting help to address their financial situation was explicitly the main or only reason behind their claim.

'I always thought he was not bad enough...[but applied] when his JSA was cut down to £15 instead of £50.'

(Interview 34: male aged 45-65 years)

'I just wanted a bit to add to the cashflow, with rent and...everything going up.'

(Interview 36: male aged 45-65 years)

Deciding to make an application for DLA was for some just one part of a general review of their financial situation and the devising of an overall financial 'strategy' to address change and difficulties. In these instances the application for DLA was one of many different approaches to the perceived problem and one of many sources of financial help considered.

'My girlfriend was looking through this booklet...so I started reading through to see what it was all about and...said, well what's this Tax Credits thing?...I might be entitled to that...there's no harm in trying for it. And then there was...DLA and I said, well I spend out a lot of money on certain things...'

(Interview 97: male aged 16-24 years)

The form really wasn't relevant...we just wrote this long story...of the situation [and] what we were trying to get and obviously it wasn't right... well, fair enough, it was just one track that we went down...'

(Interview 100: female aged 25-44 years)

For those taking stock in this way, their view of the future often entailed anticipation of a drop in earnings, whether from a change of job or from time lost to illness.

'Basically [I was looking for] a bit more financial help really. Plus I wasn't going back into the job that I was doing before [being diagnosed with a heart complaint].'

(Interview 42: male aged 25-44 years)

'To me it was the money and I thought I could do with the extra help because I'm always off sick.'

(Interview 70: female aged 16-24 years)

Indeed, for those in work the impact of their disability on their earning power was the key factor in their decision making.

'Me being off for the anxiety attacks...I had lost that much pay from work and I just realised that I can't really go on, it's getting very difficult.'

(Interview 43: male aged 25-44 years)

Specific, additional, disability-related costs were uppermost in the minds of a few applicants when deciding to claim DLA, though for mostly very limited expenditures on such things as home adaptations and equipment, which are not a primary intended target for DLA funding.

'I'd heard about phones for deaf people...the money would come in handy just for buying stuff like that.'

(Interview 36: male aged 45-65 years)

'My social worker said it would maybe help with taxis...for the children basically, just to get them to school.'

(Interview 62: female aged 25-44 years)

Differentiation of costs related to care and mobility support needs was not generally evident among the disallowed claimants. In one case general costs were quite consciously put ahead of care needs.

'I don't need a car but I'm still spending out a hell of a lot on stuff...expenses – that's what I think DLA is about...'

(Interview 97: male aged 16-24 years)

The general lack of focus around the specific entitlement criteria for DLA was particularly highlighted by the admission of several applicants that they had viewed DLA as essentially funding of last resort once other avenues had been explored or attempted. Applications undertaken in this spirit were frequently speculative 'long shots'.

'A friend's brother said they'd applied for [DLA] and...got it. So we thought, well we can try because that's the only thing to apply for...if we don't get it, we don't get it.'

(Interview 41: female aged 25-44 years)

'I thought...I must be entitled to something. Nothing ventured, nothing gained.'

(Interview 57: female aged 45-65 years)

Third parties, such as Jobcentre Plus advisers, were reported also to have pursued this line of thought when suggesting customers applied for DLA, signposting them to this benefit when they felt they had no other help that they themselves could offer.

'What made me make the claim was I was starting to go over onto... Pension Credit...and I wanted to check that my IB was right. [Jobcentre Plus] said, no you're not entitled to [more IB] but I advise you, you might be entitled to some sort of DLA.'

(Interview 4: male aged 45-65 years)

4.2 Work difficulties or employment crises

Closely linked with financial concerns in some applicants' minds were issues relating to employment. Those finding it increasingly difficult to cope with the job they were in were prompted to make a DLA application, in anticipation either of having to reduce their hours, or take a less demanding (and less well paid) job, or with the expectation of being unable to work at all in the near future.

'He is becoming deaf...also his age is going up now and he is finding it difficult to work.'

(Interview 19: male aged 45-65 years)

Equally, applicants currently not working were concerned that their disabilities would make it impossible to find employment in the future and had applied for DLA with this in mind.

'She was desperate, because she can't get a job, so applied for disability.'

(Interview 22: female aged 25-44 years)

While several had made their DLA applications in anticipation of imminent problems staying in work or finding new work, others had applied as a direct response to an actual crisis, whether this was essentially financial such as coming to the end of a period of Statutory Sick Pay, or whether it involved losing their job altogether.

'[I made a claim] when they stopped paying me sick pay...They said they didn't have any office work for me, so because I was a bricklayer I...just waited for them to get back to me...now they're going to get rid of me.'

(Interview 33: male aged 16-24 years)

In almost every case where employment issues made up an important part of the motivation for applying for DLA, applicants expressed a line of thought that reflected the widespread perception of DLA as an out-of-work benefit, or as a financial substitute for being able to work. This was particularly clearly expressed by one applicant who speculated about the future if he was unable to receive DLA:

'[I will apply again] but if I don't get it this time then I'll probably just forget about it and try to find another job that pays me more money.'

(Interview 42: male aged 25-44 years)

4.3 Onset or change in disabling condition

A similar number cited a work problem as their main reason for applying for DLA, stating their main reason to be the onset of a disabling condition or a change or deterioration in their condition. Most conditions were long-standing or progressive in nature. Applications made because of the onset of a disablement, therefore, tended to be in response to traumas, temporary hospitalisation or medical interventions and operations. Even with these types of conditions, there was frequently a delay before a DLA application had been made, during which the longer term effects and consequences had become apparent and people had weighed up their future options. A number of cases involved serious injury from, for example, car accidents or accidents in the home. In some of these, the delay to making a claim meant that by that time recovery was well underway and by the time the applicants were interviewed they were no longer affected by significant disability. It is likely that in practice some of these cases had failed to meet the six month expected duration criterion that applications should satisfy, although estimating the duration of particular conditions or need was felt by most to be extremely difficult.

Several applications had been made by people diagnosed with cancer and undergoing surgery, chemotherapy or radiotherapy. They perhaps form something of a special case, in so far as the applicants were, understandably, focused on an uncertain future at the same time as suffering disabilities from their treatment in the short term. Without being specifically aware of the 'special rules' under which those with a terminal diagnosis can be in receipt of DLA, they were aware of other cancer sufferers receiving the benefit and generally struggled to make the distinction with their own early stage diagnosis that did not necessarily entitle themselves in the same way. The label for the illness (cancer) made consideration of the practical day-to-day limitations from which they were suffering more difficult to achieve.

In less obvious ways some other applicants too were found to have been motivated to claim more through consideration of possible (even likely) future circumstances rather than their situation at the time of making an application.

A specific worsening of a long-standing condition lay behind other applications with, for example, a step up in the level of pain experienced on a daily basis, or the development of additional, often related, conditions that had arisen alongside it.

'The psoriasis I've had since [the age of] about fourteen, but the arthritis has just started getting bad in the last year...'

(Interview 68: male aged 16-24 years)

However, while health issues, not surprisingly, underlay most claims, in the majority of cases it was some other, external, factor that had acted as the 'trigger' to making a DLA application.

4.4 Changes in living circumstances

Other reasons cited for making DLA claims involved changes in applicants' living arrangements and circumstances. These changes had often brought care issues to a head and were sometimes accompanied by a deterioration of a health condition that was seen as arising as a direct consequence.

'[My sciatica] got worse basically...I think it was through moving out of my mum's into the...hostel for homeless people...It put a strain on my back with moving things...and stress doesn't help either, that seems to make it play up.'

(Interview 44: female aged 16-24 years)

Moving out of the parental home, where there had been someone around to help care for them when needed, was the key moment for some applicants, who saw DLA as a possible lifeline to maintaining their independence. More often, however because receipt of DLA was hoped to be the route to more independent living, disallowance was said to have prevented any change and several customers felt 'trapped' where they were and dependent upon parents or other relatives (even though in their 20's and in two cases with children of their own).

'She can't live independently – that's her disability...If we hadn't have got this option [of living with family] she'd have had to be living [on her own] and somebody would have had to be going round there every day – so she would have, to all intents and purposes, had a carer.'

(Interview 30: female aged 16-24 years)

Separation or divorce were the changes given as reasons for claiming DLA by other applicants. Again stress was cited as affecting health, and the reappraisal required of care needs and how to cope alone with daily living had led to a review of their financial situations and led to consideration of DLA support.

Simply having reached a certain age had triggered events for one applicant that carried important financial consequences as well. On reaching the age of 19 she had moved out of local authority care and found herself having to personally meet the costs associated with her condition that had previously been paid for by Social Services.

'I wet the bed...I'm always in pain...I might have to have a kidney transplant... My social worker said...I could put in for DLA for myself because Social Services couldn't keep giving me money to keep going out and buying bedding...The budget stopped because I turned 18...The only reason they gave it to me [before] was because I was in care.'

(Interview 78: female aged 16-24 years)

4.5 'Triggers' for applications

Whatever the explicit or underlying reasons behind the failed applications for DLA, almost all were occasioned by a specific 'trigger' event. Without knowledge of these triggers there was generally no very obvious reason why an application had been put in at the particular time that it was rather than at any other moment over a considerable length of time. In many cases applicants had lifelong medical conditions, but had not applied for DLA until specifically prompted or encouraged in that direction. A small number had made previous applications, sometimes many years earlier but for the great majority this was their first and only application.

The vast majority had been specifically advised or encouraged by a third party to make an application – whether this was informally via friends, family, neighbours, work colleagues and acquaintances, or formally, involving advice from professionals in health, education or welfare organisations.

4.5.1 Applications by previous recipients of DLA

Four applicants had previously been in receipt of DLA as children through claims for them by their parents or guardians, and had been required to re-apply in their own right at this age. Whether they had failed to re-apply at the age of 16, or had done so and been disallowed at that time, their current disallowance related to a subsequent application.⁵ All were confident of entitlement because they had received DLA before, as they saw it for the same condition they still suffered from. Only one of them recognised that their disallowance was probably related to changed care needs now they were no longer a child.

'Obviously when I was younger I did need help eating and toileting and washing and stuff because I was younger, so that could be why [I was allowed DLA then but not now].'

(Interview 75: female aged 16-24 years)

However, for the others their experience was that their condition was still essentially the same, as were their needs:

'[I was confident of getting DLA] because I'd been on it before...and nothing's change – I've still got the same problems.'

(Interview 25: female aged 16-24 years)

One further applicant, who was still aged 16 but had never been in receipt of DLA previously, perceived his needs to have increased on leaving school:

'I left school and I had to start paying for my tablets...and I would like some help [paying] for them because they're quite expensive.'

(Interview 94: male aged 16-24 years)

⁵ No cases of disallowance on renewal at the age of 16 were included in the sample, though one applicant was convinced that this was her situation. Her date of birth early in 1991 lent some plausibility to this claim, though she had poor recall of precise dates and details.

4.5.2 Informal third-party encouragement

Informal encouragement from a familiar and trusted person was very important as a trigger to making applications, especially among those less inclined to read information literature for themselves. Several said that without such encouragement they doubted that they would have applied.

'I was only prompted because somebody – a friend, a girlfriend – said, you should be on [DLA]...you are very deaf.'

(Interview 1: female aged 45-65 years)

Most frequently such informal motivation came in the form of family or friends who applicants could count on to have their best interests to heart.

'My daughter...said to me, mum why don't you apply for it, because you have had these skin problems for years and sometimes you are not well with it...she advised me to go and get a doctor's letter...'

(Interview 10: female aged 45-65 years)

'[A friend] told him that he could be eligible for this DLA, so that's why [he] applied.'

(Interview 19: male aged 45-65 years)

Although such promptings were informal, they appeared to carry a lot of weight and sometimes were reported as both forceful and insistent.

'My friend...said...I'll give you this number...she badgered me into doing these things.'

(Interview 1: female aged 45-65 years)

'I did ask one of my friends...and she said, there are parts of it [DLA] which are for people with mental health problems, so fill it in – which I did do.'

(Interview 21: male aged 25-44 years)

Particular notice was taken of the opinions of those with experience of the same disability, either themselves or in a close family member.

'Cause I know some people – friends of mine – they've got...learning difficulties themselves...and they said, just try, put in for it.'

(Interview 12: female aged 25-44 years)

'I spoke to one of my friends that had the same condition...she said do you know you can get disability for your eye condition?...I phoned her up again when I got fired.'

(Interview 13: female aged 25-44 years)

In addition to all the cases in which informal third-party advice of this sort was instrumental in deciding upon making a DLA application, there was much support and encouragement from such sources also in cases where the identified trigger lay elsewhere. Encouragement and practical support with application forms, in particular, tended to fall to family members.

4.5.3 Formal third-party advice

Although informal encouragement was important for some, the really crucial 'trigger' element for the majority of applicants was the more formal advice and support they received from health, welfare and benefits professionals. This 'official' view of their case, as applicants saw it, was absolutely decisive for many of them. Where official encouragement was coming from more than one source, it was virtually irresistible.

'She tried because 'everybody' was giving her [this] advice.'

(Interview 22: female aged 25-44 years)

Any such official voice lent authenticity to claims, and clearly in some cases the encouragement was active and forceful.

'I didn't think she'd get it, but it was the Deaf Society what said so.'

(Interview 17: female aged 25-44 years)

'I was urged to do it by my lone parent adviser at the Jobcentre.'

(Interview 44: female aged 16-24 years)

Frequently applicants said that without such official advice and support for making a claim, they were unlikely to have done so of their own accord.

'It's because [the adviser at Jobcentre Plus] actually said to me [to apply] that I thought, well OK then I'll do it. Because I'd probably never have bothered or thought about it [otherwise].'

(Interview 3: female aged 25-44 years)

'[I applied] because they [Jobcentre Plus] advised me to, that's all.'

(Interview 47: male aged 45-65 years)

'Well, I wasn't going to [apply] but I went to the Citizens' Advice Bureau and woman there actually said, you should put in for it, so I thought, well there's no harm in doing it, you know.'

(Interview 79: female aged 16-24 years)

Even those few who had taken the trouble to investigate eligibility, and to read the available information about DLA, ultimately deferred to the opinion of a professional; to a 'knowledgeable voice'.

'The very first time I picked up the leaflet myself from the Jobcentre and read all the things, I said, well it's not worth doing...because you're not going to get anything. Then when we were advised by one of the ladies in the Jobcentre, she said, well I think you should fill it in and see how you go.'

(Interview 34: male aged 45-65 years)

Advice from a professional, trusted to have better knowledge, understanding and experience of the matter, was thus frequently powerful enough to override any personal doubts and uncertainty that applicants had about putting in a claim.

'My Community Pyschiatric Nurse suggested that I might be eligible and I thought I wouldn't be but she said, no – make a claim anyway [and she] prompted me and helped me with it.'

(Interview 66: female aged 25-44 years)

Some were even persuaded to re-apply after a previous disallowance on the basis of such professional advice.

'[I applied] this time on the advice of the Social Worker. She actually said, you know you really do have a case and you should push it and just try again.'

(Interview 30: female aged 16-24 years)

It appeared that many claims were going in with the applicant still not entirely convinced of their case but swayed by advice from an authoritative source to go ahead with it.

'I didn't think I was really going to get it, and I wouldn't have thought about even applying for it unless the nurse hadn't suggested it...it's for people who are more seriously disabled than I am to be honest.'

(Interview 54: male aged 25-44 years)

Indeed, in some cases applications seemed to have been more or less out of the hands of the applicants themselves, who had little real input to the process or awareness of what they were doing or why.

'I weren't quite sure. I didn't know sort of what I was filling in really...but I thought I should be OK because that's what the Jobcentre has advised me – so I should receive it.'

(Interview 63: female aged 16-24 years)

The motivations of the professionals giving this advice to make a claim for DLA (to people subsequently deemed to be clear disallowances) must for the most part remain speculation. However, there was some evidence that professionals could be aware of the 'advantages' of DLA over some other benefits (non-means tested, unaffected by work) even where the claimants themselves were not well-informed.

'I went to Connexions and did a CV...but they suggested that I try for the DLA. They just felt that that would be much better for me than JSA.'

(Interview 7: male aged 16-24 years)

Although this led to a degree of speculation in applications, in many instances, there was also evidence that the professionals in question had the interests of the customer at heart and gave their advice in good faith.

'It was [the adviser] at Jobcentre Plus...said that I should go in for it because of my depression, my anxiety attacks...she was quite surprised when I told her I got rejected, she couldn't understand why.'

(Interview 28: female aged 45-65 years)

The professional opinions and advice that were reported as triggering applications for DLA came from a variety of sources ranging from government agencies to local authority departments and voluntary organisations. They included:

- Jobcentre Plus;
- Connexions;
- Welfare Rights;
- Social Services;
- Citizens Advice Bureau (CAB);
- hospitals and doctors' surgeries;
- community health services;
- colleges and universities.

By far the most frequently mentioned professionals were advisers at Jobcentre Plus who were cited in almost half of the cases where advice from a professional had triggered a DLA claim. Their views regarding benefits were widely viewed as authoritative, particularly if backed up by health or other welfare professionals, and presented in the light of experience of other, similar, cases.

'I was told I was entitled to some sort of DLA...At the Jobcentre they said that they've had [similar] cases...and also my doctor said that he had cases where he had people with the same illness as me and they've got some DLA.'

(Interview 48: male aged 25-44 years)

The authoritative nature of such professional opinion, as perceived by applicants, can scarcely be overstated. In one instance a young woman even felt as a result that making an application for DLA was a requirement of fulfilling her obligations in relation to her lone parent work focused interview.

'It was the Jobcentre that said to me to apply for DLA...in my lone parent's interview...I just thought, well I'll do it just in case, because they check up on you if you don't...'

(Interview 74: female aged 16-24 years)

At the other end of the scale, one applicant concluded from a visit to his Member of Parliament (MP) that it was his, and everyone's, right to have the opportunity to make their case for DLA entitlement.

'I spoke to one of our local MPs...and I asked him for some good advice... and he said to try...he was telling me basically that everyone deserves to have...a chance.'

(Interview 48: male aged 25-44 years)

4.6 Speculative applications

Among the clear disallowances there were, as might be expected, a high number of speculative applications. Applicants found different ways to express this, but there was a common thread of 'giving it a go' among many of them.

'We didn't really think – it was just literally, we'll try and if we get it then great.'

(Interview 41: female aged 25-44 years)

It was [my friend] that persuaded me. I said, oh I've tried it before, I said, I won't get anything – [but] I thought, I'll just try.'

(Interview 1: female aged 45-65 years)

Roughly half of the customers interviewed said that they were not confident of success with their applications but had gone ahead anyway. Roughly half of these said that they had done so because of professional advice or encouragement from a third party that had made them question their own scepticism. The remaining cases could be considered to be 'pure speculation', fuelled by wishful thinking and the view that it was just possible to 'get lucky'.

'Just take a chance, you've got nothing to lose, you know – you just fill it in. In my own mind I already thought, no – not going to get it, but I'll fill it in just to see what happens.'

(Interview 34: male aged 45-65 years)

'[My daughter in law] she's got a few mates that are on it ... she said, just put in for it, it's a chance that you take, you either get it or you don't.'

(Interview 29: female aged 45-65 years)

Some expressed the strong view that the entire process was essentially one of chance and, like a lottery, you couldn't win if you didn't enter. It was less the

case that the reward of having a claim allowed was seen as potentially very great, more a sense that the odds were very long because, realistically, it required the assessment and awarding process to make a mistake if they were to be allowed DLA.

'People are claiming for things all the time and don't always need them, so someone thought I might be eligible for [DLA] so I thought I would give it a go...I didn't think, oh I'm entitled to this!'

(Interview 42: male aged 25-44 years)

'You see it every day...people that claim consistently – get, and people that don't (like myself) – don't. So I filled it in. I thought...if I get it, fantastic! If I don't well I've not lost nothing really.'

(Interview 45: male aged 25-44 years)

In one instance the applicant was fully aware that under the existing rules she could not be awarded DLA because she was applying retrospectively for payment she may have been entitled to previously, when undergoing treatment, but which she had not claimed at the time. Her application was made explicitly to test whether the system of DLA administration would actually run to those rules.

'It was just an exercise really to sort of check out the system, just to see if – well there was always a chance that it might 'fall through the chinks' and they might pay the money.'

(Interview 61: female aged 45-65 years)

The same applicant gave clear expression also to the idea that even though the chance of being awarded payment was very slim, the effort required to make the application was not great either (especially as she was making an e-claim) and so a speculative claim could be made with little expenditure of time or money.

'It was just a matter of whether we could have got any of this backdated money really...I looked at the DWP website and...realised that there was probably little possibility of getting it but...I thought, well why not just put in the application, it was free, it didn't even cost a postage stamp if you did it on line.'

(Interview 61: female aged 45-65 years)

Similar sentiments were expressed by other applicants too.

'I thought, it doesn't hurt to try – ten minutes of my time – it could make a difference, but if it didn't [succeed] it was only ten minutes.'

(Interview 43: male aged 25-44 years)

At the extreme end of the spectrum of speculativeness were a small number of applications from individuals with no diagnosed condition and no apparent disability (as far as it was possible to judge at an interview with no specialist knowledge). However, such applications were very few. The great majority had

some level of genuine disability or illness and some degree of day-to-day difficulty caused by it, even though many of them strongly suspected that it would not be sufficient for them to be awarded even the lowest level of DLA.

Frequently the experience of trying to complete the application form itself was described as confirming people's suspicions that they were unlikely to qualify for benefit. However, there also appeared to be a 'momentum' attached to having filled in (or started to fill in) the form, which carried them through into submitting the application regardless.

'When I was filling the form in I thought, well I don't need help doing this, I don't need help doing that, so it was like [my answers were] No, No, No, and I thought, well I'm wasting my time, really, filling it in – but there's no harm in trying is there? So that's why I just sent it off in the end.'

(Interview 3: female aged 25-44 years)

Certain questions...gave me a bit of doubt but I still thought, no well I have got nothing to lose, so I still applied for it.'

(Interview 10: female aged 45-65 years)

Not only did several people feel at this point that having got so far they may as well complete the process anyway, because the effort had already been made, but in some cases the application was apparently put in as a 'marker' for the future, even though there was felt to be almost no chance of it succeeding on this occasion. Speculation with the current application could clearly be related in some cases to anxiety about the future.

'I think the only reason [I applied] was I thought I might get worse at the time, you know, I thought I really might seriously be incapacitated.'

(Interview 47: male aged 45-65 years)

A notion also seemed to exist with some applicants of 'registering' a case against a future possible re-application, as if there was something to be gained by getting an early 'toe on the ladder' as insurance against future deterioration in their condition.

'I thought, at least if I fill it in and it's logged, if I need [to] then [I] can go back at a certain time and apply again – I'll log it in.'

(Interview 45: male aged 25-44 years)

4.6.1 Third-party speculation

It should not be thought that all the speculative applications were the result of individuals deciding independently to chance their luck. There was much evidence of professional third parties advising customers on this basis also, or of lending their authority to claims they knew to be speculative and to have little chance of success.

'I didn't know if I were entitled to it or not but...the doctor signed it – I think the doctor knew I wasn't capable of getting it.'

(Interview 96: male aged 25-44 years)

'They [at Jobcentre Plus] said, well...you know, fill it in and see how you go.'

(Interview 34: male aged 45-65 years)

'I thought it was more perhaps to do with people who had severe disabilities and severe learning needs. She [the voluntary organisation support worker] told me, no everybody's got different needs, and to apply for it – to see how we would go.'

(Interview 95: female aged 16-24 years)

'I can't travel long distances by myself because I get lost, I don't understand, I don't know how to actually get around places...so I was telling my social worker and she said, Oh put in a claim [for DLA] and see what happens.'

(Interview 20: female aged 16-24 years)

In one case the applicant was advised by Jobcentre Plus staff to adopt a strategy of continued re-application, against the customer's own inclination not to pursue the matter further after he had been disallowed once.

'When I went into the Jobcentre they told me to try it and see what happens. So I did and I got turned down, and when I told them that I got turned down they told me to do it again...they just told me to try again and see what happens...I am just going to keep trying...I was going to give up this time but people (friends and the jobcentre) have said, don't give up just keep trying and fight it, that's all you can do.'

(Interview 49: male aged 25-44 years)

In two other cases a picture was painted indicating that in certain institutions, and with certain individual professionals, there may be contexts in which all customers that come into contact with them are encouraged to 'give it a go' with a DLA application.

'At the recovery unit, people in the same type of situation as me, with the same type of mental illnesses, were applying for [DLA] and getting turned down – most people weren't getting it...[the nurse] said, you're better to apply rather than not.'

(Interview 66: female aged 25-44 years)

'It was my nurse who suggested I make a claim...I didn't think I was eligible... she was a new nurse...I think she obviously suggested it to all the people she sees.'

(Interview 54: male aged 25-44 years)

5 The application process

The context for clearly disallowed applications for DLA, therefore, is one of poor understanding, distorted perceptions, the primacy of word of mouth over formal written forms of information, high levels of speculative claims and the crucial importance of third-party advice and encouragement particularly from trusted professionals. It is against this background that an attempt can be made to understand applicants' reported experiences of the application process itself, and explore possible points of contact and influence for policy wishing to address the problem of very high disallowance rates.

5.1 Source of application forms

Where applicants sourced their DLA claim forms from is important for a number of reasons. Not only is the source significant in terms of accessibility, but also because it presents the clearest point of opportunity for conveying information and advice directly to applicants before they start to put together their claim. It provides the opportunity both for passing on written information literature, such as leaflets and guidance notes, and for engaging verbally with the customer regarding their circumstances and their reasons for applying.

The main available sources of application forms are DCS itself (via a telephone call either to a regional DBC or to the advertised 0800 helpline number) and Jobcentre Plus offices (which provide local 'doors onto the street' for enquiries and hold stocks of forms). Other organisations will be provided with forms by DCS, at their request, which they can pass on to interested customers. Alternatively they can telephone DCS on behalf of customers and request a form to be sent either direct to the applicant or via their own organisation. Other organisations such as these that were represented among the respondents to this research included the following:

- Connexions;
- CAB;
- The Pensions Service;
- Local authority 'One Stop';

- Social Services Departments;
- Training Providers for disabled people;
- Deaf Centres;
- specialist support bodies for the mentally ill.

These other potential sources of application forms accounted for relatively few from among the 80 clearly disallowed applicants interviewed who made their applications on paper and by post. The great majority sourced their forms either directly from Jobcentre Plus or indirectly from DCS, and in roughly equal numbers.

The most direct communication was between applicants and organisations other than DCS, interactions being almost all face-to-face. The most accessible door by far was that of Jobcentre Plus, with which many applicants were already familiar. Contact, at which the question of DLA and the possibility of an getting an application form were raised, was with a variety of staff from front desk, to personal advisers and Disability Employment Advisers (DEAs), though the greatest part was with advisers. For some, DLA, and the initial idea of making a claim, was raised in the course of other business with Jobcentre Plus staff such as lone parent work focused interviews. For others the office was used in a 'drop-in' fashion to make enquiries following up the initial idea from elsewhere. Many of those who ultimately acquired their application form from DCS nevertheless first inquired at a Jobcentre Plus office to get the helpline telephone number and thus it was also an important potential first source of information, both verbal and in printed form such as leaflets. Jobcentre Plus appeared to most people to be the obvious place to take any query they might have about benefits (including DLA).

5.2 Gateways and filters

These 'gateways' and points of early contact with applicants present opportunities for helping to head off claims that have no chance of succeeding, and there appears to be considerable scope for improving the interface with potential DLA applicants. What applicants report is that whereas very often the professional advice and encouragement they received at these gateways was the key motivating factor for them going ahead with a claim, there was little in the way of information exchange about DLA or consideration of the advisability of the claim.

'They [Jobcentre Plus] said, just take this and fill it and send it...'

(Interview 11: female aged 25-44 years)

In this way the opportunity to help filter out claims almost certain to fail was being missed.

'When I mentioned it [applying for DLA] to the Jobcentre they didn't really seem to take the time to explain it to me.'

(Interview 13: female aged 25-44 years)

While the greatest opportunities perhaps exist in face-to-face situations, there are also filtering possibilities apparently being missed at points of telephone contact. Several applicants described being unsure about their eligibility to make a claim when they telephoned for application forms, but getting no guidance from the presumed expert they were talking to.

'They [DCS helpline] asked – I said I had a hand injury. They were very nice... but when I was actually filling the forms in...I thought, well this is a waste of my time and yours...I thought, anybody reading this will think well what's wrong with her?!'

(Interview 57: female aged 45-65 years)

From the accounts of some applicants it appeared that they actually received encouragement to make their claim when they telephoned, even though they were all later judged to be clear disallowances.

'I rang up for a pack for DLA...and she didn't say whether it was the right one to go for or what, she just said she would send the [application pack] out and...she wanted to know why I hadn't claimed way before now.'

(Interview 23: male aged 25-44 years)

It is probably difficult to go into a lot of detail on the telephone, but these cases should have been relatively straightforward to identify as problematic. There did not appear to be routine attempts even to verify that claimants met basic eligibility requirements, and there seemed to have been a reluctance among many of the professionals that applicants had contact with, at Jobcentre Plus, on the helpline and elsewhere, to really engage with potential DLA applicants about their likely chances of succeeding with a claim. Whether this was a wariness due to lack of experience with this benefit, a lack of information and expertise, or a perception shared with customers that the awarding of DLA was somewhat unpredictable, is hard to say.

Other potential filter points exist at the point of completing an application – on the paper form or on-screen for those making e-claims. Although many applicants had doubts raised in their minds by the questions on the forms they had to fill in, they did not interpret anything they encountered as giving a clear message that they should abandon the application because they were clearly not going to qualify.

'I thought, well maybe I have got a chance because it didn't actually say you wouldn't get it [in my situation] on the form – it was just it was down to the decision maker at the end of the day.'

(Interview 3: female aged 25-44 years)

There may be scope for some much clearer filters of this sort on the printed forms. However, the nature of DLA decision making, particularly in relation to the levels of need that qualify for an award, may well make it difficult to be precise and explicit about the minimum levels required. There appears to be an element

of deliberate non-transparency in the system currently as a way of deflecting potentially fraudulent claims.

A similar situation exists in relation to the on-line application form through which e-claims can be made. With this, however, there is possibly further scope for 'automatic' filters to be built in, perhaps of the kind that would prevent someone continuing with the application process if they had answered 'no' to a key item of eligibility. It may be that only measures such as this could counter the momentum of having started an application (see Chapter 4).

'I think it was made fairly clear on the website that retrospective claims were not entertained. But I put it in anyway – I'd started to fill the form in.'

(Interview 61: female aged 45-65 years)

5.3 E-claims

E-claimants were predominantly in the middle age range and more likely to be working than were other applicants. Submitting a claim electronically was attractive to them primarily because of the ease of instant access to the form and the time saved (when compared to a paper submission). The fact that e-claims could be completed at home in the evening was also attractive to working people, although, for some, the place of work was instrumental in providing them with access to a PC.

Those applying on line were much less likely to have been through the gateways accessed by other applicants or to have come into contact with professionals regarding DLA. They were more likely to have completed their application in isolation, and with little opportunity to benefit from informed advice and opinion. Few had had any professional help with their e-claim. They were even less likely than others to have seen or read the information leaflet about DLA, and were largely dependent upon the information available to them on screen and on the DWP website.

There is a *prima facie* case for saying that the higher rate of disallowances among this group is, at least in part, explained by this combination of circumstances. Instant (free) access to the application process meant that relatively little investment of effort was required, which in turn appeared to have encouraged more speculative claims. Indeed, in one case a recent re-application following disallowance was clearly prompted by an opportunistic grasping of the chance to get access to a PC (although it is worth noting that in this instance it was also the opportunity for further encouragement from a work colleague).

I actually applied last week again because I was in work – I'll be honest with you, he [the colleague who helped previously] was there at his desk, on the computer, and he said, let's try again.

(Interview 42: male aged 25-44 years)

In addition to having this ease of access, e-claimants were not generally subject to the existing filters attendant upon seeking and obtaining a paper application form. Despite evidence of the imperfect performance of these filters for other applicants, it has to be assumed that **some** claims **are** successfully deterred in this way.⁶ As a consequence it is likely that overall a smaller proportion of e-claimants are being successfully filtered from the system than is the case for paper claimants.

Just as e-claimants mostly relied upon on-screen information, so the on-line process was the only potential filter for their applications. Despite the opportunity this appears to offer, even to prevent an application from being submitted at all if key answers indicate a failure to meet criteria, the experience of those who had made e-claims was that this was not happening. The closest to such an effect was one applicant's frustration at what they interpreted as the need to provide 'irrelevant data':

'My recollection is that there seemed to be pages of what seemed to be irrelevant data required on it, which nevertheless if you didn't fill it in would just say, no you can't turn the page electronically, you've got to go back and fill in these sections.'

(Interview 61: female aged 45-65 years)

Perhaps the simplest 'automatic filter' would be one that would prevent a claim continuing if basic eligibility had not been met. Currently it is evidently possible for such cases to proceed. One of the applicants ineligible on grounds of residence/presence in the UK had made an e-claim that had reached assessment and subsequent disallowance.

5.4 Those who are ineligible

Fourteen of the interviewed applicants had been assessed as being ineligible because they failed to satisfy the basic requirements of residency (for example, having no passport or no leave to remain in the country) or presence in the UK for a sufficient proportion of the previous twelve months. They fell broadly equally in numbers between these two categories of ineligibility and shared the basic fact of being entirely unaware of these conditions at the time they applied.

Those failing on the grounds of having spent too great a portion of the previous twelve months out of the UK included several who had been working abroad, and others who had extended a holiday in another country into a longer period of stay. Many had suffered a breakdown of their health while abroad, others on their recent return to the UK. Almost all were shocked to discover that they were ineligible for DLA and tended to view the technicality of their ineligibility primarily as a bureaucratic irritation. Most said they would re-apply once sufficient time had passed for them to satisfy the rules on presence in the UK, although in the

⁶ This research was only directed at those who had made a claim and been disallowed.

meantime several were living under extremely difficult circumstances, especially if living alone. It appeared from the severity of their described needs that many would get serious consideration for DLA once they could meet the eligibility criteria.

Some of those failing eligibility on residency grounds were relatively recent asylum seekers who had not yet been granted indefinite leave to remain in the UK. Their problems appeared to have been exacerbated by English language difficulties, which may also have been a factor in why their ineligibility was not picked up at an early stage by the organisations such as CAB with which several had come into contact. However, a large number in this category of ineligible applicants had been in the UK for many years (up to thirty years) and were surprised to hear that they were considered to be subject to immigration control and not eligible. Many appeared to be leading relatively disorganised lives, being unable to produce a passport or any identifying documents when required to do so.

It might be assumed that ineligibility on residence/presence grounds would be easy to identify prior to an application being made. Certainly most ineligible applicants had had some contact or support from a third-party organisation, and some opportunities to filter claims on this basis must have been missed. However, it was easy to see why such apparently fundamental information could have been overlooked given the seriousness and urgency of some of their needs, the language difficulties some of them had, and the somewhat disordered nature of some of their lives.

5.5 Applicants' experience of the forms

Applicants' responses to the DLA application form covered a very wide range, from those who said they had found them 'straightforward,' clear and relatively easy to fill in, through to those who had found the experience complicated and confusing. For many, there was a feeling of having tried to force a round peg into a square hole:

'Maybe my answers might have seemed jumbled up or whatever – that's why I wrote a big explanation at the end.'

(Interview 4: male aged 45-65 years)

If there was a more generally shared perception it was that the form was very long and required considerable time and effort to complete, in some cases enough to put people off the idea of re-applying:

'I suppose I did find it really, really confusing. I don't think I'll be doing one of those again for a long time...I don't think I could cope with the form again.'

(Interview 62: female aged 25-44 years)

Not surprisingly, those with some form of learning disability, and some of the applicants suffering from a mental health condition, had found the form particularly

difficult to cope with. As one applicant (with Asperger's Syndrome and diagnosed Obsessive Compulsive Disorder) put it:

'There was quite a lot I just found too complex.'

(Interview 94: male aged 16-24 years)

And another (with sciatica):

'[It's] really quite confusing...trying to explain what your problem is.'

(Interview 44: female aged 16-24 years)

However, most of the applicants had found help completing the form, whether from professionals such as social workers, or from a member of their family. Those with the least command of the English language had worked through the interpretative help of a family member. Those who had severe problems with reading and writing had, likewise, had someone else complete their application form for them:

'My social worker filled out the form for me because I can't fill out forms.'

(Interview 20: female aged 16-24 years)

Some of the applicants had chosen to make an e-claim specifically in order to help overcome their writing difficulties, feeling that on paper it was more critical not to make mistakes, and more difficult to correct them if you did:

'It's much easier to do things on-line because if you make a mistake you just block it out and do it again – where if you do it on paper you need about half a dozen forms!'

(Interview 67: female aged 45-65 years)

Other e-claimants, however, felt that the e-form 'cramped their style' and made it much harder to go back to a previous section to change or check anything.

5.5.1 Responses to questions on the form

By far the greatest, and most widely described, problem that applicants experienced with the application forms (both the old form and the re-designed form piloted in the North West) was in trying to make the questions they were being asked to answer fit with their personal circumstances, whether this was in relation to their specific disability or to the level of their needs. As one customer's father expressed it:

'Most of the questions really referred to somebody who is really ill and they can't do anything. I don't think it caters for people – the way the questions are – for people like him.'

(Interview 34: male aged 45-65 years)

Although such views were voiced as criticisms of the form, it was clear that, in nearly every case, applicants had experienced trouble filling it in because they

were not entitled to DLA. The common misapprehension that DLA was a disability entitlement, and therefore any condition describable as a disablement would qualify for benefit (see Chapter 3) rendered the form apparently 'perverse' in its emphasis on care and mobility needs. Even when applicants had struggled with the fact that they seemed to have to answer 'no' to nearly all the questions, their interpretation of this experience was either to doubt their understanding of the process or to see it as a failing of the form:

'It was just ticking 'no' for everything because I didn't understand it at all...I thought, well I don't need any of this help but...it was as if you had to fill it in.'

(Interview 3: female aged 25-44 years)

It is testimony to the power of those factors which led to obtaining an application form (see Chapter 4) in the first place, such as the authority of professional advice and encouragement, that these applicants still failed to interpret this experience as evidence that they should not go ahead with their claim. Nor did finding that hardly any of the questions being asked were relevant to their own situation alert them to the likelihood that their understanding of DLA eligibility was mistaken. It would appear that a much stronger and more explicit written message is required on the application form if more applicants whose claims stand no chance of success are to be successfully deterred and filtered out at this point in the application process. Indeed, several applicants said that they would have welcomed clearer guidelines regarding specific (non-physical) conditions and disabilities.

Another widely expressed view of the questions on application forms were that they were 'loaded' towards individuals with physical disabilities, and that this in some way prejudiced the cases of those with sensory disability, learning difficulties or mental health conditions:

'It seems to be loaded to physical ailments that they're looking at...I thought, I've got to sit down and explain because there's nothing in that form to explain the way I am.'

(Interview 4: male aged 45-65 years)

The application forms were perceived to be 'unfair' and to have a 'bias' towards physical disability, because the emphasis on mobility and care needs was so poorly understood. Much of the reason for people remembering the form as being over-long was related to a sense of much of it being 'irrelevant' to them:

'It seemed to heavily emphasise...physical disability – I felt that I was... skipping about twenty pages before I got to my section that was appropriate to me...the area that asked about depression and bereavement or things like that.'

(Interview 14: male aged 16-24 years)

For the same reason many applicants commented on what they saw as the repetitiveness of the forms. It was not just that questions appeared to be asked a

second time in a slightly different context, in such a way as to appeal designed to 'catch out' applicants, but that the repeated questions were not seen as relevant in any case. As a blind applicant expressed it:

'One of the questions was, how much help do you need with your personal care...well, I don't...because I know where everything is in the house...so we put the answer "I don't" – but the form kept coming back to me saying, when did your issues start happening with your personal care?...I couldn't understand why I kept getting sent back when I had [already] answered it.'

(Interview 13: female aged 25-44 years)

The many pages of, sometimes repeated, questions about care and mobility support needs were viewed by some applicants not only as inexplicable and irritating, but even as insulting or demeaning, or belittling of their disability.

'...the way these questions are worded! I'm not begging for benefit.'

(Interview 4: male aged 45-65 years)

One further problem with the forms, mentioned by several applicants, was the perception that questions were too 'cut and dried', requiring the answer 'yes' or 'no' and not facilitating any elaboration or qualification of that answer:

'The forms don't give you enough scope. There's no flexibility. It's a cut and dried question like, say, "can she do it?" not "can she do this without help?"...questions that you have to answer 'yes' or 'no' to.'

(Interview 30: female aged 16-24 years)

There was no expansion on it...when you're trying to explain yourself in writing...I can't...put what it's like in two sentences – I can't explain myself...I don't know if they'd understand the way I was writing it in.'

(Interview 97: male aged 16-24 years)

In a number of instances, the more subtle point was made that answers to some questions could sound very different (and be interpreted very differently) depending on whether the initial response to be qualified or explained was given as 'yes' or 'no'.

'...that was difficult – to try and put down on paper that the answer to the question was 'yes', BUT...'

(Interview 30: female aged 16-24 years)

An applicant with a degenerative eye condition, concerned about frequent tripping and falling through not being able to see things at ground level, for example:

'It's frustrating when you're reading the thing and it says 'can you walk upstairs?' Yeah I can – but I can't...'

(Interview 4: male aged 45-65 years)

A couple of applicants had made a connection between this type of difficulty and the suspicion that perhaps acceptance or rejection for DLA might depend not just on what was put on the form, but also on how it was expressed and presented.

5.5.2 Help with completing forms

Generally, the quality of form filling, both in terms of content and expression, was not high. Completed forms were frequently very sparse on detail and showed signs that in many cases applicants were not comfortable with the written word, nor with the process of filling out official forms. Several had failed to convey on the paper form all aspects of their disability or disabilities, and had omitted needs which they nevertheless described at their research interviews. In cases where there are clues to be picked up on, then it is probable that the 'understatement of needs' scrutiny, that makes up part of the assessment process, will be able to bring some of these issues to light. However, complete omissions, such as failing to mention a complicating mental health condition in addition to another disability, will be much more difficult to detect.

Some applicants had received help with filling in their application form, though this help was mostly informal and for the most part comprised 'scribing' answers provided by the applicant rather than contributing to the way information should be presented. Those forms reported as having had professional input showed little sign of any greater expertise (though it must be remembered that only disallowed claims were explored in the research).

There was some limited recognition among a few applicants that it could be important to get professional help in completing the application form, whether this was to get the best wording and presentation, or simply to derive benefit from the authority a professional voice could lead:

'The social worker said...she would word it how other claims had gone through that had been accepted...wording that would...get the claim approved. So she was as surprised as we were when it was sent back.'

(Interview 30: female aged 16-24 years)

'It's more a question of who you've got behind you it seems to be...it's not the fact that I'm bad ill, it's...who I get to fill it in for us, is what it seems – I just shouldn't have fitted it in myself...because what I say doesn't matter... unless it's someone official behind it.'

(Interview 72: male aged 45-65 years)

Many among the disallowed claimants felt that they would have benefited from more information and advice. Reflecting the unease many of them felt with written communication, there were numerous suggestions for how this additional information could be accessed through face-to-face interaction with an informed adviser:

'It would be nice if there was more information available...even if you had to go to – not the benefits office but somewhere like on a casual drop-in basis where it's friendly...[and] they can spend like half an hour with you and go through it with you. That would be helpful.'

(Interview 21: male aged 25-44 years)

'There could be something on the paper to say, if you don't understand please contact...your doctor, or go into the jobcentre or even CAB or something, for somebody that actually knows what to help you to write down.'

(Interview 51: female aged 45-65 years)

It was face-to-face, personal contact that people were particularly keen to be able to get. The existing telephone service, whereby someone will complete a form on behalf of an applicant and then post it to them for signature and return, was not known about by most claimants, and in the very few cases where the helpline had been used at all it was for minor issues such as confirming where they should put certain factual information on the form.

Where applicants had hoped, or expected, to get face-to-face support from the professionals they had been in contact with, but had failed to get it, they felt particularly aggrieved and let down:

'I went to the Jobcentre and...they asked me if I'd got any disabilities and that and I just said about my hearing...and the woman said, well here's an application form, fill it in...they said, oh yeah you'll definitely get it.'

(Interview 3: female aged 25-44 years)

The strong preference for face-to-face dealings, rather than relying simply on a written form, extended to applicants' views of the assessment process itself, with several feeling that the form could not do justice to their case and that some type of interview would be more effective, and fairer:

'People who claim DLA should have a DLA officer come round to assess you. [The form is just] pen to paper that's all it is at the end of the day – if you're telling the truth then they can assess you a bit more in-depth.'

(Interview 48: male aged 25-44 years)

'I'd rather, like, go and talk to somebody...and explain about what the problem is...I'd just like it for people that are not good in expressing themselves in writing...there should be an option there, where they turn round and say, well you can come in for an interview or something like that.'

(Interview 97: male aged 16-24 years)

5.5.3 Self-presentation and 'truthfulness'

Previous research had found that many people with disabilities do not like to present themselves in this way. When faced with setting out their situation (as in an application for DLA) they are reluctant to do anything other than present things in as positive a light as possible, because this is their day-to-day approach to coping with their difficulties.

There were indicating that this was powerfully the case for several of the applicants interviewed for this research:

'I don't want to be 'disabled' ...!'

(Interview 66: female aged 25-44 years)

'We're not looking to be classed as 'disabled' you know.'

(Interview 100: female aged 25-44 years)

*'I got the letter through saying, we cannot give you DLA for the reason you're not getting looked after by anybody...you're not just in a care home and getting looked after by a nurse. I don't ***** want to be like that! You know what I mean?'*

(Interview 78: female aged 16-24 years)

Even making the application at all was for some people an admission of something they did not want to acknowledge, and their claims were made almost reluctantly, under pressure from a third party:

'Somebody had mentioned [DLA] a long time ago when my eyes were really bad, and it was something that I'd always said, no I'm not going to do it because if I do, that's writing myself off...so I do just try and get on with it – and you just cope with best you can don't you?'

(Interview 71: female aged 45-65 years)

One of the clearest cases of such a way of thinking was that of a man in his early thirties diagnosed as suffering from Schizophrenia. A support worker at the mental health voluntary sector agency he was attending for counselling had suggested he apply for DLA and had completed an application for him. However, on reading through the form she had completed on his behalf, the applicant decided it was not how he wanted to be portrayed. In his words it was an exaggeration that made him out 'to be a vegetable', and he described her account as 'derogatory'. Consequently he did not send off the form and instead submitted his own claim on-line.

His account of why he had made this decision illustrated the fact that it was not only a question of whether the facts were presented in a good light or a bad light. The way he presented himself to others was an important factor in his mental state. It affected how he felt about himself and his condition and consequently

was an integral part of his experience of improvement and recovery which, by the time he got round to making his e-claim, he felt to be underway.

The issue of self-presentation is not entirely straightforward however. It overlaps with an important aspect of assessment of DLA awarding criteria, namely the fact that the focus is on the actual effects on the lives of people with disabilities (regarding care and mobility support needs) and not on any judgement about whether they have, or could have, made an effort, or a greater effort, to overcome or prevent them. There is thus always contentious ground, and some saw injustice in the fact that, by making an effort to overcome the effects of a disability, it is possible to reduce one's chances of being awarded DLA. Conversely those perceived to have 'given in' to their circumstances were seen by some as less 'deserving' of benefit support.

'Some of the things [asked on the form] – you couldn't go to the toilet and all this, and you had to have somebody with you at night...I like to try and be as independent as I can, you know, try to look after myself.'

(Interview 47: male aged 45-65 years)

'Do they want me to sit here and do nothing? Do they want me to sit down and do that, or is it better if I get up and help myself? I'm just as disabled but I'm helping myself. I'm not only helping myself but I'm helping the Government as well because there are people who just sit down and say, no I'm not going to do that, come and look after me. But I don't do that.'

(Interview 4: male aged 45-65 years)

On occasion these feelings of pride and defiance caused difficulties for applicants. They appeared torn between the feeling that they had quite severe disabilities, and the need to maintain a positive attitude towards dealing with the effects of those disabilities. One expression of this tension was the frequent mention of 'truthfulness' in relation to making an application for DLA – a notion that seemed to be more about the degree to which these important subjective issues were brought into the picture, rather than any more literal meaning such as not telling lies:

'I do need help but like I don't need caring for because I'd rather care for myself.'

(Interview 97: male aged 16-24 years)

'I think I probably was a bit more truthful than I needed to be.'

(Interview 34: male aged 45-65 years)

5.6 Reactions to disallowance

Reactions to hearing of disallowance varied greatly. Some of those applicants who had been confident of success (whether through their own misunderstanding or through confidence inspired by third parties) expressed 'shock' at the outcome. Others, who had viewed DLA as a last resort source of funding even admitted to experiencing a feeling of fear that their final option for help had now apparently been closed off:

'I was very scared...getting the rejection, that kind of made me worse because I sort of knew I wouldn't get it but I didn't know where else to go for help.'

(Interview 21: male aged 25-44 years)

A more common reaction, however, was one of resignation to the fact that they were not entitled to DLA, even if the precise reasons were not always clear to them:

'I felt resigned...I'm obviously not entitled to it.'

(Interview 68: male aged 16-24 years)

Applicants who had harboured their own suspicions that they would be ineligible, expressed anger and annoyance that they had received the wrong advice from a source they had trusted, and been let down:

'I was a bit annoyed as well because...they were saying to me in the Jobcentre, you will get it because you've got a deafness thing – so it was just like you're getting misled by one person, then...'

(Interview 3: female aged 25-44 years)

The injured pride of those who felt they had been misled in this way was evident. Several applicants said that they would have much preferred to have been 'headed off' or 'filtered out' at an early stage before making a claim that was to be rejected:

'I don't think I'll ever apply again for anything – you know they were nice on the phone and they were very helpful and friendly, but personally I wish I hadn't have bothered...because it's always been one of my things, I wouldn't ask anybody for anything...well I've ruined that now.'

(Interview 57: female aged 45-65 years)

'I would have felt better about it if they had said, no...you cannot apply for this benefit, you are not eligible for this benefit because I think you are too well.'

(Interview 43: male aged 25-44 years)

Some of the applicants were also unhappy that the decision had been made purely on the basis of the application form, and clearly believed that this was the

main reason their case had been seen as unconvincing. Many wanted to have been given the opportunity to submit to a medical examination to 'prove' their disability, or otherwise to add a medical opinion to their application:

'They didn't even invite me to go and see somebody or to be tested by an individual consultant or whatever, you know, and I thought it was a little bit 'short shrift' really.'

(Interview 98: male aged 45-65 years)

'They are saying that I'm not eligible for it...yet nobody has come down to see me to have a medical which is what they should do...that way they'd understand...what I have to go through.'

(Interview 44: female aged 16-24 years)

'I think they should ask people to go for medicals.'

(Interview 3: female aged 25-44 years)

5.6.1 Acceptance/understanding of disallowance

There was a general acceptance among the majority of applicants that their claims had been disallowed, with many acknowledging the reasons and explanations they had been given and accepting that they did not qualify:

'He is OK with what they say...[to get DLA] he needs to have a lot of care and he knows he is not in that circumstance.'

(Interview 19: male aged 45-65 years)

'They just said that I didn't meet all the criteria [for] being entitled to it. So I thought, oh that's fair enough.'

(Interview 13: female aged 25-44 years)

'Yes I suppose it depends how severe it is, doesn't it, and how it affects you...it definitely does affect me, but...'

(Interview 1: female aged 45-65 years)

Several had reached the conclusion that they never should have made the application in the first place, and acknowledged their error:

'I look back on it now and I think I probably shouldn't have made the application.'

(Interview 21: male aged 25-44 years)

'I understood that bit and that's when I...thought...you've applied for the wrong [benefit] here!'

(Interview 23: male aged 25-44 years)

Not all, however, accepted disallowance with good grace, putting their frustrations with an unresponsive system as the main reason why they had not appealed the decision and were not intending to re-apply in the future:

'I accepted it [the decision] yes...I was sick of putting in for it...and getting knocked back...it's just a waste of time and it's a waste of paperwork at the end of the day.'

(Interview 29: female aged 45-65 years)

Others accepted the explanation as to why they did not qualify according to the rules governing DLA, but still expressed dissatisfaction that the rules excluded their own circumstances, or that the threshold of severity for allowance was too high:

'I just can't understand how they don't think it's bad enough when you can barely walk, you have to take time off work, and you've got to look after a child as well, I mean they're very demanding.'

(Interview 44: female aged 16-24 years)

Disallowance was seen as within existing rules but indicative of a wider problem because this was seen as leaving people with severe disabilities without any source of financial help:

'[It's] not exactly [fair] – when you have been diagnosed with severe problems then the problem needs to be fixed – there needs to be help out there for it.'

(Interview 14: male aged 16-24 years)

Despite all explanations, there were elements of basic misunderstandings about DLA that persisted throughout the application process and which informed people's responses to hearing they had been disallowed:

'It [the decision] wasn't anything to do with my [disabilities] it's because I don't need care help, which I find is really stupid. [It's fair] in ways, yeah, because there is some people need it more than myself, but in other ways, no, because I can't work...'

(Interview 25: female aged 16-24 years)

In extreme cases the disallowance was interpreted as a denial of the applicant's disability itself:

'Because it's more or less saying – well I thought it was – that there was nothing wrong with you, sort of thing.'

(Interview 58: female aged 45-65 years)

5.6.2 Appeals and re-applications

It was frequently those who had failed to understand the criteria for DLA qualification (and who still did not understand clearly after they had been disallowed) who were

the applicants saying either that they had meant to appeal the decision, or that they intended to re-apply for DLA in the future.⁷ The decision letter to applicants provides a key point of contact for trying to prevent such re-applications with no chance of success and for trying to deter people from appealing decisions on ill-conceived grounds.

There would appear to be a strong case for even greater effort to be put into explanations and argued reasons in decision letters, not least because there was evidence that applicants were more likely to read these letters with some attention than they were to read other printed materials such as leaflets and application form guidance notes. The benefits of making such an effort, in terms of heading off future potential re-applications in particular, and perhaps even 'serial' re-applications, could be considerable.

5.6.3 Piloted forms and disallowance letters

Initiative has already been taken by DCS to address this possibility and to re-work the content and layout of the documentation used in the application and disallowance process. At the time when respondents to this research were making their claims and being informed of disallowance decisions, a pilot was running in the North West to test both a new application form and a fuller and more detailed decision letter: the two key points of contact with customers for conveying information and explanation of what the rules are and how they are intended to work and why they have, therefore, resulted in disallowance.

The pilot was run through a number of teams in the Bootle and Manchester DBCs. This meant that a proportion of applicants submitted their claim on the new form, which has since been rolled out nationally, and received the more detailed decision letter, but not all the applicants in the region (and none in other parts of the country). Customers taking part in this research were drawn heavily from the two North West DBCs. Overall, half the research interviews (49) were conducted with applicants from the North West region. Of these, half (26) were found to have submitted on the new application form, under the pilot. The more detailed decision letters that were also piloted would certainly have gone to all those who applied on the new form. It is also possible that the piloted letters could have been sent out to some of those applying on the old-style forms.

There was no apparent substantial difference between the responses of applicants to the new piloted form, compared to their perceptions of the previous version, that could be discerned from the qualitative interviews conducted for this research. However, there did appear to be an important difference in the reactions to disallowance displayed by applicants who were part of the pilot. This difference

⁷ It should be noted that the sample of cases used in this research deliberately excluded anyone who had entered the appeals and reconsiderations process – leaving only those who may have considered appealing but had not done so within the allowed period of time.

is most likely to be the result of the more detailed pilot decision letters these applicants received, and it was apparent in spite of the possible dilution effect that would be caused if significant numbers of those in the North West applying on the old form had nevertheless been sent the new style of letter.

Those applying on the new form, and receiving the piloted decision letter, were more likely than other applicants to say that they understood the disallowance decision after reading the notification letter. They were also more likely to say that they accepted the decision and as a consequence were less likely to have either considered an appeal or thought about re-claiming in the near future without a major change in their disabling condition.

Although these findings cannot be attributed the same weight as results from a quantitative and statistically validated survey, they nevertheless point strongly to the new decision letters having made an impact. Good information at this stage of the DLA process, and efforts made to explain decisions and the criteria lying behind them, appeared to be proving effective at gaining acceptance of disallowance and perhaps also at preventing appeals or further applications that would stand little or no chance of being successful.

Further work at this critical point of contact may prove worthwhile for DCS, although issues still remain as to whether it is possible or advisable to be totally transparent about awarding criteria, and as to what the optimum balance might be between extra staff time spent on disallowance letters and time potentially saved by preventing further disallowances of re-applications.

6 Conclusions

The remit for the research was to explore cases of clear disallowance among applicants for DLA with a view to answering the following two key questions:

- Why were applicants making claims for DLA when it appeared to be clear from their applications that they stood no chance of being awarded benefit, either because they failed to meet basic eligibility criteria (residence and presence in the UK) or because their disability did not create care and/or mobility support needs of sufficient severity or duration to meet the qualifying criteria?
- What possibilities or opportunities for policy intervention, or changes in administration and practice, were suggested by the characteristics, circumstances, motivation and behaviour of clearly disallowed applicants, that might help reduce the current very high level of disallowances by deterring applications with no prospect of success from being made in the future?

6.1 The reasons behind 'clearly disallowed' applications

Knowledge about DLA was very limited and there was widespread misunderstanding among disallowed applicants both of the nature of DLA and of the criteria against which it is awarded. Many applicants were focused exclusively on the details of their disabling condition, its diagnosis and symptoms, rather than on the effect that this had on their daily lives. The central importance of showing needs relating to personal care and mobility support was not appreciated by most applicants at the time of making a claim, and there was a very common perception that one merely needed to demonstrate, or 'prove', that one had a disability of some kind, in order to be entitled to the benefit.

In some cases, real difficulties arising from a health condition convinced applicants of their eligibility despite there being no impact (or very little impact) of these on care and mobility needs. The threshold of severity of needs required to entitle a person to DLA was also widely misunderstood, ignored or underestimated by applicants. The necessary focus on care and mobility needs on the application form, caused particular problems for those applicants with sensory disabilities, learning difficulties and mental health conditions, who perceived this as an unjustified 'bias' towards physical disability.

Underlying reasons for applications included work and financial crises of various kinds, related to a lesser or greater degree to a health condition or disability. Other applications were occasioned by the onset of, or change in, a condition, or by changes in living circumstances, such as separating from a partner or moving house, which brought other problems to a head.

Whatever the underlying motivation of claims, almost all were actually 'triggered' at the time they were, by advice or encouragement from a third party, whether informally from a friend or family member or formally from a health, welfare or benefits professional. Informal advice and encouragement appeared to have an influence more slowly over a period of time. Professional advice and support for a claim was often absolutely decisive in the decision to apply. Even in cases where the claimant themselves had serious doubts about their eligibility and chance of success, the word of a professional was able to override such doubts and stimulate people into making an application that they probably would not have made otherwise.

Among the clearly disallowed it was found that the informal advice they received was almost entirely based on hearsay about other people claiming DLA. Positive advice received from professionals was also evidently suspect or incorrect in these cases (by definition the research did not get to interview those who had been successful with a claim for DLA following good professional advice). Ill-informed and part-informed views about DLA, who was entitled to it, and how the application and assessment process works, appeared to dominate the understanding of applicants. Word of mouth had greater prominence than written information for most of these customers, a great number of whom were uncomfortable with reading and writing.

Misunderstandings and the distorted perceptions of DLA held by applicants were hard to shift. For some, the same misconceptions that initially informed their decision to apply were still evident in their interpretations of being disallowed and their reactions to the reasons they were given as to why they were not entitled to receive the benefit. Equally, the determination to apply, instilled in many by the perceived endorsement of their case by a trusted professional, was frequently only effectively challenged by the statement of reasons for disallowance given in a decision letter.

No overwhelming differences were found between the perceptions and motivations of applicants in different disability groups or in different age bands. Some of the applicants with learning difficulties experienced particular problems expressing themselves on their application forms, though almost all had help. Those with English language problems appeared perhaps even more prone to misunderstandings about the benefit than others. Some applicants with mental health conditions said that the stress involved in applying, and in being rejected, had affected their decision-making and their choice not to appeal the disallowance. However, the strongest evidence from interviews pointed to the fact that it was external 'drivers' in the information environment and the structure of the application process itself

that were the key sites, both of problems leading to disallowed claims and of potential ways to address those problems.

6.2 Possibilities for policy intervention and change

There are, therefore, a number of key things to address in any attempt to improve the situation and reduce the numbers of claims being made for DLA that have little or no chance of success. The most prominent in the findings of this research are the following:

- applicants' failure to recognise the central place of care and mobility support needs in DLA entitlement;
- their widely held perception of DLA as a 'disability entitlement' and 'out-of-work' benefit;
- the primacy, for many, of word of mouth over written information;
- the overriding power of professional third-party advice and encouragement;
- the perception of DLA awards as inconsistent and unpredictable;
- the high level of speculative claims;
- the momentum of the application process 'against evidence'.

Clearly, some of these issues are more readily accessible to intervention than others, and some highly indirect and difficult. Any action taken by DWP/DCS is likely to be of one of three general types:

- control of the quality, availability and effective transmission of information to potential applicants;
- influence over the behaviour of third parties involved in applications in various ways;
- and tightening of the application process itself to improve the 'filtering out' of claims that will not succeed before they are submitted.

There are only a limited number of possible 'contact points' with applicants through which to convey appropriate messages to them and ensure that they are adequately informed. Pre-conceived ideas about the nature of DLA, and perceptions derived from reported experience and hearsay, are largely formed prior to such contact and are thus, to an extent, beyond intervention. General information materials, such as leaflets, may have some impact on perceptions, but it is probable that past practice in relation to awards will play a much greater role. Even a very small number of inconsistent or mistaken awards of DLA could fuel perceptions that assessment of entitlement can be capricious and that it is therefore worth 'giving it a go'.

Ensuring consistency and uniformity of awards over time and across all regional DBCs is likely to have beneficial effects over the longer term, even though it can

not prevent other perceptions from being formed erroneously in the absence of full information about 'known' cases.

One possible way of influencing people's general perceptions about DLA might be to change its name so that it better reflects the intended purposes of the benefit and the criteria under which entitlement is assessed. The current name gives prominence to 'disability' and contains no direct reference to the crucial elements of care and mobility needs. Although such a renaming would carry considerable cost implications, it may well help in preventing loose assumptions being made about 'disability benefits' that clearly can lead to inappropriate applications.

It is also of great importance that accurate and appropriate messages about DLA reach the professional third parties, who will in turn pass them on to prospective applicants and ensure that 'no hope' applications are not encouraged. Again, a change of name for the benefit might help draw professionals' attention to the specific nature of DLA and its applicability. Ensuring a more precise general reference for the benefit in materials such as The Disability Rights Handbook, that are routinely used by third-party organisations, would be a further route to achieving this.

By far the most frequently cited third-party organisation involved in DLA applications was Jobcentre Plus. There are obvious opportunities for DCS to work more closely with this sister organisation to ensure consistency of approach and understanding. The evident power of professional 'endorsement' for a DLA application suggests that there would be much to be gained from this. It would also be the prime site for tackling the misconception of DLA as an out-of-work benefit.

The application process and administration provides the most direct points of contact with customers at which initiatives might be taken to deter 'no hope' claims. These currently comprise:

- the point of request for an application form;
- for those turning 16, the letter inviting re-application;
- the activity of completing the form;
- the point of seeking help with filling the form;
- and the letter informing of the assessment decision (disallowance).

All of these points of contact provide the possibility for filtering out more of the cases that are currently being submitted only to be judged clear disallowances. Two of them – the request for a form and approaches for help with completing it – involve personal contact, either face-to-face or by telephone. Currently DCS has direct control over these exchanges in only some instances. There is a case to be made for increasing this level of control by bringing the provision of application forms entirely in-house to DCS, which would permit more initial exploration of a customer's circumstances and a greater chance of heading off inappropriate claims. Even where requests for forms come from a third-party organisation and

it is appropriate for that organisation to be acting on behalf of customers, the sending out of application packs could be agreed only on a specific case-by-case basis allowing discussion of individual particulars, rather than as at present in 'bulk' (if requested) and against expected, but as yet unknown, demand. This would also ensure greater control over the provision of printed information, such as leaflets, which are not always provided along with forms as things stand.

The opportunities raised by the remaining three points of contact with customers are essentially for including necessary and appropriately worded information and messages within printed materials, including potential filtering mechanisms. There appears to be a case for strengthening existing messages about eligibility and the appropriateness of claims, for taking the opportunity to highlight and repeat key information about the nature of the benefit and who should be applying for it, and for building in explicit filters of the sort that would say quite unequivocally *'if you have been unable to answer yes to this question you should not continue with your application'*. Such filters could be genuinely automatic on e-claims and prevent the continuation of a claim. The most obvious use of such filters might be in relation to 'residence and presence' eligibility conditions, though it would not be impossible for them also to be used in relation to demonstrated needs, duration of needs, and the level of severity of needs.

The letter sent out to DLA claimants who have received DLA in the past, when it was claimed for them as children by their parents, but who have now reached the age of 16, provides another point of contact with a sub-group of applicants. The purpose of the letter is to inform customers of the need to re-apply in their own right. Evidence from those interviewed who had been in this position in the recent past suggests that a clear explanation of why this might not be an automatic continuation of benefit could be helpful.

Finally, the letter sent to applicants informing them of disallowance, and the reasons for it, provides a preventive opportunity. Although too late in the process to stop the first application, it may well head off further claims from being made. Some evidence exists that the piloted letters with more fulsome explanations may already have had such an effect. It is arguable that the inclusion of even more explicit and fundamental messages about the basis for criteria of eligibility for DLA could be effective for some applicants who continue to harbour misunderstandings about the benefit even at this stage in proceedings.

Appendix A

Sampling and recruitment

The basis of the methodology for conducting the research and meeting the specified objectives was qualitative, in-depth interviews with disabled people who had made a claim for DLA which had been initially disallowed. Research was restricted to cases in which the applicants were adults of working age only (aged 16-64). It excluded applications that fall under the 'special rules' heading for automatic eligibility, whereby, for example, quadriplegics and those with a terminal diagnosis receive DLA.

It was also restricted to cases where DCS judged the disallowance to be obvious (clear disallowances) and for there to be no evident reason as to why the application was made. Only cases in which the allowed time for making an appeal had passed were included. All the applications were therefore 'closed' cases.

A 'long list' of cases was taken by DCS from a scan of disallowances made in the previous seven months at three of the regional DBCs: Bootle, Manchester and Wembley. Sampling was undertaken from within this long list. Cases were provided to Insite in three batches. The first two comprised 200 names each. The third was a list of 55 cases comprising only those who were either ineligible (30 cases) or whose main disability was learning difficulties (25). This last list was specifically to allow purposive sampling of these two sub-groups of applicants who made up only a very small proportion of the total of applications.

Applicants were contacted by letter and offered the opportunity to opt-out of the research. A total of 47 people took the opt-out option. Some applicants chose at this point to opt in to the research. A total of 19 opt-ins were interviewed. Not all opt-ins were included because there was a need for purposive sampling of some sub-groups to achieve minimum targets (see Table A.1).

Those not choosing to opt-out were contacted by telephone for recruitment. A total of just over 350 from among the long list of 455 cases were approached in this way, giving an overall success rate for recruitment of 28 per cent. 46 people proved uncontactable, 52 declined to take part when telephoned, and 15 people

failed to meet appointments for interview or cancelled after an appointment had been made.

Minimum targets were set for the key sub-groups of applicants, and purposive sampling of cases was undertaken to ensure adequate coverage of the range of circumstances and characteristics of applicants known or hypothesised to be significant to understanding the factors behind high disallowance rates. In particular, cases were oversampled in the following key areas due to the small proportions present in the total population of cases:

- cases ruled ineligible on grounds of 'residence' and 'presence' (less than one per cent of total disallowed claims);
- cases of electronically submitted claims (e-claims) ruled as 'clear disallowances' (approximately 1.5 per cent of total disallowed claims);
- cases in which the main disability given was a sensory disability (three per cent of claims);
- cases in which the main disability given was learning difficulties (five per cent of claims).

Table A.1 Recruitment of disallowed DLA customers

	Ideal target	Minimum target	Available in first list of 200	Available in second list of 200	Available in third list of 55	Achieved interviews
e-claims	20	15	48	25	0	20
Ineligibles	15	15	20	0	30	14
Learning difficulties	25	15	31	0	25	16
Mental health	25	20	25	38	0	19
Sensory disability	25	15	74	60	0	23
Physical disability	25	25	50	102	0	42
Age 16-24	33	25	51	57	11	26
Age 25-44	34	25	94	75	25	36
Age 45-65	33	25	55	68	19	38
Male	50	40	103	89	27	47
Female	50	40	97	111	28	53
Opt-ins interviewed						19
Opt-outs						47
Uncontactable **						46
Declined ***						52
Cancelled/no shows *						15
Total interviews carried out						100

Notes:

* including four ineligible, three with a mental health condition and two with learning difficulties.

** e.g. telephone number unobtainable or person not known at the address.

*** declined to take part when spoken to on the telephone.

One hundred face-to-face interviews were carried out with DLA applicants, in their homes during June and July 2007 using the interview topic guide included in Appendix B of this report.

Interviews covered the following main groups of customer characteristics:

- age group of the applicant (16-24 years; 25-44years; 45-65 years);
- type of main disability – grouped according to four broad categories (physical disability; mental illness; sensory disability; and learning difficulties);
- main different means of submitting claims (by post and by e-claim);
- claims ruled ineligible on grounds of failing to meet residency and presence requirements.

All interviews were tape recorded and transcribed for analysis.

Appendix B

Applicant interview topic guide

Research into DLA Disallowed Claims Customer Interview Topic Guide

Complete the following in writing and state the same on tape. Also record start and finish time in writing and on tape

Interview Code:

Name of interviewee

Address

Telephone no.

Date of interview

Researcher

Start time

Finish time

Length of interview (minutes)

Explain that we are looking at the reasons behind disallowances of claims for DLA in order to improve services in the future.

Secure consent for tape recording.

Emphasise confidentiality and the use of verbatim comments only on an anonymous basis.

Objectives:

1. To find out why people who have no obvious grounds to claim still go ahead and make an application – is it opportunistic, or due to poor advice, misinformation from friends or acquaintances etc, or lack of transparency/clarity in the published information about the benefit?
2. To assess customers' understanding of the benefit and the requirements of making an application, and to explore the sources of customers' information, motivation and support in making a claim.
3. To better understand the behaviour of applicants in order to target future DCS marketing and partnership strategies and increase the proportion of successful claims.

To begin with ask customers if they can tell you a little about themselves

Background/personal circumstances***Ask for basic information about:***

1. age
2. whether married or single
3. how they describe their ethnic background
4. the size and make up of their household and sources of household income
5. whether they live alone/with parents/with a partner
6. if they have any children and if so how many, their ages and if they live in the household
7. any paid or voluntary work that they have at the moment
8. any benefits that they are receiving at the moment (and in the recent past)

Disabilities & health conditions

9. ask them to describe in detail the health problems and disabilities that they have (try to ensure that we get an adequate description of the condition(s) and disabilities)
10. ask them if they have had a diagnosis and if so what it was
11. when they acquired their disabilities
12. how severe they see their condition as being (ask them to make a summary rating of mild/moderate/severe/or very severe)

13. explore whether their situation has changed significantly since they made their claim, and if so, in what ways it has changed and whether for the better or for worse
14. at the time of applying for DLA how long did they anticipate their disability would affect them; are their related needs constant or changing (details)
15. what are the main difficulties caused them by their disabilities and how do they affect their daily life and that of their family and household
16. ask in particular what problems they see themselves as having in getting about, walking and moving around the house and further afield and what different activities are limited by their condition(s)
17. does anyone currently care for them on a daily basis, and if so what type of care do they provide and how often
18. ask them to describe the difference between a good day and a bad day (in terms of their symptoms etc) and how many of each (good days and bad days) they would generally get in a typical week or month

Circumstances of making a claim for DLA (*key section 1*)

19. ask them to describe what led up to them making a claim for DLA
20. why did they make the claim and why did they make it at the time they did
21. did anything in particular make them claim at that time (Dec 2006 - Feb 2007)
22. find out if they have ever claimed DLA before and if so when that was and what was the outcome (eg time limited award/disallowed etc) and what were their reasons for applying again
23. what did they see as the main reasons for claiming
24. was their application 'speculative' to see whether they were eligible or not, or were they already convinced that they would be eligible
25. did anyone (or anything) encourage them to claim and if so what did they say (or what was it); can they remember any conversations they may have had with others
26. was their claim linked in any way to any other claim for benefits (such as IB?)
27. ask if anyone they know receives DLA (for example a friend or family member) and whether this influenced their decision to apply in any way
28. was there anything that happened, or anyone they spoke to that decided them to claim
29. did they make the decision to claim themselves or did someone else suggest that they should – if the latter, under what circumstances was the suggestion made

Sources of information

30. had they heard of DLA before making the claim, and if so how much did they know about it
31. ask how they came to know that the benefit existed
32. what did/do they understand about the benefit – what is it for, what are the conditions attached to it, who is eligible, how it might affect other (passported) benefits, whether it can be received while in work etc
33. where did they find out about DLA – how did they first hear about it and from whom
34. did they get their information from printed material (leaflets etc) or by talking to someone else about it
35. who did they talk to and what were they told
36. was there any one thing that they remember as influencing them to make a claim themselves
37. did they see an information leaflet about DLA at any time – if so where, who provided them with it, under what circumstances and what do they remember about it

show the customer a copy of the DCS leaflet and ask if its what they saw

38. what did they understand to be the message from the leaflet, was it clear and easily understood – did it encourage them to go ahead with a claim or put them off/raise doubts
39. did the leaflet help them understand the purpose of DLA and whether they were eligible to claim for it
40. what do they think was the main message (or main messages) of the leaflet
41. what do they remember most from the leaflet
42. how confident were they that they would be eligible for DLA, having read the leaflet and/or talked to others

Role of third parties & intermediaries

43. did they receive any help at any stage of the application from another person
44. did they get informal help or formal (professional) advice
45. if so who was it – a friend, family member, medical or advice professional
46. if the other person helping them was acting in a professional capacity, what organisation were they from and how did they get in touch with them
47. how had the person who helped them heard about DLA – how knowledgeable do they think they were
48. why did they seek help and did they find it useful

49. what was the most useful aspect of the help they received (and the least useful)
50. was there anything they wanted to know that their adviser was unable to help with
51. did they get help purely in the form of advice and encouragement or did someone actually help them to fill in the form to make a claim
52. how useful was the help they received, do they think they got good advice
53. did the person who helped them seek help/advice at any stage from DCS (eg via the telephone help line) and if so do they know what was said and whether it was helpful

The claiming process

54. what type of claim did they make – on a paper form posted in or on an electronic form on the internet
55. if they claimed electronically why did they choose that method
56. if they filled in a paper form where did they get that claim form from and how did they request it and get hold of it (eg. requested by 'phone, dropped in to an office, was offered one when conducting other business etc)
57. how did they find the form (whichever they used) – was it clear what information was required and how it should be filled in, and was it easy for them to complete
58. what problems if any did they have getting hold of and filling in the form
59. do they have any suggestions as to how the form, or any other part of the process could be improved/ could have been made easier for them
60. did they seek help/advice at any stage from DCS (eg via the telephone help line) and if so can they remember what was said to them – did they find it helpful
61. (key question) how confident were they when filling in the form that they would be successful in their application – and for what reasons
62. how long did they expect the award to be paid for if they were successful; did they understand the claim might be time limited and need renewing after a period

Outcome/disallowance (key section 2)

63. did they receive a letter explaining the reasons why their claim had been disallowed (some in the North West will have had a more informative letter)
64. what do they see as the reason their claim was disallowed – do they understand the decision

65. did they contact DCS to ask for an explanation of the decision? Were they satisfied with the answer
66. how do they feel about being disallowed, does the decision seem fair to them, are they able to judge if it was correct or not
67. have they accepted the decision or are they still considering appealing against it
68. if they are not considering an appeal why have they made that decision
69. have they gone back to any third party that may have advised them to discuss the outcome, and if so what was the result
70. do they think that they might make a further claim in the future (for example if their condition gets worse)
71. if so what do they think would have to change before they would try to claim again
72. are there any further issues they would like to raise or comments they would like to make that haven't been covered

Thank them for taking part in the research.

Explain that we would like to show our thanks by giving them a £20 cash gift. Please ask for a signature to say they have received it.

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