Disability Living Allowance and work: Exploratory research and evidence review

by Andrew Thomas and Rita Griffiths



Department for Work and Pensions

Research Report No 648

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Andrew Thomas and Rita Griffiths

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First Published 2010.

ISBN 978 1 84712 755 6

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Acknowledgements

We would like to thank the Disability Living Allowance applicants and recipients who took part in the research interviews and staff in the Department for Work and Pensions (DWP) who contributed to the research. Their participation in the research was highly valued and essential.

We would also like to thank Andrea Kirkpatrick and Mike Daly in the Disability and Carers Benefits Division of the DWP who provided immense support and guidance throughout the life of this project.

The Authors

Rita Griffiths is a Partner of Insite Research and Consulting with 20 years experience of applied social research and evaluation.

Andrew Thomas is a Partner of Insite Research and Consulting with 25 years experience of applied social research and evaluation.

Abbreviations

AA Attendance Allowance

ADHD Attention Deficit Hyperactivity Disorder

ATW Access to Work

BEL Benefits Enquiry Line

CA Carer's Allowance

CPN Community Psychiatric Nurse

CTB Council Tax Benefit

CTC Child Tax Credit

DBC Disability Benefit Centre

DCS Disability and Carers Service

DDA Disability Discrimination Act

DEA Disability Employment Adviser

DLA Disability Living Allowance

DPTC Disabled Person's Tax Credit

DWA Disability Working Allowance

DWP Department for Work and Pensions

ESA Employment and Support Allowance

FRS Family Resources Survey

HB Housing Benefit

HDS Health and Disability Survey

HMRC Her Majesty's Revenue and Customs

IB Incapacity Benefit

ILF Independent Living Fund

IS Income Support

ISdp Income Support disability premium

IVB Invalidity Benefit

JCP Jobcentre Plus

JSA Jobseeker's Allowance

LFS Labour Force Survey

MA Mobility Allowance

MS Multiple Sclerosis

NatCen National Centre for Social Research (current

abbreviation)

NCSR National Centre for Social Research (previous

abbreviation)

NDDP New Deal for Disabled People

ONS Office for National Statistics

OPCS Office for Population Censuses and Surveys

PCA Personal Capability Assessment

PDCS Pensions, Disability and Carers Service

(formerly DCS)

RTWC Return to Work Credit

SDA Severe Disablement Allowance

SPRU Social Policy Research Unit

SSP Statutory Sick Pay

WFI Work Focused Interview

WPLS Work and Pensions Longitudinal Study

WTC Working Tax Credit

Summary

Aim

The broad aim of the research was to find out more about people receiving Disability Living Allowance (DLA): more specifically to explore possible reasons for the low level of employment among DLA recipients and to examine possible disincentive or enabling effects resulting from receipt of the benefit.

Method

The research study was essentially qualitative and comprised several different elements:

- a review of evidence from previous research;
- discussion groups with Pensions Disability and Carers Service (PDCS) staff and with Jobcentre Plus and Pathways to Work providers' advisers;
- a customer focus group with disabled people;
- two telephone surveys of DLA applicants before and after receiving the decision on their DLA claim (1,005 and 637 respondents respectively);
- face-to-face qualitative interviews with 110 purposively selected individuals.

Evidence review

Available evidence indicates that employment rates among DLA recipients are very low. Two studies (in 2002 and 2006) both estimated a rate of nine per cent. Among DLA recipients who were out of work in 2007 more than three-quarters were claiming what are generally regarded as 'inactive benefits' which do not require recipients to be available for work or to look for work. Within the working-age population, people who receive DLA are much less likely to be in work than disabled people who do not, who in turn are much less likely to be in work than non-disabled people. (See Section 3.2.1)

Several hypotheses were explored in a review of evidence that:

- DLA recipients are additionally disadvantaged in the labour market;
- they are more severely impaired than other disabled people;
- they are less likely to want to work than other disabled people.

DLA recipients are over-represented in two categories which have been shown to have the effect of reducing disabled people's employment rates – being a woman and being aged over 45. Available data do not suggest any geographical concentration of DLA recipients in areas with a poor supply of jobs. They are concentrated in almost exactly the same local authority districts as the wider incapacity claimant group. (See Section 3.3)

The main factor affecting the employment rates of disabled people is their disability or health condition. The single type of condition that other research has shown to result in the greatest negative impact on disabled people's employment probabilities is mental health. A higher proportion of DLA recipients report a mental health condition compared to the wider disabled population, so DLA recipients are concentrated within the category that carries most additional employment disadvantage. (See Section 3.4.1)

A larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people: locomotor, intellectual and behavioural impairment. Existing data further indicate a degree of concentration of 'multiple disability' among the DLA population which will have an impact on employment rates. (Section 3.4.3)

The conclusion of a 1995 report was that the profile of the DLA population 'contrasts markedly' with the population of disabled people as a whole, with more people in higher severity categories. Overall, the conclusion can be drawn that DLA recipients are, on average, more severely disabled than other disabled people, and that they suffer higher levels of disadvantage and lower employment rates as a result. (See Section 3.4.4)

However, the severity of disability and disadvantage associated with eligibility for DLA does not fully explain the difference between the employment rate of DLA recipients and that of other disabled people. DLA claimants have been shown to be significantly less likely to have a job than other disabled people with a similar level of employment disadvantage. Recent secondary analyses of data sets, including DLA recipients, have confirmed a lower level of employment aspiration and expectation among DLA claimants and their greater distance from the labour market compared to other incapacity benefits claimants. (See Section 3.5)

The perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment. Although a lower proportion of DLA recipients than Incapacity Benefit (IB) recipients expecting to work would be consistent with their having more severe disabilities, it does not in itself suggest

a reason as to why disabled people on DLA might be **more likely than others** to view their disabilities as permanently preventing them working – leading to the question of whether there is a specific 'DLA factor' at work. (See Section 3.5.1)

This question has been taken up in recent secondary data analysis. Although such secondary statistical analysis cannot say whether or not there is a direct causal link between DLA receipt and lower work expectations, it was able to establish a significant association between them. Findings were that there was indeed potentially a 'DLA factor,' and that even though DLA claimants tend to be older, poorly qualified, on benefits for longer and in poorer health than other IB claimants, the fact of having a DLA claim, in itself reduces the likelihood of someone saying they would like a job (now or in the future) by more than a third. (See Section 3.6)

These reports suggest that one thing which may explain the DLA effect could be the knock-on implications from the monetary value of the award, such that being in receipt of DLA will reduce the financial incentive to take up employment. Analysis with the money value of DLA awards built in as an explanatory factor did indicate that the higher the value of award the greater the apparent 'disincentive' effect was on work expectations, although again this is not evidence of a direct causal link.

Two key areas were looked at in our primary research. First, issues relating to the **timing** and **process** of making a claim for DLA and receiving a fresh award and second, issues around the financial value of DLA and its effect on people's thinking and behaviour.

Key findings

DLA as an out-of-work benefit

For many DLA claimants, both applicants and recipients, there was a perception that DLA was a benefit for those who are unable to work, was only payable when someone was not working and stopped if they went back into work. (See Chapter 3)

The association of DLA with being out of work, carried a range of different connotations for applicants. Several people felt it carried a stigma. Others felt that, even though it could be claimed while working, people did not want or need to do so. Such feelings were only in part to do with financial need. At least as important for many people was the desire to be independent and to manage their own resources. Such feelings even extended to a sense of social injustice at claiming while working. Many had not seen it as appropriate or applicable to themselves while they were in employment. (See Section 3.1)

Such perceptions about DLA suggest that many of those who do get back into work will drop their claim for DLA or, at the very least, not apply to renew their claim at the end of a fixed period of award. Were this to happen to any significant

degree then it would contribute to further depressing the employment rate among (remaining) DLA recipients.

Another important cluster of perceptions about DLA was around the idea that DLA provides a 'badging' of disability. This could be a positive or a negative perception. For some, the awarding of DLA was seen as recognition of the long-term difficulties they had faced because of their health condition, or as some form of compensation. For others, being a DLA recipient and being 'disabled' was a label that they were uncomfortable with, particularly as it carried with it an element of admitting to themselves that they had a disability. A common aspect of this acknowledgement process was recognising that a condition was long term and probably incurable. (See Section 3.1)

DLA was, for many recipients, also seen as 'proof' that they were unable to work. When they had started to see their condition as long term and unlikely to improve was the point at which they had made their claim for DLA. Very few people thought of DLA in terms of it meeting the additional needs created by their disabilities.

Trajectories out of work

It has previously been speculated that most DLA claims and payments are associated with the process of leaving and/or remaining out of work. Analysis of data from the British Household Panel Survey indicates that while around 80 per cent of those who become disabled are in employment at the time of onset, only 60 per cent are in work the following year, and 36 per cent the year after that.

Among applicants surveyed in this study, 17 per cent of those whose claims would go on to be allowed were working at the time of making their applications for DLA. In the five months following applications there was a marked increase in the number describing themselves as out of work/not working (from 69 per cent to 80 per cent). This supports the hypothesis that many who apply for DLA are already on a clear trajectory out of work. (See Section 4.1)

Among those in work at both survey points, the great majority (91 per cent) had stayed in the same job, with a considerable shift towards part-time working – from one-third to one-half of those in employment.

Changes in employment status

Whatever the applicants' original employment status, the proportion in work five months later was, in each case, higher among those whose claims were disallowed than among those whose claims were allowed. This could indicate a work disincentive effect from receiving the benefit. However, the 'incentive' to work for those disallowed was predominantly experienced as financial pressure to resume work **in spite of** their health. Several said that they felt their house/ mortgage was under threat if they did not earn an income, and others said they had started or returned to work against doctors' advice and to the detriment of their health.

Finding work suitable to a particular health condition was the obvious (if not necessarily easy) option for many who were strongly orientated towards the labour market. Help from employers in adapting work duties, allowing gradual and graded returns to the workplace, and being flexible about hours, was frequently key to finding such work, and many people mentioned that good relations with former long-term employers had made such things possible.

Overall nearly three-quarters (71 per cent) of all those surveyed who moved into work, or back into work, in the period after making their DLA application, resumed work for employers they knew and whom they had worked for at some time in the past – almost all of those re-entering work from sick leave, but also nearly half of those who had been out of work/not working when they had made their DLA application. (See Section 4.1)

Work expectations and the timing of DLA applications

At the initial telephone interview more than three-quarters of the 124 applicants who were then off work on sick leave, said that they intended to go back to their jobs. A contrast existed between aspirations and intentions and actual behaviour, with greater numbers having left work five months later than had said they intended to. (See Section 4.1.1)

Most people had claimed DLA when they were out of work. A further significant proportion had made their claim while on sick leave. Subsequent movement out of work was most marked for those becoming DLA recipients. (See Section 4.2)

For the great majority – the health factors determining the timing of applications for DLA were overlaid and intricately bound up with financial factors. For those recently in work it was predominantly the case that financial difficulties were directly linked to issues of leaving employment and DLA was strongly associated with trying to cope with the consequences of losing employment and income.

There was much evidence from the qualitative interviews that one aspect of the timing of DLA claims was applicants' perception that they were going to be affected for the long-term by their condition. While this did not necessarily mean that people were consciously leaving the labour market for good, DLA provided a form of legitimacy to not seeking work. DLA was seen to act as a means for some people of prolonging a temporary absence from work beyond the period covered by sick pay.

Those recently in work

It was particularly noticeable that many people had made their application for DLA at the point of a severe drop-off in their income. Key moments were the point of resignation or leaving a job that could no longer be coped with, the point at which the employer's sick pay went from full wage to half wage equivalent, and the points at which Statutory Sick Pay (SSP) and/or the employer's sick pay ran out altogether. (See Section 4.2)

Most had waited until faced with financial crisis before applying, or until told by a doctor that they were unlikely to return to work. Some had stayed in employment for a considerable time in spite of their health conditions, whether for purely financial reasons, or as a result of a strong 'work ethic', or because they were concerned over not knowing the precise financial implications of stopping work. This group was characterised by having made considerable efforts to adapt and mould their work situations around the demands and limitations of their disabilities and health conditions. Despite the considerable efforts made, they had all arrived at the point of making a DLA claim, and as for others this was almost always because they had ultimately left their employment because they could no longer cope. (See Section 4.2)

One important factor in the minds of many trying to keep themselves in work 'against the odds', was an awareness of how difficult it might be for them to find another job if they were to leave their current employer. This was not merely a general concern about job availability, but an awareness of the additional difficulty they were likely to encounter in the face of their current health record.

Those long-term out of work

Three-quarters of all applicants were out of a job when they applied for DLA and of these three-quarters had not been in work for over a year, or had never worked. Overall, this group made up just over half of all eventual DLA recipients. (See Section 4.2.2)

For most a similar pattern of health and financial crisis could be discerned as for those more recently in work. In a number of cases it was primarily the difficulty people were having living on benefits which had prompted claims. Some who applied for DLA when out of work had a strong and credible intention to return to employment, others felt under financial pressure to do so, whereas yet others consolidated their status as out of work and unable to work through applying for and being awarded DLA. (See Section 4.2.2)

Those applying for DLA who were long-term out of work were more likely than others to mean 'unable ever to work again' when they said they could not work. In the five months between survey waves only one per cent of those long-term out of work and agreeing at survey 1 that they were 'unable to work' had moved into work, compared with seven per cent of those who had been out of work less than a year, and ten per cent of those who had applied while on sick leave. (See Section 4.2.2)

Face-to-face interviews with those long-term out of work found evidence that they shared many of the typical disadvantages of all long-term unemployed people, such as low self-esteem and poor confidence, and were inclined to perceive their impairments as more restricting than were working applicants.

Suitable future work

Interviews explored how potential, future work was viewed by new claimants. Most people made the assumption that work meant the specific work that they used to do. It was clearly very difficult for people to think beyond this and start addressing the question of what they might be able to do now or in the future in the way of work. (See Section 4.3)

There were those whose health conditions seemed unequivocally to rule out a return to their previous work, particularly in cases where the nature of the work was implicated in a health condition. This was particularly the case where mental health issues were concerned. In such cases working in **any** job was frequently seen as impossible because it was likely to cause stress and prevent recovery.

For most people it was their previous employment that provided the most accessible route for thinking about returning to work. Where people were still in touch with their employer it was easier and more tangible for them to think about how their job might be modified or conditions changed to allow them to continue, than it was to imagine finding a new job 'from scratch'. There were two practical reasons why such an approach appeared to make most sense: the feared likely rejection by other, 'new' employers; and the drop in wages expected to go along with a switch in occupation to something compatible with their disability or health condition. (See Section 4.3)

A variety of adjustments to household employment arrangements were common – including partners increasing their hours, changing jobs or coming out of retirement. The notion of 'suitable alternative work' for DLA recipients was far from straightforward. Many found it difficult to consider alternatives to the work they were experienced in and familiar with. A number of psychological barriers appeared to exist that **overlay** and complicated the practical difficulties of reducing hours and accepting lower wages, even if work could be found that fitted around people's disabilities. (See Section 4.3)

The role of third parties

Third parties play a significant role in the timing of applications. Even where employers know about the existence of DLA, it appears to be very rarely mentioned except in the context of someone leaving their job. There was clearly an issue about the lack of information and signposting available to people. When they did get to hear about DLA, it was very often from professionals dealing with the health or financial crises in their lives, in contexts that in some cases reinforced associations between DLA and being too unwell to work, and between making a claim and devising strategies to cope with shortfalls in income and related problems such as debt. In this way many of the common misunderstandings about DLA were reinforced by contact with professionals. (Chapter 5)

The main groups of advisers mentioned by applicants were those who were medical professionals, and those related to the provision of benefits advice through statutory

and voluntary agencies. Medical professionals were generally highly regarded, and trusted, and were very influential in people's decision-making about DLA. This high regard appeared to be well placed; applications made at their suggestion had the highest rates of success in our survey of applicants. However, exchanges with medical professionals that were reported in face-to-face interviews showed them typically to pursue an explicitly non-work agenda. Reported mention of DLA by GPs was frequently in the context of certificating absence from work. There was very little evidence of medical professionals engaging with people in discussions about whether work might be a positive influence on their health and in many cases claiming DLA was suggested specifically as an alternative to going back to work. (See Section 5.2)

The other key source of information about DLA was professionals in support and advice agencies. Most contact with them was reported as taking place in the context of addressing the financial difficulties consequent upon ill-health and unemployment. Third parties in these agencies generally saw their role as helping to counteract poverty by securing financial help for their clients from wherever they could. Some applicants expressed unease about what they were being advised to put on their application forms. Others appeared to be largely unaware of what had been submitted on their behalf, and were happy to relinquish responsibility for it to the person who had completed their form for them. (See Section 5.3)

Jobcentre Plus

The accounts of Jobcentre Plus' role formed a fairly consistent picture of separation from DLA and non-engagement. There was little to suggest any influence either over decisions to claim DLA or over the timing of applications. Several DLA recipients detected a lack of understanding or sympathy from Jobcentre Plus staff in relation to disability and health issues along with an overriding focus on getting people off benefits and into jobs regardless of their circumstances. People with mental health conditions were particularly likely to feel adverse effects from institutional pressures such as the tightening of conditionality surrounding benefits. (See Section 5.4)

Work disincentives and enablers

Secondary data analysis has found that as the value of a DLA award rises, so work expectations fall (independently of other possible explanatory factors). The explored hypotheses from our review as to why DLA receipt might be a work disincentive were that it might be due to:

- a fear of review and loss of entitlement;
- a perception of having more to lose or less to gain from employment than others.

Fear of review and loss of DLA entitlement

There was a widespread concern among DLA recipients that moving into work would trigger a review of eligibility that could lead to withdrawal or a reduction in

benefit. Many people perceived that if they felt able to work then their condition would have improved sufficiently for them no longer to be eligible to receive DLA. Whereas this feeling was applicable to most types of disabilities and health conditions, it was particularly evident among those with mental health conditions. (See Section 6.1)

It was enough to concern people, and make them pull back from trying to regain employment, to be told by an adviser that it was not possible to give them a **guarantee** that a review would **not** happen. While advisers appeared to be doing their best to allay people's fears in this regard, some other third party sources of information and influence appeared occasionally to be reinforcing them.

A very widely shared perception of the DLA awards decision-making process was that it was unpredictable, even capricious, and that even once an award was made it was all too easily lost again by doing or saying the wrong thing. (See Section 6.1)

More to lose and less to gain

DLA is a non contributory, tax free benefit not affected by other income, earnings or savings, and payable regardless of employment status. In theory, in spite of this, it could still disincentivise working to an extent; the more income somebody has while out of work, the less the incentive effect of a given increase in income will be. In a 2009 report, DLA claimants were found to have slightly higher expressed reservation wages than other incapacity benefits claimants. While we do not know what respondents were assuming about their entitlement to in-work benefits, this may suggest that DLA recipients perceive themselves to have more to lose from leaving benefits and entering work than do other disabled people, although the difference between DLA recipients and others in that study was small and not statistically significant. (See Section 6.2)

Existing data show DLA recipients to be in receipt of considerably higher than average benefit income compared with other benefit customers with disabilities. Part of the reason for this is the value of DLA itself, particularly at the higher rates of award. Another reason is the above average value of non-DLA benefits and the extra disability premiums which those with more severe disabilities may be entitled to claim. The fact that DLA recipients, who get DLA but no other benefits, appear to have the highest rates of employment, regardless of the severity of disability, is suggestive of a link between such financial disincentives and the probability of working. (See Section 6.2.1)

Interviewed DLA applicants almost unanimously viewed the benefit as 'income' which was just one contributor to an overall 'pot' of money available to live on. For those who were still working and applying for DLA it was often explicitly referred to as a wage supplement or as a partial wage replacement. If they were continuing to work full-time the benefit was seen as something of a 'bonus', or a subsidy to low paid work. If working part-time, or on enforced reduced hours or in

a lower paying job than they were previously capable of, then DLA was frequently referred to as meeting the shortfall, or contributing to filling the income 'gap'. For those who had been working in minimum or close to minimum wage jobs, and especially if not working full-time hours, the addition of DLA to their other benefits could mean that they were only very marginally worse off than they had been in work, or even slightly better off. (See Section 6.2.1)

Those applying from out of work, and at some remove from the last time they were in paid employment, had the primary intention of boosting their (benefits) income. Many claimants saw DLA as part of a 'viable package' to live on. Some quite consciously used DLA as a way of managing their exit from the labour market once they were convinced they could not stay in work very much longer, or were not likely to return to work.

Frequently DLA was part of a household adjustment to changes in the circumstances of one member. This took a variety of different forms, from partners increasing work hours, finding a better-paid job or moving from part-time to full-time work, through to coming out of retirement to earn an income or swapping the employment and child-caring roles within a couple. DLA was seen as facilitating many of these compensatory strategies, for example by taking some of the personal care requirements off the shoulders of partners to free them up for work, or by paying for transport to allow the DLA recipient to take children to school, allowing their partner to work full time.

The relative value of DLA

The wide variation in the value of possible DLA awards is heightened by the 'passported' benefits which DLA can bring and which are linked to higher level mobility and high and middle level care elements. What is true for all recipients, however, is that their DLA is a benefit that can be added to other sources of income without affecting them or being affected itself. As such it was seen as highly flexible. While IB and Employment and Support Allowance (ESA) claimants may be wary of jeopardising the security provided by their benefits, only DLA customers will have the **added** element of perceived risk relating to their DLA, which may go some way towards explaining the 'DLA factor' which affects recipients' expectations, their aspirations of working, and ultimately their collective employment rate. (See Section 6.2.2)

Benefits complexity

Many of the DLA recipients interviewed for this research had yet to arrive at a 'settled' view of their health condition or their capacity for future work, and so few had even attempted to come to terms with the regulations governing earnings disregards, permitted work, or the linking rules back into benefits if work could not be sustained. Where mention was made of these matters there was much acknowledged uncertainty and lack of understanding, and in some cases confusion. Several people commented on the difficulties they had faced

in trying to get good, comprehensive information about DLA. A number also commented on the overall complexity of the benefits system and on how difficult they perceived it to be to get information about all the different aspects of it. Even making an enquiry was seen by some as itself carrying a risk. (See Section 6.2.3)

For most of those attending the customer group there was a feeling that benefits were vulnerable and could easily be lost if care was not taken. This sense of precariousness, and the serious nature of possible consequences, was felt particularly strongly where whole families and households were relying on benefits income. Complicated benefit rules make it more difficult for individuals (and advisers) to establish with any accuracy the net income from working and the balance of financial gains and losses which may affect the whole household. Advisers participating in the discussion groups admitted to being wary of carrying out better off in work calculations for people in receipt of DLA.

Another issue affecting people's willingness to consider paid work related as much to considerations of the time and effort required and the disruption caused by moving from benefits to employment, as to purely 'better off in work' calculations and decisions. Receipt of DLA can often be central to entire 'packages' of benefits that have taken a considerable time to set up and on which entire family units depend. We found examples of people making decisions based more on minimising the risk of disruption to their income, than on maximising its monetary value. (See Section 6.2.3)

It was not uncommon to find that claimants of DLA were part of a household where there was more than one person with a disability and different care needs could be met by different people at different times, leading to complex interdependences of benefits. Any action that might disrupt these arrangements was viewed with extreme caution. This appeared more likely to be the case in the households of longer-term benefits claimants. There were several examples among our interviewed DLA claimants of highly complex household income arrangements, making decisions about work problematic. They shared an expressed concern not to risk the stability that had been achieved. Perceived risks outweighed any theoretical financial gain associated with moving into work. Where income from benefits was much higher than average, the incentive to increase it by working appeared to be that much less. (See Section 6.2.3)

DLA as a work enabler

The main effect of previous financial incentives designed to encourage the take up of paid work among disabled people has been shown to be in supporting job retention rather than in stimulating job entry (in many cases enabling a reduction rather than an increase in working hours). (See Section 6.3.3)

Evidence from our qualitative interviews with recent DLA applicants tended to support these findings. It showed that DLA also appears to have very small, if any, incentive effects on people in terms of encouraging them to take up paid work. All of the DLA recipients interviewed who had moved into employment

from being without a job, were strongly work orientated and DLA had made no difference to their decision making.

However, while disincentives operated for many, there were those for whom DLA was seen as having supported job retention. The key ways in which it had achieved this were by facilitating travel to work and allowing people to adjust the tasks they undertook and the hours that they worked in a week to better suit their reduced capabilities.

Conclusions and policy recommendations

There is still much to be learned about the DLA recipient population, in particular whether the findings from this study of recent applicants are equally applicable to the long-term claimants who make up the majority of those receiving the benefit.

Getting DLA does appear to have some disincentive effect on employment, though real and extensive health and financial difficulties exist for most recipients. Long-term claimants and those with complex household packages of benefits perceive the greatest risks and are likely to be more difficult to move (back) into work than those more recently employed. The government target of moving one million incapacity benefits claimants (many of whom are DLA recipients) into work remains a huge challenge.

There is an evident need for better information to be made available about DLA and scope for more intensive, personalised rehabilitation and employment support to applicants and recipients.

The time of application for DLA would be an appropriate point for support intervention for many people because a significant proportion of applicants are still in touch with employers and it is with known previous employers that most of the successful job adaptations and outcomes are being achieved.

DLA can successfully enable some people to remain in work, and the greatest potential from additional support may exist in focusing on job retention with those struggling to maintain employment in the face of new disability and health issues.

1 Introduction and background

1.1 Policy background

Enabling people to move from benefits into work through making work pay and offering practical support to help them find employment, are central pillars of the Government's welfare reforms. During a period of economic stability and growth, the policy achieved notable success in reducing unemployment and increasing employment, particularly among lone parents, the long-term unemployed and young people. Male and youth unemployment reverted to the levels of the 1970s, and economic activity rates for women and lone parents rose steadily. Progress in helping people who have a serious health condition or disability has been more modest. While employment rates for disabled people have increased, both absolutely and relative to overall employment rates, there still remains a substantial gap. Following the recent recession we can expect these gains to be challenged.

Disabled people and those with a long-term health condition¹ make up a sizeable share of the working-age population.² Estimates suggest that between one in six

Hereafter the term 'disabled people' is used to cover all those with a disability or long-term health condition which impacts on their day-to-day activities and the work they can do.

People of working age include all men aged between 16 and 64 and all women aged 16-59.

and one in ten working age adults,³ upwards of six million people, are disabled. At best, only half of them are in paid employment.⁴ This compares with more than three-quarters of people without a disability in work, and around 60 per cent of lone parents.⁵ Indeed, people with a serious health condition or disability now represent the largest group of working age adults who are not in paid work. In 2007, almost 60 per cent of adults with disabilities, in the region of three million individuals, were not in work compared with only 15 per cent of people without disabilities.⁶ Compared with most of the rest of Europe, the UK not only has a higher incidence of disability, but the employment rate among disabled people is lower.⁷

Although many disabled people without paid work say they would like to work, the majority are not unemployed but economically inactive, that is, they are either not looking for work or not available to start work, and around three-quarters rely on benefits as their main source of income. Most are claiming one or more incapacity or disability-related benefits for which, historically, there has been no conditionality in terms of looking for, or being available for work. These include income replacement benefits such as Employment and Support Allowance (ESA)

- There are many ways of defining disability. Most current surveys attempt to measure it in line with the Disability Discrimination Act (1995) definition, but not always using consistent questions. Both the reported incidence of disability and employment rates among disabled people are highly sensitive to the definition of disability used by different data sources (Bajekal *et al.* (2004)). Sources which use a self-reported definition of disability, that is, dependent on asking people if they consider themselves to be disabled, tend to record both a higher prevalence of disability and a greater incidence of employment than sources which use more objective or externally validated measures of impairment. Differences and changes in the phrasing of survey questions can also lead to disparities in data between sources and over time.
- Using a broad and self-reported definition of disability, the Labour Force Survey (LFS), commonly used as the official source of data on employment, records an employment rate of 50 per cent among disabled people, compared with 80 per cent for non-disabled people. On the other hand, using the Family and Resources Survey (FRS) and the Health and Disability Survey (HDS), Berthoud R. (2006 p. 32) reports a more modest employment rate of 29 per cent among disabled people, compared with 76 per cent for non-disabled people, although this was based on a narrower measure of employment.
- LFS Office of National Statistics (ONS) UK (updated 2008) as presented in The Poverty Site www.poverty.org.uk
- ⁶ LFS ONS UK (updated 2008) as presented in The Poverty Site www.poverty. org.uk
- Jones MK, Latreille PL and Sloane P, (2006). *Disability and Work: A review of the British evidence* p3.

Incapacity Benefit (IB), Severe Disablement Allowance (SDA) and Statutory Sick Pay (SSP), intended for those unable to earn an income due to illness or disability; means tested benefits including Income Support (IS), designed to top up income to contribute towards basic living expenses; together with Disability Living Allowance (DLA), a benefit to cover the additional costs of disability for people needing help with personal care or having serious difficulties walking.

In August 2009, there were 5.9 million working-age benefits claimants, of which 2.63 million were in receipt of ESA and other incapacity benefits – more than treble the number in receipt of incapacity benefits in the 1970s.⁸

With up to 60 per cent of disabled people experiencing low income⁹ and around a quarter of households with disabled people likely to be poor,¹⁰ high levels of economic inactivity and low levels of employment and income are at least as much a concern for the living standards of disabled people and their families as is the rising cost of disability benefit payments for the economy and society as a whole. Helping disabled people to overcome the disadvantages they face in work and society are guiding principles of the Government's commitment to disabled people, as set out in the Prime Minister's Strategy Unit report of 2005 *Improving Life Chances*.¹¹

1.2 Welfare reform

One of the key reasons why the rate of poverty among disabled people is comparatively high is because so few disabled people are working. ¹² Not only is work less common among disabled people, but for disabled people who are working, earnings are, on average, much lower than those of non-disabled people ¹³ (partly because they are more likely than non-disabled people to be employed part-time and in low skilled, low paid work.) Given the important role that being in work has on reducing poverty, the Government's approach to reversing the trend in rising inactivity levels and improving living standards among disabled people has focused on increasing their rates and hours of employment. Not only is paid work seen to be the most sustainable route out of poverty, but the ability to work,

- 8 DWP Quarterly Statistical Release February 2010.
- ⁹ Zaidi and Burchardt (2002) as reported by Smith Noel. *et al.* (2004).
- In 2007/08 25 per cent of those living in households with at least one disabled person were in poverty, compared to 16 per cent of those in households where nobody was disabled figures on a Before Housing Costs basis from http://www.officefordisability.gov.uk/research/indicators.php#poverty
- Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people*.
- Worklessness substantially increases the risk of poverty among disabled people. Palmer G (2006) *Disabled people, poverty and the labour market*.
- ¹³ Burchardt T (2000).

live independently and achieve an acceptable standard of living are key elements of the Government's commitment to extend the basic rights and opportunities of disabled people. The strategy is premised on the notion, well evidenced by independent research, that many disabled people without work would like to work. For example: '...among the 60 per cent of disabled people who are not in work, half would like to work'¹⁴ and 'disabled people made up 47 per cent of those who were not employed but wanted to work.'¹⁵

Recent welfare reform is based on a similar conviction that the vast majority of people making a claim for IB/ESA want or expect to work again in the future: '... there are 2.7 million people of working age receiving an incapacity benefit and well over three quarters of these would like to work' 16 and 'the vast majority of people – around 80-90 per cent – making a claim for incapacity benefits want and expect to get back to work.' 17

The strategy for increasing employment among disabled people aims to improve their labour market position through changes to the tax and benefits system and a series of policies and programmes designed to incentivise and support the transition from benefits to work. These include some specialised programmes run by Jobcentre Plus, such as Access to Work which can fund travel, equipment and workplace adaptations; providing assistance to help disabled people into work through the New Deal for Disabled People (NDDP); 18 the introduction of the Disabled Person's Tax Credit (DPTC) (now replaced by the additional payments for disabled people in the Working Tax Credit); tackling workplace discrimination through the introduction of the Disability Discrimination Act (DDA) 1995 and targeted support for claimants of IB and IS (and latterly ESA), via the Pathways to Work programme.

Pathways to Work is a series of mandatory work focused interviews combined with a programme of employment support and rehabilitation delivered by a mixture of Jobcentre Plus (JCP) and private and voluntary sector providers. It was piloted

¹⁴ Burchardt T (2000).

Disability Rights Commission (2004).

Pathways to Work: Helping people into employment (2002) Executive Summary p 1.

DWP (2006) A New Deal for Welfare; Empowering people to work p27.

NDDP is a voluntary programme of advice and practical assistance introduced in its current form in 2001 to help disabled people move into or retain paid employment.

from 2003¹⁹ for new and repeat IB claimants, extended to existing IB claimants by 2006,²⁰ and provided nationally by 2008.²¹

Since October 2008, the payment of IB and IS on the grounds of incapacity is being phased out, and IB and IS have been replaced with ESA for all new claimants. JCP will begin to migrate existing IB/IS customers onto ESA during 2010 and the process is expected to take three to four years to complete. Access to ESA is restricted to people assessed by a health professional as having a limited capability for work. Claimants assessed as having the most severe health conditions or disabilities receive the new benefit without any conditionality, but will be eligible for help and support if they want to enter or return to work. Others are placed in a Work Related Activity group. Since most people do not reportedly present with severe health conditions when they first claim IB, the expectation is that, 'with relatively manageable health conditions,'22 the prospects of an eventual return to work for this group are generally good. The Government has set an ambitious goal of reducing by one million the number of people on incapacity benefits²³ by 2015.²⁴

1.3 Welfare reform and DLA

Recent policies and programmes designed to reduce economic inactivity rates and increase employment among disabled people were beginning to show some early signs of success.²⁵ Having risen for three decades to a peak of nearly 2.8 million people of working age in 2003, the number of people claiming incapacity benefits then reduced to just under 2.6 million in 2008 (although numbers subsequently rose slightly again during the recession to a total of 2.63 million in August 2009).²⁶

- Pathways pilots were introduced for new and repeat claimants of IB in three JCP districts in April 2004 and extended to a further four in 2004.
- In April 2005 and 2006, Pathways to Work eligibility was extended to include existing IB customers.
- In December 2006, Pathways support was implemented across 18 districts to 40 per cent of all new and repeat incapacity benefits customers. In December 2007, Pathways provision was extended to a further 15 JCP Districts. The final phase of Pathways to Work implemented the programme in the remaining 16 Jobcentre Plus districts from April 2008, completing the national rollout across Great Britain.
- DWP (2002) Pathways to Work: Helping people into employment p2.
- DWP (2006) A New Deal for Welfare; Empowering people to work.
- See paragraph 5.3 of *Raising expectations and increasing support: reforming welfare for the future* (December 2008).
- DWP (2007a) The impact of Pathways to Work and DWP (2008) Evidence on the effectiveness of Pathways to Work on existing claimants.
- ONS First Release (Feb 2010): DWP Quarterly Statistical Summary.

In the ten years to 2008, the employment rate among disabled people also increased – by nine percentage points – and the gap between this and the overall employment rate narrowed by just over eight percentage points.²⁷

However, if the Government is to achieve its target of reducing by one million the number of incapacity benefits claimants, there is a need to understand better the employment constraints and support needs of the 1.3 million recipients of incapacity benefits who also get DLA. Unlike the IB caseload which has been reducing year on year since the introduction of Pathways to Work, DLA caseload and expenditure continues to grow.

DLA is a non-contributory, non-means tested, tax free benefit which was introduced in its current form in 1992.²⁸ It is awarded in recognition of the effect on everyday activities of a long-term health condition, a physical or learning disability, mental health condition, sensory impairment or multiple disabilities. Unlike other incapacity benefits, which are intended to replace earnings lost through sickness or disability, DLA is designed to offset some of the additional costs incurred by disabled people. It is payable to people with significantly restricted mobility and/ or a need for personal care.

Responsibility for the administration of DLA lies with the Pensions, Disability and Carers Service (PDCS) (formerly the Disability and Carers Service (DCS)), an executive agency of the Department for Work and Pensions (DWP). Working from a network of ten Disability Benefit Centres (DBCs) across the country, and two central units in Blackpool and Preston, PDCS administers new claims and maintains existing claims for DLA, Attendance Allowance (AA)²⁹ and Carer's Allowance (CA).³⁰ Also under the broad remit of PDCS is a Benefits Enquiry Line (BEL) which deals with the 20,000 or so weekly enquiries about disability related benefits, and a dedicated telephone helpline which deals with new and existing claims for DLA/AA.

- DWP (2007c) *In work, better off: next steps to full employment.* Green paper p7. The LFS data used in this source employs the DDA definition of disability. The DDA defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.
- DLA was relaunched in 1992, replacing the previous benefits Attendance Allowance and Mobility Allowance payable to those of working age and introducing new lower rates of award.
- Attendance Allowance is a tax free benefit paid to eligible individuals aged 65 and over who need help with personal care.
- Carer's Allowance is a benefit for people aged 16 or over who spend at least 35 hours a week caring for a disabled person getting Attendance Allowance or Disability Living Allowance at the middle or highest rate for personal care.

In contrast to virtually all other working-age benefits and tax credits, DLA is available equally to people in work as to those out of work, regardless of how many hours are worked or how much is earned. In spite of this, among working-age DLA customers, employment rates are very low. DLA recipients are significantly less likely to be in paid employment than other disabled people with similar levels of employment disadvantage calculated on the basis of condition and the type and severity of impairment.³¹

Annual expenditure on DLA in 2009/10 is £11.437 billion, and forecast to rise to £11.962 billion in 2010/11. As at August 2009, 3.1 million people were in receipt of DLA, a rise of around 97,000 on the previous year.³² Of these, just under 1.8 million (57 per cent) were of working age.³³ Working-age DLA customers now make up a large and growing proportion of people without work and claiming incapacity benefits.

1.4 Low employment rates among DLA recipients

Regardless of whether or not they are in receipt of other benefits, DLA customers are an important group of disabled people about whom relatively little is known. In spite of the high and rising number of claimants and the mounting cost of awards, compared with other incapacity benefits claimants, there is a surprising paucity of information about people in receipt of DLA. While it is known that DLA customers are much less likely to be in work than other disabled people, what is less understood or evidenced is why.

Recent evidence suggests that, although DLA may be claimed regardless of employment status, it may be viewed as an out-of-work benefit and in a manner not unlike IB or ESA, that are intended first and foremost for people unable to work.³⁴ A belief that DLA is not available in work or that moving into work might risk a review of entitlement and the possible loss of DLA, together with passported benefits, may also be acting as a disincentive. Thus perceived, far from encouraging a return to work, getting DLA could, in some cases, discourage the take up of employment opportunities.

Another possible explanation for comparatively low employment rates among DLA customers could be the greater severity of their impairment, recognised and reflected in their very entitlement to DLA. Berthoud's recent work on disability and employment reported that the probability of employment falls with severity.³⁵ Also relevant is the finding that receipt of DLA was more closely linked with severity of disability than receipt of IB. If low rates of employment can be explained, if only

Berthoud R (2006) The Employment rates of disabled people p60.

ONS First Release (Feb 2010): DWP Quarterly Statistical Summary.

ONS First Release (Feb 2010): DWP Quarterly Statistical Summary.

Thomas A (2008) Disability Living Allowance: Disallowed claims.

³⁵ Berthoud R (2006).

in part, by the higher severity of impairment associated with eligibility for DLA, then this has important consequences for welfare reform policy. For example, the expectation that IB claimants who get DLA will have equally manageable conditions and similar prospects of a return to employment as those claiming only IB, may not necessarily follow.

Understanding how big a role DLA plays in the overall decision to work or not to work and what may differentiate DLA customers who work from those who do not, are key to the goal of increasing their rates of employment. Here, disentangling the relative importance of DLA compared with other benefits may hold further possibilities, since people in receipt of DLA but no other benefits appear to have the highest rates of employment among all DLA customers.³⁶ Looking upon DLA recipients as members of a household, and a better appreciation of the wider context of financial help and support the family unit may get could also be important considerations.

1.5 DLA and work research study

Important to the achievement of the Government's target, then, is increased knowledge and a greater understanding of the specific DLA customer group, the particular constraints they face to working and how these may differ both from the wider disabled population and from incapacity benefit customers. Only then can policies be designed which address their issues and needs in a more considered and customised way.

1.6 Methodology

To increase the evidence base and support the development of DWP policy with regard to DLA and work, in 2007 DWP commissioned Insite Research and Consulting to carry out a research study designed to explore these issues in depth. The research study comprised several different elements. These included:

1.6.1 Evidence review

An important preliminary part of the study entailed carrying out an evidence review. The aim of the review was to collate existing evidence and findings about DLA working-age customers and to draw out, where possible, the constraints they face to work, highlighting any similarities or differences between this group and those in receipt of incapacity benefits. With only limited data and very little dedicated research to call upon, the purpose of the review was as much to identify gaps in the evidence as it was to synthesise current knowledge. The evidence review was not designed to be a full survey of the literature, and thus the most up-to-date reference has not always been sought and presented. Rather, the evidence

Berthoud R (1996) *Disability, Benefits and Employment: An evaluation of Disability Working Allowance*.

was used to generate hypotheses and to point the direction for investigations in the qualitative research.

By looking further afield at evidence and research on working-age disabled people and incapacity benefit customers more generally, the review combined what was known about DLA customers with findings from previous research to posit some theories about why, if DLA is payable equally to those with work as those without, DLA customers' employment rates are comparatively so low. The review helped to inform and frame the design of the study, and the robustness of many of the hypotheses generated in the review have been tested more thoroughly in other parts of the research.

The evidence review was focused on the following areas:

- descriptive data on what is currently known about DLA and DLA customers;
- evidence of the constraints to working among DLA customers;
- tentative hypotheses for how and why DLA customers may differ from, and may think and behave differently to, other disabled people of working age;
- any evidence of an employment enabling effect resulting from DLA receipt.

The outcomes of the review in the first two of these areas form Appendix A and Chapter 2 of this report. Outcomes from the other areas of enquiry are presented in Chapters 3 to 6 along with findings from telephone surveys and face-to-face interviews.

Since carrying out the evidence review, DWP has commissioned two new pieces of work that extend existing knowledge about the DLA claimant group of customers.³⁷ Both have involved carrying out secondary statistical analysis on data sets of incapacity benefits claimants to explore differences between the overall group and that part of it comprising people also claiming DLA. Reference is made in this report to findings from these studies where they have helped to throw light on our own findings.

1.6.2 Familiarization group discussions

A number of discussion groups were held in to familiarise researchers with the processes of application, assessment and support of DLA claims. These focus groups involved DLA Helpline staff, staff from the BEL team, and DLA claims decision makers.

Discussion groups were also held with advisers from Jobcentre Plus and from private and voluntary sector Pathways to Work providers, to ascertain the level of their awareness of DLA and to explore what messages about the benefit were being communicated to the customers that they were advising.

Conolly, A and Hales, J (2009) *Disability Living Allowance and Work Expectations*, NatCen, 2009 and Beatty, C *et al.* (2009) *DLA Claimants: A new assessment*, Sheffield Hallam University, 2009.

A separate discussion group was held with disabled people receiving DLA who were or had recently been working or who were involved in advising and supporting other disabled people. The purpose of this group was to provide the perspective of disabled people themselves on the process of application, to explore possible issues around work and any sensitivities prior to contacting a sample of DLA applicants.

1.6.3 Initial and follow-up telephone surveys of DLA applicants

DLA applicants were identified via PDCS. Scans of all the applicants nationally whose applications were received by PDCS on a series of dates in September and October 2008 provided a long list of names and addresses of potential research respondents. Contact letters were sent out to just over 3,500 of these applicants and short telephone interviews subsequently carried out successfully with 1,005 of them.

DLA applicants were initially contacted to establish their circumstances, employment status and work intentions at the time of applying for DLA. They were then contacted again four months later, following receipt of a decision either to award or to disallow their DLA claim. By contacting people both before and after notification of the decision on their claim, it was intended that any effect the decision might have on their attitudes and behaviour regarding work would be picked up.

Although some useful information was gathered in the short telephone interviews, their primary purpose was to act as an informed 'filter' through which to select a sample for face-to-face interview. Key 'indicative' responses to the telephone surveys were then followed up in depth at face-to-face interviews. The descriptive statistics from the telephone surveys are included in full in Appendix A. Where appropriate, reference is made in the rest of the report to specific findings.

It is important to note the specificity of this survey sample. Respondents to the telephone survey were **applicants** rather than **recipients** of DLA, and many went on to have their claim disallowed. Even with those subsequently identified as having had their claim for DLA allowed, care should be taken in comparing their descriptive statistics with data from elsewhere relating to DLA recipients, because whereas most recipients have been in receipt of DLA for more than two years, this sample was drawn from among those in the very early stages of a claim. In effect, our sample was of those newly 'flowing' onto DLA as opposed to the wider general population of existing DLA recipients.

1.6.4 Face-to-face in-depth interviews

Face-to-face interviews were carried out with a selected sample of 110 individuals from among the original 1,005 surveyed applicants. Respondents were purposively selected to achieve coverage of different types of employment status, different changes in status and different DLA claim decision outcomes.

Interviews looked in detail at changes in people's circumstances and aspirations over the months since their application for DLA, as well as exploring the circumstances leading up to a claim being made. The constraints to working that people perceived themselves to face were examined, including whether and to what extent the benefit was seen to act as a work disincentive or a work enabler. In addition, the face-to-face interviews had as a subsidiary objective to seek to understand more clearly how DLA makes a difference to the living standards and opportunities of disabled people and their families.

2 Exploring hypotheses about DLA recipients and work

2.1 DLA and economic activity

Because Disability Living Allowance (DLA) is paid regardless of whether recipients are in or out of work, there is no requirement on applicants to disclose their employment status, nor any mechanism for recording it; the DLA claim form does not include any questions about work, past or present. The exact number and proportion of DLA recipients in and out of work, whether currently or historically, is therefore not known. Employment rates must be estimated using available research and statistics collected for other purposes.

Available evidence indicates that employment rates among DLA recipients are very low. Using a definition of work which includes paid work of 16 hours or more per week, Berthoud (2006) estimated an employment rate of nine per cent. Using a sample of 1,000 applicants mostly of middle and lower rate DLA, Sainsbury *et al.* also recorded an employment rate of nine per cent.³⁸ Among 15,000 Independent Living Fund (ILF) recipients (in receipt of highest level DLA care award) less than one per cent were known to be employed.³⁹ Systematic surveys and research studies of personal assistance users have shown a rate of employment of around six per cent.⁴⁰

DLA recipients who are out of work, claiming Jobseeker's Allowance (JSA) and looking for work represented 1.2 per cent of working-age recipients in August

Sainsbury, R, Hirst, M, and Lawton, D (1995) *Evaluation of Disability Living Allowance and Attendance Allowance* p24.

³⁹ Howard M (2002) p30.

⁴⁰ Howard M (2002) p31.

2009.⁴¹ More than three-quarters (78 per cent) were claiming what are generally regarded as 'inactive benefits' which do not require recipients to be available for work or to look for work.

The economic activity rate among the one in five DLA recipients who get no other benefits is not precisely known. However, Berthoud (1996) found that people receiving DLA only were twice as likely to be in work as those also in receipt of other benefits.⁴² One in five of those receiving DLA only were working 16 hours a week or more. Single people living with their parents had the highest levels of employment of all DLA recipients – two in five were working.

2.2 Employment rate of DLA recipients

As noted, there is no 100 per cent data, nor any official statistics which currently record the number of DLA recipients in paid work. Different measures have been used to calculate the proportion of DLA recipients who are in work and how this compares to other disabled people not receiving DLA, to non-disabled people, and to the working-age population as a whole. Direct comparisons can however be difficult due to differences in data sources and variations among definitions of disability and employment.

Data from the 1996-97 Health and Disability Survey (HDS) attached to the Family Resources Survey (FRS), indicate an employment rate of nine per cent.⁴³ This figure excludes those working part-time for less than 16 hours a week. The average employment rate across all DLA recipients appears to conceal wide variations in rates between specific sub groups of claimants – from less than one per cent among those with high level support needs, to two in five among single people living with their parents, approaching the national average for all disabled people.

2.2.1 Employment rate of all disabled people

Estimates of the employment rate of all disabled people (in receipt of DLA or not) vary considerably. The Office for Disability Issues estimate derived from the Labour Force Survey (LFS) puts the proportion of working-age disabled people who were in work in 2008 at 48.4 per cent. A similarly derived figure two years previously for disabled people aged between 25 and retirement age (avoiding certain complications arising from those who are in education) puts the employment rate at 40 per cent. ⁴⁴ That from the HDS indicates an employment rate among disabled

⁴¹ DWP (2010).

⁴² Berthoud R (1996) p13.

⁴³ Berthoud R (2006) p 60 (adults aged 19 to 59).

Child Poverty Action Group (2006) A route out of poverty? Disabled people, work and welfare reform.

people not in receipt of DLA of 29 per cent, calculated on the same basis as the nine per cent rate for DLA recipients cited above.⁴⁵ The comparable calculated rates of employment for non-disabled people lie in the range from 71 per cent (HDS 1996)⁴⁶ to 80 per cent (LFS 2006).⁴⁷

The differences between employment rates derived from general surveys and from the more specific HDS can be explained in terms of the breadth of the definitions of disability used in each case. The broader self-reported definition of disability used in the LFS results in a higher estimate of numbers of disabled people in the working-age population, and shows a higher proportion in work, due to the inclusion of many less severely disabled people who experience relatively little labour market disadvantage and have as a result higher employment rates which push up the average for the group as a whole.⁴⁸

2.2.2 The relative employment position of DLA claimants

Despite such large variations in estimates from one survey to another, there is nevertheless a clear pattern evident regarding the relative employment position of working-age DLA recipients compared both to other disabled people and to non-disabled people. Within the working-age population, people receiving DLA are much less likely to be in work than disabled people not in receipt of DLA, who in turn are much less likely to be in work than non-disabled people. The employment rate of non-disabled people is very much greater than that of disabled people. The employment rate of all disabled people is likewise very much greater than that of disabled people who are in receipt of DLA.

2.2.3 Reasons for the low employment rate of DLA recipients

It is not the purpose of this report to re-present evidence for why disabled people in general have a lower employment rate than non-disabled people. The key question for this research was: Why are DLA recipients less likely to be in work than other disabled people of working age? In other words, is there any apparent reason why DLA recipients should suffer from constraints on working more acutely than other disabled people, or suffer any additional constraints as a consequence of being in receipt of DLA?

The magnitude of the difference in employment rates strongly suggests that either DLA recipients differ as a group in some key demographic or disability characteristics, suffer disproportionately from particular social or economic

⁴⁵ Berthoud R (2006) p32.

Berthoud R (2006) p31 (aged 19-59, in work 16 hours or more per week or in education – this rises to 74 per cent for those aged 19-59, in work any hours and excluding students).

Labour Force Survey (December 2006).

Berthoud R (2006) Appendix D p85, '...the LFS figures...substantially exaggerate both the number of disabled people in the working age population, and the proportion of them who are in employment.'

disadvantages; have a systematically different perception of their disability, or of their position as disabled people in the labour market, compared to others with disabilities; or indeed experience any of these factors in combination.

Several hypotheses emerged from a review of evidence, all but the last of which it was possible to pursue further in relation to **existing** research findings:

- Is it because DLA recipients are additionally disadvantaged in the labour market?
- Is it because they are more severely impaired than other disabled people?
- Is it because they are less likely to want to work than other disabled people?
- Is it because there is something specific about DLA itself?

2.3 Are DLA recipients additionally disadvantaged in the labour market?

Factors relating to disability (condition, impairment and severity) have been shown to be the most important influence on the likelihood of disabled people being in employment.⁴⁹ The 'employment disadvantage' associated with disability has been calculated as reducing average employment probability by 40 percentage points; that associated with demographic and economic factors as reducing average employment probability by seven percentage points.⁵⁰ In addition, the interaction between 'disability' factors and 'demographic and economic' factors is not uniform. For example, people with good economic characteristics, such as a prolonged education and living in a jobs-rich area, are less affected by having severe impairments than are other disabled people.⁵¹

An important further point that is made in the literature is that 'disability may be a potential consequence, as well as a potential cause, of economic disadvantage.'52 Findings that people finishing their education early are much more likely to be disabled (and more likely to be severely disabled), and also that disability is more common in areas where jobs are relatively scarce, both point to this possibility. Nevertheless, a number of demographic and economic factors have been shown independently to have the effect of reducing disabled people's employment rates overall.53 These include:

- being a woman with a partner or children;
- having a partner who is not working;
- being aged over 45 years;

⁴⁹ Berthoud R (2006) pp45-50.

⁵⁰ Berthoud R (2006) p51.

⁵¹ Berthoud R (2006) p49.

⁵² Berthoud R (2006) p2.

⁵³ Berthoud R (2006) pp32-33.

- being from a minority ethnic group (especially Pakistani or Bangladeshi);
- having left education at an early age;
- living in London;
- living in an area with a poor supply of jobs.

If it can be shown that DLA recipients are over-represented in any of these respects, compared to other disabled people, then there is a prima facie case that they will, overall, be less likely to be in work. Evidence is partial, and varies by survey sample composition, but there are a number of indications that DLA recipients are indeed over-represented in at least some of these categories.

Secondary analysis of survey data from the New Deal for Disabled People (NDDP) eligible population has shown that 'DLA recipients were more likely than non-claimants, to be female, aged 50 or older ...'⁵⁴ and another study has noted that the largest growth in DLA claims between 2002 and 2008, both in number and proportion, has been among women.⁵⁵ Overall, the same proportion of DLA recipients, as other incapacity benefits claimants, had a partner and/or dependent children.⁵⁶

In the same study, DLA recipients were found to be slightly older on average, with 70 per cent of them being aged 45 or older, compared to 60 per cent of other Incapacity Benefit (IB) claimants.⁵⁷ A slight concentration of older people among DLA recipients, compared to others with disabilities, is also indicated by comparing LFS data, which show that 42 per cent of all people of working age who have disabilities are aged between 50 and retirement age,⁵⁸ with Department for Work and Pensions (DWP) operational statistics which place 45 per cent of DLA recipients in this age bracket.⁵⁹

However, available data do not suggest any geographical concentration of DLA recipients either in London or in areas with a poor supply of jobs. Approximately 12 per cent of the disabled people of working age in Great Britain live in London. By comparison, London accounted for 9.9 per cent of the DLA caseload in Great Britain in August 2009. Equally, a strong finding in the Sheffield Hallam report

⁵⁴ Conolly, A *et al.* (2009) p1.

⁵⁵ Beatty, C *et al.* (2009) p20.

⁵⁶ Beatty, C *et al.* (2009) p55.

⁵⁷ Beatty, C et al. (2009) p39.

ONS Labour Market Trends: *Labour market experiences of disabled people*, August 2002. p416.

⁵⁹ DWP Operational Statistics: *DLA and AA*, November 2007.

ONS Labour Market Trends: *Labour market experiences of disabled people*, August 2002. p418.

⁶¹ DLA Quarterly Brief February 2010 (internal DWP document).

was that there was no evidence to suggest DLA recipients were more concentrated in the jobs-poor areas: 'DLA claimants are concentrated in almost exactly the same local authority districts as the wider incapacity claimant group,' which means that although concentrated in older industrial areas, 'the proportion of incapacity claimants in each area who receive DLA...does not vary greatly across the country.'62

Similarly, it is unlikely that any part in the lower employment rate among DLA recipients is attributable to over-representation among minority ethnic groups. The most recent Pensions Disability and Carers Service (PDCS) Customer Service Survey⁶³ showed that the proportion of survey respondents (which included all PCDS customers, not just DLA recipients) from minority ethnic groups was no greater than the seven per cent shown by LFS data to exist within the overall population of disabled people.

2.4 Are DLA recipients more severely impaired than other disabled people?

The main factor affecting the employment rates of disabled people is their disability or health condition. In seeking to show which disabled people are the most likely and the least likely to have a job, Berthoud has demonstrated that the different characteristics of their impairment make a significant difference to their employment prospects.⁶⁴ Characteristics found to be particularly disadvantaging in this regard include:

- certain types of condition (especially mental health conditions);
- certain types of impairment (notably locomotor, behavioural and intellectual impairment);
- having multiple conditions or multiple impairments;
- having more severe impairment (diseases of the nervous system and mental health tend to include more people with severe impairment).

We would expect there to be an additional negative impact on the employment rates of DLA recipients if they were found to be concentrated in these categories. There are some data that give an indication of the degree to which this is indeed the case.

2.4.1 Type of condition

The single type of condition that has been shown to result in the greatest negative impact on disabled people's employment probabilities is mental health.⁶⁵ People

⁶² Beatty, C et al. (2009) p31.

⁶³ lpsos/Mori (2007).

⁶⁴ Berthoud R (2006) p3.

⁶⁵ Berthoud R (2006) pp35-37 and Figure 5.1

with this category of condition experienced an estimated decrease in their chances of being employed of more than 37 per cent (controlling for type and severity of impairment and for standard demographic and economic variables); this was twice the impact associated with any other type of condition.

In terms of type of condition, there does appear to be a higher proportion of DLA recipients that report a mental health condition compared to the wider disabled population (although, on the other hand, the proportion with a mental/behavioural issue is lower among DLA claimants than it is among other IB claimants). ⁶⁶ Nine per cent of disabled people in the LFS give mental illness as their main condition (LFS autumn 2001). This compares with 15 per cent of DLA recipients in February 2005, and 16 per cent of DLA recipients in May 2007. Moreover, among working age recipients of DLA the single category 'other mental health cases' accounts for more than one fifth of the total 'and has been by far the largest source of growth in the working age DLA numbers since 2002.' ⁶⁷ So DLA recipients do appear to be concentrated in the category that carries most additional employment disadvantage.

2.4.2 Type of impairment

Specific types of impairment do not 'map' easily onto types of condition defined, as the latter are, in terms of general medical categories, often relating to the affected parts of the body. Types of impairment, such as locomotor, intellectual, behavioural and dexterity impairments, carry a greater power than condition types in predicting the likelihood of a person with disabilities being in or out of work.

In general terms it can be said that when types of impairment are listed in order of their negative impact on disabled people's employment rates, ⁶⁸ then the higher up that list an impairment is, the greater the implied need for care and/or mobility support will be (and thus the greater likelihood that a person with that impairment will be eligible for DLA).

A larger than average proportion of DLA recipients appears to be affected by the types of impairment that carry the greatest employment disadvantage for disabled people. Locomotor impairment has been found to carry a greater than 20 per cent decrease in disabled people's employment probabilities (controlling for condition and severity and for standard demographic and economic variables). This is the largest decrease for any single type of impairment and more than twice that associated with any other type.⁶⁹

Because one of the key eligibility conditions for receipt of DLA is focused around needs relating to mobility, there are high proportions of DLA recipients who suffer locomotor impairment. Overall, 87 per cent of DLA recipients are in receipt of

⁶⁶ Beatty, C *et al.* (2009) Table 3.10.

⁶⁷ Beatty, C *et al.* (2009) p 20 (source ONS).

⁶⁸ Berthoud R (2006) p39 Figure 5.2.

⁶⁹ Berthoud R (2006) pp38-39 and Figure 5.2.

some level of mobility element award.⁷⁰ This compares (albeit crudely) to 65 per cent of disabled people in the HDS with a locomotor impairment.⁷¹

There are certain caveats that need to be made regarding this comparison which are likely to have the effect of reducing the apparent level of difference between the two populations. Firstly, the HDS figure only relates to disabled people of working age, whereas the DLA figure will include those over retirement age whose DLA claim started while they were of working age. Secondly, there will be some people included among recipients of the mobility element of DLA whose mobility needs derive from other than locomotor impairments (for example people with severe learning difficulties or impaired sight who need to be accompanied when away from the home).

Other impairments with high impact on employment rates include intellectual and behavioural impairment. These are strongly associated with (though not to be equated with) mental health conditions which, as we have seen (above) are areas in which DLA recipients are disproportionately concentrated.

2.4.3 Multiple conditions and impairments

Both these figures for 'multiple disability' refer to the number of reported different types of impairment (thirteen in each case) and are thus broadly comparable although the categories used are not identical. Eleven shared categories are used: locomotion, dexterity, behaviour, intellectual, hearing, reaching, seeing, continence, communication, disfigurement and digestion. The categorisation used by Sainsbury *et al.* includes, in addition to these, 'personal care' and 'consciousness'. That used by Berthoud includes the additional categories of 'independence' and 'fits'.

Despite this slight methodological difference, these data indicate a degree of concentration of 'multiple disability' among the DLA population that will impact upon employment. This is particularly the case as the HDS figures include the DLA recipient population within the wider body of disabled people, and the DLA applicants sample used was both weighted towards people in receipt of lower

DLA and AA Quarterly Brief February 2010 (internal DWP document).

⁷¹ Berthoud R (2006) p27.

⁷² Sainsbury R *et al.* (1995) p32.

⁷³ Berthoud R (2006) p26.

level awards and was further 'diluted' by the inclusion of a number of disallowed applicants (although it also included all ages and was not restricted to those of working age).⁷⁴

The only other available data relate to NDDP registrants and to the NDDP eligible population (essentially IB claimants). Adelman *et al.* report figures for registrants on the NDDP programme based on types of condition, with 55 per cent reporting only one condition and 45 per cent reporting two or more.⁷⁵ It would be reasonable to expect, as these figures seem to imply, that the voluntary NDDP registrant population would be closer to the labour market than DLA recipients, and indeed closer than the wider populations of NDDP eligible⁷⁶ and all disabled people. Data on the NDDP eligible population, however, cannot provide a comparison as it deals only in terms of the 'main reported condition' rather than exploring multiple conditions or impairments.⁷⁷

2.4.4 Severity of impairment

The concept of 'severity' of disablement has been acknowledged as a complex one, made even more complex in the context of DLA due to the ways in which impairment and needs combine in individual instances.⁷⁸ Most assessments of severity have been based on the Office of Population and Census Statistics (OPCS) 'measures of disability' derived from individual capabilities within a medical model of disability.⁷⁹

Sainsbury *et al.* describe their DLA applicant sample in these terms, drawing loose inferences from the OPCS survey to derive the relationship between disabling conditions and particular impairments and measuring the proportion of respondents in each of the ten severity categories derived by OPCS researchers (from zero – no appreciable disability; to ten – very severe disability). Their conclusion is that the profile of the DLA population *'contrasts markedly'* with the population of disabled

- The DLA applicants target sample comprised the following: 1,000 applicants who had been awarded **at least** one lower rate award of DLA (some of whom were also awarded a middle or higher level element); 500 applicants rejected solely on disability grounds (as having insufficient needs to qualify); and 300 applicants recently awarded a middle or higher rate element of DLA only.
- Adelman et al. DWP Research Report W213 (2004) p3.
- Stafford *et al.* NDDP: second synthesis report interim findings from the evaluation, Research Report No 377 (2006) pp34-42.
- Pires *et al.* National Centre for Social Research (NCSR) and Social Policy Research Unit (SPRU), *NDDP evaluation: eligible population survey, wave three*, Research Report No 324 (2006).
- ⁷⁸ Sainsbury R *et al.* (1995) Annex 2.3 pp17-18.
- The process of derivation of the OPCS severity of disablement scale is described in Sainsbury R *et al.* (1995) Annex 2.2 p15.

people as a whole, with more people in the higher severity categories.⁸⁰ They also use a 'health outcomes' scale of social disadvantage to conclude that DLA is successfully targeted on people who are 'severely disadvantaged' because of their care and mobility needs.⁸¹

Berthoud's more recent analysis supports these general conclusions. Using HDS data, receipt of DLA was found to increase in line with severity of impairment, rising from about five per cent of those with severity 1, to about 70 per cent of those with severity 9/10. He concludes that DLA eligibility for the mobility element and the care element, and for their combination, do appear to be directly related to severity of impairment, and more so than incapacity-related benefits (although, somewhat unexpectedly, the amount of DLA paid was not closely associated with severity).⁸²

One further piece of evidence that DLA recipients are more severely impaired on average than other disabled people, and that this is likely to play an important role in their lower employment rate, comes from their greater representation among those with mental health conditions (see above). These have been shown to entail more severe overall impairment than most other types of condition. Furthermore the employment disadvantage associated with an extra point (on the OPCS scale) of severity of mental impairment was substantially worse than that associated with an extra point of physical impairment.⁸³ The effects of mental ill-health on employment rates are thus more, rather than less, than the effects of physical characteristics.

Overall, the conclusion that can be drawn from available data is that, where comparisons are available, they do indicate that DLA recipients are, on average, 'more severely disabled' than other disabled people, and that they suffer higher levels of disadvantage and lower employment rates as a result.

2.5 Are DLA recipients less likely to want to work than other disabled people?

The severity of disability and disadvantage associated with eligibility for DLA does not fully explain the difference between the employment rate of DLA recipients and that of other disabled people. DLA claimants have been shown to be significantly less likely to have a job 'than other disabled people with a similar level of employment disadvantage calculated on the basis of condition, type of impairment and severity.'84

⁸⁰ Sainsbury R *et al.* (1995) p33.

⁸¹ Sainsbury R et al. (1995) p24.

⁸² Berthoud R (2006) p59.

⁸³ Berthoud R (2006) p42.

⁸⁴ Berthoud R (2006) p60.

In relation to the population as a whole, there has been speculation as to why some people do not work even though they appear to have no greater an employment disadvantage, and no worse an apparent probability of working, than others who do work.⁸⁵ Does there exist an 'unconsidered' factor that might explain this? Is it just 'luck' or is there perhaps an element of 'personal determination'⁸⁶ or aspiration lacking among those not in work? And importantly: are there any reasons to suppose that such a lack of aspiration or personal determination might affect more DLA recipients than other disabled people, or affect them more acutely? And if so why?

Our final hypothesis therefore, is that DLA recipients might have lower employment rates than other disabled people because, for whatever reason, they are on average less likely to want to undertake paid work. This is a difficult hypothesis to address directly. Information of this kind from survey data is invariably based on simple questions of the sort, 'Would you like to work?' without the necessary depth of qualitative investigation that could qualify results in terms of important factors such as, under what conditions they would like to work, when that would be in relation to other factors in their life, whether they feel they are capable of work and whether they actually believe paid work to be a realistic and achievable possibility. Responses to this question when addressed to benefit claimants can be further bedeviled by respondents' concerns that there is a 'correct' answer and that saying 'No' could jeopardise receipt of their benefits.

While some people in receipt of inactive benefits may be interested in working, only very low levels of economic activity and expectation were reported among the 7,000 or so disability benefit claimants surveyed in 1993 and 1994 as part of an evaluation of Disability Working Allowance (DWA) (since discontinued and replaced with the disability element of Working Tax Credit (WTC)).⁸⁷ Only a quarter of non-working disability benefit recipients showed any attachment to work and only one in five of these was actually looking for a job.⁸⁸ The same proportion (five per cent) of our surveyed DLA applicants, who were out of work more than short term, said they were currently looking for a job.

Recent secondary analyses of data sets including DLA recipients have confirmed a lower level of employment aspiration and expectation among DLA claimants and their greater distance from the labour market compared to other incapacity benefits claimants.⁸⁹

⁸⁵ Berthoud R (2006) p54.

⁸⁶ Berthoud R (2006) p51.

Berthoud R (1996) *Disability, Benefits and Employment: An evaluation of Disability Working Allowance*.

⁸⁸ Berthoud R (1996) p13.

⁸⁹ Connolley *et al.* 2009 passim and Beatty *et al.* 2009, passim.

2.5.1 Perceptions of being permanently prevented from working

The perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment. Among those in receipt of DLA it has been noted in one qualitative study⁹⁰ that '...it was a common finding...that work was not perceived as a feasible activity and therefore not actively considered.'

In the 1997 HDS data, the majority of non-working disabled people reported that they were permanently disabled. Those who felt they would never be able to work were concentrated among IB and Severe Disablement Allowance (SDA) claimants (as opposed to Income Support (IS) claimants and those not receiving any benefits). Among existing IB and SDA claimants, more than nine out of ten (92 per cent) gave as the reason for not working that they were 'permanently unable to work'91 presumably due to their disability.

Although eligibility for benefits may influence assertions of this kind, such findings appear to sit somewhat uncomfortably alongside statements in policy documents such as *A New Deal for Welfare that 'the vast majority of people – around 80-90 per cent – making a claim for incapacity benefits want and expect to get back to work.* '92 It is important to bear in mind that the latter survey questioned IB claimants at around the time they made their claim. After several years on benefit, the majority who said they wanted and expected to return to work are more likely to have done so than the minority who did not, so that the proportion among existing customers will have fallen; and those who wanted/expected to return to work but have not succeeded will to some extent have changed their expectations. Even so, in our own survey of very recent claimants for DLA only 42 per cent said they expected to work in the future.

Although a lower proportion of DLA recipients than IB recipients expecting to work would be consistent with their having more severe disabilities, it does not in itself suggest a reason as to why disabled people on DLA might be 'more likely than others' to view their disabilities as permanently preventing them working. The phenomenon was not restricted to higher levels of severity of disablement. Looking at 'disability employment disadvantage' (defined as the gap between disabled people's experience and what they might have been expected to experience if disability had not been a source of disadvantage), Berthoud comments that '... perhaps surprisingly, more than half the men and lone women who were not working even though their disability characteristics appeared less disadvantaging (i.e. were in the four lower octiles of disability employment disadvantage), nevertheless reported that they were permanently unable to work. '93

⁹⁰ Hawkins *et al.* (2007) p8.

⁹¹ Berthoud R (2006) p58.

DWP (2006) A New Deal for Welfare: Empowering people to work p27 (our emphasis).

⁹³ Berthoud R (2006) p54.

Why might such a perception exist to a greater extent among DLA recipients than other disabled people? It is plausible that those who have already decided that work is not possible for them seek out benefits and ways to manage outside the formal labour market. It might also derive, at least in part, from the process they have undergone in applying for and being awarded DLA and from the understanding they have about the nature and purpose of the benefit itself.

2.6 Is there a specific 'DLA factor'?

Berthoud raises the question of whether there is a special factor, affecting the likelihood of being in employment, which is specific to being in receipt of DLA. It is a question that has been taken up in recent secondary data analysis. ⁹⁴ Comparing incapacity benefits claimants who also receive DLA with those who do not, and never have, received DLA, Beatty *et al.* explored the many possible factors which might explain variances between the two populations. Because both groups were out of work and claiming benefits the key measure in their statistical model was whether claimants expressed an interest in returning to work or not. Logistical regression analysis was carried out to try to isolate whether a DLA claim in itself was an influence on people's job aspirations, and to 'disentangle' it from the many other potentially systematic influences affecting individuals – their age, qualifications, length of time on incapacity benefits and self-assessed level of limitation due to their disability or health condition. However, it must be acknowledged that the analysis only had a limited measure of severity of disability and the DLA factor may also be capturing further variation in severity of health conditions.

Although such secondary statistical analysis cannot say whether or not there is a direct causal link between DLA receipt and lower work expectations, it was able to establish a significant association between them. Findings indicated that there may be a potential 'DLA factor,' and that 'even though DLA claimants tend to be older, poorly qualified, on benefits for longer and in poorer health than other IB claimants,' the fact of having a DLA claim, in itself and with all other likely factors taken into account as far as possible with the available data, reduces the likelihood of someone saying they would like a job (now or in the future) by more than a third.⁹⁵ However, as the authors concede, this may be a spurious association or reflect the 'relatively crude measurement of ill-health and disability'.⁹⁶

The other recent secondary data analysis report⁹⁷ also found a strong relationship between incapacity benefit claimants' work aspirations and their DLA status, with twice as many DLA claimants as non-claimants in the NDDP eligible population

⁹⁴ Beatty, C et al. (2009).

⁹⁵ Beatty, C et al. (2009) pp77-80.

⁹⁶ Conolly, A *et al.* (2009) p24.

⁹⁷ Conolly, A *et al.* (2009).

saying they were unsure or did not expect to work again. As in the Sheffield Hallam report, Conolly *et al.* carried out multivariate analysis using essentially the same influencing factors (sex, age, qualifications, time since worked, DLA receipt and assessed limitations of health condition) and a similar dependent variable (being unsure or not expecting to work in the future). Their results were also consistent with a possible 'DLA factor'; receipt of DLA greatly increasing the odds of people not expecting to work again. However, this study also uses a limited control for health and is very unlikely to adequately control for the effect of health on work prospects. 99

In the former study, a DLA claim was estimated to have somewhat less impact on work aspirations than any of the other four factors, including the degree of reported limitation from a health condition.¹⁰⁰ In the latter study, DLA receipt was actually shown to make a greater contribution to variation in work expectations than the extent of self-reported limiting health condition.¹⁰¹

The differences in these results will reflect a variety of factors, including the balance in the samples between new and older claims, the precise questions asked, and what factors are available as independent variables in the regression. Certainly the NDDP eligible population was concentrated around more recent benefit claims than the IB survey which essentially comprised long-term claimants. Whatever the effects of this might be, both studies acknowledge that the self-reported degree of limitation due to ill health or disability is a potential weakness in the statistical modelling.

Both reports suggest that one thing which may explain the DLA effect could be the knock-on implications from the monetary value of the award, such that 'being in receipt of DLA will reduce the financial incentive to take up employment.' Analysis with the money value of DLA awards built in as an explanatory factor did indicate that the higher the value of award the more likely the respondents were to be unsure about going back to work, 103 although in this model other factors observed in the data, such as being aged over 50 or being out of work for ten years or more were of far greater influence – by a factor of 2 or 3. It should also be noted that the monetary value of DLA is directly linked to the severity of a health condition, and so, again, this result may reflect differences in the severity of a health condition not captured in the control variable.

While such statistical analyses help demonstrate that DLA recipients are a group among claimants who are less likely to work or to want to work, there remain

⁹⁸ Conolly, A et al. (2009) p8.

⁹⁹ Conolly, A *et al.* (2009) p23

¹⁰⁰ Beatty, C *et al.* (2009) pp79-80

¹⁰¹ Conolly, A et al. (2009) p23.

¹⁰² Conolly, A et al. (2009) p80.

¹⁰³ Conolly, A et al. (2009) p25.

some questions as to precisely why this should be. In the following two chapters we try to explore these questions further with information from our qualitative interviews. Two key areas are looked at. First, issues relating to the **timing** and **process** of making a claim for DLA and receiving a fresh award, considering in particular whether:

- DLA recipients are less likely to consider work because of their perceptions about the nature of DLA as a benefit;
- DLA recipients are less likely to consider work because they are in the process of leaving employment.

Second, issues around the financial value of DLA and its effect on people's thinking and behaviour, in particular whether:

- DLA recipients are less likely to consider work because they fear they will risk losing entitlement to DLA;
- DLA recipients perceive themselves as having potentially more to lose and less to gain by working than other disabled people.

3 DLA as an out-of-work benefit

There is some evidence that many people who apply for Disability Living Allowance (DLA) are unaware that it is a non-means tested benefit and can be claimed whether or not they are in work.¹⁰⁴ Recent research into disallowed claims for DLA, for example, found:

'The most evident misunderstanding about DLA was its confusion with outof-work benefits. A great many of the disallowed claimants were under the impression that, like Incapacity Benefit (IB)...being out of work was a sufficient condition for receiving it.'¹⁰⁵

The perception of DLA as an out-of-work benefit may in part be historical, cultural and institutional, dating from 1992 when additional cost disability benefits were redesigned and launched with new lower rates of award. One of the arguments, explicit at that time, for introducing new lower rates of award was that some disabled people were less likely to be able to increase their earnings from employment. The government's report The Way Ahead: Disability Benefits for Disabled People, which announced the changes, distinguished between two groups of disabled people, those capable of some paid work, and those with moderate disabilities limiting their earnings potential but who did not qualify for existing benefits. Disability Working Allowance (DWA), To a means tested benefit designed to incentivise the movement into and retention of work, was introduced for the former group, and DLA for the latter, the implication being that those claiming DLA were not generally considered capable of, or likely to get, remunerative work.

¹⁰⁴ Carol Goldstone Associates (2007) *Knowing and understanding Disability* and Carers Service customers p35.

Thomas A (2008) Disability Living Allowance: Disallowed claims p2.

Department of Social Security (1990) *The Way Ahead: Benefits for Disabled People.*

DWA was replaced in 1997 by the Disabled Person's Tax Credit, which in turn was replaced in 2001 by the Working Tax Credit which includes additional payments for disabled people.

DLA was packaged and proactively launched in parallel with DWA. New claims for DLA were promoted among existing recipients of Attendance Allowance (AA) and Mobility Allowance (MA), which DLA superseded, while applications for DWA were encouraged from, and were only available to, people in work. One in six existing DLA recipients have claims for DLA which date from this time. Many may have had little or no contact with Jobcentre Plus (JCP) or other sources of employment advice in the intervening period. Imperfect and inaccurate information about benefits may persist over the long term, even when benefit eligibility criteria and indeed the very notion of 'incapacity' for work has itself evolved.

The separate administration of DLA by the Pensions Disability and Carers Service (PDCS) rather than Jobcentre Plus, could be a further factor in the perception of DLA as a benefit unconnected with working. Though PDCS and Jobcentre Plus both fall under the remit of DWP, they each operate according to their own particular business objectives and cultures. In spite of the two agencies having many aims, and indeed customers, in common, there have to date been few policy or operational linkages between them. Moving people into employment has not in the past been a priority for PDCS, although their latest business plan does identify an intention to 'work in partnership with Jobcentre Plus to continue to identify and implement ways of improving information exchange between the agencies with a view to better supporting disabled customers into work.'

Furthermore, while Jobcentre Plus has in recent years been pursuing a policy of employment advice based on face-to-face contact with all benefit recipients (including those who are sick and disabled), in PDCS, the normal customer experience is very little, if any, face-to-face contact. In a recent Customer Service Survey, only nine per cent of DLA customers had any face-to-face contact with PCDS staff.¹⁰⁸ This could help to explain the persistence of poor understanding about DLA eligibility conditions regarding work.

It was in this context that the current research sought to explore DLA claimants' perceptions about the benefit they were applying for.

3.1 Perceptions of the nature and purpose of DLA

For a great many DLA claimants, both applicants and recipients, there was a clear perception that DLA is a benefit for those who are unable to work, and that it is only payable when someone is not working and stops when they go back into work.

'Everyone was saying 'you must be allowed, you must be – you can't work!'
(In work applicant)

'Somebody had said...you know you should maybe apply for that [DLA]. I said, but no I'm working. I'm not entitled to that...I thought it was because you couldn't work.'

(In work applicant)

'I phoned up because I knew that I was going to be out of work.'

(In work applicant)

Whereas some applicants had subsequently realised that this was a misunderstanding, there remained many who were still assuming that they would automatically stop getting DLA if they started work.

'You know, it's like sick pay – once you're back to work it stops, and that's how I look at [DLA].'

(Applicant on sick leave)

'I thought all benefits stop when you work.'

(Out of work applicant)

'I've never asked but I would imagine if I went back to work all my benefits would stop and I'd start earning my own money.'

(Out of work applicant)

'I didn't know you could still claim [DLA] if you're working. I thought once you got a job...everything would just stop, you get your wage and that's it.'

(In work applicant)

This assumption that DLA would stop on returning to work was partly the result of a widespread tendency to view all benefits as essentially the same and to 'lump' DLA together with other out-of-work benefits. With some respondents there was also an evident confusion in their minds between DLA and IB. The tendency to view all 'disability' benefits in the same light was frequently reinforced by advice professionals and by the particular circumstances of some claims. One man had claimed DLA in the hiatus between coming off Jobseeker's Allowance (JSA), to undergo cancer surgery, and receiving payment under IB. He claimed DLA when his JSA stopped and he was still waiting for approval of his IB claim. He had no income for five weeks and was still unsure of when he would be able to return to work (if at all). Someone from the Benefits Enquiry Line (BEL) suggested applying for DLA, which he thus saw as a 'bridge' between other benefits – an alternative but similar type of benefit substituting for lost income during his ill health.

3.1.1 Apparent links with other benefits

In other instances, the association with out-of-work benefits was reinforced by apparent links between receipt of DLA and regulations governing IB and JSA. Under the IB rules that would have been in force for many of those participating in this study, there was direct linkage in so far as being on higher rate care element of DLA would have exempted them from having a Personal Capability Assessment (PCA). However, respondents perceived other links too. Moving onto higher rate IB was assumed by one customer to have been the direct result of having been awarded higher level mobility element of DLA. Others reported being told by Jobcentre Plus staff that they would be treated differently if their DLA claim was allowed, for example by no longer being required to meet full job-search conditionality under JSA or to attend Work Focused Interviews (WFIs) while on IB.

'The woman in the dole office...said to me, yeah to go for this DLA because still at that time we didn't know how long it would be...before I could go back to work. The only alternative was JSA but you have to keep saying you've done interviews [and been] applying for work...I wasn't capable of doing any of that. So while this [DLA claim] was going through I wasn't getting any pressure...I was on JSA but they weren't pushing me to look for work, pending the outcome.'

(Out of work applicant)

'I had to go [to the Jobcentre] every month and there were a week where I wasn't well and...they threatened to take some of my money off me and then I went to see someone else and I told her I were on DLA and she went 'oh well you shouldn't have to come to these interviews.'

(Applicant on sick leave)

'I had to go to the Jobcentre while I were on IB for these interviews and...I got one just as I got my DLA through, so I went down for that one and [the adviser] says 'there's no point you being here, you know, we won't be calling you again.'

(Out of work applicant)

It appeared that such linkages were in some cases being made by both Jobcentre Plus advisers and by advisers within Pathways providers, despite assurances in our discussion groups with advisers that DLA recipients were not viewed or treated any differently from other customers.

3.1.2 Perceived stigma

The frequent identification of DLA as a benefit essentially like all others, and associated with being out of work, carried a range of different connotations for applicants. Several people felt that DLA, along with all benefits (the 'benefits system') carried a stigma that they were anxious to avoid if they could.

'I would rather work than claim DLA.'

(Applicant on sick leave)

As one young mother put it:

'I did really (to begin with)...have issues with it because...I've always been an independent woman, I've always worked hard, had my own house at 21, lived on my own and everything else – so...I had a real issue about getting benefits, it came really hard to me. It wasn't me. I've never done it...for me actually getting DLA it was like 'God I'm on benefits!'...I'm going to be one of those people who live in [a local 'workless' estate] and do not do anything, and smoke and drink and eat McDonalds all day!'

(Applicant on sick leave)

A similar concern and self-image was expressed by a man in his mid-forties with a strong work ethic and a history of continuous employment, who finally claimed IB and DLA when his savings ran out. After nearly six months of illness following multiple organ failure he was just beginning to accept the seriousness of his condition and that he might not be able to work again.

'I have no desire to spend the rest of my life on benefits...I'm not a sponger! I did what I did at the time because I needed to...'

(Applicant on sick leave)

And another man in similar circumstances:

'Who wants to look like ... social scroungers?'

(Applicant on sick leave)

The other strongly felt perception about DLA was that, even if it was understood that it could be claimed while working, they did not want or need to. Such feelings were only in part to do with financial need. At least as important for many people was the desire to be independent and the taking of personal pride in managing on their own resources.

'I did not think I'd get DLA because...I can go to work — I thought it was only available to people who were not able to look after themselves.'

(In work applicant)

'My intentions were I wanted to go back to work to be honest...I didn't want [DLA] it's just that they said I should apply for it based on the condition I was in at the time.'

(Out of work applicant)

'When I was fit enough to work (and I still had this condition) I would never have dreamed of claiming it [DLA]'

(In work applicant)

'If I went back to work full time, why would I need [DLA]? It's like claiming sick money when I know I'm well.'

(In work applicant)

3.1.3 Claiming benefits in work

Indeed, such feelings even extended to a sense of social injustice at claiming any benefit while working:

'That isn't good: someone else would use that money wouldn't they...I get enough money at work. I wouldn't need it [DLA] would I?'

(Applicant on sick leave)

For some this perception extended to feelings of guilt about making claims, or had meant they had consciously put off making a claim for as long as they were able. A multiple sclerosis (MS) sufferer explained why even though affected by her condition for more than four years she had only made her DLA claim when she had had to change jobs and take a major cut in her wages:

'...Everyone said, you know, ages ago 'you're entitled to it, you should apply' and I said 'not while I'm still working, while I'm still functioning, while I'm still getting on with it'. There are people worse off than me.'

(In work applicant)

Thus, while it is undoubtedly the case that there are people struggling on in jobs despite quite severe disabilities and health conditions, they are not making claims for DLA, despite their needs, because their entire rationale about work and benefits prevents them. For some of the DLA applicants recently in work, the world of benefits had been both outside their experience and beyond their sphere of knowledge or understanding.

'When...in work you haven't a clue what to do when you're out of work.'

(Out of work applicant)

'I haven't had much of an idea because I've never been out sick before in my life to claim anything. This is my first time...it's all new to me.'

(Applicant on sick leave)

3.1.4 Lack of knowledge of DLA

While many said they had not heard of DLA until very recently when they felt their circumstances to change, even those who were aware of the benefit, perhaps through another member of their household or their wider family, had not automatically seen it as appropriate or applicable to themselves while they were in employment. One further implication of such perceptions about DLA is that they strongly suggest that many of those who do get back into work will at that point drop their claim for DLA, or at the very least not apply to renew their claim at the

end of a fixed period of award. Were this to happen to any significant degree then it would contribute to further depressing the employment rate among (remaining) DLA recipients.

3.1.5 The 'badging' of disability

One other important cluster of perceptions about DLA was found to exist around the idea that DLA provides a 'badging' or 'recognition' of disability. This was not predominantly a question of seeing DLA as the 'passport' to other help and benefits, but rather of people seeing it as a statement about, and validation of, their condition. As such, it was perceived very differently by different individuals, and could be either positive or negative. For some the awarding of DLA was seen as final recognition of the long-term difficulties they had faced because of their health condition.

'I've had to have a heart attack [for them] to find out that I couldn't walk twenty years ago!'

(Out of work applicant)

Or even as some form of compensation:

'[My support worker] said I might be entitled to a little bit of financial help through DLA...because I've suffered so long and had such a rough time...I wasn't aware there was such a thing as DLA...'

(Applicant on sick leave)

This sense of due recognition was very strong for some applicants, and even of more importance than its monetary value.

'It's about somebody recognising...what you're going through [is] a crappy time...the main word is recognition: 'we recognise that you are going through that and here is something to help you through.'

(Applicant on sick leave)

The converse was also true, that disallowance for DLA was seen by some applicants as a denial of the 'genuineness' of their condition. Although this sense of denial was often based on a misunderstanding of the eligibility and assessment criteria for DLA, with many people expressing the view that because they had been diagnosed with a particular condition then they must automatically be eligible, it was nevertheless strongly felt. A similar finding has been reported in relation to disallowed claims for DLA. 109

'When I was first refused, I was in floods of tears. Not about the money but because it was a slap in the face and the letter was more or less saying to me, 'you know what, you've got cancer...get on with it.' That was the message I got from that. I was so upset.'

(Applicant on sick leave)

For others, however, being a DLA recipient and being seen as 'disabled' was a label that they were intensely uncomfortable with, and highly resistant to.

'I didn't want to [apply] it was just stubbornness really because I didn't sort of label myself as being disabled.'

(In work applicant)

'I'm not disabled. Well, how can I be disabled? I'm just ill...It's not disabled, is it, having a heart attack?'

(Applicant on sick leave)

The partner of a young woman with scoliosis of her spine saw getting DLA (or even applying for it) as an official endorsement of disabled status:

'... As soon as she applied for [DLA] then she's officially a cripple [sic].'

(In work applicant)

But in this instance, as in several others, there was also an important perceived element of admitting 'disabled' status to oneself.

3.1.6 Recognising disabled status

A woman in her early thirties with MS who confessed to feeling 'guilty' about claiming DLA when she had a job (even though she was off sick from her work at the time) was explicit about how she saw acceptance of benefits long-term as a sign of 'giving in to the illness'. She described the impact of the DLA 'label' thus:

'It never bothered me about registering with a disability until I actually got it [DLA]...But when they said 'yeah, you are high rate care, you need help with this' I was heartbroken...I said 'Oh my God I'm disabled!'

(Applicant on sick leave)

In a more general sense, several people described how applying for and receiving DLA had in stark fashion forced them to face up to the seriousness of their situation and the real nature, and implications, of their condition. The application process itself had been very distressing for some because it had been recognised as a parallel process to that of acknowledging to themselves the extent and seriousness of their health problems (and indeed sometimes other problems as well such as financial crisis).

'Filling the forms in was depressing...it's like a microscopic examination of how you are...every time you put something into the form you're asking yourself...is it really like that? Because you don't want to believe that...'

(In work applicant)

A common aspect of this acknowledgement process was recognising that a condition was long term and probably incurable.

DLA was for many recipients not only a 'badge' of their disability, but also in some way 'proof' that they were unable to work, an objective sign that they could not work rather than an internal and subjective feeling that they could not. This is important because it was also found to work for many people 'in the other direction' – that is, when they started to see their condition as long term and unlikely to improve, that was the point at which they had made their claim for DLA. Very few people thought of DLA in terms of it meeting the additional needs created by their disabilities. Instead DLA was seen as related to their health condition itself. Medical acknowledgement and diagnosis was far more frequently the trigger for applications that any perception of additional needs or costs, although the financial difficulty many people found themselves in may itself have been related to these extra costs.

4 Trajectories out of work

Berthoud speculates that relatively few applications for Disability Living Allowance (DLA) may be made with an eye to maintaining employment and the great majority with a view to leaving work, if not permanently, then at least until their condition improves. One reason, he suggests, for lower employment rates among DLA recipients might be:

'... that DLA claims and payments are associated with the process of leaving and/or remaining out of work.'110

This seems plausible given significantly lower rates of job retention among disabled people¹¹¹ and the much greater likelihood that they will exit work compared with their non-disabled counterparts, a difference that increases markedly for people with more severe disabilities,¹¹² among whom DLA applicants are known to figure highly. Rigg, for example, reports that the difference in the probability of exiting work between more severely disabled and less-severely disabled people, is approximately twice as large as the difference between less-severely disabled and non-disabled people.¹¹³

Berthoud proposes that people may 'tend to hear about and claim DLA when out of work.' ¹¹⁴ If this is indeed the case, then the length of time that people are out of work before claiming DLA may also be of significance. Under current rules, an illness or disability giving rise to the need for DLA must have existed for at least three months and be expected to last for at least a further six months, before an individual is eligible to claim the benefit. Furthermore, as existing evidence clearly shows, the longer a person has been out of work, the more likely it is that their health will deteriorate, and the less likely it is that they will return to employment. Analysis of data from the British Household Panel Survey indicates that while around 80 per cent of those who become disabled are in employment

¹¹⁰ Berthoud R (2006) p 60.

¹¹¹ Burchardt T (2001).

¹¹² Rigg J (2005) p 28.

¹¹³ Rigg J (2005) p 28.

¹¹⁴ Berthoud R (2006) p 60.

at the time of onset, only 60 per cent are in work the following year, and fewer still (36 per cent) the year after that.¹¹⁵ Disability can also be caused by, as well as being a cause of, worklessness.

4.1 Surveyed changes in employment status

Among applicants surveyed in this study, 17 per cent of those whose claims would go on to be allowed were working at the time of making their applications for DLA. In the four to five months following applications being made, the proportion working stayed more or less constant. There was a marked decrease in the number describing themselves as 'on sick leave from a job and getting sick pay' (from 14 per cent to four per cent) and a concomitant increase in the number describing themselves as 'out of work/not working' (from 69 per cent to 80 per cent). This supports the hypothesis that many who apply for DLA are already on a clear trajectory out of work.

Table 4.1 Employment status of DLA recipients

Employment status	Recipients at point of application % (n = 371)	Recipients after 4-5 months % (n = 371)	
Working	17	16	
On sick leave and getting sick pay	14	4	
Out of work/not working	69	80	

The consistent proportion of DLA recipients in work at the two time points does not imply that these were all people **staying** in their jobs, as there was some movement between the different work status categories. Three-quarters (75 per cent) of those working at the time of the follow up survey were people who had also been working at the time of their application four to five months earlier. The remaining quarter was made up in equal parts by those who had moved back into work from a previous status of 'off work on sick leave' or who had moved into work from a previous status of being 'out of work/not working'.

Among those in work at both time points, the great majority (91 per cent) had stayed in the same job. Slightly fewer than one in ten were now working in a new, different job. Three-quarters were still also working the same number of hours as they had been previously, while the other quarter (24 per cent) had reduced their working hours, some by moving to new employment.

Bardasi, Jenkins and Rigg (2000) *Disability Work and Income: A British perspective*.

Table 4.2 Those working full-time and part-time hours	Table 4.2	Those working	full-time and	part-time hours
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	Applicants in jobs when applying		recipients i	Future DLA recipients in jobs when applying		oients 4 to 5 later
Hours worked by those in jobs	Number	%	Number.	%	Number	%
Full-time (30 hours or more per week)	86	67	51	67	30	50
Part-time (less than 30 hours per week)	43	33	25	33	30	50

Eventual recipients of DLA, who had a job at the time of making their application, showed the same pattern of full-time and part-time work as did all applicants, with two-thirds (67 per cent) being employed full-time and one-third (33 per cent) employed part time. Five months after making their application, however, recipients of the benefit who were in work showed a markedly different pattern: by this point half (50 per cent) were working part-time hours (less than 30 hours per week). This shift towards part-time working appears to be a reflection of several different factors (though the small numbers involved require caution in interpretation). Most importantly there was movement out of full-time and into part-time jobs. Nearly a third of those working part-time at the second survey had been working full-time when they made their DLA application. Also slightly more people had moved into part-time work than into full-time work among those who had not previously had any job. While the numbers of people going from a full-time job to no job at all may also be affecting the proportions working part-time at the second survey, this appeared to be of less significance. Indeed, a greater proportion of those originally in part-time jobs were actually out of work five months later compared to those in full-time jobs. This may indicate a typical progression from full to part-time working to being out of work, with those already in part-time work when applying for DLA simply being on average further along this route.

Whatever applicants' original employment status (out of work, off sick, or working), the proportion in work four to five months later was in each case higher among those whose claims were disallowed than among those whose claims were allowed. This may simply be the result of higher levels of disability among claimants allowed DLA, but it could also indicate a work disincentive effect from receiving the benefit. However, the 'incentive' to work for those disallowed was predominantly experienced as financial pressure to resume work in spite of their health.

Among those starting (or re-entering) work in the months after applying for DLA, the most commonly cited reason for doing so was 'financial'. This was particularly so for those who had been disallowed. Several said that they felt their house/

mortgage was under threat if they did not earn an income, and others said they had started or returned to work against doctors' advice and to the detriment of their health.

The next most frequently cited reasons for starting work were:

- that work had become possible again due to some recovery or improvement in health condition;
- that work had been found that was suited to the particular limitations imposed by a health condition.

Other less frequently mentioned reasons for returning to work included:

- social reasons, such as getting out of the house, meeting people, overcoming boredom, and re-introducing routine to daily life;
- reasons relating to condition management such as keeping moving, improving confidence, overcoming agoraphobia by going out to a familiar place among familiar people (from previous employment), and to prevent isolation from exacerbating mental health conditions such as depression.

The sample comprised people in the early stages of new claims for DLA, many with crises in their health, restricting mobility and giving rise to care needs in the short term, but nevertheless being conditions from which a significant recovery could be expected. As such it is not surprising to find a number of people giving improvement in their condition as the reason they had been able to return to work. Finding work suitable to a particular health condition was the obvious (if not necessarily easy) option for many who were strongly orientated towards the labour market. Help from employers in adapting work duties, allowing gradual and 'graded' returns to the workplace, and being flexible about hours, was frequently key to finding such work, and many people mentioned that good relations with former long-term employers had made such things possible.

Overall, nearly three-quarters (71 per cent) of all those surveyed who moved into work, or back into work, in the period after making their DLA application, resumed work for employers they knew and whom they had worked for at some time in the past – almost all of those re-entering work from sick leave, but also nearly half of those who had been out of work/not working when they had made their DLA application. At least one in eight¹¹⁶ of those still in work at the time of the follow-up survey or back in a job they had been off sick from were by that time doing work that involved different tasks to those involved in the work which they had been doing previously.

Due to slightly different questions being asked of different 'employment status groups' in the follow-up survey, those known to be undertaking different tasks (13 per cent) is the **minimum** figure

4.1.1 Work expectations

At the initial telephone interview more than three-quarters of the 124 applicants who were then off work on sick leave, said that they intended to go back to their jobs when their health allowed them to do so. Of those re-contacted in the follow-up survey four to five months later (78 people), just over half (41) were then out of work, a quarter (20) were back in work and the remainder (17) were still off sick and getting some form of sick pay. Most of those back in employment (13) had been disallowed DLA. Nearly all of those still on sick pay (14) had been allowed DLA.

Among those off sick when they applied for DLA, a much smaller proportion of recipients (17 per cent) were back in work four to five months later compared to disallowed applicants (55 per cent).

People's aspirations of returning to work were, to a considerable degree, overtaken by events and proven to be somewhat over-optimistic. It is perhaps not surprising that people in the relatively early stages of coping with illness and disability will try to adopt a positive view of the future, including their prospects for recovery and for employment. It is also true that these changes in circumstances were over a relatively short period of time of a few months (and less than the required six month period for which mobility and care needs must be expected to last if someone is to be eligible to apply for DLA). However, a contrast is evident between aspirations and intentions and actual behaviour.

A similar finding emerged from questions asked of applicants who were out of work at the time they applied for DLA. Not only did fewer of them in the first survey say that they **expected** to work in the future than said that they **wanted** to work, but after four to five months this expectation had dropped even further among those still out of work. While there appeared to be a steady proportion who neither wanted nor expected to work again, fewer expected to work at the latter time point and greater doubt and uncertainty was evident in the numbers responding 'don't know'.

4.1.2 Anticipated and actual effects of DLA claim decisions

Applicants were asked in the first survey to say whether they thought being awarded DLA, or having their claim disallowed, would affect their decisions about working in the future, and the results strongly suggested that for most people the DLA decision was expected to have no influence over their future employment-related behaviour.

The second survey provided an opportunity to explore whether people actually acted in line with their own stated intentions once they knew their claim decision. Relatively few applicants in jobs at the first survey said that they intended to stop working following their DLA decision. The great majority (80 per cent or more) intended to stay in their current jobs if they could, whether they were awarded DLA or not. A sizeable minority felt they would need to look for a different job.

Table 4.3 Work intentions and actual 'outcomes' after four to five months

Intentions of applicants who were in jobs at Survey1	If DLA allowed (n=156) %	If DLA disallowed (n=161) %	Actual work 'outcomes' at Survey2	Allowed DLA (n=113) %	Disallowed DLA (n=73) %
Will leave work altogether	7	9	Had left work	42	23
Will look for a different job	13	9	Was in a different job	4	6
Will stay in current job	80	83	Was working in previous job	54	70

By the time of the follow-up survey (see Table 4.3) the actual number who had left work was much greater than this (more than a third overall and as many as 42 per cent of those who had been allowed DLA in the meantime), though many still intended to go back to work again in the future if possible. Much smaller proportions of people were still working in their old jobs by the follow-up survey. Many had 'run off the end' of sick pay periods before feeling ready to return to work. The optimistic intentions or aspirations of the great majority of people to overcome or recover from their limiting health conditions sufficiently to return to work, were not borne out in many instances, and especially among those who had been awarded DLA, where little more than half (54 per cent) were back in their old jobs.

It was also the case that more people said they intended to reduce their working hours than had actually done so four to five months later and after receiving a decision on their DLA claim. In practice finding work of reduced hours or negotiating a reduction within an existing job may well be difficult and take more time than the few months covered here.

Our sample of recent claimants (the new 'flow' onto DLA) was ideally suited to exploring in detail people's recent history in and out of work, and their perceptions of the process within which they had come to make an application for DLA. There were several different aspects to this process that were investigated:

- the precise timing of applications in relation to working/not working/being off work on sick pay;
- the perceived 'triggers' for making applications and the relative importance given to different factors;
- the role and impact of information, advice or support from third parties in relation to making claims.

4.2 The timing of DLA applications

Clearly, most people do claim DLA when they are out of work, and we have seen some of the reasons and rationales behind this. Our survey confirmed that around three-quarters of all applicants had made their claim when out of a job. Moreover, a further significant proportion had made their claim while on sick leave from a job, and the great majority of these had subsequently left that job during the next five months. Whatever people's expressed hopes and expectations about working in the future were, the overall picture was one of a strong trajectory out of work and further from the labour market. Movement out of work was most marked for those becoming DLA recipients.

While in a job and working (and hence earning) many were either oblivious to the existence of DLA or perceived that they did not need it – or indeed that they could not, or should not, claim it. While the precise timing of DLA applications can be affected by several contingent factors, including hearing about the benefit for the first time, claims often indicated a response to some form of crisis that had changed people's priorities and perspectives. People generally claimed at the point when their ability to work became severely affected or their financial situation became untenable. This was not always when they first acquired a health condition or disability.

It has been noted elsewhere that making an application is frequently consequent upon a health crisis, such as a sudden deterioration of a condition or an accident, or upon a health-related financial crisis, 117 and almost all our respondents did describe their application for DLA in such terms. The nature and degree of these critical moments varied, but were essentially either health or finance-related or both. The only exceptions were the small number of people making re-applications for DLA who had previously been disallowed or who were coming towards the end of a previous fixed period award, though even in some of these cases a worsening condition had prompted re-application in the hope of being awarded a higher level of benefit than previously.

4.2.1 Applications from those recently in work

Generally the health factors determining the timing of applications for DLA were overlaid and intricately bound up with financial factors. Such financial pressures could emanate from many sources including, for example, sudden reductions in maintenance payments or mounting debt, but generally were the result of sharply reduced or terminated wages from employment. Typically a health condition had led to problems maintaining employment and the resultant drop in income had spurred an application for DLA. As one claimant succinctly put it:

'I just knew that I was off work, sick and broke, you know. We needed to put food on the table.'

(Applicant on sick leave)

It was, therefore, predominantly the case that financial difficulties were directly linked to issues of leaving employment. People who felt forced by their health condition to stop working, suffered the financial consequences of this change which led, directly or indirectly, to their making an application for DLA. DLA was strongly associated with trying to cope with the consequences of losing employment and income.

It was particularly noticeable that many people had made their application for DLA at the point of a severe drop-off in their income. Key moments were leaving a job that could no longer be coped with, the point at which employer's sick pay went from full wage to half wage equivalent, and the points at which Statutory Sick Pay (SSP) and/or employer's sick pay ran out altogether. The timescales involved here are worth noting. Typically employer's sick pay (if paid at all) drops from full to half rate after four to six months and ends altogether after a further equal length of time. SSP is paid for 28 weeks at which point recipients should get notification of how to apply for out-of-work benefits (ESA).

Thus even those applicants recently in employment (many of whom felt they still had a job they would return to) had often not actually been working for some time when they claimed DLA. Eligibility conditions for claiming DLA require disability-related needs to have existed for a minimum of three months before DLA can be awarded. In practice, however, due to the sparse knowledge and understanding of DLA at this time, almost none of our respondents had made applications to this timetable, but had waited until faced with financial crisis before applying, or until told by a doctor that they were unlikely to return to work. Only those who had been struggling on in work for some time with their condition were in a position to claim DLA immediately on stopping work. This is consistent with the finding in earlier research on claimants of incapacity benefits (Sainsbury and Davidson 2006) that 'many people with gradual health changes experienced a period of 'struggling on' at work before going off sick'.118

A number of face-to-face respondents fell into this category as people who had stayed in employment for a considerable time in spite of their health conditions, and had only left work when all else had failed. This group was characterised by having made considerable efforts to adapt and mould their work situations around the demands and limitations of their disabilities and health conditions. Measures taken included reducing working hours, sometimes in several stages, modifying tasks undertaken at work, changing jobs to minimise factors exacerbating health conditions, adjusting commute times (by moving or changing jobs), taking pay cuts and requesting assessments and modifications to working environments.

In terms of motivation these people fell into two distinct groups. There were those who had struggled on purely for financial reasons and there were those who were driven more by a strong work 'ethic', the feeling that they **should** stay in work

Sainsbury and Davidson (2006) *Routes onto incapacity benefits: Findings from qualitative research*. DWP research report 350.

if at all possible, and a determination to do so as a matter of principle. A taxi driver in his early 50s, who, because of problems with his back, had progressively reduced the hours he worked over a period of 12 months, from over 60 a week down to around 20, explained his rationale:

'I would reduce hours further if I was getting more money. You see the doctor advised me when it first happened...just to pack up and go on the disability, and I thought 'no one is explaining how much I'm going to get and whether I can afford it.'

(In work applicant)

As he was no longer enjoying his work, was often in pain and felt continuing was further damaging his spine, his sole motivation for carrying on was financial – in particular his concerns over being able to continue paying his mortgage. Others who continued working despite evident difficulties and advice not to do so, shared this man's concern over not knowing the precise financial implications of stopping work.

While there were often genuine financial concerns in the background, others emphasised that they tried to stay in work for as long as possible because that was what they had always done and what they felt was the right thing to do. A man in his early 40s, who had suffered chronic pain syndrome for some seven years and had first changed jobs with the same employer and later changed jobs to one closer to home, to accommodate his health condition, admitted to having had to take considerable time off work over the years, but explained:

'I've prided myself that when I've been out of work I've always got back on the bike and started to work again, you know.'

(In work applicant)

Now out of work and in receipt of high level mobility and medium level care DLA, this person was considering how he might be able to work from home in the future.

Despite the considerable efforts being made by people in this group, they had all arrived at the point of making a DLA claim, and as for others this was almost always because they had ultimately left their employment. Typically this was because their ill-health had reached a point where they could no longer cope, irrespective of working hours or conditions. For a few of them an additional health problem had arisen, on top of previous ones, that had proved insurmountable. For example, a woman who had struggled on with progressively worsening arthritis finally left work when her medication caused her to be hospitalised with fluid on the lungs. Another woman, with diabetes and a liver condition, said that the reason she finally left work, after several years and several reductions in her hours, was a severe bout of depression. In addition, no one was immune from other vagaries of the labour market – despite several returns to work after periods off sick with arthritis, and having had two separate assessments of his workplace carried out under the auspices of Access to Work, one man's employment ended with redundancy over which he had no control.

One final factor in the minds of many trying to keep themselves in work 'against the odds' as it were, was an awareness of how difficult it might be for them to find another job if they were to leave their current employer. This was not merely a general concern about job availability but an awareness of the additional difficulty they were likely to encounter in the face of their current health record. One man who was on sick leave explained why he was going to try to go back to work again in spite of his doctor advising against it.

'I'm trying to hold on to this job because there's no one going to employ me with my health record now.'

(In work applicant)

4.2.2 Applications from the long-term out of work

At the other end of the spectrum in terms of the timing of DLA applications were those who at the time of their claim were long-term out of work (over a year) and already in receipt of out-of-work benefits: Incapacity Benefit (IB) and Income Support (IS). Around three-quarters (77 per cent) of all applicants were out of a job when they applied for DLA and of these, just over three-quarters (76 per cent) had not been in work for over a year, or had never worked. Overall, this group made up just over half (54 per cent) of all eventual DLA recipients. Although survey participants were not specifically asked how long they had been in receipt of different benefits, they were asked how long it was since they were last in paid employment and how long they had been affected by their main disability or health condition. In the great majority of cases very similar lengths of time were given for both, suggesting that many will have been on out-of-work benefits since the time they left work. This would tend to support findings from other research¹¹⁹ that DLA recipients who also claim IB are more likely than other incapacity benefits claimants to have moved there directly from work rather than via a spell of unemployment.

For those applying for DLA when out of a job, their exit from work was, in many cases, at a considerable distance in the past. Nevertheless, for most people a similar pattern of health and financial crisis could be discerned as for those more recently in work. Thus deteriorations in conditions, new additional health problems, periods of hospitalisation, surgery and new diagnoses, all featured prominently among reasons given for making a claim, as well as mental health breakdowns of varying degrees of severity.

Health issues were also tied up with financial difficulties for the long-term unemployed, though, not surprisingly, less directly related to the loss of income from work. In a number of cases it was primarily the difficulty people were having living long term on benefits which had prompted claims. For some, but not all, the concern was related to the prospect of living on benefit income indefinitely, because they had already decided to leave the labour market, as with a woman

in her 50s with depression and fibromyalgia who had been out of work for three years and did not expect to return:

'I just got to the stage where...to help pay bills and everything...I've no money left. I rang up the DWP and I says, 'look is there any more benefits it's possible to get because I'm finding it a bit of a struggle with just getting this much a month?' and [they] just told me what to apply for.'

(Out of work applicant)

For others, with clear intentions to get back to work, it was a case of getting by in the medium term, as with a young man who had been claiming IB for two years while getting his epilepsy under control:

'It was just people saying to me that I could get a bit more money. I couldn't survive on peanuts so I found another way...Living Allowance [sic] and what have you...my sister, she knows a bit more how to get me a bit more cash to pay for groceries.'

(Out of work applicant)

Several people described being told about DLA by their doctor in response to their insistence that they could not afford to stay out of work although being advised against going back. A 50 year old man with osteoarthritis who had been made redundant three years previously and since made several attempts to work via an agency:

'I said, well I need to get back to work, I can't afford it. How am I going to manage? Well [my GP] says you can get extra things you know, DLA and all that lot. So I said OK. He told me where to get the forms and I filled them in and went from there...[otherwise] I think I'd have had to find something, even if it were just working for somebody a day here, a day there, when I felt up to it.'

(Out of work applicant)

While there were those, therefore, who applied for DLA when out of work but had a strong and credible intention to return to employment, others felt under financial pressure to do so, and yet others consolidated their status as out of work and unable to work through applying for and being awarded DLA. As the results from the telephone survey showed, at the point of applying for DLA the great majority (92 per cent) of those who were out of work said they were 'unable to work' because of their condition, and this was the same proportion as agreed with the statement among those applying while on sick leave from a job. The survey data strongly suggest that an important factor affecting these responses was a tendency for many to understand 'unable to work' to mean 'unable to work at the moment' and for people thus to see no contradiction between agreeing that they were unable to work and at the same time saying they wanted to work and expected to do so in the future. Even among applicants who were working, around a third (34 per cent) agreed with the statement that they were unable to work.

The data also suggest that those applying for DLA who were long term out of work were more likely than others to mean 'unable ever to work again' when they responded to the question. In the five months between survey waves only one per cent of those long term out of work and agreeing at survey one that they were 'unable to work' had moved into work. This compared with seven per cent of those who had been out of work less than a year, and ten per cent of those who had applied while on sick leave (see Table 4.4).

Table 4.4 Movements into work in five months following DLA applications

DLA recipients not working at time of application and who said they were 'unable to work'	Percentage working 5 months later
Those out of work more than one year (No.=187)	1
Those out of work less than one year (No.=46)	7
Those off sick from a job (No.=48)	10

The long-term unemployed applicants who were subsequently awarded DLA represent the group of respondents closest in characteristics to the existing customer population of DLA and IB recipients. As such we can reasonably assume a number of things about them. We would expect: that they will have multiple barriers to re-entry to the labour market; that their chances of regaining employment will decline the longer they have been out of work; that in addition to their health conditions they will share many of the typical disadvantages of the long-term unemployed such as low self-esteem and poor confidence; and that their health is very likely to have deteriorated over the lengthy period they have been out of work.

At an individual level, our face-to-face interviews found evidence of all of these factors, and indeed the very fact that they had all made DLA applications more than a year after claiming incapacity benefits is strongly suggestive of declining health over that period, given that they had either not applied for DLA previously or had previously applied but been disallowed. Only now did people perceive their state of health to be serious enough to make an application and Pensions Disability and Carers Service (PDCS) decision makers agree that their condition passed the DLA eligibility threshold.

'I got made redundant three years ago and then I went to work for an agency – that were for about a year – and then I started getting really bad and the doctor says 'I'll put you on the sick'. Then that went to IB, and then it went to disabled [DLA].'

(Out of work applicant)

4.2.3 A highly differentiated customer group

In terms of the timing of DLA claims, therefore, it is important to recognise that different sub-groups of recipients are at very different positions in relation to the labour market at the point they apply, and have very different perspectives on their relation to it. These in turn affect their perceptions of their disabilities and health conditions. Those applying while on sick leave from a job, or struggling on in work with increasing difficulty, had tended to 'underplay' their health problems until they had started to threaten their work and livelihood. In contrast, those making DLA claims after a year or more out of work were faced with already very considerable barriers to work even before their health was taken into account. In these circumstances, even a relatively minor health impairment presented itself as tipping the balance away from the labour market. There is evidence from the surveys that applicants in this position were therefore inclined to see their impairments as more restricting than working applicants. A greater proportion of those applying from within a job were awarded high level DLA elements than was the case for those applying from out of work. Sixty per cent of applicants with a job were awarded higher elements of DLA compared to 42 per cent of long-term out-of-work applicants.

An individual's perception of their disability has important implications. Not only is the eligibility and assessment process for DLA in part dependent on an applicant's subjective assessment of what they can do and what they are willing to put up with, but a person's view of what the consequences of their impairment are likely to be in their given labour market situation will affect their behaviour and determine what support will be most appropriate and effective.

4.2.4 Perceptions of long-term disability

There was much evidence from the qualitative interviews that one aspect of the timing of DLA claims was applicants' perception that they were going to be affected for the long-term by their condition. Several described the realisation or understanding that this was the case as having led to their claims.

'I applied for [DLA] because the hospital said you're going to be off for a long, long time...get your finances in order.'

(Out of work applicant)

'When I applied for [DLA] I knew my health wasn't good enough to go back to work — I mean for the foreseeable future I'm not up to going back to work.'

(Out of work applicant)

And the reverse was also true:

'I needed to get some money and I needed to get back to work, and the doctor wouldn't let me. She said, "you can't work how you are at the moment" and that's when she suggested this [DLA] and I said, "well surely, you know, I'm going to get better and I'm not eligible for it".'

(In work applicant)

While this did not necessarily mean that people were consciously leaving the labour market for good, they were taking a big step back from it, with DLA providing a form of legitimacy to not seeking work. Many described the effect of getting DLA as 'taking the pressure off' and providing some breathing space from feeling they had to get back to work. Not only does eligibility require that disability-related needs are expected to last for at least a further six months, but fixed period awards reinforced the feeling for many that it was accepted and officially endorsed that they could not work for that period of time. Several people stated that they felt their fixed term award removed from them any obligation to inform PDCS of changes in their condition, as their case would automatically be reviewed. At least one person was explicitly advised not to do so by her support worker.

For people aged over 50 there was a greater chance that this perception was linked to the idea of not working again and not attempting to re-enter the labour market. Several described themselves as 'retired' though only a very small number were actually in receipt of a pension of any kind. Some understood their position as having been 'retired on health grounds' by their previous employer and, significantly, had first heard of DLA at that point from their employer.

4.3 'Suitable' future work

It is a premise of current policy, and the basis for the tighter conditionality governing ESA, that many (even most) people claiming incapacity benefits will be capable of undertaking **some** work of **some** kind. In this context it will, presumably, be the basis of any employment support intervention to help people recognise what they **can** cope with and to match them to 'suitable' work. An area of interest in face-to-face interviews was how such potential, future work was viewed from the perspective of new claimants.

What was particularly noticeable was the assumption most people made that when talking about work it was meant the specific work or job that they used to do. When agreeing to the statement 'I am unable to work because of my disability or health condition', therefore, what most respondents were saying was that they were unable to do their previous job; or unable to work in the industry or occupation that they used to and with which they were familiar. This was particularly the case for those who had recently been employed, or indeed who were off sick but still had a job being held open for them to which they could, in theory, return. As we have seen, people in this situation held high expectations of recovery and a return to work at some point in the future, even if subsequent

events suggested over-optimism in this regard. Nevertheless, some of those out of work for lengthy periods of time made the same assumption.

It was clearly very difficult for people to think beyond this and start addressing the question of what they might be able to do now or in the future in the way of work. There appeared to be a number of powerful reasons for this. Firstly, the work they had previously done was familiar, concrete and well understood. Secondly, work in the future was both abstract and indeterminate because it involved speculation about the progress or outcomes of current health conditions. Third, to engage in thoughts of future, partial or limited capacity for work entailed accepting that they were unlikely ever to return to their former occupation, and required the considerable mental 'leap' of accepting that they would have a permanent disability or impairment to cope with. Many were not yet ready or able to make this leap, and those who had tried to do so, often found it a distressing process:

'I was thinking, well, I can't even work in a supermarket. I can't lift anything. I can't walk. I can't see properly...I was trying to think what else can I do if I didn't even do my own job? And it was a real struggle to think...I didn't want to think about it too much. I just wanted to be able to do something.'

(Applicant on sick leave)

There were those whose health conditions seemed unequivocally to rule out a return to previous work, particularly in cases where that work was implicated in the health crisis itself, such as for the man whose heavy physical job had led to a heart attack.

'I would like to go back to work in the future, but I know I won't be able to go back and do what I used to do.'

(Out of work applicant)

4.3.1 Primacy of previous employment

Where mental health breakdowns were concerned, with conditions such as depression and panic attacks, it was often a previous job that was cited as contributing to them, and in such cases working in **any** job was seen as impossible because it was likely to cause stress and prevent recovery. Nevertheless, for most people it was their previous employment that provided the most accessible route for thinking about returning to work. Where people were still in touch with their employer it was easier and more 'tangible' to think about how their job might be modified or conditions changed to allow them to continue, than it was to imagine finding a new job from 'scratch'.

There were also two very practical reasons why such an approach appeared to make most sense: the feared likely rejection by other, 'new' employers; and the drop in wages expected to go along with a switch in occupation to something compatible with their disability or health condition. People were only too aware that their sickness record would place them at a great disadvantage competing for jobs in the open labour market.

'I've always worked – apart from having the health issues...I think more worrying now is...there's a lot more people going for employment and I'm not going to be top of the list. There's a lot of stigma and prejudice still, even though you know people like myself...can work [even] if they have a disability.'

(In work applicant)

Negotiating a return to work with an employer who had experience of their work record prior to health breakdown, and who was familiar with their skills and experience, was a better option in most people's eyes, even if not entirely risk-free.

'[My employers] they're even thinking now I might not manage it to be honest. So it will be a balance about whether I can just do it part time or not...The plan is, really, I've got to go back and try it – and then review it and see what happens – and I don't know how flexible they'll be...'

(Applicant on sick leave)

Because most people with recent work had been with employers a considerable time, their best earning potential was generally seen to lie in the work they were experienced in and skilled at. A former retail manager with multiple sclerosis (MS) explained:

'I could come out of that job and do another job that was less physical – it was an option to consider but unfortunately with having the house, the mortgage...the level I was at, the wage that that commanded – to go on another line of work wasn't really an option financially.'

(Out of work applicant)

In this case the solution arrived at was a role-swap with his wife who had greater earning potential and thus became the main household wage earner while he looked after their young children. Even though such an option was not open to most applicants, a variety of adjustments to household arrangements were common – from partners increasing their hours or changing jobs to coming out of retirement to earn.

The prospect of not being able to stay in the same job, therefore, was seen to have major consequences that followed from the almost inevitable drop in income. If compensating arrangements could not be arrived at within the household then major lifestyle changes were often foreseen, such as selling houses and moving into rented accommodation, along with cutting expenditure to meet new realities.

4.3.2 'Struggling on' in work

As has already been noted, this appreciation of the likely practical consequences of leaving existing employment and either not working or seeking different work, often with changed tasks and reduced hours, was also the rationale and motivation for many of those who had struggled on in their jobs over many years and until that point where they finally felt they had no choice left open to them. A case in point was a woman in her mid 40s who had tried to keep working for

nearly a year with arthritis and psoriasis, but eventually found she could not cope and had to leave:

'I've had to give up my job because of it. I was a full-time carer and when I was first diagnosed I did struggle for two or three months to do full-time, 42 hours a week...then I had to reduce my time and I went down to 24 hours, and then I had to change jobs within the firm, and go from caring to activities, but I still couldn't cope with that because of my hands. I...cut my time down, then I changed jobs to what I thought would probably be an easier job, but it really wasn't. I did try to stay in work because I didn't want to leave...the thing is I don't think I'll be able to get back into work'

(In work applicant)

As for this woman, many people were in modestly paid work where long hours and overtime were required to bring their income up to the level they needed. Even just cutting back to part-time working could thus cause considerable financial difficulty. There were also relatively large numbers of people in our sample who were previously working in manual, physical occupations, with very little in the way of transferable qualifications. Earning good wages by virtue of long service with their employers, once their health prevented or compromised their ability to continue in a manual occupation they felt they had few options open to them. A young father (aged 30):

'I'm geared up for all manual work — anything like that I'm skilled in...I've got licences for things [e.g. forklift driving]...so I always knew I could pull a good wage in...But office based work? — I've never trained in any of it...so I'm looking at going in at the real low end...It's a big concern that I won't be able to pull the right type of money in.'

(In work applicant)

Even for those willing to begin to think about re-training, therefore, the prospect facing them was of a lengthy period (if ever) before they could realistically expect to re-attain their former earning power, even if they could foresee being able to work full-time in a new occupation.

4.3.3 Reducing pay and down-skilling

For a few who had been in better paid jobs there was a realistic option of taking on work in the future at a lower wage that was suited to their health condition. One example was a man who had suffered a mental health breakdown due to a combination of factors in his personal life and his pressurised accountancy job. After recovering sufficiently to return to work he had deliberately taken lower skilled and lower paid employment to avoid undue stress that might risk a repeat of his breakdown.

'There was no financial pressure on me. It was really the need to be doing something and it was just the way things worked out that I got this job... coincidentally my health was improving at the same time...chasing money is all very well but it's not everything...I used to pick up every cold that was going, but I don't think I've had a single sick day since October [in six months] – my health has been fantastic.'

(Out-of-work applicant)

The problem for those previously already in poorly paid employment was that such an option was not available. Indeed, several people believed that trying to live on minimum wage level earnings had, in itself, been a contributor to their health breakdown. A lone parent claimed that despite having a better off calculation that had indicated she would be £40 better off working than on IS, she had started working only to find that in fact the margin was barely £10 a week. Trying to cope with working, childcare and the administration of tax credits was seen as having contributed to her stress and anxiety. She had left work after only a short time and was not considering going back.

'I've not even thought about going back to work because it makes me sick... If I were working I'd be [attempting] committing suicide again because it were too stressful.'

(Applicant on sick leave)

Whereas higher earners could relatively easily consider reducing their hours and working part-time, this was a far more problematic option for those on low pay. Not only were part-time hours for these people insufficient to cover their outgoings but if they were only able to manage a few hours a week there was a real chance that they could be better off, or very little worse off, by not working and claiming benefits. Any suggestion, therefore, that working might make their health condition worse was almost guaranteed to prevent them from seeing work as a meaningful choice of action. A woman in her 40s who had suffered a stroke explained how, despite her strong preference for working over not working, the combination of a slight deterioration in her condition and the fact that, even if a suitable job could be found by her supportive employer, she only felt capable of part-time hours, had led to the decision not to try to go back.

'I could ring up tomorrow and I could get my job back...if I wanted to go part-time, but it's finding a job that's going to suit me with the condition I've got...it wouldn't be worth me going back to work the way I am.'

(Applicant on sick leave)

The notion of 'suitable alternative work' for DLA recipients who have mobility and care needs is thus far from straightforward. It can be particularly difficult for people to consider alternatives to the work they are experienced in and familiar with, particularly when still close to their previous jobs. A number of significant psychological barriers appeared to exist that overlay and complicated the practical difficulties of reducing hours and taking lower wages, even if work could be found to fit around impairments.

Although some people had successfully adjusted their duties and hours in agreement with their employers and had thus managed to continue in work for a while, by the time they came to make their claim for DLA most had arrived at the point at which they were no longer able to cope even with these adjustments. Prospects for negotiating suitable terms and conditions with **new** employers were, perhaps correctly, perceived to be an even more daunting prospect than talking to existing employers from within a job. 120 Many comments were made to the effect that great flexibility and understanding would be required – a flexibility and understanding not always particularly evident in their previous experiences with employers.

While a number of people mentioned the need and the possibility that they might retrain to undertake a different kind of work to that which they were accustomed to, training was a rather vague notion for most, consisting of the idea of some form of computer training that might permit them to work sitting down. For a lot of people the idea of training was, for the time being at least, considered to be as unrealistic a notion for them as an immediate return to work.

There was little if any mention of the role of the Disability Discrimination Act (DDA) in agreeing these adjustments. Where no adjustments were made it was not clear whether the possibility had been considered.

5 The role of third parties

The important role played by third parties in Disability Living Allowance (DLA) applications has been noted in other research. In particular, it has been reported that many people feel they need help completing application forms and that having professional help with this appears to increase people's chances of having their claim allowed. Indeed, there is currently something of an 'industry' that has grown up to provide such assistance. What is also true is that third parties play a significant role in the timing of applications too. A contributory reason why relatively few people claim DLA while in work is that, even where employers know about the existence of DLA, it appears to be very rarely mentioned, except in the context of someone leaving their job. Employees are also, understandably, reluctant to discuss with their employers the fact that health issues are making it difficult to cope with their needs.

5.1 Reinforcement of misunderstandings

Many applicants said that they made their claim when they first heard about the existence of DLA and there is clearly an issue about the lack of knowledge, information and signposting available to people. When they did get to hear about DLA it was very often from professionals dealing with the health or financial crises in their lives, in contexts that reinforced associations between DLA and being too unwell to work, and between making a claim and devising strategies to cope with shortfalls in income and related problems such as debt. In this way many of the common misunderstandings about DLA could be reinforced by professionals.

In line with this observation, of first knowledge about DLA often coming from professionals dealing with personal crises, the main groups of advisers mentioned by applicants were those who were medical professionals, and those related to the provision of benefits advice through statutory and voluntary agencies.

5.2 Medical professionals

Many applications for DLA had been suggested directly by people's GPs, by nursing staff at hospitals or by community nurses and community psychiatric nurses (CPNs). These medically-related professionals were generally highly regarded, and trusted,

and were evidently very influential in people's decision-making about DLA. This high regard appears to be well placed; applications made at their suggestion had the highest rates of success in our survey of applicants. Some claimants maintained they would not have applied without the suggestion from a medically 'credible' source.

'If it wasn't for the [hospital social worker] coming round I would never ever have put in for DLA...I know [someone who] gets it, but she's absolutely crippled with arthritis...I just don't think of [my condition] as the same thing...I think it's because I've worked all my life.'

(In work applicant)

However, exchanges with medical professionals that were reported in face-to-face interviews showed them typically to pursue an explicitly 'non-work' agenda. Reported mention of DLA by GPs was frequently in the context of certificating absence from work through 'sick notes', and a primary concern from the medical point of view was for people not to risk exacerbating their health condition, or hindering recovery through working.

'I was getting a bit worked up [going] from a full-time wage to just sick pay...[my doctor] said, 'maybe it [DLA] will help towards getting a bit of help with this ... at least you've not got the stress about finance – it will mean you can concentrate on your health'.'

(Applicant on sick leave)

This was particularly true in cases where a person's work was itself perceived as having caused or contributed to a health condition, whether through stress or through the physical nature of the tasks it required. There was very little evidence of medical professionals engaging with people in discussions about whether work might be a positive influence on their health. Indeed in those instances where DLA recipients were themselves convinced that this was the case, and that getting back to work was an important aspect of managing and overcoming their health condition, they reported having to argue **against** the advice and opinions of the medical professionals they were in contact with.

'My CPN and my GP weren't 100 per cent convinced if I went back to work it was the right decision, but it was a case of "but I have to try"...'

(Applicant on sick leave)

Thus, in many cases, claiming DLA was suggested by medical professionals specifically as an alternative to going back to work, and as a way of 'buying' recovery and adjustment time.

5.3 Support agency staff

The other key source of information about DLA and stimulus for making claims were non-medical staff and professionals in support and advice agencies of various kinds. While there were some overlaps with the medical sphere (notably social workers based in hospitals) these third parties were often not directly involved in dealing with people's disabilities and health conditions. Rather, most contact with them was reported as taking place in the context of addressing the financial difficulties consequent upon ill-health and unemployment. If we accept the typical progression for most people from health crisis to work crisis to financial crisis, then these professionals were encountered at the end of this sequence. Many described seeking financial help and debt advice from non-Departmental agencies when they perceived their situation as unsustainable, and hearing about DLA first in this context. While usually it was, at least in part, to discuss problems arising from not working/earning, it could be very much more indirect than this.

5.3.1 An anti-poverty agenda

One woman, whose husband was working full-time, described how the suggestion for her claim came about indirectly when they went to see an adviser about debt problems and she happened to mention that she had left work due to depression. As part of their debt management strategy the adviser suggested she applied for DLA, and filled out the forms on her behalf.

Similarly, a couple who were both working were advised in the course of trying to sort out arrangements for declaring themselves bankrupt that they should apply for DLA:

'The [person] dealing with all our bankruptcy filled all the forms in down at the [agency] when we told him about my knee and my back and [my wife's] hand...He says 'but don't claim it until you're discharged from your bankruptcy because if they get the money coming in...they'll just take it straight off you'. '

(In work applicant)

Third parties in these agencies generally saw their role as primarily that of helping counteract poverty by securing additional financial help for their clients whenever, and from wherever, they could manage. Suggestions to make DLA claims were just one aspect of undertaking this role, and several respondents described this support and information provision as taking place within much broader ranging activity to address the financial situation of not just individuals but couples and entire households.

5.3.2 Perceived exaggeration

There was some suggestion from our interviews that in pursuing such a line it was common practice for agencies to apply for DLA on their client's behalf to ensure the best chance of achieving an award. In one example, a woman struggling to

make ends meet on her part-time income received help to fill in a DLA application, was subsequently awarded the high level mobility element of the benefit, and was then advised by the agency to stop working in order not to put her DLA payment at risk. Although this was an exceptional case, there were several other examples of applicants expressing unease about what they were being advised to put on their application forms, variously describing it as what they saw as 'exaggeration' or 'dishonesty'. It is worth bearing in mind here the strong feelings that some applicants had about the stigma of being dependent (see Section 3.1.2) and acknowledging that in some cases, being advised not to downplay one's difficulties might be interpreted as being advised to exaggerate them. For some, however, it was enough to end their application:

'[The adviser] said, right question one, how long did it take you to walk from your car to here?...I said, well, a minute. She said oh no, no, no you can't put that you know'. It was kind of like you've got to exaggerate...and I'm thinking, that ain't me you know and I said, look don't bother...'

(Out of work applicant)

Although this man went away and filled the form himself and was eventually awarded low level DLA, others who preferred to disregard such advice were disallowed, such as this 34 year old with MS:

'I'm pretty sure that that's how some people have been given DLA – bend the truth slightly, which I won't do...the advice that I've been given [is] 'when they ask you questions, give them the answers for one of your bad days – not an average day but a bad day'...But I don't want to bend the truth.'

(Out of work applicant)

For some people, explaining what help is needed on a regular basis will entail looking at bad days as well as good days. It is not clear from the evidence whether respondents understood this or whether they believed they were being invited to exaggerate their condition to the extent of misrepresenting it. There were also a number of recipients who expressed surprise at their DLA claim being allowed, most of them after having had their application form filled in for them by a third party.

'I never expected to get it...it were quite surprising because I thought you'd have to have a lot more problems than what I've got to get it.'

(In work applicant)

In some circumstances it appeared to have been absolutely necessary for a third party to have filled out a DLA application on the claimant's behalf, in particular where claimants were suffering severe mental breakdown. However, there were many less clear-cut examples where claimants appeared to be largely unaware of what had been submitted on their behalf, and happy to relinquish responsibility for it to the person who had completed the form for them.

5.4 Jobcentre Plus

Special mention needs to be made of the role that Jobcentre Plus was seen to play in DLA applications. Although the majority of recipients had signed on for out-of-work benefits via Jobcentre Plus before making their claim for DLA, very few people reported that they had been directed towards DLA by an adviser or by a Pathways provider. Where DLA had been mentioned, people tended to be referred to another third party. This reflects comments made by some Pathways advisers in our discussion groups that they were not entirely comfortable in dealing with DLA recipients and often felt that others had more relevant expertise in that area.

Several DLA recipients detected a lack of understanding or sympathy from Jobcentre Plus staff in relation to disability and health issues along with an overriding focus on getting people off benefits and into jobs, regardless of their circumstances. Problems relating to the changeover to Employment and Support Allowance (ESA) fuelled some of these adverse interpretations of the work of Jobcentre Plus offices, made worse by a rather high frequency of reported administrative failures such as the loss of paperwork and supporting documents. Some comments about lack of accessibility to Jobcentre Plus offices for disabled people, including distances from car parking, stairs and heavy doors, were somewhat surprising.

Overall there were far more positive comments made about advisers with Pathways providers, though these were primarily from those who were already work-orientated, including those who felt unable to work at the time but were focused on returning to the labour market at some point in the future. In the few cases where people had been referred to Disability Employment Advisers (DEAs) for specialist support and job brokering help, there were also positive comments, even fulsome praise.

The accounts of Jobcentre Plus' role formed a fairly consistent picture of separation from DLA and non-engagement. Beyond the small number of claimants who had picked up leaflets about DLA while seeing advisers, there was little to suggest any influence either over decisions to claim DLA or over the timing of applications.

5.4.1 Felt lack of engagement with health issues

Perhaps predictably, one area of contention between DLA recipients and Jobcentre Plus was around the newly defined category of 'work capable' ESA claimants, though much was based on speculative and reported anxieties rather than actual experience. ESA replaced Incapacity Benefit (IB) for new claimants in October 2008 at the same time as DLA applicants were sampled for the research. Those claiming out-of-work benefits at the same time as claiming DLA, or shortly afterwards, thus fell under ESA regulations and conditionality, and had been assigned to either the Support group or the Work Related Activity group or indeed to Jobseeker's Allowance (JSA), in line with the policy premise that many incapacity benefits claimants want to work and are capable of at least some degree of paid employment.

The problems people encountered with the out-of-work benefits regime (IB or ESA) stemmed for the most part from the timing of Work Focused Interviews (WFIs), coming as they did for people in our sample very soon after claiming and being awarded DLA. As discussed above, these were people who had reached a point of crisis that had caused them to leave their jobs, who were still on that trajectory out of work, and who were very clear in their own minds that they could not at this time consider returning to employment.

'I'd told them I was on DLA and I got the higher rate, but they still put me on the programme. I'm not feeling ready for work. I can't do a job yet. When I can start living a proper life in my flat then I'll think I'm ready for a job, but at the moment I'm not! So it's really just going through the motions with it. I've got to attend because otherwise they'll stop my benefits.'

(In work applicant)

The idea of attending WFIs at this time seemed incongruous to most of them, and work was an uncertain possibility at some distance in the future. A few, for example those recovering from serious accident, actually still had jobs to which they intended to return.

'I phoned up to see if I still had to go [to a provider] because I was hardly walking...Then I had to go to a medical and...now I've got to go to see someone once a month about like training to get back into work or voluntary work...I told them that I am going back to my job but they said 'you have to go', so I do.'

(Applicant on sick leave)

5.4.2 Emphasis on 'work first'

Respondents' perception of Jobcentre Plus was thus of a regime they saw as emphasising 'work now' rather than being geared to supporting them through the period of recovery, rehabilitation and transition that they felt they needed and which was still of indeterminate length in their minds.

There is an irony here for current policy, in that while the earliest support and intervention is widely recognised as best practice, and the most effective way of preventing people staying long term on benefits and becoming increasingly difficult to move back into work, in the case of DLA recipients recently out of work this may be the most difficult (and least productive) time to intervene. At the very least it would appear to require a different approach to support services from that reported to exist currently, including greater engagement with health issues, more intensive rehabilitation support at a pace to suit individual circumstances, and a recognition of the sometimes protracted timescales that will be involved.

One of our respondents (receiving high level care element of DLA) was in the process of taking the decision to assign her to the ESA work capable group to a tribunal, on the grounds that not only was she not yet ready to return to work, but that attending was so stressful as to be likely to be detrimental to her health.

She suffered from depression and from anxiety induced spasms which had caused back problems and led to her last employment being terminated because her employer had been unable to make her work environment safe for her. Her mental health crisis coincided with other personal problems including a long-term relationship breakdown, bowel cancer surgery, debt and bankruptcy. Prior to this she had a solid work history and she expressed a determined intention to get back into employment when she could. Rehabilitation efforts she had made herself with her psychologist and with local voluntary organisations appeared to testify to the seriousness of this intent, and she was progressively extending the types of environments that she was able to venture out into on her own. She feared that the ESA process might result in her having to claim JSA instead, which she felt would undermine the achievements she had made thus far.

'I work very hard with myself...one of the charity organizations is training me up so that I can go out and encourage other people who have difficulties like my own...not to think that life is over. There's steps I've taken to get to where I am today...it's not that I'm saying I'm not going to go back to work. I want to go back to work, just not yet...I have been told that the psychiatric problems I have, the depression and what have you, may well be a lifelong thing but it can be managed — I am so much better now to what I used to be.'

(Applicant on sick leave)

People with mental health conditions were particularly likely to feel adverse effects from institutional pressures such as the tightening of conditionality surrounding benefits. They also make up a very significant proportion of all DLA recipients. Not only are people with mental health conditions concentrated within the DLA recipient population, but they have constituted the fastest growing area of working-age applications since 2002. In our surveyed sample of 371 recipients, 21 per cent reported their main disability to be a mental health condition. This compares to a figure of 16 per cent among all existing recipients in May 2007.

6 Work disincentives and enablers

Under certain circumstances, particularly where higher levels of award are involved, there is the potential for Disability Living Allowance (DLA) to be a disincentive to work. There is some evidence from secondary data analysis findings that this is indeed the case. Because of the relatively limited available information on severity of impairment, it is possible that those in receipt of higher rates of DLA had more severe limitations than those on lower rates, and to a greater degree than was picked up in these secondary analyses. Nevertheless, in multivariate analysis of the factors most likely to be affecting DLA claimants' greater tendency to say they were unable to work, or that they did not wish to work, Conolly *et al.* found that as the value of DLA award rises, so work expectations fall (independently of other possible explanatory factors).¹²¹

Our evidence review threw up three related reasons why receipt of DLA might be having a disincentive effect:

- It is possible that DLA recipients are particularly fearful of their eligibility being reviewed and of the consequent possibility of losing their benefit. The specific nature of the DLA assessment process (stressful for many) and the perceived risk of review for anyone returning to work, might in itself differentiate DLA recipients from other incapacity benefits claimants.
- The fact that DLA is non-means tested, and additional to any other out-of-work benefits someone might be getting, would add to such a differentiation, with DLA recipients perceiving themselves to have more to lose than others from moving into work (less 'push' factor to seek work). In addition to risking review of eligibility, any employment taken might prove to be unsustainable for whatever reason, causing problems re-establishing a steady income.

 Set against the potentially high levels of benefit that can be received under DLA, recipients may equally perceive themselves to have less to gain by returning to work (less 'pull' factor), whether from lower earnings potential compared to others, from higher additional costs and lower net income from work undertaken, or from a detrimental interaction with local authority care packages provision.

These hypotheses were explored wherever possible with DLA recipients in our qualitative interview sample. Some specific areas proved inaccessible due to our sample being made up of recent applicants. For example, no-one was found who was receiving a local authority care package, nor anyone accessing the Independent Living Fund (ILF). It is perhaps to be expected that these aspects of support would be more likely to apply to people who have been disabled all, or most, of their lives, and to others at a greater remove from their first application for DLA than was the case in our research, which had relatively much greater numbers of people who, for example, had become disabled overnight as a result of a stroke or a car accident.

6.1 Fear of review and loss of DLA entitlement

A frequently mentioned perception among claimants was that moving into work would undermine eligibility for, or threaten continued receipt of, DLA. When questioned directly in our telephone survey 21 per cent of respondents agreed with the statement 'my eligibility for DLA might be affected by working.'

Fear of losing DLA may in part derive from the misconception that it cannot be claimed in work, and the view of DLA as an 'out-of-work' benefit is likely to reinforce concerns in this regard. In practice, however, it is questionable whether people who believe themselves to be too ill or disabled to work actually think in these terms and whether such a misconception in fact plays a large part in their decision making about work. As Hawkins *et al.* also found in their research:

'There was little understanding of the relationship between disability benefits and work. It was common for DLA recipients to be too ill to work and, therefore, it was not an issue...It was common for those who were not yet working to assume they would no longer receive their DLA once they started work [but] the correctness of the assumption was unlikely to be explored until work became a real possibility.'122

Perhaps the more likely explanation for this widespread perception lies in a concern among DLA recipients that moving into work will trigger a review of eligibility that could lead to withdrawal or a reduction of the benefit. Disability organisations have long been aware of this issue:

'People...fear that DLA will stop if they begin work...The potential loss of DLA during a period fraught with financial uncertainty can be a huge disincentive to return to work, particularly if they are worried about their ability to cope with paid employment...[Citizens Advice Bureaux] has seen evidence that... even participation in training courses has been seen as an indication that the person is capable of work and triggered a review of DLA.'123

Although employment status is not in itself relevant to DLA eligibility, there is also something of an acknowledged grey area in terms of what changes of circumstance should be reported, due to the relationship between needs and impairments and the requirements of different types of jobs. DLA recipients have been described as being 'vague' on the issue of what changes in circumstances they felt they needed to report.¹²⁴

The simple fact that DLA reviews can be triggered by information about entry into employment which may lead to withdrawal or reduction of the benefit, and the difficulty of assessing the true level of risk, lends credence to the reported fears of our interviewed DLA customers, who claimed knowledge of cases where this had occurred. Many people perceived that if they felt able to work then their condition would have improved sufficiently for them no longer to be eligible to receive DLA. In the same way that getting the benefit was associated with leaving work, because they were no longer able to cope and expecting a long-term health problem, so returning to work was assumed to go along with an improvement in their condition and a loss of benefit. This feeling was particularly evident among those with mental health conditions for whom being able to consider returning to work was often seen as tantamount to having made a recovery.

6.1.1 No guarantee of not being reviewed

Our interviews confirmed that there was a real fear of review and loss of entitlement to DLA even among the most recent recipients. Participants quoted examples of people they knew or had heard of who had triggered a review by returning to work. Whatever the validity of these anecdotal accounts, they clearly had the power to affect views and behaviour. As several Pathways advisers pointed out in our early discussion groups, it was not sufficient for them to say to people that working would not automatically trigger a review. It was enough to concern people, and make them pull back from trying to regain employment, to be told by an adviser that it was not possible to give them a **guarantee** that a review would **not** happen. While advisers appeared to be doing their best to allay people's fears in this regard, some other third party sources of information and influence appeared occasionally to be reinforcing them.

Citizens Advice Bureaux contribution to the IB Reforms Green Paper (May 2005).

¹²⁴ Hawkins *et al.* (2007) pp 49-50.

A very widely shared perception of the DLA awards decision-making process was that it was unpredictable, even capricious, and that even once an award was made it was all too easily lost again by doing or saying the wrong thing. Pathways advisers admitted that they never offered an opinion to a customer as to the likelihood of them being successful in a DLA claim, because they themselves perceived the process to carry risks and uncertainties and not always to be very intuitive in its outcomes.

6.1.2 A sense of vulnerability

A man who had been awarded DLA high level mobility and low rate care, had been told by an advice worker to think carefully about appealing the decision and trying to get the higher level of care too because he might end up losing what he had already been awarded.

'She referred me to the benefits [enquiry line] something or other to see if I could get any more benefits and she said why didn't I put in for the higher rate of care...but then she did say you are aware that they could stop it altogether. I would like to apply for the higher paid care but I'm worried of losing the whole thing so that is stopping me.'

(Applicant on sick leave)

A re-applicant was even more specific – expressing the opinion (which she implied was widely shared) that re-claim forms were scrutinised for the slightest differences from previous claims, seeking any pretext for refusing the application.

'We're all convinced, everybody on DLA, that it's a big 'con' and they're trying not to let you renew again. So they give you the forms again and again and again, trying to make you say there's something different...and if there is anything remotely different then they go...you can't have it.'

(Out of work applicant)

This sense of the vulnerability of DLA awards was even sufficiently strongly felt to lead her into keeping it separate from her budgeting for everyday requirements as it might not always be available and she did not want to be too reliant upon it:

'I try to keep the DLA separate...as I need to be fully aware that it can be taken away.'

(Out-of-work applicant)

In this climate of uncertainty, and sense of the vulnerability of DLA awards, going into employment was a step many expected to have major negative implications.

6.2 Financial disincentives: more to lose, less to gain?

DLA is a non-contributory, tax free benefit not affected by other income, earnings or savings, and payable regardless of employment status. In theory, therefore, it should not disincentivise working. However, a large majority of DLA recipients

are also in receipt of out-of-work benefits which **are** means tested, and would thus be lost on moving into work. Moreover, some of these (primarily the Severe Disability Premium in Income Support (IS), but also, at the time our respondents were claiming, higher level Incapacity Benefit (IB) without the requirement for a Personal Capability Assessment) represent additional benefits income that people are passported to by virtue of receiving higher level DLA awards. Thus, regardless of whether their DLA itself was affected, DLA recipients might perceive themselves as having more to lose than others by returning to work. Indeed, some Pathways advisers were of the opinion that fear of losing IB/IS was a bigger factor than fear of losing DLA in disincentivising work.

That disabled people faced financial disincentives to working in the early 1990s was officially recognised in the government review *The Way Ahead: Benefits for Disabled People*, published in 1990.¹²⁵ Growing concern that disabled people might be worse off in work led to the introduction of Disability Working Allowance (DWA) in 1992, later to be replaced by the Disabled Persons Tax Credit (DPTC) in 1999. Both measures have been evaluated, ¹²⁶ but without any explicit consideration of possible DLA-specific disincentives to working and why these may be different from those affecting other disabled people.

The possibility that higher levels of out-of-work benefit income might mean that DLA recipients would need to find better paid work than other disabled people to be better off in work, is perhaps reflected in recent research looking at the wage that would make it 'worthwhile coming off benefit'. DLA claimants were found to have sought slightly higher wages than other incapacity benefits claimants, with 31 per cent of male claimants saying they would need more than £300 per week after tax compared to 29 per cent of IB claimants who did not receive DLA. 127 Although we do not know how much respondents were receiving in benefits and what respondents were assuming about their entitlement to in-work benefits – such as DLA, Housing Benefit (HB) and Working Tax Credit (WTC) – this may suggest that DLA recipients perceive themselves to have more to lose from leaving benefits and entering work than do other disabled people.

6.2.1 Higher benefit income

Existing data show DLA recipients to be in receipt of considerably higher than average benefit income compared with other benefit customers with disabilities. Part of the reason for this is due to the receipt of DLA itself which, particularly at higher rates of award, can increase weekly income markedly. Another reason is likely to be the above average value of non-DLA benefits and the extra disability premiums which DLA recipients and those with more severe disabilities may

DSS (1990) The Way Ahead: Benefits for Disabled People.

See Rowlingson, K and Berthoud, R (1996). Atkinson J, Meager N, Dewson S (2003) and Corden A and Sainsbury R (2003).

Beatty *et al.* p57 (the difference between DLA recipients and other incapacity benefits claimants was small and may not be significant).

be entitled to claim. When set against the lower earnings potential of disabled people generally, the possibility that some DLA recipients might be little better off, or even worse off in work, cannot be discounted. While most people are likely to be 'better off in work' in the sense that their earnings plus in-work benefits will exceed out-of-work benefits (provided they do not lose their DLA), they may not perceive themselves to be 'better off' overall when other costs are taken into account such as travel to work and childcare.

Working out by how much any individual with a disability might be better off, or indeed worse off by working, is difficult. Even assuming maximum entitlement to tax credits and continued receipt of DLA, there is no absolute guarantee of being better off in work. Perhaps the issue is that if the perceived benefit of moving into work is modest, and there is a related perceived risk of losing DLA, then many individuals are likely to be unwilling to take that risk.

People in receipt of a disability benefit who begin work of 16 hours per week or more, would be entitled to claim WTC if their earnings were low. Those with a disability that disadvantages them in the labour market and in receipt of a qualifying benefit, would be further entitled to claim the disability element of WTC and a Return to Work Credit (RTWC) of £40 per week for the first 12 months. People receiving the DLA care component at the highest rate would qualify for an additional severe disability element. Working parents with dependent children under the age of 16 may also be entitled to claim a childcare element equal to 80 per cent of eligible childcare costs.

On the other hand, going back to work would ordinarily mean that IB/Severe Disablement Allowance (SDA) (now ESA) and IS would stop and HB and Council Tax Benefit (CTB), which are means tested, would start to be withdrawn. Those in work and in receipt of WTC and Child Tax Credit (CTC) will often be above the threshold for HB and CTB. People coming off IS would also lose their entitlement to passported benefits, such as free prescriptions, free dental treatment and free school meals, although, again, these may continue in work under certain conditions. Unlike IS, tax credits do not include any amount towards mortgage interest payments, and the RTWC is only payable for a maximum of 52 weeks.

Given the possibility of being little or no better off in paid work, remaining entitled to and continuing to claim out-of-work benefits while doing voluntary, exempt or permitted work can be a more attractive option for some DLA recipients. Under current 'Permitted Work Rules,' for example, it is possible to work up to 16 hours a week and earn up to £93 (although if also getting IS, HB or CTB, only £20 of these earnings would be disregarded in these assessments). This is for a maximum of 12 months, but for those who were more severely disabled and 'Personal Capability Exempt (PCA) exempt,' under previous rules, this form of permitted work could be indefinite. For people getting IS and other means tested benefits, working on a voluntary basis or doing paid work of no more than a few hours to stay within the earnings disregard limit of £20, might be preferred.

Moreover, assuming no change of circumstances which might affect entitlement to benefits, there is no requirement for people engaged in voluntary or permitted work to inform Department for Work and Pensions (DWP) that they are working. Starting work of more than 16 hours, or engaging in any work that is not exempt or permitted, on the other hand, is a change of circumstance which requires formal notification and engagement with DWP, carrying with it the possibility of DLA review. For some DLA recipients, the leap between working a few hours under the earnings disregard rule or under 16 hours under permitted work rules, and moving into work of more than 16 hours and claiming tax credits, may simply be too great. This might in part explain the high proportion of employed DLA recipients who are working less than 16 hours a week.

6.2.2 DLA 'income'

A striking finding from interviews with DLA applicants was that they almost unanimously viewed the benefit as 'income'. With the exception of a few recipients of lower level awards, for whom the monetary value was incidental, DLA was viewed alongside all other existing and potential sources of income as just one contributor to an overall 'pot' of money that would be available to live on. Although people could certainly identify a range of additional costs anticipated or incurred through having a disability or long-term health condition, very few had (either mentally or actually) allocated DLA to them. DLA was one element among several that made up individual or household income for them.

This reinforced the connection in people's minds between DLA and an inability to work. One Pathways adviser in an early discussion group felt that this was an important 'barrier' in itself that needed to be overcome before she could do her job effectively, and suggested that a change of name for the benefit might help in this regard.

'A lot of people think it's an income, their wage, and I say to them, "no, it isn't, it's not a 'living' benefit, it's an 'enabling' benefit – it enables you to get in and out of bed, get your shopping, pay somebody to cook your meals for you...It's actually nothing to do with work"...So a change of name [e.g. to Disability Enabling Allowance] would be good to alter that perception.'

(Pathways adviser)

For those who were still working and applying for DLA it was often explicitly referred to as a wage supplement or as a partial wage replacement. If they were continuing to work full-time the benefit was seen as something of a 'bonus', or a subsidy to low paid work.

'I might as well keep working because the DLA then comes in extra...that's a lot better, getting your DLA while working than while you're not.'

(In work applicant)

Select Committee on Work and Pensions Fourth Report (April 2003) paragraph 81.

'While I'm working now DLA is a bonus, as in it's a bit extra and it just tops my wages up.'

(In work applicant)

Equally, those applying when their sick pay dropped to half pay after six months were clear that this was their rationale and motivation (regardless of whether they were successful or not):

'If I'd have got [DLA] it would have made it [sick pay] up to what I was getting [before].'

(Applicant on sick leave)

If working part-time, or on enforced reduced hours or in a lower paying job than they were previously capable of, then DLA was frequently referred to as meeting the shortfall, or contributing to filling the income 'gap'.

'Between the DLA and my wages it makes up for what I lost before, having to finish the job that I was doing.'

(In work applicant)

'I'd cut my hours and then I'd been off sick...So when I was getting the SSP the DLA was topping up my wages ...'

(In work applicant)

'It [DLA] saves me going out to work Saturday, Sunday and two nights ... I'd rather not work any overtime at all if I can help it.'

(In work applicant)

Those applying from out of work and at some remove from the last time they were in paid employment, had a slightly different perspective but were, nonetheless, clear that their intention was to boost their (benefits) income.

'My partner is in prison at the moment but he knows I haven't been able to do a lot, and he knows how I've been like with money and he said 'well why don't you try and get some help?'

(Out of work applicant)

While in many cases it was prompted by a health 'event' of some kind, for most the main motivation was financial. One IB claimant, for example, was spurred into claiming DLA when his rent arrears to a housing association were preventing him from 'downsizing' his accommodation which he saw as necessary to his longer term plans for getting himself back in a position to work. Another long-term claimant, who had debts which she attributed to her son's heroin habit, applied in order to have some income that he did not know about.

Jobcentre Plus advisers in one of the discussion groups made the interesting observation that they felt there was a distinction to be drawn between IB claimants and long-term IS claimants, with the former more likely to be wanting to work but prevented by health problems, whereas the latter were more likely to be motivated by trying to maximise their benefit income.

'For IB customers I've found it's mostly health-related barriers — because if they qualify for IB then they've already been working and paying their stamp, so they've got a work ethic and it's their health that's the barrier preventing them being able to return to work. With those who don't qualify for IB, they're in receipt of IS and they've been in the system a while, and they know the system...DLA is just a passport for getting more money on, so there is a financial barrier does come in with IS customers.'

(Advisers' group participant)

It was difficult to verify this view from our interview sample, as the vast majority of applicants told us they were receiving IB rather than IS, and all were in the early stages of their DLA claim, even if they had been long-term out of work. Advisers were presumably talking about customers without sufficient contributions getting IB credits only and claiming IS on the grounds of disability. However, our research sample included several examples of claimants on IS applying for DLA for what appeared to be primarily reasons of boosting income, rather than more health-related reasons.

6.2.3 Viable income 'packages'

A great many claimants saw DLA as part of a process to put together a 'viable package' to live on. For some this included working, perhaps in a scaled down form, as with a man who had recently had a heart attack and been awarded high level mobility DLA:

'I'm going back to work when I can, but doing the job I've always done – I won't be able to...physically won't be able to do it...If the consultants give me the OK to work...I can now take a part-time job, whatever it may be...£47 a week [DLA] is not a lot, but to work part-time, getting £250 a week or £200...and I get this on top – that's financially a good deal, because you're only working half the hours, plus you're getting your vehicle covered...'

(Out of work applicant)

For others the 'package' was made up of DLA and other benefits. In those instances where people had had to leave jobs commanding good wages, even higher level DLA awards did not come close to bringing their benefits up to previous income levels. However, for those who had been working in minimum or close to minimum wage jobs, and especially if not working full-time hours, the addition of DLA to their other benefits could mean that they were only very marginally worse off than in work, or even slightly better off. This was particularly likely to be the case for people receiving higher level awards. For example, a woman in her forties who

had suffered a stroke was getting high level care and mobility (£114 per week) with her Employment and Support Allowance (ESA) of £100 per week:

'DLA is less than what I was on at work but [with ESA] that's made up for my wage now.'

(Applicant on sick leave)

Another woman with both high level care and mobility elements of DLA for two years felt a similar reassurance from getting the DLA income. Altogether her IB and DLA, along with Carer's Allowance (CA) for her niece and some minor additional benefits such as not having to pay road tax, meant that her effective income was approximately £190 a week compared to previous full-time earnings of £250, which gave her peace of mind.

'It settles you to know that you've got that income coming in. When I were just getting the sick money we found it really hard...and on your mind all the time...When I was accepted for the DLA it made a huge difference...I don't 'whittle' now...I did earn more than what I get now but I'm pleased with what I get...I don't get that much less.'

(Applicant on sick leave)

Thus, although the prevailing view of DLA as an income 'top-up' was found among both those in work or on sick leave and those already out of work, there were those, recently having left work, for whom DLA and other benefit income was seen as a viable **alternative** to working. Such solutions were often felt to have been 'hard won' and some people quite consciously used DLA as a way of managing their exit from the labour market once they were convinced they could not stay in work very much longer, or were not likely to return to work. Getting DLA was mentioned as the 'first step' by several applicants.

'I knew that I needed to get some kind of help to enable me to carry on working...that was in my mind when I first applied.'

(In work applicant)

It was followed up, or accompanied by efforts to adjust other aspects of their lives, in particular reducing housing costs to a manageable level, and investigating other potential sources of income from benefits (in this case from a position of being off work on sick leave).

'The rented accommodation is going to be easier to manage, I think, if I can claim another benefit...That's what I've got to find out, whether or not I can claim another benefit on top of [DLA]...I've been told because I've paid all my stamps I should be able to, so...that's what I'm looking at.'

(In work applicant)

Not all applicants were as 'strategic' in their thinking as this, with many essentially adjusting their finances reactively, but finding they could use DLA to ease certain transitions. One man on leave from his job with a heart condition had applied for,

and been awarded, DLA, and subsequently been referred for ESA when his sick pay reduced. He saw DLA as making a contribution towards equalising his income and his outgoings but not as greatly significant.

'Obviously [DLA] is there as an income every four weeks...It doesn't cover what I've lost in salary...but it goes some way.'

(Applicant on sick leave)

6.2.4 DLA flexibility

It was a common perception that DLA could substitute for lost or reduced elements of income and be 'part of the mix' in many different situations, as either a 100 per cent add-on to other sources of income, or as a fixed and reliable base upon which to build other possibilities, even long-term and speculative ones. Two such views of DLA were expressed by recipients; the first early in her working life who saw DLA as insurance against the time she would be no longer able to work; and the second, approaching 50, who saw it as providing a basis for possibly working part-time in retirement.

'It did help me think – because you've got some support there that will help you if you've got a job or not.'

(In work applicant)

'It's quite a big, heavy job – so I don't think there's much prospect of me going back to it. They could redeploy me but the problem is going to be financial... Maybe in the future...one possibility was if I did take early retirement, I can actually go back and work up to sixteen hours a week without it affecting any of my benefits.'

(Applicant on sick leave)

A further important aspect of the nature of DLA and its perception as 'flexible' income is that it comes into consideration, not just as an element in the balance between individual income and outgoings, but also in the overall household economies of those not living alone. Frequently it was part of the household adjustment to changes in the circumstances of one member, for a partner to make changes to their own employment and income contributions. This took a variety of different forms, from increasing their own work hours, finding a betterpaid job or moving from part-time to full-time work, through to coming out of retirement to earn an income or swapping employment and child-caring roles with their partner.

DLA was seen as facilitating many of these 'compensatory' strategies, for example by taking some of the personal care requirements off the shoulders of partners to free them up for work, or by paying for transport to allow the DLA recipient to take children to school, allowing their partner to work full-time – which could be considered items of additional cost relating to disability. The overall calculations being made at the household level were essentially the same as others described individually:

'[The DLA is] massively important because [my wife] working full-time doesn't meet my old wage, but me getting my 75 per cent [sick pay] plus the DLA, plus [her] wage, all equals to what I used to earn myself...so we're balanced.'

(In work applicant)

A less quantifiable benefit derived by many from receipt of DLA was that it allowed them to feel they were contributing to the household, whereas without it they had felt guilty in that regard.

6.2.5 The relative value of DLA

It is important to recognise that DLA awards can vary enormously. At the time of this research a single low level award for either personal care or for mobility needs was £18.65 per week, whereas someone receiving high level mobility and low rate care would get £67.75 and someone with both high rate care and high rate mobility would get £119.45 per week. 129 It is thus dangerous to generalise about the importance or impact of 'DLA' on people's finances, without being clear about the size of their award. Furthermore, the value of any DLA is also highly relative to the other sources of income (past, present and future) to which the recipient makes reference. Thus someone receiving a low level mobility award was able to be almost dismissive about the importance of DLA, describing it as 'just about keeping the baby in nappies', whereas a woman recovering from bowel cancer surgery, living on IB, whose DLA award almost doubled her income, was clear that it was absolutely essential to her survival:

'I would find it difficult without it. When you live on benefit...you can't really afford anything...By the time I've paid my bills [without DLA] I'd have to go without heat...without fruit.'

(Out of work applicant)

What was true for all recipients, however, was that they saw DLA as a benefit that could be added to other sources of income without affecting them or being affected in itself. While other IB and ESA claimants may be wary of jeopardising the security provided by their benefits, only DLA customers will have this **added** element of 'fear' or 'perceived risk'. There is certainly evidence that this is the case and it would go some way towards explaining the 'DLA factor' which affects recipients' expectations, their aspirations of working, and ultimately their collective employment rate.

6.3 Benefits complexity

A specific constraint affecting DLA recipients is the difficulty of making informed choices around the number of hours that can safely be worked, and by whom

DLA rates in early 2009 were High Care £70.35; Medium Care £47.10; Lower Care £18.65; Higher Mobility £49.10; Lower Mobility £18.65.

in the household, without running the risk of losing entitlement to benefits or being worse off. The scope for confusion and mistakes is that much greater when dealing with a variety of different funders, as is often the case for disabled people with higher level needs.

Many of the DLA recipients interviewed for this research had yet to arrive at a 'settled' view of their health condition or their capacity for future work, and so few had even attempted to come to terms with the regulations governing earnings disregards, permitted work, or the linking rules back into benefits if work could not be sustained. Where mention was made of these matters there was much acknowledged uncertainty and lack of understanding, and in some cases evident confusion as, for example, where someone thought the permitted work rules applied to DLA rather than to IB. This of course is in addition to the widespread assumption that DLA would be lost if they started working.

Several people commented on the difficulties they had faced in trying to get good, comprehensive information about DLA and other benefits, what they might be eligible for, and how their personal circumstances would affect them. Many initial delays in making DLA claims were put down purely to a lack of information, but more importantly, a number of people also commented on the overall complexity of the benefits system and on how difficult they perceived it to be to get information about all the different aspects of it. Making decisions in such a context was seen as very difficult. In the customer discussion group this was again strongly confirmed by those who were longer term DLA recipients. It was widely agreed that getting good helpful information was extremely difficult and that disabled people needed to become their own experts if they were to avoid pitfalls.

'It's all so piecemeal...I don't know how people manage...It's a minefield. You have to be quite clever in the world of disability!'

(Customer group participant)

Getting information to help make decisions about working was seen as having additional, specific difficulties attached to it, not least because DWP and Jobcentre Plus were viewed with enormous scepticism as policers of the benefits system, and any enquiry was seen to carry potential risk:

'Anyone that works for the benefit system – I don't trust them. A lot of people...they're absolutely paranoid that they're just going to pick up on whatever you say. "Oh let's check up on this person". And we've all got this perception that's what they do – they're just out to get us rather than help us.'

(Customer group participant)

6.3.1 Perceived cost of disruption

With most of those attending the customer group there was a strong feeling that benefits were vulnerable and could easily be lost if care was not taken. In the absence of clear information, speculation was rife as to what could happen as a result of any actions that might upset the status quo. Sometimes these were the result of poor information and poor advice:

'A Welfare Rights worker that I saw...said to me well if you apply for IB you might lose your DLA!'

(Customer group participant)

Sometimes they were based in bad experiences from the past:

'My experience of IB links into DLA because you put your pot of money together and you say 'can I live on this money?' I was on long-term IB for a while, then was able to go back to work self-employed, then got ill again and had to claim IB. I lost my long-term. No wonder people won't go back to work because...you get penalised in the long run.'

(Customer group participant)

And sometimes were the result of hearsay and suspicion, for example about the assessment and awards process for DLA, or the knock-on effects of working on other benefits or care packages:

'Nobody ever, ever said to me...you can go to work but yes your support worker can still come in the morning to get you up. I'd go and get a job tomorrow if someone told me that was secure.'

(Customer group participant)

'Both me and my partner are disabled...and we tried to get him the next rate up [of DLA care element]...but we were frightened that if we got the next rate up then that would impact on my DLA...you know, how much DLA will they allow in one household?'

(Customer group participant)

From whatever perspective, however, the sense of vulnerability and concern for the impact of any actions on benefits was pervasive, and seen as a key issue.

'The biggest issue?...How it will affect my benefits. Definitely!...Is my DLA secure?'

(Customer group participant)

'Really it's in our best interest not to have too many changes of circumstances otherwise...every time you have a change of circumstances they can actually stop your benefits while they look into it.'

(Customer group participant)

6.3.2 Impacts of change on households

This sense of precariousness, and the serious nature of possible consequences, was felt particularly strongly where whole families and households were relying on benefits income. Not only were benefits 'packages' potentially complex, with two or more people claiming DLA, CA or IB, but they were also felt to have been 'hard won' often over several years of arguing a case at appeals and tribunals. Receipt

of DLA was often central to arrangements that had taken a considerable time to set up and on which entire family units depended.

'One of the things I think is important... to realize... disabled people they're also going to be parents and have families and all the rest of it... what happens to my benefits has a massive impact on the whole family (and actually whether you get to survive as a family in some cases)... you're not just going to throw it all away lightly. You're going to look very, very closely before you're sure that this job (for example) is going to work out.'

(Customer group participant)

Complicated benefit rules make it more difficult for individuals (and advisers) to establish with any accuracy the net income from working and the balance of financial gains and losses which may affect the whole household. The amount of provision or support from one source can also be affected by another in various forms of 'cost shunting'.¹³⁰ This, combined with lack of expertise and experience among advisers, has been reported to undermine the reliability of 'Better Off Calculations.'¹³¹ While advisers carrying out these calculations can advise with a fair degree of certainty what the implications of working would be for tax credits, HB and CTB, for example, they cannot give any guarantees on receipt of DLA or non-social security benefits. Furthermore, assessments of being better off in work are generally only made in respect of the individual, not the household unit. It is for such reasons that Benefits Enquiry Line (BEL) staff no longer carry out these calculations. Advisers participating in our discussion groups admitted to being wary of carrying out better off in work calculations for people in receipt of DLA for the same reasons.

6.3.3 Perceptions of risk

Among recipients themselves it was only those on relatively high wages who could say with any degree of confidence that they would be better off in work, and all perceived an element of risk relating as much to considerations of the time and effort required and the disruption caused by moving from benefits to employment as to purely 'better off in work' calculations.

One of the longer-term claimants interviewed, who was also a long-term DLA recipient making her fourth re-application, provided a clear example of this, and of how those who have become familiar with the benefits system can make decisions based even more on minimising the risk of disruption to their income, than on maximising its monetary value. She had calculated that if her husband claimed CA for looking after her then the household would be a net £4 better off per week. However, a bad experience when he had previously made a CA claim, resulting in a reported gap of nearly six months in other benefits, made her reluctant to try again and risk the same thing happening once more.

¹³⁰ Howard M (2203) p 22.

Arthur S, et al. (1999) New Deal for Disabled People: Early implementation.

'We kept it as it was because if we had to go through that again...! wouldn't go through that again, waiting six months for an answer was just not acceptable.'

(Out of work applicant)

Any possible action that might disrupt complex and inter-linked arrangements was viewed at the very least with extreme caution by this claimant regardless of whether she thought they would be better off financially with her working.

In this instance, the family had made arrangements that involved both her and her partner sharing the care of their three boys, who were all diagnosed with autism, and all receiving DLA, because she could not undertake all their care due to her own condition. Both had worked full-time in the past, but the household's caring needs and her disability were seen to preclude him from working. She was undertaking training with a view to working herself in the future, when she could command a salary sufficient to cover the household's modest needs, and her partner was going to specialist courses to allow him to take over the care of their children. She had been actively exploring work possibilities that she might be able to manage, which would need to be sitting down jobs with an employer willing to be flexible about the need for breaks. A Welfare Rights adviser had calculated for her that she needed to earn a minimum of £13,000 a year in order not to be worse off than currently. Despite being actively engaged with the benefits system for many years, having controlled the household budget, and having a clear plan for the future involving work, she was nevertheless still surprised to hear that she could work and receive DLA (though it was unclear whether the advice worker had factored this into the calculation of £13,000 or not).

6.3.4 Interdependencies of benefits

It was not uncommon to find that claimants of DLA were part of a household where there was more than one person with a disability, whether that was children, as in the case above, or partners, or both. Moreover, different care needs could be met by different people at different times, leading to complex interdependencies of benefits.

'Both me and my partner are disabled...there's two lots of disability benefit coming in, there's IB coming [and] SDA...it really gets tangled up'

(Customer group participant)

'My daughter has an impairment and she's my carer a lot of the time, but sometimes I'm her carer.'

(Customer group participant)

This appeared to be more likely to be the case in the households of longer-term benefits claimants, both because of deteriorating health over time and also because caring needs were a factor in making employment difficult for people.

There were several examples among our interviewed DLA claimants of highly complex household income arrangements of this sort, making decisions about work problematic. They shared an expressed concern not to risk the stability that had been achieved, though they did not all completely exclude working or the possibility of some kind of work in the future.

In one example, a man in his early 40s, living with his wife and two young children, had been made redundant in 2002 from a full-time, longstanding job, and less than a year later diagnosed with psoriatic arthritis. He had been awarded higher rate mobility DLA for three years and was thus making his second re-application in 2008. He did not feel he would ever be able to work again and was receiving higher rate IB. His wife was herself disabled and receiving higher rate mobility and low care DLA, though she was able to work self-employed from home. Her income was low but she was able to get working tax credits. Their son had been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and was also getting DLA. Overall, DLA made up a major part of their income and paid for them to run two cars which allowed her to deliver goods she was selling from home and for him to have some independence.

In a second example, a man in his late 40s, had been declared unfit to work in his former job four years ago and had been receiving DLA (high mobility, low care) on a series of short fixed-term awards since that time for needs arising from osteoporosis, asthma and arthritis resulting from obesity. Although technically on sick leave he was not going to return to this job. His strategy for managing was clearly to maximise the benefits he and his wife were receiving, rather than thinking about returning to work. While he was working and then subsequently on IB for a period, his wife also worked, though following a forced switch to IS (which is means tested) she had given up her job (to look after him). He was currently considering applying for a higher level of care award that his wife could claim CA. DLA made up approximately one-third of their disposable income. The claimant was currently on a waiting list for a gastric band operation to address his obesity, but was pessimistic about his chances of returning to work even if the operation was successful. He even expressed concern that the operation might result in his being judged capable of working and thus threaten his benefits.

Thus, even when wages could exceed benefit income, some disabled people choose to remain living on benefits for reasons of financial security and certainty. Perceived risks serve to reduce or outweigh any theoretical financial gain associated with moving into work.

'Benefits might be low but they are secure and you know what you are getting.' 132

Where income from benefits is much higher than average, as was the case with many DLA recipients, the incentive to increase it by working appeared to be that much less.

Select Committee on Work and Pensions Fourth Report (April 2003) paragraph 75.

6.4 DLA as a work incentive or enabler

A consequence of the very diverse circumstances DLA recipients find themselves in, the varying degrees of commitment to work that they have, and the different relative value of awards for them, is that while disincentives operate for many, there are those for whom DLA can be seen as having enabled employment. One of the original research questions was whether DLA might be acting in this way as an enabler of work for those receiving it.

6.4.1 Effectiveness of incentives for disabled people

The economic rationale behind financial incentives, and which underlies many recent changes to the tax and benefits system, suggests that the greater the gap between in-work and out-of-work income, the more likely a person will be to choose work over benefits. This rationale only really applies, however, if the person in question is both capable of working and able to get work suitable to their needs. For disabled people, work decisions are frequently dictated by health issues, and it is often only when these have been addressed or overcome that the financial implications of working are considered and taken into account. If in reasonable health, some disabled people would choose to work regardless of whether they were financially better off. On the other hand, if they considered their health was poor or deteriorating, no amount of financial incentive would persuade some people that work was a feasible option.

Evidence to date suggests that financial incentives make little difference to people who, for whatever reason, consider themselves unable to work because of a serious health condition or disability, or who cannot get a job that is suited to their requirements. Thus, the effectiveness of transition of in-work benefits in incentivising work among disabled people is strictly limited if they cannot get a job because of employer discrimination, for example, or cannot find work suited to their particular needs or impairments. Some disabled people may therefore be less responsive to economic arguments and more difficult to incentivise into work.

6.4.2 Previous attempts to incentivise work for disabled people

The limited effectiveness of the many attempts in the past to incentivise work for disabled people appear to testify to the considerable difficulties in designing policy instruments that can be effective in this area. Evaluations of DWA, Disabled Person's Tax Credit (DPTC), the disability element of WTC and the RTWC, indicate that financial incentives have generally had limited success in encouraging benefit recipients with disabilities into work, although they have had some success in enabling work retention and increasing income, particularly during the transition from benefits to work. The evidence from these evaluations is set out in Appendix D.

6.4.3 DLA as a work 'enabler'

In the strict sense of the word it is difficult to see how DLA could act as an 'incentive' to working. It can be claimed whether a person with disabilities is in work or out of work, and therefore should not disincentivise working. But it does

not represent any additional financial benefit or income that can only be accessed by choosing work and which might therefore help persuade people to make that choice. To date, there is no evidence to indicate that DLA as currently designed and delivered, acts as an incentive to work.

DLA could potentially be seen as a work 'enabler' in the limited sense that a person who is out of work and getting DLA and unaware that it is payable in work may be given an additional incentive to consider working if they were made aware. However, reassuring someone who already gets DLA that they will not automatically lose it by moving into work, cannot be viewed as having the same potential to incentivise as receiving an extra financial payment to which only those who move from non-work to work are eligible (as for example WTC or the RTWC).

DLA might, however, still be considered an 'enabler' of work if the money it provides helps overcome specific problems and difficulties encountered in trying to access work or in trying to stay in a job in spite of a disability or health condition. The potential enabling effect of additional payments to those looking for work was the motivation for the Job Preparation Premium for longer-term incapacity benefits claimants (see Nice *et al.* 2008). Respondents to this study identified several ways in which they felt their DLA to have had an enabling effect for them, including:

- overcoming transport difficulties in traveling to work or meeting other workrelated additional costs;
- 'buying time' allowing fewer hours to be worked or covering the cost of necessary time off;
- making the choice of taking low-paid work more financially viable than it would otherwise have been.

The following sections look at each of these possibilities in turn, in the light of the qualitative evidence derived from face-to-face interviews with applicants and recipients.

6.4.4 Meeting travel to work and other work-related costs

Among our sample of interviewed recipients the one outstanding issue regarding extra costs when in work related to transport needs. This was not simply a question of expense, but also one of the practicality of different modes of transport, the flexibility available to respond to fluctuating health conditions, personal safety and comfort when travelling, and the need to arrive at work in a fit state to carry out the job.

Those people awarded the high level mobility element of DLA had the option of buying into the Motability scheme and leasing a new vehicle. Where respondents had done this it was almost invariably identified as the single most important effect of their claim being allowed. A few had applied for DLA with this end specifically in mind from the start. For many with mobility problems, having access to a car and being able to drive were seen as absolute preconditions for being able

to consider working. Where DLA had provided a vehicle, therefore, it was seen as the major factor allowing them to work.

A woman with fibromyalgia, whose mobility was limited to the extent she could not climb stairs, was sleeping in her living room and using a neighbour's downstairs toilet, assessed the value of her Motability car as key to remaining in work. She had already reduced her working hours to 16 per week, but felt she would have had to stop work altogether, or at the least reduce her hours still further, had she not got the car.

'Because it [DLA] is giving me [the car]...I probably wouldn't have been able to get there [to work] unless I went on the bus and that would have been too much...it's only a five minute drive but it's an hour on the bus into town and out again. I probably would have given up.'

(In work applicant)

Another woman, who had severe rheumatoid arthritis, also saw her Motability car as crucial, because it was designed to be easier for her to steer with badly affected hands, wrists and shoulders, and she was, therefore, able to drive into work and get there without feeling exhausted. There were undoubtedly other factors in this case keeping her working. She saw it as beneficial to her condition to keep working. Also her husband had recently been made redundant and they were feeling financial pressures. Nevertheless Disability Living Allowance (DLA) was instrumental in making her decision to stay in work a possibility.

A similar combination of personal determination to work, made possible with the help of DLA, was evident in the case of another recipient, a family man in his mid 20s, also with severe arthritis. He was about to take possession of a new car through the Motability scheme having been awarded the higher level mobility element of DLA, following a deterioration of his condition which had greatly increased his dependency on motorised transport. In addition to making his general mobility more bearable, the new car was seen as essential for helping him to stay in work for as long as possible. He had already made great efforts to keep himself in work, including relocating to take one job and then switching to another, involving less standing and less physical duties, when that became too difficult for him to sustain. However, his new job entailed a 30 minute commute which he felt he could not continue with using his old vehicle.

Helping to manage a condition and minimising the detrimental impact of travelling to work were common factors for several people. For example, a woman who suffered from a condition (scleroderma) which resulted in her feeling cold the whole time, saw the main value of having a car and being able to drive to work as being that it allowed her to avoid waiting in the cold for public transport. In this and many other cases the effect of DLA was more indirect as she was not getting high level mobility payments, but was able to use her benefit to pay for petrol to get to and from work by car.

DLA was used in a more ad hoc way by many of those people who were working to help them cover the occasions when they were feeling particularly poorly and their usual arrangements for getting to work were unable to function. Typically this involved paying for taxis on days when they were unable to drive, with their DLA payments providing this 'back up' option for coping with fluctuations in their condition.

6.4.5 Buying time (reduced hours and days off)

Several respondents described using their DLA in ways that can best be described as 'buying time' – making direct links between receipt of the benefit and the hours they could thereby choose to work. For some this was a relatively simple calculation that with DLA as part of their income they could afford to work part-time to suit their condition, or could avoid the financial need to do overtime hours.

In most instances, it was a case of people balancing the pressure of their financial commitments against the amount they could earn if working part-time, and weighing this up against the effects that different choices were likely to have on their health. Many were seeking the solution that would keep them in work, as they were committed to working, and in some cases DLA was clearly perceived as being what made the difference between doing some work or none at all.

'I didn't want to pack it [work] up, so that allowed me to cut my hours and still carry on...I knew that I needed to get some kind of help to enable me to carry on working...and with them like accepting me and giving [DLA] to me...that was in my mind when I first applied. It was a choice of either packing up work or hopefully getting DLA.'

(In work applicant)

'Because I managed to get [DLA] that allowed me to cut my hours and still manage to go to work and keep a job.'

(In work applicant)

An interesting variation on the way DLA could help keep someone in work was provided by a young woman of 25 diagnosed with multiple sclerosis (MS). In her case she was using receipt of DLA (high level mobility and low level care awards) as a form of 'insurance' to help support her in full-time employment. The DLA allowed her to take unpaid time off work if she needed more time off than her employer was willing to cover with sick pay. She felt this gave her additional job security by helping to reassure her employers that they would not be unduly affected by her disability and the fact that she might have to take more time off sick than would a non-disabled employee.

This woman was not the only respondent to mention the stress experienced as a result of feeling obliged and under pressure to work, or to work more hours than were felt to be good for their health. Many emphasised the positive effects that being awarded DLA had had by removing some of this pressure and the associated stress.

In one such case, a young mother was under treatment for severe depression and anxiety attacks that had been triggered in great part by financial worries – getting into debt and fearing losing her house. The awarding of her DLA claim did so much to relieve both financial worries and her sense that she had no option but to go back to work, even though advised against it both by her doctor and her Community Psychiatric Nurse (CPN), that she actually thereby felt strong enough to make moves gradually back into her old job. Not feeling she must work helped her mental health condition to such a degree that she was paradoxically then able to do so, and had returned to work on light duties and on a phased basis agreed with her employer. Had she not gone back to work when she did she felt that there was a high probability of her never getting back into employment again.

'The DLA helped because I didn't have to go back to work until, say, September next year. The money would have allowed me to be able not to work...I didn't have to go back to work, but it was a case of I was frightened if I didn't...that I would end up staying [at home] and 'vegetating'... the girls would go off to school and I'd still be too frightened to go out to work every day. So it was a thing that, you know, I needed to push myself to do. The DLA would have allowed me to have more time [off]...but it was a case of 'I have to try'... It wouldn't have been a massive issue if it hadn't have worked out and I'd lost my job – not as big as if I didn't have my DLA money.'

(Applicant on sick leave who had since returned to her old job)

Another DLA customer was battling with breast cancer, and the after effects of surgery and aggressive drug treatments. Anxiety about her condition was aggravated by financial pressures. Her husband had had to go back to work out of retirement in his 60s, but was starting to have health problems of his own. For her, therefore, getting back to work was important for many reasons.

'The financial [pressure] wasn't as strong as it had been before I knew I'd got DLA...but that took the pressure off. It took a lot of pressure off me.'

(In work applicant)

Again, the psychological effects were as important as the purely financial factors. DLA provided a cash 'bonus' at the time when she most needed it, and allowed her to work a few hours (ten per week) and still feel she was contributing to the household and taking some pressure off her husband. Although she wanted to work full-time she knew she could not manage that in her condition, but doing some work was extremely important for her. Having worked all her life prior to her illness, working was part of her self-image. Getting out into some form of work, however limited, she saw as an essential part of managing her depression, which was why she had done so even against the advice of her doctor.

'The doctor said **physically** he didn't want me to [return to work] but **mentally** it's done me the world of good – definitely.'

(In work applicant)

'I need to get out to work. I need to feel that. I need to be...I need to get my life back. I've got to get control.'

(In work applicant)

Without DLA she asserted that she would have started doing too many hours of work and fallen sick as a result, probably perpetuating her sense of 'failure' and her depression. DLA could be said to have enabled a sustainable return to work which, by reducing the urgency to work more hours prematurely, would keep her in employment in the longer term.

Many people were caught between wanting to go back to work and not wanting to risk their physical or mental health further by doing so. Switching to less demanding work or reducing the hours worked (or both) were common strategies, though either was likely to have the effect of severely reducing income in comparison to working full-time at their previous job. Depending on the levels of wages being earned, and the level of DLA awarded, the benefit could be the decisive factor allowing such changes to take place.

An MS sufferer described the interaction of all these factors in her own case. She had had to give up her job as a midwife, the demands of which were threatening to make her condition worse, and take up part-time work as a school assistant three days a week.

'Because of the work that I was doing, it was high stress, my episodes were coming really thick and fast, so sometimes I couldn't see properly, I couldn't move properly, my legs would go. But as soon as I reduced my stress...you know my relapses have come down dramatically.'

(In work applicant)

'I knew that I wanted to go back to work, mainly because I wanted to get out of the house, to do something. I wanted to have that sense of achievement. But I also knew I couldn't go back to work full-time because I just wasn't capable of it any more and, you know, if I did I was risking making myself worse. So I hit a 'happy medium' – with work, but obviously the wages are rubbish in comparison. The DLA...makes up for what I lost before, having to finish the job that I was doing.'

(In work applicant)

This case illustrates the combined factors in decision-making of needing to seek work involving less hours (frequently to reduce the physical demands of the working week) and needing to seek work with less strenuous or less stressful content. In most cases both such reductions entailed facing a drop in earnings. The other key perceived role of DLA was thus to compensate for having to take work at often greatly lower rates of pay.

6.4.6 Making low pay more viable

Several people made particular mention of DLA enabling them to take lower paid jobs or to work for less money. There were considerable variations, however, in what they considered to be 'low pay'. Assessment of income was, not surprisingly, a relative value in relation to previous earnings and the lifestyle and commitments supported by them. The value of DLA awards was likewise seen in relative terms according to how the level of awarded elements (high or low awards of one or both care and mobility components) compared with previous and current wage levels.

One customer described his first job change as being mostly significant in signalling a move out of 'a career' track.

'...it paid kind of half decent money but it was never going to be a career.'

(Applicant on sick leave)

However, his subsequent change of employment, when he could no longer physically carry on in this job, involved a significant drop in wages. A DLA award of lower level care plus higher level mobility had made the new job viable for him.

'There's an extra bit of money coming in...I have had to...take a job but it is a lot less money – so it [DLA] kind of makes up the money on that...'

(Applicant on sick leave)

For those with a strong work ethic and a determination to stay in employment, DLA could also be the decisive element keeping them in a job once their earning power had dropped to levels comparable to what they might expect from out-of-work benefits.

'It got to the stage [where] I probably would...get more being unemployed than employed...so yes, it [DLA] kept me in work because it did what I wanted it to do, it kept me working, [without] I'd probably have to give it up.'

(In work applicant)

In this instance a high level mobility award had allowed the recipient to remain with the same employer, doing lower paid work than previously, and to be able to avoid being forced for financial reasons into giving up work altogether and claiming benefits.

At perhaps the other end of the spectrum was a person who was a high earner (a company MD) when diagnosed with MS. When made redundant, and encountering great difficulty finding another job, his perceived problem initially was how to maintain his lifestyle and service a mortgage. Financial pressures came to a head after six months and he applied for DLA and for JSA, still believing he would soon find a job. When his wife became depressed and resigned from her full-time job as a State Registered Nurse he actively considered the 'no work' option. However, discussions with a DEA led him to consider other options, and when awarded high level mobility element of DLA he was able to consider his current job – 30 hours per week on a flexible basis and lower salary with a voluntary sector organisation.

'[DLA] gave me the option to be able to pick...something that I wanted to do rather than something I have to do, if you see what I mean. It gave me breathing space...so I could pick that type of position that I've taken now, because otherwise, if I didn't get [DLA] then basically...I wouldn't be able to do it because financially it wouldn't add up.'

(Out of work applicant)

Receipt of DLA was enough in this case, albeit alongside a determination to work and a re-orientation of values (working to live rather than living to work as he put it), to tip the balance in favour of employment in an appropriate, suitable and indeed life affirming job.

'My salary that I earn now, because I'm part-time and so on, is nowhere near the salary [which] on its own will pay for our life...The important thing... is that you get to do something that [makes] you feel you are worthwhile again...because I was starting to feel...that I was not worth anything.'

(Out of work applicant)

6.4.7 Impacts on job retention

Previous evaluations of DWA, DPTC, the disability element of WTC and RTWC have all found that the movement from benefits into work among eligible individuals with disabilities has been low, and the overall measurable incentive effects small. The main effect of financial incentives designed to encourage the take up of paid work among disabled people has been shown to be more apparent in supporting job retention than in stimulating job entry, and in many cases in enabling a reduction rather than an increase in working hours.

Evidence from our qualitative interviews with recent DLA applicants tended to support these conclusions. They showed that DLA also appears to have limited, if any, incentive effects on people in terms of encouraging them to **take up** paid work. All of the small number of DLA recipients interviewed who had moved into employment from being without a job, were strongly work orientated and said that getting DLA had made no difference at all to their decision making. Several had not been claiming any out-of-work benefits before finding their current job, and it is indicative that, of those who were, more were claiming JSA than IB.

However, DLA had, in a number of cases, supported job retention. The key ways in which it had achieved this were by facilitating travel to work and allowing people to adjust the tasks they undertake and the hours that they work in a week to better suit their reduced capabilities.

Some recognition of the important role of DPTC in keeping people in work was reflected in the introduction in October 2000 of the Fast-Track Gateway which provided access to DPTC early on for people who become sick and disabled while they are in work, to help them remain in employment. To date there has been no corresponding recognition or policy in relation to DLA. Our evidence would suggest that it can and does perform a similar function to DPTC in supporting work retention for some people who become sick or disabled in employment.

7 Conclusions and implications for policy

7.1 Conclusions

There is still much to be learned about the Disability Living Allowance (DLA) recipient population, in particular whether the findings from this study, looking at recent applicants, are equally applicable to the long-term claimants who make up the majority of those receiving the benefit. There is also an important question to be answered about how long those who continue to work when in receipt of DLA are able to continue to do so, and whether, therefore, any job retention gains that might be made can be sustained in the long term for this customer group.

Notwithstanding the limitations of the qualitative data presented in this report, there are a number of conclusions that can be drawn in answer to the research questions that informed the study.

From the review of evidence existing prior to this study we can conclude that DLA recipients are, on average, more severely impaired than other disabled people, have a greater likelihood of multiple disabilities, including mental health conditions, and are additionally disadvantaged in the labour market because affected disproportionately by the types of impairment (locomotor, intellectual and behavioural) that carry the greatest employment disadvantage. Part of the greater distance from the labour market among DLA recipients thus derives from a greater severity of disability and a concentration of certain types of particularly disadvantaging impairments.

However, our research supports the hypothesis that there is also a DLA specific factor which makes it less likely that they will work. We found this DLA factor to comprise two key elements: one deriving from the widespread perception that DLA is a 'compensatory' income for those unable to work because of their disability or health condition; the other deriving from a possible financial disincentive effect of the greater benefit income of DLA recipients, and the perceived risk to complex benefits packages from any change in circumstances.

The DLA applicant population was made up of those still in jobs, those on sick leave and those who had been out of work for varying lengths of time. There were important differences between these groups in terms of their perceptions, expectations and motivations, many of which derived from their differing distance from the labour market. However, all faced considerable difficulties in addressing issues of work and can justifiably be considered 'hard to help'.

Evidence from the evaluation of other attempted incentive measures was reinforced by the research, which points to job retention as the area where most might be achieved, through supporting DLA recipients, to counter disincentive pressures and to address employment viability.

7.2 Implications for policy

Overall, what this study and review of evidence has shown is that dynamic factors around the process of becoming disabled, claiming disability benefits and the decision to stay in, leave work or return to work are all of major importance for devising appropriate policy in this area.

7.2.1 Moving DLA recipients (back) into work

The focus for employment policy is how the very low employment rate of DLA recipients might be raised, and the related issue of what additional factors might have to be dealt with in providing employment support to DLA recipients over and above that provided to other incapacity benefits claimants. The original target of moving one million Incapacity Benefit (IB) claimants into work was always recognised as an enormous challenge. To succeed in doing this would require a conversion rate approaching the best achieved from any employment programme in the last fifteen years, even before taking account of any effects on the demand side of the labour market from the current recession.

Furthermore, recent figures for successful job entry from Pathways shows it to be falling significantly below target. DLA recipients make up a large proportion of all incapacity benefits claimants, and other recent research has confirmed that they are on average further removed from the labour market than those not receiving DLA, and are less likely to want to work or to aspire to paid employment. To move DLA recipients into work is thus likely to be additionally difficult. Our research confirms this overall picture.

If DLA recipients are thus a more difficult group to move into work, the question remains as to how their additional problems or barriers might be addressed, and indeed whether they **can** be addressed within the current support delivery framework. Can a form of intervention be envisaged that would be more effective than what is currently available? And if so, when might it be triggered, who would deliver it, and what should it consist of?

7.2.2 The diverse nature of the DLA recipient group

Part of the difficulty derives from the extremely diverse nature of DLA recipients as a group, and the quite distinct ways in which they become part of that population, and ultimately join the population of inactive benefit claimants. Our research was designed to throw light on the 'front end' of the process by surveying and interviewing people in the first few months following a claim for DLA. While we were able to follow up actual behaviours and outcomes to a point some five months after application was made, longer-term outcomes were not accessible to us. For example, we know from our survey sample that ten per cent of reapplications for DLA were disallowed, and can infer that a minimum of ten per cent of DLA recipients do not continue indefinitely to receive the benefit. However, we can only speculate as to how many other recipients of fixed term awards recover sufficiently or for some other reason decide not to re-apply when their fixed term award comes to an end.

For recipients of DLA in the early months of their claim, we distinguished two different groups that emerged as having some important differences in terms of their attitudes to work and their perceived relation to employment: those applying from within jobs who were still employed; and those applying from a position of being already out of work. For each of these groups it was further instructive to look at constituent sub-groups. Among those with a job there was a roughly even split between those still actually working when making their application and those off sick and receiving sick pay from a job that was potentially awaiting their return. Among those applying when out of work, just under a quarter had been out of work for less than twelve months, whereas the bulk had been out of work for more than a year or had never worked. Table 7.1 shows the actual breakdown for those whose applications were approved and went on to become DLA recipients.

Table 7.1 Employment status of eventual recipients when applying for DLA

	%
Employment status	(n = 371)
Working	17
Off sick and on sick pay	14
Out of work short term	15
Out of work long term	54

While all tended to share the view of DLA as a source of replacement or additional income, their differences hold some important consequences for considering possible interventions with DLA recipients, especially as one obvious trigger for intervention might be the DLA application itself.

7.2.3 Possible support interventions

Those still in jobs were by definition closest to the labour market and, even those who had been on sick pay for six to twelve months were still in contact with an employer. Together they make up nearly one-third of all DLA applicants. This is important given that only around one in five disabled people are born with their disabilities.¹³³ Most people acquire their disabilities in later life and the vast majority of these are **in work** at the time of onset.¹³⁴ Policies designed to promote employment among disabled people have tended to neglect this large majority until such time as they have lost their jobs or left work altogether.

To date, the main focus of policy and research has been on labour market entry and the movement into work of disabled people who are claiming incapacity benefits. For those who become disabled in work, however, a more important issue may be employment retention and how working arrangements can be adjusted to accommodate their new requirements. Through targeting new claimants of DLA, some of whom were still working, some off work on sick leave, others contemplating leaving work altogether or having very recently left work, the current study has shed some light on the importance of this transitional period.

This group offers perhaps the best opportunity for making gains through intervention, specifically by supporting job retention and helping to stem the onflow of DLA recipients to the ranks of out-of-work incapacity benefits claimants. A focus on keeping people in jobs makes sense, especially during a recession.

The point at which people made their DLA claim involved a degree of chance as to when they first became aware of it, and that they might be eligible, but many of those applying while continuing to work (albeit in some cases on reduced hours) displayed the strongest determination to be in paid employment and were struggling on in their jobs while seeking a manageable solution. Several had already undertaken discussions with their employers about adjusting their hours and their work tasks to accommodate their health condition. Very few, however, were aware of available in-work support and there would appear to be an opportunity for support intervention to assist and facilitate the process of keeping them in work, by providing information about available funding through tax credits and Access to Work, clarifying the nature of DLA, linking people to rehabilitation services and liaising with employers about possible flexibilities. DLA recipients who had remained in work stressed the crucial importance of having the support and understanding of their employer in agreeing changes. This was in sharp contrast to the concerns of those who had left work, that re-entry to a job with a new employer would be doubly difficult once carrying a poor recent health record and without the benefit of a known, often long-term, work history.

¹³³ Burchardt T. (2003) p 3.

¹³⁴ Burchardt T. (2003) p 3.

Earlier knowledge about DLA would have led to an application sooner for several recipients who were on sick leave, or who had recently run off the end of a sick-pay period. There is a case to be made that making that information more widely available, and even promoting DLA through, for example, workplace HR departments, might pay dividends in keeping more people in work for longer. Set against the potential advantages of engaging with DLA applicants while they are still in touch with employers are the drawbacks that derive from still at this point being very close, in many cases, to the health crisis that has led to the claim. As we have seen, this raises a number of psychological barriers to thinking about alternative work possibilities and arrangements which may be difficult to tackle until some time has elapsed. Engaging more directly with people's health and disability issues is likely to be required, as well as allowing for individual timescales in rehabilitation and condition management.

7.2.4 Job retention

The theoretical possibility thus exists for an intervention aimed at job retention, for approaching one-third of DLA applicants, triggered by their application and consisting of information, support and employer liaison services perhaps in the mould of those formerly provided by Jobcentre Plus Disability Employment Advisers (DEAs). Although such an intervention (a Work Focused Interview type meeting or series of meetings linked to practical support) could perhaps be delivered by DEAs, there is not currently any mechanism for linking between Pensions Disability and Carers Service (PDCS) and Jobcentre Plus, even if that were thought to be appropriate. A somewhat differently accented intervention via PDCS might be an alternative, although this would require a local presence which this agency of DWP does not currently have. It would also entail something of a cultural change for the PDCS which has until now maintained a 'work neutral' position in line with DLA's status as a non-taxed and non-means-tested benefit. There will be some risks associated with starting to link DLA with questions about work. However, links are already being drawn in some people's minds between what are perceived to be the parallel processes of assessment and eligibility for DLA and ESA.

For DLA applicants who are in work or on sick leave, it will be their DLA application that is made first, and any application for ESA if it gets made will follow at the point sick pay runs out or later. This makes the point of DLA application the most appropriate time for an early intervention. For those making an application from out of work the reverse is generally true, with the great majority already being in receipt of other benefits for greatly varying lengths of time.

7.2.5 The longer term out of work

Within the out-of-work group of applicants, those who had been out of a job for more than a year were significantly further from the labour market than those more recently in work. Indeed, a number of those out of work less than a year were not in markedly different circumstances from many of those describing themselves as on long-term sick leave, although their DLA applications had been

delayed for various reasons. Longer-term claimants were found to be making their applications for DLA primarily as a means of boosting their benefits income and frequently saw this allowance as confirming and consolidating their out-of-work status. Intervention at this point could be argued to be too late, and the point of claiming incapacity benefits to have been the better time for effective action. The conditionality associated with ESA has been designed to address issues at this point for future claimants. Further action linked to DLA receipt may need to be different in emphasis, with a greater concentration on rehabilitation support and household organisation than on a 'jobs first' approach.

Some financial disincentives to working were found to operate for all DLA claimants by virtue of DLA being **additional** to other benefits and the 'passport' to further help. The risk associated with disrupting long-standing (and often perceived as 'hard won') benefits packages, however, was greatest for longer term claimants and households with complex interrelations of roles and benefits. Of particular importance in this regard were caring responsibilities and mutual caring arrangements, which directly affected work decision-making for all household members. This area of constraint might be one which 'later' DLA support interventions could tackle in the future.

In addition to any possible employment support interventions that might be linked to DLA receipt, there are some specific measures that might help address limited aspects of perceived risk in considering moves from benefits into work for disabled people and long-term health conditions. The provision of a **guarantee** that working will not lead to a review of DLA eligibility would be one such possibility, perhaps backed up by a fixed timetable of reviews for all claims. In the meantime, a minimum aim must be to ensure that moves towards rehabilitation, condition management, personal development and re-training are not automatically interpreted as evidence of 'job-readiness' but are properly considered within meaningful individual timescales.

Appendix A DLA and DLA customers

Eligibility and assessment criteria¹³⁵

Disability living Allowance (DLA) replaced and extended Attendance Allowance (AA) and Mobility Allowance (MA) in April 1992 for people who became disabled before the age of 65. It is payable to people who are disabled and have personal care needs, mobility needs, or both. The benefit consists of two components and five payment bands: a care component for personal care needs, paid (at the time of this research) at three weekly rates, low (£18.65), middle (£47.10), and high (£70.35); and a mobility component paid at two rates, low (£18.65) and high (£49.10). In what Berthoud calls 'a fit of bureaucratic madness,' successful applicants are awarded one of 11 possible combinations of components and rates (although because the lower rates of mobility and care components are the same, there are in fact ten discrete levels of combined benefit in terms of monetary value).

Applicants must satisfy a series of care or mobility 'tests'¹³⁷ to qualify for DLA. The starting point for the lowest rate of award for the care component is that applicants must be so severely disabled, physically or mentally, that they require attention, care or supervision from another person in connection with bodily functions or in carrying out everyday activities, for example, cooking a meal. For the middle rate of the care component, the need for attention, care or supervision should be frequent or continual throughout the day. For the highest rate of award, the care need must be constant or prolonged both during the day and at night.

For a comprehensive account of DLA eligibility and assessment criteria see Disability Alliance (2009) *The Disability Rights Handbook April 2009-April 2010*.

Berthoud R, et al. (1993) The economic problems of disabled people.

Although called 'tests' in the official DLA guidance, the process is initially one of self assessment. Thereafter, decision-makers can seek additional information and evidence, which can (but rarely does) include an examination by a DWP-appointed medical practitioner.

For the higher rate mobility component, the applicant must be unable or virtually unable to walk or be suffering from a condition such that the exertion required to walk would be life threatening or pose a significant risk of deterioration in their health. Lower rate mobility component is intended for people who are physically able to walk but need supervision or guidance outdoors, for example, people who are blind or have a serious learning disability. These quite rigorous standards of disability severity are one key reason why around half of all applications for DLA are initially disallowed.¹³⁸

To be eligible for DLA, the need for help must have existed for three months (the qualifying period) and be expected to last for at least a further six months (the prospective test). People who are not expected to live longer than six months because of an illness are on 'special rules' and do not have to satisfy either the qualifying period or the prospective test. People on special rules currently account for less than two per cent of the DLA caseload.¹³⁹

DLA awards are made on either a fixed term or indefinite basis. Currently, around one third of the DLA caseload is on fixed awards (32 per cent at May 2009). Among the new claimant respondents to our telephone survey whose claim for DLA had been allowed and who were able to say what period their award was for, 70 per cent were on fixed term awards and 30 per cent on indefinite awards. This is likely to reflect the particular characteristics of our survey sample who were new applicants in the early months of their claim. Many expected to recover from illness and not go on to claim DLA long-term.

DLA will continue to be paid as long as the qualifying rules and conditions of entitlement are continuously met. If the claim for DLA is made before the claimant reaches 65, DLA will be paid for as long as they continue to meet the eligibility criteria. Once awarded the benefit, recipients are at liberty to spend the allowance in any way they wish; mobility and personal care needs notwithstanding. What matters is the effect of a disability, not whether any help needed is actually provided, procured or purchased.

It is the responsibility of DLA recipients to notify the DWP of any change in circumstances which might affect their entitlement to benefit, for example an improvement or deterioration in their condition. There is also a system of periodic checking of awards whereby some recipients may be asked to provide updated information about their condition and circumstances, although recipients who are very severely sick or disabled, or whose fixed period of award ends within the next three years, are exempt from review. Currently, less than one per cent of awards are subject to random checks annually¹⁴⁰ (that is, not including reviews at renewal of fixed term awards) and once awarded DLA, some recipients may never

Thomas A (2008) p1 'There is an overall disallowance rate of 52 per cent.

Hansard 28 January 2009 columns 564W-565W cite 44,500 people in May 2008.

Disability Alliance 2009. Disability Rights Handbook 2009-2010. p37.

be contacted by Pensions Disability and Carers Service (PDCS) during the entire period of their claim.

Working or starting work is not, of itself, a notifiable (change of) circumstance. However, if a person is able to start work because their care needs or mobility difficulties have lessened, then the DLA claim can be terminated, suspended or the rate of award reduced. On the other hand, going to work may increase a recipient's needs and the rate of award required.

Means testing and 'passported' benefits

DLA is ignored as income for means tested social security benefits including Income Support (IS), Housing Benefit (HB), Council Tax Benefit (CTB), and tax credits, and is payable in addition to all other benefit income, savings and earnings. The mobility component has special protection against means testing and practically never counts as income. DLA care component is, however, usually taken into account in respect of the non-social security means testing operated by most local authorities and the Independent Living Fund (ILF) in determining eligibility and entitlement to support for community care services.

DLA is not only an important component of the overall 'benefit basket,' but its award, particularly at the middle and higher rates, is also a gateway to other forms of help, allowing eligible recipients to access further benefits and income:

- receipt of DLA at the lowest rates of award and above can trigger disability premiums for eligible claimants in receipt of IS, income based Jobseeker's Allowance (JSA), HB, CTB, Child Tax Credit (CTC) and Working Tax Credit (WTC);
- DLA mobility component at the higher rate entitles the recipient to exemption from road tax, parking and congestion charging concessions through the blue badge scheme, and Motability¹⁴³ help to hire or purchase a car, motorised scooter or wheelchair. Those on DLA middle rate or highest rate care and higher rate mobility can also receive concessions on public transport;
- care component at the middle and higher rate entitles the recipient's carer (if they have one) to claim CA, and at the highest rate entitles the recipient to apply for ILF financial support.

DLA mobility component can only be taken into account as income if there is a law (rather than a policy or practice) which specifically states it should count.

The ILF is a government funded independent trust which works in partnership with local authorities to devise joint care packages for severely disabled people with high level personal care needs.

Motability is a charity which helps disabled people to use their higher rate mobility component of DLA as a contribution towards the purchase or lease of an adapted car, powered wheelchair or mobility scooter.

Demographics of DLA recipients

At August 2009, there were 3.10 million recipients of DLA, of which 57 per cent were of working age, 50 per cent were male and 50 per cent female.¹⁴⁴

As the incidence of disability increases with age, so does the receipt of DLA. People aged 55-65 represent approximately a third (30 per cent) of working-age recipients with those aged between 50 and State Pension age comprising 45 per cent. A little over half (55 per cent) of all working-age recipients are nevertheless under the age of 50. Ten per cent are aged 16-24 and 45 per cent are aged 25-49. These age profiles roughly mirror those of IB claimants. There is strong regional variation in the geographic distribution of DLA awards, with recipients concentrated in some of the poorest and most deprived areas of the country. Overall, the pattern exhibited is similar to the regional variation shown in claims for incapacity benefit. ¹⁴⁵

Data on the ethnic origin of DLA claimants is not routinely collected. The DLA application form does not include an ethnic monitoring question so the administrative data cannot be analysed in this way. However, a PDCS Customer Satisfaction Survey in 2007¹⁴⁶ indicated that the proportion of PDCS customers from minority ethnic groups (seven per cent) broadly matched the figure shown by 2001 Census data to exist within the UK population as a whole (eight per cent).¹⁴⁷

Main disabling condition

The main disabling condition covered by DLA allowances is arthritis (19 per cent), followed by mental health conditions (17 per cent) and learning difficulties (11 per cent). Back ailments account for eight per cent of allowances, muscle, joint or bone disease seven per cent, heart disease five per cent, stroke four per cent and chest diseases three per cent. Blindness accounts for two per cent and deafness one per cent. Malignant diseases, epilepsy, multiple sclerosis and diabetes each account for two per cent of allowances. The remaining allowances are for 'other' conditions. 148

Composition of mobility and care components

Awards for DLA are concentrated in the middle and higher rate payment bands for the care component and in the higher band for the mobility component. Almost

DWP Quarterly Statistical Summary (February 2010).

¹⁴⁵ Beatty *et al.* (2009) Figure 2.3.

lpsos/Mori (2007) Customer Service Survey 2006/2007.

¹⁴⁷ Ipsos/Mori (2007) p16.

Information derived from the DWP Tabulation Tool at http://research.dwp. gov.uk/asd/tabtool.asp

three-quarters (74 per cent) of DLA customers are in receipt of either the care or mobility component at the higher rate. More than half of DLA customers (56 per cent) receive the middle or higher rate care component, either with a mobility component or on its own; and more than half (57 per cent) receive the higher rate mobility component, either with a care component or on its own. Lower rate care component on its own accounts for eight per cent of awards, and lower rate mobility component alone for three per cent.

Duration of claim

The vast majority (87 per cent) of DLA customers have been in receipt of the benefit for two or more years and over two-thirds (70 per cent) have been receiving DLA for five or more years. One in six customers have claims of 15 years or more duration, many dating from the original launch of DLA and introduction of new lower rates of award in 1992/93.

The growth and spread of DLA

Since its introduction in 1992 with two new lower rates of award, DLA caseload has grown continuously, with an annual rate of growth in recent years averaging about three per cent.¹⁵¹ In 1993, a year after the launch, 1.76 million people had been awarded DLA.¹⁵² By 2009, this figure had risen to 3.1 million,¹⁵³ equal to 1 in 20 of the UK population and approximately half of all disabled people. The fastest growth in DLA caseload in recent years has been women over the age of 60 and children under 16.¹⁵⁴ However, people of working age still comprise the largest proportion of all DLA recipients.

While there have been increases across all components and rates of DLA, the steepest rises have been in respect of the newly introduced lower rates of award. In spite of this, customers receiving the middle or higher rates of award nevertheless represent the largest proportion of claimants.

Reflecting the significant increase in the DLA caseload, annual expenditure has risen incrementally, year on year. Forecast DLA expenditure for 2009/2010 is £11.4

- Information derived from the DWP Tabulation Tool at http://research.dwp. gov.uk/asd/tabtool.asp
- Information derived from the DWP Tabulation Tool at http://research.dwp.gov.uk/asd/tabtool.asp
- Information derived from the DWP Tabulation Tool at http://research.dwp. gov.uk/asd/tabtool.asp
- The Spread of Disability Living Allowance M Noble et al 1997 p744.
- DWP Quarterly Statistical Summary (February 2010).
- DWP (2007b) Disability Living Allowance and Attendance Allowance Quarterly Brief, May 2007.

billion (of which £6.2 million will be for people of working age). DLA expenditure is forecast to rise to £11.7 billion in 2010/11. 155

DLA and other benefits

Less than a quarter of working-age DLA customers (22 per cent) get DLA on its own; more than three-quarters (78 per cent) are in receipt of other social security benefits.¹⁵⁶ The vast majority of these, receive at least two benefits in addition to DLA – IB, Severe Disablement Allowance (SDA), Employment and Support Allowance (ESA) and IS being the most common. A little over half of DLA customers receive three or more benefits in addition to DLA, and a third receive four or more benefits.

In August 2009, among working-age DLA recipients, 1.3 million (75 per cent) got DLA together with IB, SDA or ESA and 657,000 (38 per cent) got DLA with IS either in addition to IB, or on its own.¹⁵⁷ The majority of these recipients will also be claiming other non-disability-related benefits including HB and CTB.

A further 387,000 working age adults (22 per cent) get DLA but no other benefits, either because they are working or because they do not qualify for incapacity or unemployment benefits (for example if they live with parents or a partner who is working or claiming benefits on their behalf).

Levels of income

When income from DLA is combined with other social security benefits, there are significant numbers of claimants who receive much higher than average benefit income. In 2007, approximately half of DLA customers received social security benefit income in excess of £200 per week and about a quarter in excess of £250 per week. People living in low income households are also able to claim HB and CTB, while those with higher level mobility and care needs may be entitled to additional financial help from their local authority and the ILF. For many disabled people getting DLA is important in enabling them to maximise their household income, live independently and achieve a reasonable standard of living, whether they work or not.

DWP Budget Tables 2009, outturn forecasts for 2009-10: DLA £11.394 billion; IB/ESA £6.803 billion. For 2010-11: DLA £11.74 billion; IB/ESA £6.909 billion.

DLA and AA Quarterly Brief February 2010 (internal DWP document).

DLA and AA Quarterly Brief February 2010 (internal DWP document).

This does not include HB or CTB. DLA Quarterly Brief November 2007 (internal DWP document).

Appendix B Telephone surveys of DLA applicants

A total of 1,005 Disability Living Allowance (DLA) applicants were surveyed by telephone prior to receiving a decision from Pensions Disability and Carers Service (PDCS) on their applications. This represented a 38 per cent success rate among all individuals making an application for benefit within a specific and limited time frame in September and October 2008. Inclusion was determined by whether or not contact could be made in the relatively short time between applications being made and decisions received. The telephone survey was undertaken in such a way as to be as inclusive as possible. Options for self-completing questionnaires were taken up by people with hearing difficulties, people whose first language is not English, by people lacking the self-confidence to undertake a telephone interview but who nevertheless wanted to participate, and by individuals who wished to enlist help in completing their answers from a parent, friend, carer or other adviser. In all other respects, the sample was randomly selected and therefore the descriptive statistics presented here can be considered to have validity in representing DLA applicants in general.

B.1 All applicants: descriptive statistics (survey 1)

The profile of respondents to the survey in terms of their ethnic background, age, and gender was as follows:

Table B.1 Ethnic background

Ethnic background as described by respondents	% (n=1005)
White British/Irish	89
Asian or Asian British	4
Black or Black British	4
All other/mixed	3
None stated	1

Table B.2 Gender

Gender profile of respondents	% (n=1005)
Female	53
Male	47

Table B.3 Age profile

Age grouping	% (n=1005)
18-24 years	10
25-39 years	28
40-49 years	34
50 years and over	28

Respondents were from a wide variety of family and household backgrounds, and nearly half of all applicants (46 per cent) had dependent children.

Table B.4 Household types

Household characteristics	% (n=1005)
Living with spouse/partner	44
Living alone	22
Lone parent	16
Living with parent(s)	12
Living with other relative(s)	1
Living with friend(s)	1
Living with flatmate(s)	1
Living in a hostel	1

Two per cent of the applicants had someone else in their household who was already in receipt of DLA, and three per cent of those interviewed were making re-applications for DLA from the position of being in receipt of a fixed term award that was coming to an end. Overall, nearly a third (31 per cent) of applicants had made a previous claim for DLA, the great majority (84 per cent) of these being over a year previously and the majority (56 per cent) of which had been disallowed on that occasion.

Making the current application had been suggested to applicants by a wide range of different professional and non-professional people. Most commonly mentioned were GPs, family members and Jobcentre Plus/Benefits Advisers.

Table B.5 Application suggested/encouraged by

DLA application suggested by:	% (n=1005)
GP or hospital doctor	28
Family member	23
JC+/Benefits Adviser/DEA/DWP	20
Social Worker/ Support Worker	10
Other medical professional	8
Non-Departmental advice agency	6
Someone else (eg employer)	5
Not suggested by anyone	12

Applicants were asked to categorise their main health condition or disability as one of four broad types: physical, mental health, sensory (deafness and blindness), or learning difficulty. The great majority were physical disabilities, followed by mental-health related conditions, with relatively few in the categories of sensory disability and learning difficulties.

Table B.6 Category of disability

Disability/Health Condition	% (n=1005)
Physical	74
Mental Health	21
Sensory	3
Learning difficulty	2

Although one fifth of applicants (19 per cent) reported that they had been affected by their condition for less than a year, nearly half (45 per cent) said they had been affected for more than five years.

Table B.7 Length of time affected by condition

Length of time affected	% (n=1005)
Less than a year	19%
One to five years	36%
More than five years	26%
Most of my life	13%
All my life	6%

The great majority (95 per cent) said their condition affected the type of work they could do, and nearly as large a proportion (88 per cent) said it affected the hours they could manage. Applicants' expressed expectations of their condition in the future were not optimistic. Although 16 per cent expected their condition to improve, 45 per cent thought it would stay the same or get worse, while the remainder were unable to offer an opinion (some because their condition fluctuated too much to make a sensible assessment).

Table B.8 Expectations for health conditions in the future

	% (n=1005)
Expect condition to improve	16
Expect condition to stay the same	14
Expect condition to get worse	31
Condition fluctuates too much to say	10
Don't really know	29

One in ten of the applicants interviewed said that they were in receipt of some form of care from their local authority Social Services department. For nearly all this was later found to be low level input from occupational therapists, home adaptations etc.

Nearly three-quarters of applicants (73 per cent) said they received some form of informal care, which in the great majority of cases was from members of the family. Four-fifths (81 per cent) of these said they received informal care on a daily basis.

Applicants were asked whether they agreed or disagreed with a number of general statements about the relationship between their disability/ health condition and working. Table B.9 sets out their responses (multiple answers were possible so the percentages do not total to 100).

Table B.9 Statements about disability/health condition

Statement	% agreeing (n=1005)
I am unable to work because of my health condition or disability	80
My health condition or disability makes it difficult for me to work	91
Employers' attitudes towards my health condition or disability make it difficult for me to work	37
My GP or hospital doctor has told me not to work	51
My family do not want me to work	48

About half (51 per cent) agreed that that they had been told not to work by a doctor, and a similar proportion (48 per cent) agreed that their families did not want them to. While just over a third (37 per cent) were willing to attribute some of the difficulty they faced, in finding a job and in working, to the attitudes of employers, the great majority clearly perceived the main constraint they faced to lie within the nature of their condition itself, and as many as four out of five (80 per cent) perceived their health condition or disability to render them **unable** to work.

Around a third (34 per cent) of all applicants had no qualifications, two-fifths (40 per cent) had qualifications at NVQ levels 1 and 2, and a quarter (25 per cent) had qualifications at NVQ level 3 or above. (For the NVQ equivalents used in the survey see Appendix B)

Table B.10 Highest level of qualification

Highest level of qualification held	% (n=1005)
No qualifications	34
NVQ level 1	22
NVQ level 2	18
NVQ level 3	13
NVQ level 4	9
NVQ level 5	3

More than half (58 per cent) of the DLA applicants were currently living in totally workless households (households where no-one was in paid work), and two-thirds (64 per cent) were in receipt of out-of-work benefits of one kind or another. In addition there were some instances in which another member of the applicant's household was in receipt of out-of-work benefits.

Table B.11 Receipt of main out-of-work benefits

Benefits currently received	Applicants (n=1005) %	Others in household %
Incapacity Benefit only (IB)	27	3
Incapacity Benefit and Income Support (IB+IS)	11	1
Income Support only (IS)	22	2
Disability Premium with IS	3	1
Jobseeker's Allowance (JSA)	4	2

Table B.12 Other benefits

Benefits received	Applicants (n=1005) %	Others in household %
Council Tax Benefit (CTB)	39	4
Housing Benefit (HB)	37	4
Child Tax Credits	25	5
Carers Allowance	5	4
Social Services direct payments	1	
Blue Badge	8	3

Table B.13 In-work benefits

Benefits	Applicants (n=1005) %	Others in household %
Statutory Sick Pay (SSP)	8	
Employer's sick pay	3	
Access to work	1	
Working Tax Credits (WTC)	8	3
(Severe) Disability element of WTC	1	

The stated previous work histories of applicants are shown in Table B.14 A small number (five per cent) had never been in paid work, and a further eight per cent had been engaged primarily in education or training since leaving full time education. Five per cent had been primarily engaged in looking after their family rather than working. While a fifth of applicants (21 per cent) described their past work history as predominantly unemployment or a pattern of 'churning' in and out of work, three-fifths (60 per cent) said they had previously mainly been in long-term jobs or in self-employment.

Table B.14 Work history

Stated work history	% (n=1005)
Never been in paid work	5
Mainly looking after family	5
Mainly in education or training	8
Frequently in and out of work	3
Mainly unemployed	18
Primarily in long-term jobs	58
Primarily self-employed	2

The clear picture that emerges when these work histories are viewed next to the figures for receipt of out-of-work benefits, is one of steady, long-term work and employment for the majority of applicants in the past, but a similar majority being out of work at the time of their DLA application (presumably in many cases as a direct result of a disability or health condition).

However, equally as important to note is the fact that a significant number remained in work and were either still working, or still had a job from which they were absent on sick leave, at the time of making their application. At the time of their telephone interview (four to six weeks after their applications were received by PDCS) more than a quarter (27 per cent) were currently in jobs, while the remaining 73 per cent were currently out of work.

Table B.15 shows the breakdown for those 281 applicants with a job. They were subsequently asked also how long they had been in their current job, and what would be the normal weekly hours they worked. Those applicants who described themselves as 'off work on sick leave' were asked additionally how long they had been off work, and whether they intended to go back to their job.

Table B.15 Those currently with a job

	%
Work situation	(n = 281)
Off work on sick leave	46
Working full-time	25
Working part-time	23
Working self-employed	6
Voluntary work	1

The great majority (83 per cent) of those with a job had been in that job for over a year. Nearly half (48 per cent) had been in their job for more than five years.

Table B.16 Length of time in current job

Time in current job	% (n = 281)
Less than 3 months	5
Between 3 and 6 months	5
Between 7 and 12 months	6
More than a year but less than 5 years	35
More than 5 years	48

Only one-tenth (ten per cent) were working part-time below the 16 hour threshold for Tax Credits, although a further 26 per cent were working less than 30 hours per week.

Table B.17 Weekly hours normally worked

	%
Hours per week	(n = 193)
Up to 15	10
16-29	26
30-40	53
More than 40	11

Table B.18 shows the responses of those who were off work on sick leave (but still had a job to return to) to the question how long they had been off sick. More than half (61 per cent) fell within the 28 weeks maximum period that would be covered by Statutory Sick Pay. The remainder had been off work for more than 28 weeks and would either be relying on Employer's Sick Pay or would no longer be getting any sick pay at all.

Table B.18 Length of time off work for those on sick leave

	%
Number of weeks	(n = 129)
Up to 28 weeks	61%
29-52 weeks	27%
More than 52 weeks	13%

More than three-quarters (78 per cent) of those off work on sick leave said that they intended to go back to their jobs when their health allowed them to do so.

Table B.19 shows the breakdown of work related situation for those people currently without a job.

Table B.19 Those currently without a job

Out of work situation	% (n = 729)
Out of work and interested in working	44
Out of work but not interested in working	28
Unable to work due to health condition	15
Looking after home/family (including carers)	7
Early retired	3
In education or training	2
Other	1

Those currently without a job had typically been out of work for a considerable time. Three quarters (76 per cent) had either never worked or had not worked for over a year.

Table B.20 Length of time since last worked

	% (n = 726)
Never had a job	7
Less than 3 months	4
Between 3 and 6 months	9
Between 7 and 12 months	11
More than a year but less than 5 years	31
More than 5 years	38

Among those describing themselves as currently out of work, almost two-thirds (63 per cent) said they would like to work and more than half (56 per cent) that they expected to work in the future. However, only around one in five (22 per cent) thought that they actually would be back in work in six months time.

 Table B.21 Work aspirations among those currently out of work

	% (n = 726)
Would like to work in the future	63%
Expect to work in the future	56%
Think they will be in work in 6 months time	22%

Among those currently in work or off work on sick leave, a very much higher proportion (69 per cent) said that they thought they would be in work in six months time.

Applicants were asked whether they thought that an award of DLA would make it any more or less likely that they would be in work in six months time. Seventeen per cent said they thought that getting DLA might, or definitely would, make it more likely. Sixty-three per cent said it would make no difference at all, and two per cent said it would make it less likely.

Table B.22 Anticipated effect of DLA award on likelihood of working

Approval for DLA	% agreeing (n= 729)
would definitely make it more likely that I will be in work in 6 months time	7
might make it more likely that I will be in work in 6 months time	10
would make no difference at all to whether I will be in work in 6 months time	63
would make it less likely that I will be in work in 6 months time	2
Don't know what difference it would make	18

Of those not in work, 14 per cent were currently looking for jobs and 61 per cent said they were aware of the help that was available to them to help them move back into work.

Although there was no space within the telephone survey to explore in depth people's attitudes to DLA, the applicants were asked to say whether they thought being awarded DLA, or having their claim disallowed, would affect their work-related behaviour in the future.

Specifically, those in work were asked whether the decision on their DLA claim would affect whether they left work altogether, stayed in their current job, looked for a different job, or either reduced or increased the hours they were working. The responses are set out in Table B.23.

Table B.23 Anticipated impact of DLA claim decision (those in work)

	% agreeing (n =281)			
	If DLA awarded	If DLA disallowed	Overlap	
Will leave work altogether	7	8	78	
Will stay in current job	63	67	95	
Will look for a different job	14	11	76	
Will reduce work hours	21	16	68	
Will increase work hours	3	3	43	

The very similar proportions responding to each option in relation both to DLA being awarded and to it being disallowed, as well as the very high degree of

overlap between those responding to each option under the two different potential circumstances, strongly suggests that for most people the decision on their DLA claim is not expected to influence their future decisions and behaviour.

Similarly, those currently out of work and looking for a job [(1) in Table B.24] were asked if the outcome of their DLA decision would affect their job search, and those currently out of work but not looking for a job [(2) in Table B.24] were asked if their DLA decision would affect whether they started to job search. Similar high levels of coincidence were found in these responses too.

Table B.24 Anticipated impact of DLA claim decision (those out of work)

	% ag			
	If DLA If DLA awarded disallowed			
(1) Will continue looking for work (n= 98)	94	92	99	
(2) Will start looking for work (n= 625)	13	11	92	

Some further understanding of applicants' views was sought through their responses to three statements about the perceived relationship between benefits, labour market activity and paid employment – specifically whether they felt they would be better or worse off financially on benefits or in work, and whether they perceived that their eligibility for DLA might be affected by working.

Table B.25 Perceptions about DLA, work and benefits

	Of those currently in work (n = 276)	% agreeir Of those currently out of work n = 729)	Of all respondents (n = 1005)
I am/would be worse off on benefits than in work	13	22	19
I am/would be better off on benefits than in work	62	43	48
My eligibility for DLA might be affected by working	22	21	21

More than twice as many people perceived that they were/would be better off on benefits than perceived they were/would be better off in a job. Almost a fifth of all respondents (19 per cent) felt that they were, or would be, worse off on benefits than in work, while around half of respondents (48 per cent) thought the opposite to be true and that they were, or would be, better off on benefits. A third of respondents (33 per cent) were unwilling or unable to offer an opinion either way.

Broken down by current employment status, and looking separately at those currently in work and those currently out of work, shows that a greater proportion

(75 per cent) of those currently in work felt they were able to offer an opinion, but that their perceptions were even more weighted towards being better off on benefits than in work, than were the perceptions of those currently out of work. Well over half (62 per cent) of those currently in work perceived that they would better off on benefits. This would seem to suggest a strong non-financial motivation to work for many people, perhaps coupled with the perception of available work as being low paid. Of those currently out of work, a smaller, but still large, proportion (43 per cent) perceived that moving into work would be financially disadvantageous for them, while 22 per cent perceived that they would be better off working than on benefits.

Regardless of their current employment status, about a fifth (21 per cent) of applicants perceived that their eligibility for DLA might be affected by working. Given that none were yet in receipt of DLA when interviewed, this must be seen as a general perception of some form of link, among those feeling able to give a response, rather than evidence of any real disincentive at that stage.

Finally, respondents to the survey were asked the open-ended question of how DLA would make a difference to them were they to receive it. Table B.26 shows the breakdown of answers coded from free text responses (multiple answers possible).

Table B.26 How receiving DLA would make a difference

	% (n = 1005)
General financial help	62
Help with the general cost of living	45
Reduce financial pressure on family	14
Provide short-term cover for period of illness	2
Allow for savings	1
Mobility	39
Cover transport costs	26
Help with getting 'out and about' (including socially)	7
Buy mobility aids (wheelchair, sticks, crutches etc)	3
Help make home modifications	3
Personal care needs	10
Allow employment of outside help	10
Pay towards supported accommodation	<1
Work/employment related	10
Supplement income/ make able to work fewer hours	6
Help in becoming more job-ready	2
Assist with training/education (costs and access)	2
Other	6
No comment/ Does not know	5
Will not help	1

Of note were the ten per cent of answers related to employment, in particular the perception that DLA would allow fewer hours to be worked (of those saying this, three-quarters were currently in a job).

B.2 The application and awards process

At the second survey, the 637 respondents had received a decision on their DLA claim. The sample split as follows in terms of whether their claim had been allowed or disallowed.

Table B.27 DLA decisions

	,	%
Decision on DLA claim	No.	(n=637)
Allowed straight away	332	
Allowed on appeal after initial disallowance	39	
Total Allowed	371	58
Disallowed – no appeal	230	
Disallowed even after an appeal	36	
Total Disallowed	266	42

The 'bias' (given a national 50/50 split) towards those whose claims were allowed is likely to be the result of three factors:

- those disallowed being disgruntled and refusing to participate in the second survey;
- extended appeals processes for some disallowed claimants meaning they had yet to get a final decision;
- some people only having participated in the first survey because they thought (despite all assurances to the contrary) that it might affect their application if they refused to do so.

Table B.28 shows the breakdown of awards decisions in terms of the different possible elements (care and mobility) and levels (high, medium, low) of DLA, for those allowed respondents able to answer this question (338). The awards show a concentration of higher level mobility elements and low level care elements.

Table B.28 Elements and levels of awards

	High level	Medium level	Low level
Care element	52	65	131
Mobility element	157		79

If the many different combinations of award elements are looked at together (Table 5.3) it can further be seen that the most common combinations were low care/no mobility, higher mobility/no care and higher mobility/low care.

Table B.29 Numbers receiving award elements/levels

	High care	Middle care	Low care	No care element	A care element (level unknown)
Higher mobility	31	33	43	45	5
Lower mobility	16	19	23	20	1
No mobility element	4	11	59		4
A mobility element (level not known)	1	2	6	8	7

A fairly high proportion of people (one in seven) did not know whether their DLA award had been made for a fixed period subject to review or awarded indefinitely. Of those able to answer this question (318 respondents), 70 per cent had been given fixed period awards and 30 per cent indefinite awards. There was no strong correlation between the levels of awards and whether they were fixed term or indefinite. However, with fixed term awards, the length of time that 'low' level awards were made for tended on average to be shorter than the length of time 'high' level awards were made for. The great majority of all fixed period awards (nearly two-thirds of them) were made for periods of between one and two years.

The data that follow are split by decision, comparing figures for those allowed and now in receipt of DLA with figures for those whose claim for DLA was unsuccessful. Where the allowed/disallowed split for sub-categories is significantly different from the overall ratio (58:42) within the total achieved sample, there may be structural reasons underlying the difference in the distribution of claim decisions that require explanation.

The great majority (90 per cent) of re-applications were approved, though one in ten were disallowed this time round. Applicants with unsuccessful claims for DLA in the past were slightly more likely than average to be turned down again.

Table B.30 Previous DLA claims

	Allowed (371) 58%		Disallowed (266) 42%	
Previous DLA claims	No.	%	No.	%
Re-applications by those already getting DLA	45	90	5	10
Had made a previous unsuccessful claim for DLA	47	51	46	49

Making the current application had been suggested to applicants by a wide range of different professional and non-professional people. Most commonly mentioned were GPs, family members and Jobcentre Plus/Benefits Advisers.

Our sample suggests that applicants advised to apply by medical professionals, and by social workers or other support workers, were more likely than average to

be allowed; those advised by others less likely than average to be allowed. Those advised to apply by Jobcentre Plus staff and benefits advisers had the lowest rate of success.

Table B.31 Application suggested/ encouraged by

	Allowed (371) 58%		Disallowed (266) 42%	
DLA application suggested by:	No	%	No.	%
GP or hospital doctor or other medical professional	147	68	68	32
Social Worker/Support Worker	36	67	18	33
Someone else (eg employer or agency)	40	55	33	45
Family member	73	54	62	46
JC+/ Benefits Adviser/ DEA/ DWP	65	46	76	54
Not suggested by anyone	49	59	34	41

A considerably greater proportion of white British or Irish applicants were allowed (60 per cent) compared to those from other ethnic backgrounds (44 per cent). Black and Black British applicants appeared to have the lowest level of approvals. There are several possible factors at work here. For some non-White British applicants, especially recent immigrants to the UK, there are likely to have been language difficulties filling in the form, problems understanding the eligibility criteria, and difficulty of access to support services for help in making the application, resulting in more, and more clear-cut, disallowances among these groups.

Table B.32 Ethnic background

	Allowed (371) 58%		Disallowed (266) 42%	
Ethnic background as described by respondents	No.	%	No.	%
White British/Irish	345	60	231	40
Asian or Asian British	9	_	10	_
Black or Black British	9	} 44	17	} 56
All other/mixed	6	J	4	J
None stated	2		4	

Disallowed claims did not appear to be happening disproportionately among any particular age groupings, though overall a slightly greater proportion of those under 40 years of age were allowed compared to those aged 40 and over. The close connection in many people's minds between ceasing to work and claiming DLA may be an underlying factor here.

Table B.33 Age profile

	Allowed (371) Disallowed (26 58% 42%			
Age grouping	No.	%	No.	%
18-24 years	34	62	21	38
25-39 years	101	63	60	37
40-49 years	131	56	101	44
50 years and over	105	56	84	44

If allowance/disallowance rates are further broken down by gender it would appear to be the case that it is particularly younger men who are more likely than average to be allowed, and men aged over 50 who are more likely than average to be disallowed. Strong conclusions should not, perhaps, be drawn because of the small numbers involved (especially among the 18-24 year old group).

Table B.34 Age profile by gender

		Allowed (371) 58%			Disallowed (266) 42%			
	M	ale	Fer	nale	М	ale	М	ale
Age grouping	No.	%	No.	%	No.	%	No.	%
18-24 years	17) co	17) [0	6	} 32	15	1 42
25-39 years	48	} 68	53	} 58	25	} 32	35	} 42
40-49 years	63	59	68	54	44	41	57	46
50 years and over	55	50	50	57	55	50	38	43

The wide range of different household types was fairly evenly reflected across both allowed and disallowed applicants. Lone parents appeared to have their claims accepted slightly more frequently than average.

Table B.35 Household types

	Allowed (371) 58%		Disallowed (266) 42%	
Household characteristics	No.	%	No.	%
Living with spouse/partner	172	58	123	42
Living alone	77	54	65	46
Lone parent	68	64	39	36
Living with parent(s)	43	59	30	41
Other household types	11		9	

The reported length of time affected by health conditions did not appear to affect the likelihood of success with a DLA application. One fifth of those re-interviewed at survey2 (21 per cent) reported that they had been affected by their condition for less than a year and nearly half (45 per cent) had said they had been affected for more than five years. A greater proportion of claims were allowed from people who had lifelong health conditions than were allowed from those with more recent onset of conditions, though numbers in this category were too small to draw firm conclusions, and included a disproportionate number of those making re-applications.

Table B.36 Length of time affected by condition

		Allowed (371) 58%		Disallowed (266) 42%	
Length of time affected	No.	%	No.	%	
Less than a year	80	59	55	41	
One to five years	123	56	95	44	
More than five years	99	58	71	42	
Most of my life	46	58	34	42	
All my life	23		11		

Sixteen per cent of applicants reported that they expected their condition to improve, whereas 47 per cent thought it would stay the same or get worse and 37 per cent were unable to offer a prognosis. There was no greater likelihood of claims being allowed from those thinking their condition would deteriorate. Indeed overall, applicants' expectations of their condition in the future did not appear significant in relation to allowance or disallowance.

Table B.37 Expectations for health conditions in the future

		Allowed (371) 58%		Disallowed (266) 42%	
Expectations	No.	%	No.	%	
Expect condition to improve	55	55	45	45	
Expect condition to stay the same	55	59	39	41	
Expect condition to get worse	120	58	86	42	
Condition fluctuates too much to say	33	58	24	42	
Don't really know	108	60	72	40	

B.3 Surveyed DLA recipients

Respondents to the follow-up telephone survey had all received a decision on their DLA claim. A total of 371 individuals had been awarded some level of DLA benefit. This section presents descriptive statistics for this group of allowed claimants – now DLA recipients.

The profile of surveyed DLA recipients in terms of broad demographics of age, gender, ethnicity and reported type of main health condition was as shown in the tables below.

Table B.38 Gender of recipients

(n = 371)	Number	%
Female	188	51
Male	183	49

Table B.39 Age of recipients

(n = 371)	Number	%
(11 = 37 1)	Number	70
18 - 24 years	34	9
25 - 39 years	101	27
40 - 49 years	131	35
50 years and over	105	28

Table B.40 Ethnic background of recipients

(n = 371)	Number	%
White British/Irish	345	93
Asian or Asian British	9	2
Black or Black British	9	2
All other/mixed	6	2
None stated	2	1

Table B.41 Main type of health condition of recipients

(n = 371)	Number	%
Physical	271	73
Mental health	77	21
Sensory	11	3
Learning difficulty	12	3

In survey1, around a third (34 per cent) of all applicants had no qualifications, two-fifths (40 per cent) had qualifications at the equivalent of NVQ levels 1 and 2, and a quarter (25 per cent) had qualifications at NVQ level 3 or above. Among those whose claims went on to be allowed a similar distribution existed, with a very slight increase in the proportion of those with higher level qualifications.

Table B.42 Highest level of qualification of recipients

	DLA reci	pients
Highest level of qualification held (n = 371)	No.	%
No qualifications	117	32
NVQ level 1	75	20
NVQ level 2	71	19
NVQ level 3	53	14
NVQ level 4	46	12
NVQ level 5	9	2

Equally, the pattern of previous work history among recipients was very similar to that overall among applicants, regardless of the outcome of their claims, with the majority having been primarily working in long-term jobs.

Table B.43 Recipients' work history

	Applicants at Q1	DLA r	ecipients
Stated work history	% (n = 1005)	No.	% (n = 371)
Never been in paid work	5	13	4
Mainly looking after family	5	24	6
Mainly in education or training	8	26	7
Frequently in and out of work	3	17	5
Mainly unemployed	18	53	14
Primarily in long-term jobs	58	230	62
Primarily self-employed	2	8	2

Data from the follow-up survey allowed the identification of successful applicants, for whom it was then possible to refer back to information given by this group (now DLA recipients) at the time of their application and first telephone interview. Table A44 shows receipt of out-of-work benefits at the time of their DLA application and at the point of their interview for the follow up survey (approximately four months later).

Table B.44 Receipt of out-of-work benefits by eventual recipients

(n = 371)	On app	On application		Following decision	
Out-of-work benefits received	No.	%	No.	%	
Employment and Support Allowance (ESA)			23	6	
Incapacity Benefit only (IB)	100	27	92	25	
Incapacity Benefit and Income Support (IB and IS)	41	11	47	13	
Income Support only (IS)	81	22	75	20	
Jobseeker's Allowance (JSA)	15	4	9	2	
Not receiving out-of-work benefits	134	36	125	34	

Two-thirds of the new DLA recipients were in receipt of out-of-work benefits both at the point they made their DLA application and when they knew the decision on their claim a few months later. A small number who had made a new claim since October 2008 were receiving ESA by the time of the follow-up survey, and there were small, but undramatic, changes in the numbers on other benefits while the overall pattern remained generally stable.

A more detailed indication of proximity to the labour market can be derived by looking more closely at those DLA recipients who, at the time of their application, were neither working nor off on sick leave from a job. This group had been asked at the first survey (S1) how long it was since they were last in paid employment, and around three-quarters (77 per cent) said it was a year or more, whereas about a quarter (23 per cent) said less than a year.

As might be expected, those who had been longer term out of work (over a year) showed clear signs of being further from the labour market than those who had left work more recently. Considerably fewer of them said that they wanted to work, expected to work again in the future, or were currently looking for work.

Table B.45 Recipients who had been out of work at S1

		Would like to work		Currently looking for work		Expect to work in the future	
Status at Q1		No.	%	No.	%	No.	%
Out of work less than one year	Yes	36	68	9	17	34	64
	No	12	23	44	83	13	25
	D/K	5	9			6	11
Out of work for one year or more	Yes	107	54	9	5	98	49
	No	64	32	191	96	67	33
	D/K	29	15			36	18

Changes in work status between the two telephone surveys provided further evidence, with only two per cent of the longer term out of work moving into employment in a four to five month period, compared to eight per cent of those out of work for a shorter time when making their application, despite being better informed about available support.

Table B.46 Awareness of support and moves into work

		Out of work less than 1 year at S1		Out of work 1 year or more at S1	
		No.	%	No.	%
Aware of available support at C1	Yes	28	53	140	70
Aware of available support at S1	No/DK	25	47	60	30
Employment status at C2	In work	4	8	4	2
Employment status at S2	Out of work	49	92	197	98

Greater awareness of available employment support among those out of work for a year or more is likely to have been largely due to greater contact with Jobcentre Plus through claims for benefits. Four-fifths (80 per cent) of those out of work a year or more were already in receipt of incapacity benefits when they applied for DLA, compared to a little over half (57 per cent) of those out of work for less time. The proportion of both groups receiving incapacity benefits had increased slightly by the second survey, with the short-term out-of-work group becoming more like the longer-term out-of-work group with the passing of time.

Table B.47 Benefits receipt by length of time out of work (DLA recipients)

DLA recipients	Out of work at S1	Out of work at S2
Out of work < 1 year (at S1) and in receipt of incapacity benefits	57	65
Out of work > 1 year (at S1) and in receipt of incapacity benefits	80	83

Among respondents, therefore, was a sizeable group with the following characteristics: they were not in a job at either survey point; they were allowed DLA; they were receiving incapacity benefits; and they had been out of work for at least 16 months at the follow-up survey (at least 18 months by the time some were interviewed face-to-face). This group comes the closest to being comparable with the groups explored in secondary analyses of data sets of incapacity benefits customers also receiving DLA (see footnote 50). In terms of work expectations, for example, 51 per cent were unsure about working in the future or did not expect to work again. This compares to 60 per cent of DLA claimants in the study of New Deal for Disabled People (NDDP) eligible population survey data.¹⁵⁹

In all, this group accounted for just under half (44 per cent) of our total survey sample.

B.4 Work status changes: expectations and outcomes

Seventeen per cent of eventual recipients were working at the time of making their applications for DLA. As Table B.48 shows, in the four to five months following applications being made, the proportion working stayed constant. However, there was a marked decrease in the number describing themselves as 'on sick leave from a job and getting sick pay' (from 14 per cent to four per cent) and a concomitant increase in the number describing themselves as 'out of work/not working' (from 69 per cent to 80 per cent).

Table B.48 Employment status

	Recipients at point of application	Recipients after 4-5 months	
Employment status	% (n = 371)	% (n = 371)	
Working	17	16	
On sick leave and getting sick pay	14	4	
Out of work/not working	69	80	

The consistent proportion of recipients in work at the two time points does not imply that these were all people **staying** in their jobs, as there was some movement between the different work status categories. Three-quarters (75 per cent) of those working at the time of the follow up survey were people who had also been working at the time of their application four to five months earlier. The remaining quarter was made up in equal parts by those who had moved back into work from a previous status of 'off work on sick leave' or who had moved into work from a previous status of being 'out of work/not working'.

Among those in work at both time points, the great majority (91 per cent) had stayed in the same job. Just under one in ten were now working in a new, different job. Three quarters were still also working the same number of hours as they had been previously, while the other quarter (24 per cent) had reduced their working hours, some by moving to new employment.

Table B.49 shows the breakdown between those working full-time (30 hours per week or more) and those working part-time (less than 30 hours per week) among, firstly applicants, then DLA recipients at the point of making their application, and then recipients four to five months later.

Table B.49 Full-time and part-time hours

Hours worked	Applicants in jobs when applying		Future DLA recipients in jobs when applying		DLA recipients in jobs 4 to 5 months later	
by those in jobs	No.	%	No.	%	No.	%
Full-time						
(30 hours or more per week)	86	67	51	67	30	50
Part-time						
(less than 30 hours per week)	43	33	25	33	30	50

Eventual recipients of DLA, who were working at the time of making their application, showed the same pattern of full-time and part-time work as did all applicants, including those subsequently to be disallowed. In each case, two-thirds (67 per cent) were working full-time and one-third (33 per cent) were working part-time. Four to five months after making their DLA application, however, recipients of the benefit now/still in work showed a markedly different pattern, with a shift towards part-time working. By this point half (50 per cent) were working part-time hours, both a greater number and a greater proportion than previously.

Whatever applicants' original employment status (out of work, off sick, or working), the proportion in work four to five months later was in each case higher among those whose claims were disallowed than among those whose claims were allowed.

Among those starting (or re-entering) work in the months after applying for DLA, the most commonly cited reason for doing so was 'financial'. This was particularly so for those who had been disallowed. Other cited reasons for starting work were:

- that work had become possible again due to some recovery or improvement in health condition;
- that work had been found that was suited to the particular limitations imposed by a health condition;
- social reasons, such as getting out of the house, meeting people, overcoming boredom, and re-introducing routine to daily life;
- reasons relating to condition management such as keeping moving, improving confidence, overcoming agoraphobia and to prevent isolation.;

Overall, nearly three-quarters (71 per cent) of all those surveyed who moved into work, or back into work, in the period after making their DLA application, resumed work for employers they knew and whom they had worked for at some time in the past – almost all of those re-entering work from sick leave, but also nearly half of those who had been out of work/not working when they had made their DLA application. At least one in eight of those still in work at the time of the follow-up survey or back in a job they had been off sick from were by that time doing work that involved different tasks to those involved in the work which they had been doing previously.

At the initial telephone interview more than three-quarters (78 per cent) of the 124 applicants who were then off work on sick leave, said that they intended to go back to their jobs when their health allowed them to do so. Of those recontacted in the follow-up survey four months later (78 people), just over half (41) were then out of work, a quarter (20) were back in work and the remainder (17) were still off sick and getting some form of sick pay. Most of those back in employment (13) had been disallowed DLA. Nearly all of those still on sick pay (14) had been allowed DLA.

If these figures are split between those whose DLA claims went on to be allowed (recipients) and those whose claims were disallowed (failed applicants), it can be seen that fewer (69 per cent) of the eventual recipients of DLA initially expressed the intention to return to their job (compared to 100 per cent of those who went on to be disallowed) and that a much smaller proportion of recipients (17 per cent) actually were back in work four to five months later (compared to 55 per cent of failed applicants).

Table B.50 Work expectations of recipients and failed applicants

		d claimants off sick at S1	Recipients who wo		
Work expectations at S2	No.	%	No.	%	
Said at S1 they intended to go back to job when fit	20	100	36	69	
Of which					
At S2 were back in a job	11	55	6	17	
At S2 were still off work	1	5	11	31	
At S2 were out of work	8	40	19	53	

A contrast is evident between aspirations and intentions, and actual behaviour.

A similar finding emerged from questions asked of applicants who were out of work at the time they applied for DLA. Not only did fewer of them in the first survey say that they expected to work in the future than said that they wanted to work, but after four to five months this expectation had dropped even further among those still out of work. Table B.51 shows the responses to these questions by DLA recipients who were out of work both at the time of their application and four to five months later. While there appeared to be a steady proportion who neither wanted nor expected to work again, fewer expected to work at the latter time point and greater doubt and uncertainty was evident in the number responding 'don't know'.

Table B.51 Work aspirations and expectations among those out of work

Recipients out of work at both survey	(At S1) Would like to work in the future?		(At S1) Expect to work in the future?		(At S2) Expect to work in the future?	
points S1 and S2	No.	%	No.	%	No.	%
Yes	135	55	125	51	104	42
No	76	31	79	32	78	32
Don't know	35	14	43	17	65	26

Applicants were asked in the first survey to say whether they thought being awarded DLA, or having their claim disallowed, would affect their decisions about working in the future, and the results strongly suggested that for most people the DLA decision was expected to have no influence over their future employment-related behaviour.

The second survey provided an opportunity to explore whether people actually acted in line with their own stated intentions once they knew their claim decision. Table B.52 sets out the actual situations of people at the time of the follow-up survey alongside their intentions prior to hearing the decision on their DLA claim (those in a job – working or on sick leave – at the time of their application).

Table B.52 Intentions and actual 'outcomes' after four to five months

Intentions of applicants in jobs at S1	If DLA allowed (n=156) %	If DLA disallowed (n=161) %	Actual work 'outcomes' at S2	Allowed DLA (n=113) %	Disallowed DLA (n=73) %
Will leave work altogether	7	9	Had left work	42	23
Will look for a different job	13	9	Was in a new job	4	6
Will stay in current job	80	83	Was working in old job	54	70

Relatively few applicants in jobs at the first survey (S1) said that they intended to leave work following their DLA decision. The great majority (80 per cent or more) intended to stay in their current jobs if they could, whether they were awarded DLA or not. A sizeable minority felt they would need to look for a different job.

By the time of the follow-up survey (S2), the actual number who had left work was much greater than this (more than a third overall and as many as 42 per cent of those who had been allowed DLA in the meantime), though many still intended to go back to work again in the future if possible. Much smaller proportions of people were still working in their old jobs by the follow-up survey. Many had 'run off the end' of sick pay periods before feeling ready to return to work. The optimistic intentions or aspirations of the great majority of people to overcome or recover from their limiting health conditions sufficiently to return to work, were not borne out in many instances, and especially among those who had been awarded DLA, where little more than half (54 per cent) were back in their old jobs.

Table B.53 looks at people's intentions and 'outcomes' in relation to their working hours.

Table B.53 Intended changes to hours and actual 'outcomes' after four to five months

Intentions of applicants in jobs at \$1	If DLA allowed (n=186) %	If DLA disallowed (n=186) %	Actual work hours 'outcomes' at S2	Allowed DLA (n=113) %	Disallowed DLA (n=73) %
Will reduce work hours	24	18	Had reduced working hours	10	14
Will increase work hours	2	3	Had increased working hours	0	0

More people also said they intended to reduce their working hours than had actually done so four to five months later and after receiving a decision on their DLA claim. In practice finding work of reduced hours or negotiating a reduction within an existing job may well be difficult and take more time than the few months covered by the surveys. This may also indicate that a supportive intervention at this point would be beneficial.

Appendix C NVQ levels and equivalent qualifications

NVQ Level	Description	Equivalent Qualification
1	Basic level	• 3-4 GCSEs grades D-E
	 Foundation 	• SCE
	 Semi-skilled 	• CSE
	 Pre-training 	 City & Guilds level 1
		 City & Guilds part 1
		• RSA Stage 1
		 Vocational Certificate: BTEC first certificate
2	 Middle level 	 5 GCSEs grades A*-C
	 Skilled 	 1 A level, 1 GNVQ or 1 SNVQ
		• RSA Stage 2
		RSA Diploma
		 Pitmans intermediate
		 City & Guilds Craft; BTEC first diploma
3	 Middle level 	• 2 or more A levels
	 Full craft/technician 	 BTEC ordinary diploma (OND)
	 Intermediate academic 	• City & Guilds level 3
		 City & Guilds part 3
		City & Guilds advanced
		 GNVQ's or SNVQ's
4	 High level 	• First Degree (BA, BSc, BEd, etc)
	 Advanced technical 	 BTEC Higher National Certificate (HNC) or
	 Semi-professional 	Higher National Diploma (HND)
	 Graduate academic 	 Nursing & teaching qualifications
5	High level	Master's degree
	 Full professional 	• PhD
	 Advanced academic 	• PGCE

Appendix D Health crises precipitating DLA claims

Some health crises were easily identified. Due to the nature of our sample, comprising mostly those in the early weeks and months of their claims, it included relatively large numbers of people applying following traumatic injury, for example in car accidents, or sudden health incidents such as strokes and heart attacks. Eligibility rules dictate that Disability Living Allowance (DLA) will not be paid until at least three months after such incidents, although applications can be made earlier than this and the direct relationship was generally clear.

In some cases, even though the relationship to an original health crisis was evident, there had been considerable delays before a DLA claim had been made. The main reasons put forward to explain these delays were either that people were unaware of the existence of DLA and only applied when they found out, or were initially convinced they would not be eligible, or perceived there to be a stigma attached to claiming any benefit and so had resisted making an application until feeling compelled to at a later date by their circumstances.

A clear example of this was a man in his late 40s with a heart condition, who had had to leave work following a heart attack and who had resisted applying for DLA for two years until the spiraling costs of looking after his son (who was autistic) had overcome his 'pride' and finally made him apply. In an even more extreme example, a man had struggled with the effects of an unexplained condition, that resulted in cataracts, heavy weight gain and damage to the knees, for more than ten years before making his DLA claim. He was able to use his savings to supplement his declining income as a self-employed musician, but when they ran out he did finally make a claim for DLA (and was awarded lower rate care element and higher rate mobility).

Other types of health crisis included hospitalisation and surgical operations, chemotherapy following diagnosis of cancer, kidney failure, sudden onset of debilitating arthritis, attempted suicide and being sectioned under the Mental Health Act. Somewhat less clear-cut health 'crises' involved particularly bad periods within progressive conditions such as multiple sclerosis, osteoarthritis, ME and mental health conditions, such as depression and anxiety. One woman had made her claim for DLA at the point where an, as yet undiagnosed, neurological condition affecting her legs had started to seriously affect her mobility. In this case, the claimant, who was awarded middle level care and higher level mobility elements of DLA for a year, was already out of the labour market long-term when she applied for DLA. She had left work 23 years previously to bring up her family and then to care for her mother (who had multiple sclerosis (MS)) and she was not entitled to any other benefits in her own right. As such, the only significant factor in her DLA application appeared to be the sudden deterioration in her health.

Appendix E Evaluations of previous work incentives for disabled people

Disability Working Allowance

Disability Working Allowance (DWA) was introduced in 1992 as an in-work benefit for disabled people working for more than 16 hours a week. A means-tested financial incentive designed to encourage the take up of paid work among disabled people, it was replaced in October 1999 by the DPTC. An evaluation of DWA was conducted over the first three years following its introduction and a report published in 1996. Given the explicit policy intent of providing an employment incentive for disabled people, the evaluation had, as one of its central research questions, whether there was evidence that such an incentive effect had indeed been created.

Take up and use of DWA was found to be very low and the impact of its introduction less than expected.¹⁶¹ There was evidence of some misunderstanding of the means-tested element of the benefit among disabled people, with many thinking that it would only be payable to those on lower wages than they were currently on or were seeking to earn.¹⁶² Many had simply not heard of DWA. Only one in five of those people eligible for the benefit were actually claiming it.¹⁶³

Equally, the evidence was clear that DWA had not enabled or encouraged many disabled people into work. Despite the fact that a majority of respondents to the research felt that DWA had made, or would make, a difference to their work chances, only a very small percentage (two per cent) of non-workers in receipt of the qualifying benefits for DWA – Income Support disability premium (ISdp),

Rowlingson K & Berthoud R (1996).

¹⁶¹ Rowlingson *et al.* (1996) p 4.

¹⁶² Rowlingson *et al.* (1996) p 14.

¹⁶³ Rowlingson *et al.* (1996) p 16.

Invalidity Benefit (IVB), Severe Disablement Allowance (SDA) – moved into full-time jobs in the three and a half years of the study. ¹⁶⁴ Furthermore, and equally significant, virtually all of those who made the transition from benefits into work did so **without** the help of DWA. ¹⁶⁵

Most recipients of DWA had only heard about the benefit once they were already in work and many had been in work for some time before claiming DWA. 166 Rather than acting as an incentive for entering work, DWA's main positive effect was found to be to help keep people in work who were already working. Some two-fifths of those people who were still in work two and a half years after claiming DWA said that they would not still be in a job without it. 167 The main role of DWA was seen as being 'a medium term subsidy to disabled people in low paid work', 168 while acknowledging that for some it acted as a 'buffer' against a return to incapacity benefits. 169

In conclusion the evaluation of DWA stated that 'this research casts some doubt on the extent to which a means tested in-work benefit can provide an incentive to take a job'¹⁷⁰ and that it was likely to be 'very difficult if not impossible to increase the flow [of disabled people] into work substantially'¹⁷¹ by this means.

Changes were made to DWA in 1995 specifically to attempt to enhance its work incentive effect. Changes included help with NHS charges, a 30 hour allowance, a disabled child allowance, and allowances for lone parents and single persons. An evaluation in 1997 found that the incentives continued to have a greater effect on people who were already in work and that 'the overall impact of the changes in terms of increasing the numbers of people moving into work appears to be fairly limited.'172

Disabled Person's Tax Credit and the disability element of Working Tax Credit

DPTC was introduced in 1999 and essentially replaced DWA as the main in-work benefit available to disabled people, building on DWA but extending eligibility and providing more generous financial support through a higher earnings threshold

- ¹⁶⁴ Rowlingson *et al.* (1996) p 50.
- ¹⁶⁵ Rowlingson *et al.* (1996) p 203.
- ¹⁶⁶ Rowlingson *et al.* (1996) p 15.
- ¹⁶⁷ Rowlingson *et al.* (1996) p 208.
- ¹⁶⁸ Rowlingson *et al.* (1996) p 16.
- ¹⁶⁹ Rowlingson *et al.* (1996) p 198.
- ¹⁷⁰ Rowlingson K *et al.* (1996) p 210.
- ¹⁷¹ Rowlingson K *et al.* (1996) p 204.
- Arthur S, and Zarb G (1997) Evaluation of the 1995 changes to Disability Working Allowance p iv & p 15.

and a lower taper. In 2003, DPTC was replaced by Working Tax Credit (WTC), which included a disability element to provide additional support for people whose disability puts them at a disadvantage in getting a job. An element was also included for people with more severe disabilities.

DPTC was evaluated during 2001 and the disability element of WTC in 2007 through both quantitative and qualitative survey methods.¹⁷³ Many of the main findings in relation to DWA were confirmed by these evaluations, though a slightly more positive picture emerged regarding incentive effects for some people,¹⁷⁴ especially in relation to decisions about remaining in work and working part-time following the onset of a disability or health problem.

The personal characteristics of DPTC recipients were not significantly different from the characteristics of those previously in receipt of DWA, except that recipients of DPTC who never received DWA were much more likely to have children (as a result of the greater number of lone parent recipients).¹⁷⁵ DPTC recipients were also more likely to be working part-time than working disabled people generally, with half working less than 30 hours per week and half of these working less than 20 hours per week. Indeed, nearly a quarter (23 per cent) of those not working when they found out about DPTC said that DPTC had enabled them to work fewer hours than they otherwise would. Only 13 per cent of recipients said that DPTC had encouraged them to work more hours than they would otherwise have done.¹⁷⁶

Approximately one-third (32 per cent) of DPTC recipients surveyed in 2001 reported that DPTC had allowed them to work, or had made work more worthwhile financially, either for themselves or for their partner.¹⁷⁷ More than half (56 per cent) of those who were not working when they first heard about DPTC said that DPTC had proved a positive incentive to work, with most of these identifying it as the decisive factor – though 37 per cent said it had been of no importance in their decision.¹⁷⁸ However, these were a minority of all respondents and, as with DWA, the great majority (72 per cent) were already working when they first found out about DPTC, the inference to be drawn that DPTC was not a strong influence on their decision of whether to work or not.¹⁷⁹

As was found to be the case with DWA, the greatest impact from DPTC was on those who said they would not be doing their present job without DPTC and that it

Atkinson J, Meager N, Dewson S, (2003) Evaluation of the Disabled Person's Tax Credit; Corden A, and Sainsbury R, (2003) Evaluation of the Disabled Person's Tax Credit; Turley C, McAlpine C, Thomas A, (2007) The disability element of Working Tax Credit.

¹⁷⁴ Corden A et al. (2003) pp 62-64.

¹⁷⁵ Atkinson J *et al.* (2003) p 12.

¹⁷⁶ Atkinson J *et al.* (2003) p 1-2.

¹⁷⁷ Atkinson J *et al.* (2003) p 2.

¹⁷⁸ Atkinson J et al. (2003) p 18-19.

¹⁷⁹ Atkinson J et al. (2003) p 18-19.

had been the decisive factor in their decision to keep working. In the earlier DPTC surveys, this group comprised nearly a quarter (23 per cent) of recipients, with women, older people, self-employed and lone parents all being over-represented within it. ¹⁸⁰ The more significant the job, either in terms of the income derived from it or the hours committed to it, the less likely were respondents to say that DPTC had influenced them to take it or stay in it. ¹⁸¹

In-work support, provided by DPTC and cited by recipients as helping them retain jobs, was diverse and included:

- 'Enabling people to do work which suited them;
- Making jobs or self-employed work financially worthwhile;
- Increasing financial security;
- Compensating for not having earnings from a previous family member;
- Protecting the welfare of children;
- Maintaining health and social participation;
- Supporting family preferences;
- Providing 'platforms' in trajectories of employment and health/impairment;
- Financing sick leave;
- Supporting business development and maintaining business diversity. '182

The perceived helpfulness of DPTC was found to be related predominantly to the 'direct income effect' of the additional money, with many respondents reporting that it had made a contribution to their household income, standard of living and self-esteem:

'Recipients' perceptions about the helpfulness of DPTC to them turn rather more on the direct income effect, and on the subsequent effect of that cash on their psyche and general well-being, than it does on their participation in work and the quality of their working lives.' 183

Furthermore, the propensity not to work in the absence of DPTC was found to change systematically against three factors. The proportion of recipients who would not have taken (or stayed in) their job in the absence of DPTC: increased as the absolute value of DPTC payments increased; increased as the proportion of gross income represented by the DPTC award increased, and increased as the number of hours worked decreased.¹⁸⁴ Essentially the credit enabled recipients to

¹⁸⁰ Atkinson J *et al.* (2003) p 2.

¹⁸¹ Atkinson J *et al.* (2003) p 19.

¹⁸² Corden A (2003) p 64.

¹⁸³ Atkinson J *et al.* (2003) p 17.

¹⁸⁴ Atkinson J *et al.* (2003) p 109.

take low paying jobs, work part-time or reduce their working hours by helping them to manage financially.

The later evaluation confirmed these findings. This found that receiving the disability element of WTC had acted as an incentive for some people who had become disabled in work to remain in work by allowing them to reduce their working hours. Without this ability, many said they would have given up work and claimed out-of-work benefits, so as not to compromise their health.¹⁸⁵

Return to Work Credit (RTWC)

Return to Work Credit (RTWC) is one of a package of measures that form the Pathways to Work Reforms pilot introduced in selected areas in 2003 and rolled out nationally in 2008. It is a non-taxable weekly payment of £40 payable for a maximum of 52 weeks designed to incentivise the movement into work among disability and incapacity benefits recipients. RTWC is available to people who have been in receipt of a qualifying disability benefit for at least 13 weeks who have found work of not less than 16 hours and whose gross earnings do not exceed £15,000 per annum. The payment is additional to tax credits and, unlike Child Tax Credit (CTC) and WTC, is not treated as income for housing or council tax benefit purposes.

An evaluation of RTWC in 2006¹⁸⁶ found that there were some incentive effects from the credit. It found that some people would not have gone to work or would not have returned so quickly without it, and that payment of RTWC supported lasting transitions to work from incapacity benefits for some people. However, there was considerable deadweight within the initiative. Advisers reported in our discussion groups too that RTWC was mostly taken up by customers who they felt would probably have returned to work without it. A synthesis report of the Pathways to Work pilot similarly concluded that, although the credit had been effective in providing financial support in the transition from benefits to work, its scope to incentivise work was constrained because most people heard about it after they had found a job or moved into work. Some job ready customers reported that RTWC had enabled them to take a lower paid job than they would have otherwise considered. Another key effect was in allowing individuals who had found employment to work fewer hours than they would otherwise have done, to suit their health limitations.

¹⁸⁵ Turley C, *et al.* (2007).

Corden A (2006) Pathways to work from incapacity benefits: A study of experience and use of Return to Work Credit.

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This report presents the findings from a review of evidence about recipients of Disability Living Allowance (DLA) and a qualitative study of recent applicants for the benefit. The report explores a number of hypotheses as to why DLA recipients have particularly low rates of employment, even compared to other, similarly disadvantaged disabled people, and seeks to throw light on what effects DLA receipt may have on people's decision making about work.

A telephone survey of 1,005 applicants for DLA was carried out prior to them hearing of the decision on their claims, and 637 were successfully re-contacted once they knew whether they had been awarded the benefit. There were 110 face-to-face interviews subsequently carried out with purposively selected individuals according to changes in their employment status.

If you would like to know more about DWP research, please contact: Paul Noakes, Commercial Support and Knowledge Management Team, 3rd Floor, Caxton House, Tothill Street, London SW1H 9NA

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