

This is a repository copy of *The Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*.

White Rose Research Online URL for this paper:  
<http://eprints.whiterose.ac.uk/73528/>

---

## **Monograph:**

Corden, A, Sainsbury, R [orcid.org/0000-0002-1217-6818](http://orcid.org/0000-0002-1217-6818), Irvine, A [orcid.org/0000-0002-6082-5675](http://orcid.org/0000-0002-6082-5675) et al. (1 more author) (2010) *The Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*. Research Report. Department for Work and Pensions Research Report, No. 649 . HMSO , Norwich.

---

## **Reuse**

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

## **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.

**The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research**

by Anne Corden, Roy Sainsbury, Annie Irvine  
and Sue Clarke

**Department for Work and Pensions**

**Research Report No 649**

# **The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research**

**Anne Corden, Roy Sainsbury, Annie Irvine and Sue Clarke**

A report of research carried out by The University of York on behalf of the Department for Work and Pensions

© Crown Copyright 2010. Published for the Department for Work and Pensions under licence from the Controller of Her Majesty's Stationery Office.

Application for reproduction should be made in writing to The Copyright Unit, Her Majesty's Stationery Office, St Clements House, 2-16 Colegate, Norwich NR3 1BQ.

First Published 2010.

ISBN 978 1 84712 756 3

Views expressed in this report are not necessarily those of the Department for Work and Pensions or any other Government Department.

# Contents

Acknowledgements .....	v
The Authors.....	vi
Summary .....	1
1 Introduction .....	7
1.1 Recent research on Disability Living Allowance and Attendance Allowance .....	8
1.2 Research aims and objectives .....	10
1.3 Research design and methods.....	11
1.3.1 <i>Discussions with professionals</i> .....	11
1.3.2 <i>Desk-based review of current research instruments</i> .....	12
1.3.3 <i>Interviews with DLA and AA claimants</i> .....	12
1.4 Structure of the report .....	13
2 Giving information to DLA and AA claimants: The role of advisers in Jobcentre Plus, PDCS and external agencies.....	15
2.1 Talking about DLA and AA to potential claimants .....	16
2.2 Views on the purpose of DLA and AA.....	18
2.2.1 <i>Spontaneous views on the purpose of DLA and AA</i> .....	19
2.2.2 <i>Prompted views on the purpose of DLA and AA</i> .....	19
2.3 Views on the difference DLA and AA make to people's lives.....	21
2.4 Discussion.....	22
3 Methodological findings .....	25
3.1 Design of interview and topic guide.....	26

3.2	The introductory and contextual enquiry .....	27
3.3	DLA, AA and general household income .....	29
3.4	Managing money and meeting expenses .....	30
3.5	Exploring what difference was made by DLA and AA .....	31
3.5.1	<i>Spontaneous comments</i> .....	31
3.5.2	<i>Direct questions</i> .....	32
3.5.3	<i>Prompts</i> .....	33
3.5.4	<i>Exploration of advice received</i> .....	33
3.5.5	<i>Exploration of perceived reasons for receipt</i> .....	34
3.5.6	<i>Exploration of perceived relationship between DLA, AA and paid work</i> .....	34
3.5.7	<i>Exploration of feelings about receipt</i> .....	35
3.5.8	<i>Exploration of practical money management</i> .....	35
3.5.9	<i>Inviting response to hypothetical scenarios</i> .....	36
3.6	Summary .....	36
4	Recipients of Disability Living Allowance and Attendance Allowance: Current income sources .....	39
4.1	Awareness and understanding of receipt of DLA or AA .....	40
4.1.1	<i>Adult DLA recipients</i> .....	40
4.1.2	<i>AA recipients</i> .....	41
4.1.3	<i>Parents of children receiving DLA</i> .....	41
4.2	Links from DLA and AA to other benefits and services, including Carer's Allowance .....	42
4.2.1	<i>Carer's Allowance</i> .....	42
4.2.2	<i>Other 'links' to benefits and services</i> .....	44
4.3	Overall household incomes .....	45
4.3.1	<i>Adult DLA recipients</i> .....	45
4.3.2	<i>AA recipients</i> .....	46
4.3.3	<i>Households with children receiving DLA</i> .....	47
4.4	Significant recent changes in income .....	47

4.5	Perceived importance of different income components .....	48
4.6	Summary .....	49
5	Recipients of Disability Living Allowance and Attendance Allowance: Current expenses of daily living .....	51
5.1	Accommodation .....	52
	5.2.1 <i>DLA and AA recipients</i> .....	52
	5.2.2 <i>Parents of child DLA recipients</i> .....	52
5.2	Paying for fuel .....	53
	5.2.3 <i>DLA and AA recipients</i> .....	53
	5.2.4 <i>Parents of child DLA recipients</i> .....	53
5.3	Paying for food.....	54
	5.3.1 <i>DLA and AA recipients</i> .....	54
	5.3.2 <i>Parents of child DLA recipients</i> .....	54
5.4	The cost of getting shopping .....	55
	5.4.1 <i>Adult DLA and AA recipients</i> .....	55
5.5	Paying for personal care.....	56
	5.5.1 <i>Adult DLA and AA recipients</i> .....	56
	5.5.2 <i>Children receiving DLA</i> .....	57
	5.5.3 <i>Special equipment</i> .....	57
5.6	Paying for health care .....	58
	5.6.1 <i>Adult DLA and AA recipients</i> .....	58
	5.6.2 <i>Children receiving DLA</i> .....	58
5.7	Paying for housework, gardening and small jobs.....	59
5.8	Paying for mobility aids and transport .....	59
	5.8.1 <i>Adult DLA and AA recipients</i> .....	59
	5.8.2 <i>Parents of children receiving DLA</i> .....	61
5.9	Buying clothes .....	61
5.10	Paying for social activities, and education.....	62
	5.10.1 <i>Adult DLA and AA recipients</i> .....	62
	5.10.2 <i>Children receiving DLA</i> .....	63

5.11	Buying gifts .....	64
5.12	Summary .....	65
6	Perspectives on the impact of DLA and AA.....	67
6.1	How did people conceptualise DLA and AA? .....	67
6.1.1	<i>Adult DLA recipients</i> .....	67
6.1.2	<i>AA recipients</i> .....	69
6.1.3	<i>Parents of children getting DLA</i> .....	70
6.2	How were DLA and AA being used? .....	71
6.2.1	<i>Adult DLA and AA recipients</i> .....	71
6.2.2	<i>Parents of children receiving DLA</i> .....	75
6.3	What other roles did DLA and AA have? .....	78
6.3.1	<i>DLA recipients of working age</i> .....	80
6.3.2	<i>Parents of children getting DLA</i> .....	82
6.4	What were DLA and AA recipients' current feelings about their overall financial and personal circumstances? .....	83
6.4.1	<i>Adult DLA recipients</i> .....	83
6.4.2	<i>AA recipients</i> .....	84
6.4.3	<i>Parents of children getting DLA</i> .....	85
6.5	What would happen if recipients had less money? .....	86
6.6	What difference did recipients think DLA or AA made for them? .....	88
6.6.1	<i>DLA and AA recipients</i> .....	88
6.6.2	<i>Parents of children getting DLA</i> .....	90
6.7	Summary .....	90
7	Implications for policy and research .....	93
7.1	Summary of substantive findings about impact .....	94
7.1.1	<i>Money management</i> .....	94
7.1.2	<i>Spending</i> .....	95
7.1.3	<i>Impacts</i> .....	96
7.1.4	<i>Contributory factors to impacts other than spending</i> .....	97



7.2	Lessons from the approach to enquiry used in the study .....	98
7.3	The future measurement of the impact of DLA and AA .....	99
7.3.1	<i>The potential of using 'quality of life' as a composite indicator of impact</i> .....	100
7.3.2	<i>The counterfactual</i> .....	100
7.3.3	<i>Do information requirements go beyond the counterfactual?</i> .....	101
7.3.4	<i>Setting out the options for future research</i> .....	102
7.3.5	<i>Question sequencing and wording</i> .....	103
7.4	Final reflections for developing policy .....	105
Appendix A	Discussions with people who advise potential recipients of DLA and AA: Research methods .....	107
Appendix B	Qualitative interviews with recipients of DLA and AA, and parents of children in receipt of DLA: Research methods .....	109
Appendix C	Research instruments .....	113
Appendix D	CASP-19 measure of 'quality of life' .....	139
References	.....	141

## List of tables

Table 1.1	Characteristics of the study group .....	13
Table 7.1	Types of disability-related spending mentioned in interviews .....	96
Table B.1	Age and sex of people in study group .....	111



# Acknowledgements

Our first thanks go to the Disability Living Allowance (DLA) and Attendance Allowance (AA) recipients and their families who took part in the research interviews and to the professionals working in the agencies of the Department for Work and Pensions (DWP) and external advice agencies who took part in the group discussions. Their willingness and cooperation were not only much appreciated but essential. We cannot do our job without them.

We also thank Andrea Kirkpatrick and Mike Daly of the Disability and Carers Benefit Division in the DWPs for working with us, through all the frustrations not of our or their making, to bring this project to fruition. Their professionalism and cooperative good humour have helped us immensely.

In the Social Policy Research Unit (SPRU) we have been assisted as ever to the highest standards by Sally Pulleyn and the other members of the support staff. Thank you all. Again.

# The Authors

The authors all work in the Social Policy Research Unit at the University of York.

**Anne Corden** is a Senior Research Fellow.

**Roy Sainsbury** is a Research Director leading the Welfare and Employment Team within SPRU.

**Annie Irvine** and **Sue Clarke** are Research Fellows.

# Summary

## The aims of the study

The aims of the qualitative research reported here were to investigate the use and impact of Disability Living Allowance (DLA) and Attendance Allowance (AA), to increase understanding of the difference these benefits made to people's lives, and to contribute towards development of questions that might be used in further surveys.

## Research methods

The study used the following methods:

- Six group discussions with 24 professionals and advisers in touch with people who claim or might be entitled to DLA or AA.
- Qualitative interviews with 15 adult DLA recipients, 15 AA recipients and 15 parents of child recipients of DLA.
- A desk-based review of relevant survey instruments.

Group discussions were held in early 2009. The 24 people who took part in the discussion groups included DWP staff in the Benefits Enquiry Line, and Carer's Allowance office; staff in six local offices of Pension Disability and PDCS; local authority staff from adult services in seven local authorities; staff working in advice agencies and people working in voluntary organisations.

The study group of adult DLA and AA recipients and parents of children receiving DLA was purposively selected from a sample supplied by DWP of benefit recipients who lived in one of three locations (a city, an urban and a rural environment) in Great Britain. Fieldwork was conducted during the summer of 2009. The overall group included a range of people with different ages and personal circumstances, and a roughly equal gender balance. One third of the adult DLA recipients were aged over 65 years. Interviews were recorded, and transcriptions used for thematic qualitative analysis.

## Substantive findings about use of and impact of DLA and AA

### **Information and advice about DLA and AA**

There was a wide range of circumstances in which DWP staff and personnel in other statutory and voluntary services talk to people about DLA and AA (Section 2.1). Advisers' experience was that general levels of knowledge about these benefits were low, and they spend considerable time correcting misunderstandings and wrongly based concerns. Advisers frequently discussed with potential applicants and their families what DLA or AA was for and how it might be used (Section 2.1).

The consensus among advisers was that, generally, DLA and AA had a major positive impact on recipients' lives (Section 2.3). From their experience, they believed that DLA and AA benefited people by helping them:

- maintain independence and control (Section 2.2.2)
- meet some of the extra costs of disability (Section 2.2.2; 2.3)
- improve quality of life (Section's 2.2.2 and 2.3)
- keep jobs or maintain contact with the labour market (Section 2.2.2)
- access other help and services (through 'passporting') (Section 2.2.2)
- enhance physical and mental health (Section 2.3)
- maintain warmer, cleaner, more comfortable homes (Section 2.3)
- relieve financial pressures (Section 2.3).

### **Recipients' conceptualisation of DLA and AA**

Adult recipients of DLA and AA perceived entitlement to be related to effects of long term medical conditions and the need for help or care, or as a general boost to income for people with problems related to their condition (Section 6.1). Parents also related entitlement to their child's medical condition and the additional expenses involved, and some saw wider purpose in enhancing family life, taking pressures off parents, and replacing lost earnings.

### **Using DLA and AA**

Findings showed an important difference between the practical money management of DLA and AA received, and the way in which recipients explained how the benefits enabled spending. The former was to do with the way bank accounts and post office accounts were used, how people made direct debits and standing orders to pay some bills, and which partner took responsibility for different parts of household budgeting (Section 6.2). In addition, while some people separated out their DLA or AA (and sometimes other particular income streams) for particular purposes, others preferred a 'general pot' approach,

thinking about the total money available to them, and paying for things as they were needed (Section's 3.5.2 and 6.2). Payment intervals for different pensions and benefits, including DLA or AA, the relative amounts received, and people's approaches to saving were all influential.

When we turn from practical money management to thinking about how DLA or AA was being used to enable spending, findings show that DLA and AA paid to adult recipients enabled them to meet expenses of:

- personal care (Section 5.5);
- transport (Section 5.8);
- food (Section 5.3);
- fuel (Section 5.2);
- home maintenance, including cleaning, gardening and small jobs (Section 5.7);
- health care, medical equipment and supplies (Section 5.6);
- telephones and computers (Section 5.10);
- social activities (Section 5.10);
- giving presents, gifts and 'treating' (Section 5.11).

Findings showed that most direct personal care and support of elderly and disabled people living in the community was unpaid, and provided by partners, adult children and other family members. For many DLA and AA recipients, managing daily living also depended on finding solutions and working out ways of doing things which reduced the amount of direct help they needed, and enabled them to maintain control and some independence. Life was managed by being able to afford market prices for housework, laundry, garden maintenance, odd jobs and taxi rides; by buying frozen meals or buying hot meals outside the home; by relying on frequent use of telephones, and by running private vehicles (Section 5.12). DLA and AA helped people to be able to afford these things (Section 7.1.3).

All parents of child recipients of DLA wanted opportunities to give their child the best possible life chances. They spent money on the particular equipment or activities that would help (Section 5.10), and on treatment and tuition (Section 5.10). Some parents had heavy expenditure on heating (Section 5.3), electricity (Section 5.3), transport (Section 5.8) and costs of maintaining or replacing appropriate clothes and shoes (Section 5.9). Expenses spread across other family members, and into all areas of family life. Having DLA helped them pay for such items and services.

### **Other roles for DLA and AA**

In addition to the way in which DLA and AA enabled people to afford what they needed, people attributed other roles to the benefits (Section 6.3):

- Helping practical money management.
- Enabling access to other kinds of support (through 'passporting').
- Providing a safety net, especially during financial transitions.
- Preventing, or helping management of, debts.
- Enabling people to live at home.
- Keeping people part of society.
- Acknowledging people's condition.
- Enabling paid work.

### **What difference did recipients think was made by DLA or AA?**

DLA recipients of working age were unanimous in expressing views that DLA made a big difference to them (Section 6.6). All the adult DLA recipients in our study group were people who had been living on low out-of-work incomes for some time. Typical comments were that DLA 'enables me to live'. Some said, without DLA, they would not be able to pay their bills, or get the help they needed. Parents of child recipients who were living on low incomes said their children's lives would be adversely affected, for example, spending less on items needed for their disabled child, such as extra lessons. However, the more generally reported effect would be reduction in living standards for the whole family.

Among DLA recipients over state retirement age and AA recipients who engaged with the idea of what difference the benefit made most also used strong language. Some said it made the difference between poverty and a reasonable standard of living (Section 6.6.1) and without AA they could not afford the help they had, could not afford chiropody, or keep their home clean and warm.

### **Policy implications of substantive findings**

Findings showed a wide range of ways in which DLA and AA are currently enabling elderly and disabled people to afford to pay for services and items they need (Section 7.1.3). The benefits have preventive roles in helping people avoid moves into residential care or nursing homes, and maintaining or avoiding deterioration in health. Importantly, while DLA or AA often does not go directly towards paying for personal care, the benefits have a key role in reducing potential demand for formal services. This happens by enabling people to find their own solutions, both in the market place, and in accessing services from voluntary organisations, which are often not cost-free for users. DLA and AA recipients also believed that the gifts and 'treats' they were able to give to relatives and friends who gave practical care



and help helped to maintain the channels of informal support within families and communities, on which they depended.

For child recipients of DLA, parents were using the benefit in ways that will enhance their child's future life chance and opportunities. They were paying for tuition, physiotherapy, speech and language therapy, and equipment to encourage learning and stimulate response, all with a view to the future development of the child. In some families, DLA was being used in ways which support and strengthen family life.

## Methodological findings

Our qualitative approach in interviews with DLA and AA recipients was to seek contextual information about effects of health circumstances and managing daily life (Section 3.2), sources of income (Section 3.3), money management, expenses and spending decisions (Section 3.4). Embedded throughout this discussion were different opportunities to consider the contribution made by DLA or AA. We were able to explore the difference made by DLA or AA in a number of ways (Section 3.5), (through spontaneous comments; direct questions; prompts; exploration of advice received; exploration of perceived reasons for receipt; exploration of perceived relationship between DLA, AA and paid work; exploration of feelings about receipt; exploration of practical money management and response to hypothetical scenarios of loss and gain in income).

Useful information came from each of these different ways of investigation, but the overall picture of how DLA and AA were being used and what difference they made depended on our having used all the approaches (Section 3.6).

## Policy implications of methodological findings

One of the principal aims of the research was to inform the possible development of quantitative research instruments for measuring the difference made by DLA and AA. The main relevant findings were:

- Measuring impacts of DLA and AA does not require asking questions about the use of the benefits.
- Process questions would provide a fuller understanding of the role of DLA and AA in people's lives.
- There are significant differences between the needs and experiences of adult benefit recipients (of DLA and AA) and parents of child recipients of DLA.

The two main options are therefore to design a survey based on inputs and impacts only, or to design a survey that includes questions about how DLA and AA are perceived and used. The first option would not require constructing questions about DLA and AA while the latter option would definitely require a suite of questions that does not currently exist.

It was outside the scope of this study to make any assessment or recommendations about whether any existing survey could in some way contribute to, or be used as the basis, for a survey of DLA and AA recipients. However, scrutiny of relevant surveys suggests that none appears sufficient to measure the impacts of the benefits. A comprehensive understanding of the impacts of DLA and AA would therefore require a large dedicated survey instrument.

# 1 Introduction

This report presents the findings of a qualitative research project commissioned by the Department for Work and Pensions (DWP) to investigate the impact on people's lives of receiving either Disability Living Allowance (DLA) or Attendance Allowance (AA). The research was conducted by the Social Policy Research Unit (SPRU) at the University of York. The report is based on discussions held with advisers in touch with people who claim or might be entitled to DLA or AA; qualitative interviews with 45 DLA and AA recipients and their families, and a desk based review of current research instruments.

DLA and AA were introduced in 1992 as non-means-tested benefits to contribute to meeting the extra costs of disability. DLA can be claimed by people under 65 years old (including children) on the basis of their care and mobility needs. It has two components: DLA (care) paid at three different rates and DLA (mobility) paid at two rates. Claimants awarded DLA before they are 65 years old can continue to receive it beyond 65 as long as they continue to meet the eligibility criteria. Attendance Allowance can be claimed by people over 65 years old and is assessed on the basis of their care needs only. There are two rates of AA but the benefit has no component for mobility needs.

The number of people receiving DLA in May 2009 was 3,070,610 of whom around 366,540 were children under 18, and over 792,380 were over 65 years old. The number of AA recipients in May 2009 was 1,585,790.<sup>1</sup>

There has been considerable interest in DLA and AA in recent years. For example, the cross government Independent Living Strategy touches on the role of the benefits in supporting independent living. More recently, they have been mentioned in the context of the future of social care.

This study was conducted as part of a programme of research being carried out by DWP on disability benefits. It has been informed by an initial paper by Berthoud (2009) which set out to investigate the feasibility of measuring robustly the impacts of DLA and AA, which he defined as 'what difference they make to claimants'

---

<sup>1</sup> Statistics accessed on 14.12.09 from DWP website - <http://83.244.183.180/100pc/tabtool.html>

care and mobility arrangements, to their overall standard of living, and to their social inclusion and sense of identity', and about which he suggested 'remarkably little is known' (p. 1).

Berthoud's paper concluded with recommendations for a research plan, the first part of which was for qualitative work to investigate people's views on how DLA and AA affect their lives. This project was commissioned to respond to this suggestion.<sup>2</sup>

In this chapter we begin with a brief review of recent research into DLA and AA followed by a summary of the main research questions that we addressed in the study, and our methodology for doing so. We describe briefly the characteristics of our study group of benefit recipients (with a short summary of the methods for the study being available in Appendices A, B and C). The final section outlines the structure of the rest of the report.

## 1.1 Recent research on Disability Living Allowance and Attendance Allowance

DLA and AA have been the subject of considerable research interest from government in recent years. For example, Kasparova *et al.* (2007) conducted a feasibility study into measuring take-up of the two benefits; Purdon *et al.* (2005) examined the information needs of DWP on disability, which included income, costs of disability, benefit receipt and social participation; and Thomas (2008) analysed the characteristics of disallowed DLA claims. More recently, there has been research interest into the relationship between DLA and employment. Beatty *et al.* (2009) analysed new survey data and national benefits data to identify similarities and differences in the characteristics of people who claim both DLA and Incapacity Benefit (IB), and those who claim only IB<sup>3</sup> and Thomas and Griffiths (2010, forthcoming) have been investigating the employment records and aspirations of DLA applicants.<sup>4</sup>

---

<sup>2</sup> A companion research project was commissioned from the Policy Studies Institute (PSI) to carry out secondary data analysis of The English Longitudinal Survey of Ageing (ELSA) and the 1996/1997 Family Resources Survey (FRS) Disability Follow-up survey to explore the impact of DLA upon recipients compared with DLA eligible non-recipients across a wide range of outcomes including respondents' circumstances and well-being. At the time of writing the PSI research was ongoing.

<sup>3</sup> This research was carried out before Employment and Support Allowance replaced IB for new claimants in October 2008.

<sup>4</sup> In this project survey respondents were first interviewed at the point at which they had made an application for DLA but had yet to receive notification an award decision. A second wave of interviews was conducted approximately five months after the award notification.

However, despite this research interest and activity (and to echo Berthoud again) we still know very little about the difference that receiving DLA or AA makes to people's lives. One useful contribution comes from an Age Concern paper in which findings are presented from a survey of over 650 older people who had used their information and advice services (Age Concern, 2008). Of the people who had gone on to make a successful claim for benefit (mainly Attendance Allowance) over half used at least part of the money for cleaners and gardeners, a quarter paid for household repairs and decoration, a fifth spent money on health-related adaptations and a further fifth on household appliances.

Only 24 per cent paid for care services. The report concluded from this that 'much of the extra money was spent on ensuring that those with failing health and disabilities could remain in their own homes with a degree of dignity and comfort' (p.6). Further findings were that nearly half of the respondents said they spent money on essentials such as food and clothing. Of relevance for the current study's interest in assessing impacts, the survey found that '68 per cent reported that they worried less and had improved mental health' (p.6). These findings have been useful in developing topic guides for DLA and AA recipients and for contributing to understanding how spending can be associated with impacts.

Also of help here is Berthoud's useful discussion of how we can conceptualise the impact of DLA and AA. He frames his discussion by asking how DLA and AA can contribute to providing for the additional needs associated with disability. He notes that such needs are difficult to define but offers four 'approaches to the issues' (2009: 16).

- *Supporting additional expenditure* recognises that one of the effects of disability is that some people have to spend more (than non-disabled people) on specific items, such as personal care, household services, heating, food, medical expenses, or transport.
- *Improving specific outcomes*, i.e. reflecting the distinction between spending per se and the effect of that spending, for example whether buying additional fuel makes the benefit recipient warm enough.
- *Generalised compensation for additional expenditure*, i.e. referring to the practice of some disabled people of cutting back on some items of expenditure in order to pay for the additional costs generated by disability. So, for example, someone might cut back on food or clothing in order to pay for additional heating costs. Hence, DLA and AA can be seen as compensating people for those additional costs.
- *Countering the effects of being disabled*, i.e. in ways not directly associated with the additional costs of disability, such as paying for activities that enhance social participation.

These are useful ways of thinking about how DLA and AA might have an impact on people's lives and can inform thinking about how to frame questions for a possible survey in the future. We return to these in the concluding chapter. One

important point to take from this analysis (which was also implicit in the Age Concern survey cited above) is that *spending* does not equate directly with *impact*.

The costs associated with long-term sickness and disability are integral to debates about the role of DLA and AA, but not the principal focus of this study. A useful review of research on the extra costs of disability (Tibble, 2005) concludes, in what is probably something of an understatement, that 'currently there is disagreement within the evidence over the size of extra costs of disability, what drives/affects extra costs and how best to measure or estimate extra costs'. Nevertheless there is no disagreement that disability does incur extra costs (p.1). An international comparison linking the costs of disability to adequacy of disability benefit payments similarly revealed conceptual and measurement difficulties and concluded that there was 'very little information about how to objectively determine the size and adequacy of allowance payments' (Stapleton *et al.*, 2008: 1). However, the authors also usefully consider ways of using existing data sets in the UK, or undertaking new primary data collection, that could inform an assessment of DLA and AA. We will return to some of their ideas in Chapter 7.

Turning to research on the experiences of DLA and AA claimants there is a useful study by Hawkins *et al.* (2007) who carried out qualitative research with 100 people in contact with the Disability and Carers Service.<sup>5</sup> They found that people became aware of DLA and AA (and Carers Allowance) from a variety of third party sources including 'professional' sources (i.e. advisers in and outside government, and medical professionals) and informal sources (family and friends). What was unusual however was for claimants to have any awareness of benefits before the onset of their illness or disability. These findings confirm the need in this research project to understand better the roles of these third parties in what claimants know about the benefits.

This brief review of some of the recent research into DLA and AA probably raises more questions than provides answers to the issue of how DLA and AA impacts on people's lives. Nevertheless, it does provide useful insights that we were able to carry forward into the design of research instruments and into the consideration later of how impacts might be measured in the future.

## 1.2 Research aims and objectives

The overall aims of the study were to:

- contribute to greater understanding of the use and impact of DLA and AA;
- increase understanding of the *difference* made to people's lives by receipt of DLA or AA;
- contribute towards development of questions that might be used in existing or new surveys of disabled people.

---

<sup>5</sup> Disability and Carers Service has now amalgamated with the Pensions Service to become the Pensions, Disability and Carers Service (PDCS).

We should emphasise that this study was intended to be an early step towards a possible large scale survey of DLA and AA recipients. At the time it was commissioned in late 2008 it was expected to lead to further work to test possible question sequences and wording. The task for the current research team was therefore to gather data on how people talked about DLA and AA, the concepts and language they used their understanding about the purpose of the benefits, and, in their own terms, what impact DLA or AA had on their lives. The study was a means therefore of exploring the 'counterfactual' question of how people's lives would be different *without* DLA or AA.<sup>6</sup>

### 1.3 Research design and methods

The research design comprised:

- six group discussions with professionals and advisers in touch with people who claim or might be entitled to DLA or AA;
- a desk-based review of current research instruments;
- qualitative interviews with 45 recipients of DLA and AA.

#### 1.3.1 Discussions with professionals

We know that a range of professionals and other people providing services in the community to disabled and older people are key sources of information and advice about DLA and AA, encouraging and triggering applications (Hawkins *et al.*, 2007). It is likely therefore that what such people say about DLA and AA to disabled and older people and their family and carers will have some influence on their conceptualisation, understanding and use of the benefits.

The aim of the discussion groups was to increase our understanding of some of the ways in which potential claimants may get ideas and suggestions about the purpose of the benefits and how they might be used. Such contextual information was intended both to inform development of topic guides for the interviews with recipients, and to help us understand later what recipients told us about their knowledge of the two benefits.

Six discussion groups were held with 24 'front line' people from professional and support organisations, including:

- DLA/AA telephone help-line staff;
- staff from local offices of the Pensions, Disability and Carers Service of DWP;
- local authority social work and benefits staff;
- staff working in local authority and independent welfare advice organisations;
- people working in voluntary organisations supporting people and families.

---

<sup>6</sup> One way this was done was by presenting research respondents with hypothetical scenarios, as described and evaluated in Chapters 3 and 6.

The following topics were addressed in the group discussions:

- Views on the purpose of DLA and AA, and the basis for such understanding.
- Circumstances in which about DLA and AA are discussed with disabled and older people.
- How benefits are explained and the language used.
- Whether and how the benefits are promoted, and claims encouraged.

### **1.3.2 Desk-based review of current research instruments**

A number of surveys include questions that are relevant for thinking about the use and impact of DLA and AA. It was thought plausible therefore to expect that suggestions for questionnaire wording in future surveys could either use existing questions or develop and add to them.

We therefore reviewed some of the principal survey instruments to inform the interviews with DLA and AA recipients, and to make an assessment of their potential usefulness in addressing information needs about the impact of benefits. These included:

- General Household Survey.
- British Household Panel Survey.
- English Longitudinal Survey of Ageing.
- Expenditure and Food Survey.

We have also looked at the usefulness of the CASP-19 measure of quality of life.<sup>7</sup>

### **1.3.3 Interviews with DLA and AA claimants**

The core of the research design was 30 interviews with DLA recipients and 15 interviews with AA recipients. There was a dual purpose to these interviews. First, we aimed to investigate the way people thought about the benefits and the language they used, and the best way of getting information about what difference DLA and AA made. We also aimed to gather substantive findings about the impact of DLA and AA on people taking part in the study.

Half the DLA interviews were with adult recipients and half with parents of child recipients. Fieldwork was conducted in three locations (a city, an urban and a rural environment) in Great Britain.

The respondents were purposively selected from a sample supplied by DWP. We aimed to include a range of people with different ages and a roughly equal gender balance. Table 1.1 shows these characteristics for people in the study group. One-third of the adult DLA recipients were aged over 65 years.

---

<sup>7</sup> The CASP-19 instrument is set out in Appendix D which also explains how it is used to generate an overall measure of quality of life.



**Table 1.1** Characteristics of the study group

	Men/boys	Women/girls
<b>Adult DLA recipients</b>		
30-49 years	3	3
50-64	4	0
65 and over	3	2
<b>AA recipients</b>		
65-79	3	4
80 and over	1	7
<b>Child DLA recipients</b>		
2-9	5	2
10-15	4	4

We did not select respondents according to the health conditions recorded on the DWP database. However, in the interviews, information about health and disability was usually volunteered. Many people described more than one condition. Adults in receipt of either DLA or AA mentioned a range of fluctuating and chronic conditions including musculo-skeletal conditions, circulatory and heart disease, severe mental illness, sensory impairments and learning difficulties. Parents of children in the study group described a range of impairments and health conditions among their children.

There was a range of household types and family settings. Most adult recipients had done paid work at some stage, and most child DLA recipients lived in families where one or both parents currently did some paid work.

## 1.4 Structure of the report

Chapter 2 summarises the findings from the discussion groups with professionals and advisers, including how they talk to potential claimants about DLA and AA, their views of the purposes of the two benefits, and the impacts of DLA and AA they had seen on the lives of recipients. The chapter reflects on the implications of the discussions for future research on the impact of the benefits.

The rest of the structure of the report reflects the dual aims of the study. Thus, Chapter 3 presents the methodological findings and Chapters 4 to 6 the substantive findings.

Chapter 3 discusses our approach to enquiry, the salience of this issue, and how people responded to different ways of asking questions and inviting discussion. We discuss the usefulness of including a hypothetical question in the topic guide about the effect of losing £50 from their weekly income as a means of exploring the 'counterfactual' in the absence of using experimental methods of inquiry.

Chapter 4 is concerned with the income sources of the study respondents, including DLA and AA awards and other components of household income. This is an important topic because the way in which people think about and spend DLA or AA is likely to be influenced by how the benefits contribute to and fit in with overall household income.

Chapter 5 is about how people spent their income to meet regular and occasional expenses, and how this was related to age, ill-health or impairment, need for help and support, and family life. We explore how some people used their benefit for specific expenditures, while others considered DLA or AA as part of their general household budget from which all expenses had to be met.

Chapter 6 presents the substantive findings about impact, including how DLA and AA were being used, the roles they played in people's lives, and people's own assessments of the difference the benefits made.

Chapter 7 concludes the report by considering the implications of findings for future research on the impacts of DLA and AA. The potential use of existing surveys, and specific question sequences and wording, are assessed.

Throughout our report, words and phrases in italics are those used by the people who took part. We present such verbatim quotations from transcripts to show how people used language, and how they constructed and explained their views about income, meeting expenses, DLA and AA and what difference these made.

The report includes a bibliography, and appendices A, B and C present a summary of research methods. A separate methodological technical appendix 'Appendices to The impact of Disability Living Allowance and Attendance Allowance – findings from exploratory qualitative research', available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf), presents full technical details of the research methods and instruments.

## 2 Giving information to DLA and AA claimants: The role of advisers in Jobcentre Plus, PDCS and external agencies

It is known that a range of professionals and other people providing services in the community to disabled and older people are key sources of information and advice about Disability Living Allowance (DLA) and Attendance Allowance (AA), encouraging applications and giving practical help with claims. Included here are DWP staff in the Benefits Enquiry Line (BEL), Pensions, Disability and Carers Service (PDCS); health service personnel (hospital discharge and community nursing teams); local authority social services staff, welfare rights advisers, and people in organisations which support particular groups (for example, Age Concern, Carers UK, and mental health support groups). Such people are also often in touch with those family members and friends who support and care for older people, disabled or chronically sick people and are themselves often key actors in claims for DLA and AA, and recipients' budgeting and money management.

It is likely that what such people say about DLA and AA to disabled and older people and their families and carers will have some influence on their conceptualisation and use of the benefits. There is therefore much to learn from talking to such professionals and advisers, to gain a picture of ways in which the benefits are presented, explained and promoted.

The research design for the study thus included a series of discussion groups with people who advise and inform potential claimants about DLA and AA. The aim was to increase our understanding of some of the ways in which potential claimants may get ideas and suggestions about the purpose of the benefits, and how they might be used. Such contextual information was intended both to inform the

development of topic guides for the DLA and AA recipient interviews, and to help to us understand later what recipients told us about their knowledge of the two benefits.

Six discussion groups were held in early 2009 in which 24 people took part. These included:

- DWP staff (DLA/AA telephone help-line/central administration for Carer's Allowance);
- team leaders and customer liaison officers based in six local offices of PDCS;
- local authority staff from adult services in seven different authorities (including benefits advisers, social workers and visiting officers);
- staff working in independent advice agencies;
- people working in voluntary organisations.

The discussions covered the following topics:

- Occasions and circumstances in which advisers talked about DLA or AA to people using their services and their families.
- What kinds of things people wanted to know about DLA and AA.
- Views about why some people claim and some do not.
- Views about the purpose and use of the benefits.

Appendix A provides a summary of research methods, including recruitment of participants, data collection, and techniques for interpretation and analysis. The topic guide used to moderate discussion is at Appendix C.

In this chapter we summarise briefly how DWP and other advisers said they talked to potential claimants about DLA and AA, their views of the purposes of the two benefits, and their personal experiences of seeing the impact of DLA and AA on the lives of recipients. The chapter ends with a brief reflection on the implications of the group discussions for any research in the future on the impact of the benefits.

## 2.1 Talking about DLA and AA to potential claimants

There was a wide range of circumstances in which the advisers taking part talked to people about DLA and AA:

- benefits checks;
- onset of illness or disability;
- moves into hospital or care home;
- response to financial hardship;

- new claims – helping fill in forms;
- assessments for some form of social service provision;
- appeals against adverse decisions;
- response to relatives providing support and care.

In some circumstances staff provided information in response to enquiries, such as the staff in the benefit helpline offices. However, staff of PDCS and other organisations were often proactive in encouraging people to put in claims for DLA or AA when they identified likely eligibility and thought that additional income would benefit the person. Talking to relatives about DLA or AA was often important here.

Participants' experience was that people's knowledge and understanding about DLA or AA prior to making an application was highly variable. Generally, levels of initial knowledge were thought to be low, although in the group of local authority staff there was some agreement that people were becoming more aware of benefits, and more ready to ask for help in dealing with forms. However, they all had experience of people's concerns and doubts about claiming, especially among older people.

Overall, people who had direct personal contact with potential claimants, and their relatives and carers, said they spent quite a lot of time correcting misunderstandings and wrongly based concerns. A common misunderstanding reported from all groups was that people had to have somebody helping them, to qualify. Advisers felt the name of AA, in particular, misled many people into thinking they would not qualify because nobody came to their home to help them. Other people were concerned that if they did get AA somebody unwanted would then visit them. Some people thought they were '*not disabled enough*', for example because they did not use a wheelchair. On the other hand, comparisons with others sometimes led to wrong assumptions of entitlement, for example '*because I have arthritis too*' or '*I am worse than him*'. Another fear often met was that getting DLA or AA would mean some reduction in other benefits including state retirement pension, Pension Credit, Income Support, Housing Benefit or Council Tax Benefit. In particular, people did not want to lose any of their housing benefits when household budgeting arrangements had been built around the prioritisation of housing costs.

As well as having to correct misunderstandings, staff almost always had discussions with potential claimants about what DLA or AA was for and how it might be used. Practice varied widely however. PDCS officers' experience was that older people often say they would like some extra money for cleaning their house and keeping their garden tidy, and being able to go shopping. Taxis feature largely in what older people want – being able to afford taxis to the hospital and doctor, or to do some shopping; some would welcome being able to give relatives money for petrol or parking. Some PDCS officers said they were careful not to mention

specific ways of spending, but use general terms such as *'to pay for things to keep you independent and help you stay at home'*, *'to cover the additional costs you have'* and *'to help make life easier for you'*. Otherwise, their experience was that people remembered one particular word or phrase and misunderstandings arose, for example older people phoning-up later, or telling their friends, to ask about *'that taxi benefit'*. Key areas of need for attention or supervision in the assessment for entitlement for AA are preparing food, personal care and dressing.

Local authority staff and other non-DWP advisers saw no constraints in suggesting areas for potential spending or use of the benefits. Some advisers always emphasised to older people that the money might be used for anything that made them happier and helped them look after themselves, suggesting better food, seeing family more often, having heating on longer, better hygiene, visiting a friend who lived away, and even dog-walking, if this meant a valued pet might be kept longer. If somebody said how hard it was to get to the shops because of frailty and fatigue, social workers would readily say that AA might meet taxi fares for easier shopping.

Suggestions about how to use DLA, in order to encourage claims, happened less frequently with people of working age who lived in their own homes. However, advisers who supported people of working age with mental health conditions and their families did often spend time making suggestions for using DLA, to encourage claims. For example, advisers sometimes explained how DLA might help pay for the sandwiches bought when lack of motivation meant people did not cook; the long telephone calls people made to help-lines and support agencies, or the heavy prescription charges faced by some people whose daily medication was dispensed in small quantities.

The phrase *'taking the pressure off'* was mentioned in various discussion groups, and appeared to be a useful way of talking, in a variety of circumstances. Some older people, for example, reluctant to describe need for help or care, readily agreed that there were financial pressures. Advisers of people with mental health conditions were also responsive to suggestions that some pressures might be lifted by having extra money to ease situations and help recovery. *'Taking the pressure off'* relatives or carers was another way in which advisers sometimes suggested that having DLA or AA would be useful. Availability and use of DLA and AA was also generally part of any discussions about people's options and arrangements for supported accommodation or residential care.

## 2.2 Views on the purpose of DLA and AA

We thought it likely that the personal views of DWP staff and other advisers about the purposes of DLA and AA would influence what they told people about the benefits, which in turn would affect ways in which recipients themselves thought about the benefits and used them. Hence, when professionals and advisers talk to people about claiming and using DLA or AA, their own underlying perceptions

and beliefs are likely to have some influence on what they say and how they say it. In the group discussions we therefore explored the participants' own beliefs about the purpose of the benefits.

Two kinds of evidence emerged from the groups. The first comes from *unprompted* comments and observations about the purpose of the benefits and what they offer people. Such comments occurred throughout the discussions, for example when people talked about the way they encouraged claims. The second kind of evidence comes from *responses to specific questions* (later in the group discussion) when we asked participants directly to reflect on this topic. While the first kind of evidence may give particularly strong indications of people's underlying feelings and beliefs, both kinds of evidence are likely to reflect to some extent the purpose and culture of the organisations in which participants worked.

### **2.2.1 Spontaneous views on the purpose of DLA and AA**

Benefits help-line staff generally talked in terms of extra money for care and mobility needs, to enhance quality of life. Some suggested the benefits were not being used properly if they just went into the 'general household pot' but others argued that disabled people already on low incomes may need money for everyday things. There were some comments about genuine deserving people and others who were not. Among some DWP staff who visited mainly older people, AA was associated with meeting personal care needs such as bathing, dressing and getting upstairs, but others saw wider purpose, in enabling people to shop or clean their house, or stay in their own home with greater comfort.

Non-DWP participants were much more likely to use concepts less directly linked to formal criteria of entitlement. Various participants talked about the benefits in terms of empowering people, enabling them to participate, giving them choice, making them feel included, giving some independence, enabling people to pay for things themselves, enabling people to give back rather than just offering thanks, giving people reasons for coping and carrying on, lifting feelings of just being a burden, and making people feel better.

Our findings suggest that people are getting a range of different kinds of ideas about using the benefits, and different suggestions about the difference they might make, according to which professionals or helping organisations they are in touch with.

### **2.2.2 Prompted views on the purpose of DLA and AA**

In considered response at the end of the group discussion, and sometimes also having talked about this to other colleagues or service users in preparation for the group discussion, participants suggested a range of ways that the benefits could help people.

Maintaining independence and control

- To maintain or regain independence.
- To maintain life as they wanted to live it.
- To exercise choice and control.
- To be less dependent on other people's preferences and choices.
- To be able to live in the community longer, before a move to residential care.

Meeting costs

- To meet extra costs of disability.
- To overcome obstacles related to disability or health condition.
- To access care at home.
- To be more mobile.

Improving quality of life:

- To feel happier and find life easier.
- To have more social contacts.

Enabling paid employment:

- To try to keep jobs or contact with the labour market.

Accessing other help:

- To access other help and services (through 'passporting').

Participants in the group also suggested a range of purposes that were more related to wider goals rather than enhancing the lives of individuals. These included:

- Support for social inclusion.
- To prevent financial burdens on disabled and ill people.
- To provide opportunities for children and enhance their lives.
- To take different kinds of pressure off people and families.
- To give people a reasonable standard of living, and alleviate costs of care and caring.
- To go towards long-term costs of living with disability and illness, such as loss of earnings.

All participants said their ideas came mainly from experience of working with people and, for some, going into people's homes and seeing how they managed. Social workers and non-DWP community advisers said their views came through understanding the diversity of people's needs and seeing how different people could be helped in different ways. Few could remember any formal training or



instruction about the purpose of DLA and AA. Some people's ideas came from working on local DLA take-up campaigns; helping people put together care packages; observing the increase in an ageing population with care needs and thinking about how best to support them. There was some recognition that there might well be differences between government policy makers' ideas about the purpose of the benefits, and the ideas of professionals and advisers working directly with people who saw a range of potential uses and advantages from the benefits.

### 2.3 Views on the difference DLA and AA make to people's lives

Participants in the group discussions were asked for their views on the impact DLA and AA made on people's lives. We were aware that using interviews to ask for data about third parties' experiences is usually not a preferred method of social enquiry. However, we were interested to know, firstly whether DWP staff and external advisers had views here and what they were, and secondly, in order to inform later thinking about possible large scale work, what questions might be included in a survey.

The responses in the groups demonstrated clearly that staff who were in contact with recipients after an award of benefit could identify ways in which the additional income had an impact. Further, there was consensus that, generally, DLA and AA had a major, positive impact.

From personal experience, participants talked about awards to individual people benefiting them in the following ways:

Relieving financial pressures:

- Providing regular money to spend on what was needed.
- Making substantial difference to overall financial situations, especially when people accessed additional premiums on income-related benefits, paid less council tax and used 'passports' to local services.

Meeting costs:

- Enabling access to home care.
- Increasing mobility and safety.
- Supporting family caring situations, by reducing pressure on relatives for caring tasks, and enabling people to 'give back' in money gifts.

Improving quality of life:

- Enabling a major purchase such as a responsive chair, a wide-screen television, washing machine or fridge/freezer, or more suitable vehicle.
- Increasing social participation and inclusion, and interaction with other people.

- Increasing quality of life for families with disabled children.
- Enabling tidier gardens for older people, thus reducing frustration and embarrassment.

Enhancing physical and mental health:

- Improving meals and nutrition.
- Warding off depression caused by financial struggle and anxiety.
- Helping to maintain physical health.
- Enabling warmer, cleaner, more comfortable homes, with less anxiety about meeting fuel bills.

Participants agreed that for a few older people, the main impact was probably just to increase bank balances. But one view was that having the financial security of savings did enhance life for some older people; they felt more secure and more ready to approach their own or their partner's death.

There were also a few specific negative impacts identified by the group participants. For example, it was suggested that extra money is actually unhelpful to some people, for example enabling people to drink more alcohol. Experience of people who provided services to people with alcohol-related illness was that extra money could put people in a better position for rehabilitation, and can sometimes just entice some people who have given up on life back into receiving services.

A useful observation from some participants was that negative impacts of DLA or AA receipt were not material or social, but emotional in nature. The concept of 'care' and 'caring' were constructs that were hard to accept for some couples, and for some parents and children, causing hurt and straining relationships.

The application process and experience of receipt of DLA reinforced negative feelings for some people, related to being 'disabled' or categorised as 'mentally ill'. People who did not understand the benefit were known sometimes to be reluctant to try going back to work, or volunteering, in case they lost DLA and this could hinder recovery or development. Perceptions of ownership of the benefits (and Carer's Allowance) and the way the benefits were used in household budgeting sometimes led to conflict and tension, especially for young adults.

## 2.4 Discussion

Findings from this exploratory approach were valuable in providing context and pointers for the interviews with DLA and AA recipients later in the study. Findings emphasised the importance of information from and discussion with professionals and advisers, and practical help with form completion, in achieving successful claims. We understood better how people in touch with different kinds of advisers are likely to hear different kinds of suggestions for using DLA and AA, especially when advisers see for themselves how extra financial resources might meet needs,

reduce constraints and improve quality of life. We were alerted to some potential and important areas of impact such as additional premiums in income related benefits, and access for relatives to Carer's Allowance.

We were also alerted to important psychological and emotional components in the decisions people make. Thus, people's conceptualisation of 'care' and feelings about themselves or their relative as 'disabled' or 'ill' influence claims and the way benefits are used, as do the personal dynamics in caring relationships.

It is also useful to reflect on the implications of this component of the study for any possible large scale survey on the impact of DLA and AA in the future. Findings have reinforced the importance of family and household budgeting patterns in understanding the impact of DLA and AA. Social workers met situations in which tensions and conflicts arose when a young person nearing adulthood needed access to their DLA, initially awarded in childhood and now fully integrated into household budgeting. Complex relationships between perceived ownership of DLA and AA (and Carer's Allowance) and ways in which families share resources and manage money are likely to influence the impact of the benefits.

There was general agreement that in some families and households, people misunderstand or lose sight of whose money DLA or AA is. Benefit help-line staff, PDCS visitors and local authority staff had all been in touch with some older people who had forgotten, or never realised that AA was being paid into their account. They drew money as they needed it, and some accumulated savings. Some had passed most financial responsibilities to family members, and lost touch with income and spending.

It is clear that the impact of DLA and AA often extends beyond the individual benefit recipient. There is a question therefore about who would be the appropriate person or persons to interview in a survey. We will return to this issue later in the report, alongside other implications for future research raised in the following chapters exploring the impact of DLA and AA from the perspectives of benefit recipients and their families.



## 3 Methodological findings

The previous chapter reported findings from our series of group discussions with people who advise and help potential claimants and recipients of Disability Living Allowance (DLA) and Attendance Allowance (AA), and their families. This chapter begins our report of findings from the next component in our study, a series of qualitative interviews with current recipients of DLA and AA.

This part of the study was conducted during summer 2009, in three locations in England, Scotland and Wales. We conducted depth interviews with 15 adult recipients of DLA, 15 recipients of AA and 15 parents of children for whom DLA was paid. Adult recipients across all age groups took part, and parents of children from 2 to 15 years. Appendix B provides a brief account of research methods, including recruitment of the study group, conduct of interviews, topic guides to moderate discussion, data collection and analytical techniques. Also included in Appendix B are some of the main characteristics and circumstances of people who took part. A separate working paper 'Appendices to The impact of Disability Living Allowance and Attendance Allowance – findings from exploratory qualitative research', available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf), provides full technical details of the research methods, and a fuller account of participants' characteristics and circumstances.

As explained in Chapter 1, the aim of these interviews was both to seek substantive qualitative information about how people conceptualised, managed and used the benefits and what difference they made, and to explore ways of getting such data in order to inform development of any further large-scale work. As the purpose of the study was exploratory, this chapter explains our research approach in some detail.

### 3.1 Design of interview and topic guide

We adopted a semi-structured interview approach, moderated with a topic guide. There were a number of important requirements for design of the interview and topic guide. We aimed to get substantive qualitative information about how people used the benefits, and what difference they made. Thus we wanted to explore the range of ways in which the benefit payments were conceptualised, managed, spent, saved or given to other people, and the outcomes that people perceived.

Of equal importance was exploring appropriate ways of getting such data. The aim here was to find out how far people's awareness and understanding of the benefits, and their ideas about using the money and the impact on their lives might enable later quantitative enquiry, using structured survey instruments. This required topic guides appropriate for people's own use of language, and the sensitivities involved in talking about personal circumstances and needs related to old age, impairments and illness.

We wanted to see how close we could get to the difference there might be between people's current situation (with DLA or AA) and the hypothetical situation in which they would be without the benefit. Exploring hypothetical situations is hard, and raises issues of reliability and validity of data. Our aim here was to investigate what kind of approach and question worked well, what worked less well and what kind of prompts or suggestions led to useful information or encouraged people to think hypothetically.

The topic guide had to cover a wide range of personal characteristics and situations, encompassing the circumstances and needs of disabled children and their families, adults of working age, and older people, some of whom were very frail. The respondents would include children and adults living in families, people living alone in the community, and people living in supported accommodation and residential care. It was likely that respondents would include older people whose partner had recently died. As DLA and AA are not means tested benefits, there was likely to be a range of income levels. People would be managing their money and household budgets in different ways.

We were also aware, in designing the interviews, of some potential constraints. Although people were recruited to take part on the basis that they received DLA or AA and were ready to talk about their financial matters, there was still likely to be some lack of awareness or understanding, and some confusions and forgetfulness, for example about names of benefits or pensions. There might be some sensitivity attached to different kinds of income. It was possible that the relevant information lay with other people not present in the interview, for example partners, or other relatives or advisers who helped with financial matters.

Most importantly, we took into account that while some people might describe exactly how they 'earmarked' DLA or AA for a particular budgeting role, there were several other possibilities. Some people might seem unaware they received the benefit, by the time of the interview (as did happen, see Chapter 4), and some

people might not know how much money they received (again, this proved so). Some might suggest the benefit just went into their general 'pot' along with other monies (see Chapter 5) and we would have to work hard, going beyond direct questions to tease out what was happening. Some people might seek to give what they perceived to be 'the right answer' according to whether they thought the benefit should be spent in a particular way.

The design of the interview and topic guide reflected these requirements and potential constraints. The researchers drew on some of what was known already from research about the costs of disability (see Tibble, 2005); and care (see Horton and Berthoud, 1990); and the economic circumstances of disabled people (Berthoud *et al.*, 1993). The researchers also drew on wide experience within the Social Policy Research Unit of research with families of disabled children (Beresford and Clarke, 2009; Beresford, Clarke and Sloper, 2005; Clarke, Mitchell and Sloper, 2004). Findings from the earlier series of discussions with professionals and service providers in touch with potential recipients (see Chapter 2) informed the design of the interview and topic guide. The design was also influenced by the researchers thinking forward to the analytic framework that would be used for analysis of the appropriateness of questions and prompts, and 'what worked well'.

Our general approach in designing the interview and topic guide was to seek contextual background information about the person (topic guide question 1), and the effects of their health circumstances or impairments, and how they managed these (question 2). We encouraged discussion about DLA or AA (question 3) at a fairly early stage in the interview, and then widened this discussion into other sources of income for the household (question 4), and money management and spending decisions, with particular focus on expenses related to health conditions or disability (question 5). Embedded throughout this discussion were different opportunities for people to consider the contribution made by DLA and AA – how people perceived the benefits fitting in to the way they chose to use their resources and meet their needs, and what difference they made. In the final part of the interview, when people had looked across their current needs, thought about their incomes and how they made spending decisions about general living expenses, we asked people what difference DLA and AA made.

We go on by discussing this in more detail; first, looking at the introductory and contextual enquiry; second, enquiry about DLA or AA and general household income; third, enquiry focused on managing money and meeting expenses, and, finally, exploring how the benefits were used and what difference they made.

### 3.2 The introductory and contextual enquiry

Starting interviews by inviting people to tell the interviewer a bit about themselves (question 1) worked well. People readily gave a simple 'pen picture' of their household, wider family, and current and past employment circumstances. Other people taking part in interviews, including partners and adult children also usually

contributed. As well as providing a generally relaxed introduction to the interview, information emerging at this stage was sometimes important in alerting the researcher to issues likely to be important later on, such as availability or not of unpaid family support, or whether somebody was receiving Carer's Allowance. Early discussion about employment history of family members alerted the interviewer to kinds of income and levels of resources likely to be relevant in each interview.

The introductory discussion, as hoped, led naturally and easily to discussion about the person's health circumstances, the effects on daily living and how they managed (question 2). The researchers chose words carefully when children were present, and when talking to adults with learning difficulties, for example uses phrases such as *'finding some things hard'* or *'needing a bit of help'* rather than referring directly to health problems or disability. By encouraging people to explain how they managed, and how they addressed and dealt with practical issues, the aim was to focus positively towards people's decisions, how they solved problems and managed daily living. In discussions with parents of disabled children, interviewers always asked first how the child liked to spend time and their interests and skills, before asking about health problems or constraints.

In this study group, the picture among adult recipients was largely one of long-term and cumulative ill health. It was not unusual for people to describe several different kinds of illness or impairment. Some adults described worsening health and increasing frailty stretching back 10 to 20 years; some had lifetime conditions. Most people talked about their health circumstances using medical terminologies, such as arthritis, diabetes or cancer, although some AA recipients used more everyday language such as saying *'my legs have almost gone now'*. There was not always a match between the way in which people described their condition and the main condition recorded in the Department for Work and Pensions (DWP) database. This may reflect how circumstances change for some people over a period of receipt of DLA or AA. There are implications for using recorded condition as a sampling criterion in any further research.

The approach taken in question 2 generally worked well in providing a good overall picture of the kind of life led by the person taking part. There was rich data about managing personal care, dealing with shopping and laundry, making meals, maintaining a home and garden, getting around, and keeping up social contacts. Parents of child recipients often had much to say about their child's learning, education and social activities, and the general impact on parents and other children.



### 3.3 DLA, AA and general household income

Having established background information about personal and health circumstances, interviews were generally guided towards a focus on DLA or AA (see question 3 on topic guide). The researchers explored:

- awareness and understanding of receiving DLA or AA;
- what was recalled of the circumstances of the application;
- perceptions of reasons for award;
- how DLA or AA was used;
- perceptions and use of 'links' between DLA or AA and other benefits and services;
- awareness of, and account taken of Carer's Allowance;
- any influence of getting DLA or AA on thoughts about paid work.

From the focus on DLA or AA, discussion was widened to enquiry about the participant's general household income. We would expect the impact of DLA and AA might be different according to its relative value in relation to other sources and levels of income. We aimed to explore people's conceptualisation and understanding of their different income streams, the relative importance attached to different kinds of money and financial support, and their own assessment of their position on the income scale.

Interviewers generally took a direct and simple approach here and asked what were the main sources of income for people and their households (question 4) sometimes using everyday language, such as '*money coming in*'. Overall we judged that this approach led to a good overall picture of the income sources of households in which an adult or child received DLA. Among AA recipients, however, there were sometimes gaps in memory and understanding, especially when people relied on others to help them manage financial matters, or found it hard to talk about different components of income. Interviewers sometimes stopped prompting in order to avoid people becoming embarrassed or flustered by poor memory, and to avoid lengthy searches for correspondence from DWP or banks. Partners and relatives taking part were often helpful in putting the picture together. The main gaps in information probably lie in some non-reporting of Pension Credit and Council Tax Benefit. In all sub-groups, people with savings appeared ready to acknowledge this although not everybody remembered to include interest from savings as an income stream until this was mentioned by interviewers.

When researchers asked people which of their various income streams was the most important, some found it interesting to think through their reasons for prioritising one income source (or not). The question worked least well with some AA recipients, including people who did not easily bring to mind the money values

of different benefits. We explored ways of asking people about their overall income level, to find out how people thought about this, what kinds of information they gave, and whether there were sensitivities here. There was wide diversity in the kinds of answers given, and some inaccuracies appeared likely, for example when people were uncertain about rates of benefits. Differences between gross and net earnings were rarely considered. These issues would be important in any further quantitative enquiry.

In some interviews, the effect of major changes in life circumstances permeated much of the discussion about income, for example when a partner had died recently, when people described putting their lives together again after disruption from severe mental illness, or starting to live as a sole parent after break up of a relationship.

### 3.4 Managing money and meeting expenses

Interviewers asked people to consider how priorities for spending were set, how they managed different income streams with different periodicities, and which person in the household took practical responsibility for managing the money and paying the bills (topic guide questions 5 and 6). As part of this, people were encouraged to think back to their earlier discussion about how they managed their health condition, the help and support received from other people, any services or equipment used, or arrangements they made themselves to deal with special needs or constraints on activities (topic guide question 2). Interviewers had made written and mental notes as to whether these were private arrangements, informal family care, public services, or services provided by voluntary or community organisations, support groups or charities, and were thus equipped to explore in some detail later on the ways in which people afforded to pay particular or additional expenses they themselves related to their health condition.

In retrospect, we judge this dual approach to have worked well. Most people readily gave useful information about what was required in order for them to manage life. For example, some gave detailed descriptions of the complexities involved in shopping; explained carefully how many hours weekly they had visits at home from a 'carer', a cleaner or a handy-person or how various family members came at weekends and how they helped. Later in the interviews, such people then readily responded when interviewers explored how they funded what they had described, how they afforded it and how they fitted it into household budgeting priorities.

Our dual approach led to gaining useful information from everybody in the study group. People apparently unaware they received AA, people uncertain which components of DLA they received and people who found it hard to give overall figures for income were all ready to talk about the ways in which they spent money and made sure that priorities were met. Some elderly people whose relatives helped them manage financial matters were still interested to explain how they used the money they had in their purse every week.

Interviewers' experience was that it was sometimes challenging to keep mental note of particular needs and arrangements mentioned early in the interview, in order to return to them later for full exploration of the financial implications. Analysis of the transcripts shows, however, that all the interviewers quickly developed the expertise required, and there are no particular gaps in data here due to interviewer fatigue or lack of recall.

### 3.5 Exploring what difference was made by DLA and AA

The interview and topic guide were designed specifically to seek qualitative evidence for the difference made by DLA and AA in a number of different ways. The aim was both to enable as much evidence as possible to emerge, and to explore various ways of seeking information in order to understand what line of discussion and what kind of questions worked well, in what circumstances.

Interviews were designed to include:

- Spontaneous comments.
- Direct questions.
- Prompts.
- Exploration of advice received.
- Exploration of perceived reasons for receipt.
- Exploration of perceived relationship between DLA, AA and paid work.
- Exploration of feelings about receipt.
- Exploration of practical money management, and
- Response to hypothetical scenarios, of loss and gain in income.

In what follows we look at each of these different ways of seeking information, and consider how useful they were.

#### 3.5.1 Spontaneous comments

Interviewers were alert to any spontaneous comments, during recruitment and during the research interview, about how DLA and AA were used, what expenses they met and what would happen without the benefit.

Spontaneous comments during telephone calls at the recruitment stage were sometimes early indicators of how people were thinking about DLA or AA. For example, some people told the interviewer they just put all their monies together and spent what they needed, which was helpful in planning and guiding the discussion.

During introductory discussions about family, employment and health circumstances, people's references to DLA or AA sometimes gave early insight into the salience of the benefits. For example, a person with a fluctuating condition who described currently being in a 'good patch' reflected that this had much to do with having established a good package of care, which DLA helped fund. In other interviews, discussions about managing effects of a health condition were peppered with references to DLA and AA, as when people talked about reliance on car or taxis and said spontaneously that DLA or AA went towards petrol or fares.

As we would expect, people who lacked awareness of their award, and some who relied on other people for help with financial matters, rarely made spontaneous observations about the benefits.

### 3.5.2 Direct questions

We inserted direct questions at different stages throughout the interview, nested within discussion about different topics, and from different perspectives. In various parts of the interview we asked people directly whether they used DLA or AA for anything in particular (question 3), what happened to DLA or AA when they dealt with the practicalities of managing money (question 5); whether they thought of DLA or AA as covering any item in particular to meet needs they had identified as related to their health condition or impairment (question 6) and what difference DLA or AA made for them (final question).

Asking people whether they used DLA or AA for anything in particular led to three kinds of response, in all sub-groups. Some people made no distinction between sources of income, but said all their money went into '*the general pot for spending*'. People with low incomes (claiming Jobseeker's Allowance, or Pension Credit for example), were particularly likely to describe this way of thinking about their money, for example explaining that they '*just need it all to live on*'.

Another kind of response came from people who said they did not specifically earmark their DLA or AA, but they knew what it enabled them to spend money on. They described expenditures, for example, on taxis, personal care, house cleaning, or children's shoes and said getting DLA or AA helped them afford these items.

Finally, were people whose DLA or AA was kept separate and used for a specific purpose. An example here came from parents who said their child's DLA award had led to purchase of a large touring caravan, and now financed the regular holidays which the whole family enjoyed together in the caravan.

Asking people if they used DLA or AA for anything in particular led to other insights. Some people described how use of the benefit changed over time. It was not unusual to move from ear-marking money that seemed 'extra' in early months of a new claim towards a less prescribed spending allocation, as household bills became pressing, or personal circumstances changed. It was less usual to move from a 'general pot' approach to more specific use of the benefits.

Finally, there was some evidence of people perceiving responsibility to use the benefit in what they judged to be 'the right way'. Some were keen to say they used it for things they needed, and they did not waste the benefit, such as an elderly couple who stressed that AA was not used for entertainment.

Asking people directly what difference DLA or AA made usually came at the end of the interview, after discussion about general financial circumstances and sense of well-being, and after inviting people to think about the possible consequences of a fall or rise in income. This was where people were invited to sum up what difference the benefit made, and in some cases interviewers handled this by inviting people to give 'the main message' for policy makers. The location of the question and the interviewers' approach were both likely to influence response, coming right at the end of more than one hour's reflection and detailed discussion about financial circumstances, but also enabling people to wrap up their views and experiences into a short and strong message. The approach generally worked well, and findings are reported in Chapter 6.

### **3.5.3 Prompts**

At various stages throughout discussions interviewers made prompts and gave reminders to help people explain spending decisions and practices, using language such as '*how do you afford that?*', '*how do you pay for that?*' and '*what money does that come from?*'. They avoided, wherever possible, using language such as '*do you use DLA for that?*' which might lead some people to give 'easy answers' or what they perceived might be 'the right answer'.

This proved a fruitful way of seeking information. In the context of talking about daily life experiences, people readily explained, when prompted, how they managed to pay for needs they described. Detailed information was provided after interviewers' prompts, giving us deeper understanding of the way the benefits were used for general living expenses, as well as the particular uses which people identified more easily when asked direct questions. It was this approach that led to information, in many interviews, about ways of paying for meals, high fuel bills and purchases of equipment.

### **3.5.4 Exploration of advice received**

The researchers knew it was likely that some people had received information or advice about how they might use DLA or AA (see Chapter 2). We explored this further, and found that some people had clear memories of what advisers had said to them about the purpose of DLA and AA and how the benefits might be used. Most people who could recall their initial claim were using the benefits in ways they remembered as having been suggested, for example to help them get around or, among parents, to enhance their child's life.

We do not know, of course, how far advisers' suggestions had subsequently influenced use. What such findings show is the congruence between the way in which DLA and AA are used, the way advisers believe they are used, and the suggestions for possible use made by advisers to potential applicants.

### 3.5.5 Exploration of perceived reasons for receipt

We explored people's views about why they received DLA or AA (topic guide question 3) to help us understand better what role people perceived for the benefits (discussed in Chapter 6) and how they used them.

This line of enquiry did not always work in the way intended. For example, one reason described for being awarded DLA or AA was that the person helping with the application knew how to deal with the application form.

Among those who did relate their successful application to personal circumstances, we saw the following groupings:

- Some people in all sub-groups related their award to their medical diagnosis of a severe health condition.
- Some people in all sub-groups related their award to being unable to do things for themselves; needing several different kinds of help or, among parents of child recipients, their having to give care and attention to their child that was 'out of the normal range'.
- Being otherwise unable to live on Income Support or Pension Credit was another reason some suggested for their getting DLA or AA. Included here were some parents who said they needed more money than the Income Support they claimed.
- Among parents of child recipients, one reason suggested for their child getting DLA was government recognition of the impact of reduction of earnings for parents who provided intensive care, and their need for some compensation for their financial costs.

### 3.5.6 Exploration of perceived relationship between DLA, AA and paid work

We explored, with people of working age, whether getting DLA (or their child getting DLA) affected how they felt about doing paid work (question 3). There were a number of reasons for this interest. It has been suggested that some people might take DLA into account when thinking about financial incentives or disincentives in doing paid work, and that some people fear a move into work might trigger a reassessment of their DLA and possible reduction or loss (Beatty *et al.*, 2009). Other possibilities are that getting DLA enables some people to do the kind of work or number of hours that suit them, and that some parents may feel their child's DLA enables them to spend more time at home. Thus, it was important that interviewers introduced this topic in a completely 'open' way, so that responses showed people's own interpretation of what this question meant, as well as generating discussion.

### **3.5.7 Exploration of feelings about receipt**

Some people made spontaneous comments about their feelings about getting DLA or AA, for example when talking about making the initial application, when they described changes in rates or components of award and when they talked about budgeting strategies. Some people were asked more directly whether getting DLA or AA made any difference to their feelings (see final question on topic guide). Useful information was gathered in both these ways, reported in chapter 6.

### **3.5.8 Exploration of practical money management**

Discussions about practical money management (topic guide question 5) provided valuable insights. There was general interest in and readiness to explain the various systems people had for receiving different monies into bank and post office accounts, and the way they then distributed the monies, for spending, gifting or saving. People who had partners explained divisions of responsibilities here, and everybody said their own system worked for them. There was a wide spectrum of arrangements, and a full analysis of practical money management was beyond the scope of this study. The following brief account demonstrates how this line of enquiry helped us understand how DLA and AA fitted in. Knowing which account held DLA or AA payments, how withdrawals were decided and managed, and how monies were then spent provided us with additional perspectives on how benefits were used.

The simplest management systems were those in which all sources of income were paid into one bank account or post office cash account, from which regular outgoings were made, for example using direct debit or standing orders. From the balance, people drew cash for other expenses. This system was wide-spread in all sub-groups, especially low income households, and suited people with and without partners. People who used such a system were generally among those who described DLA or AA as going 'into the general pot' and those who did not specifically ear-mark the benefit, but knew how it was spent. An interesting finding was the way in which the payment intervals for DLA and AA influenced the way different monies were used. People relying on out-of work benefits explained how knowing there would be a relatively large monthly DLA payment influenced its use for items that could not be afforded from weekly Income Support, such as children's shoes, or a big shopping order at the supermarket. One person said he sometimes phoned a telephone help line to check exactly which date DLA would be paid so that there was sufficient balance in his account to meet direct debits.

Having more than one account suited some couples, especially when one or both had earnings, and also people who, for practical or historical reasons, chose to have benefits or tax credits paid into separate accounts. Included here were adults who knew they used DLA or AA for expenditures such as running the car, taxi fares, help in the house or garden, and parents of disabled children who used DLA for the family holidays, or paying for out of school activities or special equipment or toys.

We do not have a full picture of people's savings, in this study, or how they were managed. Trying to save any DLA or AA was not much mentioned, apart from situations where using the benefit for a specific purpose involved keeping it separate. Occasionally, part of a child's DLA was transferred into a separate account in their own name or to a grandparent with a savings account for the child.

### 3.5.9 Inviting response to hypothetical scenarios

Asking people to consider, hypothetically, what would happen if income went down by £50 per week, or up by the same amount (question 6) might, we hoped, throw further light on what difference the benefits made. These were amounts of money roughly equivalent to middle rate care component of DLA or lower rate AA. Around half the adult DLA recipients in our study group received more than £50 DLA weekly, all AA recipients received at least £47.10 weekly, and around half the children getting DLA had awards worth more than £50 (see Chapter 4). The researchers emphasised that this question was different from others asked, in that it was *'set up'* or *'like a game'* to see how people reacted to the idea of change in income.

As discussed above, asking people about hypothetical situations is always hard and findings must be considered with care. However, our exercise was judged to have been useful with adult DLA recipients and parents of children receiving DLA. Asked about a hypothetical loss of income, most made an immediate response which summarised their feelings, and then followed this by thinking through where they might cut spending. Not all AA recipients engaged with this hypothetical exercise; some were tired at the end of the interview, and some found the idea hard, for example if other people took a major part in helping them manage their financial affairs. From those who did engage, there were useful responses. Findings are discussed further in the following chapter.

## 3.6 Summary

This concludes our descriptions and explanation of the qualitative approach to exploring the contribution made by DLA and AA. The topic guide was designed to suit a wide range of awareness and understanding of money received in DLA and AA and different ways of practical money management, as well as enabling us to gather information about people's conceptualisation of the benefits, and their views on their purpose and role. We can set this information into the context of the different sources and levels of income of people in the study group and their different needs for expenditure, with particular focus on spending related to disability and health conditions.

Systematic analysis of the transcripts of the interviews shows that useful information came from each of the different ways we tried to gather information about the difference made by DLA and AA. However, the overall picture of how DLA and AA were being used and what difference they made depended on our having used



all of the different approaches. Direct questions about how people used DLA or AA were useful when people did use this money for specific purposes, or when they knew what they could afford because they had the benefits. Direct questions were insufficient, however, when people put all their monies together, and tried to keep within budgets to meet their needs. The less direct approaches, asking people first how they managed their lives and what they spent money on worked better here, and generally helped to build up the picture with all participants. Prompts could be helpful, but required particular care in avoiding easy answers, or suggesting that some ways of using the money might be more appropriate than others. In some cases, for example, it was a spontaneous comment, exploration of advice given, or description of how bills were paid that provided key pointers to what was happening.

The exercise in which we asked a hypothetical question was interesting. It worked well in confirming other findings, but would be insufficient as a main means of investigation.



## 4 Recipients of Disability Living Allowance and Attendance Allowance: Current income sources

The previous chapter explained our methodological approach in seeking qualitative information about how people conceptualised, managed and used Disability Living Allowance (DLA) and Attendance Allowance (AA) and what difference these benefits made. This chapter begins our report of substantive findings from our interviews with 15 adult recipients of DLA, 15 recipients of AA and 15 parents of children for whom DLA was paid.

The impact of DLA or AA for individual people is likely to depend partly on how the benefit fits into their general household income. For example, for a young disabled person not doing paid work a high DLA award may have higher money value than their income replacement benefit. For a family with two parents with professional earnings and some income from savings, a low DLA award for their disabled child may represent a relatively small addition to income.

This chapter thus provides essential contextual information. We report on people's understanding of the DLA or AA received (Section 4.1), awareness and use of 'links' between DLA and AA to other benefits and services (Section 4.2), the patterns of their overall household incomes (Section 4.3), recent changes in income which people considered important (Section 4.4) and some perceptions of the importance of different components of income (Section 4.5). Where possible, we set these findings in the context of life stage, employment histories and health trajectories. It is important to remember, throughout, that data from a single qualitative interview gives only partial information about developments in a person's life, especially when people have lived for a long time.

## 4.1 Awareness and understanding of receipt of DLA or AA

We might expect the impact of DLA and AA for individual people to be related to the actual value of the money received. Thus, interviewers explored people's awareness of the money they received in DLA or AA,<sup>8</sup> and the language and terminology used. All adult DLA recipients and parents of child recipients were aware they received this benefit, and were ready to discuss what they understood of components, rates or amounts. This was not the case with some AA recipients. Two of the oldest participants, who relied on other people to help them manage their money, did not recognise the name of the benefit when interviewed, and no prompts or suggestions led to any indication that they realised the benefit was being paid.

### 4.1.1 Adult DLA recipients

Most adult DLA recipients in our study group could generally put an approximate date to their first claim and, overall, there was a fair match with the dates recorded in information supplied to the researchers from the Department for Work and Pensions (DWP). Lengths of receipt ranged from 16 months to over 20 years.

As explained in Appendix B, eight of the 15 adult DLA recipients in our study group were over state retirement pension age. We saw no evidence of people having claimed DLA as they approached 65 years in order to gain access to the mobility component, which is not part of AA (see Chapter 1).

Most people remembered some of the circumstances leading to their application. Particular professionals or advisers were described as having drawn attention to DLA, encouraged applications or helped directly with form filling included staff in hospitals, outpatient clinics and hospices; community mental health services; citizens advice bureaux; social security local offices; voluntary organisations and support groups and, for one person, a parent.

People explained the value of their award in different ways. Some talked about amounts of money, in terms of weekly, fortnightly or monthly receipts (although some amounts mentioned were those in payment before the 2009 April uprating). Some described components or rates, without monetary value attached, for example saying they had '*middle care*'. Some people did not know the monetary value of their DLA, especially when it was paid into a bank account and used for general day to day expenses along with other sources of income. Putting together information from various parts of the interviews showed that the group included people receiving lower and higher rates for mobility; and people receiving lower, middle and higher rates for care. Most people had various combinations of care and mobility, with a small number receiving one component only.

---

<sup>8</sup> No details of DLA or AA awards, such as components or rates of payment, were supplied by DWP to the researchers, due to DWP rules governing transfer of personal data and data security.

For purposes of analysis, we converted all receipts into correctly uprated weekly amounts, which showed that awards received ranged from £37.30 (lower rates care and mobility) to £119.45 (highest rates care and mobility), with about half the group receiving more than £50 per week. Several people received the highest possible awards.

As we might expect, there was variable recall about the application process. It was not the case that people who first claimed many years ago were most likely to have forgotten what happened. Similarly, the most recent applications were not the best remembered, especially by people affected by severe mental illness and people with learning difficulties.

#### **4.1.2 AA recipients**

Among AA recipients who acknowledged receipt of this benefit, recall and understanding of details of claims and awards was lower than among DLA recipients. Partners or adult children present in the interview helped in remembering the circumstances of the applications. When people remembered the time when they applied, this usually matched the date recorded in the DWP database. The earliest date of claim, as recorded by DWP, was 1998; several claims were made in 2006 or more recently.

As with the DLA recipient sub-group, among those who could remember applying, advice and help from professionals or advisers was generally mentioned. The significant advisers had been staff in DWP, citizens' advice bureaux, local authority social services, and voluntary organisations, who had observed people's circumstances and encouraged applications, sometimes alongside help and encouragement from relatives or personal friends.

In this sub-group, most people who were able to discuss the value of their award talked about '*highest rate*', '*low rate*' or '*full allowance*', and some of these also quoted a money value. Putting together information from the transcripts enabled the researchers to establish the value of nine of the 15 AA awards. This showed a rough balance between lower and higher awards (equivalent to £47.10 and £70.35 weekly). In two couples, the man received a lower award and his wife the higher amount.

#### **4.1.3 Parents of children receiving DLA**

All the parents who took part in interviews understood clearly that DLA was paid for their child, and all offered some details about the award, either components, rates, or money value. Most parents had clear memories about the way they learned about DLA and the process of making an application. There was some evidence to suggest that the availability of the mobility component was not always understood, particularly among parents whose child had not yet reached the age threshold for lowest rate mobility component.

Putting together all information in the interviews, the researchers calculated the weekly value of the children's award in all cases but one. Among 14 children in receipt of DLA there were examples of children receiving only one of each of the two components, and various combinations. All rates of care component and both rates of mobility component were represented. The lowest awards received were equivalent to £18.65 weekly (for lower rate care or low rate mobility) and the highest awards were equivalent to £119.45. Some pattern was discernible among the children's awards in that nearly half the group received middle rate care and low mobility components, equivalent to £65.75 weekly.

## 4.2 Links from DLA and AA to other benefits and services, including Carer's Allowance

DLA and AA serve as eligibility criteria in a number of other income maintenance and disability support systems, including premiums in income related benefits and tax credits, a child-care disregard in Housing Benefit, 'Blue Badges' for vehicle parking access, and some local authority and commercial price reductions for leisure facilities. Receipt of Carer's Allowance by another person providing care and support depends on the person cared for receiving AA, or middle or higher rate care component of DLA. DLA and AA recipients' use of these additional resources is an important part of the actual economic difference made by the benefits, and is also likely to influence how people think about the benefits.

### 4.2.1 Carer's Allowance

In our overall study group, one-fifth of the DLA and AA awards were linked to a relative's Carer's Allowance; most of the caring relatives were parents of child recipients. People claiming a Carer's Allowance in respect of an adult recipient of DLA were recipients' wives, and the person who claimed a Carer's Allowance for an AA recipient was an adult child, who shared the home. All those receiving Carer's Allowance took part in interviews, and gave some of their own views, reported separately at the end of this section.

#### *Carer's Allowance linked to adult DLA*

Among adult DLA recipients in this study group, the link to Carer's Allowance was fairly well known. Some people described having previously claimed this themselves in relation to support they gave an elderly parent, and some said their partners already knew they were not entitled, having applied and been refused or having made enquiries at a citizens advice bureau. One person said a previous partner had claimed, and a new partner was now waiting for an application form.

Some of those aware of Carer's Allowance said that this was something that might be needed later on if their condition deteriorated, and they had to apply for higher rates of DLA or needed more intensive care. Those adult DLA recipients who seemed confused about Carer's Allowance or apparently unaware were people over state retirement pension age living alone.

### *Carer's Allowance linked to AA receipt*

State retirement pension and Carer's Allowance are subject to 'overlapping benefits' rules.<sup>9</sup> This may have been a contributory factor in our finding of less general understanding of the availability of Carer's Allowance among AA recipients than among DLA recipients. Some couples remembered having applied some time earlier but been refused. One person said the matter had been discussed among her adult children, but none had claimed. In one interview, talking about Carer's Allowance led the AA recipient and the interviewer to wonder whether an informal 'helper' who called every day might be entitled to claim Carer's Allowance.

### *The views of carers of adult recipients of DLA and AA*

People receiving Carer's Allowance for supporting adult recipients of DLA and AA in this study group were present in the interviews. They described, variously, giving help with dressing, showering, medication and pain control, getting around, and managing financial matters. They all felt the person cared for would not be able to manage without such help, and they preferred to give such support themselves, in their role as partner or daughter, rather than expect help from service providers. Taking on the main caring responsibility had meant, variously, giving up previous paid work, giving up the idea of looking for a job after starting to live as a couple, moving from a previous home, and having to buy a car in order to manage the caring activities. None were currently considering working outside the home: this just did not seem possible in view of the amount of help constantly required, or the fluctuation in condition and variation in day-to-day needs of the person supported.

When Carer's Allowance paid to partners went into the same single bank or post office account as other income sources, it formed part of the general pot of money available for household budgeting. There were some comments on the low money value of Carer's Allowance. Although described as better than nothing, it seemed '*a pittance*', or not much in comparison with amounts carers saved the government having to spend on providing equivalent levels of care. One person said one factor in being able to manage financially on Carer's Allowance was that the constraints on social and leisure activities which came with providing constant care meant relatively low personal expenses.

---

<sup>9</sup> As a result, if a person claiming Carer's Allowance begins receiving a state retirement pension higher than Carer's Allowance (not including age- or earnings-related additions) payment of Carer's Allowance stops. If the state retirement pension is less than Carer's Allowance, the state pension is paid and topped up with Carer's Allowance to the basic weekly rate of Carer's Allowance. If all that prevents payment of Carer's Allowance is state retirement pension, a carer addition is included in calculation of Pension Credit for that person, and a carer premium included in calculation of Housing Benefit and Council Tax Benefit (HB/CTB).

### *Carer's Allowance linked to a child's DLA*

As explained at the beginning of this section, in this study group most of the DLA and AA awards linked to a Carer's Allowance were DLA awards made to children. The sub-group included one parent who claimed Carer's Allowance during a few months each year when there was a gap in earnings. Most parents claiming Carer's Allowance, however, did not have other paid work, and said either that they were fully occupied with the care of their family or that their own poor health meant they could not have a job.

Parents not claiming Carer's Allowance were mostly aware of this benefit; and some knew their earnings took them over the threshold for eligibility.

Parents' views about getting Carer's Allowance were closely linked to views about their child's DLA. In this study, we cannot easily separate parents' views on Carer's Allowance from their views on use of DLA.

### **4.2.2 Other 'links' to benefits and services**

Awareness and understanding of the range of so-called 'passport benefits' and links to other services through receipt of DLA or AA were highly variable. Entitlement to 'passports' from DLA and AA is a complex area, encompassing a number of benefits and tax credits, with different rules and approaches to income assessment. As explained, some people whose benefits or tax credits were linked in this way were unaware of the particular premiums or additional amounts that affected them. There are also variations among local authorities in the way 'Blue Badges' (for vehicle parking access) are administered, and local differences among commercial and voluntary organisations in recognition of receipt of DLA or AA as a pathway to reduced prices or enhanced access.

Our analysis can give only a partial picture of use of these passports and links, based on those links recognised by people taking part in the research. The picture is also clouded because in some households it was other members' DLA or Carer's Allowance which provided such links, for example people whose partners' mobility component gave access to transport concessions.

Among families with children receiving tax credits there was general understanding that their assessments took account of their child's DLA. Among younger adult DLA recipients, those who were aware of the disability premiums in their Income Support or income based Job Seeker's Allowance were people who had received some financial advice in the recent past, for example advice about dealing with debt, losing Incapacity Benefit, managing a care package or re-establishing a home. One young person made links between receipt of DLA and their access to the Independent Living Fund. Links between DLA, AA and housing benefits were sometimes mentioned spontaneously, or recognised when prompted by interviewers, but overall levels of understanding of how this worked were probably fairly low, and clouded by some confusion with reduction of council tax for single occupancy.



Understanding links with Pension Credit was highest among couples who had received some financial advice about their situation when one partner had a spell in hospital, and older people whose relatives helped with financial advice.

There were both current and previous users of the Motability scheme among DLA recipients and parents of child recipients, and awareness extended to others who did not use the scheme, including people ineligible because they did not receive higher rate mobility component. There was little mention of Motability among AA recipients (who are not entitled anyway). Blue Badges were much mentioned and highly valued across all sub-groups, and those people who were exempt from road tax said this was a great help. DLA recipients who used public transport valued their bus pass or disabled person's rail card, and some people said they had a bus pass which entitled a companion to travel with them free of charge. People using these transport and travel concessions said their activities were much extended as a result, which we discuss later in Chapter 7.

There were recipients of DLA and parents of child recipients who told us that getting DLA meant they had their lofts insulated free of charge (the Warm Front<sup>10</sup> scheme, or Warm Deal in Scotland). Mentions by particular adult DLA recipients included a free cinema pass, a taxi-card and a rail card. In some families with a child receiving DLA free access to local commercial facilities for parents and child, and sometimes also other children, was a valued resource. Mentioned here were cinemas, sports centres and, in one local area, a zoo. Access to the Family Fund<sup>11</sup> had helped several families pay for household equipment, and items for children.

### 4.3 Overall household incomes

In order to understand the potential impact of the DLA and AA awards we need to set them in the context of overall household incomes.

#### 4.3.1 Adult DLA recipients

We gained a generally good picture of overall household incomes for the adult DLA recipients in our study group. These were generally low income households without earnings, whose incomes came largely from state pensions and benefits.

Most DLA recipients were some distance from the labour market, either having passed state retirement age and not expecting to do paid work again, or not well enough to do work. Among those of working age, those most strongly motivated

---

<sup>10</sup> Warm Front is a government funded scheme which provides grants of up to £2,700 to make a home warmer, healthier and more energy efficient, in a package of advice, insulation and heating improvements tailored to each property.

<sup>11</sup> The Family Fund is a government funded charity which helps low income families caring for severely disabled children, by making grants relating to the child's needs.

to do paid work had not had regular earnings during the past six months, although one had just started a new job in the week of the research interview. Among people receiving state retirement pension, any additional occupational pensions were generally described as very low. Several older recipients claimed Pension Credit. People of working age were claiming Incapacity Benefit, Employment Support Allowance, Jobseeker's Allowance, Severe Disablement Allowance and Income Support, and a DLA recipient with dependent children had Child Benefit and tax credits.

When we look to other members of the household, there were no partners who had paid work. Partners were either over state retirement age themselves, unwell and claiming disability benefits in their own right (including DLA), receiving Carer's Allowance in relation to the support they gave their partner, or at home caring for young children. One younger DLA recipient who lived with both parents said that one parent had part-time earnings. Only one DLA recipient shared a home with a person who had full time earnings, in this case an adult child who made a contribution to household expenses. Most people in this sub group relied on CTB, and those who paid rent generally relied on HB.

#### **4.3.2 AA recipients**

While we gained a good overall picture of the income sources of households in which an adult or child received DLA, there was not so full a picture of household incomes among AA recipients. There were some gaps in memory and understanding. Some people who relied on others to help them manage financial matters found it hard to talk about components of income, although partners and relatives taking part were often helpful in putting the picture together. Overall, among AA recipients the main gaps in information probably lie in some non-reporting of Pension Credit and CTB; possibly, also, income from savings and investments.

It seems likely that there was a wider income range in the AA sub-group than in the DLA sub-group.

Everybody claimed a state retirement pension or widow's pension, and most people also described some kind of private or occupational pension, either of their own or through a late partner. While some of these non-state pensions were said to be very small (as among the DLA recipients over state retirement age) there were both men and women who said their non-state pensions from their own or a late partner's previous employment were valuable.

Some households were clearly managing on low incomes, including single people and couples in receipt of Pension Credit and sometimes CTB. But some people not in receipt of Pension Credit and with non-state pensions (sometimes two or more) appeared to have comparatively higher incomes. One person received rental from property.

Again, none of the households currently had any regular earnings going in, although one couple was very unusual in that both partners had done paid work beyond the age of 80. Adult children of working age who shared the home were not currently doing paid work, but one AA recipient claiming Pension Credit also received formal financial support for care of a young person.

### **4.3.3 Households with children receiving DLA**

The picture of household income sources in families where children received DLA was quite different from that in households with adult DLA recipients. In all except one of the two-parent families, one or both parents had paid work, and there were examples of both men and women main earners. Among the sole parent families, all of whom were headed by women, one mother of older children had full time earnings and another, also with an older child, was currently receiving sickness pay from her employer. Parents not doing paid work were either choosing to be at home to care for their children or in poor health themselves, and some had out of work income from Income Support or Incapacity Benefit.

Families were all receiving Child Benefit, and most also receiving tax credits (Child Tax Credit, Working Tax Credit or both). The few families who said they were beyond the scope of tax credits either had two parents with earnings, or a father with full time earnings. Some of the sole parents were receiving financial support from children's fathers. The other source of income for some of these families was Carer's Allowance, being claimed both by parents who did not do paid work and parents with small earnings. Families living in rented accommodation generally claimed housing benefits.

## **4.4 Significant recent changes in income**

Changes in personal or household circumstances, whether or not related to changes in a health condition, may affect sources and levels of income, and lead to reassessments of the importance of different components of income.

Among AA recipients and the older DLA recipients, the death of a partner was the most widely mentioned reason for a major change in income. Widows said they were less well off after their husband died, due mainly to loss of men's occupational pensions, and finding it more expensive to maintain their home as a single person. Some widowed men living on low incomes also noted that they felt worse off since their wife died; losing entitlement to Pension Credit had led to lower housing benefits for one man, while another mentioned loss of his wife's AA and reduction of already small occupational pensions. In bereavement, some people felt their own DLA or AA had grown in importance to them. These findings echo those in a recent study on the financial implications of death of a life partner (Corden *et al.*, 2009).

Only one person among the adult recipients of DLA and AA had to deal with a recent loss of regular earnings – the wife of a man who had only recently retired from full-time work. For DLA recipients who tried to do paid work but found it hard to sustain regular earnings, it was the transitions between in work and out of work income that led to financial disruptions. DLA was the one regular and reliable income source while earnings stopped and started, and other benefits and Working Tax Credit stopped, started or were reassessed. This is discussed further in later chapters.

Among parents of child recipients of DLA, the biggest recent changes in sources and levels of household income described (apart from a recent DLA or Carer's Allowance award) were due to ill health, and family dissolution. Moving from full-time earnings to the employer's sickness pay scheme had required major adjustments, as did getting used to living as a sole parent with out of work benefit income in comparison with life with a working partner. When earnings from part-time self employment came erratically, depending on the amount of work done and the way payment was made, there were frequent swings in household income. Again, the financial changes that resulted from death of a partner were remembered as having a major impact.

#### 4.5 Perceived importance of different income components

When people were asked how they perceived the relative importance of their different income components, DLA recipients and parents for children receiving DLA were generally interested in this topic, with a variety of responses. People did not immediately point to the income component of highest money value, but said that the benefit payment intervals were also important because these determined the way they made money stretch across expenses. The way different income components were used also influenced views, for example some said without housing benefits they would not have a roof over their head, or without DLA mobility they could not get out. Those who were unable to put priority on any of their sources of income, as they were all important, included those with the largest number of components of income, as well as those who had one main out of work benefit and DLA.

Some people identified DLA as their most important source of income. For one person, DLA (equivalent to £65.75 weekly) was the constant reliable back-up, which also brought entitlement to HB higher up the income scale, so important while trying to establish paid work. For another, Severe Disablement Allowance and Income Support were both important, but it was DLA (paid at the highest rates) that was the '*door opener*' to so many other forms of support, including the Independent Living Fund, higher premiums in income related benefits, and reduced taxi and bus fares. An older couple agreed that DLA (equivalent to £119.45 weekly) plus the linked Carer's Allowance was the largest component of their income. The weekly payment of Carer's Allowance was also a help to their cash flow, so they saw DLA as the most important.

When parents of children receiving DLA were asked to judge the relative importance of different income components, they generally suggested those components which brought in the largest share. For several families this was the earnings of the parent who brought in the main or only earnings. But for one couple their tax credits were higher than earnings, so these provided the most important share. Another two parent family who described low earnings also said that tax credits and DLA together were what kept them from struggling financially. And a sole parent who said tax credits were more valuable explained that these were higher than her Income Support, and were particularly important in managing her cash flow. Parents who said all their various income components seemed important, as they would find it hard to manage without any of them, were people who had already talked about being on low incomes.

It proved harder for AA recipients to think about the relative importance of their different income sources. Those who suggested the component with highest money value included one person who pointed to her occupational pension, as well as people who decided on their state retirement pension. But others explained that this was not an easy question for them – while state retirement pensions were bigger, their AA was essential, for example in enabling them to get around or managing their budgets. Couples taking part sometimes discussed this together, which showed different ways of thinking. For example, a wife thought of her AA as the most important part of her personal income while her husband felt that their retirement pension with Pension Credit was the most important for household budgeting.

## 4.6 Summary

This chapter has described the general awareness and understanding of their DLA or AA award among people in our study group, in the context of their overall household incomes.

We considered each sub-group in turn. Among the adult DLA recipients in this study group the lengths of award varied from 20 years to 16 months. Nearly half this sub-group were people over state retirement pension age, but we saw no evidence of people having claimed DLA as they approached 65 years in order to gain long-term access to the mobility component.

People talked about components, rates and money value of their DLA award in a variety of ways, with some inaccuracy in recall. For purpose of analysis, we brought together information from various parts of the interviews and standardised money values to weekly amounts. This showed that the sub group included the full range of rates of payment and various combinations of components of DLA.

Adult DLA recipients in this study were generally living in low income households. Most recipients were some distance from the labour market, and their own incomes therefore were largely made up of pensions and benefits. Only one person lived in a household in which somebody had full-time earnings. Views varied as to

the most important component of income, taking into account aspects such as periodicity of receipt, 'passporting' and whether benefits were income-related, in addition to the relative money values.

Among AA recipients there was a rough balance between people receiving high and low awards. It seemed likely that there was a wider income range among AA recipients, with some men and women describing valued non-state pensions. None of the households in which the AA recipients lived currently had any earnings going in, although one person received formal financial support for care of a young person.

Among the DLA awards to children all rates of care components and both rates of mobility components were represented. Some pattern was discernible in that nearly half the children received middle rate care and lower rate mobility components. The picture of household incomes of their parents was quite different from the household incomes of adult recipients who took part. In most families, one or both parents had earnings or employer's sick pay. The sub-group included families in which parents had salaries from professional and career jobs, as well as families who talked about relatively low earnings. There were also families who relied on Incapacity Benefit and Income Support.

Overall, one-fifth of the DLA and AA awards in this study group were linked to a Carer's Allowance, most of these claimed by parents of children receiving DLA. In addition, people perceived links between DLA and AA and premiums and additional amounts in a range of other benefits and tax credits, and used the access bestowed by their awards to transport and travel schemes, leisure facilities, the Independent Living Fund and the Family Fund. It is likely that there is some under reporting here, but even the partial picture obtained provides some perspective on the wide economic impact of DLA and AA.

Findings in this chapter help us understand more about people's understanding and conceptualisation of DLA and AA, and how these benefits fit within the context of overall household income. We have begun to see how people attach different importance to different kinds of money and financial support. We return to these topics in further chapters as we build up the picture of the difference made by DLA and AA. Chapter 5 is concerned with people's perceptions of the current expenses of daily living.

## 5 Recipients of Disability Living Allowance and Attendance Allowance: Current expenses of daily living

This chapter discusses how people taking part in this study met their general living costs, including their routine household budgeting expenses and more occasional expenses, for example holidays. We see how some people had to budget carefully for expenses related to managing needs described as related to their health condition, impairment or old age, or caring for a disabled child. The information in this chapter is important in understanding what was happening when people said their Disability Living Allowance (DLA) or Attendance Allowance (AA) just went towards their general living expenses.

This was a qualitative study, and there was thus no attempt to seek data which would enable a detailed breakdown of household expenditures. Rather, we report what people said about their routine general living expenses, such as payments for rent or mortgage, utilities and food. We also report on the expenses which people themselves saw as related in some way to their health condition. This was either because they required items or services they perceived as 'extra' or when they perceived having to 'pay more' for the same kind of things they had before they were ill, or that other people or other families with children had. (Such expenses are sometimes referred to in literature as the extra costs of disability.) Some people in the study group observed also some gaps in expenditure, or reduced expenses, for example when their condition meant they were no longer able to go on holiday.

Expenditure also involves matters of taste and choice, and most people, whether or not they have health conditions or impairments, prioritise spending in some way and are affected by some form of income constraint. It is also important to

remember that people have different levels of interest, ability and experience in managing financial matters. What follows is essentially a qualitative analysis. It shows the kinds of expenses which people themselves saw as important in their current lives, and were ready to talk about with an interviewer. For purposes of presentation, the material is organised according to different items of expenditure.

## 5.1 Accommodation

### 5.2.1 DLA and AA recipients

Most adult DLA recipients in this study group lived in rented accommodation, and there was widespread reliance on housing benefits. Paid-up owner occupation was more widespread among the AA recipients, including people who had moved into sheltered accommodation as they grew older.

For most adult recipients, the suitability of their accommodation was a more pressing concern than paying for it. Those who lived in purpose-built adapted accommodation appreciated this. Others described home adaptations and equipment as essential in being able to manage at home. Much of this had been installed by social services at no expense, or through the Welsh Assembly Care and Repair scheme. People who had paid themselves for home adaptations said they had received their full allocation of free bathroom aids but wanted additional rails or a particular bath lift, or they wanted items put in quickly without waiting for assessments by social services.

People who had paid up mortgages on homes which suited current needs said it was an advantage to have no regular housing costs. But some paid-up family houses were now proving hard for older people to manage. Some believed they would soon have to make large financial contributions towards an upstairs bathroom conversion or a stair-lift. Options for equity release which had been explored were unattractive. Elderly people who had looked into moving from the house they owned said they could not afford rents in adapted accommodation.

### 5.2.2 Parents of child DLA recipients

There was generally less discussion about the suitability and costs of accommodation among parents of disabled children, although one family did feel they needed a bigger house, to make plans for the care needed by their child in adulthood. In this study group, no parent mentioned being in rent or mortgage arrears. Having a suitable garden was often mentioned as important. Being out in the garden or playing on outdoor toys was calming for some children, or provided stimulation and exercise. Gardens also meant it was easier to have family pets which were mentioned as particularly helpful by some families.



## 5.2 Paying for fuel

### 5.2.3 DLA and AA recipients

Among people who paid for gas and electricity themselves, this was generally one of the budgeting priorities. Several people said it was important for their health condition that they kept warm, and needed extra heating in the winter to combat respiratory problems, and pain and stiffness in joints. When homes were hard to heat, or people had particularly high consumption, managing to pay for fuel was a concern. Some people over 60 years of age said how much they valued their winter fuel allowances.

However, high fuel costs were not just seasonal expenses. Some people said they had high electricity bills throughout the year, related to need for extra strong lighting; having lights on through the night; charging up wheelchairs and mobility scooters, and running equipment such as nebulisers, air conditioners and some oxygen supplies. Heavy use of washing machines and driers also increased electricity consumption. This was described by people who dealt with incontinence, people who spent days in bed, those whose condition led to spilling drinks and food, and some older people who managed their laundry themselves by doing frequent small loads. People who found it hard to manage laundry at home were typically paying around £10 per week for a commercial service or help from a friend.

### 5.2.4 Parents of child DLA recipients

Parents of disabled children also prioritised fuel expenditure, and it was common for them to say their fuel bills were high, especially for electricity. Some children needed extra warmth at home, for example children with severe asthma. Large amounts of laundry often pushed up electricity bills. Some parents dealt with daily washing and drying of several changes of bedding, day and night clothes, on top of the laundry for the rest of the family.

Electricity bills were further inflated by need for extra baths and showers, charging electric wheelchairs, and frequent use of food processors, fans and hair driers. In some families, televisions and computers ran continuously when children were at home, meeting various needs of the disabled child and other siblings.

Nobody in our overall study group said they were in arrears for fuel payments but managing to pay for fuel consumption was hard for some in all the sub-groups. One parent said that keeping out of fuel arrears meant buying other items on credit, where debt was building. Improving their home insulation had helped some with heating bills but it was harder to reduce some of the needs for extra power.

## 5.3 Paying for food

### 5.3.1 DLA and AA recipients

Among both adult DLA and AA recipients, problems in making meals were widespread. Cooking was hard for people with sight impairments, nausea or vertigo, for those unable to balance or stand in the kitchen, and those with problems in holding dishes and utensils, or taking things safely from the oven.

There was a wide spectrum of ways in which people dealt with difficulties in making meals. In residential care, meals were provided within the charges. Some people had a partner who did the cooking. Relying mainly on relatives other than partners for help with the cooking was described by people whose adult daughters lived with them.

It was common for people to describe increased reliance on using prepared or frozen meals, and greater use of microwave ovens. People generally tried not to rely mostly on ready meals, because they were monotonous and considered relatively expensive. However, carers who came into the home, as part of social services or private agency care packages, were said to expect to find ready meals in the freezer. Two-half hour care visits each day to heat lunch and prepare a light supper cost one elderly person £58 per week. A more common arrangement was a weekly mix of some ready meals, people's own small-scale cooking, meals in local relatives' homes, and meals bought in venues outside the home. People who could manage the journeys involved had found various venues which gave, they judged, good value main meals. These included lunch clubs run by voluntary organisations; supermarket cafes; garden centres; town centre tea shops and pubs. Meals eaten out of the home in this way were described as helpful in other ways – helping to structure otherwise lonely days and, if a friend went too, providing company and reducing taxi fares. One elderly man went every day to the local pub for his breakfast, which cost £2.99, and then spent most of the morning in the comfortable environment, with his friends.

People with particular nutritional requirements, for food supplements and diabetic foods not provided on prescription, said that these added to their food expenses. Paying around £15-£20 per month for nutritional supplements was reported by a young person with chronic ill health.

### 5.3.2 Parents of child DLA recipients

All parents were keen that their families ate good food; they bought food and cooked meals according to different choice in eating as well as the budget available. Low income parents with more than one child said it was always a challenge to afford nutritious meals. On the other hand, parents who described themselves as 'middle income' said they could afford to eat well.

Incorporating any additional expenses related to the costs of feeding a disabled child thus had different impact for parents. It was common for the child to be a

'picky' eater, and there was extra expense involved in buying different foods to tempt appetites, or having to waste rejected meals. When all meals had to be pureed, parents bought nutritious food which pureed well and the child accepted, and this tended to be more expensive. As explained by one mother, this meant buying expensive butternut squash rather than carrots. When children had poor appetites, pieces of fruit were often tempting, but it was hard for families on low incomes to afford fresh fruit for all children at mealtimes. Making different meals for different children took longer, and was generally more expensive. Parents who bought Halal food said their food bills were comparatively higher anyway; and one parent whose older child had a condition which led to compulsive eating said this was costly.

## 5.4 The cost of getting shopping

### 5.4.1 Adult DLA and AA recipients

Adult DLA and AA recipients able to do their own shopping fairly easily were unusual in our study group. Problems were related to the location of shops and supermarkets and the journeys involved, the lifting and carrying necessary, conditions such as sight impairments and learning difficulties, fatigue and pain. Some people dealing with mental illness found it hard to go out of their home, use public transport or be inside shops. People with partners often relied on them for shopping. For others, shopping had to be planned carefully, and often required help from another person and led to expense.

Most people aimed to get much of their household shopping in a supermarket. There was widespread reliance on private transport for this purpose, and Blue Badges were much mentioned here. People who drove their own car, or had a partner who drove, said their vehicle was essential for shopping. When supermarket staff were helpful and parking was easy, some people who used wheelchairs and walking aids still managed to do their shopping. Other elderly people with relatives or friends who drove made arrangements for a regular weekly trip together to the supermarket.

When private transport was not available, taxis were used. Home deliveries by supermarkets were a help to some people, and some supermarkets delivered large orders free. However, people living on their own often did not buy enough for a free delivery, and several were paying charges of £3-£6 weekly for home deliveries. One elderly man paid a personal friend to do all his shopping and an elderly woman gave £1 to her neighbour for each visit to the local shop, having discovered that help with shopping organised through social services would cost her £11 each time.

The youngest physically active DLA recipients used their bicycles for shopping in town centres. Using bicycles a lot in urban areas meant having to deal with occasional large expenses of theft of the bicycle or bicycle parts.

Among parents of children receiving DLA, getting the shopping was rarely raised as an issue for discussion. It appeared that parents were so used to organising this part of family life, and fitting it around their children that the financial expense involved was not a matter to mention.

## 5.5 Paying for personal care

### 5.5.1 Adult DLA and AA recipients

Most of the adult DLA recipients in this study needed help with some aspects of personal care. Some needed help with dressing, bathing, using the toilet and dealing with incontinence, both during the day and often during the night. In this study group, it was mostly people's partners who provided such intensive help, sometimes with additional regular support from adult children and personal friends. One younger person without a partner received a substantial package of professional care, of seven hours daily and nine hours overnight.

Among people who said they needed continuous emotional and psychological support, motivation to engage with life, and encouragement to keep taking medication and care for themselves, it was again people's partners who generally provided such help on a daily basis.

Other people said they needed some but not continuous help, either with a particular aspect of personal care such as bathing, managing aspects of life that required greater cognitive skills, or on particularly 'bad days' when pain or stiffness in joints prevented them doing things they would usually manage themselves. Some people relied on being able to summon help quickly when they 'got stuck' or were ill. Again, the help that was being provided came from partners, but also adult children, adult brothers and sisters living close by and, for one young person, a parent.

This picture of care needs and provision among DLA recipients provides further evidence of what is known already, that most personal care and support for disabled and elderly people living in the community is provided informally by relatives and friends. Some, but not all, of the partners who provided high levels of direct care received Carer's Allowance. In this sub-group of DLA recipients, only one person was making formal payment for the personal care received. However, people acknowledged support and help from adult children, brothers and sisters, and personal friends in other ways, including making financial gifts. This is discussed further in Section 5.12.

Among AA recipients in this study, we see some similarities in the overall picture of provision of personal care. People living in care homes and sheltered accommodation had help from staff when problems arose. Among those who lived at home, partners helped each other. Otherwise, people relied on adult children, professional care services, and local people paid for help. One person shared a home with a daughter who gave daily personal care and claimed Carer's

Allowance, and another paid a personal friend £25 per week as a 'helper'. An elderly person in Scotland said 15 hours care per week was provided free of charge by social services.

Help with hair washing was often mentioned. Hairdressers who visited women at home were said to charge around £8 weekly.

### 5.5.2 Children receiving DLA

As we would expect, most of the children's needs for personal care and attention at home were met by parents. There was wide variation in what this involved, related to the children's different ages and health conditions. Parents' variously described bathing, dressing, feeding, lifting, dealing with incontinence, and turning through the night of children up to 15 years old; giving injections; constant supervision, management and encouragement, and dealing daily with pain, distress, compulsive or inappropriate behaviour. Some parents also had other children to care for.

In this study, mothers were taking major daily responsibility for children with needs for intensive personal care; the sole parents were all mothers. Fathers living with their families all played a major part when they were at home. Some families received regular respite care for the child, away from home, organised by social services and provided free of charge. Regular support at home for some pre-school children and their families was also being provided free of charge through Homestart.<sup>12</sup>

Other key people were grandparents, the child's older siblings and parents' own siblings. In only one such case was there a regular financial arrangement, when parents gave a relative £100 for occasional fortnightly stays of the other child in the family, giving the whole family a welcome break.

### 5.5.3 Special equipment

There was need among both adult and child recipients for various items of equipment (separate from mobility aids, discussed later). Adult personal alarm systems, linked to a call centre, were generally rented from social services departments, and typically cost £15 a month. Aids for dressing, and reaching curtains and switches; kitchen gadgets and tap turners had generally come free, from social services or NHS rehabilitation programmes. Other items considered essential to maintain health and daily living had been paid for privately, including replacement and adapted beds, table top ovens and an electrically controlled armchair.

Some of the children also needed special equipment. Hearing equipment and special aids to communication had been supplied free of charge. Items bought by parents included adapted cutlery, drinking beakers and kitchen ware.

---

<sup>12</sup> The Homestart Service delivers one-to-one support, friendship and practical help to young families. Homestart is delivered through a national network consisting of Homestart UK, an independent charity, and more than 300 local schemes, each based on a nationally agreed model.

## 5.6 Paying for health care

### 5.6.1 Adult DLA and AA recipients

As we would expect, adult recipients of DLA and AA were heavy users of the National Health Service (NHS) services and facilities across primary care provision; hospital and out-patient services; and pharmaceuticals and medical supplies. There was little use of private or alternative medical services, but it was not unusual to have private chiropody to supplement NHS provision when NHS appointments made available were not frequent enough. Charges for private chiropody were described typically as around £17 every two to three months.

Some people who had nebulisers at home had bought these privately (at £50); in a different local area a person said he paid rental for a machine supplied by NHS. Disposal bags for a home commode were said to cost £4 per night. A person who used catheterisation at home said NHS equipment was supplied free, but hygiene gloves and talc which made things easier had to be bought privately.

### 5.6.2 Children receiving DLA

In the same way as adult recipients, NHS services were of major importance to children receiving DLA. The spectrum of use covered GP services, and a wide range of hospital services and specialist clinics. Some children received regular occupational therapy, speech and language therapy, physiotherapy, or support through Children and Adolescents Mental Health Services (CAMHS), and some had taken part in courses for breathing management, relaxation technique and anger management, all arranged via NHS. Parents helped many children with medication and home treatment schedules; in some families pharmaceutical supplies were delivered to the home, occasionally to a fridge supplied for the purpose through NHS. Hearing aids, glasses and leg splints used were all free of charge.

There was geographical variation in whether nappies for older children were supplied through the NHS. In one area, a four year old child received a free nappy service. In another area, parents of a child of the same age said they had to buy nappies themselves. For a low income family, weekly expenditure of £16.49 on nappies was a major budgeting item.

Chiropody was also mentioned as an area for private spending for children. A parent told there was no local NHS chiropody service for children regularly spent £50 on private treatment, and regularly bought dressings at the chemist to look after feet affected by problems in walking. Several parents said there appeared to be a shortage of resources for physiotherapy and occupational therapy for children, and would have liked more for their child. Parents with higher earnings were paying for private treatment here – in one case, fortnightly language therapy cost £74; a physiotherapy course cost £230 every six months.

## 5.7 Paying for housework, gardening and small jobs

Among adult DLA and AA recipients it was unusual to be able to manage housework and small household jobs without help. Those who were able included younger people with mental health conditions, for whom establishing and maintaining a home was an important part of recovery from acute illness.

Most other adult recipients currently needed some kind of help with cleaning and odd jobs around the home. Keeping a home clean, tidy and well decorated was a priority for many of those who took part, important both to maintain self-esteem and feelings of being in control and managing, and to maintain a comfortable environment in which they had to spend so much time. Older people in particular spoke of struggling to maintain their standards. Partners who were able did housework, and adult children and grand children were of key importance. Direct cash payments for practical help in the home from relatives were occasionally made, generally to the men involved, for example £20-£30 for weekend work in the garden. Other ways of acknowledging the help are described in Section 5.12.

Help with home maintenance from outside the family was generally paid for. Across DLA and AA recipients, people were paying for up to three hours weekly cleaning, in private arrangements with commercial agencies or personal friends. Rates of payment being made were generally £10-£12 per hour. The Age Concern Handyperson service was mentioned as helpful in doing odd jobs; people who had used this remembered it as being free of charge.<sup>13</sup>

People with gardens often said they needed increasing help here. Even small gardens, with a bit of lawn and hedge, were often more than could be managed without help. Sons and sons-in-law were often helpful, and some people had neighbours who came in occasionally to cut grass or sweep leaves but it was not unusual to pay for professional gardening. Rates of payment described were similar across the three locations: £20 for a regular fortnightly session, and £5-10 for an extra job.

Among parents of children receiving DLA only one couple, whose child required intensive personal care and who both undertook some paid work, said they paid a domestic cleaner. Other parents managed housework themselves, sometimes with help from other children or relatives who lived locally.

## 5.8 Paying for mobility aids and transport

### 5.8.1 Adult DLA and AA recipients

Managing to get around outside their home was an issue of importance to all the adult recipients who took part in this study. Those who had access to a private car saw this as an advantage, when they or their partner could still drive.

---

<sup>13</sup> Currently, Age Concern Handyperson services in some areas do set charges for this service.

DLA recipients with a vehicle which they or their partners drove all had higher rate mobility allowance; all knew about Motability, and some used the scheme. Views on Motability varied, according to people's income level and car use. One person who had recently started using Motability felt that the £46 per week contract was expensive, but having the car had reduced the couple's taxi bills, and they valued the independence gained. A young person had initially considered using Motability but opted for buying a private adapted vehicle, with financial help from family.

AA recipients who still drove emphasised how important this was. Even people who could walk only short distances could still get to the supermarket, the doctor, hospital appointments, the bank and community activities because they had a car. There were spontaneous observations that having AA helped pay the expenses of running a car. Some elderly people who understood the mobility component of DLA said it was frustrating that this was not also available to AA recipients. One couple felt their car expenses would be more affordable if they had access to the mobility component claimed by other elderly people receiving DLA, and said this seemed a form of '*discrimination*'.

As explained, some people who were physically fit made great use of their bicycle, but this was unusual. Most adult recipients had bus passes, some of which also enabled free bus travel for a companion. But some could no longer manage buses, and among people who did not drive themselves there was heavy reliance on getting lifts from other people, and using taxis. There were only a few mentions of using 'taxi card' schemes (taxi fares subsidised by some local authorities). Most people who used taxis were paying full fare. Trips to the GP, the supermarket or the bank typically involved taxi fares of £5-£15. Return fares to hospital appointments as high as £20 were described. These expenses came regularly; it was not unusual to have to make two or three such essential trips a week, before adding in any taxi trips for social reasons such as going to church or a club.

Both people who drove themselves and those who had lifts from friends and family said how useful were their Blue Badges. Some had arranged with the local authority to have a designated disabled parking bay marked on the road outside their home. This had been free of charge for some, but others described having to pay around £100 for this service.

Some people had chosen to buy mobility aids privately, when they wanted items not supplied through NHS or did not want to wait. People who had bought a walking frame had typically spent £80-£90. An expensive electrically powered wheelchair used by a young person had been bought with financial help from family. Electrically powered 'scooters', for going short distances on the pavements, were described as essential by some AA recipients. People had paid various amounts for their scooter; some had tried more than one model, or used the second hand market. The most expensive scooter had been bought recently and cost £3,000. The person concerned had saved up for this for a long time, and the back payment from the recent AA award made the purchase possible. The



increased access to shops, greater flexibility in managing time, and reduction in fatigue had proved of great value.

### **5.8.2 Parents of children receiving DLA**

Getting around as a family with a disabled child, and helping older disabled children get around more independently, was a subject for much discussion in the interviews with parents.

Children who used customised wheelchairs were supplied these free through NHS; their parents had bought cars which accommodated the wheelchairs and needs of other family members. Such vehicles were sometimes described as more expensive to run (less economical and more expensive to insure) than vehicles they would choose had a child not been disabled. Car owners said they made heavy use of their vehicles, and expenses were high.

Parents without cars sometimes had occasional help here from relatives who owned vehicles and had time to help. Parents of some of the youngest children who used standard buggies could walk to local venues, such as shops and surgeries, or use buses when there were routes available. There appeared to be local variation in arrangements for bus passes for children below secondary school age. When older children could never travel unaccompanied, bus fares mounted and were hard to meet in some low income families.

Several parents commented on their additional expenses in taking their child out in the rain. They said that wet weather protection for wheelchairs and special buggies had to be bought privately. Essential rain cover and tray for a wheelchair for a five year old had cost £70. In a lower income family, unable to afford rain cover for buggy travel for two children, rain meant the whole family stayed at home.

## **5.9 Buying clothes**

We know that buying clothes and shoes means extra expenses for some disabled adults, related to the need for frequent replacements or clothes not easily found in standard retail outlets. In this study, this was not a key issue for most of the DLA and AA recipients taking part, probably reflecting their characteristics and ages. Some people who would have liked to spend more on clothes just said other expenses took priority.

For parents of children receiving DLA, however, this was often an issue of particular importance. All parents have to deal with continuous replacement of clothes and shoes as children grow, and additional expenditures when clothes get torn or lost. For some parents of disabled children, considerable additional financial outlay was required. For example, the special vests that can be bought to help keep incontinent children dry were described as expensive. Some parents looked for clothes that children could manage most easily, in order to dress themselves as far

as possible. They said that standard, cheaper children's items often have buttons and zips; searching for age appropriate and manageable items took them into higher price ranges.

Children who had special shoes supplied through the NHS were said to be entitled to one pair at a time. One pair of shoes was not enough, and good quality, well fitting shoes appropriate for children with walking and gait problems were said to be expensive. When children's feet were different sizes, replacing shoes always meant buying two pairs at a time. Even when children wore standard shoes in cheaper ranges, shuffling and scuffing, uneven gait, walking on tiptoe or having low fastening splints all led to need for frequent replacements.

In some families, it was children's behaviour that increased spending on clothes. Parents knew that all children occasionally lose or spoil clothes, but some parents in this study had to deal with this on a regular basis, and were used to frequent replacement of lost outdoor coats, and PE kits.

## 5.10 Paying for social activities, and education

### 5.10.1 Adult DLA and AA recipients

Constraints due to people's health conditions, reduced mobility, low income, and modest aspirations meant that adult DLA and AA recipients often had fairly restricted social lives. Going out alone for a drive, or family visits were often important. For some people for whom getting around was very hard, it was enough to enjoy reading, television or music at home, have a household pet, or buy a specialist weekly magazine or food for garden birds.

Older people who enjoyed more companionship described regular afternoons at local clubs. There were generally some expenses attached – going to a weekly Blind Club cost £5 to cover the 'donation' on entry, buying tea and a raffle ticket, with additional taxi fares for people who did not drive. Some older people were more active members of churches, social clubs or pensioner groups, and took part in coach trips and outings, or regular craftwork sessions. Again there were expenses for attendance, tea, and contributions to the costs of trips or buying materials for craft work.

Younger DLA recipients varied in their aspirations for social activities. Subsidised fees for disabled horse riding were reported as £7 weekly; for wheelchair dancing £50 per term. Some younger people with mental health conditions had special interests which helped them deal with symptoms. Fishing, alone or with a relative, was described as really useful in managing one person's depression and anxiety. It was, however, considered a relatively expensive hobby for a couple living on out of work benefits, involving an annual licence fee of £27.50, plus local permits at around £35 each, and the cost of bait.

Ownership of a telephone was often described as '*absolutely essential*'. This was true among DLA and AA recipients alike, and people said telephone costs were high. Some described heavy use of a phone at home, for calling taxis, ordering shopping, contacting GPs and pharmacists. Having a mobile phone also meant people felt more secure going out, because they could summon help quickly. It was thus not unusual to have a landline and a mobile phone, to reduce costs of phone calls from home and to enable phone use outside the home. Among some of the younger DLA recipients, computers were used a lot to get information, seek advice, and keep in touch with families.

Across the adult DLA and AA recipients, holidays were not much mentioned, and some people no longer thought about staying away from home. Those who did expect to have an annual holiday included people whose family paid towards this.

### 5.10.2 Children receiving DLA

All parents wanted to enhance quality of life for their disabled child, and provide as much support and encouragement as possible for learning and development. Some had other children to include here, and all tried to maintain some personal and social life for themselves.

The range of ages and personal characteristics of children receiving DLA meant that there was wide variation in the kinds of toys, equipment and activities that suited them. Toys often had to be replenished frequently, in order to maintain attention, or when children became destructive. Specialist toys and equipment, designed to meet special needs, were considered expensive. Some families had several televisions, to meet the particular needs of the child, and accommodate the needs of other children. Parents of older children who could manage mobile phones paid for them and encouraged ownership and use: as a learning tool, to help with communication, to help keep in touch with friends and, for teenagers who went out without parents, to increase confidence and bring a sense of security on both sides.

Playing outside helped some children. All-terrain buggies and customised tricycles, generally costing more than £500, gave some children in higher income families different opportunities for outside activities. Free entry to swimming baths for the child, and in some cases accompanying parents, was appreciated by parents of children who liked swimming. Not all children could manage public swimming baths, and some parents paid for membership in private gyms so that children could use quiet pools with appropriate changing facilities at times of the day that suited the family.

In some homes, family pets were important. For all families, there are expenses involved in owning a pet, but some families in this study said they had extra expenses in having a dog or cat. There was need for greater hygiene and minimising risk of infection, and animals sometimes went frequently to the vet or grooming parlour to keep them in top condition.

As we might expect, the families were often keen to go on holiday. Aspirations varied, influenced by income and resources, family structure and children's ages, cultural and family traditions, in addition to the needs of the disabled child. Some parents relying on out-of-work benefits had appreciated the low-cost short breaks organised by some local family support organisations, and put aside small amounts of money from weekly benefits over a period of months to cover costs. Other families relying on benefits for their main income saw no possibility of going on holiday. The sub-group also included families with higher incomes, who expected to go for a fortnight's annual holiday abroad, or a UK holiday. CentreParcs holidays, going away in a camper-van or large caravan, or going to stay with relatives were all popular with some families.

All children of school age in our sub-group of DLA recipients were currently receiving publicly provided education. Paying for additional private teaching or coaching was unusual, but there were parents at both ends of the income spectrum who did this. Parents of an older child, approaching GCSE, paid £160 a month for two different kinds of learning support.

### 5.11 Buying gifts

The final item of expenditure included in this account is the financial outlay involved in making gifts. For parents of disabled children, gift giving outside the immediate family generally fitted traditional and cultural patterns for families with children, such as presents for friends at birthdays or festivals.

Among adult DLA and AA recipients, however, making gifts was often an important way of acknowledging otherwise unpaid care and support. Cakes and fruit were bought regularly by some older people, so these were always available in the home to acknowledge any help from neighbours or personal friends. Some people expected to make money gifts regularly, especially to friends who enabled car journeys and shopping trips. For a few older people, spending on informal gifts of money, food and plants in this way sometimes reached around £30 per month. Some gave generous birthday and Christmas presents to friends who provided particular kinds of help, such as keeping accounts or decorating. Gift giving was also one way, people hoped, that relationships might be strengthened so that support continued. Some people said they 'treated' friends when they went out to tea or lunch together, acknowledging that such outings were only possible with the friend's support. But there could be tensions attached to wanting to treat friends – some young friends expected to pay for themselves on social occasions, especially those with earnings, and did not always understand that their disabled friend wanted to pay for them, because taking part was not possible without them.

## 5.12 Summary

This chapter has presented qualitative information about the current expenses of daily living described by the people who took part in our interviews. Our findings provide many examples of the way in which some disabled and elderly people have to pay extra for items and services that feature in most people's daily living expenses, thus explaining the reasons for their inflated fuel costs, high phone bills, and more expensive food. There are also many examples of additional expenses related to poor health or impairment, such as equipment to enable personal care and moving round. The study shows how parents perceive and deal with some of the expenses involved in having a disabled child, and how meeting such expenses affects other children as well as themselves.

Among adult recipients in this study, paying for personal care provided professionally was unusual, although all required some help and support, occasionally or continuously. Our findings underlined how most direct personal care and support of elderly and disabled people living in the community is unpaid, and provided by partners, adult children and other family members, sometimes neighbours and friends, or made available through voluntary organisations. Although such support was largely unpaid, there were often expenses attached for the person receiving support, in the form of gifts given at the time, financial help with running cars, 'treating' people who gave support, and enhanced generosity in presents traditionally given at birthdays and festivals.

Although the adult recipients received help from other people, managing daily living also often depended largely on their finding solutions and working out ways of doing things which reduced the amount of direct help needed, and enabled people to maintain control and some independence. Such solutions often required spending money; sometimes relatively small amounts when considered on their own, but reaching more substantial sums when we consider frequency of payments and the number of separate outgoings for individual people. For many of the adult recipients we spoke to, life was managed by being able to afford market prices for housework, laundry, garden maintenance, 'odd jobs' and taxi rides; by buying frozen and prepared meals, or buying meals outside the home; by relying on frequent use of telephone and home computers for day-to-day living arrangements; and by running private vehicles, sometimes judged by the people concerned as an expensive use of their resources.

Among families with children, our findings showed how all parents wanted opportunities to give their disabled child the best possible life chances. They spent money on what we might term 'additional expenses' to provide the particular toys, equipment or activities that would help, and they spent money to fill some gaps in NHS or education services which they perceived. For some parents there was heavy 'extra expenditure' on heating and hot water, electricity, transport, and costs of maintaining and replacing appropriate clothing and shoes.

Expenses were not confined to care for the disabled child, but spread across other members and into all areas of family life. In this study, parents with higher earnings said that it was probably not as hard for them to meet some of their expenses as parents on low incomes, but meeting such expenses meant their family life styles were very different from those of their personal friends, relatives or work colleagues. The different accounts of ways in which parents met their living expenses demonstrate clearly the sometimes stark inequalities between families, and the risk of child poverty as the result of looking after a disabled child.

## 6 Perspectives on the impact of DLA and AA

In this chapter we bring together the empirical findings about the contribution of Disability Living Allowance (DLA) and Attendance Allowance (AA) in the lives of people who took part in this research, and what difference these benefits made, putting together information obtained in a number of ways, as fully described in previous chapters. For purposes of presentation, we present findings which answer key questions:

- How did people conceptualise DLA and AA?
- How were DLA and AA being used?
- What other roles did they have?
- What were DLA and AA recipients' feelings about their overall financial and personal circumstances?
- What would happen if recipients had less money?
- What difference did recipients think the benefits made for them?

### 6.1 How did people conceptualise DLA and AA?

#### 6.1.1 Adult DLA recipients

Adult DLA recipients, who all understood they were getting DLA, generally thought of it as a benefit available to people with medical conditions that meant they were limited in what they could do for themselves. Some associated the benefit with needing extra help or having problems in getting around, and some made associations with needing 'care'. People thought of the benefit as providing extra money to help them afford what they needed. There was widespread belief that DLA was a benefit for people whose problems were going to be long-term. It was not unusual for people to stress the regularity and reliability of the benefit as key characteristics, rather than the actual money value, especially among those with long-term awards and people who tried to sustain paid work.

Some people remembered how DLA had been explained to them by advisers who had helped with applications, and retained the conceptualisations presented to them at that time. For example, some remembered being told that the benefit might be used for whatever was needed to help them manage; some remembered how welcome was the suggestion that DLA might be used to pay for taxis.

There was evidence that some people of working age, and their partners, perceived DLA as an income replacement benefit for people unable to work because of long-term health problems, discussed further below.

There were some feelings that recipients had personal responsibility not to 'waste' the benefit by spending it on things they did not really need. A few people believed that using DLA in the wrong way, for example in the pub, could lead to losing the benefit if found out. Among others who had no expectations that use would be formally monitored in any way, feelings about not being seen 'to waste' the benefit were sometimes complex – one person wondered whether she should be out enjoying life by using DLA when she was supposedly 'ill'. There were some feelings of dislike of being categorised as 'disabled', a label which was particularly unwanted by some people managing mental illness or learning difficulties.

There was general awareness of DLA having two components, and different rates. People knew they had received such details about their own award, and those whose award included a mobility component generally referred to this, commonly using language such as '*the mobility*' or '*the one for transport*'. Language used to describe the care component was sometimes less specific, with people talking about '*the disability*', '*disability allowance*' or '*living allowance*'. DLA recipients who remembered the actual money value of their award without checking paperwork were generally people who kept some kind of accounts or checked bank statements regularly, and people whose circumstances had changed recently or would change if they got paid work. It was not unusual for people living on low incomes to say they knew how spending matched income, by checking bank balances at cash-points and looking in their purse, so they did not need to remember how much DLA they got. The payment interval of DLA received was, however, generally known, and considered an important factor in budgeting by people living on low incomes.

Among elderly DLA recipients there was some awareness of AA, especially people who had claimed in their 60s. We saw no evidence of anybody in this study group having claimed before reaching 65 years with a view to securing the mobility component. Those people who had full understanding of this potential incentive had experience themselves as benefit advisers, or been active in local politics; and they perceived some inequities for older people here.

There was evidence that some people did not realise DLA was not an income-related benefit. It is important to remember here that DLA recipients in this study were all living on low incomes. Most had already been assessed for income-related benefits such as Income Support, Pension Credit and housing benefits, and were



thus used to their benefits being income-related. It was people who had thought about or tried paid work who suggested spontaneously that DLA was income related. We read what DLA recipients said about the links they perceived between getting DLA and doing paid work in Section 6.3.

### 6.1.2 AA recipients

In comparison with the DLA sub-group, there was more limited information about the way in which AA recipients thought about the benefit. We have already explained that not everybody understood they were getting AA, and some who did know said that relatives dealt with financial matters for them.

As with DLA recipients, some people described the benefit as money available to people who needed 'help'; people who were ill and people who could not do things themselves. Some described the benefit as being money for people who did not otherwise have enough to live on. Elderly people's ideas about AA and what it was for often matched what they remembered being told about AA by advisers, when they first applied. For example, there was a close match between one person's concept of AA and what they later described an Age Concern visitor having told them about AA. One person believed that her circumstances had led to a judgement that she 'deserved' the benefit, having never done anybody harm and not being responsible herself for being ill.

The name of the benefit led some to think of it as a benefit for people who had 'attendance', that is somebody else looking after them. Although this did fit some people's circumstances, for example the couple who explained that one partner was ill and the other looked after her, there was also evidence that thinking in this way led to non-take-up. One person who had known about AA for many years had thought she was not entitled, because she received no direct help from anybody. An adviser explained her misunderstanding, and helped with an application that led to a lower rate award and a large back payment. Another whose wife had received AA when he looked after her did not realise he would be entitled himself when he lived alone after her death, until a 'welfare visitor' encouraged him to claim.

The benefit was generally referred to as '*Attendance Allowance*' or just '*attendance*'. Awareness and understanding of the two rates of payment and the money value of the award was patchy, but strongest among people whose awards had changed following review and couples where partners received different rates. Again, the payment interval featured strongly in the way some elderly people thought of their benefit, for example when they talked about '*my monthly money*'. Some who were aware of differences between DLA and AA regretted that they were unable to '*go for mobility*' despite relying on a car, in comparison with other people in similar circumstances who had applied for DLA at an earlier stage of life. One person who had been told by friends that he had missed out in this way had not really understood the point, but knew there was some issue here.

As in the DLA sub-group, there had been some feelings of unease among AA recipients, in getting what seemed a valuable benefit. One elderly person had told friends about feelings of '*guilt*' and been reassured of her entitlement, not only because of her need for help but also through having paid National Insurance contributions all her life.<sup>14</sup>

### 6.1.3 Parents of children getting DLA

The way in which parents thought about the DLA their child received was closely linked to the particular circumstances of the child and family. Thus different parents spoke of the benefit being for physically disabled children, for children who needed more care than others, children who needed extra attention and had problems going out, children who needed extra things because of their condition, and children who were particularly dependent and difficult. Others thought of the benefit in relation to the wider family: available to help parents who had major extra responsibilities and tasks, to ease pressures on parents and enable them to do more for and with their child, or to compensate for additional costs and burdens on the whole family.

Less widespread, but mentioned by some, was the child's DLA acting as income replacement for parents unable to do paid work because of the child's needs for care, or DLA being money for parents who otherwise just did not have enough. Parents who had experienced recent major changes in personal circumstances, or who had fluctuating earnings, mentioned regularity and reliability of this income stream when they thought about DLA.

Although there was no evidence of non-take-up for this reason, some parents had not expected their income was not taken into account in assessing their child's DLA.

As described similarly by adult DLA recipients, some parents were surprised to find that their child fitted the label of 'disabled'. This categorisation was sometimes unwelcome, and like a '*sting in the tail*' from DLA. In this study group, it was parents of children with learning delays and communication difficulties, but not physical impairments, who made this point. Applications had not been delayed by such feelings once parents knew the benefit was relevant to their child, but one mother spoke of underlying feelings of hope that her child would not need DLA for long. Another strand in negative associations in DLA for some parents was wanting to be like other families, and not need '*extra things*'. The parent who explained this acknowledged that expenses that might be contained within an ordinary budget when a child was very young might increase considerably as the child grew.

---

<sup>14</sup> In fact, DLA and AA are non-contributory benefits. This person was the only one across the whole study group who said anything spontaneously about National Insurance contributions, in relation to DLA and AA. Interviewers did not raise this topic themselves.

## 6.2 How were DLA and AA being used?

An important finding was the difference between how DLA and AA were actually being spent, in the practical money management of various income streams with different periodicities, and how the benefits enabled spending because of the way they were taken into account in budgeting decisions.

When participants helped us trace the DLA payments into and out of bank and post office accounts, and through purses and wallets, we saw how this money was actually being spent. It went widely into meeting direct debits, standing orders, debt recovery schemes, and onto fuel pre-payment cards and mobile phone cards. Thus it paid, variously, rent, council tax, gas and electricity charges, water charges, television licensing, previous partners, care providers and commercial agencies.

This was more to do with the way the payment intervals matched direct transfer arrangements and practical money management than with decisions about how DLA or AA was to be used. From purses and wallets money from DLA and AA actually went to supermarkets and retail outlets, friends and relatives, taxi drivers and bus companies, small businesses, churches and voluntary organisations. Again, the ultimate destination here was partly to do with practical money management – which source of income filled purses, or which partner put their hand in their pocket for particular items.

This picture of how DLA and AA were actually spent was interesting, but goes only a little way towards understanding how the benefits were being used, in terms of enabling spending, or saving. People made notional allocations as well as actual separations of monies, and made decisions on the basis of what they knew they could afford within overall income. So a fuller picture of how the benefits were being used comes by putting together material gathered in all the different ways we sought information in each interview, as explained in the previous chapter, and a deeper analysis. Understanding how DLA and AA were used depends on understanding how people were enabled to afford things because they knew DLA or AA was going into bank and post office accounts.

For purposes of presentation we look first at DLA and AA recipients, drawing attention to any differences between the two sub-groups, and then at families of children receiving DLA.

### 6.2.1 Adult DLA and AA recipients

DLA and AA paid to adult recipients was being used to enable spending on:

- **Fees for residential care, and warden assistance in sheltered accommodation**

Our study group included an AA recipient living in residential care, and elderly DLA recipients and AA recipients living in sheltered accommodation with warden assistance. This study does not provide detailed information about the charges paid

by people living in residential care and sheltered accommodation, or how charges were met, for example how far relatives contributed financially. It seemed likely, however, from our own knowledge about funding structures, and how residents talked about their money, that they depended on some AA being available to meet fees and charges.

- **Personal care.**

Among DLA recipients, paying for personal care (washing, dressing, preparing meals) from formal providers or friends was not widespread, but the person who did need a substantial care package explained how this was possible through using DLA. More commonly reported was spending on chiropody, and hairdressing.

Those AA recipients who had help at home with washing or showering, dealing with incontinence, dressing and making meals, and paid for this privately or in contributions to social services were relying on AA being paid in affording such care (except in Scotland, where the recipient told us she had three daily visits from social services free of charge). Being able to afford private chiropody and hairdressing at home through having AA was also widespread among the elderly people.

- **Transport.**

There was widespread acknowledgement that having DLA and AA enabled people to get around outside their home and make the journeys essential for managing to live in their own home – to get their shopping; go to GPs, hospitals and clinics; go to the chemist, bank and post office; or go for hot, cooked meals, as well as take part in social, community, and leisure activities and, among younger people ready for work, to look for jobs. The latter aspects of social participation and inclusion were particularly important to some people in maintaining morale and self-esteem, combating loneliness and managing mental illness.

Thus having DLA and AA enabled some people to afford to run their own cars (some DLA recipients through Motability), or to be able to contribute to costs of other people's cars, when people relied on being driven by relatives or friends. For some people with partners, running a car was essential for being able to make some journeys together. When local authorities charged to paint a designated parking bay in front of homes, having DLA had helped people afford the cost. Knowing they had money from DLA or AA enabled people without cars to afford taxis, and enabled some car owners to get around on days when they were not well enough to drive. DLA enabled maintenance and safe keeping of a bicycle that was an essential part of life for one young man. A large AA back payment had all been used directly to help pay for a mobility scooter, which had made a great difference to one elderly person.

- **Food.**

Having DLA or AA meant being able to afford better quality food, meet particular dietary needs, and buy nutritional supplements. The payment interval meant, for

some adult recipients, having a sum of money each month which allowed them to do sufficient shopping to qualify for free delivery of goods. For some, knowing they had DLA or AA enabled people to afford to buy the frozen ready meals which could be dealt with in a microwave oven. Also, widely important, both DLA and AA enabled people to be able to afford to access hot meals by finding their own solutions when using ovens was beyond their capacity in the kitchen and making meals at home was hard. Having DLA and AA meant being able to afford to travel to a local venue which served hot meals, and to afford to pay for a cooked dinner, evening meal or even breakfast.

- **Fuel.**

Knowing DLA or AA payments were being made enabled people to afford to use the amounts of fuel necessary to keep warm, and to meet their need for electricity to power the washing machines, tumble driers, wheelchairs, televisions and computers, and medical equipment in their home which people across the age range described as essential in managing their lives. When people knew that the DLA or AA going into their bank account would meet the direct debits or standing orders for gas and electricity, this was a great relief.

- **Home maintenance.**

Being able to take DLA into account meant being able to keep homes clean, by affording domestic help. Being able to replace a worn vacuum cleaner from a monthly DLA payment meant that people paid to clean could work more efficiently. Among AA recipients, there was particular emphasis on the importance of being enabled to maintain their home, through relying on AA to afford cleaners, gardeners, window cleaners, and people who did small jobs in the home.

Saving up small amounts of money, made possible through having DLA, meant being able to redecorate a room, described as so important in maintaining morale. Replacing floor coverings, through similar small-scale savings possible through having DLA, also reduced risks of falling for people with balance and mobility problems. People starting a home from scratch, after a period of disruption or homelessness, were able to get together basic equipment and household items because DLA boosted out of work incomes. AA recipients also valued being able to afford to have rooms decorated or replace worn furnishings, generally through small savings made for this purpose after meeting other essential needs.

Being able to replace worn-out items such as washing machines, fridges or televisions by using a monthly DLA payment had been helpful. Among elderly people who could not manage laundry themselves, having AA was enabling them to afford a commercial laundry service, or pay a friend to take their washing.

- **Medical equipment and supplies.**

DLA and AA recipients told us that having the benefit had helped them buy wheelchairs and mobility 'scooters', and both DLA and AA had gone directly towards paying for bathroom aids not supplied free, or needed quickly. DLA helped to meet the costs of incontinence.

- **Telephones and computers.**

Reliance on telephones was widespread among both DLA and AA recipients, as described in Chapter 5 and, for some people, being able to use a computer and the internet was an important link in managing life with poor health or impairment. Knowing that DLA or AA was coming in regularly helped people pay for these services.

- **Social activities.**

In the sub-group of DLA recipients, constraints of poor health and low income led to fairly modest aspirations for social activities. However, people who had particular hobbies, went to clubs or church, met with friends in a café or pub, did craft work or read at home all said both that these activities were important in maintaining well being and mental health, and that there were expenses attached. Knowing they had DLA encouraged them to pay for transport required to take part, small membership fees, a coffee or snack, or buy a specialist magazine. People whose activities involved higher outlay made notional allocations in their budgeting on the basis that DLA was there to help pay for things that helped them combat depression, loneliness, or to control feelings of anger. For some people, taking part in activities outside home also meant paying for a carer or friend to go with them, and knowing they had DLA enabled them to do this. A small group of DLA and AA recipients bought cigarettes from money available for general housekeeping.

Having AA similarly enabled some elderly people to afford to travel and take part in local social activities such as going to church, and to pay charges or 'donations' for attendance and tea at community groups, to pay towards residents' outings, and be able to make small charitable donations or put their name on 'sponsorships' for younger people's initiatives for charity. Some of the AA recipients we spoke to expected to take part in more expensive activities such as going to the theatre, or going abroad for a holiday, and some of these activities appeared to depend on financial support from families.

- **Saving.**

For most DLA recipients in this low income group, 'saving' meant leaving any small amounts left in bank and post office accounts to accumulate to a sum sufficient for a planned purchase. In this way, monies from DLA had contributed to small scale saving towards buying a new bed, or a holiday. It was unusual for actual diversion of DLA into separate savings accounts. However, one DLA recipient who initially put all income sources together into her '*general pot*' including Pension Credit, then found it possible to move small amounts of money into a savings account for herself and one for a grandchild.

Among the AA recipients there was more mention of making some regular savings from income, sometimes explained as providing a sense of security in case anything was needed, or making sure funeral costs could be met. Couples

in which both partners received AA had systems for making regular savings, and transferring money into a savings account. Such savings had been drawn on to help replace an inefficient heating system (an expense of £5,000), to help pay for an automatic garage door when it became hard to manage existing doors, and to help pay for household equipment needed.

### **6.2.2 Parents of children receiving DLA**

Actual diversion of DLA into a separate bank account was more widespread among parents of child recipients. Those who did this were generally parents who used the DLA for particular large expenses, such as the family holiday. More commonly described, however, was drawing on DLA as part of a general pool of money held by the parent(s) in one account, or one of two or more accounts holding different combinations of earnings, benefits and tax credits. Our overall analysis shows that children's DLA was being used to enable spending on:

- **Food.**

Knowing there was DLA helped parents to buy good quality food for the family, especially when they needed to spend extra to tempt poor appetites; to make or buy special kinds of food required; when children wasted or spilt food, or when children had problems with compulsive eating. Parents at both ends of the income spectrum mentioned DLA enabling spending on food for their disabled child; parents in lower income groups explained how quality of food for other children and themselves was also maintained by knowing they had DLA.

- **Clothes and bedding.**

With DLA payments, parents found it easier to afford extra clothes and bedding which children needed as a result of incontinence, vomiting, dribbling, spilling food, or frequent falls outside. Further expense related to frequent loss of clothing or kit for games and activities was more easily managed through having DLA. DLA helped to replace the expensive quality shoes which some children needed to help balance, and encourage and sustain walking.

Parents were helped to afford to buy the nappies needed by incontinent children of all ages because DLA was being paid. Parents of older girls were helped to afford the extra nappies and pads needed, both to encourage them to learn to manage things themselves and to use the same kind of articles that their friends used.

- **Fuel.**

Parents took DLA into account in meeting fuel bills, which they knew were inflated by need for extra warmth, need for continuous hot water, and heavy demand for electricity to power household equipment such as washing machines and driers, lights during the night, and TV and computer systems.

- **Transport.**

Parents were helped to afford the family's needs for transport by knowing that DLA was being paid, and could be stretched to pay towards fuel and running costs for their own vehicle, taxi fares for medical appointments, and sometimes bus fares for parents who always had to accompany children even on short journeys. Parents who felt able to afford all-terrain buggies or customised tricycles for their children said that having DLA had helped them here. Such expensive items were valued when they enabled a family to go out together, or helped a child develop motor control and exercise muscles.

- **Telephones and computers.**

Having DLA helped parents afford to equip older children with mobile phones, as part of keeping them safe and encouraging their personal and social development. Parents were less worried about high bills for their own telephone use and the costs of computers used by children when they knew that DLA was being paid.

- **Treatment and tuition.**

In our study group, the children's needs for personal care and attention at home were all being met mainly by parents. The children were in publicly funded education, nursery or pre-school provision, and their medical care came through the NHS. However, some parents, across the income spectrum, were paying extra for treatment, therapy and tuition they believed would help their child, and knowing they had DLA helped them to afford this. Thus DLA was enabling some parents to afford a chiropody service for their child; helping them pay for extra speech and language therapy; extra physiotherapy, and music therapy. Parents said having DLA helped them pay for out of school tuition when children had particular learning needs, or when older children were aiming at school exams.

Some families had respite care provided free of charge by social services, but some families used specialist private play schemes, or had worked out regular 'respite' arrangements with relatives, and DLA helped to meet the expenses involved.

- **Equipment at home.**

In contrast to the accounts from adult recipients, it was unusual for parents of child recipients to be paying for domestic work at home, and parents expected to manage their gardens themselves. It had been necessary for some parents to have stair rails and bathroom aids fitted, but in this study group there had been little use of DLA to help pay for home adaptations. Back payments of DLA had sometimes been earmarked to pay for replacing a child's bed.

- **Activities and toys.**

There was widespread agreement that DLA helped parents afford the kinds of activities their child enjoyed and had positive effects in stimulating or calming them, or encouraging learning and development. It is important to remember here that many activities also required a parent's participation, and sometimes



other children too. Thus the frequent mentions of DLA enabling swimming often included the costs of travel as well as bath charges for children and adults, or gym memberships for parent and child. Other activities which DLA was helping parents afford for their children included drama; out-of-school clubs for cricket, wildlife and board games; and joining Guides and Army Cadets. We described in Chapter 5 that joining in such activities often required buying uniforms or equipment, and such expenses were considerable when children tried different group activities to find one that suited.

It was important to parents that families did things together, and having DLA helped some families afford what was necessary here – buying an all-terrain buggy for a teenager; paying for family outings to theme parks, castles, children's farms and zoos. Parents explained that while all families enjoyed going together to such a venue as an occasional expensive outing, their family perhaps went more often because this was the kind of venue that had good facilities for disabled children, and thus was a positive experience for the whole family. Having DLA helped them to afford these trips.

Enabling older children to go out with their own friends was an aim for some parents, and DLA helped them afford telephone expenses, extra clothes or shoes, and taxi fares to keep children safe, and maintain confidence and self esteem with their friends who were not disabled. In the same way as adult DLA recipients explained, for a disabled teenager going out with friends sometimes involved paying friends' expenses, because they could only go out like this if they went with friends who would look out for them.

At home, all parents wanted to buy toys, books, garden games, computer hardware and software, or materials that best suited and helped their child, and had seen such items at school or nursery, or in catalogues or on websites. Parents faced hard spending choices here, especially when they had low incomes or there were other children to consider, and not all liked the idea of asking a charity or trust for money. Having DLA helped parents afford some of the items they would like.

As explained in Chapter 5, having a family holiday was often considered very important for parents in this sub-group, especially parents with older children. A teenager told the interviewer how going on a holiday improved sleep patterns and helped control Tourettes. Going to stay with relatives or going on holidays offered by voluntary support organisations were options for some parents but, for those who chose different kinds of holidays that suited their family in caravans, camper-vans, CentreParcs, holiday cottages or apartments, having DLA helped them to afford the cost and we have explained how some parents ear-marked DLA specifically for such spending. Parents without earnings could not afford the kind of 'traditional' family holiday just described. However, having DLA enabled some to afford to take part in low-cost weekend breaks away from home offered by some family support organisations.

Finally, we mention the family animals, which some parents described as so helpful for their child. As one parent explained, they did not have the dog because they had DLA, but having DLA coming in regularly made it easier to afford the costs of having the dog in their family.

### 6.3 What other roles did DLA and AA have?

In addition to the way in which DLA and AA enabled people to afford what they needed, people attributed other roles to the benefits. Most of these have already been described in earlier parts of the report, but it is useful to bring them all together here.

Adult recipients and parents of children getting DLA described roles for DLA and AA in:

- **Helping practical money management.**

The monthly, or sometimes fortnightly, payment interval helped cash flow for people living on low incomes. This happened in various ways. Date of payments from accounts by direct debits and standing orders was sometimes synchronised with dates of receipt of DLA, ensuring sufficient money was available and preventing overdrafts, described by both DLA recipients and parents of children getting DLA. People in all sub-groups explained how notional allocations of DLA or AA, and sometimes actual separation of monies were worked out to fit the payment cycles of other benefits, pensions and tax credits. Nobody said the periodicity of payment of DLA or AA was inconvenient or unhelpful.

In two-parent families in which children were getting DLA, the parent with day to day responsibility for buying food, children's clothes and shoes, and paying for out of school activities (in this study, generally mothers) sometimes said it was helpful to have the DLA paid into an account they personally drew on, so they could make spending decisions as required.

- **Enabling access to other kinds of support.**

We described in Chapter 4 the various 'passports' and 'links' from DLA and AA which people used. There was widespread appreciation, in all sub-groups, leading one younger person to talk about DLA as '*the door opener*' and an elderly man to confirm the view of his adviser that once '*on Attendance Allowance, the floodgates open, you can get anything*'. Parents of children getting DLA particularly valued some of the concessional charges for leisure activities and travel which extended to accompanying adults, and in some cases to other children in the family.

- **Providing a safety net.**

Both DLA and AA recipients talked about the benefits being a '*safety net*'. This was mentioned particularly by people with experience of major change in financial circumstances, such as starting or leaving paid work and reduction of out-of-work benefit following reassessment. Their experience was that the regular DLA

income, unaffected by change in work status, provided a reliable financial base from which to adjust.

Parents of children getting DLA did not use a language of *'safety nets'* when talking about the role of their child's DLA, but some did refer to the sense of financial security it brought, for example by talking about DLA as providing *'a bit of reserve'* and being available should unforeseen circumstances occur.

- **Helping debt management.**

Some DLA recipients described having the benefit as enabling them to reduce problem debts, and others said it kept them out of debt, mentioned particularly by people who had experienced problem debt in the past.

In the same way, some parents said their child's DLA prevented their going into debt, or reduced what they owed on credit cards.

- **Enabling people to live at home.**

Both elderly people and younger DLA recipients said having the benefits enabled them to go on living at home, because there was money to afford what was needed. One AA recipient believed the government made this money available specifically to keep elderly people in their own homes. Some saw a role for AA in enabling other people to look after the recipient at home, either a relative who received Carer's Allowance or who shared domestic budgeting, or an elderly person who needed support to go on looking after their partner. One elderly person whose financial affairs were managed by sons thought that AA went to the sons to enable them to make the care arrangements.

- **Keeping people in touch with family and friends.**

Both DLA and AA recipients saw a role for the benefits in helping them to keep in touch with family and friends, through helping them afford phones and computers, or making journeys to see them. This was particularly mentioned by people whose relatives lived at some distance. One man said having DLA helped him keep in touch with children of a previous relationship (through frequent phone calls and computer messages) and helped him afford to send their mother some financial support. A mobile phone, afforded through having DLA, was described as essential for keeping in touch with friends for a young adult without reading or writing skills.

We have already described how parents of older children pointed to the way mobile phones, afforded more easily because DLA was being paid, helped their children keep in touch with friends.

- **Keeping people part of society.**

DLA recipients who had experienced long periods in acute or psychiatric hospital, and sometimes lived on the streets, said that DLA had helped them be part of society again. They talked about having used DLA to re-establish a home, alone or with a partner.

Some parents also referred to a role for DLA in helping to keep their family '*normal*', by enabling social participation in the same way as other families.

- **Enabling people to 'give'.**

Both DLA and AA recipients acknowledged a role for the benefits in enabling them to '*give back*' or '*take part*' by enabling them to afford to make gifts; to acknowledge help received by '*treating*' friends and neighbours, or giving money to relatives; to give to selected charities or make donations at church; and to take part in fund-raising for local organisations.

- **Acknowledging people's condition.**

As discussed in Section 6.1, entitlement to DLA and AA was perceived by some people as acknowledgement of their condition as a disabled or ill person, or a person with particular needs. This was sometimes unwelcome, as described among both adult DLA recipients and some parents of children getting DLA.

For others, however, it seemed a relief to have such an identity. A young man whose condition meant he was unable to do paid work found it helpful that since receipt of DLA, there had been less pressure from DWP to consider working, just as his psychiatrist had suggested. An elderly person said that getting AA had boosted her confidence and self-esteem, because she '*felt that someone cared*' about her life. A mother of an older child getting DLA, who herself received Carer's Allowance, valued the recognition of what she was doing that she perceived came with being called '*a carer*'. She said that the financial recognition of her unpaid work, albeit small, did make her feel '*that bit more valued*'.

- **Thinking about paid work.**

### **6.3.1 DLA recipients of working age**

DLA recipients well past state retirement pension age, and some younger people with severe conditions no longer saw any likelihood of doing paid work again. But most people below state retirement age in this sub-group said they would like to be able to have a job, perhaps in the future when well enough to work. Younger people claiming job seeker's allowance had been actively seeking work during the past six months and one person had just started a job when interviewed.

Those people, who thought about working or had looked for work had considered what might happen in respect of their DLA, and some had talked about this to partners. There was a range of perceptions.

There was some belief that DLA was an out-of-work benefit. One young man firmly believed that people did not get DLA if they worked. At the same time, he believed that he was not expected to seek work if he got DLA. His symptoms were such that he was currently some distance from paid work, and his current priorities were re-establishing medical treatment and support for a severe long-term condition. An older couple, approaching state retirement age, also appeared to believe that DLA was an income replacement benefit and, as such,

the recipient's partner argued it was not really equivalent to a basic wage. Their belief was not influencing the recipient's thoughts about working, however, as poor health made this impossible. The recipient's partner speculated that if they put Carer's Allowance into the equation, as this would also be lost if DLA was withdrawn, one or other of them would have to secure a very good wage for the couple to be better off in work than when claiming highest rate DLA and Carer's Allowance. But they emphasised that there was no prospect of either of them doing paid work – one needed intensive care and the other gave it. Another person who believed DLA would be withdrawn in paid work thought that there was now an in-work 'Disability Working Allowance'<sup>15</sup> which would partially compensate for loss of DLA. Again, however, such belief was not influencing behaviour because the person concerned was now too ill to work.

Although other people who thought about work knew they could continue to get DLA, there was some belief that DLA was earnings related. A young person who had been advised to 'be careful' in choice of job so that DLA was not affected found it hard to remember in the research interview what this meant, but thought it probably meant it was better not to take more highly paid work.<sup>16</sup>

There remain those people who sometimes thought about working, or had just taken a job and knew that DLA would continue to be paid. The 'better-off calculations' which they had made took into account the expenses of working, the likelihood of low earnings capacity and, for some, the need to pay for more care and support to enable them to sustain work. For example, having even a part time job would mean, for one person, being too tired to do some of those things at home now managed on their own. The person who had just started work of 15 hours weekly had done careful calculations and was confident in being financially a bit better off. What might happen at the end of the year, when DLA review was due, was a concern however. If DLA was not awarded again, consequent reduction in housing benefits would mean being no better off than on Jobseeker's Allowance, with additional loss of some of the DLA 'passports' that were important. For this person, withdrawal of DLA would seem a positive indication of recovery and a welcome move away from the idea of being 'disabled'. But the financial implications and constraints would be stressful and unhelpful. Past experience was that trying to use Working Tax Credit on variable earnings from short-term contracts and self-employed work – the likely future working pattern – involved a volume of reassessments, changes in income and uncertainties that would have negative impact on control of symptoms and recovery.

---

<sup>15</sup> Disability Working Allowance has been replaced by Working Tax Credit, which is payable in addition to DLA.

<sup>16</sup> The view of the researcher who conducted this interview was that the advice given had been wrongly interpreted here.

### 6.3.2 Parents of children getting DLA

In this study group, it was unusual for both parents or a sole parent to work full-time. Most parents said their family and caring responsibilities meant that one parent needed to be at home much of the time, available to support their disabled or sick child and, for some, care for other children. The general pattern among two parent families in which parents were not themselves in poor health and unable to work was for one parent to be working full-time, and the other working part-time or not at all. In couples with one parent in work, this was generally the father. However, when both parents did some work it was sometimes the mother who was the main earner, when fathers did the kind of work that could be more easily fitted around the child's needs. Most sole parents did not do paid work, but one was pursuing further education with a view to getting qualifications to enable her to get a paid job.

Some parents spoke about the impact of their child's condition on working patterns and careers. Some mothers missed their work outside the home, but gave priority to the needs of their children. Mothers who previously had professional work were sometimes able to continue working part-time as self-employed, largely from home. There were advantages in still being able to prioritise their child's needs for care, but some disadvantages in working in this way including irregular or unpredictable earnings, and loss of occupational pensions. Fathers' careers had been affected by their heavy family responsibilities. This had included being dismissed for poor attendance at work when a child was ill, and missing out on promotions, career development and building pensions in order to focus on family needs.

Parents interviewed, when asked directly about this, all said that getting DLA for their child had not influenced their decisions about work. Some pointed out that their decisions about working had been made before the DLA award, and their patterns of work had not subsequently changed. All emphasised that it was primarily their children's needs that influenced decisions taken about working. One mother commented that although her child's DLA did not influence the way she worked (fitting freelance work around the child's needs), knowing that DLA was being paid regularly did help her feel more relaxed about working in this way, which was insecure and brought irregular earnings.

Sole parents who hoped to return to work when they had secured some qualifications or when children were a bit older said they did not take into account their child's DLA when they thought ahead in this way. However, a sole parent who planned to return to work when her own health improved had thought ahead to the possibility that her child's DLA would be withdrawn at the next review. An initially high award had been progressively reduced as the child's condition improved, and it seemed possible that after review at the end of the year, it would not be renewed. Knowing this gave extra urgency to pursuing diagnosis and treatment for herself, and getting a good job again.

In this study group, parents had given more thought to the relationship between Carer's Allowance and paid work. Those who received Carer's Allowance generally knew it was earnings related and also depended on the number of hours of care they provided. Some had worked out what this would mean for them, if and when they chose to try doing paid work, and some thought decisions might be influenced by 'better-off' calculations taking Carer's Allowance into account. At the moment, however, the main influence on their decisions about working was the needs of their children.

After parents had given these general views about paid work, DLA and carers' allowance, they were asked later in the interview to consider the hypothetical situation of loss of £50 per week income. It was at this point that some said they would need to make up the lost income and possibly think about getting some paid work. The women who said this had partners who did paid work and were currently choosing to be at home themselves, to focus on the needs of their family.

## 6.4 What were DLA and AA recipients' current feelings about their overall financial and personal circumstances?

Findings in this section are based on questions asked about people's overall financial situation, and their general sense of well-being (see topic guide question 6).

### 6.4.1 Adult DLA recipients

We remind readers here that in this study group, DLA recipients all had low out of work or retirement incomes. Generally, however, they summed up their overall financial circumstances in fairly positive terms. Both elderly people and people of working age described themselves using language such as '*comfortable enough*', '*not bad*', '*satisfied*', '*making it do*', '*no complaints*' or '*just enough*'. In making such assessments people made comparisons with other times in their lives, or the circumstances of their peers, and described being used to living on a low income, being careful and not wasteful, and having financial matters planned and under control. Some elderly people were grateful that they were not in financial hardship at this stage in their lives. DLA recipients who used fairly positive terms could generally describe items or activities they would like to be able to afford including a new car, better clothes and shoes, going more often to the theatre, buying a new sofa, having a trip to see family abroad, renewing the shed roof, or decorating a room. However, they did not generally identify things they needed badly but could not afford. A person who felt a wheelchair was now needed was planning to approach social services. Those things which people said would make a big difference to their lives such as having a car, or an automatic bed (priced at £2,000), or a major bathroom conversion seemed out of financial scope and people were resigned to managing without. The person who said being able to

afford driving lessons and a driving test would make a big difference to his life, through extending employment options, was not currently well enough either to drive or look for work.

Those DLA recipients who had a more negative slant on their current financial circumstances were all people of working age, with partners who did not have earnings and, in one case, with dependent children. A recent big drop in income, through having to give up work or having a benefit withdrawn had been hard to manage by some of these couples. This small group of people talked about themselves as *'just surviving'*, *'not satisfied at all'* and *'merely existing'*. Items needed that they could not afford included better shoes and clothes for children, a new washing machine, redecoration of rooms, more fuel, a new bed and a third rail in the bathroom (priced at £20). One family wanted to reduce and pay back loans. These couples said, variously, that being able to afford a mobility scooter, an automatic bed or a car would have made a big difference to their lives.

There was almost unanimous view among DLA recipients that feelings about their financial circumstances influenced their feelings about life in general, their morale, and ability to deal with their health condition, and for some their mental health. Those who described themselves as *'having a good life'* or feeling *'not bad at all'*, relating this to having a good family, good health care or having been in much worse circumstances in the past, were all people who had positive slants on their financial circumstances. Those who said that things were bad for them described severe health conditions, talked about limited life expectancy, or said they were deeply grieving a previous partner, and included some of those who had described financial circumstances in negative terms. People who looked forward hopefully to improvement in a severe mental health condition said that having their financial situation under control was a major factor in their prospects here.

#### **6.4.2 AA recipients**

The picture among AA recipients was very similar. Elderly people who described their current financial circumstances as *'excellent'* or *'very good'*, or said they *'were content'*, *'had no problems'* or *'had enough'* included single people and people with partners, and people on low incomes (as defined by receipt of Pension Credit) as well as people with higher incomes. It was common for such people to say they felt fortunate or lucky to be in such circumstances in old age, which they variously linked with having been careful with money, making plans for retirement, having supportive family or appreciating the government's financial support. Such people generally could not think of anything they needed badly but could not afford. Some mentioned things that would make a big difference to their lives, which they felt they could not afford including a portable nebuliser (priced at £700) and a major bathroom conversion (estimated to cost more than £8,000). In some cases, discussions about savings suggested that funds were available towards such items but if used would reduce amounts kept back for 'emergencies' and thus reduce feelings of security. Some liked the idea of being able to go on holiday if more money was available. Items people wanted and were saving towards were a new



fire surround and a repair to a garage door, but some elderly people found it hard to think how they would spend any extra money that came their way.

AA recipients who did not have quite such a positive view of financial circumstances and said they were *'just about getting by'* were single people living in residential care or warden assisted accommodation. Neither were aware that AA was in payment. They would have liked to be able to buy more 'extra' if more money was available for personal use, mentioning here clothes, a holiday, or trips to the theatre.

Elderly people who said they certainly *'were not satisfied'* or *'would have liked a better standard of living'* both lived with partners, and appeared to be disappointed with their current material standard of living despite both partners, in both couples, having done paid work beyond state retirement age. There was nothing they needed badly but could not afford, but both couples regretted being unable to afford now the kind of holiday they would have enjoyed.

As described for the DLA recipients, there were mixed feelings about life in general among AA recipients. Despite general frailty and ill-health some were keen to say how lucky they were, and emphasised positive aspects of life such as their family, or being able to get around. Some elderly people were grieving deeply for partners who had died recently, when interviewed. Others, whose partners had died some time ago also spoke of bereavement as having been a very bad time for them, but now feeling much better. Some said they generally tried to keep positive, but did have some low times when they were affected by pain, feelings of loneliness or isolation, or frustrated at not being able to do things for themselves. There were shared views that worrying about money made people feel worse and was bad for their health, and people who were satisfied with material standards of living felt grateful they were relieved of financial anxiety.

Among both DLA and AA recipients were people who said their religious belief or personal philosophy led them to try not to think about money but to be grateful for what they had and focus on more important parts of life. One elderly man said he was quite successful here – what he had not got he could not spend so he did not use up his time thinking about it. But other people found it harder, however, to put such principles into practice, especially young DLA recipients trying to establish homes, and maintain relationships and social networks.

### **6.4.3 Parents of children getting DLA**

Parents who felt *'quite happy'* or *'satisfied'* or said that, financially, things were fine included those with partners, where one or both had some paid work and a sole parent with earnings, but also a sole parent of a very young child, who relied on out of work benefits. Although such parents were generally satisfied with their material standard of living they could all think of things they could spend extra on – savings for future needs, buying large household items outright instead of using credit, better holidays, a new pram. Some identified things they felt they needed quite badly that they could not afford. Parents caring for a teenager and

looking to the future said they needed a larger and appropriately adapted house, and to be able to afford to pay for personal care as their child got older. A sole parent wanted her garden making more suitable for outdoor toys and equipment, which would benefit the child greatly. One couple very much wanted a car, and to be able to afford driving lessons and a test for the non-driving partner. They estimated current annual expenditure on taxis and public transport at £4,500, and having a car would cut these costs. A sole parent said her child needed a new bed, and several parents mentioned needing to spend money on their houses, such as replacing a roof.

Parents who were currently struggling financially or finding it *'hard to get by'* were people whose own health problems meant they were currently living on out of work benefits. Items needed which they could not afford included a bed for a child, rain cover for a buggy, and clothes and a replacement mobile phone for a teenager. Parents who said things *'could be better'* or they *'only just managed'* included people relying on out of work benefits. In one family, a teenager explained that two children in the family needed more communication aids for their sensory impairment, and none of the children could join in activities and outings run by their local multi-cultural group, because their mother could not afford this. There were also parents with professional earnings who said they were only just managing. In terms of actual incomes, they had more money than some of those parents who had said they were happy with their material standard of living. But some of their outgoings were higher (linked with home ownership, location, travel needs) and some prioritised their child's needs for additional therapy and tuition.

Interviewers were particularly careful in introducing discussion about feelings of general well-being to these parents. Some had already told us they were bereaved by death of their partner, or their own parent; dealing with a recent, and feared diagnosis for their child; dealing with recent breakdown of their relationship with their partner; and isolation through ethnicity. It was common for parents to describe themselves as very tired, but it was often inappropriate to probe more deeply. What we can say is that those parents who said that, generally, they were alright and their children happy, and they felt optimistic about the future, were parents who also described being satisfied or quite happy about their current financial circumstances. Those parents who said they currently felt highly stressed, were being treated by their GP for depression, and were receiving formal family support at home were all people who described themselves struggling financially.

## 6.5 What would happen if recipients had less money?

Asking adult DLA and AA recipients what would happen if their income was reduced by £50 each week (see topic guide question 6) led, in nearly all cases, to strongly negative reactions.

DLA recipients of working age generally said it would make a big difference; some thought they *'would not be able to live'*, *'couldn't manage'* or could not think how they could cope. People who could not cut down heating bills said fuel

bills would go into arrears, and others thought unpaid bills and credit card debt would mount. Some people would have to cut out the social activities that helped maintain their physical and mental health, and one young person said it would be even harder to look for work (without a phone, and his informal networks). The one person who had just got a job said the impact would depend on which source of income was cut. Thoughts were that if £50 went from wages, the loss would be manageable but any financial incentive from work would go; if £50 went from DLA and this reduced Housing Benefit (HB) (through loss of the premium) then rent could not be met.

DLA recipients over state retirement age and those AA recipients who engaged with this question also generally foresaw *'a massive effect'*; *'a major impact'*. Some talked about losing £50 a week as *'catastrophic'* or said they would be *'on our backsides'*. Elderly people in particular used strong language, saying it would affect them *'dreadfully'* or *'drastically'*; *'it would be a disaster'* or *'it would kill me'*. Two elderly people said that even thinking about the hypothetical loss was leading to feelings of panic. It was noticeably hard for elderly people to say what they would do. Nobody suggested they could cut down on the costs of getting around, and we have already seen how essential was getting out to do shopping, or get meals, and going to medical appointments.

Nobody suggested they could cut down on money spent on personal care, either formal payments or gifts to friends or relatives. Only one elderly person thought that help with housework would stop, leading to depression and a poor home environment for the young person who shared the home. Often, the only areas where elderly people saw some possibility for spending less was buying poorer quality food, or buying second hand clothes. There were a few suggestions of selling personal items to generate cash, or dipping into savings for everyday expenses. One elderly person said they just couldn't live and would have to get *'help from social security'*. Those elderly people who thought about what it would mean for them not to give presents to grandchildren, not to have the extra TV channels that were a main source of enjoyment at home, not go to 'Blind Club' or not be able to care so well for their companion animals said how much this would reduce their quality of life. People who smoked said they would try to cut down, but some with long smoking habits said they didn't think they would be successful here.

Those people over state retirement age who were exceptional in apparently not being so worried about a potential loss of £50 income each week were both people who had some savings and investments. By living even more carefully, and perhaps cutting down on cigarettes or spending on skin care, they thought the dip in income would be manageable.

When we asked parents of children getting DLA about the effect of this hypothetical drop in income there were strong negative reactions from those parents who had already described themselves as really struggling financially. They could not see how they would manage to pay fuel bills or clothes and shoes for the children; one parent said she would be unable to pay her rent. Other parents all said £50

less a week would certainly make a difference, and thought through how they would manage this. Cutting back on quality food was mentioned, as was trying to reduce fuel bills, or buying fewer clothes. All members of the family would be affected, as would happen if parents cut out some of their family outings and activities. One sole parent thought it might mean getting rid of her car, and some parents would have to cut holidays.

As described in Section 6.3, for two couples loss of £50 per week might mean that the parent currently at home to care for the disabled child and other children would have to reconsider this. They would prefer not to have to change the current pattern of one parent working full-time and one at home, but financial pressures might mean having to seek a second wage.

## 6.6 What difference did recipients think DLA or AA made for them?

There were some spontaneous comments, throughout the interviews, to the difference which DLA or AA made for people. By the end of the discussions people had talked in some detail about the effects on their lives of their health condition or impairment, their incomes and resources, how they spent money, and how they felt they were managing. It was from this context that they summed up what difference DLA or AA made for them, when invited to return to this topic right at the end of the interview.

### 6.6.1 DLA and AA recipients

DLA recipients of working age were unanimous in expressing views that DLA made a big difference to their lives. Some used strong language, explaining that DLA '*enables me to live*', or saying that having DLA kept a roof over their head, or made the difference between being in debt and being able to survive. Without DLA, some said they '*wouldn't survive*', '*would struggle*' or would be '*in dire straits*'. Some said that without the benefit they would not be able to get the help they needed or pay their bills, and would have to ask relatives for loans. DLA recipients who were parents said their children's lives would be affected, for example when it was harder to replace their shoes. Those people who said they would not be able to get around without their DLA, or use taxis for urgent journeys included people getting the mobility component. Such views were expressed by people receiving the lower rates of DLA and people getting the highest possible awards. It is important to remember that all the DLA recipients in this study group were people who had been living for some time on low out-of-work incomes.

In their summing up of the difference DLA made, some people returned to the difference made to their psychological well-being of knowing that DLA was coming in, saying again that they felt more secure, felt they had a safety net (especially during changes in circumstances), or felt that the money enabled them to do things that encouraged them to go on.

When interviewed, one young person was currently awaiting the results of a recent DLA review. This was a time of anxiety, in case of reduction from the high award that enhanced independence and quality of life. Another young person knew a review was due in a few months, and had mixed feelings. On the one hand, it would be nice to have a medical assessment that reflected '*being better*'; on the other hand, if the move to paid work turned out not to be successful, life would be financially hard again, with effects on mental health. One other person remarked on the negative psychological impact that came through the association of the benefit with 'disability', and how much they would prefer to be able to get out and work and not be 'disabled'. Given the circumstances, however, and being unable to do paid work, DLA was a great help financially.

Among DLA recipients over pension age and AA recipients were elderly people who also used strong language about the difference their benefit made. Elderly DLA recipients talked about '*a world of difference*', '*a terrific difference*' and the '*difference between poverty and a reasonable standard of living*'. AA recipients who engaged with this discussion generally said AA made a '*great difference*' or '*all the difference in the world*'. Some said they could not do without AA, or said that without AA they could not afford the help they had, could not afford chiropody, keeping their home clean or the level of warmth they needed in the house. Elderly DLA recipients who expressed such strong views all appeared to be claiming Pension Credit, and £49.10 or £67.75 DLA weekly.

AA recipients who said they felt like this appeared to be claiming lower or higher AA (£47.10 or £70.35), and included some who were claiming Pension Credit, as well as people with occupational pensions or survivors' pensions and benefits, who appeared not to be receiving Pension Credit (although we did not have full details of income from all these AA recipients). One couple felt that getting AA had changed their lives, giving them access to Pension Credit and housing benefits. An observation that although AA made a lot of difference, it was not high enough, came from a couple who both received AA but still could not afford to run a car that would make so much difference to their lives.

The only person in this study who was over state retirement age, engaged with the issue of what difference DLA made and did not have a firm view was a long-term recipient, used to integrating DLA in her general budgeting, and currently feeling fairly comfortable financially.

Findings from this study do not enable us to say more about any patterns there might be between levels of income of elderly DLA and AA recipients, amounts of benefit in payment, and views on what difference the benefit was making. This is because we do not have full income details, particularly among those elderly people who may have had the higher incomes; we do not have full details of awards, and some elderly people were unaware that they received AA.

### 6.6.2 Parents of children getting DLA

All the parents in this study said that their child's DLA made a definite positive difference to their family. The couple who said they could not manage without the DLA which boosted Income Support by £47.10 weekly had previously talked about struggling financially. Parents with higher incomes talked about DLA making '*a dramatic positive difference*' or '*a really big difference*'. Included were parents with and without partners, with and without earnings, and parents with younger children as well as parents of teenagers. They talked, variously, about DLA enabling their whole family to have good food, have a more 'normal' life, and go on holiday. DLA, parents said, enabled their disabled child have extra tuition and therapy, go swimming, go away to camp and holidays, take part in activities, have suitable toys and equipment, and have clothes and shoes that did not identify them as 'different' among their friends, all of which enhanced their child's quality of life, boosted morale and confidence and stimulated development. For one parent, knowing there was a specific stream of money for their child enabled her to experiment in trying to find a toy or activity that engaged the child – she would not have spent money in this way without DLA, but had found toys that worked by being able to bring them home. Having DLA, some parents said, made their own lives easier and less stressful, took away some of their financial concerns, gave some peace of mind, encouraged them in their care and, for some parents whose partner was the only or main breadwinner, made the difference between having to go out to do paid work themselves and being able to make choices about paid work which suited their family situation.

## 6.7 Summary

Adult recipients of DLA perceived entitlement to the benefit to be related to effects of long-term medical conditions and the need for help or care, or as a general boost to income for people who had problems related to their condition. There was some dislike of being categorised under a label of 'disability'. AA recipients also perceived their benefit as related to a need for help or care, but there was evidence of some non-take-up due to earlier belief that entitlement depended on having somebody 'in attendance'. We saw no evidence of people claiming DLA before the age of 65 in order to access a mobility component, although there was some knowledge among both sub-groups of this potential incentive, and some perceptions of inequities here.

Parents of child recipients also related entitlement of DLA to their child's medical condition, and the extra and additional expenses this involved. Some saw a wider purpose in the benefit, enhancing family life generally, taking pressure off parents, compensating for additional burdens and replacing lost earnings.

Adult recipients of DLA and AA used these benefits to enable spending on charges in residential and warden assisted accommodation; personal care; transport; food; fuel; maintaining a home; medical equipment and supplies; telephones and computers, social activities and savings. Parents also used their child's DLA to enable spending on such items. They gave special mention to spending on food, clothes and shoes for the child, treatment and tuition, toys, equipment and social activities, and explained that having DLA affected budgeting for the whole family.

Across the study group, additional roles were perceived for DLA and AA. These included helping practical money management; enabling access to passport benefits and other financial opportunities; acting as a safety net; helping debt management; enabling people to stay at home; keeping people in touch with family and friends; keeping people in society; acknowledgement of personal circumstances, and a factor in thinking about paid work.

There was a spectrum of feelings about financial circumstances, and feelings about life in general, in all sub-groups, but general agreement that these were linked.

There was concern and strong negative reactions to the idea of having less income (a hypothetical £50 per week), particularly among adult DLA and AA recipients. Across the whole study group, DLA and AA were generally perceived as making a big, positive difference to people's lives, and the family life of child recipients.





## 7 Implications for policy and research

In this final chapter we look at the implications of findings for a possible quantitative evaluation in the future of the impact of Disability Living Allowance (DLA) and Attendance Allowance (AA) on recipients and their families. It draws on the 45 qualitative interviews with recipients of DLA and AA, on the preparatory group interviews with benefit professionals and advisers, and the desk-based review of existing survey instruments.

To recap, the dual aims of the study were:

- to contribute to greater understanding of the use and impact of DLA and AA, and increase understanding of the *difference* made to people's lives by receipt of DLA or AA;
- to contribute towards development of questions that might be used in existing or new surveys of disabled people.

We can think of the first aim as essentially *substantive* and the second as *methodological* but they are linked in that what we can say about methodological development is informed by the substantive findings. In this chapter we begin, in Section 7.1, by summarising the substantive findings about the impact of DLA and AA on people's lives, drawing mainly on the analysis in Chapter 6. The picture we will draw is a complex one of interrelationships between receipt of DLA or AA, the way people make decisions about what they can afford and how they need to spend money, and a range of impacts. We have also learned much from this study about how we need to ask questions about the lives of DLA and AA recipients in order to tease out the impacts of getting the benefits. We have summarised the lessons we need to take forward here in Section 7.2. The overall implications from the study for the future measurement of the impacts of DLA and AA are presented in Section 7.3.

We should point out at this stage however that, although we carried out 45 interviews with a diverse range of DLA and AA recipients, our study group was not comprehensive in coverage. We are aware that there were few people in the

overall study group among higher income groups, and few DLA recipients in paid work. Others groups also possibly under-represented include:

- People in residential care and nursing homes.
- People with dementia.
- Adults with learning difficulties.
- People with specific impairments (such as deafness).
- Minority ethnic groups.
- People with terminal illness.

Some of these gaps are likely to be related to relatively high rates of 'opting-out' to initial invitations to take part. They are also related to problems in recruiting people, once contacted, and the discretionary decisions made by researchers not to pursue some interviews, for example when issues of confidentiality arose in recruiting through third parties and when there were major problems in communication with confused elderly people. These gaps do not undermine the findings presented in earlier chapters but they will need to be addressed in any further survey or qualitative work.

As we explained in Chapter 1, the study was commissioned in response to the paper by Berthoud (2009) in which he suggested that qualitative research should be carried out 'to find out, in an open way, how people think about the subject matter (i.e. the use and impact of DLA or AA)'. From there he envisaged that question sequences and wording could be developed and tested to inform a possible large scale survey later (reflected in the second aim noted above). We explain in Section 7.3 how far we feel able, from this study, to contribute to the development of survey questions.

## 7.1 Summary of substantive findings about impact

As we explained in Chapter 5 it was possible to identify in many of the interviews how DLA and AA were linked to different types of expenditure and different kinds of spending behaviour. Sometimes this was possible through a fairly direct line of questioning, with people who said they did separate and use their benefit for certain items, and when people said they knew what having DLA or AA enabled them to afford. More often, however, the picture for individual people had to be built up in a number of ways, including asking for evidence about the way people could afford to meet the costs of extra needs related to their health conditions or disabilities.

### 7.1.1 Money management

An important set of findings are about how people think about and use DLA and AA. So, from the data we know that there were two principal ways in which people could explain how they used their benefit. Some said that they separated

out and used their benefit for something in particular (sometimes but not always linked to extra needs). Others used it as part of their general money management, for example arranging dates for direct debits for fuel from their bank accounts to match dates of payment of DLA and AA into *their* accounts. However, most people said they treated their DLA or AA like other sources of income going to the 'general pot' of their household budget from which all spending was made. Although such people did not actually allocate DLA or AA specifically, they often had a mental picture of what having the benefit enabled them to afford. Hence people's approach to money management is crucial in understanding the connection between receipt of DLA or AA and how they talked about impacts.

### **7.1.2 Spending**

In Table 7.1 we summarise the main general patterns of expenditures that people in this study group mentioned in the research interviews. We have grouped adult DLA recipients and AA recipients together in the table because of the similarities in the response from the two groups (one-third of the adult DLA sub-group were over 65 years, and thus overlapped the AA recipient group). In Table 7.1 we see that while there were some common types of expenditure, there were important differences between adult recipients (DLA and AA) and parents of child recipients. Families were not generally spending DLA on residential care or personal care since most care was provided by parents in the home, but they did spend money on child-centred items such as toys and activities; treatment and tuition; and they spent extra money on clothes and shoes for children. For many adult recipients, particularly older people, being able to spend on presents and gifts to acknowledge support and help was highly important to their sense of reciprocity and dignity. Younger adults also explained that without spending on 'treating' their friends on outings they would not be able to take part in such activities, because their participation depended on being able to go with friends.

There was evidence that how people spent their DLA or AA was influenced by views about the purpose of the benefits and perceptions about what they could or should be spending them on. Some of these views were informed by what people had been told by advisers when they had first learned about DLA or AA.

**Table 7.1** Types of disability-related spending mentioned in interviews

Type of expenditure	DLA adults and AA	DLA children
Residential care	✓	
Personal care at home	✓	
Transport	✓	✓
Food	✓	✓
Fuel	✓	✓
Home maintenance/cleaning/gardening	✓	
Medical supplies/equipment	✓	✓
Telephones/computers	✓	✓
Social activities	✓	
Clothes and bedding		✓
Treatment/tuition		✓
Activities/toys		✓
Giving presents, gifts and 'treating'	✓	

Table 7.1 is useful in giving a general overview of how DLA and AA were meeting costs related to impairment and poor health. It is important to remember the difference here between spending DLA or AA, and being able to spend as a result of having DLA or AA. We mentioned this in Section 7.1.1 and give some further examples here. A few people actually put aside their benefit for a particular item of spending such as a family holiday – their DLA or AA was actually being used for this purpose. More common was to take DLA or AA into account when making spending decisions, with 'notional ear-marking', for example planning journeys that involved a taxi on the basis that a taxi ride could be afforded because DLA or AA was being paid.

We can see now how any future survey of DLA and AA would need to capture data on all these types of expenditure, and different ways of allocating and using the money. Our findings showed how it was possible for people to know what having DLA or AA enabled them to afford without remembering how much benefit was being paid.

### 7.1.3 Impacts

Apart from data on spending, the interviews also revealed a number of other roles that DLA and AA played in people's lives. These included:

- Helping money management.
- Providing a financial safety net.
- Helping debt management.
- Enabling people to live at home.

- Enabling people to keep in touch with family/friends.
- Keeping part of society/social inclusion.
- Acknowledgement/legitimation of condition.
- Enabling paid work.

A different way of thinking about the impact of DLA and AA is *preventive*. Findings showed preventive roles in:

- avoiding moves into residential care or nursing homes;
- avoiding deterioration in health;
- making fewer demands on formal health and social care services.

When people talked about being able to afford things that enabled them to stay in their own homes, they were implicitly or explicitly referring to the alternative – having to go into residential care. Similarly spending on items like chiropody, and medical supplies and equipment was preventing deterioration in health, or stabilising their condition. Spending on getting meals outside the home was effectively reducing potential demand for formal social services meals provision. We would argue that this preventive role is an important impact of DLA and AA that policy makers need to consider.

Also important was the way in which parents of child recipients were using DLA in ways that would enhance their child's *future life chances* and opportunities. They were paying for tuition, physiotherapy, speech and language therapy, and buying equipment to encourage learning and stimulate response, all with a view to the child's future development.

#### **7.1.4 Contributory factors to impacts other than spending**

In the last two subsections we have set out the types of spending that people in the study talked about and the difference that such spending made to their lives. However, it is also important to note that from people's accounts in this study that it was not only spending which contributed to these impacts. There were a range of other contributory factors, including:

- Social networks.
- Help from family, friends and neighbours.
- Services supplied through local authorities, health services, or voluntary organisations.

From this summary of the substantive findings from the study we can see that there is evidence to support each of Berthoud's interpretations of the aims of DLA and AA, set out in Chapter 1. There are clearly many examples of the benefits supporting additional expenditure, improving specific outcomes, compensating for additional expenditure on 'normal' household items, and countering the effects

of disability. Before we explore the implications of these findings for measuring the impact of DLA and AA we summarise a different set of relevant findings, i.e. about the various ways we used in the qualitative interviews to encourage people to talk about DLA and AA and the difference that these benefits made.

## 7.2 Lessons from the approach to enquiry used in the study

It is clear from the findings presented in Chapters 3 to 6 is that identifying the impact of DLA and AA is far from simple. How DLA and AA affect people's lives is sometimes direct, immediate and easily identifiable, but we have seen from this qualitative and exploratory study that for many people the effects are more subtle, intricate and variable. But in using the techniques of in-depth interviewing and a topic guide designed to collect data in different ways we have shown that it is possible to uncover the subtleties of the connection between DLA and AA and impacts. Particularly important is the finding of the importance to people of the *enabling* and *preventive* roles of these benefits, and the roles perceived by parents in enhancing their child's future life chances.

Our experiences of conducting the interviews have raised some issues and challenges relevant to possible survey work in the future. These include:

- It was often not possible to identify all the sources of income, particularly among elderly DLA and AA recipients. Indeed, some AA recipients (identified as such from the DWP database) were unaware of receipt of this benefit.
- It is important to remember that DLA and AA recipients often live in households and families such that partners budget together, and parents budget for the whole family. There are effects of benefit receipt on partners and other children. Quality of life of a partner may be as important as quality of life of the DLA/AA recipient particularly if the partner is the principal carer; or if parents' relationships are to be sustained.
- Questions about *using* DLA and AA were rendered effectively meaningless for people who did not know how much benefit they received or did not earmark the benefits for particular disability-related expenditures, but added their benefit income to the 'general household pot'.
- The language used in the interviews was that of 'the difference made' by the benefits, and the 'effects' rather than the 'impact'. Interviewers rarely used the word 'impact', and people did not talk in this way spontaneously. We do not know how people would generally respond to a question using the word 'impact'.
- Findings suggest that the difference made by the benefits may be partly related to the length of award, changing over time. For example, an initial award or back payment that enabled the immediate reduction of a debt or purchase of a large household item was perceived to have a different effect from that of becoming used to regular payments that became part of the 'general pot'.

The implications of these findings appear to be that a survey that asks direct questions about the *use* and *impact* of DLA and AA would effectively exclude some recipients (particularly older claimants of both DLA and AA) and fail to capture the full impact of the benefits. A language of 'difference made' and 'enabling people to afford' would be likely to generate better data.

With any qualitative enquiry that uses hypothetical questions to generate data we must always acknowledge that responses cannot be equated with real experiences. However, in this study, our attempts to tease out people's views on the difference made by DLA and AA included a variety of approaches (direct and indirect questioning, probing, returning to the topic at various points in the interview, and hypothetical scenarios). We therefore have reason to be confident that we have achieved high levels of reliability and validity in the data. This is not to argue that the qualitative approach taken in this study is the sole, or even the best, method of assessing 'difference made' or to suggest that further survey work is not desirable. On such a complex topic the use of multiple methods will always be advisable.

### 7.3 The future measurement of the impact of DLA and AA

The qualitative method of enquiry used in this study has uncovered a highly complex, though sometimes incomplete, picture of the relationship between the receipt of DLA and AA and how people live their lives, which adds to the understanding generated in previous studies (such as Hawkins *et al.*, 2007; Age Concern 2008). What we can say at this point therefore is that in order for a survey to cover this complexity it would have to contain sections (or domains) on the following:

- Sources of household income.
- Personal and household characteristics.
- Practical money management.
- Spending.
- Impacts/difference made.
- Other factors contributing to impacts.

In the rest of this section we address a number of issues that have a bearing on how research on the impact of DLA and AA could, or should, be pursued in the future.

### 7.3.1 The potential of using 'quality of life' as a composite indicator of impact

We raise this as a relevant issue for two reasons. Firstly, the way people spoke about their lives and DLA and AA was often couched in very general, or overarching, terms rather than referring to the types of impacts we have been discussing so far. So, for example, people talked about being '*content*' or '*having a good life*'. Secondly, some studies have adopted measures of quality of life (or well being) as being appropriate measures of social policy interventions.

One such measure that would appear worth consideration, at least for adult recipients of DLA and AA, is the CASP-19 measure of quality of life. The approach to measuring quality of life using CASP-19 is to ask people to respond to 19 statements organised under four categories – control, autonomy, self-realisation and pleasure. (Appendix D lists the statements in full, and explains how they are scored to give an overall measure of quality of life.)

### 7.3.2 The counterfactual

We know from this and other studies that there are additional costs associated with disability, that people value and appreciate DLA and AA, and that people say they would lead different lives (usually impoverished in same way) without it. It seems likely that we do not need further evidence to confirm this. The question is now whether it is possible to put a figure on the *difference* that DLA and AA make to people's lives. The answer lies, as Berthoud has explained, in whether the *counterfactual* can be measured:

*If we want to know what difference DLA or AA has made to disabled people and their families, it is important to measure not only what their position is now, with the benefit, but also to estimate what that position would have been in some alternative circumstances, without the benefit. This alternative is often known as the 'counterfactual'.*

(Berthoud, 2009: 23)

Berthoud gives a full consideration to this question in his review and identifies six ways in which getting a measure of the counterfactual can be attempted, of which only two in his assessment are in any way feasible as possible ways forward for measuring impact of DLA and AA. His first method is for exploiting 'cross-sectional comparisons, controlling for disability characteristics', i.e. comparing the spending patterns and lifestyles of DLA and AA recipients with a comparison group of the population with very similar patterns of impairment (2009: 23). The second possibility raised by Berthoud as promising would be a 'before and after' study of people before they make a claim for DLA or AA and sometime after a successful claim.

We cannot contribute to resolving the question of whether either of these approaches is the most useful. But a discussion of the counterfactual does raise an important question that does have a bearing on any future survey design. The question can be simply stated:



*In wanting to know about the impact of DLA and AA how important is it to know the processes by which impacts occur?*

If we think about the range of impacts that this study has identified, or about an overarching measure such as quality of life, and want to measure them, then we do not necessarily need data on the intermediary processes and decisions that contribute to those impacts. So, if we look at the list of domains of questions in Section 7.3 above there is a case for arguing that data on money management, and on spending, becomes irrelevant. If we take two samples, of DLA and AA recipients and a comparable sample of non-recipients and measure objective data (sources of income, personal and household characteristics, and those 'other factors' that contribute to impacts) then we could estimate the counterfactual. There would be no need to broach the difficult topics of how people understand the benefits and how they allocate them in their household budgets. Nor would data on spending be necessary.

This approach has the additional advantage of not relying on people knowing their rate of benefit or whether they were getting benefit at all. No-one need be excluded from such a survey (not for this reason at least). So to recap: the core principle in measuring impact in this way is to collect data on inputs/resources and data on impacts from comparable populations of claimants and non-claimants and to perform appropriate statistical analyses to isolate the effects of receiving DLA or AA. The limitation of this is that while it would produce measures of statistical correlations between DLA and AA and impact, it would not generate explanatory data about how or in what way the benefits contribute to impacts. However, this may not be a drawback given the amount of survey and qualitative data that has been produced in recent years on how people view and spend DLA and AA (including this current study, but also Hawkins *et al.*, 2007; Age Concern, 2008). There is an existing and growing body of knowledge to help us understand the mechanisms by which people use benefit income to achieve desired impacts.

So, an approach to measuring the counterfactual which does not rely on asking survey respondents any direct questions about DLA or AA seems at least feasible. It might also lead us to thinking that existing surveys might do a good enough job here. However, this question is outside the remit of this study, but the ongoing work by the Policy Studies Institute (mentioned in Chapter 1) will go some way to answering it.

### **7.3.3 Do information requirements go beyond the counterfactual?**

Having set out a rationale for measuring the impact of DLA and AA without asking questions about the benefits, we now consider whether there is a policy need for more information beyond the counterfactual.

One conclusion we could make on the basis of this study is that a survey that tried to explore the kind of complexity we have identified in how DLA and AA are thought about and used may be difficult to the point of being unfeasible.

In contrast, a survey that worked on inputs and impacts only could provide an answer to one of the principal policy questions – what *difference* do the benefits make?

However, while it is possible that such an approach would yield robust statistical findings on overall impacts it might not satisfy the information requirements of all users. For example, analysis that demonstrated impact on one or more indicators such as social inclusion or well being but failed to generate information about what people spend their DLA and AA on might not be sufficient for people for whom such data would be useful.

### **7.3.4 Setting out the options for future research**

So far we have summarised the substantive findings from the interviews with DLA and AA recipients, and the lessons learned about how to ask question about the benefits, and we have raised a number of issues that have a bearing on how research strategy might develop. We now set out what we see are the main options.

Firstly, though we make three main points that have a bearing on future research direction:

- Measuring impacts of DLA and AA does not require asking questions about the use of the benefits.
- Process questions would provide a fuller understanding of the role of DLA and AA in people's lives.
- There are significant differences between the needs and experiences of adult benefit recipients (of DLA and AA) and parents of child recipients of DLA.

The two main options are therefore to design a survey based on inputs and impacts only, or to design a survey that includes questions about how DLA and AA are perceived and used. We set out the options in this way – rather than positing a choice between a setting up a new survey and adapting an existing survey – because taking the first option would not require constructing questions about DLA and AA while the latter option would definitely require a suite of questions that does not currently exist. And regardless of which approach was taken there would be a need for customised questions for the parents or carers of child DLA recipients. We should also point out here the potential of further qualitative work for reaching particular groups such as people with learning difficulties, or in residential care, or people from minority ethnic groups.

Our view is that a decision needs to be taken about what the information needs of policy makers are going to be in the next few years. If all that is required is to know whether DLA and AA make quantifiable difference to people's lives (on the range of impacts discussed, and/or on a quality of life measure) then the task of devising question sequences and wordings will not be needed. If greater understanding of the mechanisms and processes by DLA and AA affect lives is required then that task will be crucial.

### 7.3.5 Question sequencing and wording

Although in Berthoud's review there is the suggestion that this early qualitative work might lead quickly to cognitive testing of questions about the impacts of DLA and AA, there are a number of reasons we feel it is inappropriate at this stage to make suggestions for wording individual questions, principally because there are a number of policy decisions that probably need to be taken before we reach this stage, most importantly whether a survey should be undertaken at all.<sup>17</sup>

At this stage therefore we feel the principal contribution that this study can make to thinking about future survey work on DLA and AA is to identify the topics that we have found to be relevant to people's lives and how these might fit into the structure of a survey. The findings from this study would however have more to contribute to individual question wordings, should the decision be taken to proceed to with a survey.

As discussed above there appear to be two main options for thinking about measuring impact: to collect data on inputs and impacts only, and to collect additional data on how people think about and use DLA and AA.

We will consider these in turn, but we must also remember the findings from the analysis of how people responded to questions in the qualitative interviews. If a survey of AA recipients were to undertaken it is likely that many people, particularly the very old and those with cognitive impairments, would be either unable to participate themselves. These people are the most likely either to be in residential care or be receiving care packages at home. Also many are likely to have limited, and sometimes, no understanding of receiving benefits. There would therefore need to be extensive use of proxy respondents. Otherwise a survey would be likely to under-represent care users and underestimate the use of DLA and AA in paying for care.

---

<sup>17</sup> Question wordings also depend on the resources available for a survey, for example the extent to which they allow for the extensive use of open questions rather than closed, pre-coded questions. Open questions are more expensive as they require more interviewer time and time for post-coding later. For a future survey on DLA and AA that aims to uncover the complexity of people's thinking and use of the benefits, there is a case for using open questions more frequently than perhaps is usual. It is interesting that in the current study by Thomas and Griffiths (2010, forthcoming) survey questions about the use of DLA are all open-ended.

### *A focused survey of inputs and impacts*

Some of the inputs that affect the impacts of DLA and AA are familiar from a range of social surveys. Any future survey will need to include question sets on these:

- Household and family composition.
- Household income, including benefits.
- Health and disability.

There are already examples of question wordings in existing surveys and there is no evidence from this study that they would be in any way inappropriate or inadequate for a survey of DLA and AA impacts. We do not propose therefore to make any suggestions for alternative approaches here.

Turning now to the impacts that a survey would need to address, we have identified a wide range of impacts from analysis of the interview data. These include:

- Physical and mental health.
- Sense of security.
- Financial well being/security.
- Material deprivation.
- Adequate personal care.
- Mobility.
- Independent living.
- Development and learning for children.
- Social integration.
- Family life.

These impacts are not of course necessarily independent of each other. Enhanced mobility can mean people can get to shops, cafes or clubs which promotes social integration for example. And a sense of financial security can contribute to good mental health. However, they are conceptually distinct in a way that would allow a set of questions to be asked about them. Again, some existing surveys have suites of questions that address some of these impacts. In addition we have already raised the idea of using an overarching measure of quality of life that could be used in addition to (or even in place of) measuring individual impacts.

### *A more comprehensive approach*

If policy makers' information requirements extend beyond only inputs and impacts then additional sets of questions would be required on spending and savings, but also on what we have identified as 'other contributory factors' that also influence impacts (in some cases by substituting free goods and services for spending). So

to summarise, data would be required on:

- spending;
- savings;
- other contributory factors, including:
  - social networks;
  - help from family, friends and neighbours;
  - services supplied through local authorities, health services, or voluntary organisations.

## 7.4 Final reflections for developing policy

Although this study was driven by methodological needs we have been able to generate a large amount of substantive empirical findings as part of the process. We have therefore added a greater depth to other recent research studies on the use and impact of DLA and AA and the difference they make to people's lives. These findings have perhaps assumed greater salience over the course of the project given the ongoing and developing debate about future funding of social care.<sup>18</sup> Ironically, where the greatest policy need is - on AA - the greatest problems lie in doing a survey.

The driver behind the Berthoud review and this study has been the desire to know what difference DLA and AA make to people's lives. It is not to measure the living standards or the material deprivation of DLA and AA recipients against some standard, such as a poverty line or other threshold. However, this might be a useful way of thinking for the future.

It is outside the scope of this study to make any assessment or recommendations about whether any existing survey could in some way contribute to, or be used as the basis, for a survey of DLA and AA recipients, but from our scrutiny of relevant surveys we agree with Berthoud that '*none of the existing data sets has the detailed questionnaire coverage on disability and outcomes required for the wide-ranging evaluation of benefit impact*' ... (2009: 35). It seems therefore that a comprehensive understanding of the impacts of DLA and AA would require a large dedicated survey instrument covering each of the domains discussed.

We make one final observation. The second, methodological, research aim for this study was 'to contribute towards development of questions that might be used in existing or new surveys of disabled people'. It would be possible from the findings of the study to begin to suggest how questions might be sequenced or framed

---

<sup>18</sup> See Department of Health Green Paper (2009) *Shaping the Future of Care Together*. More recently the future of disability benefits for older people was the subject of a House of Commons debate on 9 December 2009 (Hansard col 154ff.).

in a future survey or development of an existing survey. However, there is also value in reflecting on whether such a development in future would be justified. Berthoud makes a similar point in his review (2009: 36) when he recommends that secondary analysis of existing data be carried out before any decisions are taken about future strategy. (As mentioned earlier in the chapter, at the time of writing this secondary analysis is being carried out by the Policy Studies Institute.) In talking prospectively about secondary analysis he reflects:

*It might even lead to the conclusion that the new survey should not be undertaken after all (either because the research questions had already been answered adequately, or because the questions seemed unanswerable).*

One of the main lessons from this study is that Berthoud's observation would repay serious thought.

# Appendix A

## Discussions with people who advise potential recipients of DLA and AA: Research methods

This appendix is a short summary of a more detailed account published in a methodological working paper 'Appendices to The impact of Disability Living Allowance (DLA) and Attendance Allowance (AA) – findings from exploratory qualitative research', available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf) covering recruitment to six small discussion groups, use of a topic guide to moderate discussion, and approach to analysis of data.

### A.1 Recruitment of participants

With help from DWP research managers, and using our own research networks, we invited staff in public sector and voluntary organisations in touch with DLA and AA recipients and their families to join small discussion groups. We chose areas for recruitment in the north of England and London in which there were likely to be sufficient pools of potential participants, all with relatively easy access to central venues.

We conducted six group discussions during the period 27 January - 2 April 2009, and one telephone interview with a person unable to come to a group. Twenty-four people took part including:

- DWP staff who worked on the DLA/AA telephone help-line, and in the central administrative office for Carer's Allowance.

- Team leaders and customer liaison officers based in six local offices of Pension, Disability and Carers Service (PDCS), some working mainly with pensions and benefits for people of state retirement age, but some also working with families with disabled children.
- Local authority staff from adult services, including benefits advisers and trainers; social workers in teams serving elderly people, people with physical impairments, and people with sensory impairments; and visiting officers dealing with financial assessment for home care charges. Staff from seven different local authorities took part, in two discussion groups.
- Staff working in general advice offices (local authority and independent offices in central city locations), giving both generic advice and with particular expertise in health related matters.
- People working in voluntary organisations supporting people and families dealing with mental health conditions, including paid staff and a volunteer with personal experience as a 'carer'.

## A.2 Conduct of meetings

The discussions were facilitated by the researchers, using a simple topic guide (Appendix C) to guide discussion across the areas of interest:

- Occasions and circumstances in which participants talked about DLA or AA to people using their services and their families.
- What kinds of things people wanted to know about DLA and AA, and what interested them.
- Views about why some people claim and some do not.
- Views about the purpose and use of the benefits.

Discussions generally lasted one and a half hours. Contributions from everybody who took part generated valuable findings and useful new perspectives, and the researchers are grateful for people's interest and the time they spent.

## A.3 Data extraction and analysis

Recordings of discussions were transcribed professionally. The main researcher handled the data extraction and analysis. After reading all transcripts carefully and marking up issues arising, data were extracted manually under thematic headings. We looked for areas of general agreement; areas where people had different ideas or took different approaches, and areas in which people said they were sometimes uncertain about the approach they should or might take when talking to people about DLA and AA. Other material included in the analysis included notes from a telephone interview, and a short written submission, from two people who had been unable to get to group discussions.



# Appendix B

## Qualitative interviews with recipients of DLA and AA, and parents of children in receipt of DLA: Research methods

This appendix is a short summary of a more detailed account published in the methodological working paper 'Appendices to The impact of Disability Living Allowance and Attendance Allowance – findings from exploratory qualitative research', available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf), and covers recruitment of the study group; topic guides used in interviews; conduct of the interviews, the approach to analysis of data from 45 qualitative interviews, and some characteristics of people in the study group.

### B.1 Recruitment to the study group

The aim was achieved in conducting interviews with 15 recipients of Attendance Allowance (AA), 15 adult recipients of Disability Living Allowance (DLA), and 15 parents or carers of children in receipt of DLA. The study group was drawn among people living in three locations, in England, Scotland and Wales.

Names, addresses and telephone numbers from the disability benefits database were passed to the Social Policy Research Unit by research managers in the Department for Work and Pensions (DWP). The researchers sent letters describing the research and inviting participation, using an 'opt-out' approach to adult recipients and an 'opt-in' approach to parents.

Exploration of recruitment approaches and response was an important component of this study, and is discussed in full in the working paper 'Appendices

to The impact of Disability Living Allowance and Attendance Allowance – findings from exploratory qualitative research’, available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf)

## B.2 Developing the topic guide

A ‘family’ of topic guides was designed to facilitate discussion both to seek substantive qualitative information about how people used the benefits, and what difference they made, and to explore appropriate ways of getting such data. This is fully discussed in Chapter 3. The first interviews conducted by each of the three interviewers served as pilots for the topic guides, with debriefing and discussion within the team.

## B.3 Conducting interviews

Three members of the research team shared the fieldwork. Most interviews took place in people’s homes, including some residential care and sheltered accommodation settings, and generally took around one hour or a bit longer. Adult benefit recipients who had partners who were at home during the daytime generally chose to take part with their partner. The parents of children in receipt of DLA who took part in interviews were generally mothers. Overall, the researchers met nine of the children in receipt of DLA. The researchers asked for some reflection on the interviews, before leaving people, and there were no negative comments.

## B.4 Data extraction, display and analysis

The recordings from the interviews and the dictated accounts were transcribed professionally. Data were extracted from the transcripts, alongside any additional notes made by the researchers during or after the interviews. The ‘Framework’ method was used for data extraction, display and analysis. Framework is a matrix based method for ordering and synthesising qualitative data, originally developed during the 1980s by the National Centre for Social Research. Ritchie *et al.* (2003) provide a full explanation of the Framework approach currently widely used by qualitative researchers.

## B.5 Characteristics of people in the study group

Thirty adult recipients of DLA and AA took part in interviews, and parents of 15 children who received DLA.

## Age and gender

**Table B.1 Age and sex of people in study group**

<b>Recipients of DLA</b>		
Age group	Men	Women
Under 30 years	1	1
30-39 years	1	1
40-49 years	1	1
50-59 years	1	-
60-64 years	3	-
65-69 years	-	2
70- 78 years	3	-
<b>Recipients of AA</b>		
Age group	Men	Women
65-69 years	1	1
70-79 years	2	3
80-89 years	1	6
90 years	-	1
<b>Child recipients of DLA</b>		
Age group	Boys	Girls
2-4 years	3	1
5-9 years	2	1
10-12 years	2	1
13-15 years	2	3

Most adult recipients in the study group had done paid work at some stage. Most of the children over five years old went to mainstream schools, where some were in units or classes for children with special needs, or in mainstream classes with teaching assistance, and most lived in families in which one or both parents did some paid work. Most adult recipients described a number of chronic illnesses, severe impairments, acute relapsing mental health conditions, or increasing frailty and debilitation due to ageing. Children’s special needs arose, variously, from autism or Asperger’s; general developmental delay; chromosomal abnormality; learning difficulties; hearing impairment; cerebral palsy; epilepsy; severe asthma; hemiplegia; blood abnormalities; impaired speech and language; ADHD; behaviour problems and Tourettes. Again, it was not unusual for parents to describe their child having needs related to several such conditions.



# Appendix C

## Research instruments

Here we present the topic guides used in discussions with advisers, and in the interviews with Disability Living Allowance (DLA) and Attendance Allowance (AA) recipients and parents of children receiving DLA. Other research instruments, including copies of invitation letters and consent forms, may be seen in the separate methodological working paper 'Appendices to The impact of Disability Living Allowance and Attendance Allowance – findings from exploratory qualitative research', available to download at [www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf](http://www.york.ac.uk/inst/spru/pubs/pdf/dlaAppendices.pdf).

### What difference do Disability Living Allowance and Attendance Allowance make?

#### **Topic guide for group discussion with advisers**

##### *Interviewer's introduction*

- Thank you for coming; I am Anne Corden. My colleague is Annie Irvine, and we are social researchers at SPRU, which is an independent research organisation and part of the University of York.
- This research is funded by the Department for Work and Pensions. The aim of the overall research is to find out more about what difference DLA and AA make. This is information needed by the government in their overall review of the two benefits. We know that the information and advice about DLA and AA provided by people in statutory and voluntary organisations is important in influencing claims for these benefits. So as an early part of our research, we want to hear from people like yourselves who have first-hand experience in talking to disabled and elderly people, and their carers and families, about DLA and AA.
- This discussion is one of a series, with different groups of people, in different parts of the country.

- The discussion will be relatively informal – a sharing of your views and experiences, with us mainly listening and learning. There are some key topics for us to explore. So I will explain how the morning will go:
  - We will start with introductions, so that we know everybody's role in their particular organisation.
  - Then we would like to hear about the occasions and circumstances in which you talk to people about DLA and AA.
  - We are interested in what kinds of things people want to know about the benefits, what do they ask you or say to you?
  - We would like to hear your views about why some people claim and others do not.
  - And importantly, what are your own views about the purpose and use of these benefits?

I shall guide the discussion across these topics, so that we keep the discussion on time. We shall do our best to finish promptly at 12.30pm.

- With your permission we would like to record the discussion, so that we can look carefully at everybody's views. The recording is transcribed professionally, and seen only by the research team.
- The discussion is confidential, in that your views will all be included in a report for the Department for Work and Pensions, but not in a way that identifies you or the name of your organisation.
- Is there anything I have not explained fully and you would like to know?

There is a formal agreement to take part, so if you happy with everything may I ask you to sign the consent form.

If asked what we mean by 'complying with the Data Protection Act' explain that we will:

- keep all data in a secure environment;
- allow only members of the research team (including administrators and transcribers) access to the data;
- keep the data only as long as is necessary for the purposes of the research and then destroy it.

### 1. Introductions

May we start with some introductions, telling each other your name, the organisation you work with, and what your main role is there?

### 2. Talking to people about DLA and AA

We would like to hear about the circumstances and situations in which you talk to people about DLA and AA. How does the topic come up?

- in answering queries or giving new information?
- different groups of people, carers and family members
- different kinds of financial circumstances
- need for resources and services
- paying for accommodation
- people's prior knowledge or ideas – correct or incorrect? sources of such knowledge?

### 3. What people want to know about DLA and AA

When you talk to people about DLA and AA, do you talk generally about what DLA/AA is for, or how the benefits might help?

Do you emphasise any of the ways DLA/AA might be helpful or used?

What kinds of things do people want to know about the benefits?

- amounts, source of money
- application process – what do you say about this?
- criteria of entitlement – what do you say about this?
- links to DLA, including Carer's Allowance; local authority services; parking badges – what do you say about these?
- do you emphasise any of these aspects? why is this?

From what people say to you, do you get any sense of how they think the extra money from the benefits might be used, that is before they get it?

### 4. Claiming DLA/AA

We are interested in why some people claim these benefits and some do not. What do you think, from your personal experience?

- which situations and circumstances influence claims?
- which people are influential? (carers, family, advisers)
- influence of need for resources and services.

## 5. The purpose and use of DLA and AA

DLA and AA are quite complex benefits. We are interested in your thoughts about the purpose of the benefits. What do you think they are for?

Where have your ideas here mostly come from?

Do you have any views about how the extra money is actually used by people who do get it?

Or what difference does it make for people?

Thank you very much.

Check that people are happy for the recording to be used as explained earlier.

That discussion was a very helpful contribution to the research. Understanding how people like yourselves talk to those who might claim the benefits and their families is the first important part of this research. I hope you also found the morning interesting.



## Qualitative Research on the Impact of DLA and AA

### Topic guide for interviews with DLA recipients

#### *Interviewer's introduction*

- This research is funded by the Department for Work and Pensions. The work is being done by the Social Policy Research Unit, an independent research organisation at the University of York.
- The aim of the research is to find out what difference Disability Living Allowance (and Attendance Allowance) makes for the people who receive it. Lots of people in different kinds of circumstances get this benefit, and the government is keen to understand what people think about DLA, and in particular what difference it makes for them. This will help them plan the best ways of supporting people, in the future.
- We will talk fairly informally, and you will choose how much to say about things. I would like to guide our discussion around DLA through these areas:
  - some background about yourself, and your health
  - your main sources of income, including DLA and any changes there have been
  - how money is managed in your household
  - how you feel about your standards of living, and any changes there have been.
- This will take us between an hour and 90 minutes; we can stop for breaks, just as you choose. Will this be all right for you?
- Taking part is completely voluntary, and will have no effect on any of your benefits or other income. Nobody in DWP knows who we talk to in these interviews. When we have finished the interviews we write a report for the government. Your views will be included there along with other people's, but they will be anonymous. The government is interested in the overall picture of what people generally think and do.
- Are you happy about all this? Then may I ask for permission to use my recorder. Recordings are typed up professionally and dealt with confidentially in our office, and seen only by the research team.
- We use a formal consent form for your agreement to take part (for signature).
- There is a gift of £20 as a token of thanks for taking part. Please will you sign the receipt for me.

If asked what we mean by 'complying with the Data Protection Act' explain that we will:

- keep all data in a secure environment
- allow only members of the research team to see it, including administrators and transcribers
- keep data only as long as necessary for purposes of the research and then destroy it.

**1. May we start by your telling me a bit about yourself, to put me in the picture?**

- household composition; age/age group of household members
- current employment/education situation: retired; not working (and other household members); paid work – explore occupation and hours
- general employment/education history
- how long have you lived here (tenure)
- other significant family members (children, parents living elsewhere).

**2. Disability Living Allowance is paid to people who experience health problems or disability. May we talk about your health circumstances, and how you are affected?**

How is your health at the moment?

- general picture
- main conditions mentioned – trajectories of time and severity
- current treatment, and significant treatment history (hospital; NHS/other treatments)

How does this health condition mainly affect you, at the moment?

- symptoms: feeling ill; pain; fatigue; mood; communication; behaviour
- need for medication/treatment/therapies
- effect on everyday activities at home
- personal care; making meals; housework; laundry
- effect on moving around, at home and going out
- effect on employment situation (and partner's situation)
- other effects mentioned – relationships; family responsibilities, social activities

For each aspect mentioned, ask how they manage or what happens.

Look for input from other people, services, aids/equipment, and ask when arrangements started.

Look also for gaps in life, and unmet needs.

Prompts/reminders

Help from other people:

- partner/other household/family members (think Carers Allowance)
- formal care arrangements – health professionals; carers (LA or private)
- house-cleaning; gardening; handyman services
- friends, neighbours, volunteers, e.g. Age Concern (think Carer's Allowance)
- employers/work colleagues
- support groups
- supported employment; supported accommodation
- respite care/short breaks

Services/equipment:

- aids/equipment in home/personal alarms; house extensions; technology
- meals on wheels; prepared foods
- private vehicle (ask blue badge/Motability)
- taxis/community transport (ask blue badge)
- support groups/helplines
- Access to Work

Other:

Thank you for explaining that – I have got a good picture now. We may come back to some of those things later on.

I would like to move on to talk about money now.

### **3. May we think first about Disability Living Allowance?**

- can you remember when you first claimed that?
- what circumstances influenced your claiming DLA?
- did somebody help you with it? how did they help? What did they say about DLA?
- do you know which rate/how much you get in DLA? any changes?
- why do you think you got DLA?

- do you use DLA for anything in particular?
  - ask vehicle owners/electric wheelchair users if they use Motability
- there are links between DLA and some other benefits – are you affected by any of these?
  - e.g. premiums in income-related benefits; blue badges/local concessions; tax credits; mental health related council tax exemption
- does anybody get a Carer's Allowance for the help they provide for you?
  - If not, have you looked into this?

Does getting DLA affect how you feel about doing paid work?

Explore

Now we have talked about DLA, may we talk more generally about financial issues?

#### 4. What are the main sources of income for you/your household?

- earnings (self and others)
- pensions (state retirement pension, war pension, occupational/private pension)
- benefits (establish which ones as far as possible)
- tax credits (Child Tax Credit; Working Tax Credit)
- individual budgets; direct payments
- maintenance/child support from a relationship
- money from other people – parents, adult children
- investment income; interest on savings; property lets
- compensation; criminal injuries/Trust funds.

Which of all those are the most important part of your income?

- what makes you say that?

Do you have a figure in your head for your overall income, I mean all the money coming in?

People who don't know, or prefer not to say, may be able to decide between 'middle income' or 'low income'.

Have there been any big changes lately in any of those sources of income?

- what has been the main effect for you of that?

**5. Thank you for telling me about the money you have coming in. May we move on to talk about managing it and paying for things you need?**

Note: questions in 5 are designed for adults who live with other adults in a shared household. Adapt questions with asterisk for adults who live alone, or live with dependent children only.

People have different ways of managing their money, and some people share responsibilities. May we talk about what you do?

Do you put the different parts of income together or keep them separate?

- pooling all or part of income – which components (separation by person)
- \*keeping separate the monies from different sources (separation by source)
- \*shared/individual/different bank accounts (separation by person, source or purpose)

So what happens to DLA here?

How do you make decisions about spending?

- which person decides what – regular expenses, big bills
- \*‘pots of money’ or general pool (separation by purpose)
- \*do you have priorities for spending?

Who takes practical responsibility?

- for buying and paying for shopping
- paying rent/mortgage
- paying other bills (utilities; vehicle)
- paying for telephone; taxis
- dealing with HMRC; DWP; banks; insurance
- paying for care
- \*does anyone else help you manage finances or deal with practicalities? (accountant; brokers for individual budgets)

**6. The last part of the discussion is about how you feel about your financial situation and what you are able to do.**

Thinking overall, do you have enough money for the things you need to spend on?

- how long has it been like this?

All through our discussion you have told me about some of the things that help you manage, with your health condition. May we go back to some of them, and see how you afford to pay for them?

- Prompt from previous discussion:
  - formal care; aids, equipment; personal alarms; house cleaning; gardening; handyman; a private vehicle; taxis; meals on wheels; other prepared foods; extra fuel; telephone costs; using helplines; extra laundry; extra clothing; bedding; incontinence supplies; pharmaceuticals; prescriptions.
- Seek some examples of actual amounts and frequency, e.g. how much do you spend on your prescriptions each month?

Sometimes, when people get help they don't have to pay for, they like to give something to the people helping them, or treat them. Does this ever happen to you?

- explore how often money or presents are given, to whom, ask for examples of amounts.

Do you think of DLA as covering any of these things in particular, or not like that?

How satisfied are you with your standard of living at the moment, I mean your overall material standard of living?

- prompt if necessary, what you can afford to buy or do

Are you able to save money?

- regularly, occasionally
- do you have something in mind for these savings?
- how important for you is saving?

And what about using loans or borrowing?

- regularly? occasionally? formal/informal sources? purpose?

Are there things you need badly but can't afford?

- how long has it been like this?
- is this related to your health condition
- how do you manage without?

Lets suppose your income went down for some reason, say £50 a week, what effect would that have? (Reassure here)

And supposing your income went up by £50 a week? What effect would that have?

- how would you use the extra money?

Thinking about your life more widely, how would you describe your general sense of well-being? (Include partner here)

- Prompt: are you able to take part in things you want to do? I mean, taking part in social activities, seeing people
- How important is your financial situation on the way you feel here?

We have reached the end of the interview now. We have talked about a lot of things. The last question I'd like to ask you is 'What difference does DLA make for you?'

- does getting DLA make any difference to how you feel?

If appropriate, separate difference for respondent, difference for partner or rest of family, difference for carer.

Thank you.

Remind about confidentiality.

Check respondent happy for interview to be used.

Has it raised any issues of concern or uncertainties? Deal with them.

## Qualitative Research on the Impact of DLA and AA

### Topic guide for interviews with AA recipients

#### *Interviewer's introduction*

- This research is funded by the Department for Work and Pensions. The work is being done by the Social Policy Research Unit, an independent research organisation at the University of York.
- The aim of the research is to find out what difference Attendance Allowance (and Disability Living Allowance) makes for the people who receive it. Lots of people in different kinds of circumstances get this benefit, and the government is keen to understand what people think about AA, and in particular what difference it makes for them. This will help them plan the best ways of supporting people, in the future.
- We will talk fairly informally, and you will choose how much to say about things. I would like to guide our discussion around AA through these areas:
  - some background about yourself, and your health
  - your main sources of income, including AA and any changes there have been
  - how money is managed in your household
  - how you feel about your standards of living, and any changes there have been.
- This will take us between an hour and 90 minutes; we can stop for breaks, just as you choose. Will this be all right for you?
- Taking part is completely voluntary, and will have no effect on any of your benefits or other income. Nobody in DWP knows who we talk to in these interviews. When we have finished the interviews we write a report for the government. Your views will be included there along with other people's, but they will be anonymous. The government is interested in the overall picture of what people generally think and do.
- Are you happy about all this? Then may I ask for permission to use my recorder. Recordings are typed up professionally and dealt with confidentially in our office, and seen only by the research team.
- We use a formal consent form for your agreement to take part (for signature).
- There is a gift of £20 as a token of thanks for taking part. Please will you sign the receipt for me.

If asked what we mean by 'complying with the Data Protection Act' explain that we will:

- keep all data in a secure environment
- allow only members of the research team to see it, including administrators and transcribers



- keep data only as long as necessary for purposes of the research and then destroy it.

**1. May we start by your telling me a bit about yourself, to put me in the picture?**

- household composition; age/age group of household members
- how do you generally spend the day – any paid work, activities, clubs, Day Centre (and other household members)
- general employment history – very briefly
- how long have you lived here (tenure)
- other significant family members (children, parents living elsewhere).

**2. Attendance Allowance is paid to people who experience health problems or disability. May we talk about your health circumstances, and how you are affected?**

How is your health at the moment?

- general picture
- main conditions mentioned – trajectories of time and severity
- current treatment, and significant treatment history (hospital; NHS/other treatments)

How does this health condition mainly affect you, at the moment?

- symptoms: feeling ill; pain; fatigue; mood; communication; behaviour
- need for medication/treatment/therapies
- effect on everyday activities at home
- personal care; making meals; housework; laundry
- effect on moving around, at home and going out
- (effect on employment situation (and partner's situation))
- other effects mentioned – relationships; family responsibilities, social activities

For each aspect mentioned, ask how they manage or what happens.

Look for input from other people, services, aids/equipment, and ask when arrangements started.

Look also for gaps in life, and unmet needs.

Prompts/reminders.

Help from other people:

- partner/other household/family members (think Carers Allowance)
- formal care arrangements – health professionals; home carers (LA or private); staff in care home
- house-cleaning; gardening; handyman services
- friends, neighbours, volunteers, e.g. Age Concern (think Carer's Allowance)
- (employers/work colleagues)
- support groups
- supported employment; supported accommodation
- respite care/short breaks

Services/equipment:

- aids/equipment in home/personal alarms; house extensions; technology
- meals on wheels; prepared foods
- private vehicle (ask blue badge/Motability)
- taxis/community transport (ask blue badge)
- support groups/helplines
- Access to Work

Other:

Thank you for explaining that – I have got a good picture now. We may come back to some of those things later on.

I would like to move on to talk about money now.

### **3. May we think first about Attendance Allowance?**

- can you remember when you first claimed that?
- what circumstances influenced your claiming AA?
- did somebody help you with it? how did they help? What did they say about AA?
- do you know which rate/how much you get in AA? any changes?
- why do you think you got AA?
- do you use AA for anything in particular?

- there are links between AA and some other benefits – are you affected by any of these?
  - e.g. premiums in income-related benefits; blue badges/local concessions; tax credits; mental health related council tax exemption
- does anybody get a Carer's Allowance for the help they provide for you?
  - If not, have you looked into this?

(Does getting AA affect how you feel about doing paid work? Explore)

Now we have talked about AA, may we talk more generally about financial issues?

#### 4. What are the main sources of income for you/your household?

- earnings (self and others)
- pensions (state retirement pension, war pension, occupational/private pension)
- benefits (establish which ones as far as possible)
- (tax credits (Child Tax Credit; Working Tax Credit) – unlikely)
- individual budgets; direct payments
- maintenance/child support from a relationship
- money from other people – parents, adult children
- investment income; interest on savings; property lets
- compensation; criminal injuries/Trust funds.

Which of all those are the most important part of your income?

- what makes you say that?

Do you have a figure in your head for your overall income, I mean all the money coming in?

People who don't know, or prefer not to say, may be able to decide between 'middle income' or 'low income'.

Have there been any big changes lately in any of those sources of income?

- what has been the main effect for you of that?

**5. Thank you for telling me about the money you have coming in. May we move on to talk about managing it and paying for things you need?**

Note: questions in 5 are designed for adults who live with other adults in a shared household. Adapt questions with asterisk for adults who live alone, or live with dependent children only.

People have different ways of managing their money, and some people share responsibilities. May we talk about what you do?

Do you put the different parts of income together or keep them separate?

- pooling all or part of income – which components (separation by person)
- \*keeping separate the monies from different sources (separation by source)
- \*shared/individual/different bank accounts (separation by person, source or purpose)

So what happens to AA here?

How do you make decisions about spending?

- which person decides what – regular expenses, big bills
- \*'pots of money' or general pool (separation by purpose)
- \*do you have priorities for spending?

Who takes practical responsibility?

- for buying and paying for shopping
- paying rent/mortgage
- paying other bills (utilities; vehicle)
- paying for telephone; taxis
- dealing with HMRC; DWP; banks; insurance
- paying for care
- \*does anyone else help you manage finances or deal with practicalities? (accountant; brokers for individual budgets)

**6. The last part of the discussion is about how you feel about your financial situation and what you are able to do**

Thinking overall, do you have enough money for the things you need to spend on?

- how long has it been like this?

All through our discussion you have told me about some of the things that help you manage, with your health condition. May we go back to some of them, and see how you afford to pay for them?

- Prompt from previous discussion:
  - formal care; aids, equipment; personal alarms; house cleaning; gardening; handyman; a private vehicle; taxis; meals on wheels; other prepared foods; extra fuel; telephone costs; using helplines; extra laundry; extra clothing; bedding; incontinence supplies; pharmaceuticals; prescriptions.
- Seek some examples of actual amounts and frequency, e.g. how much do you spend on your prescriptions each month?

Sometimes, when people get help they don't have to pay for, they like to give something to the people helping them, or treat them. Does this ever happen to you?

- explore how often money or presents are given, to whom, ask for examples of amounts.

Do you think of AA as covering any of these things in particular, or not like that?

How satisfied are you with your standard of living at the moment, I mean your overall material standard of living?

- prompt if necessary, what you can afford to buy or do

Are you able to save money?

- regularly, occasionally
- do you have something in mind for these savings?
- how important for you is saving?

And what about using loans or borrowing?

- regularly? occasionally? formal/informal sources? purpose?

Are there things you need badly but can't afford?

- how long has it been like this?
- is this related to your health condition
- how do you manage without?

Lets suppose your income went down for some reason, say £50 a week, what effect would that have? (Reassure here)

And supposing your income went up by £50 a week? What effect would that have?

- how would you use the extra money?

Thinking about your life more widely, how would you describe your general sense of well-being? (Include partner here):

- Prompt: are you able to take part in things you want to do? I mean, taking part in social activities, seeing people.
- How important is your financial situation on the way you feel here?

We have reached the end of the interview now. We have talked about a lot of things. The last question I'd like to ask you is 'What difference does AA make for you?'

- does getting AA make any difference to how you feel?

If appropriate, separate difference for respondent, difference for partner or rest of family, difference for carer.

Thank you.

Remind about confidentiality.

Check respondent happy for interview to be used.

Has it raised any issues of concern or uncertainties? Deal with them.

## Qualitative Research on the Impact of DLA and AA

### Topic guide for interviews with recipient families

#### *Interviewer's introduction*

- This research is funded by the Department for Work and Pensions. The work is being done by the Social Policy Research Unit, an independent research organisation at the University of York.
- The aim of the research is to find out what difference Disability Living Allowance (and Attendance Allowance) makes for the people who receive it. Lots of people in different kinds of circumstances get this benefit, and the government is keen to understand what people think about DLA, and in particular what difference it makes for them. This will help them plan the best ways of supporting people, in the future.
- We will talk fairly informally, and you will choose how much to say about things. I would like to guide our discussion around DLA through these areas:
  - some background about your family and your child's health and special needs
  - your main sources of income, including your child's DLA and any changes there have been
  - how money is managed in your household
  - how you feel about your family's standards of living, and any changes there have been.
- This will take us between an hour and 90 minutes; we can stop for breaks, just as you choose. Will this be all right for you?
- Taking part is completely voluntary, and will have no effect on any of your benefits or other income. Nobody in DWP knows who we talk to in these interviews. When we have finished the interviews we write a report for the government. Your views will be included there along with other people's, but they will be anonymous. The government is interested in the overall picture of what people generally think and do.
- Are you happy about all this? Then may I ask for permission to use my recorder. Recordings are typed up professionally and dealt with confidentially in our office, and seen only by the research team.
- We use a formal consent form for your agreement to take part (for signature).
- There is a gift of £20 for your family as a token of thanks for taking part. Please will you sign the receipt for me.

If asked what we mean by 'complying with the Data Protection Act' explain that we will:

- keep all data in a secure environment

- allow only members of the research team to see it, including administrators and transcribers.
- keep data only as long as necessary for purposes of the research and then destroy it.

**1. May we start by your telling me a bit about your family, to put me in the picture?**

- household composition; ages of family members
- parents' current employment/education situation: paid work; retired; not working (and other household members)
- parents' general employment/education history
- how long have you lived here (tenure)
- other significant family members (children, parents living elsewhere).

Tell me a bit more about (name):

- nursery/school
- interests, what is enjoyed, how spends time

**2. Disability Living Allowance is paid to children with health problems or special needs. May we talk about (name's) health circumstances, and how you she/he is affected?**

- general picture
- main conditions mentioned – trajectories of time and severity
- current treatment, and significant treatment history (hospital; NHS/other treatments)

I'd like to talk about the main effects of this at the moment.

Ask about effects for child, and for the rest of the family:

- symptoms: feeling ill; pain; fatigue; mood
- communication
- behaviour
- need for medication/treatment/therapies
- effect on child's everyday activities at home (eating, sleeping, keeping safe)
- child's personal care
- effect on child's moving around, at home and going out
- attendance at playgroup, school, nursery
- effect on parents' employment situation



- effect on running household: making meals; housework; laundry; shopping
- other effects mentioned – child’s friendships and relationships; family responsibilities, social activities for child and family.

For each aspect mentioned, ask how they manage or what happens.

Look for input from other people, services, aids/equipment, and ask when arrangements started.

Look also for gaps in life, and unmet needs.

Prompts/reminders

Help from other people:

- partner/other household/family members (think Carer’s Allowance)
- formal care arrangements – health professionals; carers (LA or private); education professionals; playgroups; clubs
- house-cleaning; gardening; handyman services
- friends, neighbours, volunteers, (think Carer’s Allowance)
- short breaks/respite care
- support for parents at work - employers/work colleagues
- support groups/parent groups
- (supported employment; supported accommodation)

Services/equipment:

- aids/equipment in home/personal alarms; house extensions/adaptations
- special toys/play equipment
- (meals on wheels); prepared foods
- private vehicle (e.g. blue badge/Motability)
- taxis/community transport (e.g. blue badge)

Other:

Thank you for explaining that – I have got a good picture now. We may come back to some of those things later on.

I would like to move on to talk about money now.

### **3. May we think first about Disability Living Allowance?**

- can you remember when you first claimed that?
- what circumstances influenced your claiming DLA?

- did somebody help you with it? how did they help? what did they say about DLA
- do you know which rate/how much you get in DLA? any changes?
- why do you think you got DLA?
- do you use DLA for anything in particular?
  - ask vehicle owners/electric wheelchair users if they use Motability
- there are links between DLA and some other benefits – are you affected by any of these?
  - e.g. premiums in income-related benefits; blue badges/local concessions; tax credits; (MH related council tax exemption)
- do you get a Carer's Allowance for looking after (name) or does anybody else?

Do you take DLA into account when you (or your partner) think about doing paid work?

Now we have talked about DLA, may we talk more generally about financial issues?

#### 4. What are the main sources of income for you/your household?

- earnings (self and others)
- pensions (state retirement pension, war pension, occupational/private pension)
- benefits (establish which ones as far as possible)
- tax credits (Child Tax Credit; Working Tax Credit)
- individual budgets/direct payments
- maintenance/child support from a previous relationship
- money from other people – parents, adult children
- investment income; interest on savings; property lets
- compensation/criminal injuries/Trust funds

Which of all those are the most important part of your income?

- what makes you say that?

Do you have a figure in your head for your overall income, I mean all the money coming in?

People who don't know, or prefer not to say may be able to decide between 'middle income' or 'low income' groups.

Have there been any big changes lately in any of those sources of income?

- what has been the main effect for you of that?

**5. Thank you for telling me about the money you have coming in. May we move on to talk about managing it and paying for things you need?**

Note: questions in 5 are designed for adults who live with other adults in a shared household. Adapt questions with asterisk for adults who live alone, or live with dependent children only.

People have different ways of managing their money, and some people share responsibilities. May we talk about what you do?

Do you put the different parts of income together or keep them separate?

- pooling all or part of income – which components (separation by person)
- \*keeping separate the monies from different sources (separation by source)
- \*shared/individual/different bank accounts (separation by person, source or purpose)

So what happens to DLA here?

How do you make decisions about spending?

- which person decides what – regular expenses, big bills
- \*‘pots of money’ or general pool (separation by purpose)
- \*do you have priorities for spending?

Who takes practical responsibility?

- for buying and paying for shopping
- paying rent/mortgage
- paying other bills (utilities; vehicle)
- paying for telephone; taxis
- dealing with HMRC; DWP; banks; insurance
- paying for care
- does anyone else help you manage finances or deal with practicalities? (accountant; broker for individual budgets)

**6. The last part of the discussion is about how you feel about your financial situation and what you are able to do.**

Thinking overall, do you have enough money for the things you need to spend on?

- how long has it been like this?

All through our discussion you have told me about some of the things that help you manage, with your health condition. May we go back to some of them, and see how you afford to pay for them?

- Prompt from previous discussion: childcare; playgroups; after school clubs; respite/short breaks; private health care; electric/specialist wheelchairs; child's toys/games/activities; aids, equipment; personal alarms; house cleaning; gardening; handyman; a private vehicle; taxis; meals on wheels; other prepared foods; extra fuel; telephone costs; using helplines; extra laundry; extra clothing; bedding; incontinence supplies; pharmaceuticals; prescriptions.

Sometimes, when people get help they don't have to pay for, they like to give something to the people helping them, or treat them. Does this ever happen to you?

- explore how often money or presents are given, to whom, ask for examples of amounts.

Do you think of DLA as covering any of these things in particular, or not like that?

How satisfied are you with your family's standard of living at the moment, I mean your overall material standard of living?

- prompt if necessary, what you can afford to buy or do

Are you able to save money?

- regularly, occasionally
- do you have something in mind for these savings?
- how important for you is saving?

What about using loans or borrowing?

- regularly? occasionally? purpose?

Are there things you need badly but can't afford? I mean things for (name) and things for the family

- how long has it been like this?
- is this related to (name's) condition
- how do you manage without?

If your family income went down for some reason, say £50 a week, what effect would that have?

And supposing your family income went up by £50 a week? What effect would that have?

- how would you use the extra money?

Thinking about life more widely, how would you describe your general sense of well-being? I mean you and partner here.

- Prompt: are you able to take part in things you want to do? I mean, taking part in social activities, seeing people.

We have reached the end of the interview now. We have talked about a lot of things. The last question I'd like to ask you is 'What difference does DLA make for you?'

Can you separate difference for child, and difference for you and your partner, and the rest of the family?

- does getting DLA make any difference to how you feel about looking after [name]?

Thank you.

Remind about confidentiality.

Check respondent happy for interview to be used.

Has it raised any issues of concern or uncertainties? Deal with them.



# Appendix D

## CASP-19 measure of 'quality of life'

The CASP-19 measure consists of 19 statements that people are asked to respond to on a scale of zero to 3. Thus total scores can range between zero (equivalent to a complete absence of any quality of life) to 57 (indicating complete satisfaction with life).

### Statements used in the CASP-19 quality of life measure

#### **Control**

- My age prevents me from doing the things I would like to.
- I feel that what happens to me is out of my control.
- I feel free to plan for the future.
- I feel left out of things.

#### **Autonomy**

- I can do the things that I want to do.
- Family responsibilities prevent me from doing what I want to do.
- I feel that I can please myself what I do.
- My health stops me from doing things I want to do.
- Shortage of money stops me from doing things I want to do.

#### **Pleasure**

- I look forward to every day.
- I feel that my life has meaning.

- I enjoy the things that I do.
- I enjoy being in the company of others.
- On balance, I look back on my life with a sense of happiness.

**Self-realisation**

- I feel full of energy these days.
- I choose to do things that I have never done before.
- I feel satisfied with the way my life has turned out.
- I feel that life is full of opportunities.
- I feel that the future looks good for me.

As an indication of its use the mean quality of life score for all older people in the English Longitudinal Study of Ageing was 42.2.



# References

Age Concern (2008) *Transforming Lives. Tackling Poverty and Promoting Independence and Dignity through Information and Advice*, Age Concern, London.

Beatty, C., Fothergill, S. and Platts-Fowler, D. (2009) *DLA Claimants – A New Assessment: The characteristics and aspirations of the Incapacity Benefit claimants who receive Disability Living Allowance*, DWP Research Report 585, HMSO, Norwich.

Beresford, B. and Clarke, S. (2009) *Improving the well-being of disabled children and young people through improving access to positive and inclusive activities*, *Disability Research Review 5*, Centre for Excellence and Outcomes in Children and Young People's Services.

Beresford, B., Clarke, S. and Sloper, P. (2005) *Integrating Services for Disabled Children, Young People and their Families: Consultation project*, Social Policy Research Unit, University of York, York.

Berthoud, R. (2009) *The Impact of Disability Benefits. A feasibility study*, DWP Working Paper No. 58, The Stationery Office, London.

Berthoud, R. and Hancock, R. (2008) *Disability Benefits and Paying for Care*, Institute for Social & Economic Research, Essex.

Berthoud, R., Lakey, J. and McKay, S. (1993) *The Economic Problems of Disabled People*, Policy Studies Institute, London.

Caring Choices Coalition (2008) *The Future of Care Funding. Time for a change*, King's Fund, London.

Clarke, S., Mitchell, W. and Sloper, P. (2004) *Care and Support Needs of Children and Young People with Cancer and Leukaemia and their Families*, Social Policy Research Unit, University of York, York.

Corden, A., Hirst, M. and Nice, K. (2009) *Financial Implications of Death of a Partner*, Social Policy Research Unit, University of York, York.

Available at <http://www.york.ac.uk/inst/spru/research/pdf/Bereavement.pdf>

Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for all adults at the end of life. Guidance*, DH, London.

Hawkins, J., Goldstone, C. and Bhagat, M. (2007) *Knowing and Understanding Disability and Carers Service Customers*, DWP Research Report No.439, Corporate Document Services, Leeds.

Horton, C. and Berthoud, R. (1990) *The Attendance Allowance and the Costs of Caring*, Policy Studies Institute, London.

Kasparova, D., Marsh, A. and Wilkinson, D. (2007) *The Take-up Rate of Disability Living Allowance and Attendance Allowance: Feasibility study*, DWP Research Report No. 442, Corporate Document Services, Leeds.

Purdon, S. et al. (2005) *Meeting DWP's Long-term Information Needs on Disability: A feasibility report*, DWP Research Report No. 267, Corporate Document Services, Leeds.

Ritchie, J., Spender, L. and O'Connor, W. (2003) Carrying out qualitative analysis, in Ritchie, J. and Lewis, J. (eds), *Qualitative Research Practice*, Sage, London, pp. 219-62.

Stapleton, D., Protik, A. and Stone, C. (2008) *Review of International Evidence on the Cost of Disability*, DWP Research Report No. 542, Corporate Document Services, Leeds.

Thomas, A. (2008) *Disability Living Allowance: Disallowed claims*, DWP Research Report No. 490, Corporate Document Services, Leeds.

Thomas and Griffiths (2010, forthcoming) *Disability Living Allowance and Work: Exploratory research and evidence review*, DWP Research report.

Tibble, M. (2005) *Review of Existing Research on the Extra Costs of Disability*, DWP Working Paper 21, Department for Work and Pensions, London.

This report presents findings from qualitative research on Disability Living Allowance (DLA) and Attendance Allowance (AA) recipients. This report investigates the use of these benefits and the impact they have on people's lives. Findings can contribute to the development of questions that might be used in further surveys about the benefits.

Discussion groups were undertaken with 24 professionals and advisers in touch with people who claim or may be entitled to claim DLA or AA. Face-to-face qualitative interviews with 15 adult DLA recipients, 15 AA recipients and 15 parents of child recipients were also carried out to explore how they use the benefits. This was followed by a desk-based review of relevant survey instruments.

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

<http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>