

Appendices to the impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research

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Department for Work and Pensions

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

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Introduction

A qualitative research study commissioned by the Department for Work and Pensions (DWP) to investigate the use and impact of Disability Living Allowance (DLA) and Attendance Allowance (AA) was conducted by the Social Policy Research Unit (SPRU) at the University of York.

The study was completed in 2009 and a full report is available (Corden *et al.*, 2010). That report included short appendices summarising the research methods. Here we present full details of the research methods and instruments used in the empirical work in that study.

The overall aims of the study were:

- to contribute to greater understanding of the use and impact of DLA and AA;
- to 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.

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.
- Qualitative interviews with 45 recipients of DLA and AA.
- A desk-based review of current research instruments.

In what follows, Appendix A describes recruitment to the series of discussion groups with professionals and advisers; the topic guide used to moderate the discussion, and our approach to analysis of the material generated. Copies of research instruments used are included.

Appendix B describes research methods used in the component based on qualitative interviews with DLA and AA recipients, including recruitment, development of the topic guide for use in interviews, the conduct of fieldwork, data extraction and analysis, and the main characteristics of people in this study group. Again, we attach copies of research instruments used.

The methods used in the third component of the overall study, a desk based review of current research instruments, are described in the main report from the overall study (Corden *et al.*, 2010).

Appendix A

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

This appendix describes 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

The initial aim was to convene a series of six small discussion groups comprising one group each of:

- The Department for Work and Pensions (DWP) 'front line staff' in the Pensions Service who visit older people at home.
- DWP staff in Pensions, Disability and Carers Service (PDCS) who have direct contact with DLA recipients, by telephone or at home.
- Local authority social services staff working in adult and children's social care.
- National Health Service (NHS) personnel in hospitals and primary care.
- Advisers from welfare rights and general advice services.
- People working in third sector organisations which support people with mental health conditions.

The first stage in recruitment was through letters of introduction to managers and human resource personnel in each of the organisations approached. The letter (copy attached) explained the research, the nature of the discussion group, topics for exploration, and date and time of the meeting. We asked for suggestions of named front line staff with relevant experience to whom personal invitations might be sent.

At this stage the decision was taken not to include representatives from children's services within this series of group discussions. We judged that the particular issues relating to children's receipt of Disability Living Allowance (DLA) required more focused attention than would be possible within a group of staff working mainly with adults.

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. The venues included city centre meeting rooms, university and DWP premises.

We received help from DWP research managers in making first contacts with DWP and NHS staff. It proved hard to recruit to some of the planned groups, and several repeat approaches and new invitations were required. Most of those people to whom we wrote agreed initially that the matter was relevant to their organisation, but there were different levels of interest and people took different approaches to passing on invitations to front-line staff.

Some managers explained that if staff took part this meant service withdrawal for clients during that morning, and felt unable to prioritise the research. Some front line staff who accepted invitations were unable to attend on the day. We were unable to convene a group of NHS personnel. On the other hand, there was particular interest among staff working in local authority adult services, and two concurrent discussion groups were convened from those who arrived for this meeting.

Overall, therefore, 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/Attendance Allowance (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 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 (attached) 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.

After full explanation of the purpose of the research and procedures involved in analysis and reporting, permission was sought to audiotape the discussions. Participants signed a formal statement of understanding and consent to participation (attached). There was full discussion at each meeting of all the main topics of interest.

Discussions generally lasted one and a half hours. Refreshments were available at each meeting, and payments were offered to meet expenses of travel and care responsibilities.

Contributions from everybody who took part generated valuable findings and useful new perspectives for the researchers, who 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.

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Date

Dear Manager

Research on the impact of Disability Living Allowance and Attendance Allowance

I am writing to tell you about some important research in which we hope an adviser from [name of organisation] will take part.

The Social Policy Research Unit at the University of York has been commissioned by the Department for Work and Pensions to conduct exploratory research on the impact of Disability Living Allowance and Attendance Allowance (DLA/AA). You know that these are valuable benefits available to help meet the extra costs of disabled living. The impact and use of these benefits is currently under review.

As part of our research, we would like to meet with some people who, as a normal part of their professional or voluntary work, talk to some disabled and elderly people about DLA and AA when discussing financial resources and/or need for services.

One aim is to hold a small group discussion for front-line staff in advice agencies and voluntary organisations who are regularly involved in talking to disabled and elderly people and their families about income and resources, and thus have some experience of discussing DLA/AA or helping with applications. We are inviting people from 6-8 such organisations in the [name of area]. We believe that advisers who give financial advice to people with learning difficulties will also have relevant experience, and we hope that an adviser from [name of organisation] would like to take part.

The group discussion will take place at [time] on [date] at the [name of venue], and will last an hour and a half. Topics to be explored between staff and representatives include:

- Occasions and circumstances in which they talk to disabled and elderly people and people with learning difficulties, and their families about DLA/AA.

Continued

- What interests disabled and elderly people, and people with learning difficulties, and their families about DLA/AA and what kinds of things people ask or say about these benefits.
- Any views or experiences about why some people claim these benefits or not.
- Staff and representatives' own views about the purpose and use of DLA/AA.

The discussion will be confidential. The aim is for us to understand what happens in interactions about DLA/AA between disabled and elderly people and professional or voluntary workers. We are conducting a number of other such discussions with staff representing different kinds of statutory and voluntary organisations and services. What we learn from the discussions will help us design the next stage of the research in which we shall talk directly to some disabled and elderly people.

I am the researcher who will guide discussion across these main topics, and my colleague Annie Irvine will also take part.

We do hope you will want your organisation to take part in this important research, and will kindly suggest an appropriate person who would like to come to the discussion and can fit this into their schedule. When we have their name and contact details we will then follow up shortly after the Christmas break, to send them a personal invitation and an information sheet, with full details of venue and arrangements. We are able to reimburse reasonable travel expenses, and shall offer refreshments.

My contact details are at the top of my letter, and I look forward to hearing from you.

Yours sincerely

Anne Corden

Senior Researcher

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 12.30 pm.

- 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.

Research study on Disability Living Allowance and Attendance Allowance

Consent Form

I have received information about the research and understand the purpose of the research and what it involves.

Yes No

I understand that the information I give to the researchers will be treated in strict confidence according to the Data Protection Act.

Yes No

I understand that the research report will include my views along with the views of other people, but I will not be identified.

Yes No

I understand that I can withdraw from the research at any time without giving a reason.

Yes No

I agree to take part in a discussion group, with a researcher.

Yes No

Name _____

Signature _____

Date _____

Appendix B

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

This appendix describes the recruitment of the study group; development of the interview topic guides; conduct of the interviews and the approach to analysis of data from 45 qualitative interviews.

B.1 Recruitment to the study group

The aim was to achieve 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.

In order to recruit adult recipients, a letter describing the general purpose of the research was sent from the Social Policy Research Unit (SPRU) to 50 people in receipt of AA and 50 in receipt of DLA in each of the three locations (300 letters overall). Names, addresses and telephone numbers from the disability benefits database were passed to the research unit for this purpose by research managers in the Department for Work and Pensions (DWP). The introductory letter (attached) requested people who did not want to be approached to take part in the research to get in touch with the research unit. After two weeks, the researchers started to telephone those people who had not 'opted out' in this way. When contact was made, the researchers reminded people about the letter and asked whether

they were interested in taking part in an interview. Some people wanted further information at this stage, such as how the research unit knew their names and addresses, and what would be involved in a research interview. Some declined the invitation but others were interested in meeting a researcher to talk about their financial situation and paying for the items and services they needed. Appointments were made at times and places to suit the respondents, and an information sheet with further details about the research was included with the letters the researchers sent to confirm the appointments (attached).

Recruitment of parents of children in receipt of DLA was handled differently. The information initially passed from the DWP did not include telephone numbers of parents. It was thus not possible to adopt an approach based on 'opting out' with telephone follow-up. Instead, the introductory letter from the research unit (attached) was sent to 50 parents in each location. This letter explained the research and invited interested parents to get in touch with the research team to talk about the possibility of taking part, or to send their telephone numbers so that the researchers might contact them directly. Reply slips and pre-paid envelopes were included with this letter, and parents who preferred to make telephone or email contacts had these details on the letterhead.

The approach to parents was phased in order to avoid, as far as possible, over-recruitment and having to tell parents who wanted to take part that quotas had been filled. There was considerable interest in taking part among parents in the first phases, however, and quotas here were filled quickly. This meant that some parents who had expressed interest could not be included. The researcher made personal contact again with these parents, explained the situation, thanked people for their interest, invited any particular comments or observations they wished to have taken into account, and offered an early summary of findings, when these were available.

In building the overall study group, the researchers' initial aim was to achieve a gender balance among recipients, with a spread of ages and range of health conditions, and to include some people whose claim had started fairly recently as well as people who had been in receipt of DLA or AA for several years. We were always aware that this might be hard, and would depend on whether levels of response gave options for any purposive selection of respondents. Although we wanted to be as inclusive as possible, it had always seemed likely that impairments such as dementia, severe learning difficulties, and general frailty of extreme old age would mean that some people would be unable to take part. There were also likely to be issues of confidentiality in recruiting people whose correspondence, telephone communication, and general day-to-day living was mediated by carers, or staff in supported accommodation and residential care or nursing homes.

Exploration of recruitment approaches and response was an important component of this study. Findings inform decisions about the feasibility and management of any further quantitative research with DLA and AA recipients.

In contacting adult recipients, the researchers made some discretionary decisions. After some initial unsuccessful attempts to recruit AA recipients living in nursing homes, the researchers decided on ethical and pragmatic grounds not to try to make further contacts with people close to or over 100 years old who were living in residential care or nursing homes, and recorded as experiencing dementia or senility. There were issues of confidentiality in trying to make contacts through receptionists and care staff, and it seemed likely that there would be issues of mental capacity and confidentiality in any discussions that might be arranged. When adult recipients were recorded by DWP as having a terminal illness, and were living in hospital or nursing home or their address for correspondence was a private address described as 'care of', the researchers generally did not try to make contact.

It seemed likely that people in such circumstances were very ill, and it would be unethical to try to recruit them. An exploratory telephone call to one person described as having a terminal illness, with a private home address, was answered by the person's recently bereaved partner. Although in this case the bereaved partner was also a recipient and agreed to take part, the decision was taken at this stage not to approach any more people recorded as having a terminal illness. It is possible that some very old people and some terminally ill people who might have taken part in interviews were excluded.

Ethical and pragmatic issues of this kind arose less frequently in recruitment of younger DLA recipients, and parents. However, there was one situation in which initial communication with a younger DLA recipient's care managers led to a decision that it would be inappropriate to pursue an interview.

In any further work with AA and DLA recipients, we would recommend more systematic decisions, at the design stage, about whether and how to include people with advanced terminal illness, dementia, extreme old age and severe learning difficulties, including people living in residential care and nursing homes.

Using the approaches described above, 15 interviews with adult recipients of DLA were achieved during the main fieldwork phase in June and July 2009; 14 interviews with AA recipients, and 14 interviews in families with children in receipt of DLA. The decision was taken to pursue a second round of recruitment to try to fill the proposed quotas for AA recipients and parents of children in receipt of DLA.

In order to recruit another AA recipient our first approach was trying to make telephone contact with some people with whom the researchers had not yet spoken directly, in one location. This proved unsuccessful, either because there was still no response to the researcher's telephone calls, or because people who did not recall receiving the introductory letter (sent six weeks earlier) were not interested in hearing about the research. The next attempt was to try writing to the remaining AA recipients in this and one other location with whom the researchers had not yet made direct contact. Second letters (attached) were mailed to 16 such people, reminding them of the initial approach, including another information sheet, reply slip and pre-paid envelope. There was one reply from a person offering to take part later in the year, and this interview was conducted in October.

In order to recruit another parent of a child in receipt of DLA a second 'opt-in' component was conducted in one location, sending the same invitations as previously used to 15 families not yet approached at all in this research. Nobody got in touch as a result, but there was one late reply to the first mail-out, which completed the target component.

The 45 interviews achieved included one with the bereaved partner of the person included in the AA database, who was also in receipt of AA; and two other interviews in which both partners received AA, and contributed to the discussion.

The final picture of recruitment and response is represented in Table B.1

The researchers' experience of recruitment

Recruitment for this study was time-consuming and resource intensive. At the first stage of recruitment in all sub-groups some letters were returned as 'undelivered' to the SPRU. Reasons included incomplete addresses, addressees unknown or gone away. It is likely that some moves had been related to health conditions and need for care. Additionally, some relatives of previous AA recipients got in touch to say that the person had died. Table B.1 shows a relatively high rate of 'opting-out' among adult recipients; rates of opting out were higher among AA recipients than among DLA recipients, but similar across the three locations.

In the next stage of recruitment of adult recipients, the researchers found that telephone numbers in one location were wrongly recorded in the data received from DWP. Further work was required by the researchers to locate correct and complete numbers, using the online BT telephone directory, and some trial and error. Across the sample, some telephone numbers were not working and some did not accept incoming calls. When phones were not answered the researchers tried different times of the day or early evening but some numbers repeatedly rang out or were constantly diverted to answer phone. There are issues of confidentiality in responding to answer phones and the researchers generally left only brief messages that they had called, which were rarely returned.

There were also issues of confidentiality in talking to third parties answering the telephone. When a relative or carer answered the telephone, identified themselves as significant in enabling communication with the person concerned and already knew the University might get in touch, the researchers felt confident in discussing the research and whether it might be possible to conduct a research interview. Some relatives did not want to take the matter forward, for example if the person concerned had gone into hospital, or was considered too ill or elderly to take part.

There were some language barriers in making contacts, for example when relatives answering the phone said the people concerned (all elderly women) spoke no English and were very frail. Some suggested that any discussion would have to be managed through younger men in the family or by grandchildren after school. The decision was taken that this way of trying to discuss personal circumstances of health and care requirements with an elderly woman from a minority ethnic group would be inappropriate, and these contacts were not pursued.

Table B.1 The study group: recruitment and response

	Location		
	A Scotland	B Wales	C England
AA recipients			
Introductory letters sent (May/June)	50	50	50
Mail delivery unsuccessful	2	2	1
Withdrew to SPRU	20	18	18
Family/care staff reported recipient had died	2	1	-
Opt in by telephone or letter	-	1	1
Contact achieved by researcher with recipient, family, or care staff	12	10	10
Declined to take part (recipient)	3	4	3
Declined to take part (family or care staff on behalf of recipient)	4	-	4
Interviews arranged	5	6	3
Interviews achieved	5	6	3
Second invitation sent (late July)	10	-	6
Declined by telephone	1	-	1
Interviews arranged	-	-	1
Total interviews achieved with AA recipients = 15			
DLA recipients			
Introductory letters sent (May/June)	50	50	50
Mail delivery unsuccessful	4	2	-
Withdrew to SPRU	10	16	14
Opt in by telephone, letter or email	2	2	2
Contact achieved by researcher with recipient, family, or care staff	7	10	8
Declined to take part (recipient)	2	3	2
Declined to take part (family or care staff on behalf of recipient)	-	2	1
Interviews arranged	5	5	5
Interviews achieved	5	5	5
Total interviews achieved with DLA recipients = 15			
Parents of child recipients of DLA			
Introductory letters sent (May/June)	50	50	50
Mail delivery unsuccessful	1	6	-
Opt in to SPRU by reply slip or telephone	10	12	6
Anonymous opt-out	-	1	-
Declined on contact	-	-	1
Interview arranged	5	6	5
Interview achieved	5	6	4
Introductory letters sent (August)	15	-	-
Mail delivery unsuccessful	-	1	-
Interest expressed but no further contact	1	-	-
Total interviews achieved with parents of child recipients = 15			

Reasons given by AA and DLA recipients themselves, who said they did not want to take part when contacted by telephone, included being ill, expecting to go into hospital soon, not having time, there being too much else going on for them and being too old to bother (although the researchers made it clear that they would welcome talking to very old people). Other reasons for not being interested included people not recognising that they were getting the benefits, and leaving relatives to deal with most things. Some people said they were very satisfied with support received and had no need to talk about this further. A few people responded initially by saying there was no point to the research. They believed that because the government was paying these benefits, it must know already that DLA and AA were essential for old and ill people. When the researcher suggested that it was important for the government to understand why the benefits were essential, and how exactly they contributed to household budgeting, such people were usually more interested in taking part. One person in Wales objected to receiving correspondence written in English, an important consideration for any further research.

B.2 Developing the topic guide

There were a number of important requirements for design of the topic guide. The researchers sought substantive qualitative information about how people used the benefits, and what difference they made. The aim here was 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 which led to findings about people's own use of language, and the sensitivities involved in talking about personal circumstances and needs related to old age, impairments and illness. The aim here was for the interviews to show what kind of approach and question worked well, what worked less well and what kind of prompts or suggestions the researchers tried.

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. 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.

The design of the topic guide reflected these requirements. 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 Appendix A here, and Chapter 2 of the full report) informed the design of the 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’. The content of the topic guide and the actual questions and prompts used are fully discussed in the body of the main report.

The first draft was designed for use with DLA adult recipients. Some slight amendments were then made for interviews with AA recipients, for example interviewers did not usually expect to discuss decisions about paid work. The draft topic guide for discussions with parents of children receiving DLA was discussed at length with the member of the research team with particular experience of research with families with disabled children, who suggested useful additions and adjustments. Development of the topic guide in this way led to a ‘family’ of three slightly different research instruments, all with the same general format (attached).

The first interviews conducted by each of the three interviewers served as pilots for the topic guides, with debriefing and discussion within the team. No substantial changes were made.

B.3 Conducting interviews

Three members of the research team shared the fieldwork. Most of the interviews with parents of child recipients were conducted by the researcher with particular expertise in research with families with disabled children. Most interviews took place in people’s homes, including some residential care and sheltered accommodation settings. One person chose to talk to the researcher while going for a walk, and then sitting in a café.

Adult benefit recipients who had partners who were at home during the daytime generally chose to take part with their partner. This was particularly helpful when partners had responsibilities for money management and budgeting, or received carer’s allowance in recognition of support provided. As explained above, there were two interviews in which both partners received AA and both took part in the discussion. Other household members who took part in some interviews included adult children of recipients, in some cases receiving carer’s allowance.

The parents of children in receipt of DLA who took part in interviews were generally mothers. One interview was conducted with a father, and three discussions included both parents. In several of the interviews in families with children there were pre-school children present, who watched television or played in the same room. In all cases, the researchers checked parents’ preferences about children listening or

taking part. Older children at home because of school holidays generally played in adjoining rooms or the garden most of the time, but some older children expected to take part. In one family, three children were interested in the topics discussed, and took part with their mother. In another interview, a teenage boy took a full part with his parent. Overall, the researchers met nine of the children in receipt of DLA.

Other family members whom the researchers met during the overall series of interviews included a child recipient's father who usually lived apart; adult recipients' brothers, parents and adult children, and child recipients' brothers and sisters. Professional workers who were in some recipients' homes included a family support worker, a community nurse, carers, home helps and a gardener. These people took no part in the research interviews, but in all cases the respondent had mentioned significant support received from them. It appeared to the researchers that some such people may have arranged to be in the home at the time of the appointment, to check what was happening and ensure the welfare of the person they supported.

There was one situation where it became apparent that the person taking part was a personal friend of another person who had also been recruited for the research and lived close by. The interviewer maintained strict confidentiality, but there are lessons here about sampling strategies in local areas, in any further research with this population.

Interviews always began with discussion about the aim of the research and the topics that would be covered. People living on low incomes were sometimes uncertain that it would be easy to talk about 'what difference DLA or AA made' if they felt the benefits were essential for daily living. However, everybody agreed it would be possible to talk about how they managed to pay for the things they needed, and were generally happy to take part. Those taking part were asked to sign formal consent forms (attached). This sometimes involved the researcher reading out the components on the form and ticking the boxes for people before they signed, where people's impairments prevented their reading. One person declined to sign a consent form, although accepting all the conditions on the form, on the grounds of wanting to be certain that her views could not be traced back to her as an individual. This person was happy for the interviewer to explain these feelings on the consent form and sign it herself.

Permission was sought to record the interviews, in most cases, and all except one person asked gave permission. This was a person who did not want a recording made of what she said. In a few situations, the researcher concerned judged that recording and transcription were unlikely to work well, and it would be better to make notes. Such situations included interviews that took place while walking outside and in a café; interviews with constant background noise from young children and the television they were watching; one interview with an older person who moved round her home while talking, and one interview in which communication was affected by a speech impairment. In all these situations, the researcher concerned recorded an account of the interview immediately afterwards, using the notes made.

Throughout the interviews the researchers monitored the apparent acceptability of the issues being explored. Nobody said they preferred not to discuss issues raised by the interviewer, although two older people said they did not want to talk about actual amounts of income or pensions. Some people's current circumstances were very difficult, including recent bereavement or family breakdown; facing their own or a child's diagnosis, deteriorating condition or terminal illness; loneliness and social isolation, and financial hardship. The researchers sometimes made discretionary decisions in how far they explored topics, for example not asking for detailed information about practical money management from a person who said that having to deal with all the practical financial issues after recent death of a partner was causing considerable emotional distress. Another challenging situation was that in which it became apparent that the person interviewed did not understand they were getting AA, as discussed in Chapters 3 and 4 of the main report. Generally, however, all the topics in the interview guide were covered in some way, for everybody who took part. Managing this series of discussions was demanding work for the researchers, and support came from team cohesion, frequent debriefings and sharing interview experiences, throughout and after the fieldwork period.

In preparing for the fieldwork, the researchers had compiled information sheets for their own use, if needed. The information set out included the general structure and entitlement criteria for DLA and AA; some details about carer's allowance, and linked services and benefits such as Blue Badges (for on-street parking and access), and council tax concessions. This sheet (attached) was designed as an aide memoire for the researchers, for example helping them understand income sources when people did not remember names of benefits or pensions. The sheets were also designed to enable the researchers to provide correct details, when people said they wanted to know more about particular things mentioned by the researcher. In practice, the sheets were not often used.

Interviews were designed so that matters might be discussed in little more than one hour, but recognising that up to two hours might be necessary, to give adequate time for talking to some elderly or disabled people, and to enable breaks and rests. It was known that some people would get tired, and have to deal with symptoms, and parents of disabled children have particular demands on their time and energies. In practice, it was not unusual for the researchers to be in the home for up to two hours. Some people took rests, or wanted time to move around to ease discomfort or take medication. In some situations, it was important for interviewers themselves to remember the time schedules for taking medication or using nebulisers, so that treatment programmes were not disrupted. Some elderly people and some socially isolated younger adults expected to extend the research interview, by sharing tea and social conversation. The researchers made individual judgments here, balancing the need for a 'professional approach' to interviewing with the need for kindness and consideration, and avoidance of negative impact of the research, as far as possible.

The researchers asked for some reflection on the interviews, before leaving people, and there were no negative comments. When people had been upset or unwell during the discussion, the researcher checked that the person concerned had access to a relative or friend who might offer support, or talk through issues that had arisen. On reflection, none of the interviewees felt that discussions they had guided had been experienced as over-intrusive or exhausting.

From the office, the researchers sent individual letters of thanks and, in a few cases, further public information specifically requested, such as how to apply to support organisations mentioned during interviews, and contact details of a free confidential helpline for parents.

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. As described by Ritchie *et al.* (2003), the central component is a thematic framework, which is used for classification and organisation of data according to key themes, concepts and categories. Some of the themes and concepts are issues initially identified by the researchers, within the aims of the enquiry, and some are emergent categories, which evolve through study of the transcripts and development of the researchers' understanding. The main themes divide into a succession of related subtopics, providing an integrated thematic framework.

The thematic framework was drawn up as a series of charts, using Excel worksheets for electronic file management and storage. Themes and topics were displayed as column headings and each interview or case formed a new row in the worksheet. Descriptive comments and explanations from the transcripts were entered in each cell of the matrix accordingly. The charts were then printed on A3 sheets of paper, for visual display and inspection, to facilitate interrogation of the data and interpretation. This approach enabled practical management of a substantial amount of qualitative data; and both within-case and across-case thematic analysis.

Data were extracted as soon as possible after each interview, by the member of the team who conducted the interview. This meant that all the qualitative material was accessible to the other members of the team as it was collected, and could be interrogated and discussed as the fieldwork progressed. During data extraction, the team kept closely in touch, checking with each other for consistency in approach. One member of the team then took responsibility for

the overall analysis, showing draft chapters to the other members, as soon as they were written, inviting comments and suggestions.

B.5 Team working

The three members of the research team who recruited respondents, conducted the interviews and extracted the data from the transcripts were all experienced in conducting this kind of social policy research interview, in which people talked about sensitive and personal issues concerning ill health and disability. Individually, they each brought particular interests and expertise which were valuable to the project, namely experience in research with disabled and chronically sick children; with people with mental illness; with elderly and bereaved people; with low income groups; expertise in the language and discourse of research encounters; and wide knowledge and understanding about employment decisions and 'caring'.

One of the research team had less previous experience than the others of using the Framework approach with Excel worksheets, but was proficient.

It was important for this small group to keep closely in touch, and share their thoughts and experiences throughout. Ways of doing this included frequent face to face meetings, briefings and debriefings; sharing written notes electronically, and an hour's group discussion when most of the data extraction had been completed, which was recorded and transcribed for consideration in the final reporting. This way of working helped:

- Shared understanding of the two-fold aims of the research.
- Building up an appropriate study group.
- Rapid feedback from early interviews, leading to refinement of topic guides.
- Learning from each other's particular knowledge and expertise.
- Consistency in guiding interview discussions and asking questions.
- 'Problem solving', for example decisions about third party involvements.
- Support following interviews experienced as particularly hard or sad.
- Development of the approach to analysis and design of Framework charts.
- Design of structure of report.

B.6 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.

B.6.1 Age and gender

Table B.2 Age and sex of people in study group

Recipients of DLA		
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	-
Recipients of AA		
Age group	Men	Women
65-69 years	1	1
70-79 years	2	3
80-89 years	1	6
90 years	-	1
Child recipients of DLA		
Age group	Boys	Girls
2-4 years	3	1
5-9 years	2	1
10-12 years	2	1
13-15 years	2	3

As shown in Table B.2, the study group included men, women and children across all age groups. The DLA recipients in our study group who were aged 65 years and over were people who had claimed DLA before reaching age 65 years, and who thus continued in receipt beyond the age at which they would no longer have been entitled, had they made a new claim. (Within the overall DLA population, a third of higher rate mobility component payments go to people over 65 years old, see Berthoud and Hancock, 2008.)

People were not asked about their ethnic background but some chose to talk about this. There were examples of first and second generation immigrants among those who took part in the research, and among AA recipients were elderly widowed people who had initially come to live in Britain during population movements in the second world war.

B.6.2 Employment or educational circumstances

Table B.3 Employment or educational circumstances of DLA and AA recipients in study group

	Adult recipients		Child recipients
	DLA	AA	DLA
Doing some paid work	1	-	-
Seeking work	1	-	-
Not doing paid work	7	-	-
Retired from work, over state retirement pension age	6	14	-
Never worked, over state retirement pension age	-	1	-
Home Start support	-	-	1
Playgroup and Home Start	-	-	1
Integrated nursery	-	-	2
Mainstream school	-	-	10
Special school	-	-	1

Table B.3 shows that most adult recipients in the study group had done paid work at some stage. Only one AA recipient had never had paid work; and had spent most of her working life caring for family members. Two of the youngest DLA recipients were keen to do paid work. One had just started a new job when interviewed, and the other was receiving support to get a job, and actively trying various ways of getting paid work. Others of working age said their health conditions meant they were unable to do paid work, although they wished otherwise. DLA recipients over state retirement age considered themselves ‘retired’.

All the child recipients under school age in the study group went to nursery or playgroup, or received support through Home Start. 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. One teenager with multiple needs went to a special school. None of the children in our study group attended residential school. In the main report, we describe how some parents paid privately for additional educational services, to meet their children’s special needs.

Table B.4 Employment or education circumstances of parents of children receiving DLA

Couples	
Both parents work full-time	-
One parent works full-time, one part-time	5
One parent works full-time, one does not do paid work	4
Neither parent does paid work	1
Sole parents	
Sole parent works full-time	1
Sole parent in further education	1
Sole parent not doing paid work	3

Table B.4 shows that most of the child recipients of DLA in this study group lived in families in which one or both parents did some paid work. Parents who did not do paid work were either choosing to be at home to care for their families, or were in poor health themselves and 'off sick' or not working because of ill-health. One sole parent was currently engaged in further education, with a view to getting qualifications that would help her get a job soon.

B.6.3 Household circumstances

Table B.5 Household circumstances of DLA and AA recipients in study group

	Adults		Children
	DLA	AA	DLA
Lives in residential home	-	1	-
Lives alone	7	10	-
Lives with partner	4	2	-
Lives with partner and dependent children	1	-	-
Lives with partner and adult child(ren)	1	1	-
Lives with adult child	-	1	-
Lives with dependent child	-	1	-
Lives with parent(s)	-	-	3
Lives with parent(s) and siblings	1	-	12

Table B.5 shows that all the children in the study group lived in family settings, with one or two parents (five and ten children respectively). Parents on their own were all women, and included a widowed mother. Twelve children lived with siblings, and three were only children. One older child had been looked after in local authority care in an earlier part of life.

The adult recipients in the study group lived in a variety of household circumstances. One person lived in residential care, and around half the group lived at home in the community by themselves (sometimes in sheltered accommodation settings). Others generally lived with a partner, or adult child. In three couples both partners received AA or DLA. The youngest adult DLA recipient lived with parents and siblings, and one AA recipient lived with a dependent child, and received formal financial support for this arrangement.

Nobody in this study group had a trained support animal. However, in a number of households, dogs or cats were described as important members of the household, as discussed in the main text.

B.6.4 Health conditions

The interviewers did not seek systematic information about diagnoses or the names of medical conditions, as the focus of the research was on daily living and how people managed, and paid for what they needed. People chose whether and how to describe their actual medical condition, or that of their children. Most of the adult recipients described a number of chronic illnesses, severe impairments, acute relapsing mental health conditions, or increasing frailty and debilitation due to ageing. From what people told us, we understand that the adult study group included people who had to manage circulatory and heart disease, including the effects of stroke; respiratory disease; musculo-skeletal conditions, including arthritis; severe mental illness; epilepsy; chronic fatigue syndrome; diabetes; sensory impairments; cancer, and learning difficulties. It was not unusual, especially among those in the oldest age groups, for people to describe several such different conditions.

Parents of children in the study group talked about their children's special needs as arising, 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.

B.6.5 Accommodation

Table B.6 shows that most of the children in the study group lived with their families in an owner occupied house, with a garden. The gardens were often considered very important by parents, as described in the main text. Parents who owned their houses were generally making mortgage payments.

The pattern of accommodation arrangements was different among the adult recipients. Older people had sometimes moved to bungalows or flats as retirement homes, or in moves to rented sheltered accommodation to suit their needs for support. Most of the owner occupiers had paid off their mortgages. Most of those who rented accommodation, including nearly all those of working age, depended on housing benefits.

Three of those receiving DLA described having previously spent periods living on the streets or in shelters for homeless people.

Table B.6 Accommodation arrangements of people in study group

	Adults		Parents of child DLA recipients
	DLA	AA	
House or bungalow			
Owner occupied	1	5	10
Local authority rental	2	3	2
Housing association rental	1	2	-
Private rental	1	-	1
Tenure not known	-	-	1
Flat			
Owner occupied	1	-	-
Local authority rental	5	3	-
Housing association rental	2	-	-
Private rental	1	-	-
Tenure not known	-	-	1
Lives with parents and contributes to costs	1	-	-
Lives rent free in family owned home	-	1	-
Residential care	-	1	-

AC/SP/AA

E-mail: pac2@york.ac.uk

5 June 2009

Dear

I am a researcher at the Social Policy Research Unit and I am writing to ask for your help with some important research on Attendance Allowance. The research is funded by the Department for Work and Pensions and is being carried out by a team of researchers here at the Social Policy Research Unit, which is an independent research organisation at the University of York. I am getting in touch with you because we understand that you are currently receiving Attendance Allowance.

The aim of the research is to find out what Attendance Allowance means for the people and families who receive it. People in many kinds of circumstances get this benefit, and the government is keen to understand what people think about it, and in particular what difference it makes for them. This will help in planning the best ways of supporting people in the future.

In a few weeks a researcher from the Social Policy Research Unit may get in touch with you by telephone to tell you more about the research, answer any questions that you have and ask if you would be willing to take part in an interview. The researcher will also discuss with you any requirements you may have which will make it easier for you to take part. The interview will probably last somewhere between an hour and an hour and a half and we can hold it at a place and time convenient to you. Please be assured that taking part is voluntary and will not affect any benefits you receive or any dealings you have with any government department or agency. Anything discussed will be treated in strict confidence. Each person taking part will receive £20 as a token of thanks for their help.

I hope that you would like to take part in the study. If you do not wish to take part, would you please let us know by Friday 19 June. You can either use the reply slip at the end of this letter and the pre-paid envelope or telephone Sally Pulleyn at the Social Policy Research Unit on 01904 321951. If you would like to know more about the research, you can also call me on 01904 321962 or send an email to pac2@york.ac.uk.

Thank you for taking time to read this and I hope you will be interested in taking part in this important research.

Yours sincerely

Anne Corden

Attendance Allowance Research Team

Research study on Disability Living Allowance

Reply slip

Please only return this slip if you do not wish to take part in the research.

Thank you.

Name: _____

Signature: _____

Date: _____

Please return using the enclosed pre-paid envelope to:

Sally Pulleyn
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

Research study on the impact of Disability Living Allowance and Attendance Allowance

In 1992 two social security benefits were introduced to help people pay for the additional costs of disability. Disability Living Allowance (DLA) was introduced for people under retirement age, including children, and Attendance Allowance (AA) was introduced for people over retirement age.

The Department for Work and Pensions has asked the Social Policy Research Unit (SPRU) at the University of York to undertake research into experiences and views of people who receive these benefits. They are particularly interested in what difference the benefits make to people's lives. This will help them and the government consider how best to support disabled people in the future.

We are inviting 45 individuals and families to take part in the research project and we will be carrying out the work in three locations in England, Scotland and Wales. We hope to complete the collection of data by the end of June or early July.

Taking part in this study will mean:

- Meeting a researcher at a time and place convenient to you.
- Spending about 60 - 90 minutes of your time talking to the researcher.
- Discussing your views and experiences of receiving DLA or AA, how it fits in with your overall income and spending, and what difference it makes to your life.

The researchers will be glad to make arrangements to enable people with particular requirements for communication to take part.

Taking part in the research is voluntary and everything you discuss with the researcher will be dealt with in confidence. A gift of £20 will be given to each family who take part and this will not affect any benefit claims.

In the months after the interview the researchers will write a report of the study findings which will include the views of the people who have taken part, but will not identify them. The findings from the study are intended to provide information to the Department for Work and Pensions, benefit recipients and organisations representing disabled people to help contribute to the development of benefit policy in the future.

All information provided to us during the evaluation will be dealt with in confidence in line with the Data Protection Act. Study findings will be published and available to download at <http://www.dwp.gov.uk/asd/>

In addition, findings will be made available in summary form to people who contributed to the research.

Contact details

The research team works in the Social Policy Research Unit (SPRU). Key contact details and information about the team is given below.

Anne Corden E-mail. pac2@york.ac.uk

Annie Irvine E-mail. aj513@york.ac.uk

Sue Clarke E-mail. sec15@york.ac.uk

Roy Sainsbury E-mail. rds2@york.ac.uk

01904 321951 Fax: 01904 321953

Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

For more information on SPRU visit: www.york.ac.uk/inst/spru/

SC/SP/DLA/AA

Parent or Guardian of [Child's name]

E-mail: sec15@york.ac.uk

15 May 2009

Dear Parent or Guardian of [Child's name]

I am a researcher at the Social Policy Research Unit and I am writing to ask for your help with some important research on Disability Living Allowance. The research we are doing is funded by the Department for Work and Pensions and is being carried out by a team of researchers here at the Social Policy Research Unit, which is an independent research organisation based at the University of York. I am getting in touch with you because you are the parent or guardian of [Child's name] and we understand that [Child's first name] is a DLA recipient.

The aim of the research is to find out what Disability Living Allowance means for the people and families who receive it. People in many kinds of circumstances get this benefit, and the government is keen to understand what people think about it, and in particular what difference it makes for them. This will help them plan the best ways of supporting people in the future.

We hope you will be interested to know more about the research or would like to take part. If so, we would be very pleased to hear from you. You can fill in the enclosed form and return it in the pre-paid envelope, or you can telephone on 01904 321951, or write to me at my email address (sec15@york.ac.uk).

We are hoping to interview a small number of families in the [name of area] at a place and time convenient to people for somewhere between an hour and an hour and a half. Please be assured that taking part is voluntary and will not affect any benefits people receive or any dealings with any government department or agency. Also, anything discussed will be treated in strict confidence and each family taking part will be given £20 as a small token of thanks for their help.

Thank you for taking time to read this and I hope you will be interested in taking part in this important research.

Yours sincerely

Sue Clarke

DLA Research Team

Research study on Disability Living Allowance

Reply slip

I have received your letter about the research study on Disability Living Allowance and would like to know more about it.

My name is: _____

My child's name is: _____

My telephone number(s) is: _____

The best times to contact me are: _____

Signed: _____ Date: _____

Please return using the enclosed pre-paid envelope to:

DLA Research Team

Social Policy Research Unit, University of York, Heslington, York,

YO10 5DD

PAC/SP/AA

Insert name and address here

E-mail: pac2@york.ac.uk

7 August 2009

Dear

You may remember that we wrote to you in June telling you about some important research about Attendance Allowance.

The research is funded by the Department for Work and Pensions, and we are a research team at the Social Policy Research Unit, at the University of York, which is carrying out this work.

The aim of the research is to find out what difference receiving Attendance Allowance makes to people who get it, what people think about the benefit and how it helps pay for things that are needed. This will help the government plan the best ways of supporting older people.

Over the last few weeks we have met with several people living in Oxford who receive Attendance Allowance, and have learned a lot of useful things from talking to them. However, we would like to talk to a few more people, and particularly people who are over, or approaching, 70 years old.

Taking part in the research would involve my visiting you, in a place and time which suits you. We would talk informally about what you have to pay for and how Attendance Allowance fits in. I enclose an information sheet which gives you more detailed information.

If you are interested in hearing more about this, and perhaps taking part, I would be delighted to speak to you. I am sending a reply slip and paid envelope for your convenience. If you would prefer to get in touch by telephone, please ring the Social Policy Research Unit on 01904 321951, and ask to speak to me, Anne Corden.

Thank you for considering this letter. I would be very pleased to hear from you.

Yours sincerely

Anne Corden

Senior Researcher

Enc

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 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 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.

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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.

Research on the impact of Disability Living Allowance and Attendance Allowance

Consent Form

I have received the information sheet and understand the purpose of the research and what it involves. Yes No

I understand that the information I give to the researchers will be treated in strict confidence according to the Data Protection Act. Yes No

I understand that the research report will include my views along with the views of other people, but I will not be identified. Yes No

I understand that I can withdraw from the research at any time without giving a reason. Yes No

I agree to take part in an interview with a researcher Yes No

Name _____

Signature _____

Date _____

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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:
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<http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>