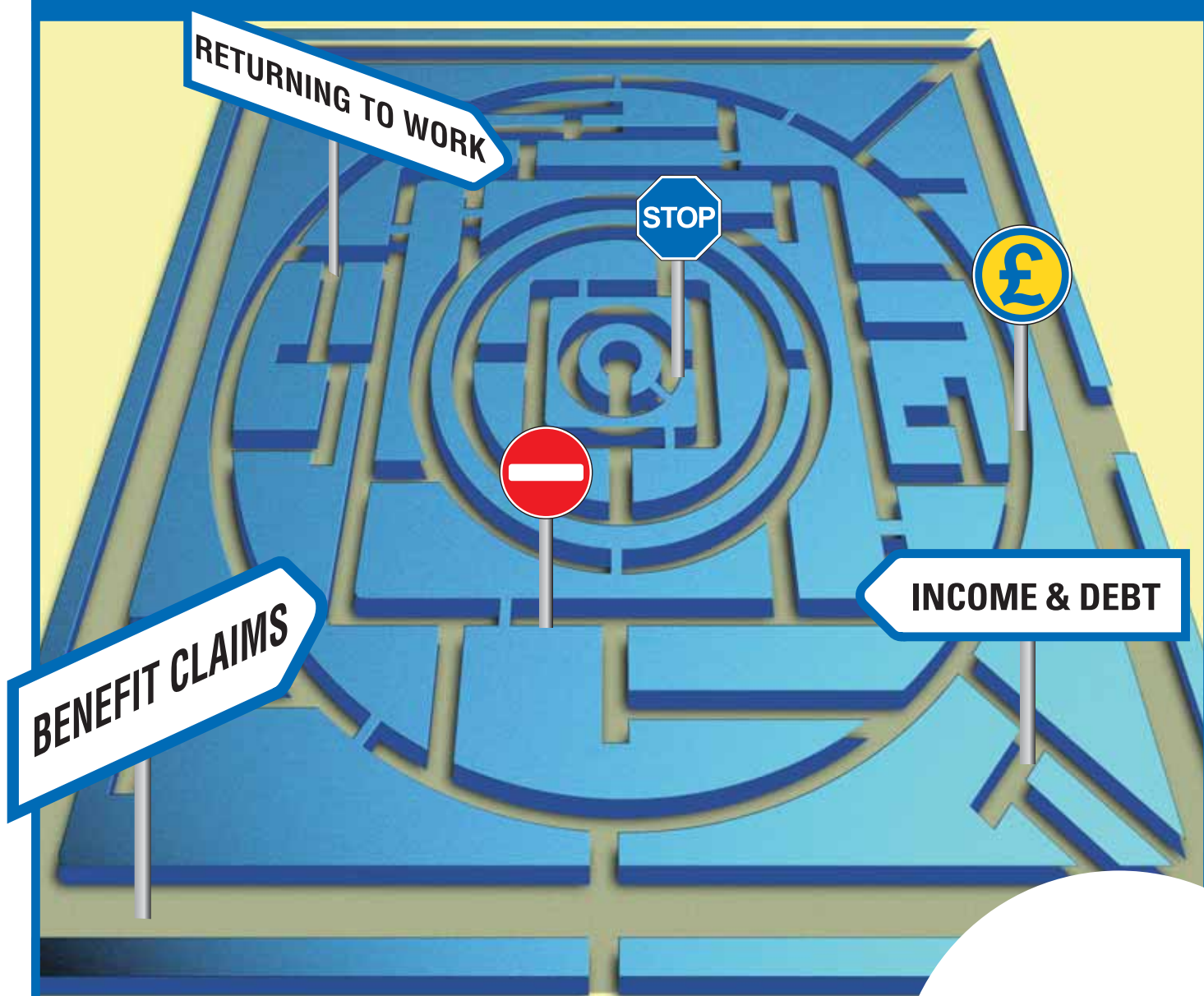


Paying the Price:

The real costs of illness and disability for CAB clients

based on the evidence of Citizens Advice Bureau clients across Scotland



by Clare Lardner
Clarity

July 2006

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Scottish Association of Citizens Advice Bureaux



Paying the price: The real costs of illness and disability for CAB clients

By Clare Lardner, Clarity

Citizens Advice Scotland and its 76 CAB offices form Scotland's largest independent advice network. CAB advice services are delivered through 208 service points throughout Scotland, from the islands to city centres.

The CAB service aims:

to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities, or of the services available to them, or through an inability to express their need effectively

and equally

to exercise a responsible influence on the development of social policies and services, both locally and nationally.

The CAB service is independent and provides free, confidential and impartial

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Executive summary and recommendations

The aim of this research was to gather quantitative evidence about the experiences and circumstances of CAB clients who were under retirement age and claiming Incapacity Benefit (IB) or Disability Living Allowance (DLA), or both. The research findings are intended to help Citizens Advice Scotland (CAS) inform and influence the UK Government's proposed welfare reforms, as well as other policies relating to people with long-term illnesses or disabilities. Research evidence was gathered via a questionnaire survey administered by CAB advisers, to a total of 417 clients, during March and April 2006.

Key findings

Profile of respondents

Compared with the general population, respondents were more likely to be aged 35-65, living in social rented housing and be in single parent or single adult households. Of the sample, 29% were claiming IB, 19% were claiming DLA and 52% were claiming both benefits.

Main illness or disability

Just over half of respondents (53%) reported a physical disability as one of the main conditions or the sole condition affecting their ability to work. Just under two-fifths (38%) reported a mental health condition as one of the main conditions or the sole condition affecting their ability to work. Overall, nearly a quarter (23%) reported more than one main condition, indicating multiple health problems. Nearly 80% said their health was fluctuating or getting worse.

Impact of illness or disability on work and income

Illness or disability had prevented nearly all (84%) respondents from working and almost half (46%) had been out of work for five years or more. Nearly two-thirds (62%) had incomes consisting solely of benefits and/or tax credits. Just under a third (29%) had a monthly household income of less than £400. Over two-thirds (69%) were on a monthly income of £800 or less, compared to a national figure of 18% on approximately this income level. Low income was particularly marked among single adult households.

Claiming Incapacity Benefit

The majority (69%) of IB claimants had made only one previous application. Approximately one-third (34%) had completed an IB50 self-assessment form twice or more and just over one-third (36%) had attended a medical twice or more. There was a success rate of approximately 63% amongst those who had appealed a decision, suggesting that a significant proportion of initial decisions are incorrect.

Commenting on their experiences of claiming IB, 17% said they had experienced no problems, but the vast majority of the remainder described difficult or negative experiences including problems with form-filling, medicals, delays in payment, the

difficulty of living on the IB level of income and the impact that claiming had had on their health.

Claiming Disability Living Allowance

Almost half (47%) of DLA claimants had made only one previous application for DLA and a fifth (22%) had made two previous applications. More than two-fifths (43%) had been refused all or part of their DLA at least once before. There was a success rate of approximately 52% amongst those who had appealed a decision, once again suggesting that a significant proportion of initial decisions are incorrect.

Commenting on their experiences of claiming DLA, only 10% reported no problems (compared with 17% for IB). The vast majority of the remainder described problems with complexity of forms, appeals or tribunals, the difficulty of meeting criteria, the effect of claiming on their health and problems with medicals.

The impact of illness or disability on personal finances

Respondents were more than five times as likely as the general population to be in financial difficulty. The main reasons reported for this were their own illness or disability (83%) and/or low income (69%). More than half (57%) had outstanding debts or arrears, with credit card debt being the most common (45%). Most were trying to manage their debt by juggling their finances (50%), seeking advice (48%) and/or reducing expenditure (45%).

Many had extra needs associated with their illness or disability, including prescription costs (51%) and transport/mobility (49%) – but less than one-third (32%) were exempt from prescription charges and less than one-fifth (18%) had a concessionary travel pass. They were trying to meet these extra needs through help from friends or family (53%) or by reducing expenditure on other things (47%). Almost a quarter (24%) said some of their extra illness/disability related costs were not met.

Nearly half (48%) of respondents had reduced their heating, lighting or cooking because of difficulty paying for fuel.

Future work and support needs

Over one-quarter (29%) of respondents said they thought they would possibly be able to work again - but nearly half (46%) said they would definitely not be able to and a further quarter (25%) were unsure. Those that thought they could work again said they would need a range of forms of help and support, including training, job search skills and work experience. More than half (53%) thought they would need benefits protection whilst they tried work. Help from employers was also needed, such as a lighter workload, aids and adaptations and flexibility about employment conditions.

Recommendations

It is clear from the research that a range of measures are needed to address the problems faced by this CAB client group in relation to severe financial hardship, employment and benefits claiming. Based on the results of the research, and subsequent discussions with members of the Working Group and Advisory Group, CAS makes the following recommendations.

Financial support

CAS recommends that:

- The UK Government addresses the current inadequacy of sickness and disability benefit levels which, combined with the extra costs of sickness and disability, mean that many people do not experience an acceptable standard of living.
- The UK Government, Scottish Executive and financial institutions extend and improve access to alternatives to high-cost sources of credit for people on low incomes. This could be via credit unions, high street banks and building societies, as well as through reform of the Social Fund.

Support with additional costs

CAS recommends that:

- The UK Government extends the additional support provided by passported benefits (e.g. free prescriptions and assistance with travel costs) to claimants of IB.
- The Scottish Executive introduces a significant change in the existing system of prescription charges for those with chronic illness or disability and those on low incomes, to eliminate the financial barriers to treatment that currently exist.
- The UK Government, Scottish Executive and fuel companies ensure that people with illnesses or disabilities who are on low incomes have access to help with their fuel costs.
- The Scottish Executive introduces a national concessionary rail travel scheme similar to the national bus travel scheme introduced in April 2006. Additionally, CAS recommends that the Scottish Executive (re: the national bus scheme) and local authorities and local rail operators (re: local rail schemes) review the illness and disability eligibility criteria for all existing travel schemes, and ensure that they are well-advertised to generate maximum take-up.

Support into employment

CAS recommends that:

- The UK Government ensures that sick and disabled benefit claimants are not penalised for trying out work and provides improved transitional financial help for people returning to work from benefits.

- The UK Government and Scottish Executive ensure that claimants with illness and disabilities, those on low incomes and those living in rural areas are not penalised by difficulties in gaining access to compulsory work-related activities and opportunities for training.
- The UK Government, Scottish Executive and employers recognise that many people have complex needs (e.g. multiple health problems, worsening/fluctuating health, training needs) and reflect this in the types of return to work support and advice that are available.

Support with benefits claiming

CAS recommends that:

- The UK Government simplifies the application processes for DLA and IB and ensures transparency of decision-making and a significant increase in the accuracy of initial decisions.
- The UK Government and its contracted service providers improve the quality of customer service throughout the DLA and IB claiming processes.

Integrated policies

- The complex interaction between reserved and devolved issues means that, for Scottish people with long-term illness or disabilities, it is essential that policies and procedures are effectively integrated across government departments and other agencies and organisations.

Notes about Incapacity Benefit and Disability Living Allowance

Incapacity Benefit

Incapacity Benefit (IB) is the key contributory benefit for people who are incapable of work because of illness or disability. In order to qualify for IB, claimants must be incapable of work, not entitled to Statutory Sick Pay (SSP), and have sufficient National Insurance (NI) contributions. Claimants who have not made sufficient NI contributions but fulfil all the other qualifying conditions for IB can receive Income Support on the grounds of incapacity for work. Although the benefit they are actually paid is Income Support, they will have an underlying claim for IB. This means that they will be credited with NI contributions, and hence these claimants are sometimes referred to as IB credits only.

IB is payable at three rates: a lower short-term rate, a higher short-term rate and a long-term rate, according to the length of time the incapacity has lasted.

Length of incapacity	Benefit payable	Basic weekly rates (claimants under pensionable age)
First 196 days	Lower rate short-term IB	£59.20
197th to 364th day	Higher rate short-term IB	£70.05
365th day onwards	Long-term IB	£78.50

In some cases, claimants may be automatically treated as incapable of work. However, most claimants will be obliged to satisfy one of two tests demonstrating that they are incapable of work: the own occupation test or the Personal Capability Assessment (PCA).

The own occupation test applies to claimants with a regular occupation who are within the first 28 weeks of incapacity. Claimants must provide the Department for Work and Pensions (DWP) with medical evidence of their incapacity for work, usually in the form of a medical note from their GP. The Decision Maker will use this evidence to decide on the person's capacity for work. Sometimes, they might decide there is a need for additional information and will appoint a DWP contracted Medical Services doctor.

The PCA applies to people who do not have a regular occupation, and people with a regular occupation who have already had 28 weeks of incapacity. It examines a claimant's ability to do any work rather than just their normal job, and assesses the impact of their illness or disability on their ability to perform specific activities. All claimants must complete a self-assessment questionnaire, the IB50. Approximately 50% of claimants will also have to attend a medical examination conducted by a Medical Services doctor.

The question of whether a person is incapable of work is decided by a Decision Maker acting on behalf of the Secretary of State for Work and Pensions. If a claimant is found capable of work following either the own occupation test or the PCA, they can challenge the decision by asking for it to be looked at again or by

making a written appeal. Claimants who are waiting for their IB appeal to be heard can claim Income Support, although they face a sanction of a 20% cut in benefit levels. Alternatively, they can claim Jobseeker's Allowance but they must meet the availability for work criteria.

If a claimant is found incapable of work and satisfies the other entitlement conditions, they will be awarded IB. It is current policy that most IB claims must be reviewed by conducting a new PCA at least every three to five years. However, in reality, many claims are actually reviewed far more frequently than this, e.g. six-monthly or annually. The PCA review comprises a self-assessment questionnaire (which may be supplemented by medical evidence from a GP or other health professional) and/or an examination by a Medical Services doctor.

Disability Living Allowance

Disability Living Allowance (DLA) is a non-contributory, non-means tested benefit for people aged under 65 who can demonstrate certain care or mobility needs as a result of illness or disability. It is intended to help with the additional costs associated with illness or disability. DLA is made up of two components: a care component for help with personal care needs, payable at one of three rates (lower-rate, middle-rate and higher-rate) and a mobility component for people who have physical walking difficulties or require accompaniment, payable at one of two rates (lower-rate and higher-rate). The rate at which DLA is received can passport a claimant to different benefits and/or further help. For instance, an award of the higher-rate care component will exempt the claimant from the IB Personal Capability Assessment.

A person may receive one, or both, of the components paid at the rate appropriate to their care and/or mobility needs. For example, a person could be awarded the middle-rate care component and the lower-rate mobility component. DLA is paid at the following rates:

DLA care component	Weekly rate
Lower-rate	£16.50
Middle-rate	£41.65
Higher-rate	£62.25
DLA mobility component	
Lower-rate	£16.50
Higher-rate	£43.45

A claimant's eligibility for DLA is decided by a DWP Decision Maker acting on behalf of the Secretary of State for Work and Pensions. DLA claimants are required to complete a DLA claim form. Prior to December 2005, the form comprised two sections – the first covered basic eligibility criteria, and the second was made up of a self-assessment questionnaire detailing the claimant's care and mobility needs. A new document, combining sections one and two into a shorter form, was introduced in December 2005. Additional evidence can also be supplied with the DLA claim, such as supporting statements from health professionals or evidence of hospital admissions. Before making a decision, the Decision Maker may refer the claimant for a home examination by a Medical Services doctor.

If the claimant is not awarded DLA, they can challenge the decision by asking for it to be looked at again or by making a written appeal. If the claimant is awarded DLA, each component can be awarded indefinitely, or for a fixed period (minimum of six months) based on how long the Decision Maker estimates the claimant's needs will last. If both components are awarded for a fixed term, they are awarded for the same length of time. However, it is possible for one component to be awarded for a fixed period with the other being awarded indefinitely meaning that, in effect, the care and mobility components can be awarded for different lengths of time. If the award is for a fixed period, the client will be sent a renewal pack up to six months before the award expires. Clients applying for renewal of an expired component may have their entitlement to the continuing component looked at again. Fixed term and indefinite awards can also be subject to periodic review. These reviews are carried out through written periodic review forms and, in some cases, a subsequent home medical examination. Some DLA recipients are exempt from review, for instance, if they have a specific named condition or are terminally ill.

Introduction

1. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland's network of 76 Citizens Advice Bureau (CAB) offices. These bureaux deliver frontline advice services through 208 service points throughout the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.
2. This research was commissioned to provide information that will help CAS to inform and influence the proposed welfare reform agenda and other policies relating to people with long-term illnesses or disabilities. In addition, it aimed to investigate further the impact of illness and disability on CAB clients' financial situations, which had been identified as a cause for concern by earlier research carried out with CAB debt clients¹.
3. This report is based on a questionnaire survey of 417 CAB clients claiming Incapacity Benefit (IB), Disability Living Allowance (DLA), or both. It was conducted during March and April 2006 by CAB advisers located in 21 bureaux across Scotland. Although all clients who completed the questionnaire were claiming IB, DLA, or both, they did not necessarily present at the bureau with an issue relating to one of these benefits. Full details of the research methods are given in Appendix 1.
4. The quantitative data is supplemented by case studies of the actual experiences of anonymised CAB clients. This is made possible by the CAB service's social policy feedback mechanism. Bureaux throughout Scotland highlight the problems in their area by sending in specific case examples that are indicative of wider issues. This information is collated and analysed by CAS in conjunction with social policy statistics from each bureau.
5. The overall aim of the research was to assess the impact of illness and disability on CAB clients, with a specific focus on clients' experiences of claiming IB.
6. The objectives of the research were to:
 - assess CAB clients' circumstances and experience of claiming a sickness or disability benefit;
 - determine any differences between those with physical and those with mental disabilities;
 - obtain information about the relationship between sickness and/or disability and debt problems;
 - ascertain these clients' support needs in relation to employment or volunteering.

¹ On the cards: The debt crisis facing Scottish CAB clients, Citizens Advice Scotland, February 2004

Background to the research

Illness, disability, work and benefits

7. The 2001 Census² showed a large increase in the proportion of people in Scotland reporting a long-term illness, health problem or disability that limited their daily activities or the work they could do, up to 20% from 14% in 1991. The highest proportions of people with 'not good' self reported health were found in the social rented sector (18%) and in households living rent free (18%), compared with 10% for all persons in households.
8. The Disability Rights Commission³ reports that, among the working age population, disabled people are less likely to be in employment than the non-disabled population (45% compared with 82%) and that 42% of households with a disabled person have an annual income of £10,000 or less.
9. Across the UK, approximately 2.7 million people claim IB, with just under 1.5 million actually receiving it. Comparable statistics for Scotland show that there are approximately 307,000 claimants of IB, of whom just under 205,000 actually receive it. Scotland is one of a few areas of the UK where the numbers claiming incapacity benefits are particularly high – 10% of the working age population, compared with 7.4% across Great Britain as a whole, and only 4.6% in the South East of England⁴. The welfare reform green paper⁵ states that the number of people claiming IB increased between the late 1970s and the 1990s due to the collapse of traditional industries. Since then, although the number of new claimants has reduced, the length of time people stay on the benefit has increased, so that the total number of people on the benefit has remained fairly constant. The characteristics of claimants have changed, however, with a third of new claimants citing mental health conditions as the primary cause of their incapacity, compared with one-fifth in the mid 1990s.
10. The number of people in receipt of DLA has also increased, up from 2.4 million in 2002 to 2.7 million in 2005⁶.
11. Many disabled people want to work. A Joseph Rowntree research report⁷ found that around 800,000 disabled people aged 25 to retirement age across the UK are 'economically inactive but want to work'. Additionally, it found that, for any level of qualification, disabled people were more likely to lack work or be in low paid work than the general population and concluded that this was evidence that the labour market discriminates against disabled people.
12. In 2004/05, enquiries about disability benefits (Disability Living Allowance, Attendance Allowance, Carer's Allowance, Severe Disablement Allowance and Industrial Injuries Disablement Benefit) accounted for 19% of all benefits

² <http://www.gro-scotland.gov.uk/press/news2003/cenresprs.html>

³ http://www.drc-gb.org/uploaded_files/documents/10_668_DRC_FactsFigures_2004.doc

⁴ Includes IB, NI credits only and Severe Disablement Allowance; Scotland's incapacity benefit claimants: A briefing by Professor Steve Fothergill, Futureskills Scotland, 2005

⁵ http://www.dwp.gov.uk/aboutus/welfarereform/executive_sum.asp

⁶ http://193.115.152.21/100pc/dla/ccdate/cnage/a_carate_r_ccdate_c_cnage.html

⁷ Monitoring poverty and social inclusion across the UK, JRF Research Findings, 2005

enquiries brought to the Scottish CAB service, making it the largest category of enquiry in relation to social security benefits. Additionally, it was the second largest area of enquiry across all issues brought to the Scottish CAB service. In the same year, the second largest area of benefits enquiries related to sickness benefits (Incapacity Benefit and Statutory Sick Pay), which accounted for over 10% of all benefits enquiries. Riding the Benefits Rollercoaster, an evidence report published by CAS in 2003, described a range of problems clients experienced with the process of qualifying for, claiming or appealing decisions relating to disability and sickness benefits. Other research undertaken by CAS in 2003 showed that clients seeking help for their debt were more likely to be ill or disabled than the population as a whole.

Policy context

13. In January 2006, the UK Government published a green paper on welfare reform. The UK Government aims to reduce the number of people on incapacity benefits by one million, and help 300,000 lone parents and one million older people into work
14. The proposed reforms to the incapacity benefits system detailed in the green paper⁸ were to :
 - improve workplace health by creating healthy workplaces, improving occupational health support and facilitating better absence management
 - improve the 'gateway' on to benefits by:
 - i. changing the Personal Capability Assessment (PCA) to focus on capability rather than entitlement to benefit
 - ii. ensuring that no-one is eligible for more benefit than they would be on Jobseeker's Allowance until they have completed the PCA
 - iii. reviewing both the physical and mental health components of the PCA with a focus on ensuring that the assessment reflects the type of mental health conditions prevalent today and improving the efficiency of the process so that appeals are minimised
 - require more from GPs and primary health care teams in helping people back to work by introducing incentives if they take active steps to support individuals to remain in or return to work, piloting employment advisers in GP surgeries and revising the process of sickness certification
 - reform Statutory Sick Pay to ensure it helps people stay in work;
 - increase the number of people who leave benefits to return to work quickly by:
 - i. increasing return to work support for claimants
 - ii. extending the Pathways to Work pilot across the UK by 2008 and extending provision of Pathways to Work to the voluntary and private sectors

⁸ http://www.dwp.gov.uk/aboutus/welfarereform/docs/Contents_Page-Foreword-Executive_Summary.pdf

- iii. introducing a new Employment and Support Allowance which will be conditional upon attendance at work-focused interviews and action planning
 - ensure that those who have the most severe health conditions and disabilities, and could not be expected to work, receive the benefit without conditionality and at a higher rate;
 - work more proactively with existing claimants to encourage them to undertake work-related activities and ensure that they receive regular reviews and checks on their eligibility for benefit.
15. The 12 week consultation period on the green paper ended on 21 April 2006. CAS submitted a response⁹ which welcomed some aspects of the proposed reforms, including support for healthier workplaces and better retention of employees who become ill, but expressed concern about:
- the proposed delay in receiving full benefit until the PCA is completed;
 - the quality of decision-making in relation to incapacity benefits;
 - the proposed distinction between people who are capable of work and those who are not;
 - the challenges of completing the PCA within three months and rolling out the Pathways to Work pilots across the country, in the light of proposed staff cuts in the Department for Work and Pensions (DWP);
 - proposed lower levels of benefits for under 25s;
 - proposed conditionality and sanctions which people with fluctuating conditions, in particular, may find it hard to comply with;
 - additional scrutiny and compulsion for existing claimants without the guarantee of additional support or increased benefit rates;
 - the proposed introduction of a unit to undertake checks, as existing safeguards to detect and prevent fraud are adequate.
16. In addition, CAS expressed concern about the impact of reforms in Scotland, where there are higher numbers of people on IB than other parts of the UK. The reforms will require increased levels of face-to-face contact by claimants, to attend work focused interviews and take part in other work-related activities, but the rural nature of much of Scotland may make this more difficult, especially given the closure of local offices by the DWP.
17. In June 2006, the UK Government published its response to the green paper consultation¹⁰. It acknowledges that, in many of the 600 responses it received, there was 'strong opposition' to the introduction of a two-tiered allowance, but has rejected the calls to re-think this element of the reforms. Responding to other concerns evident in the responses, the UK Government has: created review groups to look in detail at the Personal Capability Assessment; amended the proposal that would see under 25s receiving lower levels of benefits;

⁹ A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006

¹⁰ A new deal for Welfare: Empowering people to work – Consultation report, Department for Work and Pensions, June 2006

decided not to proceed with the proposed changes to Statutory Sick Pay and decided that existing incapacity benefits claimants will be migrated across to the new benefit, in time.

18. In June 2006, the Scottish Executive published Workforce Plus: An Employability Framework for Scotland¹¹, developed from the work of the Executive's Cabinet Delivery Group on Closing the Opportunity Gap which aims to tackle poverty and disadvantage in Scotland. The Framework is an action plan intended to help 66,000 people off benefits and into work. Through additional funding and increased engagement with employers, it aims to improve support for specific groups facing barriers into employment, including people with disabilities. The Framework was developed in conjunction with the UK Government, and the DWP will be a member of the National Workforce Plus Partnership.
19. Presently, entitlement to IB does not mean entitlement to free prescriptions. In January 2006, the Scottish Parliament voted against the member's bill introduced the previous year which would have abolished all prescription charges. On the same day, the Scottish Executive announced a three month consultation exercise on the current system of NHS charging, and sought views on a number of proposals such as reviewing arrangements for multiple prescriptions, and extending the concessionary arrangements to students and trainees. Consultation on the proposals ended on 30 April 2006 and CAS submitted a written response¹², highlighting the difficulties faced by CAB clients with the present system, particularly for those with low incomes and/or chronic conditions.
20. The UK Government is also working to tackle the discrimination faced by disabled people. In 2005, it passed the Disability Discrimination Act which made it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services or the disposal or management of premises; to make provision about the employment of disabled persons; and established a National Disability Council.

¹¹ Workforce plus – An employability framework for Scotland, The Scottish Executive, June 2006

¹² NHS prescription charges and exemption arrangements in Scotland: A response from Citizens Advice Scotland, May 2006

Research findings

Profile of respondents

Summary of key points:

- Of the sample, 29% were claiming IB, 19% were claiming DLA and 52% were claiming both
- Research respondents were more likely than the general population to be:
 - Male
 - Aged 35-65
 - Living in social rented housing
 - In single adult or single parent households
 - Unemployed
 - Not working due to a health problem or disability.

21. The profile of the research respondents was examined in terms of gender, age, housing tenure, household composition, employment status and whether they were claiming Incapacity Benefit (IB) or Disability Living Allowance (DLA). Where possible, the characteristics of the respondent group are compared with that of overall CAB clients in Scotland¹³ or the Scottish population, to see whether disability and sickness issues affect particular groups disproportionately.

Gender

22. Just over half (51%) of the 417 questionnaire respondents were male and just under half (49%) were female. This compares with general population proportions, for 16-65 year olds, of 49% males and 51% females. It suggests that, amongst CAB clients claiming IB or DLA, there are slightly more males than females. This contrasts with the Scottish CAB service's overall figures, in which women account for 54% of CAB clients¹⁴.

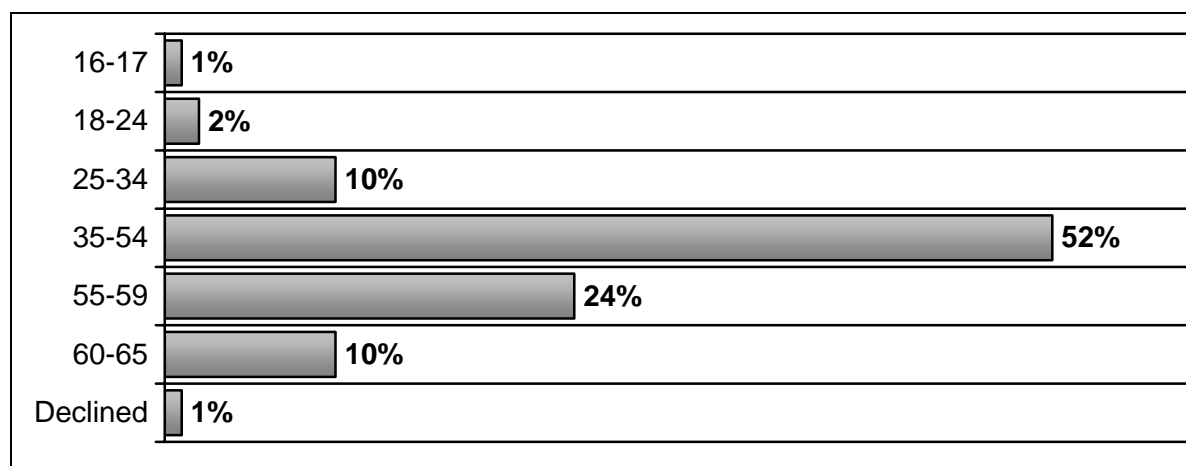
Age

23. Figure 1, overleaf, shows the age profile of respondents. The majority of the respondents (52%) were aged 35-54, almost a quarter (24%) were aged 55-59 and approximately one-tenth each were aged 25-34 (10%) and 60-65 (10%).

¹³ Information drawn from the Social profiling report 2003-05, Citizens Advice Scotland, 2006

¹⁴ Social profiling report 2003-05, Citizens Advice Scotland, 2006

Figure 1: Age profile of respondents



Base 416

24. Table 1 shows the age profile of respondents compared to the overall population of the same age range, bearing in mind that the research was targeting only those age 16-65 and excluded those aged 60-65 on state retirement pension
25. The research sample had a lower proportion of those aged under 35 than the general population and a higher proportion of older adults, particularly those aged 55-59. This may partly reflect the core CAB client base, which is predominantly older adults.

Table 1: Age profile of respondents compared to Scottish population

Age group	Illness/Disability research respondents %	Scottish population % of those aged 16-65 ¹⁵
16-17	1	3.8
18-24	2	13.7
25-34	10	18.6
35-54	52	44.2
55-59	24	10.1
60-65	10	9.6
Declined to give age	1	N/A
Total	100	100

Base: 416

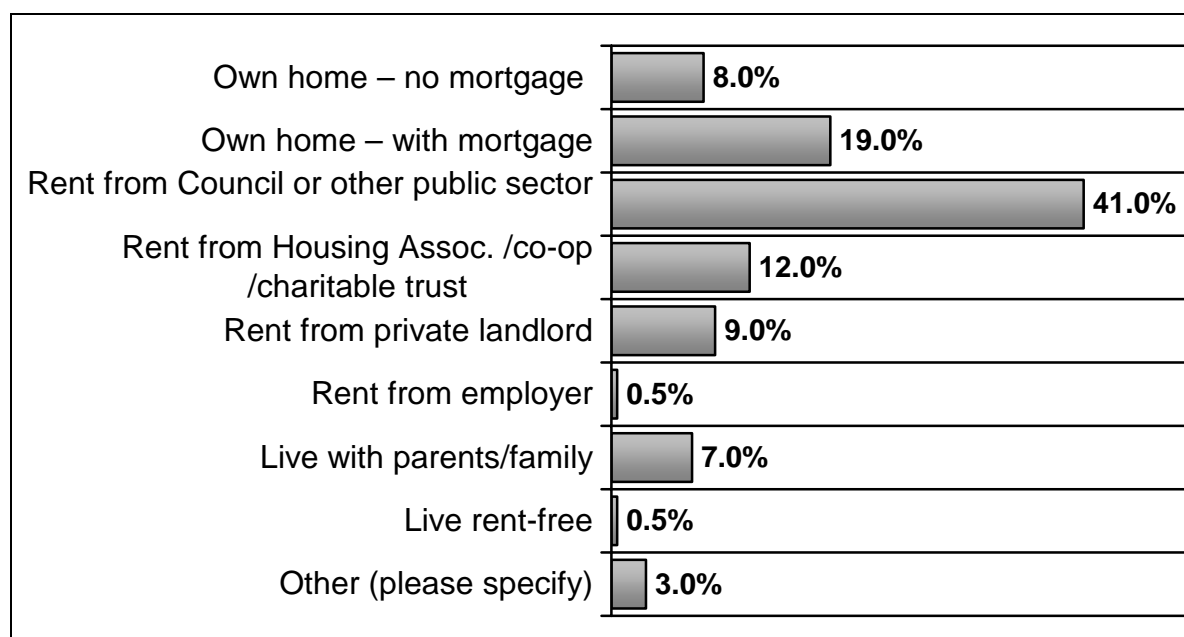
Housing tenure

26. Figure 2, overleaf, shows the housing tenure of respondents. Two-fifths of respondents (41%) were living in a home that was rented from the council or other public body and over one-fifth were in another form of rented housing, mainly renting from a housing association, co-operative or charitable trust (12%), or from a private landlord (9%). Over a quarter of respondents (27%) lived in their own home, with just under one-third of these having no mortgage to pay. A further 7% lived with parents or family and 0.5% lived rent-free. The 'other' category included a small number of respondents who were living in

¹⁵ Based on Registrar General's Mid Year Estimate, 2005

mobile homes, part-rent, part-buy arrangements, supported accommodation, tied accommodation or who were homeless.

Figure 2: Housing tenure of respondents



Base: 417

Table 2: Housing tenure of research respondents compared to CAB clients and Scottish population

Tenure	Illness/Disability research respondents %	CAB clients (2003-05) %	Scottish population 2003/4 ¹⁶ %
Owned outright	8	32.1	15
Owned with mortgage	19		50.8
Social rented	53	43.2	24.7
Other	20	14.2	9.2
Total	100	89.5¹⁷	100

27. The housing tenure of respondents compared with the general population and overall CAB clients is shown above in Table 2. It indicates that the respondent population was approximately twice as likely as the general population¹⁸, and more likely than overall CAB clients, to be in social rented housing. This probably reflects the much lower levels of household income of respondents compared with the general population (as shown in Table 6) and the high levels of dependence on benefits (as shown in Figure 8). It is also in line with the Census figures quoted in the background to this research.

¹⁶ Scottish Household Survey (SHS), Scottish Executive, 2003/4

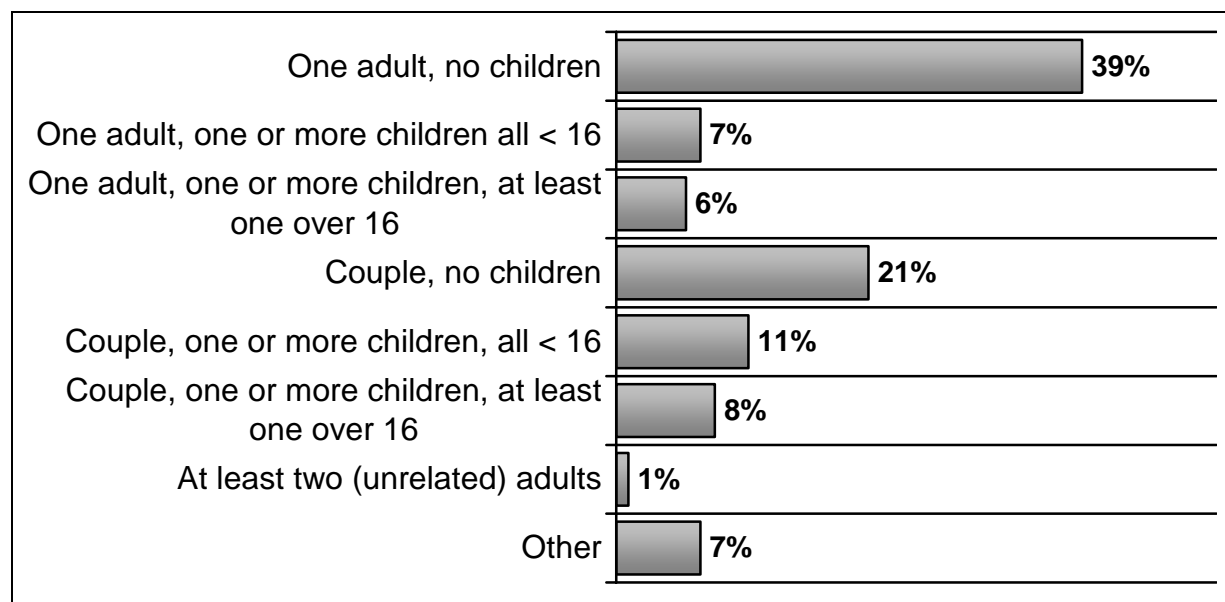
¹⁷ Social profiling report, Citizens Advice Scotland, 2006 – does not provide categories for remaining 10.5%

¹⁸ The SHS figures for household tenure exclude 'older smaller' and 'single pensioner' households

Household composition

28. The household composition of respondents is shown in Figure 3. Almost two-fifths (39%) of respondents were in single adult households with no children and a further one-fifth (21%) were part of a couple with no children.

Figure 3: Household composition of respondents



Base: 415

29. Overall, 32% of respondents were in households with children, including 13% in single parent households and 19% in couple households with children. Overall, 18% were in households with children aged under 16. The 'other' category included nine other households with children and 20 households of various combinations of adult members.
30. Household composition categories are not entirely comparable with those used in the Scottish Household Survey (SHS), but those that are comparable are shown below in Table 3. Single pensioner and 'smaller older' households in the SHS have been excluded when calculating percentages.

Table 3: Comparison of household composition of respondents with Scottish Household Survey results (2003/4)

Household composition	Illness/Disability research respondents %	SHS 2003/4 ¹⁹ %
Single adult (non pensioner), no children	39	23.6
All households with children	32	38.1
Single parent	13	8.4

31. The proportion of single adult/no children households in the survey, 39%, was significantly higher than the proportion in the general population, which was

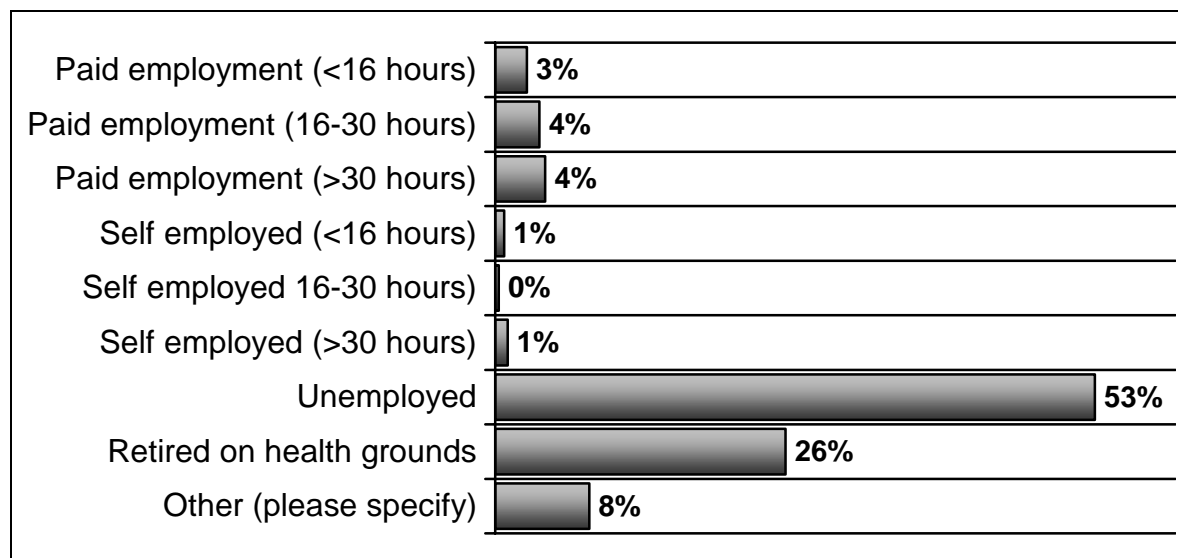
¹⁹ Scottish Household Survey (SHS) 2003/4.

24% in 2003/4. The proportion of all households with children was slightly lower than the general population (32% compared with 38%), but there were just over 50% more single parent households in this sample than in the Scottish population (13% compared with 8%). These results suggest that CAB clients claiming IB or DLA are more likely than the general population to be in single parent households or single adult households.

Employment status

32. The employment status of respondents shows that the majority of research respondents were unemployed, as would be expected, given the nature of the research and the target respondents. Figure 4, below, shows that 53% of respondents were unemployed (compared to 21% of overall CAB clients) and a further 26% were retired on health grounds. Just over a tenth (11%) were employed, full- or part-time, and 2% were self employed, full- or part-time.
33. The 'other' category included a range of situations, including being a student or carer.

Figure 4: Employment status of respondents



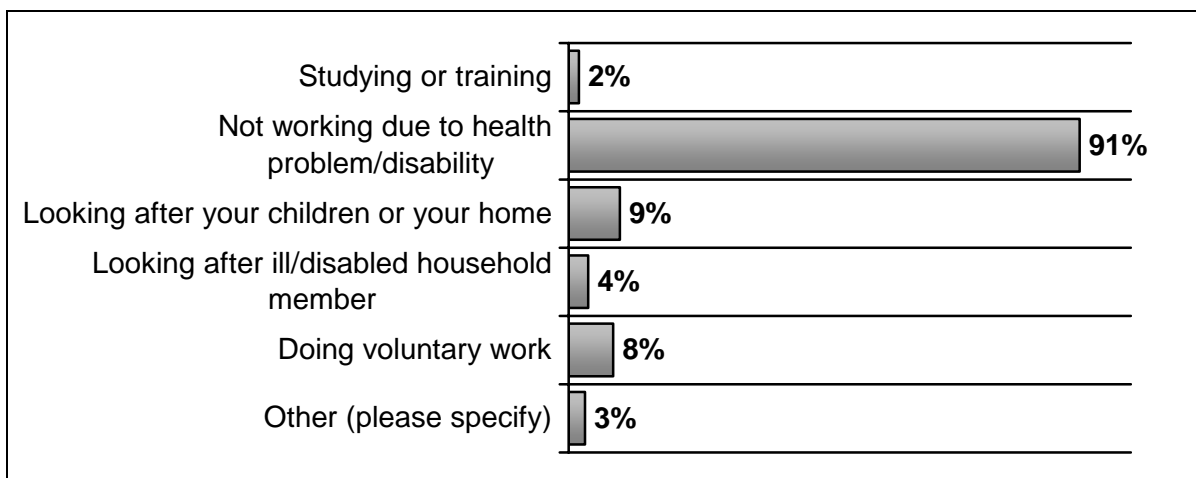
Base: 363

34. Respondents were asked if they had any additional work-related circumstances to report. Their responses are shown in Figure 5, overleaf, and add up to more than 100 because respondents could choose multiple additional circumstances. The vast majority (91%) of respondents reported that they were not working due to a health problem or disability, which demonstrates that the research reached its target group. Just under a tenth (9%) of respondents were looking after their family or their home. Twelve respondents (4%) stated they were looking after an ill or disabled family member, indicating that at least two people in these households had a disability or health problem. Twenty-seven respondents (8%) were doing voluntary work, which suggests that they both want to and are able to work, but may have been unable to find paid work which accommodated their health condition, or, for various reasons, may have a preference for voluntary work. For instance, voluntary work may offer greater flexibility of workload and

hours and claimants may perceive that it will be less likely to impact on their benefits.

- 35. Only 2% of respondents were studying or training. This contrasts with the finding that nearly half of those who thought they might be able to work again if their health improved sufficiently said they would like training or to learn new work-related skills (see Figure 21).
- 36. Those who ticked the 'other' category in relation to employment status gave a range of circumstances (not all of which were relevant to the question), including "previous business failed", "job seeking", "I stopped work to bring up children but my health now stops me working" and "on course to get back to work".

Figure 5: Additional circumstances



Base 341

Claimants of Incapacity Benefit and/or Disability Living Allowance

- 37. The CAB clients targeted for this research were those who were either already claiming, or in the process of claiming IB or DLA, or both. Table 4 shows the percentage claiming these benefits. The figures in Table 4 are based on 384 valid responses (92% of the respondents), as 33 respondents skipped one, or both, of these questions and are therefore excluded. Nevertheless, the figures demonstrate that the research largely reached its target group.

Table 4: Percentage of respondents who were already claiming or starting a new claim for IB, DLA or both benefits

IB %	DLA %	Both %	Total %
29	19	52	100

Base: 384

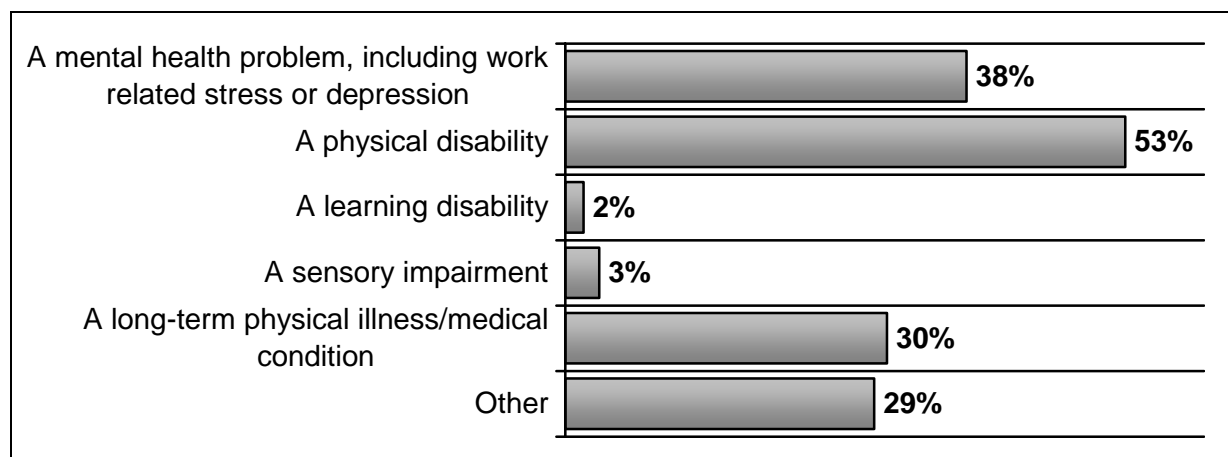
Main illness or disability

Summary of key points:

- More than three-quarters (77%) of respondents reported only one main illness or disability condition and 23% reported more than one
- The majority of respondents (53%) said their main condition was a physical disability
- A mental health problem was the main condition experienced by almost two-fifths (38%) of respondents
- Just under one-third (30%) of respondents reported that a long-term illness or medical condition was their main condition affecting work
- More than three-quarters (78%) of respondents said their health was fluctuating or getting worse
- These findings have important implications for benefit reforms, particularly indicating the need for flexibility and support.

38. This section describes the type of illness or disability that had affected the ability of research respondents to work and the stability of their condition.
39. Respondents were asked what was the main illness or disability which had affected their ability to work. Responses are shown in Figure 6. The percentages add up to more than 100 because respondents were able to identify more than one main condition. Overall, 23% of respondents gave more than one main condition.
40. More than half (53%) of respondents reported having a physical disability and almost two-fifths (38%) had a mental health problem. Just under one third (30%) had a long-term physical illness or medical condition. Only 3% had a sensory impairment and 2% a learning disability. There were no significant differences between respondents with different health conditions in the proportions claiming IB or DLA.

Figure 6: Main illness or disability which has affected respondents' ability to work



Base: 411

41. The 'other' category shown in Figure 6 includes those who gave additional (rather than alternative) information about their condition. Some of the comments illustrate both the multiplicity of health problems which some respondents experience and the impact that their condition has had on their ability to work. They include:

"I have epilepsy which makes a lot of jobs out of my reach. Can't get driving licence which has also stopped employment at interview stage"

"At college, but mood swings affect getting work"

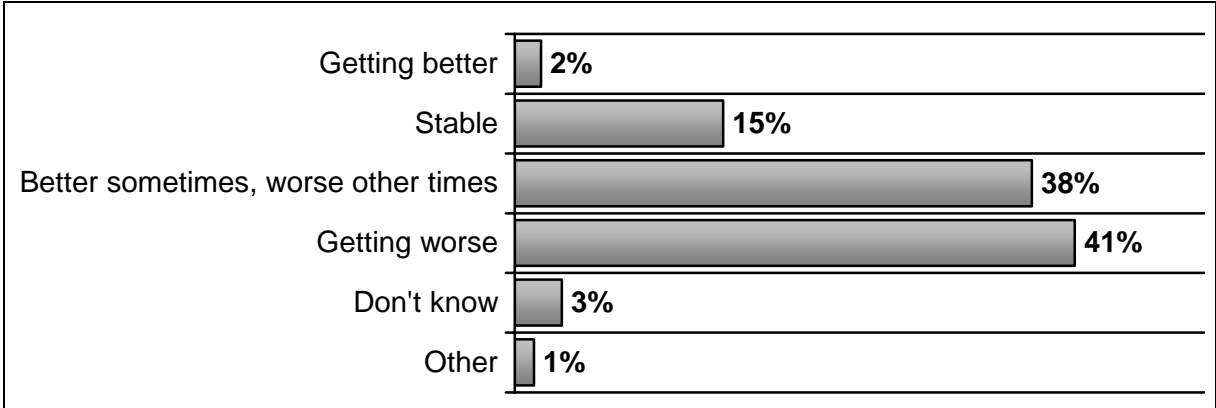
"A degenerative disease which is very limiting. Part-time voluntary work is all I am capable of"

"Suffered brain damage after motorcycle accident - suffered memory loss as result, now anxiety/depression"

"Ischaemic heart disease, arthritis, depression"

42. Figure 7, below, shows that less than one-sixth of respondents (15%) reported that their health was stable and only 2% reported that it was getting better. The majority of respondents reported that their health was getting worse (41%) or was better sometimes and worse other times (38%).

Figure 7: Stability of respondents' health



Base 416

43. The information on respondents' main condition and the fluctuating or worsening nature of their health has important implications for the proposed reforms of IB. The revised Personal Capability Assessment process and requirements to undertake work-related tasks, such as work-focused interviews and personal action plans, should take into account the often fluctuating or worsening nature of people's health problems and provide appropriate flexibility and support. The following case study illustrates why this is necessary.

An East of Scotland CAB reports of a client in receipt of IB, who had had depression for a number of years. His condition had worsened recently following the death of his mother and his being made redundant. The client stated that in terms of his health, he has good and bad days — some days he does not eat at all and frequently sleeps on the sofa in his living room. He had been dealing with Jobcentre Plus regarding his benefits, and commented that they were trying to help him back into work although he did not feel ready for this.

44. The proposal to introduce a two-tier structure for the new Employment Support Allowance will call on DWP Decision Makers to decide on the level of benefit to be awarded, based on the assessed severity of a claimant's health condition and their perceived capability for work. Research commissioned by the DWP has noted the difficulty of finding a fair and effective way to divide benefit claimants into these two categories²⁰.
45. In addition, the UK Government's proposals to improve workplace health, as outlined in the welfare reform green paper, should encourage a flexible approach by employers to employees (or prospective employees) who have fluctuating health conditions. The case study below gives an example of one employer's positive approach.

Case study: Stepping Stones for Families traffic light scheme

Stepping Stones for Families is a Scottish voluntary organisation that employs 70 people. One of its employees suffers from a recurring psychotic illness which means that she sometimes finds it hard to do parts of her job, needs a break, or needs to modify her working day. Along with her employer and psychologist, she developed a 'traffic light' scheme, which helps her to manage her work and stay employed. She said, "Now I simply say to my employer that it's a green, amber or red day and she knows what I mean." Green means she carries out all her usual duties, including facilitating meetings, responding to consultation documents and internet-based work. Amber means modifying her day's work, perhaps working alone with flexible hours, or from home, until she feels better again. Red means she calls the doctor. The system has been so successful that Stepping Stones for Families has now adopted it for all employees, not just those with mental ill health.

Based on a Guardian Unlimited article, Nov 2005. For further information, see <http://society.guardian.co.uk/careers/story/0,7916,1606046,00.html>

²⁰ Taking the long view, Institute for Social and Economic Research, ISER report 2005/06. Cited in, A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006

The impact of illness or disability on work and income

Summary of key points:

- For the vast majority (84%) of respondents, illness or disability had prevented them from working.
- A small proportion of respondents (13%) were still in employment or self employment
- Nearly half (46%) had been out of work for five years or more
- More than two-thirds of respondents (69%) were on a low income of less than £800 per month, and 29% had a monthly income of less than £400
- Low income was particularly marked among single adult households
- Sixty two per cent of respondents only had income from benefits or tax credits
- The majority of respondents were dependent on IB or DLA, or both, which are subject to review, can be withdrawn and do not bring automatic entitlement to 'passport' benefits, such as exemption from prescription charges and access to the Social Fund.

46. For the vast majority (72%) of respondents, their illness or disability had caused them to stop being employed and for 12% it had prevented them from ever being employed.
47. However, a small proportion of respondents (13%) reported being employed or self employed. These respondents were asked a supplementary question about whether they were attending work, as it is possible for some people to be in receipt of, or claiming, IB or DLA and be employed, but sometimes not actually attending work due to ill-health.
48. In this sample, 35 respondents (8% of the total) were employed but not attending work. Most of these were already claiming, or about to claim, IB and a small number were claiming DLA. About half were employed full-time and half part-time. Thirteen respondents (3% overall) were employed and attending work, most of them part-time, and either claiming or making a new claim for DLA. Only a few of these were claiming IB.
49. Respondents who are still employed are in an important transition period, during which steps to improve retention by employers could have a significant impact. The UK Government's proposals for welfare reform include facilitating better absence management by employers and early intervention and support to encourage people to stay in work or return to work. The following example given by a respondent illustrates this point.

“In the year 2001, I had been employed for 20 years as a supervisor. An employee, who was there for a year, made allegations and invented stories about my conduct. I continued working for six months after this happened and asked management for support but this didn't happen. In July 2001, I faced a grievance procedure and had 13 allegations made against me by this employee. I never found out the outcome. By October I left my job due to stress, went to the GP and was given medication (which continues) and was pensioned off two years ago. I could still be in a job earning £300 a week if proper support was in place”

50. Respondents whose illness or disability had caused them to stop being employed were asked when they were last employed. Table 5, below, summarises the data by year of last employment. Of the 177 who responded, more than one-third (35%) had last been employed in 2004 or later and almost one-half (46%) had been out of employment for more than five years. The year of last employment ranged from 1979 to 2006.

Table 5: Year of last employment among respondents whose illness or disability stopped them from being employed

Year of last employment	Approximate number of years since last employment ²¹	% respondents
2004-2006	0-2	35
2002-2003	3-4	15
1997-2001	5-9	21
1982-1996	10-14	23
1981 or earlier	>15	2
Not sure	N/A	4
Total		100

Base: 177

51. The longer a person has been out of work, the more difficult it may be for them to return. The UK Government's pilot Pathways to Work programme has reported some success in assisting sick and disabled people back to work, through the provision of appropriate help and support. It is proposed to roll out this programme nationally by 2008. However, “the statistical success of the Pathways programme is largely based on the experiences of new claimants”²², so it is essential that the Pathways programme is also able to provide comprehensive, appropriate and tailored support to the larger proportion of people who have been out of work for a longer period.
52. The Scottish Association for Mental Health (SAMH) recommends that, for people who have been out of work for some time, there should be pre-

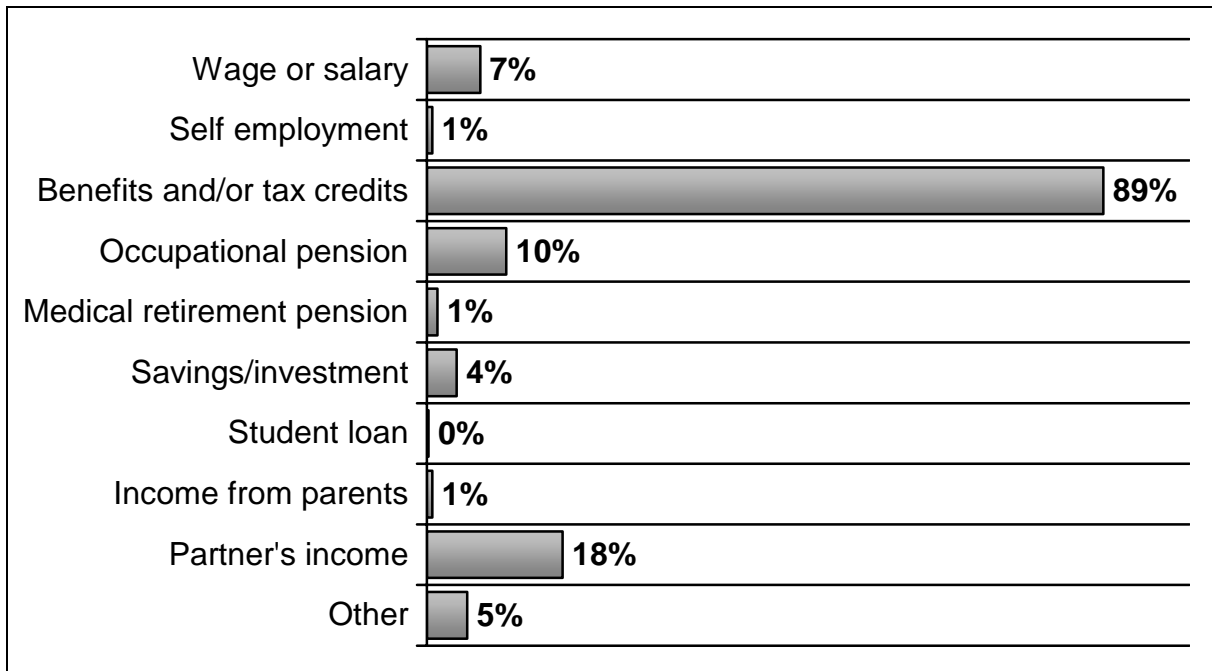
²¹ Exact number of years cannot be given as respondents did not always give month of last employment. Research took place in March and April 2006.

²² From, A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006, p.11

vocational training on self esteem and confidence-building, a therapeutic work scheme and provision of support for people to undertake voluntary work, which can often be a step towards employment²³.

53. Respondents' sources of income are shown in Figure 8, below. The percentages add up to more than 100 because respondents could have more than one source of income. The vast majority of respondents (89%) received some income from social security benefits and/or tax credits. This would be expected, given that most respondents were not working.

Figure 8: Sources of income of respondents



Base 415

54. Almost one-fifth (18%) of respondents reported that they had income from a partner. Ten per cent were in receipt of an occupational pension and 7% were receiving a wage or salary. Of those who replied 'other', two respondents had no income at all (one of whom was in the process of applying for benefits) and the remainder had various sources of income including maintenance, rent, educational allowance, contributions from family and grants.
55. For 259 respondents (62%), their *only* source of income was benefits or tax credits. This is a higher proportion than for CAB debt clients, where benefits or tax credits was the sole income source for just over half of respondents in the debt research conducted by CAS in 2003.
56. The monthly household income of respondents is shown overleaf, in Table 6. In the current research, nearly a third (29%) of respondents had a monthly household income of less than £400 and over two-thirds of the sample (69%) had a household income of £800 or less per month. A monthly income of £800 equates to an annual net income of £9,600. This allows a comparison between

²³ Scottish Association for Mental Health response to consultation, A new deal for welfare: Empowering people to work, SAMH, April 2006

the levels of income in this research and the national data from the SHS²⁴, in which only 18% of the general population (excluding single pensioner and smaller older households) had an annual income of £10,000 or less. It indicates that the respondent population was approximately four times as likely as the general population to have an income of under £10,000 (69% under £9,600 compared with 18% under £10,000).

57. The basic weekly rate of IB for those on the short-term benefit is either £59.20 (lower rate) or £70.05 (higher rate). Those on the long-term rate receive £78.50 per week. These figures can be compared with UK median gross weekly earnings in April 2005 of £431²⁵, equivalent to an annual income of over £22,000, which helps to explain the high levels of low income among the research respondents compared to the general population.

Table 6: Household income

Monthly household income level (number of respondents)						
Household type	Less than £400	£401-800	£801-1200	£1201-1600	£1600-2000	£2000+
Single adult	88	56	13	0	1	1
Single parent	8	38	6	1	0	1
Couple with no children	9	32	16	10	6	4
Couple with children	5	18	18	16	9	5
Other	2	8	5	5	2	0
TOTAL	112	152	58	32	18	11
% of respondents	29	40	15	8	5	3

Base: 383 (Data excludes 28 households with more than one adult who gave only individual income)

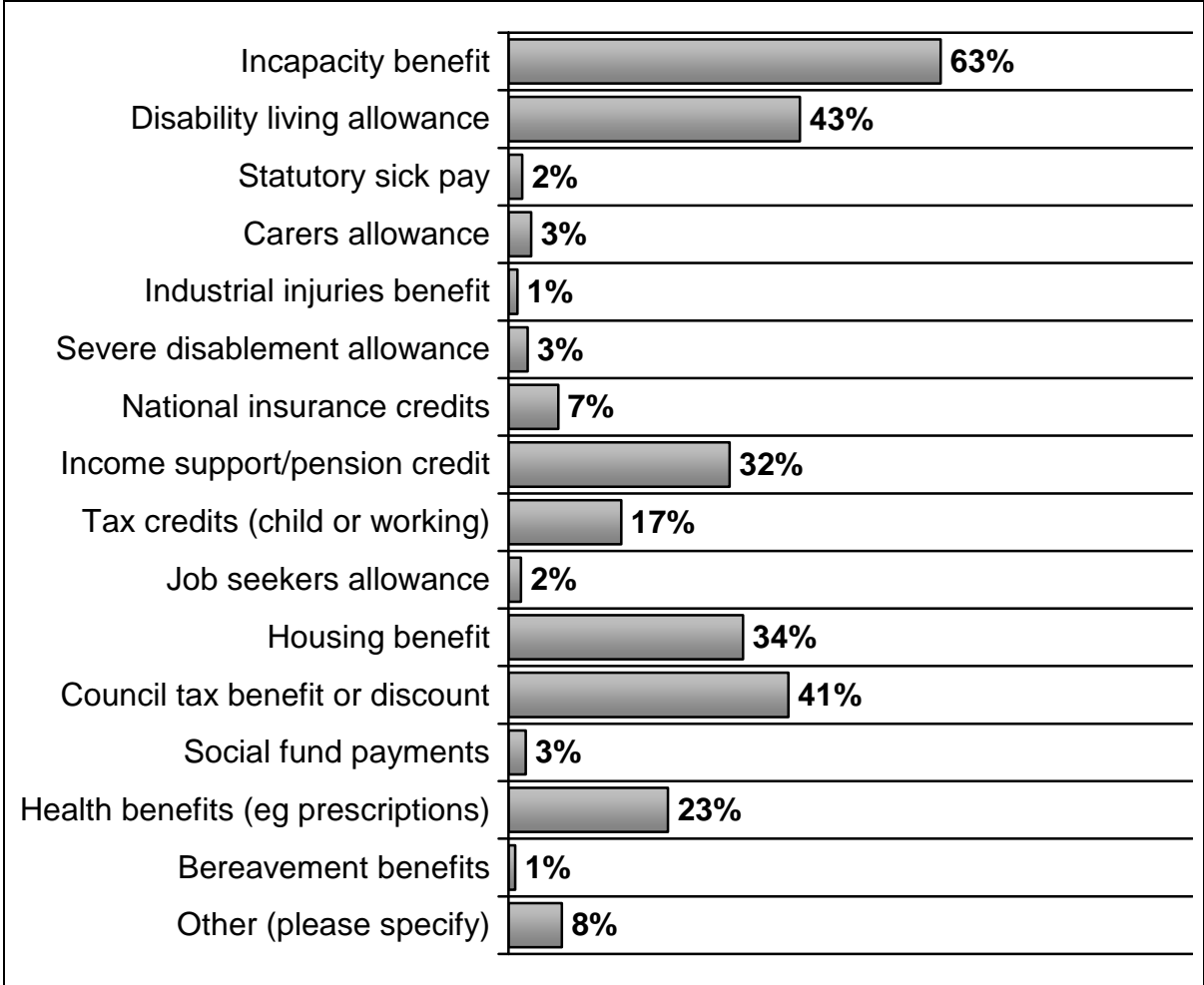
58. The household income levels of respondents in this research are also lower than in the 2003 debt research, which showed that 54% of debt clients had monthly household incomes of less than £800. This reflects the fact that most respondents in the disability/illness research (89%) are in receipt of benefits or tax credits and more than three quarters are not working. In the debt research, about half of the sample was receiving income from work. Furthermore, both the debt research and the SHS are based on data from 2003, meaning that the income levels of respondents in the current research are even lower, relatively, because of subsequent inflation.
59. In this survey, very low income is particularly marked among single adult households, though they are also likely to have lower household costs. More than three-quarters (79%) of those with an income of less than £400 per month were single adults, although single adults made up only 39% of the overall sample. This may be because they are less likely to have additional household income (e.g. from a partner) or to qualify for benefits related to having children.

²⁴ Scottish Household Survey (SHS), Scottish Executive, 2003/4

²⁵ <http://www.statistics.gov.uk/cci/nugget.asp?id=285>, based on full-time employees

60. The types of benefits that respondents were receiving are shown in Figure 9, below. Respondents could be receiving more than one benefit. Almost two-thirds (63%) of respondents were in receipt of IB and nearly half (43%) were in receipt of DLA.

Figure 9: Type of benefits received by respondents



Base: 399

- 61. Other sources of benefit income included Council Tax Benefit or discount (41%), Housing Benefit (34%) and Income Support or Pension Credit (32%).
- 62. Given that nearly all respondents reported a health problem or disability, a relatively low proportion (23%) were receiving health benefits (such as free dental treatment or prescriptions). Seventeen per cent of respondents were receiving Child or Working Tax Credits, which is a similar proportion to those who had one or more children under 16. Seven per cent of respondents were receiving national insurance credits.
- 63. Fewer than 5% of respondents were receiving Statutory Sick Pay (SSP), Carers Allowance, Industrial Injuries Benefit, Severe Disablement Allowance, Jobseeker’s Allowance, Social Fund payments or bereavement benefits. Of the 31 respondents who said they were employed but not attending work and that their illness or disability had stopped them attending, only five (16%) were on SSP. SSP is paid by an individual’s employer for a maximum period of 28 weeks, at which point the person transfers to IB (short-term higher rate).

64. A high proportion of respondents are dependent on IB and DLA as a major source of income. However, the cycle of review and re-assessment that forms part of the claims process for both these benefits can result in entitlement being reduced or removed altogether. Although in many cases benefits are reinstated at appeal, the whole process can result in quite significant income fluctuations and financial uncertainty. In addition, people on IB or DLA do not have automatic entitlement to 'passport benefits' such as free prescriptions or access to the Social Fund. These issues were discussed in some detail in CAS's 2003 report, *Riding the Benefits Rollercoaster*. The following case studies illustrate some of these difficulties.

An East of Scotland CAB reports of a client who had been in receipt of IB for eight years. He was in receipt of the long-term rate, as well as an age addition for being under 45 years old. He failed a Personal Capability Assessment, and failed to win his tribunal which he attended without representation. Some months later, he made a new application, which was also turned down. With help from the bureau, the second claim has now been accepted — but it will not be backdated to the date of the failed Personal Capability Assessment, although the client's condition is unchanged. As a result of this, the client will be treated like a new claimant and will lose the age addition as he is now over the age limit for the age-related addition.

A West of Scotland CAB reports of a client who had appealed an IB decision which had found him capable of work. His tribunal was scheduled to take place ten months after the appeal started, and he was suffering severe financial hardship due to the length of time he had to wait.

A West of Scotland CAB reports of a client who had been living on reduced rate Income Support for the previous three months, whilst he had been appealing an IB decision. The appeal had been upheld and the client was advised that this decision should take one week to process. A month later, the client was still receiving the reduced rate of Income Support and was struggling financially. He had found the Jobcentre Plus staff unhelpful, and was struggling to resolve the problem on his own as he had chronic fatigue syndrome.

An East of Scotland CAB reports of a male client who had recently been discharged from psychiatric hospital. The client was in receipt of IB but not Income Support. The client was worse off than he would have been on Income Support as he was not entitled to passported benefits. As well as having to contribute to his housing and council tax costs, this meant he also had to pay all of his prescription charges.

65. Previous CAS publications²⁶ have demonstrated that Council Tax Benefit and Housing Benefit can be poorly administered and this exacerbates hardship for those on low incomes.

²⁶ Council tax: CAS briefing paper, Citizens Advice Scotland, January 2006; A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006

Claiming Incapacity Benefit

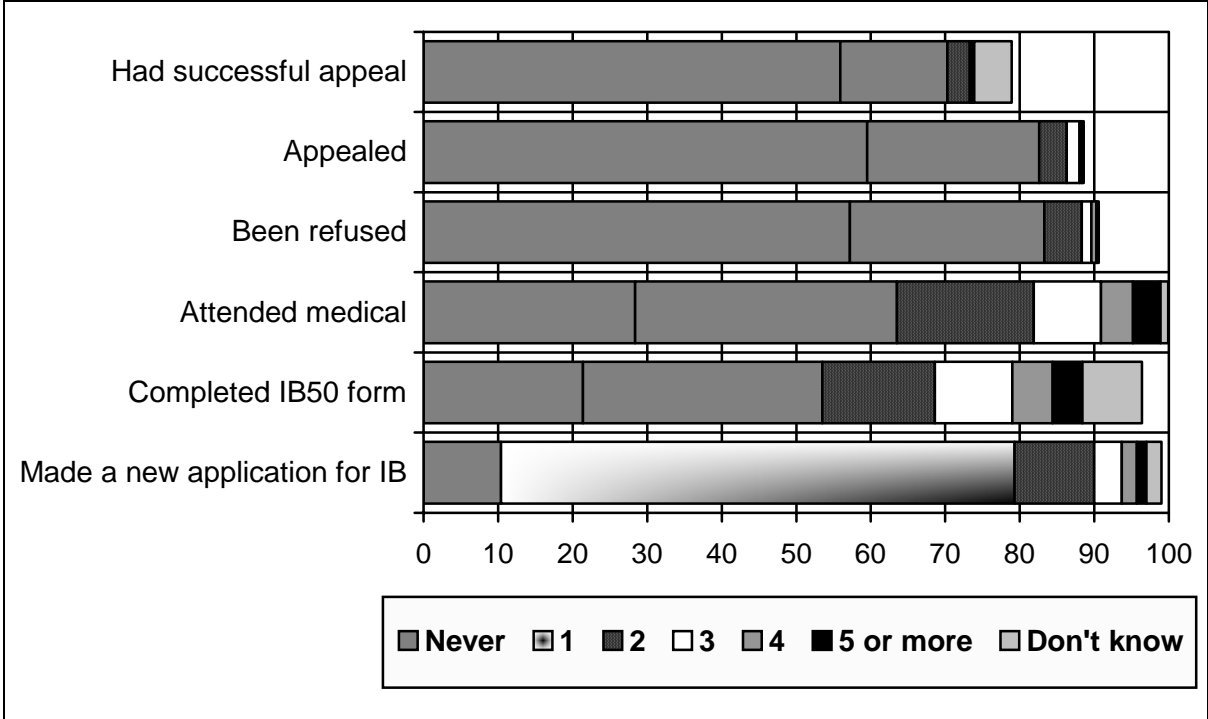
Summary of key points on claiming Incapacity Benefit

- The majority of respondents (69%) had made only one previous application for IB
- More than one-third (34%) of IB claimants had completed a self-assessment IB50 form twice or more and more than one-third (36%) had attended a medical twice or more
- One-third (33%) of IB claimants had been refused IB at least once before
- The number of successful appeals indicates a success rate of approximately 63%, which suggests that a significant proportion of refusal decisions are incorrect
- Just over one-sixth (17%) of those commenting had no problems claiming IB
- The majority (four-fifths) of those commenting described difficult or negative experiences with the process of claiming IB, including problems with form-filling, doctors, medicals, delays in payment, the detrimental effect on their health or well-being and the difficulty of living on the IB amount.

66. Incapacity Benefit (IB) is the key contributory benefit for people who are incapable of work because of illness or disability. In order to qualify for IB, claimants must be incapable of work, not entitled to Statutory Sick Pay, and have sufficient National Insurance contributions. IB is payable at three rates: a lower short-term rate, a higher short-term rate and a long-term rate, according to the length of time the incapacity has lasted.
67. In some cases, claimants may be automatically treated as incapable of work. However, most claimants will be obliged to satisfy one of two tests demonstrating that they are incapable of work: the own occupation test or the Personal Capability Assessment (PCA). For further details of these tests, please see the Notes about Incapacity Benefit section (p10).
68. The question of whether a person is incapable of work is decided by a Decision Maker acting on behalf of the Secretary of State for Work and Pensions. If a claimant is found capable of work following either the own occupation test or the PCA, they can challenge the decision by asking for it to be looked at again or by making a written appeal. Claimants who are waiting for their IB appeal to be heard can claim Income Support, although they face a sanction of a 20% cut in benefit levels. Alternatively, they can claim Jobseeker's Allowance but they must meet the availability for work criteria. If a claimant is found incapable of work (and satisfies the other entitlement conditions), they will be awarded IB. It is current policy that most IB claims must be reviewed by conducting a PCA every three to five years. However, in reality, many claims are actually reviewed far more frequently than this, e.g. six-monthly or annually. The PCA review comprises a self-assessment questionnaire (which may be supplemented by medical evidence from a GP or other health professional) and/or an examination by a Medical Services doctor.

69. In this survey, almost four-fifths (80%) of respondents were either already claiming, or making a new claim for, IB. Figure 10, below, and Table 7, overleaf, summarise the process of claiming IB which they have experienced²⁷.

Figure 10: Respondents' experiences of claiming IB



Base: 299 (only those already claiming/receiving IB or starting a new claim for IB).

70. The majority of respondents claiming IB (69%) had made only one previous application and 10% were making their first application that day. Eighteen per cent had made two or more applications. The majority of respondents (66%) had completed an IB50 form at least once in the past, with more than one-third (34%) completing one at least twice. The majority of respondents had also attended a medical, with over one-third (35%) attending once before and more than one-third (36%) attending twice or more. It is not possible to distinguish between those who had made multiple applications for IB during a single period of incapacity for work and those whose multiple applications related to separate periods of incapacity. In addition, the numbers going through review may reflect the fact that 46% had been unemployed for five years or more.

71. More than one-quarter (26%) of respondents had been refused IB once in the past and a further 7% had been refused twice or more. More than one-quarter (29%) of respondents had appealed a refusal of IB at least once and 18% had successfully appealed, suggesting a success rate of approximately 63% for IB appeals. Five per cent of respondents did not know if their appeal had been successful and a number of other respondents commented elsewhere in the questionnaire that they had an appeal decision pending. The figures in this research do not show those who decided not to appeal.

²⁷ Percentages do not always add up to 100, because some respondents skipped some parts of the question

Table 7: Process of claiming IB experienced by respondents

No. of times	Made a new application for IB	Completed IB 50 form	Attended medical	Been refused	Appealed	Had successful appeal
Never	31 (10%)	64 (21%)	85 (28%)	171 (57%)	178 (60%)	167 (56%)
1	206 (69%)	96 (32%)	105 (35%)	78 (26%)	69 (23%)	43 (14%)
2	32 (11%)	45 (15%)	55 (19%)	15 (5%)	11 (4%)	9 (3%)
3	11 (4%)	31 (10%)	27 (9%)	4 (1%)	5 (2%)	1 (<1%)
4	6 (2%)	16 (5%)	13 (4%)	2 (1%)	1 (<1%)	1 (<1%)
5 or more	4 (1%)	12 (4%)	11 (4%)	0 (0%)	0 (0%)	0 (0%)
Don't know	6 (2%)	24 (8%)	3 (1%)	1 (<1%)	1 (<1%)	15 (5%)
Total	296 (99%)	288 (95%)	299 (100%)	271 (90%)	265 (90%)	236 (79%)

Base: 299 (only those already claiming/receiving IB or starting a new claim for IB).

72. CAS has previously expressed concern about the standards of decision-making in relation to IB claims and the detrimental effect this can have on clients²⁸. In its response to the green paper on welfare reform, CAS quoted figures from The Appeals Service which showed that across all appeal types, 48.8% of IB appeals relating to a PCA were successful. Where both the claimant and a representative such as a CAB adviser attended the appeal hearing, the success rate rose to 73.6%²⁹. The figures obtained in the current survey are broadly consistent with this, showing that of the 86 respondents who had appealed an IB refusal, 54 (63%) had had a successful appeal. This suggests that a relatively high proportion of refusals may be incorrect. The case studies below illustrate problems with decision-making and the appeals process.

A West of Scotland CAB reports of a client who had been in receipt of IB for two years. He was diagnosed as suffering from chronic and acute back pain, gall stones and an enlarged prostate gland, as well as depression following an acrimonious separation and divorce. His claim for IB was disallowed following a medical at which he was awarded only six points. His appeal was rejected, but, when the client proceeded to tribunal, he was awarded 23 points and his IB was reinstated and backdated.

²⁸ A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006

²⁹ A new deal for welfare: Empowering people to work – A response from Citizens Advice Scotland, April 2006

An East of Scotland CAB reports of a client who was awarded IB. Following a medical assessment just six months later, it was withdrawn when she was awarded only five points under the mental health descriptors. She appealed the decision and the tribunal reinstated the benefit. Six months later the client was again required to attend a medical. She was once more awarded five points under the mental health descriptors and her IB was withdrawn. The client appealed the decision, and again her benefit was reinstated at tribunal.

An East of Scotland CAB reports of a male client with ischaemic heart disease, who was awarded IB for life in 2000. In 2003, he was sent a PCA form which he completed himself, believing that it related only to his heart disease and not other conditions he had subsequently developed. At a medical the doctor did not listen to his heart and his IB was withdrawn. The case went to appeal in 2003 and was unsuccessful, despite including evidence from his GP and hospital consultant. The client has been living on a reduced income whilst waiting for the appeal. Since then he has re-applied for IB and the outcome is not yet known.

A West of Scotland CAB reports of a male client with agoraphobia whom, due to his condition, did not attend a medical for his IB. The case went to tribunal and, again, the client felt unable to attend, so his mother went to speak on his behalf. The tribunal was unsuccessful, mainly because the Chair was unwilling to accept the mother's evidence. After an appeal to the Commissioners, a re-hearing was ordered, and this time the client was successful. Less than a year later, the client was asked to attend another medical and after protracted intervention by the bureau, it was agreed that this could be held at the client's home. The client was awarded sufficient points for the renewal of his benefit.

73. Additionally, some of the comments made by respondents illustrate problems with decision-making and the appeals process.

"Taken off about five years ago, appealed and won three months later."

"Always a worry that I will be taken off IB"

"At the start of receiving IB I was recalled every six months to fill out forms and have a medical. This was an ordeal. Now my doctor has had this changed to every three years³⁰."

³⁰ The rules governing IB do not allow doctors to make such decisions. However, the respondent's perception that this is the case illustrates the confusion that can arise for claimants in relation to the IB decision-making process.

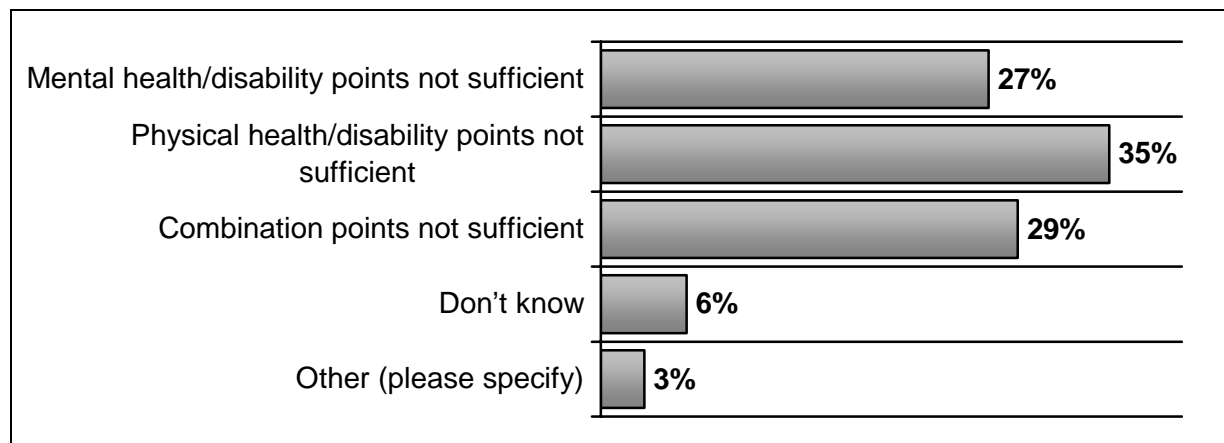
“Too complicated and stressful. When one appeal is successful it seemed like no time until I was sent for a medical again. Couldn't have managed without help.”

“I have worked for 43 years and never claimed any state benefit and when I had to claim IB for a genuine reason that I couldn't work I only received IB for approximately six weeks before it was stopped after a medical”.

“Having to go to tribunals is very stressful and makes my condition worse”.

74. Figure 11, below, shows that 101 respondents gave information about their most recent refusal of IB. Over one-third (35%) had been refused on the grounds that their physical health or disability points were insufficient, over a quarter (27%) because their mental health points were insufficient and 29% because their combined physical and mental health points were not sufficient.

Figure 11: Reasons for most recent refusal of IB



Base: 101

75. Two people provided other comments about a refusal, as quoted below:

“My first appeal had to go to the social security commissioners where it was returned for a hearing which was then successful. Second appeal successful, next new claim successful”

“Couldn't attend second date for medical due to illness and DWP refused to accept this as a good reason”

76. The vast majority (95%) of people on IB had not undertaken 'permitted work' whilst on the benefit. Among the 12 respondents who had, ten were no longer doing permitted work, eight because it had adversely affected their health, one because it adversely affected their benefits and one because they had completed a trial programme. The green paper on welfare reform recognised that the permitted work rules were not as effective as they could be and that they were underused. It is proposed that previously announced changes to the

permitted work scheme will be carried forward into the latest reforms and that return to work credits will be paid to remove the financial disincentive to work.

77. Respondents were asked if they would like to make any comments on their experience of claiming IB. One hundred and seventy two respondents did so, which is just over half (53%) of those claiming IB. Their comments are summarised below, in Table 8.
78. Seventeen per cent of those commenting said they had no problems or commented positively on their experience. It is possible that these neutral and positive experiences were shaped by the help and support these clients had received from bureaux at an early stage in the benefit claiming process. In other words, those who reported no problems might have had no problems specifically because they were being assisted by a trained CAB adviser. The remaining four-fifths made largely negative comments, although it is important to bear in mind that those with negative experiences may be more likely to comment. The most common negative comments were in relation to forms, the DWP contracted Medical Services doctor and/or the medical and the delays and bureaucracy involved. The number of comments by theme adds up to more than 172, because some comments covered more than one theme.

Table 8: Comments on the experience of claiming IB

Theme	Number	% of those commenting
Forms difficult to fill in, complex, confusing	31	18
No problems, fine, straightforward	30	17
Problems with doctors or medicals, e.g. doctor did not understand, medical too far away, embarrassing, demeaning or inaccurate recording of condition/incapacity	24	14
Bureaucracy, red tape, delays	18	11
Adverse effect of process of claiming on health or well-being	14	8
Amount of benefit is too low	14	8
Problems meeting criteria, definitions of conditions/incapacity	12	7
Lack of respondents' awareness or understanding about entitlement and claiming process	11	6
Problems with the general process	11	6
Problems with appeals or tribunals	10	6
General negative comments	6	4
Help required with claiming	5	3
NI insufficient to receive benefit	4	2

79. Some examples of comments are quoted below by way of illustration.

“No problems - everything has been pretty easy and straightforward”

“Forms very confusing and difficult”

“Get confused filling in forms owing to mental health problems”

“The medical was really rough, I was ill for days afterwards because of the exertion required. I had to pick up a two pence piece and I couldn't and the Doctor made me. He didn't help me up and I had to crawl to a chair. The medical took two hours. My second medical was better and only lasted one hour.”

“Examining Doctor was Greek and I couldn't understand him, he couldn't understand me. I suffer from Parkinsons, getting worse. Found fit for work. What a joke, I can't even write my name.”

“Never received IB for seven weeks after applying, due to paperwork being left in a tray at the local Job Centre”

“I feel I have been treated appallingly by the DWP in regard to my claim for IB. From the onset of my illness I worked 35 years and never been off work and have been misguided, misled all the way through the process of my claim since attending for a medical examination. I am now sitting entitled to no benefit because of insufficient credits and being unaware of this situation”.

“The system doesn't work, The law says I am entitled to make an advance claim (Reg13(1)). The mechanics of the system prevent me from doing this. The staff in the system are unaware of advance claim entitlement. Their mindset is that it is means tested & if they cannot verify every detail they will not even examine the claim. The computer cannot accept advance claims. Call centre staff and managers were adamant that I could not make an advance claim. Presented with evidence that I could, the system was still unable to do this. All I achieved was the promise of staff retraining. I had to then make manual claims which were challenged. Both the Job Centre Plus and Processing Unit are un-contactable because of overload. Security staff at Job Centre were pleasant, reception staff were not. Reception staff made me discuss personal details in front of others. Attitude was abrasive. This continued when interviewed. IS and IB claims now made together to a Call Centre since 18/1.”

“Having to go to tribunals is very stressful and makes my condition worse.”

“Due to writing and reading difficulties, I do not understand what I am signing and do not get explanations”

“Does not give enough to live on”

Claiming Disability Living Allowance

Summary of key points:

- Almost half (47%) of respondents had made only one previous application for DLA
- The majority of DLA claimants (over 60%) had never had their level of award either decreased or increased
- Over two-fifths (43%) of DLA claimants have been refused all or part of their DLA at least once before
- The number of successful appeals indicates a success rate of approximately 52%, which suggests that a significant proportion of refusal decisions are incorrect
- Just over one-tenth (11%) of those commenting had no problems claiming DLA
- The majority of those commenting described difficult or negative experiences with the process of claiming DLA, in particular with the complexity of forms, problems with appeals or tribunals, the difficulty of meeting criteria, problems with doctors or medicals, and the detrimental effect of the process on their health or well-being.

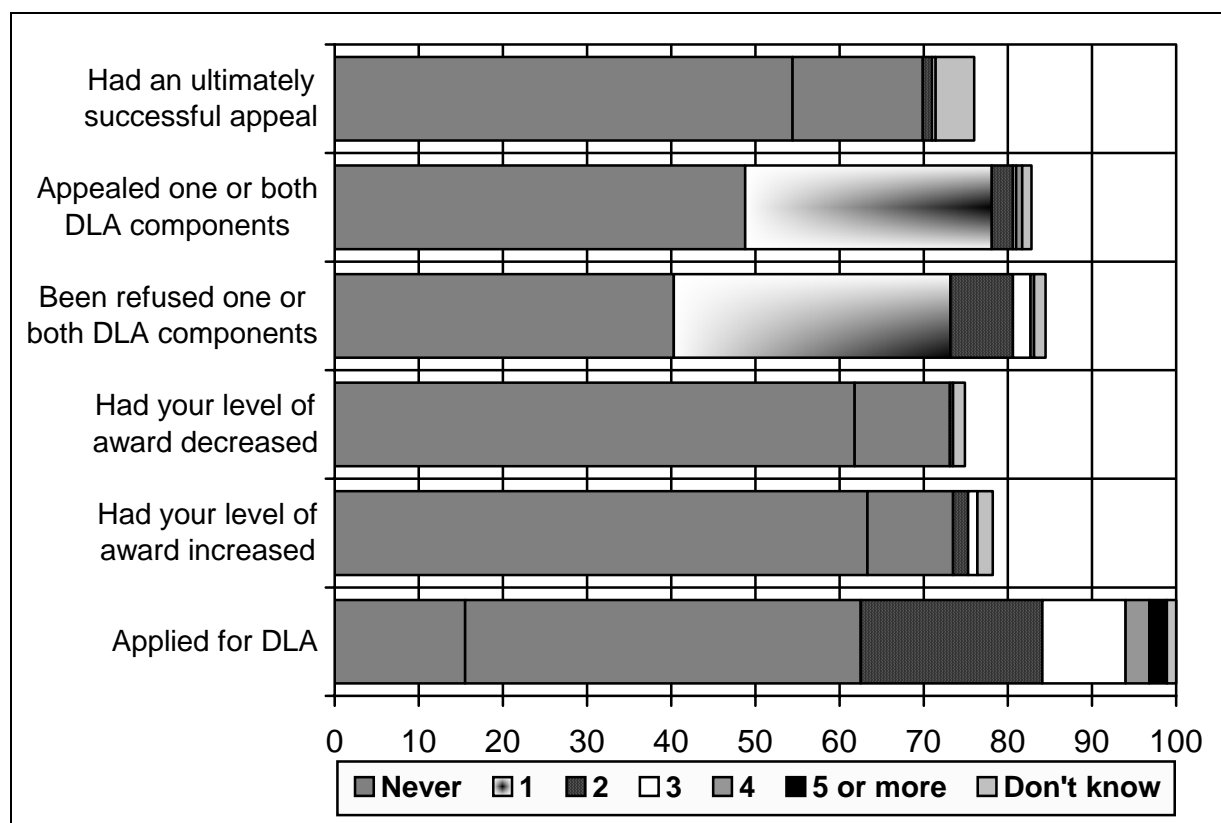
80. Disability Living Allowance (DLA) is a non-contributory, non-means tested benefit for people aged under 65 who can demonstrate certain care or mobility needs as a result of illness or disability. It is intended to help with the additional costs associated with illness or disability. DLA is made up of two components: a care component for help with personal care needs, payable at one of three rates (lower-rate, middle-rate and higher-rate) and a mobility component for people who have physical walking difficulties or require accompaniment, payable at one of two rates (lower-rate and higher-rate). The rate at which DLA is received can passport a claimant to different benefits and/or further help. For instance, an award of the higher-rate care component will exempt the claimant from the IB Personal Capability Assessment.
81. A claimant's eligibility for DLA is decided by a DWP Decision Maker acting on behalf of the Secretary of State for Work and Pensions. DLA claimants are required to complete a DLA claim form. Prior to December 2005, the form comprised two sections – the first covered basic eligibility criteria, and the second was made up of a self-assessment questionnaire detailing the claimant's care and mobility needs. A new document, combining sections one and two into a shorter form, was introduced in December 2005. Additional evidence can also be supplied with the DLA claim, such as supporting statements from health professionals or evidence of hospital admissions. Before making a decision, the Decision Maker may refer the claimant for a home examination by a Medical Services doctor.
82. If the claimant is not awarded DLA, they can challenge the decision by asking for it to be looked at again or by making a written appeal. If the claimant is awarded DLA, each component can be awarded indefinitely, or for a limited period (minimum of six months) based on how long the Decision Maker

estimates the claimant's needs will last. If both components are awarded for a fixed term, they are awarded for the same length of time. However, it is possible for one component to be awarded for a fixed period with the other being awarded indefinitely meaning that, in effect, the care and mobility components can be awarded for different lengths of time. If the award is for a fixed period, the client will be sent a renewal pack up to six months before the award expires. Clients applying for renewal of an expired component may have their entitlement to the continuing component looked at again. Fixed term and indefinite awards can also be subject to periodic review. These reviews are carried out through written periodic review forms and, in some cases, a subsequent home medical examination. Some DLA recipients are exempt from review, for instance if they have a specific named condition or are terminally ill.

83. Figure 12 and Table 9 (both overleaf) summarise the process of claiming DLA which has been experienced by respondents³¹. Almost one-half (47%) of respondents had made only one application for DLA and 15% were making their first application that day. Over a third (37%) had made two or more applications. As with IB, it is possible that this number includes some people whose condition has improved and then worsened, so they have come off the benefit and then later made a new application.
84. Thirteen per cent of respondents had had their level of award increased, at least once, compared with 12% who had received a decrease. More than two-fifths (43%) of respondents had been refused all or part of DLA at least once.
85. Nearly one-third (33%) of respondents had appealed a refusal of DLA at least once, of which 17% were successful, suggesting an appeal success rate of approximately 52%. Five per cent of respondents did not know if their appeal had been successful and a number of other respondents commented elsewhere in the questionnaire that they had an appeal decision pending. The figures do not show those who decided not to appeal a benefit decision.

³¹ Percentages do not always add up to 100, because some respondents skipped some parts of the question

Figure 12: Respondents' experiences of claiming DLA



Base: 283 (only those already claiming/receiving DLA or starting a new DLA claim)

Table 9: Process of claiming DLA experienced by respondents

No. of times	Applied for DLA	Had your level of award increased	Had your level of award decreased	Been refused all or part	Appealed all or part	Had an ultimately successful appeal
Never	44 (15%)	179 (63%)	175 (62%)	114 (40%)	138 (49%)	154 (54%)
1	133 (47%)	29 (10%)	32 (11%)	93 (33%)	83 (29%)	44 (16%)
2	61 (22%)	5 (2%)	1 (<1%)	21 (7%)	7 (3%)	3 (1%)
3	28 (10%)	3 (1%)	0 (0%)	6 (2%)	1 (<1%)	1 (<1%)
4	8 (3%)	0 (0%)	0 (0%)	1 (<1%)	2 (1%)	0 (0%)
5 or more	6 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Don't know	3 (1%)	5 (2%)	4 (1%)	4 (1%)	3 (1%)	13 (5%)
Total	283 (100%)	221 (78%)	212 (75%)	239 (84%)	234 (83%)	215 (76%)

Base: 283 (only those already claiming/receiving DLA or starting a new DLA claim)

86. As with IB, CAS has expressed concern about the quality of decision-making in relation to DLA³² and the detrimental effects of this on clients. Some respondents' comments on the review and appeals processes are quoted below:

"I was truly taken aback by being refused as I have serious mobility problems and extensive care needs."

"Had an appeal accepted 26/1/06 but instead of an increase, no DLA at all has been paid since 31/1/06, despite numerous telephone calls, with each department passing the buck. Bathgate, Blackpool and Glasgow, all saying Bathgate should pay, while they say instruction has not come from Blackpool".

"Currently under appeal. I find the process of claiming and appealing the decision very complicated and confusing. I feel I am being dismissed without consideration".

"Appeal pending. Nightmare "

"Appeal pending. Feels like it's a lottery."

"Too complicated - I did this without help and failed and didn't appeal."

87. Respondents were asked if they would like to comment on their experience of claiming DLA and 183 did so, equating to 66% of those claiming DLA. Their comments are summarised by theme in Table 10, overleaf. Only 11% of those who commented said the process had been straightforward and, again, it is possible that these positive experiences resulted from the help and support they received from the CAB at an early stage in the benefit claiming process. It must also be remembered, however, that those who had experienced difficulties may be more likely to comment.

³² Riding the benefits roller-coaster – CAB clients' experiences of claiming sickness and disability benefits, Citizens Advice Scotland, December 2003; Evidence and decision-making in medically-assessed social security benefit, Citizens Advice Scotland, Citizens Advice England and Citizens Advice Wales, July 2004

Table 10: Comments on the experience of claiming DLA

Theme	Number	% of those commenting
Forms too complex, confusing	74	40
Problems with appeals or tribunals	26	14
Needed help with claim	25	14
Problems with general process	21	12
No problems, straightforward	20	11
Problems with doctor or medical	15	8
Adverse effects of claiming on health	14	8
Problems with criteria or definitions	12	7
Need for more information or clarification	9	5
Specific problems for people with mental health problems	7	4
Bureaucracy or delays	5	3
Other comments	7	4

88. A large proportion of people commented on the complexity of forms (40%) and their need for help in making their claim (14%). This is more than double the proportion of those claiming IB who commented on the complexity of forms. It should be noted, however, that the majority of respondents' comments in relation to form-filling will be based on their experiences with the previous more complicated DLA form, as the simplified version was only introduced three months prior to the research. In comparison to the comments on IB, fewer people commented on the medical aspects of the claim process but many more on the process of appeals or tribunals, some of which are quoted above. Other comments included the adverse effect of claiming on people's health, the difficulty of understanding or meeting criteria, and the need for better information. The total number of comments by theme adds up to more than 183, because some respondents made comments encompassing more than one theme.
89. Some comments are quoted below to illustrate some of the issues:

"It was very quick and easy and the people in CAB were very helpful, friendly and extremely supportive"

"They keep changing the goalposts and they should tell us what the goalposts are. I was awarded DLA for life and was taken off this in 2002, despite my health deteriorating."

"I was taken off DLA on the evidence of an examining doctor who didn't witness me walking outdoors"

"Form horrendous - very complex"

"I find having a mental health problem to be a problem when applying for DLA. It's difficult to explain what happens inside my mind when I get really bad"

“Medical examiners don't look at person's difficulties in real life situations – i.e. walking outdoors is different to walking from room to room where you walk at different speeds and have different footwear”

“I get it year by year and I worry every year about losing it to the point I self harm”

“It was a complete shambles. The system is not suitable for people with major cancer who are receiving active treatment but do not qualify for the "fast-track" system. I would not have been able to apply or fight the refusal without the help of CAB”

“Confusing and could not get any information from benefits agency on entitlement”

“Asked for review of award. Gave new medical information in form of letters from GP, backed up with x-ray scan results, benefit increased”

“It has been a slow and difficult process. Having been awarded DLA by the Edinburgh DBC it was very disheartening to lose it on a review by Blackpool who criticised the original Edinburgh decision.”

“Examining doctor's first comment "hello I'm Dr M_____, I'm here to weed out the fakers and shirkers". Just the thing you need to put you at ease.”

90. Bureau case evidence further illustrates these issues.

A West of Scotland CAB reports of a client who had been admitted to a psychiatric ward with depression, paranoia and psychosis. She had been advised to apply for DLA and was sent the relevant application pack, including a form of approximately 45 pages that she was required to complete. The client was angry at how long the form was, and confused as to why she was required to repeat the same information multiple times, She felt that the questions were designed to 'catch her out', and came to the CAB's outreach clinic in the hospital for help completing her application.

A North of Scotland CAB reports of a client who had experienced a progressive deterioration in her ability to walk over the previous nine months. She was still undergoing tests for a diagnosis, but her doctor suspected it might be nerve damage at the base of her spine and down one leg, and had signed her off work. The client had applied for DLA with the help of the CAB, but her initial application and appeal had both been refused. The client was very distressed, as she could only walk ten metres before stopping due to pain, and required taxis to travel everywhere.

A West of Scotland CAB reports of a client who had been awarded DLA high-rate mobility for life ten years previously. He had recently had a stroke which resulted in care needs, but the client and his wife were terrified that if they re-applied for DLA hoping to be awarded the care component, his mobility component might be removed.

A West of Scotland CAB reports of a client who suffered from chronic fatigue syndrome and wanted to apply for DLA. He found the form very confusing and did not have the energy to fill it in himself. Additionally, he was not sure what to write and stated that he would have given up after 30 minutes. Even with the bureau adviser's help, it took over two hours to complete the form.

The impact of illness or disability on finances

Summary of key points:

- Respondents were more than five times as likely as the general population to report being in some form of financial difficulty (62% compared to 11%)
- The main reasons for their financial difficulty were their own illness, health problem or disability (83%) and/or low income (69%)
- More than half of respondents (57%) had outstanding debts or arrears
- Levels of debt were lower than in the earlier CAS debt research, with the majority (61%) owing £5,000 or less
- The most common types of debt were credit card debt (45%) and Council Tax debt (43%)
- Respondents were most commonly trying to manage their debt by juggling finances (50%), seeking advice from other agencies, such as the CAB (48%) and/or by reducing expenditure (45%)
- The most common extra needs associated with respondents' health problems or disabilities were prescription costs or other chemists' items (51%) and transport/mobility needs (49%)
- Less than one-third (32%) were exempt from prescription charges and less than one-fifth (18%) had a concessionary travel pass
- Most met the extra costs of their health problem or disability within their family (53%) or by reducing expenditure on other things (47%)
- Almost a quarter (24%) said that some of the extra costs of their health problem or disability were not met
- Nearly half (48%) of respondents said they had reduced their heating, lighting or cooking in their home because of difficulty paying for fuel.

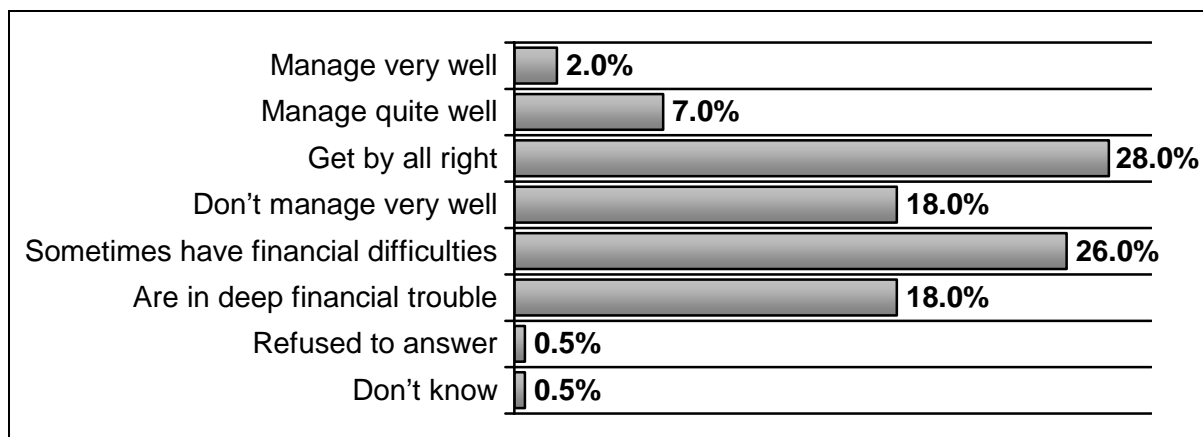
91. Respondents were asked how they managed financially and their responses are shown in Figure 13, overleaf. The question was constructed in a way that would allow broad comparison with results from the SHS³³. Less than 10% of respondents said that they managed very well or quite well. This compares to a figure of 47% in the SHS³⁴. A further 28% said that they got by all right, compared to 42% in the SHS. One per cent refused to answer or did not know.
92. Two hundred and fifty five respondents (62%) were in some degree of financial difficulty, made up of 18% who said that they did not manage very well, 26% who sometimes had financial difficulties and 18% who were in deep financial

³³ The question differed in one respect as, after the pilot of the disability and sickness questionnaire, the wording of one statement was changed to read 'Sometimes have financial difficulties', rather than 'have some financial difficulties', to reflect findings that, for example, people might be managing alright until they get a large bill which places them in financial difficulty.

³⁴ All SHS financial management figures are from the SHS 2003/04. See <http://www.scotland.gov.uk/Publications/2005/08/03155211/52432#642>

trouble. This compares to a total of 11% in the SHS³⁵ who reported being in some form of financial difficulty. The proportion of people in financial difficulty was therefore more than five times higher in this research than in the Scottish population as a whole, though it should be noted that the figures from the SHS include pensioner households, so the figures are not exactly comparable.

Figure 13: How respondents report they manage financially



Base: 414

93. The three-fifths of respondents who were in some degree of financial difficulty were asked an open question regarding what they thought was the main reason for their financial difficulty. The reasons they gave are summarised overleaf, in Table 11.
94. The reason for financial difficulty most frequently given was low income, stated by more than two-fifths (41%) of respondents. A much smaller proportion cited a drop in income (13%) and the cost of living (11%) as reasons. Many people described the difficulty of making ends meet on benefits and commented that their level of benefit was simply not enough to cover the costs of living. Surprisingly few (8%) mentioned their own health problem or disability as a reason, although when prompted more than 80% gave this as a reason (see Figure 14). This may be because, when unprompted, respondents were thinking of the immediate financial difficulty of making ends meet, rather than the preceding causative factors.
95. A small proportion of people cited debt repayments as a reason for their financial difficulty. In some cases, this was linked to a drop in income, when people had a number of financial commitments when they had been working and then suffered a drop in income when they stopped work, but still had debts to pay off.

³⁵ Including pensioner and small adult households

Table 11: Reasons for financial difficulty - unprompted

Theme	Number	% of those responding
Low income	99	41
Drop in income	32	13
Cost of living	27	11
Own health problem or disability	19	8
Debt repayments	15	6
Money mismanagement or budgeting problems	10	4
Child-related expenses	9	4
Benefit problems	8	3
Easy access to credit	6	3
Job loss	5	2
Delays in paying benefits	4	2

Base: 239

96. Some examples of respondents' explanations for their financial difficulty are quoted below.

“Just find it difficult to manage on my benefit allowance”

“Extreme drop in finances due to unemployment”

“As I was on good salary, when I had to depend on IB the outgoings, which were based on salary, became too much to cope with. We had to re-mortgage our home to lessen payments”

“My benefit keeps changing so I don't know how to budget. In the last 18 months my husband has died, I was then on bereavement benefit, then incapacity and the housing & council tax people keep sending me letters telling me about overpayment and underpayment of benefit. When I am sick myself it is too complicated”.

“My DLA was reduced. So my Income Support was stopped and I got into arrears with my rent”

“Receive all benefits but no money left for children”

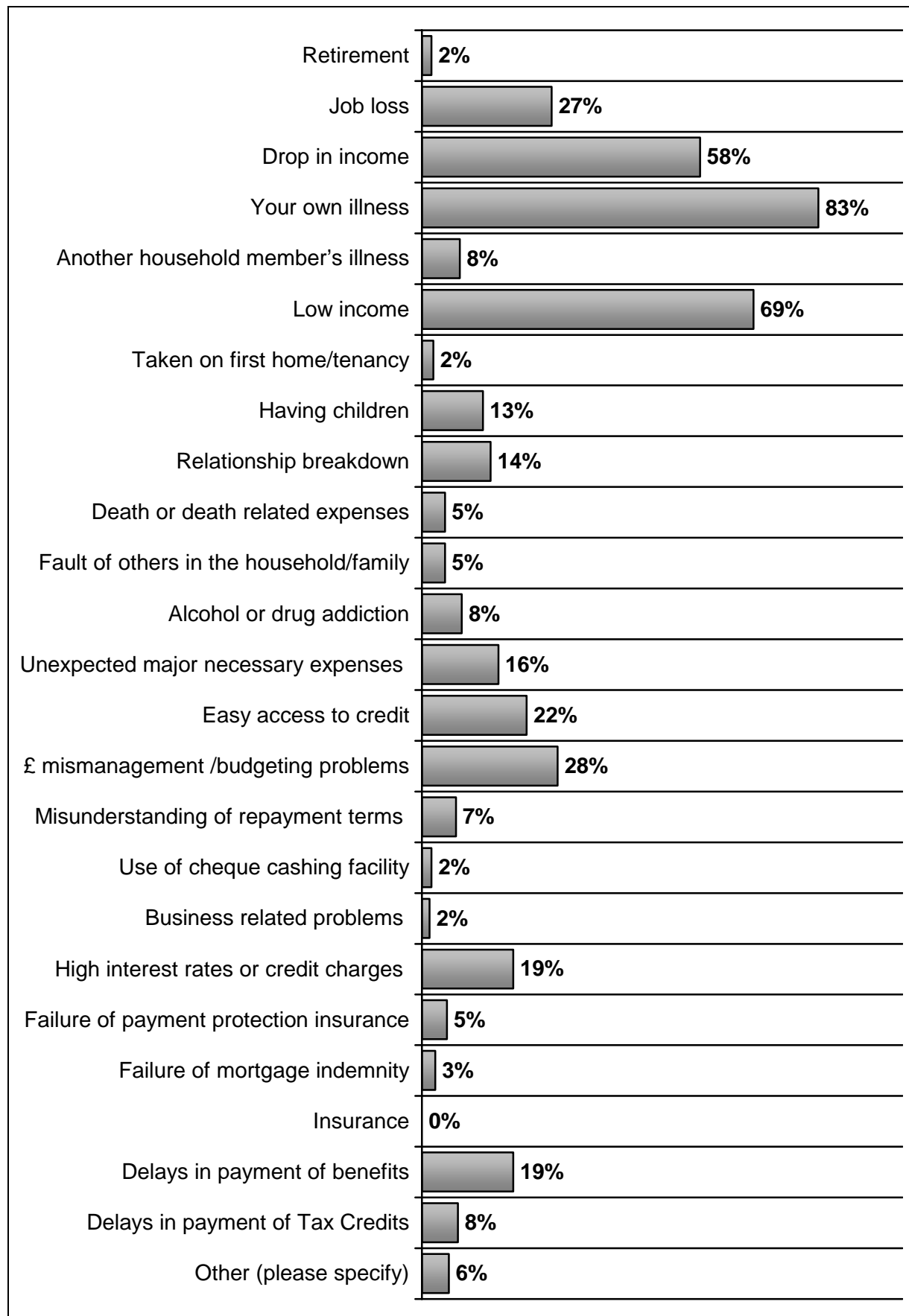
“Low income, rise in utilities, rise in cost of living”

“My wife works as a school classroom assistant. She gets paid every month – however, as she is on a low rate of pay, five week months, Christmas, holidays, birthdays etc cause a lot of financial difficulties.”

“When I had a nervous breakdown three years ago, I was not fit to make decisions and took on loans without realising I would not be able to repay them on my very low income”.

97. Respondents were then asked again what they thought was the main reason for their financial difficulty, but provided with a pre-defined list of possible reasons. Respondents were able to tick as many reasons as applied to them. The responses are shown in Figure 14, overleaf.

Figure 14: Reasons for financial difficulty



Base: 252

98. More than four-fifths (83%) of respondents in financial difficulty gave their own illness, disability or health problem as a reason. The second most common reason for financial difficulty was low income (69%) and the third, a drop in income (58%).
99. Much less frequently given reasons were money mismanagement/budgeting problems (28%), job loss (27%), easy access to credit (22%), high interest rates or charges (19%) and delays in payment of benefits (19%).
100. A smaller percentage of respondents had been affected by a range of other causes for financial difficulties, including unexpected major necessary expenses (16%), relationship breakdown (14%) and having children (13%). Of the 14 respondents who ticked 'other' and gave further details, half (seven respondents) said they had experienced problems with benefits or tax credits including over-payments, reductions in payments and interest on benefit debt.
101. Apart from health reasons, as discussed above, the main reasons given when prompted and unprompted were similar, these being low income and a drop in income. Only 4% gave money mismanagement or budgeting problems when unprompted, compared to 28% when prompted. This may be because, in the second question, respondents were able to tick more than one reason and budgeting/money management problems may have been a contributory reason for financial difficulty, but not the main one.
102. Table 12, overleaf, compares the prompted reasons for financial difficulty given by respondents in this research and in the debt research CAS conducted in 2003. Only one-third of respondents in the debt research gave illness or disability as a reason for their financial difficulty compared to over 80% in this sample. Clearly this reflects the fact that the previous research did not select clients on the basis of their health, whilst this study focuses on those claiming sickness and disability benefits.
103. Notably, clients in the current research were much less likely to attribute their financial difficulty to money mismanagement or budgeting problems than in the previous debt research. In addition, low income and a drop in income were significantly more common reasons cited by respondents in this research. These findings indicate that this client group perceives the reasons for their financial difficulty in a markedly different way from CAB debt clients in general.

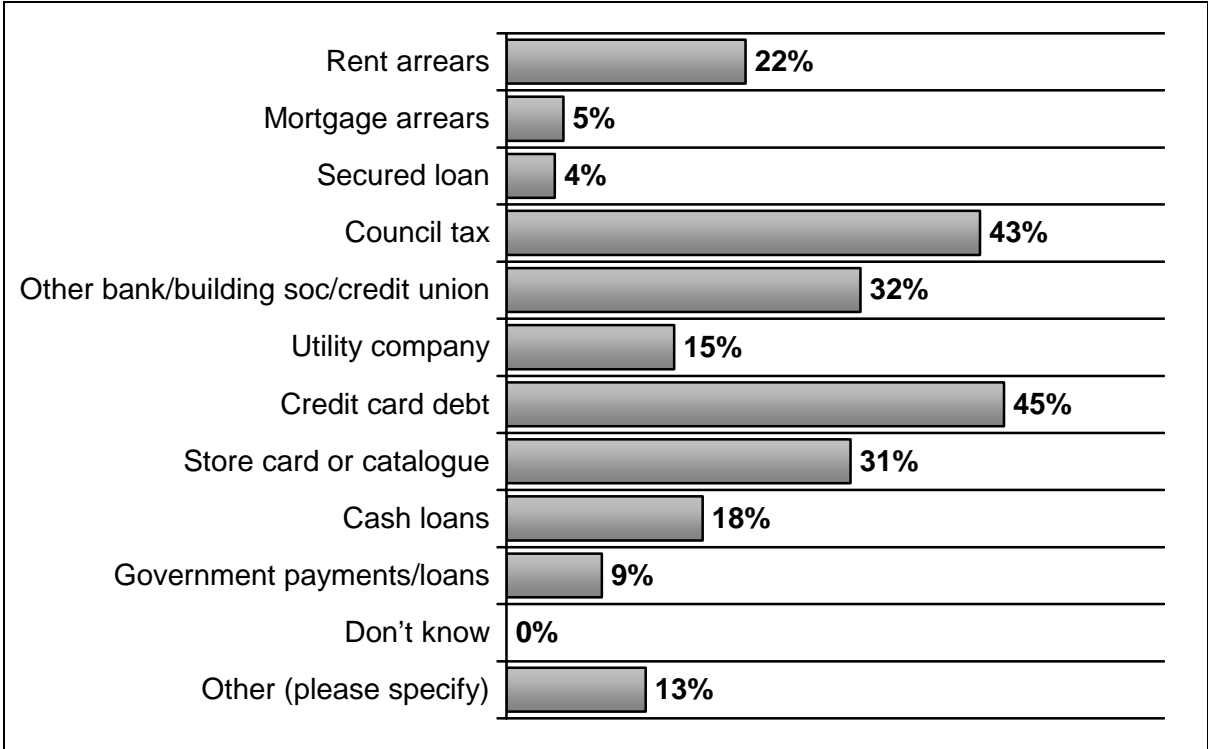
Table 12: Comparison of prompted reasons for financial difficulty in illness/disability research and debt research (top 6 reasons)

Reason	Illness/Disability research respondents %	Rank	Debt research respondents %	Rank
Your own illness, disability or health problem	83	1	33 ³⁶	5
Low income	69	2	40	2
Drop in income	58	3	40	2
Money mismanagement/ budgeting problems	28	4	46	1
Job loss	27	5	27	6
Easy access to credit	22	6	34	4

104. More than half (57%) of all respondents in this research reported that they had outstanding debts or arrears. The types of debt or arrears are shown in Figure 15, overleaf. The most common were credit card debt (45% of those in debt or arrears) and council tax debt (43%). Just under one-third of those in debt or arrears had other bank, building society or credit union debt (32%) or store card/catalogue debt (31%).
105. More than one-fifth of respondents were in rent arrears and 18% had cash loans. Fifteen per cent owed money to utility companies and 9% had Government payments or loans outstanding (e.g. benefit overpayments). Relatively few respondents had mortgage arrears (5%) or secured loans (4%). The 'other' debts owed by respondents included business debts, student loans and insurance debts.

³⁶ Figures in debt research could include illness or disability of another family member

Figure 15: Types of debt or arrears owed by respondents in debt or arrears



Base: 229

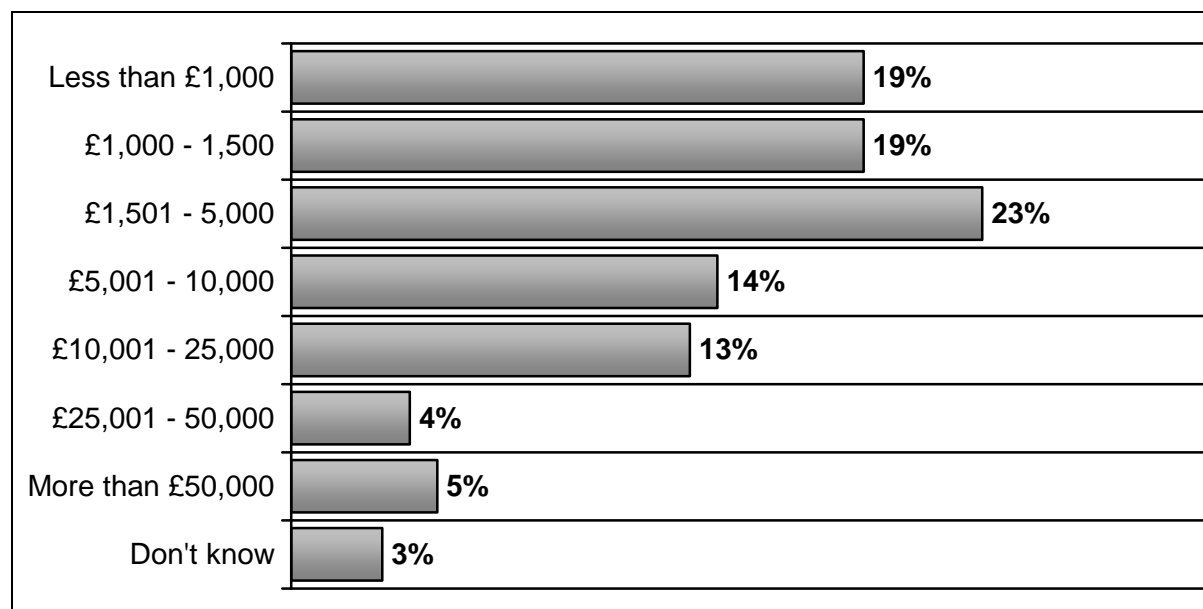
- 106. When clients come to bureaux with debt problems, CAB advisers prioritise the debts according to risk. The top priority debts to tackle are those where the client is in danger of losing their home or their fuel supply, i.e. rent arrears, mortgage arrears, utility company or Council Tax debt. In this research, more than a half (51%) of all respondents in debt had at least one of these priority debts.
- 107. Table 13, overleaf, compares the prevalence of different types of debt between the respondents in the illness/disability and debt research groups, focusing on the top six types of debt. Note that some categories differed between the two research projects, and are therefore not directly comparable. As with the current illness/disability research, the most common type of debt reported in the debt research was credit card debt, owed by 55% of respondents. Respondents in the illness/disability research were far more likely than the debt respondents to have council tax debts (43% compared with 25%) and also more likely to have rent arrears (22% compared with 9%).

Table 13: Comparison of type of debt between illness/disability and debt research respondents (top 6 types³⁷)

Type of debt	Illness/Disability research respondents %	Rank	Debt research respondents %	Rank
Credit card	45	1	55	1
Council tax	43	2	25	4
Other bank etc	32	3	N/A	-
Store card or catalogue	31	4	44 ³⁸	3
Rent arrears	22	5	9	9
Cash loans	18	6	17	6
Personal unsecured loan	N/A	-	53	2
Overdraft	N/A	-	25	4

108. Figure 16, below, shows the size of the total debt among the 229 respondents who were in debt or arrears. Twenty three per cent owed between £1,501 and £5,000 - a significant amount, given that the majority of the total sample had a monthly income of £800 or less. More than a third of those in debt had smaller debts, of £1,500 or less, whilst 14% had larger debts of £5,001 to £10,000. The proportion of those in debt who owed more than £10,000 was 22%, a high figure given the low levels of household income found in this research.

Figure 16: Size of current total debt among respondents with debt



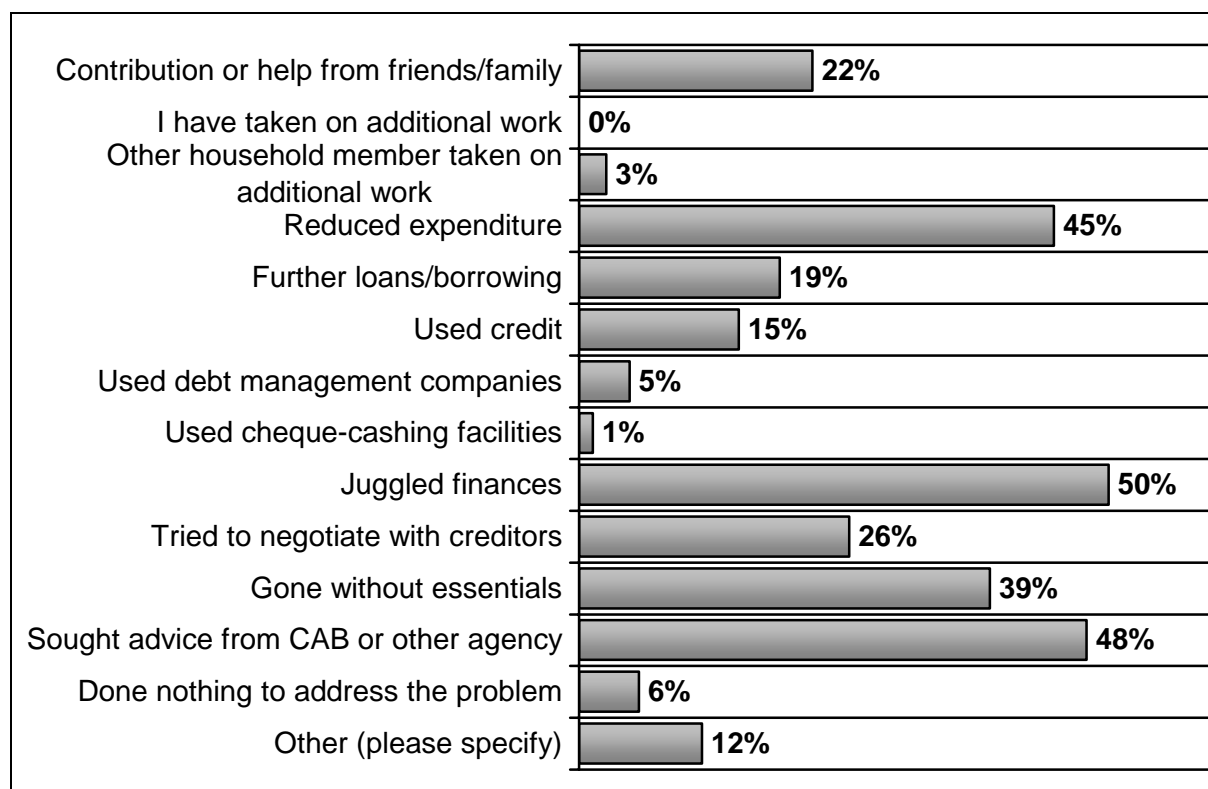
Base: 229

³⁷ The disability and sickness research did not prompt for as extensive a list of debt types as in the debt research because this was not the sole focus of the research. Where categories are not directly comparable for this reason, this is indicated by N/A.

³⁸ Store card and catalogue debts from the debt research are combined.

109. In the debt research, just over one-third (35%) of respondents had debts of up to £5,000, compared with more than three-fifths (61%) in this research. A further 19% in the debt research had debts of up to £10,000, compared with 14% in this research. Higher levels of debt were therefore much more prevalent in the debt research, with 47% owing more than £10,000 compared to only 22% among current research respondents.
110. Respondents who reported being in debt or arrears were asked how they were managing their debt. The responses are shown below, in Figure 17.
111. The majority of respondents had tried to manage the debt by employing strategies such as juggling finances (50%), seeking help from the CAB or other agencies (48%), reducing expenditure (45%), going without essentials (39%) or trying to negotiate with creditors (26%).
112. Less commonly, respondents had raised funding from elsewhere, for example through a contribution from friends or family (22%), further loans or borrowing (19%), using credit (15%) or debt management companies (5%). Six per cent had done nothing to address the problem and only a very few people had used cheque cashing facilities or had another household member take on additional work.

Figure 17: How respondents in debt or arrears reported managing their debt



Base: 230

113. 'Other' ways that respondents said they were managing their debts were mainly via deductions from their benefits, selling or re-mortgaging their house and seeking charitable help. Some comments about debt management are quoted below:

"I have no debts other than the Social Fund loan that is deducted from my benefit"

"I am very careful, re: not going into debt - debt I have incurred is due to official error or housing/CTB department"

"CAB made an agreement for me to repay in small amounts per week "

"House sold and living with parents"

"Salvation Army food parcels "

"Use card meters gas and electric but often self-disconnect"

"I am very strict with spending money"

114. Comparison with the earlier debt research³⁹ is shown in Table 14, overleaf. The debt management strategies available to many people with illness and/or disabilities in the present research are more limited, because of their inability to work. Those in the current research are more likely to seek advice than general debt clients and are less likely to cope by taking on additional work or further borrowing. They are also less likely to have 'done nothing' and more likely to employ financial strategies such as juggling finances and going without essentials. The debt research did not ask about whether people had reduced expenditure, but in the disability and sickness research, nearly half of respondents in debt said they had done so.

³⁹ The wording in the disability and sickness questionnaire was slightly different to that in the debt research, as can be seen by comparing the wording in Figure 17 with that in Table 14.

Table 14: Comparison of debt management strategies between illness/disability and debt research respondents

Debt management strategy	Illness/Disability research respondents %	Debt research respondents %
Advice seeking		
Previously sought advice from CAB/other	48	41
Used debt management companies	5	3
Work and earnings		
Taken on more work/overtime	3	10
Taken another job	0	5
Financial strategies		
Juggled finances	50	48
Tried to negotiate with creditors	26	35
Gone without essentials	39	32
Used cheque cashing facilities	1	3
Reduced expenditure	45	N/A
Further borrowing		
Borrowing from family/friends	22	29
Further loans/borrowing	19	24
Used credit	15	26
Other		
Done something else/other	12	5
Done nothing		
Done nothing to address problem	6	13

115. All respondents in the disability and illness research, not just those in debt, were asked if they had ever reduced their heating, lighting or cooking in their home because of difficulty paying for fuel. A large proportion, nearly half (48%), said that they had reduced their heating, lighting or cooking because of difficulty paying for fuel. Some examples of how people manage fuel use are given below, via quotes from the respondents.

“Use card meter for gas & electricity. It is the best way to budget for me and my family. I will often not use the heating or limit its use”

“Often use emergency gas and electricity cards/keycard. May have to borrow from other family members to keep heating on”

“Cost of outside care, cost at day centre, lunches, outings etc, cost of electricity/gas - we use card meters, would have to self-disconnect if it was not for help from my child's granny”.

“Powercard meter therefore have to budget accordingly”.

“Reduction in benefits - DLA has been stopped. Great difficulty in managing with current finances. Worried about paying next electricity bill, house is all electric. Currently keeping the heating off whenever possible.”

116. Case evidence from bureaux also demonstrates the problems that ill and disabled clients face in relation to fuel consumption and fuel poverty.

An East of Scotland CAB reports of a client with a disability in receipt of DLA. The client, his partner and children had moved into a housing association property two years previously and noticed immediately that the electricity costs seemed very high. Both the utility company and the housing association checked the meter and indicated that there were no problems. The client had recently received a letter from his utility company stating that he owes £700, and they installed a meter to recoup £35 a week — a level of repayment he cannot afford. The client has turned off all the heaters except one in the living room, and the flat is very cold. This is particularly problematic as the client is in very poor health — he has had two strokes and two major heart attacks and currently has uncontrolled angina.

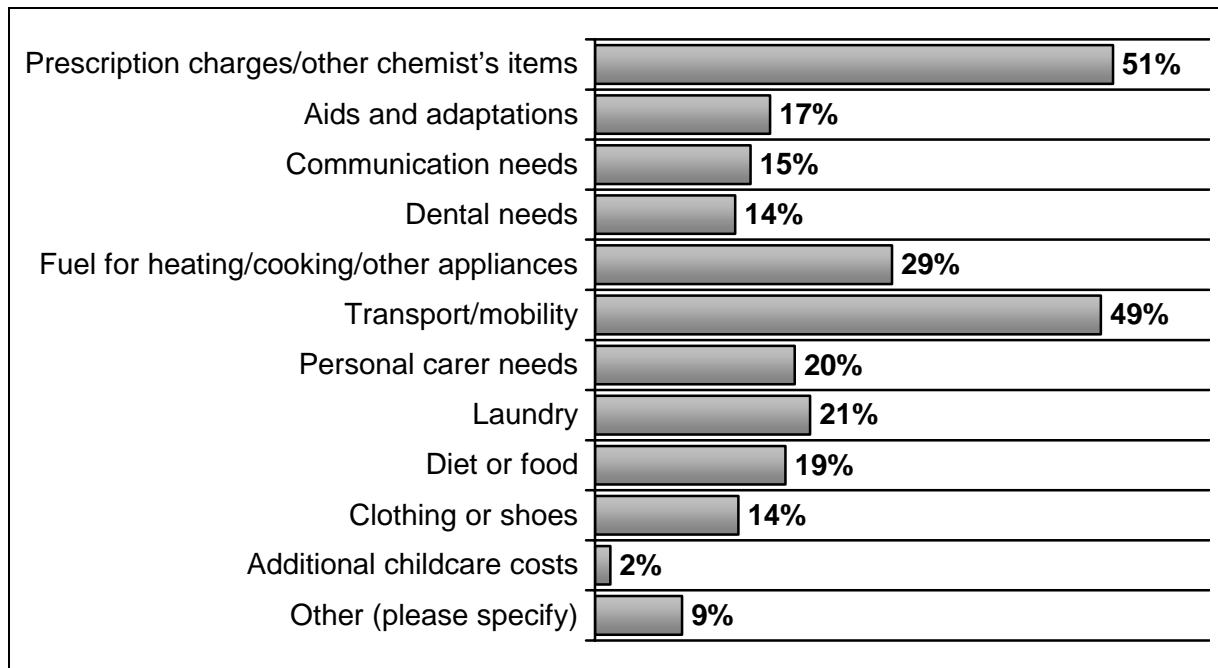
A West of Scotland CAB reports of a client who had been awarded IB following a serious heart operation. However, due to delays in processing his claim, he had not yet received any payments. Instead, he had been given emergency payments of £40 per week. The client lived in an electrically heated home with a pre-payment meter costing at least £15 per week — or over a third of his benefit. The bureau reports that the client was in severe financial hardship and feeling suicidal.

117. DLA is a benefit paid to people in recognition of the additional mobility or care costs of people who have a disability or illness. In this research, respondents were asked whether they had a range of extra needs because of their health problem or disability. The responses are summarised in Figure 18, overleaf.
118. The most common extra needs were prescription charges or other chemists items, cited by over half (51%) of respondents and transport or mobility related needs, cited by just under half of respondents (49%). The additional needs related to transport and mobility have important implications for the proposed welfare reforms, as clients may be more likely to have to travel to attend mandatory work-related activities and assessments.
119. Nearly one-third (29%) of respondents had extra needs for fuel (though note that nearly half had had to reduce fuel use because of difficulty paying for it),

over one-fifth (21%) had additional laundry, cleaning or household needs and almost one-fifth (20%) had personal carer needs.

120. Less common extra needs included diet or food (19%), aids and adaptations (17%), communication needs (15%), clothing or shoes (14%) and dental needs (14%). Only five respondents (2%) had additional childcare costs due to their health problem or disability.

Figure 18: Extra needs associated with health problem or disability



Base: 328

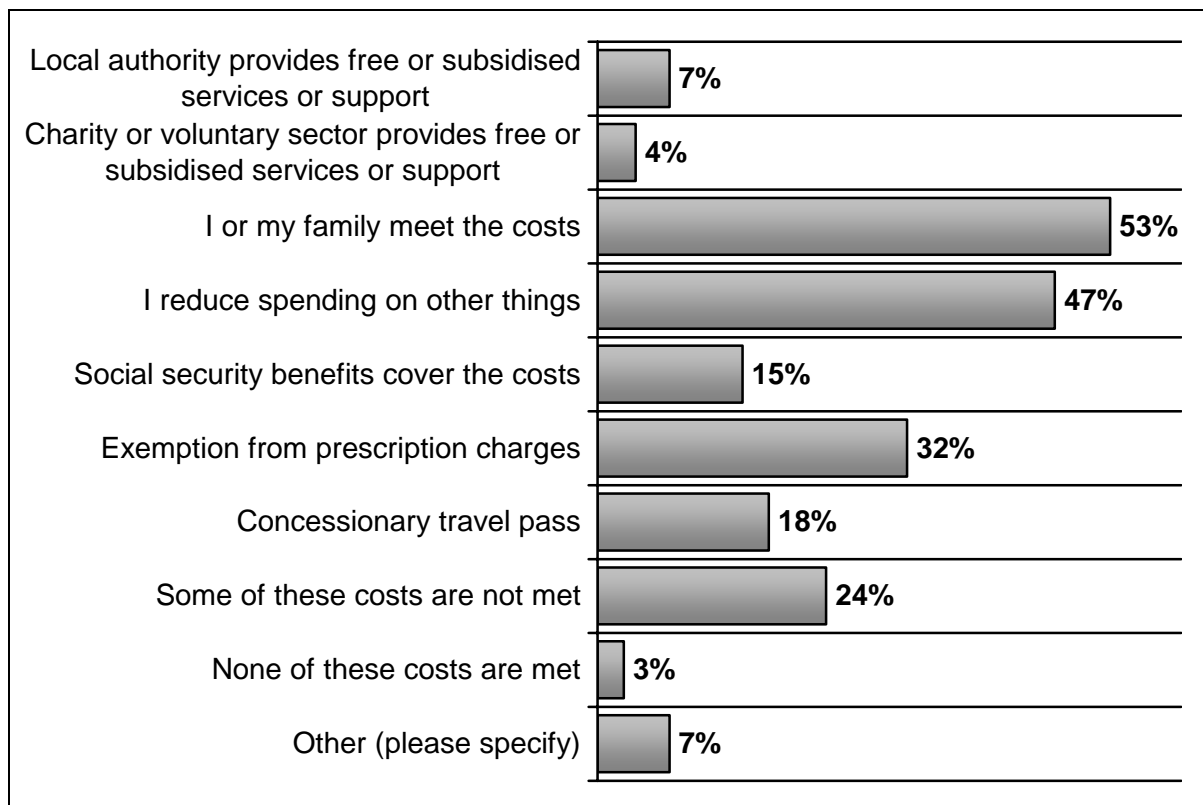
121. Some examples of those who had 'other' extra needs are quoted below:

"Chiropractic treatment, digestive supplements"

"Want to have talking therapy but NHS psychiatrists are useless and don't help me at all. I would need to pay for this myself - that's why I wanted DLA"

122. Respondents were asked how they met the costs of their extra needs and the responses are shown in Figure 19, below. Respondents were able to tick more than one item.

Figure 19: How the costs of additional needs are met by respondents



Base: 336

123. The majority of respondents who have extra needs associated with their health problem or disability report meeting the costs of these within the family (53%) and/or by reducing spending on other things (47%). Although more than half of respondents report having extra needs associated with prescription charges or chemists' items, less than a third report receiving exemption from prescription charges. This seems low, given the levels of household income in the sample. The case studies below illustrate the financial difficulties that can be created by having to pay for prescriptions when on a low income.

A West of Scotland CAB reports of a male client in receipt of SSP following a stroke. He had several illnesses, all of which required medication, amounting to prescription charges of approximately £40 per month. The client was having difficulty in meeting these costs. He was not entitled to free prescriptions, however, as he was not in receipt of a qualifying benefit or diagnosed with an illness included in the list for automatic exemption.

A West of Scotland CAB reports of a male client who has a disability and receives DLA and SSP. He has recently been diagnosed with terminal cancer and his wife has signed off work to care for him. If they apply for Carers Allowance it will take them out of the Income Support bracket, but they will be £20 better off. However, due to high prescription costs they would prefer to apply for Income Support as they would have immediate access to free prescriptions, dental treatment and travel costs to the hospital, instead of having to wait for Carers Allowance and the outcome of their application for assistance with health benefits. The client knows that he is terminally ill and is worried about the time that these benefits will take to sort out. They do not have the finances to pay for the medical costs up-front, and then reclaim them.

124. Similarly, although extra transport/mobility-related needs were cited by almost half of respondents, only 18% reported having a concessionary travel pass⁴⁰. These additional costs fall disproportionately on those having to make longer journeys, and so this issue is of particular relevance to Scotland, which has a large rural population. A recent report by Macmillan⁴¹ found that, compared with the rest of the UK, patients in Scotland spent the most on travel and parking throughout the course of their cancer treatment – an average of £636, compared with only £318 in Wales.
125. Less common forms of help included social security benefits, which were reported to cover the costs of extra needs by 15% of respondents, and help from the local authority (7%) or voluntary sector (4%). Respondents already claiming DLA were more likely to say that social security benefits met their extra costs, with just over one-fifth (20%) stating this, compared to 10% of respondents claiming IB but not DLA.
126. Almost a quarter (24%) of respondents reported that the costs of some of their extra needs are not met and 3% that none of the extra costs were met. ‘Other’ ways that respondents met these extra costs included in-kind help from family and friends, taking out additional loans, insurance, help from other services or going without. Some examples are quoted below:

“Family provide care, family do household & laundry”

“Costs not met are covered by insurance policies”

⁴⁰ In April 2006, since the bulk of this research was conducted, a new Scotland-wide concessionary travel scheme was introduced which provides free bus travel for people in receipt of the higher-rate mobility and/or higher- or middle-rate care components of DLA, people who are partially sighted and those who are profoundly or severely deaf. Prior to this, different schemes, with varying criteria, operated in different parts of Scotland. There is no similar national scheme for train travel and different eligibility criteria apply for concessionary train travel in different parts of Scotland. Some areas have no concessionary travel scheme.

⁴¹ Cancer costs: The hidden cost of getting treatment, Macmillan Cancer Support, June 2006

“Using my savings to live and pay all bills. Things are getting harder, really worried regards future”

“My social security benefits usually cover my expenses. If I really need help I ask my Mum or my girlfriend”

“Take out another Provident loan”

Future work and support needs

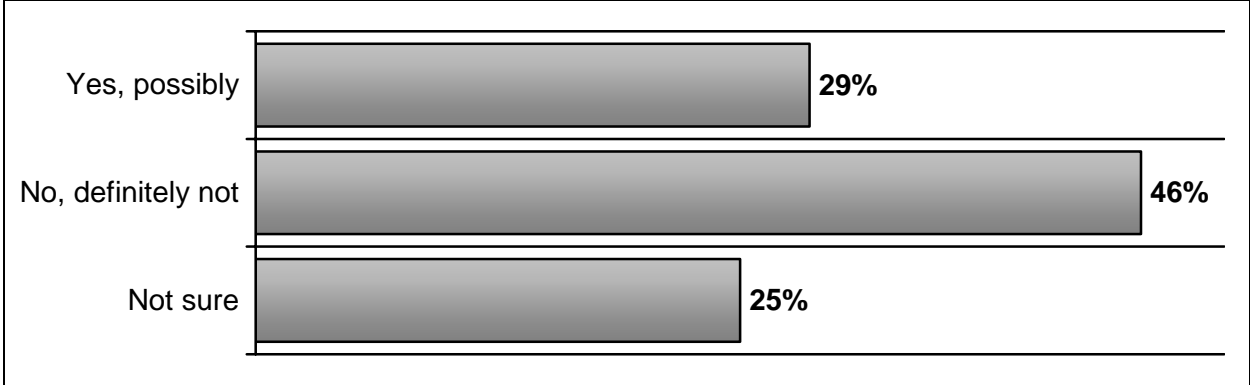
Summary of key points:

- Just under half (46%) of respondents said they would definitely not be able to work again
- More than one-quarter (29%) said they might possibly be able to work again and a quarter (25%) were not sure
- Those that considered working again said they would like a range of forms of help and support, including advice, training, information, job search skills, work experience
- More than half (53%) said they would like benefits protection whilst they tried work
- The responses suggest that tailored packages of help and support are required to help people back into work
- Help from employers is also required in the form of providing a lighter workload, support in the workplace, aids and adaptation and a degree of flexibility about working terms and conditions.

127. The Government aims to reduce the number of people on IB by one million, partly through requiring most new and existing claimants to participate in work-focused interviews, produce action plans and engage in work-related activity.
128. The pilot Pathways to Work programme has provided IB claimants with a menu of help and support which can be tailored to each individual, including work focused interviews and assessments, specialist advice, condition management programmes, training, financial incentives to take up work and in-work support.
129. To gauge CAB disability respondents' thoughts about the possibility of returning to work, the questionnaire asked those respondents who were not currently working, whether they thought they would be able to do paid or voluntary work in the future⁴². Their responses are shown in Figure 20, overleaf. Just under half, 46%, said they definitely would not be able to work again, 29% thought they might possibly be able to work again and 25% said they were not sure.

⁴² In formulating this question, note was taken of a critique in the Disability Rights Bulletin of the wording of a similar question about desire to work in a recent Labour Force Survey, A million hidden workers?, Disability Rights Bulletin, Spring 2004

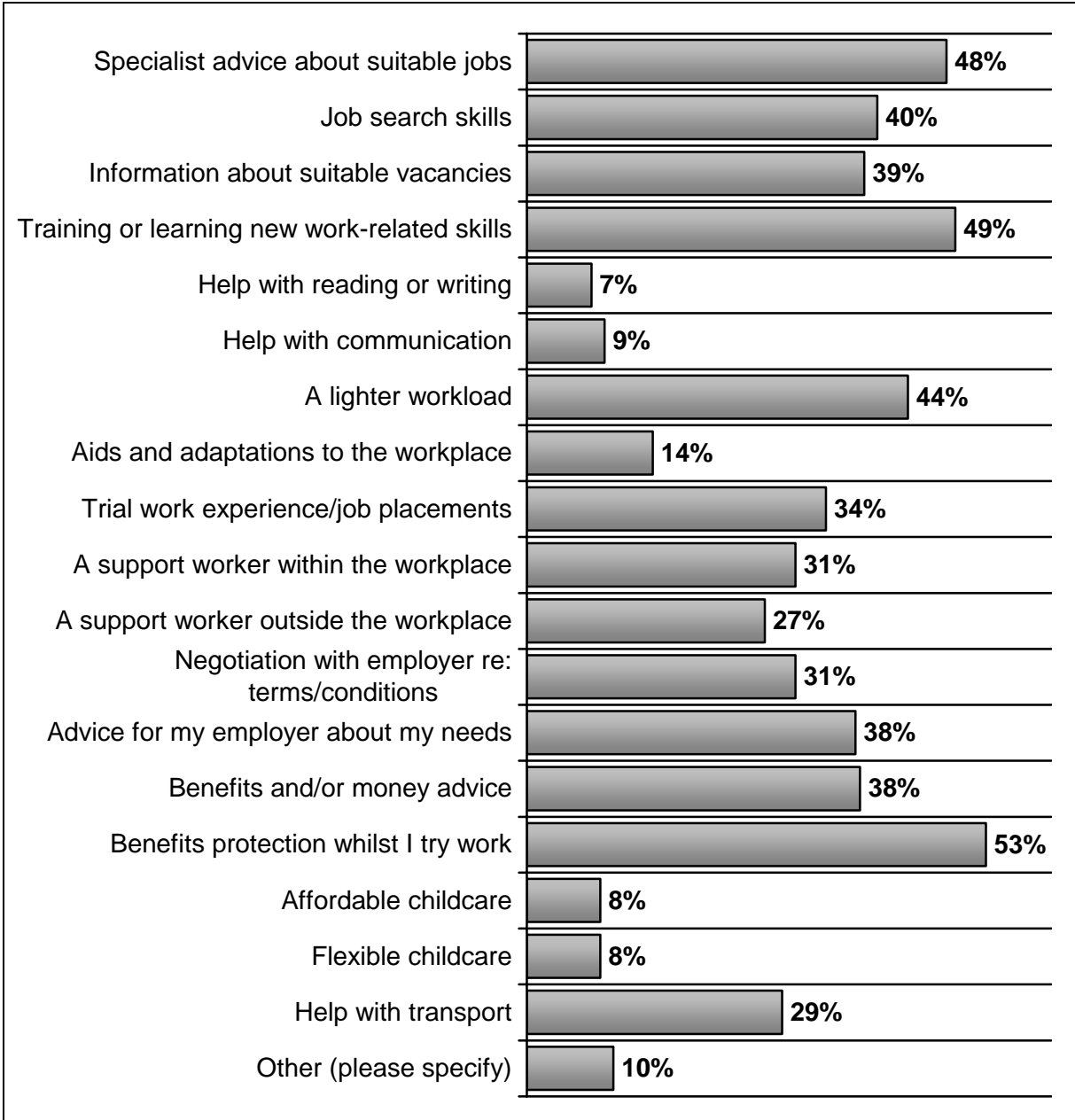
Figure 20: Whether respondents not currently working thought they would be able to work again in future



Base: 381

- 130. Those that considered they might be able to work again, or were not sure, were asked what types of help and support they thought they would need to enable them to work. Their responses are shown overleaf, in Figure 21. They were able to select more than one response.
- 131. Most respondents ticked multiple and various forms of help and support, suggesting that packages of support are needed, rather than a single main type of help.
- 132. More than half (53%) of respondents said they would need benefits protection whilst they tried work. Almost half (49%) said they would need training or learning in new work-related skills and a similar proportion (48%) said they would need specialist advice about what sort of job would suit them.

Figure 21: Types of help and support respondents thought they might need to work again



Base: 202

- 133. Other forms of support that were most frequently selected were a lighter workload (44%), job search skills (40%), information about suitable vacancies (39%), benefits and/or money advice (38%), advice for my employer about my needs (38%), work experience or placements for a trial period (34%), a support worker in the workplace (31%) and negotiation with my employer about terms and conditions (31%).
- 134. Less frequently required were a support worker outside the workplace (27%), aids and adaptations to the workplace (14%) and help with communication (9%) and reading and writing (7%).
- 135. ‘Other’ responses given included guaranteed interviews, therapy/mentoring in a work context and flexibility on the part of employers.

136. The responses indicate that, in addition to providing personalised support for claimants, work with employers is also needed to bring about more flexible employment conditions, for example, lighter workloads, aids and adaptations and in-work support.
137. The case studies below illustrate the difficulties some CAB clients have experienced when trying to work or attend training.

A West of Scotland CAB reports of a client who started working after being on IB. Because she had been on IB and then started working more than 16 hours per week, she was entitled to claim the disability element of Working Tax Credit. However, after 12 months the disability element stopped, making her financially worse off than before she worked. Her choice was either to work more hours, which she felt unable to do, or go back on to benefits, which she did not want to do.

A West of Scotland CAB reports of a female client who was on long-term IB and DLA care and mobility lower rates. Her main condition was epilepsy but she also had back problems, anxiety and depression. She began a part-time job, without realising she had to ask the DWP for permitted work. The work was under the earnings threshold and the CAB adviser considered that it would have been accepted as permitted work. She was investigated by the DWP, sent for a medical and failed the PCA. This decision was successfully appealed with the help of the CAB. In the meantime, her DLA was stopped and she was issued with an overpayment notice for over £2,200, on the basis that they considered she had misrepresented her situation (by deliberately not informing them of her job) and that her IB medical was inaccurate. They took into account a statement she made about the details of her job, but did not seek further medical information, contact the client or her GP.

A West of Scotland CAB reports of a male client with bipolar affective disorder and anxiety, who had been on DLA middle-rate care allowance since 1992. His benefit was stopped suddenly in 2006 and he was told by the Disability Benefits Centre that he had been taken off benefit because he had attended a Healthy Living course. However, the client had been unable to complete the course because of his condition. The client asked for the decision to be reviewed and received a letter stating this could take up to 11 weeks. The CAB assisted the client to submit a written appeal in case the decision is not changed.

138. Twenty seven respondents were already attending paid or voluntary work and listed the types of help or support they had received. The most common was benefits protection and information about vacancies, each received by seven respondents. A lighter workload and help or support with job search skills were each cited by six respondents whilst training or learning work-related skills, a support worker in the workplace, advice for their employer and benefits or money advice were cited by five respondents each.

Conclusions and recommendations

139. The overall aim of the research was to assess the impact of sickness and disability on CAB clients with a specific focus on clients' experiences of claiming Incapacity Benefit.
140. The objectives of the research were to:
- assess CAB clients' circumstances and experience of claiming a sickness or disability benefit;
 - obtain information about the relationship between sickness and/or disability and debt problems;
 - determine any differences between those with physical and those with mental disabilities;
 - ascertain these clients' support needs in relation to employment or volunteering.
141. This research has shown that many CAB clients who are claiming IB or DLA are in difficult circumstances. Most are in some degree of financial difficulty due to being unable to work, dependent on benefits, and consequently on a low income. Many are, therefore, in debt and have little prospect of improving their financial situation through a return to paid work. Many have been out of work for five years or more and those that could work again will need support and training before they can return to work.
142. The periods of transition between working and stopping work, and then if returning to work after being on benefits, are times when people find it difficult to cope with changed income levels.
143. The research respondents were also characterised by financial insecurity, with most in social rented housing and dependent on benefits which can be withdrawn. More than half of respondents had 'priority debts' where their home or fuel supply is at risk if they do not pay off the debt. Nearly half of respondents had reduced heating, lighting or cooking in their home because of difficulty paying for fuel.
144. In addition to experiencing a drop in income when having to give up work, many respondents also incurred additional costs because of their illness or disability, which compounded their financial difficulty. These additional costs include the cost of prescriptions and transport/mobility, yet less than one-third were eligible for free prescriptions and less than one-fifth had a concessionary travel pass.
145. Respondents' experiences of claiming IB and DLA indicated that a significant minority had experienced a refusal of these benefits at some point. In addition, the success rates for those who appealed suggested that more than half of decisions in these cases were incorrect.
146. A majority of those claiming IB and DLA commented on their experiences. Most of the comments were negative and included problems with the complexity of forms (particularly in the case of DLA), medicals, doctors, appeals, tribunals, problems meeting the criteria and the effect of the claiming process on their health. A number of respondents commented on the demeaning nature of the claiming process.

147. There were no significant differences in the numbers claiming IB or DLA by type of main condition (for example mental health or physical disability).
148. The majority of respondents said their health was fluctuating (38%) or getting worse (41%). Despite this, over a quarter said they thought they might be able to work again. The majority would like benefits protection and a large proportion said they needed advice about what sort of work would suit them. Other forms of help needed were training, job search skills, information, work experience and support and help both in work and outside work. Multiple responses indicated that multiple forms of help and support tailored to individual needs are required.

Recommendations

149. It is clear from the research that a range of measures are needed to address the problems faced by this CAB client group in relation to severe financial hardship, employment and benefits claiming. Based on the results of the research, and subsequent discussions with members of the Working Group and Advisory Group, CAS makes the following recommendations.

Financial support

150. CAS recommends that:

- The UK Government addresses the current inadequacy of sickness and disability benefit levels which, combined with the extra costs of sickness and disability, mean that many people do not experience an acceptable standard of living.
- The UK Government, Scottish Executive and financial institutions extend and improve access to alternatives to high-cost sources of credit for people on low incomes. This could be via credit unions, high street banks and building societies, as well as through reform of the Social Fund.

Support with additional costs

151. CAS recommends that:

- The UK Government extends the additional support provided by passported benefits (e.g. free prescriptions and assistance with travel costs) to claimants of IB.
- The Scottish Executive introduces a significant change in the existing system of prescription charges for those with chronic illness or disability and those on low incomes, to eliminate the financial barriers to treatment that currently exist.
- The UK Government, Scottish Executive and fuel companies ensure that people with illnesses or disabilities who are on low incomes have access to help with their fuel costs.
- The Scottish Executive introduces a national concessionary rail travel scheme similar to the national bus travel scheme introduced in April 2006. Additionally, CAS recommends that the Scottish Executive (re:

the national bus scheme) and local authorities and local rail operators (re: local rail schemes) review the sickness and disability eligibility criteria for all existing travel schemes, and ensure that they are well-advertised to generate maximum take-up.

Support into employment

152. CAS recommends that:

- The UK Government ensures that sick and disabled benefit claimants are not penalised for trying out work and provides improved transitional financial help for people returning to work from benefits.
- The UK Government and Scottish Executive ensure that claimants with illness and disabilities, those on low incomes and those living in rural areas are not penalised by difficulties in gaining access to compulsory work-related activities and opportunities for training.
- The UK Government, Scottish Executive and employers recognise that many people have complex needs (e.g. multiple health problems, worsening/fluctuating health, training needs) that are reflected in the types of return to work support and advice that are available.

Support for benefits claiming

153. CAS recommends that:

- The UK Government simplifies the application processes for DLA and IB and ensures transparency of decision-making and a significant increase in the accuracy of initial decisions.
- The UK Government and its contracted service providers improve the quality of customer service throughout the DLA and IB claiming processes.

Integrated policies

154. The complex interaction between reserved and devolved issues means that, for Scottish people with long-term illness or disabilities, it is essential that policies and procedures are effectively integrated across government departments and other agencies and organisations.

Appendix 1: Research design

1. The purpose of this research was to gather primarily quantitative evidence about CAB clients' experiences and circumstances when claiming IB or DLA. It was designed to complement the qualitative data already gathered by CAS from bureaux, in the form of case studies.
2. CAS established a working group of representatives from the bureaux who wished to participate in the research. The working group met first to discuss the key issues that the research should cover, based on their day-to-day experiences of dealing with clients claiming these benefits. The working group met on three subsequent occasions: to help formulate the questionnaire, to discuss the pilot and the practicalities of the research and to consider the results and the recommendations arising from it.
3. An advisory group was also established and met on two occasions: to advise on questionnaire design, and to discuss the results and recommendations and their dissemination.
4. The questionnaire was designed to be administered by CAB advisers with clients, either face-to-face or on the telephone. It was piloted with five bureaux who administered it to a total of 27 clients. Feedback from the pilot led to some changes to the content and length of the questionnaire.
5. Prior to the full research, bureau staff received briefing sessions which covered issues such as respondent eligibility for the research, confidentiality, obtaining informed consent and administering the questionnaire. Publicity materials were also provided to encourage clients to participate and to remind bureaux staff who to recruit. Clients who wished to receive feedback on the research were provided with a postcard on which they could write their name and address. They will be sent a summary of the report.
6. Twenty-one bureaux took part in the research, from a mixture of urban and rural areas across Scotland. Each bureau was given a target quota of questionnaires to complete. This was a percentage of the total required, based on the number of issues relating to sickness and disability benefits each CAB had seen in 2004/05. The purpose of this was to give them a target figure to aim for, rather than to give them a strict limit.
7. The data collection took place over a six-week period between 6 March and 13 April 2006. All CAB clients who made an enquiry at a participating bureau during the research period, and who were already claiming or making a new claim for either IB or DLA, were invited to take part in the research. A total of 417 valid questionnaires were completed in that time, of which 87% were completed face-to-face and 13% over the telephone.
8. Table (i), overleaf, shows the number of valid questionnaires returned by each bureau during the research period.

Table (i): Numbers of valid questionnaires returned by bureaux

CAB	No of valid returned questionnaires	% of valid returned questionnaires
Airdrie CAB	50	12
Argyll & Bute CAB	10	2
Banff & Buchan CAB	8	2
CAB West Lothian	17	4
CARF	57	14
Central Borders CAB	5	1
Clackmannanshire CAB	13	3
Dumfries CAB	33	8
East Ayrshire CAB	20	5
East Dunbartonshire CAB	11	3
Edinburgh – Central CAB	17	4
Glasgow – Easterhouse CAB	15	4
Glasgow – Maryhill CAB	17	4
Grangemouth & Bo'ness CAB	15	4
Hamilton CAB	13	3
Lochaber CAB	4	1
Motherwell & Wishaw CAB	43	10
Musselburgh CAB	4	1
Penicuik CAB	13	3
Perth CAB	48	12
Roxburgh CAB	3	1
<i>One unidentified questionnaire</i>	1	1
TOTAL	417	100

Note that an additional 15 questionnaires were returned that were invalid – six because they had been completed with a client who was on retirement pension and nine that were returned too late to be included in the analysis

Appendix 2: Questionnaire

DISABILITY AND SICKNESS RESEARCH PROJECT 2006

Instructions for advisors

This questionnaire is to be used with adult clients already claiming, or starting the process of claiming, Incapacity Benefit or Disability Living Allowance, whom the CAB is advising during the **period 6th to 31st March 2006 inclusive**. It should be completed with people aged 16-65, but not those over retirement age who are in receipt of state retirement pension.

Advisers may complete this form in person or over the telephone. Where a **couple** comes and both are eligible and wish to take part in the research, they should be asked to complete a separate questionnaire for each member of the couple. If a client comes in with **another person**, including a carer, check if they are happy for the other person to stay whilst they are completing the survey.

Questions are numbered and written in bold. *Instructions to advisors are in bold, red italics.*

Please complete the questionnaire **as fully as possible**. It may be possible to fill in some of the information after an interview, as you will need it for the purposes of advising the client. In such cases, please make sure you collect all other information from the client, before ending an interview. Remember to fill in the administrative items on the **back page**.

In general, advisers should ask the client the question **as it appears on the form**. Most have pre-coded answers that require you to **circle one appropriate response**. Those where you can circle more than one state **“Circle all that apply”** after the question. To avoid confusion, please circle the number/s carefully.

Some questions will not apply to all clients. Follow the instructions that **route** you to the next relevant question, but take care not to miss out any relevant questions.

Advisers should **familiarise** themselves with the questionnaire before the beginning of the research period. If you make any mistakes, please cross them out clearly.

Completed questionnaires should be stored in a secure place and returned to CAS at the end of each week.

TO START: CHECK THE CLIENT HAS NOT COMPLETED A QUESTIONNAIRE ALREADY.

Please explain the following to the client

- We are doing a questionnaire survey to find out about the impact of disability and ill health on bureau clients. The results will help Citizens Advice to inform and influence policy on disability, work and benefits.
- The questions are about your household, health, work and income, benefits and your financial situation
- We expect several hundred people to take part in this survey.
- It is confidential. We will not be putting your name on the questionnaire and no individual client will be identifiable in the reporting of the results.
- Participation in the survey is entirely voluntary; it will not affect in any way how the CAB adviser will assist you to deal with your query. Some of the questions are similar to those that the adviser will need to ask anyway to help with an enquiry. Others are only necessary for the purpose of the research. Would you like to help this research by completing the questionnaire with me? It will take approximately 20 minutes.
- If applicable - Would you like your partner/carer/friend to stay with you whilst you answer the questions?
- If you would like a summary of the results of the research please let your adviser know. ***(Advisers, please note the clients name and address on a separate sheet or give them a postcard to complete. Please stress that their contact details will be kept entirely separate from their questionnaire and that research results are likely to be available in the summer.)***

Yes ***(please circle 'Yes' to confirm client has given informed consent to take part in the research)***

DEMOGRAPHICS

1. What is your age? (*Reminder: Do not include people aged 60-65 and in receipt of retirement pension in the survey*)

16-17	1
18-24	2
25-34	3
35-54	4
55-59	5
60-65	6
Declined to answer	99

2. Gender:

M	1
F	2

3. What is your housing situation?

Own home – no mortgage	1
Own home – with mortgage	2
Rent from Council or other public sector	3
Rent from Housing Association/co-op/charitable trust	4
Rent from private landlord	5
Rent from employer	6
Live with parents/family	7
Live rent-free	8
Other (<i>please state</i>)	9

.....

4. How many adults and children live in your household? That is, who lives in your home with you, regardless of whether they are related to you? *Include the client when calculating household size.*

One adult, no children	1
One adult, one or more children all under 16	2
One adult, one or more children, at least one over 16	3
Couple, no children	4
Couple, one or more children all under 16	5
Couple, one or more children, at least one over 16	6
At least two (unrelated) adults	7
Other (<i>please state</i>)	8

.....

5. Are you:

- Already claiming Incapacity Benefit (whether receiving it or not) 1
- Making a new application for Incapacity Benefit today 2
- Neither of the above 3

6. Are you:

- Already claiming Disability Living Allowance (whether receiving it or not) 1
- Making a new application for Disability Living Allowance today 2
- Neither of the above 3

WORK AND INCOME

7. What is your current employment status? (Circle one number between 1 and 9 then go to additional circumstances below)

	Less than 16 hours per week	Hours 16-30 hours per week	More than 30 hours per week
Paid employment (including those still employed even if they are not currently attending work)	1	2	3
Self employed	4	5	6
Unemployed		7	
Retired on health grounds		8	
Other (please state)		9	

.....
Circle as many of the following additional circumstances which currently apply

- Studying or training 10
- Not working due to a health problem or disability 11
- Looking after your children or your home 12
- Looking after an ill or disabled household member 13
- Doing voluntary work 14
- Other **(please state)** 15

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8. If you are currently in employment or self employment (excluding voluntary work), please circle one of the following:

- I am attending work 1
- I am not attending work 2
- Other *(please state)* 3

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9. Has your illness or disability *(circle one)*

- Stopped you from attending work but you have remained employed 1
- Caused you to stop being employed 2
- (Give month and year of last employment.....)*
- Prevented you from ever being in employment or self employment 3
- Had any other effect on employment or work *(please state)* 4

.....

10. If you have an illness or disability which affects your ability to work, what is the MAIN condition which has affected you? *(circle more than one if the client cannot identify the MAIN condition)*

- A mental health problem, including work related stress or depression 1
- A physical disability 2
- A learning disability 3
- A sensory impairment 4
- A long term physical illness or medical condition 5

If the client volunteers any other information about their condition/s, please write it below.

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11. Would you say your health is:

- Getting better 1
- Stable 2
- Better sometimes and worse other times 3
- Getting worse 4
- Don't know 5
- Other *(please specify)* 6

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12. What are your individual sources of income this month? (*Circle all that apply*)

- Wage or salary 1
- Self employment 2
- Benefits and/ or tax credits 3
- Occupational pension 4
- Medical retirement pension 5
- Savings/investment 6
- Student loan 7
- Income from parents 8
- Partner's income 9
- Other (*please state*) 10

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13. What is your net monthly individual and household income? *Please include income from all sources including benefits (except housing and council tax benefits) and after tax and national insurance deductions. Circle one number in each column, unless it is a single person household, in which case use only the 'Individual' column.*

	Individual	Household
No income	1	1
Less than £400	2	2
£401-800	3	3
£801-1200	4	4
£1201-1600	5	5
£1600-2000	6	6
£2000+	7	7

BENEFITS

14. What benefit/s are you currently receiving? (*Circle all that apply*)

Sickness & disability-related benefits		Other benefits	
Incapacity benefit	1	Income support/pension credit	8
Disability living allowance	2	Tax credits (child or working)	9
Statutory sick pay	3	Job seekers allowance	10
Carers allowance	4	Housing benefits	11
Industrial injuries benefit	5	Council tax benefit or discount	12
Severe disablement allowance	6	Social fund payments	13
National insurance credits	7	Health benefits (e.g. dental, prescriptions etc)	14
		Bereavement benefits	15
Other, any type (<i>please specify</i>).....			16
.....			

INCAPACITY BENEFIT

The next 5 questions are **ONLY** for people claiming Incapacity Benefit (IB), or in the process of review or appeal for Incapacity Benefit. Include people who are on Income Support on grounds of incapacity for work. Otherwise, please go to Q20.

15. How many times before today have you...? (*Circle one number in each column*)

	<i>Made a new application for IB</i>	<i>Completed IB 50 form</i>	<i>Attended medical</i>	<i>Been refused</i>	<i>Appealed</i>	<i>Had an ultimately successful appeal</i>
<i>Never</i>	0	0	0	0	0	0
<i>1</i>	1	1	1	1	1	1
<i>2</i>	2	2	2	2	2	2
<i>3</i>	3	3	3	3	3	3
<i>4</i>	4	4	4	4	4	4
<i>5 or more</i>	5	5	5	5	5	5
<i>Don't know</i>	99	99	99	99	99	99

16. If you have ever been refused on medical grounds, what were the reasons given for the most recent refusal? *(If the client does not understand or remember, you may need to prompt them by showing a copy of the sheet they would have got explaining reasons for refusal)*

- Mental health/disability points not sufficient 1
- Physical health/disability points not sufficient 2
- Combination points not sufficient 3
- Don't know 4
- Other *(please state)* 5

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17. Have you ever done permitted work whilst on Incapacity Benefit?

- Yes 1
- No 2 *(Go to Q19)*
- Don't know 3 *(Go to Q19)*

18. If you are no longer doing this, why did you stop?

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19. Would you like to make any comments on your experience of claiming Incapacity Benefit? *(If yes, please note them below)*

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DISABILITY LIVING ALLOWANCE

The next two questions are **ONLY** for people claiming Disability Living Allowance (DLA), or in process of review or appeal for Disability Living Allowance. Otherwise, please go to Q22.

20. How many times before today have you...? **(Circle one number in each column)**

	Applied for DLA	Had your level of award increased	Had your level of award decreased	Been refused all or part	Appealed all or part	Had an ultimately successful appeal
Never	0	0	0	0	0	0
1	1	1	1	1	1	1
2	2	2	2	2	2	2
3	3	3	3	3	3	3
4	4	4	4	4	4	4
5 or more	5	5	5	5	5	5
<i>Don't know</i>	99	99	99	99	99	99

21. Would you like to make any comments on your experience of claiming Disability Living Allowance? (If yes, please note them below)

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IMPACT OF DISABILITY

The next few questions are about the impact of illness or disability on your financial situation.

22. Thinking about your current situation, how would you say you and your household manage financially these days?

- Manage very well 1 **(Go to Q 25)**
- Manage quite well 2 **(Go to Q 25)**
- Get by all right 3 **(Go to Q 25)**
- Don't manage very well 4
- Sometimes have financial difficulties 5
- Are in deep financial trouble 6
- Refused to answer 7 **(Go to Q25)**
- Don't know 8 **(Go to Q25)**

23. Please tell me the main reason you think you have financial difficulties?

Don't prompt; please record full reason

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24. Now looking at this list (*show card*) are there *any other reasons* why you think you are having financial difficulty?
(Circle all that apply)

Retirement	1	Unexpected major necessary expenses	13
Job loss	2	Easy access to credit	14
Drop in income	3	Money mismanagement/ budgeting problems	15
Your own illness, disability or health problem	4	Misunderstanding of repayment terms	16
Another household member's illness, disability or health problem	5	Use of cheque cashing facility	17
Low income	6	Business related problems	18
Taken on first home/tenancy	7	High interest rates or credit charges	19
Having children	8	Failure of payment protection insurance	20
Relationship breakdown	9	Failure of mortgage indemnity insurance	21
Death/death related expenses	10	Delays in payment of benefits	22
Fault of others in the household/family	11	Delays in payment of Tax Credit	23
Alcohol or drug addiction	12	Other (<i>please specify</i>)	24
		

25. Do you have any outstanding debts or arrears?

- Yes 1
No 2 **(Go to Q29)**

26. If yes, what is the type of debt and/or arrears? *Circle all that apply*

- Rent arrears 1
Mortgage arrears 2
Secured loan 3
Council tax 4
Other bank, building society or credit union debt 5
Utility company 6
Credit card debt 7
Store card or catalogue 8
Cash loans 9
Government payments or loans 10
(e.g. tax credit or benefit overpayments)
Don't know 11
Other **(please state)** 12

.....

27. What is your total debt at the moment (excluding your mortgage)?

- Less than £1,000 1
£1,000 to 1,500 2
£1,501-5,000 3
£5,001-10,000 4
£10,001-25,000 5
£25,001-50,000 6
More than £50,000 8
Don't know 9

28. How have you been managing your debt until now? *Circle all that apply*

- Contribution or help from friends/family 1
- I have taken on additional work 2
- Another household member has taken on additional work 3
- Reduced expenditure 4
- Further loans/borrowing 5
- Used credit 6
- Used debt management companies 7
- Used cheque-cashing facilities 8
- Juggled finances 9
- Tried to negotiate with creditors 10
- Gone without essentials 11
- Sought advice from CAB or other agency 12
- Done nothing to address the problem 13
- Other (*please state*) 14

.....

29. In the past year, have you ever reduced your heating, lighting or cooking in your home because of difficulty paying for your fuel?

- Yes 1
- No 2

30. Do you have any of the following extra needs associated with your health problem or disability? *Circle all that apply*

- Prescription charges or other chemist's items 1
- Aids and adaptations 2
- Communication needs, including higher telephone bills 3
- Dental needs 4
- Fuel for heating or cooking or other appliances 5
- Transport/mobility 6
- Personal carer needs 7
- Laundry, cleaning or household chores 8
- Diet or food 9
- Clothing or shoes 10
- Additional childcare costs 11
- Other (*please state*) 12

.....

31. How do you meet these costs? *Circle all that apply*

- Local authority provides free or subsidised services or support 1
- Charity or voluntary sector provides free or subsidised services or support 2
- I or my family meet the costs 3
- I reduce spending on other things 4
- Social security benefits cover the costs 5
- Exemption from prescription charges 6
- Concessionary travel pass 7
- Some of these costs are not met 8
- None of these costs are met 9
- Other (*please state*) 10

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SUPPORT TO WORK

If client is currently attending work (either paid or voluntary), please go to question 33b. If not currently attending work, start at question 32.

32. Do you think you will be able to do either paid or voluntary work in future?

- Yes, possibly 1 (*Go to Q33a*)
- No, definitely not 2 (*Go to Q34*)
- Not sure 3 (*Go to Q33a*)

33a. If you are not currently attending work, but think you might be able to attend work again, what type of support or help do you think you might need? *Circle all that apply.*

Specialist advice about what type of job would suit me	1
Job search skills, e.g. preparing a CV, interview techniques	2
Information about suitable vacancies	3
Training or learning new work-related skills	4
Help with reading or writing	5
Help with communication	6
A lighter workload	7
Aids and adaptations to the workplace	8
Work experience or job placements for a trial period	9
A support worker within the workplace who could help me with any problems.....	10
A support worker outside the workplace who could help me with any problems.....	11
Negotiation with my employer about terms and conditions	12
Advice for my employer about my needs	13
Benefits and/or money advice	14
Benefits protection whilst I try work	15
Affordable childcare	16
Flexible childcare	17
Help with transport	18
Other (<i>please specify</i>)	19

.....

Now go to Q34

33b. If you are currently attending work (paid or voluntary) and have an illness or disability, what support have you received or are you receiving? *Circle all that apply*

- Specialist advice about what type of job would suit me 1
- Job search skills, e.g. preparing a CV, interview techniques 2
- Information about suitable vacancies 3
- Training or learning new work-related skills 4
- Help with reading or writing 5
- Help with communication 6
- A lighter workload 7
- Aids and adaptations to the workplace 8
- Work experience or job placements for a trial period 9
- A support worker within the workplace who could help me with any problems 10
- A support worker outside the workplace who could help me with any problems 11
- Negotiation with my employer about terms and conditions 12
- Advice for my employer about my needs 13
- Benefits and/or money advice 14
- Benefits protection whilst I try work 15
- Affordable childcare 16
- Flexible childcare 17
- Help with transport 18
- Other (*please specify*) 19

.....

Ask all clients:

33. Do you have any other comments you wish to make?

.....

Thanks:

Thank you very much for completing the questionnaire. We appreciate your time. The results will help us to inform and influence government policy on disability, work and benefits.

Please remember to take contact details or complete postcard if client would like feedback.

TO BE COMPLETED BY ADVISER AT THE END OF THE INTERVIEW:

Name of advisor completing form.....

Form was completed:

In person 1
Over the phone 2

Time taken to complete:minutes

Circle your CAB number:

Airdrie CAB	1
Argyll & Bute CAB	2
Banff and Buchan	3
CAB West Lothian	4
CARF	5
Central Borders CAB	6
Clackmannanshire	7
Dumfries CAB	8
East Ayrshire CAB	9
East Dunbartonshire CAB	10

Edinburgh Central CAB	11
Glasgow Easterhouse CAB	12
Glasgow - Maryhill CAB	13
Grangemouth CAB	14
Hamilton CAB	15
Lochaber	16
Motherwell & Wishaw CAB	17
Musselburgh CAB	18
Penicuik CAB	19
Perth CAB	20
Roxburgh	21

TO HELP WITH PROCESSING, PLEASE RETURN QUESTIONNAIRES AT THE END OF EACH WEEK

Dates: 10th March, 17th March, 24th March and 31st March 2006

PLEASE RETURN ALL QUESTIONNAIRES NO LATER THAN 5 APRIL 2006

To:
Disability Research
Social Policy Section
Citizens Advice Scotland
Spectrum House
2 Powderhall Road
Edinburgh
EH7 4GB

Citizens Advice Scotland and its member bureaux form Scotland's largest independent advice network. CAB advice services are delivered using service points throughout Scotland, from the islands to city centres.

The CAB service aims:

to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities, or of the services available to them, or through an inability to express their need effectively

and equally

to exercise a responsible influence on the development of social policies and services, both locally and nationally.

The CAB service is independent and provides free, confidential and impartial advice to everybody regardless of race, sex, disability or sexuality.

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