

Research report

Customers' experiences of contact with the Pension, Disability and Carers Service

by Grahame Whitfield, Amanda Waring, Jackie Goode, Viet-Hai Phung, Katherine Hill and Liz Sutton

Department for Work and Pensions

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Work and Welfare Central Analysis Division, 3rd Floor, Caxton House, Tothill Street, London SW1H 9NA

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The Authors

Grahame Whitfield is an Assistant Director at the Centre for Research in Social Policy (CRSP) and was the Project Director. He is interested in a broad range of social policy issues around disadvantage and equality, but his main area of interest is in research on the position, experiences and aspirations of disabled people.

Amanda Waring is a Research Associate at CRSP and joined in 2004 after completing her PhD which explored the health behaviour of adults living in UK cities. She is particularly interested in the application of qualitative research methods and has a wide range of research interests including health and physical activity, lifestyle, social capital and social exclusion. Her research experience includes focus groups with adults and young people, interviews and observations.

Jackie Goode is a Senior Research Associate at CRSP and was the Project Leader. She is a sociologist with expertise in the field of financial decision-making within the family.

Viet-Hai Phung is a Research Associate at CRSP with experience of conducting both quantitative and qualitative research. His main research interests centre on inequality and disadvantage, with a particular focus on issues of ethnicity, poverty and employment.

Katherine Hill is a Senior Research Associate at CRSP. She has experience of predominantly qualitative research, including longitudinal studies and policy evaluations. Katherine has a range of research interests; her most recent work being around older people and the resources people draw on in later life, and welfare policy, with a particular interest in the client or claimant perspective.

Liz Sutton is a Senior Research Associate at CRSP. She is an experienced researcher who has worked on a wide range of qualitative research projects that explore the lifestyles and living standards of vulnerable groups. Her research interests lie in social exclusion and inequality particularly in relation to children, young people and families.

Abbreviations

AA	Attendance Allowance
CA	Carer's Allowance
CTB	Council Tax Benefit
DCS	Disability and Carers Service
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
PDCS	The Pension, Disability and Carers Service
RILL	Resources in Later Life
TPS	The Pension Service

Glossary

Attendance Allowance	Attendance Allowance (AA) is a tax-free benefit for people aged 65 or over who need someone to help look after them because they are physically or mentally disabled. It is administered by the Disability and Carers Service (DCS).
Carer's Allowance	Carer's Allowance (CA) makes a contribution to the financial needs of people who, for 35 hours a week or more, care for severely disabled people in receipt of the middle or high rate of Disability Living Allowance (DLA) or AA. It is administered by the DCS.
Council Tax Benefit	A means-tested benefit available to help cover the costs of Council Tax. Available to people renting and to owner-occupiers.
Disability and Carers Service	This now forms part of the Pension, Disability and Carers Service (PDCS).
Disability Living Allowance	<p>Disability Living Allowance (DLA) is a tax-free benefit for disabled children and adults (under the age of 65 at time of claim) and the disability means that one or both of the following apply:</p> <ul style="list-style-type: none">• They need help with personal care or someone to supervise them for their own or someone else's safety.• They cannot walk, find walking very hard or need help to get around. <p>It is administered by the DCS.</p>
The Pension, Disability and Carers Service	This is a new executive agency of the Department for Work and Pensions (DWP) formed in April 2008.
Pension Credit	Pension Credit is an entitlement for people aged 60 or over which was introduced in October 2003, replacing the Minimum Income Guarantee. It provides a guaranteed income for pensioners, and is administered by The Pension Service (TPS).
Resources in Later Life	The 'Resources in Later Life (RILL)' study conducted by CRSP.
State Pension	State Pension is paid to entitled people who claim it having reached State Pension Age (this is currently 65 for men and 60 for women). It is based on National Insurance (NI) contributions, and is administered by TPS.
The Pension Service	Now forming part of the PDCS.

Summary

This research was commissioned by the Pension, Disability and Carers Service (PDCS) to investigate the circumstances surrounding the ways in which people who were customers of both The Pension Service (TPS) and the Disability and Carers Service (DCS) came into contact with the agency's services. It also explored the factors most likely to trigger further contacts, the role of networks and professionals in this process and people's needs, preferences and expectations of service delivery.

The research involved in-depth interviews with 30 men and women in their 60s, 70s and 80s who were drawn from the PDCS customer database. It also involved three discussion groups: two with people over State Pension Age and one with carers. A third element of the study involved re-analysis of data from the 'Resources in Later Life' (RILL) study¹.

The findings provide PDCS with a comprehensive insight into the characteristics, experiences, needs and expectations of its customers. They raise a number of issues which PDCS may wish to consider when developing future ideas for service delivery. These include:

- enhancing service design and delivery by developing a better understanding of the role of PDCS in the wider context of older people's lives;
- overcoming the barriers people experience in becoming aware of and contacting the service, making claims and in understanding the information provided and required by PDCS;
- harnessing the key role of family, friends and local partners in raising awareness among, and providing support to, older people in accessing services;
- better understanding and responding to customers' preferences and needs, and managing customers' expectations of the service; and
- better understanding the particular pressures experienced by carers, in particular by mutual carers.

Barriers and triggers to contacting PDCS (Chapter 2)

The research explored the events and circumstances in older people's lives that initiated or resulted in their contacting PDCS. The findings highlight a number of barriers to PDCS achieving its aim of ensuring that those older people who are entitled, are aware of and receive the full financial assistance, services and support that are available to them:

- Overall, there was a general lack of awareness of the availability of financial assistance from PDCS. There was also considerable sensitivity around issues of eligibility and claiming, with many people feeling that demonstrating their entitlement was a process in which they had to 'jump through hoops'.
- Many people simply 'did not know where to start' in the process of claiming their benefit entitlements. Complex application forms, difficulties contacting the correct staff within PDCS and little understanding of interactions between benefits resulted in confusion and frustration.

¹ Hill, K., Sutton, L. and Cox, L. (2009) *Managing Resources in Later Life: Older People's Experience of Change and Continuity*. York: Joseph Rowntree Foundation.

- Contact with PDCS was rarely the result of a single ‘trigger’ event, but rather a result of a combination of events over time. As such, many people commonly contacted PDCS some time after the onset of a health condition or disability. Some did so after taking on caring responsibilities, meaning people did not know about or receive assistance at a time when they may have needed it.

The role of networks and partners (Chapter 3)

The research looked at the nature and role of local networks that were involved in helping, encouraging or enabling people to make and maintain contact with PDCS. The findings highlight a number of ways in which older people themselves became aware of PDCS and provide insight into some additional means by which the service might raise awareness for those who are entitled to claim at a local level:

- The role of family, friends and neighbours was often critical in helping older people become aware of their entitlement and of how to make claims. For some, this involved the provision of support, assistance and encouragement. For others, it involved taking on the role of advocate or representative. However, the ability to help was often constrained by insufficient awareness, knowledge or expertise.
- The assistance of staff in community-based organisations was a key factor in helping some older people to make contact with PDCS and claiming their entitlement. Initial contact with such organisations was often for reasons other than benefit entitlement, and staff provided advice and support with the added benefit of local knowledge.
- For some older people, retirement had led to loss of contacts which, in turn, increased their risk of not gaining access to relevant information. However, it was often the case that ‘chance’ discussions with people often prompted older people to contact PDCS or other local organisations to discuss benefit entitlement.

Customer views on communication and contact with PDCS (Chapter 4)

The research explored older people’s views and experiences of the different channels of communication through which PDCS delivers its services, and examined which channels they regarded as most effective in different circumstances. The findings highlight older people’s views on these methods and on how they felt the service might improve its communication with them:

- There was strong support for face-to-face contact, particularly for people with complex circumstances or certain health conditions or impairments, but little expectation that this should be generally available.
- Written communication was valued, especially as it provided older people with a record of contact and a point of reference. However, significant concerns were raised about written communication not always being accessible or understandable.
- Telephone contact was viewed positively for simple transactions. However, difficulty getting through to the right person and having to provide and repeat information over the telephone proved problematic for many people.
- There was little appetite for internet-based services. This was mainly due to the cost of equipment and connection, the ability to use computers (for reasons relating to impairments) and concerns about data security and privacy.

Experiences of contact with PDCS (Chapter 5)

The research explored older people's experiences of contact with PDCS in the context of their lives. The findings highlight the experiences of people with complex circumstances and with particular needs with an emphasis on the experience of carers (including mutual carers). In-so-doing, it raises some specific issues that might assist PDCS in thinking about meeting the needs of some of its most vulnerable customers:

- In respect of simple and straightforward transactions, most people's expectations of PDCS were met and the perception of the service was positive. However, less straightforward transactions often resulted in confusion, frustration and disengagement due to complex forms, 'technical' letters, and providing the same information to different PDCS staff. More complex interactions often occurred during times of significant change and distress.
- For some older people, the complexity of their everyday lives made engaging with the service more difficult. In this respect, people thought PDCS staff needed to have a better understanding of the nature of their lives and the impact of long-standing health conditions, and that empathising with their situation would improve their interaction with the service.
- The experience of carers (particularly mutual carers and people caring for more than one person) was often stressful and frustrating. This was sometimes exacerbated by the lack of joined-up service delivery they experienced and staff not always being aware of, or sensitive to, their needs.

Conclusions

The main findings of this research indicate that older people would like to see PDCS services delivered in a way that ensures it:

- makes its customers aware of how the organisation is structured;
- provides clear, accurate and timely explanations (both written and spoken);
- minimises the administrative burden on customers, in particular extensive completion of complex, repetitive forms;
- ensures continuity in service delivery by effectively sharing information in the form of details of earlier contacts and customer circumstances between the relevant agencies; and
- where appropriate, makes a single point of contact, such as a complex case worker available.

The report concludes by setting out two examples of further activity for PDCS to consider in light of the key messages arising from this research:

- To build on its existing partnership working programme, running stakeholder workshops and/or conducting local case studies would help PDCS gain a clear picture of how it might influence, develop or build on the current landscape of provision that gives older people invaluable support.
- Gaining further understanding of the experience of carers (particularly mutual carers), appointees and people with Power of Attorney would help PDCS gain a detailed understanding of how services might be tailored to meet their often complex and demanding needs and preferences.

1 Introduction

1.1 Background

This research investigated the circumstances around which customers of the Pension, Disability and Carers Service (PDCS) came into contact with the service, the factors that were most likely to trigger further contacts and the role of networks and professionals in this process. It also aimed to explore people's needs, preferences and expectations in respect of the different services provided by PDCS and to give a clear indication of the issues that should be considered when thinking about future service delivery. It differs from previous research in that it was the first to look at the experiences of people who were customers of both The Pension Service (TPS) **and** the Disability and Carers Service (DCS).

The Department for Work and Pensions (DWP) and PDCS have carried out a range of initiatives over a significant period of time to promote awareness and encourage individuals to take up benefits to which they are entitled. Despite these initiatives, it is believed that a significant minority of older people (the size of which is difficult to measure) fail to claim all that they are entitled to². In addition, other research³ identified that many people over State Pension Age (SPA) were somewhat isolated and disconnected from information networks and recommended a more proactive approach from TPS to counteract the relationship between long-standing health conditions/disability and reduced confidence and lack of assertiveness.

Research that focused on the administration of Attendance Allowance (AA) had two main findings⁴. Firstly, that the probability of an individual over SPA making a claim for AA appears to rise strongly with their degree of disability, irrespective of personal and household circumstances. This suggests that disability benefits make an effective contribution to the system of support for disabled older people. Secondly, it argued that there was evidence of a substantial volume (possibly 30 per cent or more of the over-65 household population) of unpursued but potentially successful AA claims.

Research undertaken by DWP found that Disability and Carers Service (DCS) customers who did not speak English as their first language or were from an ethnic minority were found to have a number of barriers. These included:

- lower levels of understanding of the benefits system;
- the length of time it took eligible customers to access relevant information about how to make contact;
- the challenges posed by the complexity of application forms; and

² Bunt, K., Adams, L. and Leo, C. (2006) *Understanding the relationship between the barriers and triggers to claiming Pension Credit*. DWP Research Report No. 336.

³ Sykes, W., Hedges, A., Ward, K., Melvin, K. and Bose, M. (2005) *Understanding the service needs of vulnerable pensioners: Disability, ill-health and access to The Pension Service*. DWP Research Report No. 263.

⁴ Pudney, S. (2009) *Participation in Disability Benefit Programmes. A Partial Identification Analysis of the British Attendance Allowance System*. Institute for Social and Economic Research/ESRC.

- the responses to customers with a strong accent by service staff⁵.

The Pension Service has been increasingly pro-active in its efforts to understand the types of events that ‘trigger’ people to make contact with them and in encouraging older people to claim their entitlements. Recent research⁶ suggests that departments administering benefits effectively signpost people with a history of claiming towards other benefits to which they may be entitled. However, it also suggests that inexperienced claimants tend to rely more on researching and collecting information from the internet, reading leaflets or talking to friends/advisers themselves before making their first contact with TPS or DCS.

The potential use of the internet as a means of service provision is a particularly important issue for PDCS in respect of the age group that the research focused on. A recent report to inform the future of digitalisation of public service delivery comments that the expansion of e-Government is a central plank of the UK public sector reform agenda, giving rise to wide-ranging research to assess citizens’ receptiveness to online services and to evaluate initiatives aimed at promoting uptake⁷. However, the tensions inherent in this centre on: maintaining the security, accuracy and integrity of benefits systems; delivering the best customer experience; and maximising efficiency and minimising running costs.

There is also the issue of the so-called ‘digital divide’, defined by the Organisation for Economic Co-operation and Development (OECD) where different sectors of the population have little or no access to the internet and the resources it can offer, or have limited knowledge of how it can be used⁸. Other recent research observed that users of some public services may not wish to engage with information communication technologies⁹. In the context of Jobcentre Plus, it refers to evidence of a divide in terms of socio-economic status, educational attainment, occupational grouping and health status¹⁰. In the current research, age is also relevant, although it is important to note that the population over SPA is very diverse and service delivery needs to reflect this diversity in order to be effective.

This research explored some of the barriers associated with contacting PDCS, examined the channels through which contact takes place and aimed to improve the understanding of the impact/contribution of life events in facilitating older people’s contact with PDCS. These events may act as a trigger, prompting an older person to contact the service and make a claim. Alternatively, they may trigger eligibility for certain benefits, which may in turn result in pro-active approaches by PDCS. In addition to individual life events, wider economic events may have a profound impact upon older people’s resources and result in them seeking advice and support.

⁵ Jones, M. and Tracy, I. (2010) *Ethnic minority customers’ experience of claiming disability benefits*. DWP Research Report No. 609.

Stockley, R., Lawless, S. and Slade, Z. (2010) *Summary of main findings from The Pension Service research into potential causes of lower overall satisfaction from non-white customers and customers with a long-term illness or disability*. DWP Research Report No. 568.

⁶ Bunt, K., Adams, L. and Leo, C. (2006) *Understanding the relationship between the barriers and triggers to claiming Pension Credit*. DWP Research Report No. 336.

⁷ Whitfield, G., Perren, K., Stuart, D. and Norris, M. (2010) *Literature Review to Inform the Future Digitisation of Jobcentre Plus Service Delivery*. Commissioned by DWP.

⁸ OECD (2006) *Glossary of Statistical Terms: Digital Divide*. [Available at: <http://stats.oecd.org/glossary/detail.asp?ID=4719>, accessed 2 June 2010].

⁹ Dutton, W. H., Helsper, E. J. and Gerber, M. M. (2009) *The Internet in Britain in 2009* [Available at: http://www.oii.ox.ac.uk/research/oxis/OxIS2009_Report.pdf].

¹⁰ Whitfield et al., 2010. See Footnote 7.

The recent recession and government responses inevitably have a different impact upon different groups in society. In the recent recession, media attention was generally drawn towards people of working age, who were most visibly at risk of experiencing unemployment. However, where people above SPA need to, or have a desire to, undertake paid work, it may be the case that the impact on them will be less visible. Similarly, while many working age people may benefit from the current low interest rates, people over SPA on fixed incomes and/or who rely on interest from savings may suffer a real decline in disposable income, exacerbated by continuing high fuel and food prices. One consequence of this could be that a tranche of older people who, in the past, were relatively self-sustaining now need additional assistance.

1.2 The Pension, Disability and Carers Service

On 1 April 2008, PDCS was officially launched as an executive agency of DWP. It was made up of two existing agencies, TPS and DCS. The two agencies continue to operate publicly under their individual names and customers continue to receive services from them as usual. Over 50 per cent of the DCS customers are also customers of TPS, thus the focus here on 'overlapping customers'.

1.2.1 The Pension Service

TPS provides information about entitlements and delivers benefits such as State Pension and Pension Credit to current pensioners and their representatives. In doing so, it works with other statutory and voluntary organisations. As well as working with those currently receiving pensioner benefits, TPS also provides pension-related information and advice to future pensioners, for example, forecasts of likely pension entitlement.

Since 2005, TPS has delivered the majority of its service functions through Pension Centres, mainly by telephone. The aim of this is to provide a more efficient service that allows customers to have their application for benefits managed within one phone call.

Local Service staff offer face-to-face contact for the most vulnerable customers, including the elderly and those with long-term illness or disability or health conditions, who may find it difficult to contact organisations like TPS by telephone or post. They operate in the community, offering home visits and have also developed a network of services in the community including the creation of Joint Working Partnerships with local authority staff and voluntary sector staff. The aim is to operate as one team, undertaking a single visit, covering all benefit and financial-related activities with the customer.

1.2.2 The Disability and Carers Service

The DCS provides financial support for disabled people and carers through the administration of: Disability Living Allowance (DLA); Attendance Allowance (AA); Carer's Allowance (CA); and Vaccine Damage Payments.

The DCS customer groups are disabled people of all ages and their carers. Customers can make contact with DCS by telephone, email or post. Telephone contact can be made via the Benefit Enquiry Line (for general advice or information about benefits for disabled people), Disability Living Allowance and Attendance Allowance Helpline, Carer's Allowance Helpline and the Vaccine Damage Payment Line. Face-to-face contact is also available to customers:

- Local Service staff may visit more vulnerable DCS customers.
- Some DCS offices have facilities to accept customer visits.
- Customers can contact DCS via their local Jobcentre Plus office.

1.3 Aims

The aims of this study were to:

- determine the events most likely to trigger contact with PDCS, for example, relating to a life event, financial circumstances or the onset of/change in illness/disability;
- determine customers' needs and expectations of PDCS at the time of the 'trigger event';
- understand the customers' networks, including the use of 'partners' as an avenue into contact with PDCS, and the effectiveness of these;
- determine what aspects of the service customers are the most and least satisfied with including satisfaction with the various channels of communication or modes of contact;
- detect where PDCS might be more pro-active in servicing this customer group;
- understand the impact of 'trigger events' on the 'benefits package', for example, whether certain triggers lead to amendments of the range of benefits received; and
- locate the research findings within a context of what we know about the resources older people draw upon in later life.

1.4 Method

The study used a qualitative approach involving a combination of face-to-face in-depth interviews and discussion groups. A sample of 30 men and women in their 60s, 70s and 80s living in Derby, Derbyshire, Leicester and Leicestershire was drawn for interview from PDCS' customer database. The sample covered a range of people in relation to self-reported health conditions; marital/partnership status; household type; family circumstances; and support arrangements.

Three discussion groups were also conducted: two with people over SPA and one with carers. An older people's and a carers' group took place in the East Midlands, the participants drawn partly from original interviewees and partly through a carers' organisation; a second older people's group took place in Glasgow, the participants for which were also drawn from PDCS' customer database.

The topic guides used in the research are in Appendix A. Details of the sample and of issues that arose during the conduct of the fieldwork are set out in Appendix B.

In addition, this study involved a reanalysis of data collected in the 'Resources in Later Life' (RILL) study¹¹, which consisted of two waves of in-depth interviews with 78 households of people aged between 65 and 84. This reanalysis focused on older people's experiences of using a wide range of services (including PDCS) and provided an insight into the main 'triggers' and barriers to their use, people's needs, preferences, and their experience of receipt of services including dealing with changes in service provision. This analysis was undertaken in order to add depth to the findings of this research.

The RILL analysis informed the way in which the analysis of the data collected in the current research was undertaken and are summarised in Appendix C should readers wish to look at this in more detail. This report presents integrated findings from the individual face-to-face interviews, group discussions and the RILL analysis.

¹¹ Hill, K., Sutton, L. and Cox, L. (2009) *Managing Resources in Later Life: Older People's Experience of Change and Continuity*. York: Joseph Rowntree Foundation.

1.5 The report

This report is structured as follows:

- **Chapter 2** explores the barriers people reported to contacting PDCS and the ‘triggers’ that initiated the contacts they had;
- **Chapter 3** looks in-depth at the nature and role of local networks that were involved in enabling people to make and maintain contact with PDCS;
- **Chapter 4** examines the experiences of, and preferences for, different channels of communication that people had with PDCS;
- **Chapter 5** looks in more detail at the nature of people’s experiences of contact with PDCS; in particular, it contrasts differences between straightforward contacts and more complex ongoing interactions; and
- **Chapter 6** then brings together the findings in this report to draw some overarching conclusions. These findings may then provide PDCS with insight into some issues that may inform how the service can overcome the barriers older people experience in contacting the service, better understand and respond to customers’ needs and respond to the particular pressures experienced by carers.

Chapters 2-5 contain a short summary of the key points at the end.

2 Barriers and triggers to contacting PDCS

This chapter explores the events and circumstances in older people's lives that initiated or resulted in their contacting the Pension, Disability and Carers Service (PDCS). It sets out that lack of awareness, pride and stigma were important aspects in determining whether, how and when people contacted PDCS. In so doing, it highlights issues that PDCS might consider in developing strategies to effectively and efficiently raise awareness of its services and of the ways in which people can access them.

2.1 Barriers to Contact with PDCS

The accounts gained in this research identified a number of key barriers that older people need to overcome before they will make contact with PDCS. These include:

- lack of awareness of what is available and of eligibility criteria;
- people not knowing 'where to start';
- sensitivity around being a 'claimant';
- misunderstandings around the differences between means-tested and needs-tested benefits, and of the interactions between them;
- the complexity of the system; and
- the impact of earlier contacts.

Many people, prior to coming into contact with PDCS, had little awareness of the kinds of benefits that were available to people in their circumstances. This lack of awareness was not limited to the benefits administered by PDCS and extended to a broad range of benefits and services administered by a variety of both national and local public service organisations. Even amongst those who had some awareness that there was financial assistance available, there was often uncertainty as to whether they might be eligible to claim. There was also a widespread lack of knowledge as to how they might start the process of contacting PDCS and/or making a claim. For example:

'I sometimes think, you know, that it's a bit confusing to some people to know exactly what they are entitled to.'

(Male, above SPA, Leicestershire pensioner's group)

Clearly, low levels of awareness represent a significant barrier to making initial contact with PDCS and thus to the potential of claiming their entitlements. They also represent a challenge to PDCS as people in these circumstances are likely to be difficult for the service to reach and in turn convince them to claim their potential benefit entitlements. This is of particular concern as people in financial difficulty that do not receive financial help with the extra costs incurred as a result of their health condition or disability are at additional risk of falling into poverty.

Even when people became aware of the availability of particular benefits or of the existence of PDCS itself, there was often real sensitivity around accepting and then demonstrating their potential eligibility in relation to all forms of welfare provision, whether means-tested or needs-tested. For some, this was a major barrier to overcome before they would even consider approaching PDCS.

This was partly a feature of the sense of pride and financial self-reliance amongst people in the 'older generation' that was commonly raised as a key issue in shaping how they thought about the process of claiming benefits. This process was made more difficult in the context of public portrayals of benefit claimants as 'scroungers', 'fraudulent' or more generally 'undeserving'.

This resulted in many of the older people we spoke with needing to be convinced of the legitimacy of any potential claim before they considered making any contact with PDCS (or other similar agencies). Further, many expressed a strong need to be able to readily demonstrate to others that any claim they might make was genuine. It was important for them to be able to do so in a straightforward way that did not make them feel as though others (including family/friends and PDCS officials) might consider them to be seeking to claim something to which they were not entitled. The concern over this issue was neatly captured as follows:

'We're not asking for anything that we're not entitled to.... I've never, never in all my life asked for help off anybody, you know, we wouldn't do a thing like that.'

(Female, 71, Leicestershire)

This was a significant issue for many older people and was, for some, a fundamental barrier, which represents a further challenge for PDCS in how it promotes and communicates with potential customers. This issue exemplifies the difficult balance the service has to make between determining eligibility in a robust manner while ensuring those people making claims do not feel stigmatised. This is discussed further in Chapter 4.

Another important barrier to people contacting PDCS (initially, subsequently or in the future) related to experiences of, or perceptions about, the complexity of 'the system'. People referred to a number of common issues that were problematic for them in respect of making a claim and communicating with PDCS about a range of specific issues (such as changes in their circumstances). These included:

- the length and complexity of application forms for benefits and services;
- where to go to make initial contact and how to do it; and
- understanding which office in which part of the country was responsible for different services.

The research collected many accounts of the nature of PDCS claim forms and the processes people associated with making a claim (and indeed, claim forms and processes for public services in general) and these are discussed further in Chapter 4. Overall, the kinds of issues people raised about forms requiring health or disability-related information included:

- being unable to complete forms themselves due to formatting and length;
- being unable to complete forms due to health condition or impairment;
- being unable to follow the logic of the questions;
- becoming confused about the relevance of many questions; and
- being concerned about the apparent need for so much personal and 'intrusive' information.

A useful illustration of the kinds of issues that were raised in respect of the interaction between ageing/impairment and the design of the forms is as follows:

'[The forms] are not easy to follow: 'If you're answering yes to this one, go to question "x"...then you come to the next paragraph, but by the time I start to read that, my brain has forgotten that paragraph.... I can remember a long time ago, but my short-term memory is failing me fast.'

(Female, 76, Leicestershire)

In this respect, whilst some older people overcame this barrier by asking others (such as family or friends) to help them complete forms; this was something that others were uncomfortable with for a number of reasons (see Section 3.1 for more discussion on this issue).

In addition to the complexity of the claims process, there was a widely held view that negotiating their way through PDCS as an organisation was problematic. In fact, many people were unable to distinguish between a range of agencies (including ones with no connection to DWP) and this often caused additional confusion. When talking specifically about PDCS, however, some older people provided examples of the way in which attempting to contact and engage with the correct parts of the organisation was difficult or confusing:

'...you can phone the benefits office and they will tell you, it might be Blackpool, it might be Newcastle, and then they'll say, "Ahh you're in the wrong office here! You want to be Northern Ireland".'

(Female, over SPA, Leicestershire focus group)

The widespread lack of understanding of the difference between 'means-tested' (such as Pension Credit) and 'needs-tested' (such as DLA and AA) benefits represented a further barrier. For example, confusion between the two criteria led some people to respond to invitations to apply for Pension Credit when their income meant they were not entitled. It also led to people **not** pursuing claims for DLA or AA because they thought their income ruled this out. Sometimes, older people were making these decisions in light of incorrect or contradictory information from a variety of sources. An example of this was found where a family assumed (on the basis of what **they** knew) that their father would not be entitled to a (needs-tested) disability-related benefit because of his existing occupational pension:

'I said ..."we just assumed that...he's probably getting too much money, because he gets a works pension". She said "That's nothing to do with it at all...it doesn't matter who's living there, how much anybody is earning, it's what he's entitled to".'

(Daughter of male, 84, Derbyshire)

The combined impact of the perceived complexity of the benefit system; the lack of clarity (or understanding) of how PDCS should be contacted; and the risk of people making decisions on the basis of incorrect advice, all shaped older people's perceptions and experiences of the service. The outcome of this was that some may be reluctant or unwilling to contact the service in the future and others may quickly disengage should the contact become too onerous or confusing. The clear risk of PDCS (and public services more generally) not overcoming such barriers is that older people do not receive their full entitlement. Further, it is also possible that people acting on incorrect information may advise others to act in a similar way.

The importance of this issue was emphasised in that it was sometimes negative experiences of claiming and contact with one part of PDCS that inhibited further contact with another. Where this arose, it was usually in respect of people being advised that their claim had been unsuccessful. In some cases, people were reluctant to make further contact due to a negative (and disappointing) outcome itself, whereas in others it was related to the way in which this information was conveyed and how it was interpreted. In a small number of cases, people's negative experience related to them being awarded benefit and then discovering that they had previously missed out on benefits to which they had been entitled, but which could not be awarded retrospectively.

Some older people indicated that their generation were 'culturally averse' to questioning authority. In the face of what they considered inadequate explanations for being declined benefits, lack of experience of claiming benefits and an underlying sense of their probable non-entitlement, they were unlikely to appeal against a decision or make further contact. This was illustrated as follows:

'We are inclined to, you know, not to push.... I think you ought to be encouraged more, if you're turned down, to talk to somebody about it and find out why...when you don't know what you're doing because you've never done it before, you tend to give up. And I think a lot of people tend to give up.'

(Male, 84, Derbyshire)

2.2 Triggers to contact with PDCS

The accounts given by people in this research strongly indicated that the 'triggers' to older people making contact with PDCS were not necessarily a consequence of one-off 'events' that occurred at a single point in their lives. Rather, contact was commonly a result of the cumulative impact of a range of factors taking place over a period of time followed by a specific event that acted as the impetus to make contact.

While this was not the case for all people, the most commonly reported scenario for this 'trigger event' was one where a third party (such as a friend, neighbour or health professional) encouraged, initiated or mediated contact with PDCS after the claimant themselves met eligibility criteria (e.g., for AA) some time earlier. In other cases, contact was related to a change of circumstances relevant to a benefit a customer was already receiving. In some cases, contact was initiated by PDCS itself, through written contact informing people of a benefit uprating or other administrative change. It is important to highlight (as discussed below) that it was often difficult to clearly identify a single 'trigger' within an ongoing process or journey for people already in PDCS' system. This is important as the notion that there are single 'trigger' events resulting in contact with PDCS does not always reflect the experiences of older people.

The following two sections look first at the 'underlying conditions' which did not, in themselves, usually lead to contact with PDCS and the 'precipitating factors' that actually triggered contact with the service.

2.2.1 Underlying conditions

The underlying conditions reported by the older people in this research can be broadly categorised as health-related and income-related.

Health-related

Across the three PDCS customer groups (see Appendix B), changes in health or disability status often meant that people had become eligible for DLA or AA as a result of a gradual deterioration of their health involving a range of conditions or as a result of their long-standing or acquired disability status.

In many cases, it appeared that they may have been eligible for benefits for some time before making a claim and that the initial contact with services (including PDCS) was sometimes made by a third party – usually a partner or relative – rather than the person themselves. This was illustrated in one account where a woman had contacted DCS when her husband's deteriorating health had required her to take on additional caring responsibilities:

'...I expected an allowance for, you know, regarding looking after my husband, which of course I have to do because he had this triple bypass and then after that he found out he had had two or three minor strokes which gave him short-term memory loss.'

(Female, 74, Derbyshire)

In such situations, it was common for people to explain that they developed a general ‘sense’ (as opposed to ‘knowing’) that they might be entitled to a benefit because of their (or their partner/relative’s) deteriorating health or financial circumstances. Further, for some older people who had experienced deterioration of their health or acquired a disability after they had reached State Pension Age, the idea of ‘having a go’ led them to contact PDCS, rather than a response to any specific event that had occurred.

For example, one 66-year-old man felt he might be entitled to benefits of some kind due to his severe hearing impairment, spondylosis and diabetes and he decided to contact the PDCS himself with no input from others. He, like many others, was unable to identify what had actually made him aware of his potential eligibility before contacting PDCS. What was evident from the research, however, was that many people experienced ill-health, disability or caring responsibilities as part of their daily lives, and often this had been the case for a long period of time. Taking steps to find out about and claiming their (likely) entitlement had not occurred to them until some form of ‘personal threshold’ was crossed. This point is highlighted as it stresses that some older people made decisions using informal rather than administrative criteria.

In a number of cases, people experienced what might be called a ‘health event’ – for example a brain haemorrhage, heart attack, stroke or a fall down the stairs – which subsequently resulted in a long-term health condition or impairment. One woman described her husband’s brain haemorrhage as the beginning of his health problems. Despite this event prematurely (and suddenly) ending his career, it was not until several years later that he made a claim for AA. The ‘trigger’ to contact PDCS was a chance encounter with an acquaintance who had formerly worked for Age Concern (now Age UK), who alerted them to the availability of this benefit. In retrospect, they were baffled as to why this advice was not offered at the hospital at the point of discharge, or subsequently by their GP. While the claim was ultimately health related, it is highlighted here as it did not occur simultaneously with the health event itself.

Income-related

For some people, it was concerns over their financial situation that led them to contact PDCS. This was often in relation to a claim for Pension Credit as opposed to a health or disability-related benefit. For others, the two factors were connected, in that, underlying health conditions or an existing disability had an impact on their earning potential whilst they were still of working age, on their income after SPA and on their wider financial circumstances. In this sense, ‘becoming eligible’ was a two-step process. For some, ill-health or disability meant that they had been unable to work prior to reaching SPA and in some cases, this had been a long-term problem. For others, their health condition had led them to take early retirement, which in turn had a negative impact on their finances. For example:

‘I had the first heart attack in 1996, I had another one in ‘97, and then I had one this last June... when I had the first heart attack.... I had to go and visit [the doctor] and...he knew just by looking at me I was going to become diabetic, and within 12 months I was diabetic.... I couldn’t do the job properly to my full ability, so I applied for early retirement and they let me have it’.

(Male, 68, Derbyshire)

It is important to stress that not all people in these two very different sets of circumstances had been in receipt of health and disability-related benefits prior to reaching SPA. In some cases, even though they had experienced health problems for many years prior to SPA, they had not claimed DLA/AA until after retirement.

For some people, a deterioration in their health resulted in associated costs, including the need to purchase care, specialist equipment or pay travel costs for hospital visits. For those whose deteriorating health led to giving up work, the fall in their income meant that they were unable to independently meet the additional costs of care, and this eventually led to contact with PDCS¹². For example, one woman reported that she had applied for Pension Credit as it was ‘a bit of struggle’ to pay the necessary taxi fares to get her to and from her hospital appointments and she ‘felt’ (but didn’t know) that there must be some form of financial assistance available.

Interestingly, given that PDCS is a single entity it would seem likely that people contacting TPS with respect to Pension Credit may benefit from the opportunity to discuss their broader circumstances and, if appropriate, from being re-directed to DCS staff (or even to other agencies about other matters). Of course, this situation equally applies in reverse and in respect of other organisations.

2.2.2 Precipitating factors

As already discussed, many people had underlying conditions or circumstances that potentially made them entitled to Disability Living Allowance (DLA) or Attendance Allowance (AA) (or their carers to Carer’s Allowance (CA)), but this did not necessarily lead to immediate contact with PDCS. In many cases, it took an additional ‘precipitating factor’ to trigger this contact and it was common for these to be separated in time.

This was particularly the case for older people that made a claim for health and disability-related benefits before or after, rather than at the point of reaching SPA. In other words, it was common for older people to appear to have been eligible for both means-tested and needs-tested benefits for several years before they actually made contact with PDCS to see if this was the case.

People gave examples of different ‘events’ that resulted in contact with PDCS. Sometimes, these occurred concurrently; so, for example, people might have seen an advertisement in a newspaper and also heard about benefits from friends or family. In other cases, they were separated in time, illustrating the ‘cumulative’ effect of a series of occurrences which led people to contact PDCS. The main factors or events that were mentioned are discussed below.

Advertising/promotion

A number of people recalled advertisements in newspapers or on television raising their awareness either of the extent of unclaimed benefits generally or of individual benefits in particular. Others had been prompted by the issue being included in factual or drama programming. In some cases, exposure to these messages had directly resulted in people deciding to ‘have a go’ or doing so after having gone on to discuss it with a member of staff at the local authority or in a local organisation. For example:

‘It was on the telly – a chap speaking no end of times, that there’s millions not accounted [for]. You know, people should collect a lot more money than what they’re receiving.’

(Male, 80, Derbyshire)

‘It was in the local paper, wasn’t it? A piece [about pension credits]...we just said to each other “Oh, we’ll go for it” ...and the rates people, they said “Go for it”...we did send off for the papers.’

(Female, 76, Leicestershire)

Others recalled having received written information from PDCS (although it was uncommon for people to be able to recall the exact nature of this correspondence) which had prompted them to make contact.

¹² These ‘additional costs’ form part of the rationale for the provision of DLA, AA and CA.

The loss of a partner or relative

A number of people contacted PDCS following the death of a partner or relative. For those who reported this event as a trigger to contact, the contact was generally reported as having been relatively straightforward and unproblematic.

For example, one woman explained that she had contacted PDCS following the death of her husband and had found this to be a simple process, which had left her satisfied with the way her situation had been dealt with:

'When my husband died I had a lot of contact with them, an awful lot of contact because I had to notify them that he'd passed away and give them all his insurance numbers and everything and there was quite a lot going on then, an awful lot. They were quite good.'

(Female, 73, Derbyshire)

For others, it was the impact that a death in the family had on their personal circumstances, such as their financial situation or their need for health support, which triggered contact with PDCS. For example, one woman described how her father's death had resulted in a 'transfer' of the caring responsibilities he had undertaken for his wife, which had led to her mother moving in with her. In time, this led to a new claim for AA:

'I lost my dad, so that left mum in [name of place] and she just didn't want to be on her own. She just went to pieces. I think it was a few weeks or months before we realised that I could get an Attendance Allowance.'

(Female, 62, Leicestershire)

Informal relationships and chance encounters

For some participants their contact with PDCS was triggered by the general awareness of friends, family, neighbours or 'associates', some of whom were themselves in receipt of benefits administered by the service. In this respect, many interviewees talked about knowing someone 'down the road' who received or knew about benefits. In addition, in a number of cases, becoming aware of the existence of, and their potential eligibility for, a benefit came about by chance.

For example, one person had accompanied a friend to an appointment with a welfare rights officer and, as a result of sitting in on the discussion, began to think they might be eligible for AA. Similarly, one man had a chance encounter with someone at a bus stop who had asked him whether he was in receipt of any benefit for his mobility impairment:

'...it's a time I met a lady...and she asked me if I'm getting anything for my legs...I tell her no. So she says why, because she's getting, and she's walking, and when she on the bus - and I am walking worse than her...so if it wasn't for her, I wouldn't be getting anything at all up to now, because I didn't know that I could have claimed.... My doctor never told me anything that I could have claimed for my knees or nothing, so I didn't know. So after the lady say that, that's why I went there, and put all the facts to them.'

(Male, 83, Leicestershire)

Others had been actively encouraged to apply by a friend or relative, which was sometimes as a result of their professional role (e.g., as ex-social workers). The role of friends and relatives is discussed in greater detail in Chapter 3.

2.2.3 Change in circumstances

The issue of contacting PDCS due to changes in circumstances is discussed separately given that claimants are required to keep PDCS informed of anything that may affect their entitlement. Overall, the accounts obtained in this research suggested that older people were generally highly attuned to the requirement to inform PDCS of any change of circumstances. This was explained in both positive terms (in that it worked well) and in legal terms (in terms of it being an obligation that they needed to meet).

An example of an engagement with PDCS regarding a change of circumstances was given by a man who returned to the Caribbean fairly regularly and who saw the two-way communication between himself and PDCS on this subject in a very positive light. He would tell ‘them’ when he was going and when he returned and he would be contacted by them to ensure that he was getting his money when and where he should be. In respect of the legal obligation to contact PDCS, compliance with reporting a change of circumstances reflected a common desire to be ‘above board’ in dealings with the service and also in the context of an awareness of risk associated with not meeting this requirement:

‘...it says on there [the letter] something, if your circumstances change, get in touch with us, yeah. That’s fair isn’t it. You can’t be any fairer than that. Like if you get, if someone leaves me some money.’

(Female, 85, Derbyshire)

‘I got a letter, it must be about two or three years ago now, about this underlying pension credit again, and asking had any situation changed, and I was quite nervous about this because the thing I really don’t want to do and you’re scared of doing, is putting down wrong information, you know, I worry about that because whatever we say it is the truth, we hide nothing’.

(Male, 80, Derbyshire)

As far as PDCS-administered benefits were concerned, however, there was some confusion as to what constituted a change of circumstances. For some, this led to concern that if they actively informed PDCS of a change in circumstances, this would invariably result in them losing money, even if they did not think the change was material to their health condition. Others were concerned that if they didn’t inform PDCS of a change, they would lose money (and have to pay some back) if/when it became known.

For example, one woman consulted her GP after becoming anxious about how ‘legitimate’ it was for her to have taken up bowling when she was receiving a benefit in relation to arthritis in her knees. She was concerned as to whether she should inform PDCS of this and whether her claim might be cancelled if she was deemed too ‘able’ or if the activity was thought to contribute to a deterioration of her condition. As she put it herself:

‘They ask if anything’s changed...like my disability...they’ve only got to get in touch with my doctor...with the bowling you see, I didn’t want them to find out I’m bowling and I shouldn’t be, so I got in touch with the doctor, and she said yes [it was OK].’

(Female, 76, Leicestershire)

This need to demonstrate their honesty in their dealings with PDCS also reflected commonly-held views about the distinction between people who are ‘genuine’ and those were making fraudulent claims. In relation to the latter, people sometimes referred to others whom they believed had been making false claims, and this had an impact on how they felt they might be perceived:

'I could take you to no end of houses in this village...and they are getting everything sort of thing. I don't want anything for nothing, I would like what is due to me. I don't want anything which I'm not entitled to because I don't want plod knocking on the door and saying, you know, "You're arrested" ...'

(Female, 71, Leicestershire)

2.3 Key points

This chapter highlighted that there are a number of barriers to PDCS achieving its aim of ensuring that older people are aware of, and receive, their full entitlement to the financial assistance, services and support available to them:

- overall, there was a general lack of awareness of the availability of financial assistance from PDCS. There was also considerable sensitivity around issues of eligibility and claiming, with many people feeling that the process of demonstrating entitlement was one in which they had to 'jump through hoops';
- many people simply 'did not know where to start' in the process of claiming benefits to which they might be entitled. Complex application forms, difficulties contacting the correct staff within PDCS and little understanding of interactions between benefits resulted in confusion and frustration;
- contact with PDCS was rarely the result of a single 'trigger' event, but rather a result of a combination of events over time. As such, many people contacted PDCS sometime after the onset of a health condition or disability or after having taken on caring responsibilities, and may therefore have been living without a benefit which they may have needed or been entitled to.

3 The role of networks and partners

This chapter looks at the nature and role of local networks that were involved in helping, encouraging or enabling people to make and maintain contact with the Pension, Disability and Carers Service (PDCS). It sets out the critical role of family, friends, neighbours and local networks in raising awareness of benefit availability and encouraging and helping older people overcome their reluctance to claiming. In so doing, it provides the service with an indication of some potential means of raising awareness of the financial assistance available and of reaching out to older people who might not consider contacting PDCS themselves.

3.1 Families, friends and neighbours

The research highlighted the significant role of family, friends and neighbours as providers of care and support for many older people in the community. This finding reflects the increasing recognition and importance in recent years of the role of family, friends and carers for older and disabled people, as well as the emphasis on the increasing role of not-for-profit organisations in this provision¹³.

In particular, the role of older people's adult children was an important one, yet the extent of involvement varied considerably. In some cases, they helped their parents to complete forms or write letters. In others, they checked forms and letters which their parents had completed themselves. Some older people discussed their options with adult children or other relatives and listened to their opinions to ensure they had provided PDCS with the correct information they required. A common scenario was reported as follows:

'...normally we ask the boys [sons] for their opinion or they help us. My eldest son's wife, she's very good, she helps us quite a bit if we want it. And the others do as well, you know, and that's how we do it...'

(Female, 76, Leicestershire)

In other cases, however, older people preferred not to involve their children in dealing with issues around benefits and/or services. This was sometimes because they did not want to 'bother' them or because they felt that their children were not able to provide them with the necessary information or support. In other cases, it was because they considered such matters private and they would rather do it themselves or ask someone outside of the family for their advice or assistance. For example:

'I don't ask my family, rely on my family for help unless they want to give it. I don't put on them, I would rather pay somebody to come and do it.'

(Female, 70, Derbyshire)

In addition to immediate family, many people reported that friends, neighbours and acquaintances were useful for identifying benefits or other sources of support (e.g., social care). Very often this was a result of these other people having personal experience or expertise.

¹³ And which began to develop in earnest in light of, for example, Griffiths Report, 1988; National Health Service and Community Care Act, 1990.

'You find out through people who have had the same experience. They'll say "Oh have you not put in for this? You're entitled to this...". Nobody tells you you're entitled to it. That's how I found out – through a friend.'

(Female, above State Pension Age (SPA), Glasgow pensioner's group)

As discussed in Section 2.1, many older people were reluctant to apply for help either because they had no idea what might be available or because they thought all benefits were means-tested and felt that they would not be entitled. Having a family member or friend suggest that they apply appeared to make an application more likely and seemed to increase their feelings of legitimacy and entitlement. If an application was turned down, it was often the case that a friend or neighbour encouraged them to make an appeal. For many, a lack of this kind of support would have resulted in a lack of awareness about PDCS-administered benefits, of how to approach PDCS, or scepticism about the legitimacy of their claim for financial assistance.

Family, friends and neighbours who were also 'insiders' or who had specialist knowledge sometimes provided advice or assistance. Examples of these 'insiders' included retired social workers or advisers in organisations such as Age Concern (now Age UK). In many cases, older people felt that their claim would have greater validity if they had been advised by someone with specialist knowledge than if they had received that advice from their families. This often made it more likely that they would make an application for support or, at the least, make enquiries. For example:

'A friend of mine was a social worker; she said I might be entitled to this Carer's Allowance because I look after my mother. That is how I heard about that, but that is the only time I've ever had to contact them [Carers Service] for anything.'

(Female, 63, Derbyshire)

However, not all older people had family and friends nearby or knew their neighbours sufficiently to discuss personal and financial matters. Indeed, for some older people, retirement had led to a loss of social networks on which they had relied for many years. These networks may have proved useful in helping them in their transition into retirement and during a period in which their health and social circumstances may change considerably. However, even without strong social networks, older people often experienced fleeting social interaction which led to contact with PDCS as the following account illustrates:

'Someone said to me one day when I was out at the bingo, they said "Do you get state pension credit?" I said "What?" So I said "Not that I know of". So she said "Well you want to apply for it then".'

(Female, 68, Leicestershire)

3.2 Community-based services

Many of the community-based organisations that the older people had contact with had staff with the specialist knowledge (or access to it) to raise awareness among older people about their possible entitlements and/or to assist them in making applications for support and benefits. In some cases, community-based organisations were a hub for a range of voluntary and statutory advice.

Experiences of the support accessed through community organisations were discussed in both the interviews and the discussion groups. The role of such organisations was clearly important in bringing together a broad range of expertise and knowledge under one roof and therefore the remit of such groups was often considerably wider than the provision of advice on benefit entitlement. In this sense older people came into contact with local organisations in a number of ways, and often by chance, for example:

'Mum went for her flu jab and there was a lady from the [...] Voluntary Action Group. She was at the doctor's handing out leaflets, and it was all about carers' forums and things. I did send off for a form and asked to be kept in touch of various meetings.... I think they sometimes have speakers that cover the benefit side as well.'

(Female, 62, Leicestershire)

Int: 'Has anybody...ever drawn on people and resources at [community centre] for information about pension or disability carers services?'

R1: Well we did have, when we had [name] working here.

R3: He knew everything there was to know about social services, about money to get, where to go....

R4: ...every so often you get a person come...from County Hall...I have been collared by one: "Why aren't you on that?" "Well, I'm not entitled to it" – because you don't know. So he comes round here quite often with his Attendance Allowance business...'

(Leicestershire pensioner's group)

Specific advice on benefit entitlements and support with applications was obtained by a number of people from 'Welfare Rights' services, in particular when there was confusion over the information required to demonstrate entitlement and when appealing against decisions that were felt to be wrong. This kind of support often assuaged concerns over the legitimacy of their claim and of challenging the decision of a government agency. The type of support people received included:

- support with completing application forms;
- advocacy support, such as enquiring about issues relating to entitlement of an existing claim; and
- general advice or signposting to other agencies.

Community-based organisations also offered invaluable support to widows or widowers. This was especially important where the late partner had been the one to deal with financial matters or paperwork in general. The woman below explained that the support she had from the local Citizens Advice Bureau (CAB) office had been invaluable in this context:

'When my husband was alive, you see, I'd never filled no forms in or nothing, because he did everything – I never paid any bills or anything. And somebody said they're [the CAB based at a local Community Centre] quite good. So I went and they were good, they helped me do it [apply for Disability Living Allowance].'

(Female, 63, Leicestershire)

This reflects the circumstances many older people find themselves in, whereby they need to contact a range of agencies to sort out the financial affairs of their deceased partner, despite having no previous dealings with such organisations. That some people in these circumstances reported being confused about where they could seek support is of particular concern, especially as the confusion arose at a time of considerable personal and financial turmoil.

Although people didn't refer to it by name, they also gave accounts of their experiences of local service delivery. They were generally positive about local services within the community as these services had effectively helped to resolve difficulties and were regarded as a repository of information, advice and support. As such, it may be beneficial for PDCS to work more closely with local services which provide advice and support to older people about claiming the benefits to which they may be entitled and about other services that are available.

3.3 Health and social care professionals

Older people living with ill-health or disability are likely to come into contact with professionals from health and social care. There were numerous examples of such professionals offering help and advice about how to apply for additional support, both practical and benefit-related:

'...it was the nurse that came to see me...she said "Aren't you getting Attendance Allowance?" And she said "I'll bring you a paper and explain how to fill it in...".'

(Male, 87, Derbyshire)

As health and social care staff were viewed as specialists, their opinions were particularly valued and they could readily help older people overcome issues surrounding legitimacy and eligibility to a greater extent than friends, family and neighbours. Such professionals were also in a position to reassure older people with regard to medical conditions and the type of care and treatment that might be beneficial. This puts them in a unique position to persuade those who are reluctant to seek support of the necessity and legitimacy of doing so. The following accounts illustrate some of the experiences that were reported:

'She [assistant at Low Vision centre] said "Well I think you ought to have a disability allowance." Because up until about three years ago blindness wasn't seen as a disability, and so it never occurred to me that I needed it.... But anyway, she said "I think you ought to contact them".'

(Female, 83, Derbyshire)

'Well that's where your social worker sometimes comes in, they know all the ins and outs of it ... Well the social worker up in the Redwood Flats, they were good for me, and they're pretty helpful, they go out of their way to help you...'

(Male, above SPA, Glasgow discussion group)

Interestingly, where older people had provided care and support for their parents or relatives in the past, they often had knowledge and experience of the support available from health and social care professionals. In such cases, people said they felt better equipped to negotiate the process and the system. For example, one woman who cared for her sister for more than 30 years found that she knew where to turn for support and advice when her husband subsequently became disabled.

Finally, a discussion in one of the focus groups highlighted the role of an agency which provided a single point of contact for vulnerable people aged 60 and over. Its aim was to promote safe and independent living and it worked closely with a range of organisations such as: Adult Social Care, the local Police and Fire and Rescue services and the CAB. In order to identify the needs of vulnerable older people and make appropriate referrals to relevant services, the agency used a checklist. A worker from any of the organisations involved who came into contact with an older person whom they thought might need more support completed the checklist, which was then forwarded to a central point. Any referrals received were then forwarded to the appropriate organisations in a co-ordinated way.

Although we had no specific examples of older people's experience of this latter initiative in practice, this co-ordinated response provided an example of how local networks and partners may be able to support the work of PDCS. This touches on the need for better information sharing discussed elsewhere in the report.

3.4 Key points

This chapter highlighted a number of ways in which older people became aware of PDCS and may provide insight into some additional means by which the service might raise awareness and encourage people to claim their entitlement at a local level:

- The role of family, friends and neighbours was often critical in helping older people become aware of their entitlement and of how to make claims. For some, this involved the provision of support, assistance and encouragement. For others, it involved taking on the role of advocate or representative. However, the ability to help was often constrained by insufficient awareness, knowledge or expertise.
- The assistance of staff in community-based organisations was a key factor in helping some older people to make contact with PDCS and claim their entitlement. Initial contact with such organisations was usually for reasons other than benefit entitlement, and staff provided advice and support with the added benefit of local knowledge.
- For some older people, retirement had led to loss of contacts and an increased risk of their not gaining access to relevant information. However, it was often the case that ‘chance’ discussions with people who shared information with them on noticing their disability or health condition led to contact with PDCS or other local organisations.

4 Customer views on communication and contact with PDCS

This chapter explores older people's experiences of the different channels of communication through which the Pension, Disability and Carers Service (PDCS) delivers its services, and examines which channels they regarded as most effective in different circumstances. It suggests that unclear information and there being no single point of contact within PDCS caused many people difficulties. This provides an insight into how older people feel about the way in which PDCS provides its services and how it might do so in the future.

4.1 Face-to-face contact

Face-to-face contact with PDCS was relatively rare. Some of those who had not had face-to-face contact with PDCS did experience it with other agencies, such as Social Services, local authorities, Welfare Rights and medical professionals. There was often confusion, however, in identifying the agency with whom they had face-to-face contact, illustrating people's confusion around distinguishing between government agencies in general.

The views expressed about face-to-face contact, among those who had and those who had not experienced it, were overwhelmingly positive. One context in which it was seen to be appropriate was in enabling customers to demonstrate the authenticity of their claim, for instance, if their circumstances or needs had changed. In a context where older people felt the need to actively demonstrate their legitimacy, face-to-face contact was seen as a means by which they could give details more readily than via other modes of contact. Further, not only could those making assessments hear **what** was being said but could also see the evidence of claims being made about their health/disability status for themselves, and this was seen by many as better enabling them to communicate their own trustworthiness to PDCS:

'... face-to-face is better than just being on one end of the phone, because then nobody will see you to know exactly what you're saying is true. So I would prefer face-to-face because then they will come in and they will see me and they will see what I'm talking about is correct, it's not a lie, you see.'

(Male, 83, Leicestershire)

For some older people, face-to-face contact was also seen as a mode of communication that could help overcome the problems arising from telephone and internet based service provision for people with health conditions or impairments. There were also perceived advantages over other modes of contact in terms of PDCS being able to communicate customers' entitlements to them in a more accessible way. The interviewees also felt it gave them the opportunity to take time and to think about what they were being told and also to ask questions about their situation, which in turn enhanced their understanding:

'Well if you're looking at somebody as they're talking you understand what they're saying better, a lot better, and you can always query it if you don't. Face-to-face is always better...and also you have time to think; when you're on the phone you don't.'

(Male, above State Pension Age (SPA), Leicestershire pensioner's group)

Face-to-face contact was also seen as an effective antidote to the complexity of the system. A couple of interviewees felt that a face-to-face encounter would facilitate a more personalised relationship between them and PDCS, which they welcomed. This said, despite the strong support for face-to-face contact, it was acknowledged that it would not always be possible to provide this service due to it being resource-intensive. This is illustrated by the following account:

‘Well I suppose when you think about it there are millions and millions of people, I suppose it would be a sheer impossibility for them to come to your house wouldn’t it really.’

(Female, 73, Derbyshire)

Whilst people were generally very positive about the prospect of face-to-face meetings, therefore, this was not something which was expected as a routine provision. It was felt to be more appropriate for more complex cases or where an older person (or their carer) was unable to communicate effectively with PDCS by other means.

4.2 Written communication

Almost all the older people had had written contact with PDCS. Their experiences of this were mixed, with some people being positive about their experiences, and some raising a number of issues which had left them dissatisfied or caused them concern.

A commonly held view was that written communication from PDCS helped people document their contact with the service. This supports the findings from other research¹⁴. It was seen as valuable by many people as a means of their being able to keep a record for reference purposes, for clarification and for ‘proof’:

‘...if you miss something you can go back to that, whereas a telephone call you’ve probably forgotten what they’ve all said.’

(Male, 83, Leicestershire)

‘I’d rather have something in black and white than a phone call, because you can refer to it again can’t you? And you can take it with you and say “Well look, I’ve had this letter.”’

(Male, 66, Derbyshire)

In other instances, people especially welcomed being kept abreast of how PDCS were dealing with their application. Familiarity with letters as a form of communication was also cited in its favour, and there was some suggestion that this positive view of written communication might be a generational issue:

‘I like to write because that’s the way we were brought up. In those days we didn’t have lots of things like what you have now. Most everybody was writing a letter.’

(Female, 71, Leicestershire)

Apart from a comment from one participant that the use of case studies often confused them, people were generally positive about the PDCS booklet that explains entitlements to the benefits they administer. However, it was evident that not all people who had received information in this form read it thoroughly. There were some examples of people receiving a leaflet and putting it away as they had not realised that it contained additional information about other benefits to which

¹⁴ See, such as, Sykes, W., Hedges, A., Groom, C. and Coleman, N. (2008) *Opportunity Age Information Indicators Feasibility Study*. DWP Working Paper 47. Norwich: HMSO.

they might be entitled. However, for many of those in our study, having a printed copy of relevant information 'to hand' was considered to be useful. In addition, written material (such as booklets), which sign-posted people to relevant contact numbers, was particularly welcomed.

Importantly, letters which managed to get the tone in which it addressed customers 'right' were also very much appreciated. As discussed in Chapter 2, there was considerable concern amongst many older people about the legitimacy of their claims. There were also concerns raised about finding a balance between ensuring that the bureaucratic process verifies the legitimacy of their claim while reducing the stigma attached to claimants. The way in which older people are communicated with can help address these concerns. In some cases, the tone and content of letters from PDCS had struck the balance between officialdom and being personable well.

However, a common complaint about written contact from PDCS was that communication was sometimes unclear and difficult to understand, which sometimes caused confusion and/or upset. For example, one woman explained that she had received a letter that referred to her entitlement, but she had not understood what the letter was trying to convey. Indeed, it was evident that she found the complexity of the benefit system confusing and frustrating:

'... why are they saying you're entitled to it, and then in the very same, the paragraph down from it, "but because you are...", you know whatever, "you don't get this benefit". A carer's benefit: "if you're entitled to ... a carer's allowance" – "But because..." you know – whether it's because I've got an occupational pension and a state pension, I'm not sure at the moment. That's why I said the letter could be more specific...'

(Male, above SPA, Glasgow focus group)

In some cases, dissatisfaction related to a failure to explain decisions clearly. Many people also found it difficult to relate to the technical language which was felt to be somewhat alienating, patronising and potentially misleading:

'I think when they send letters – make it easier to understand, because sometimes you read it and you think "Yeah, got that" and then you think "No, let me read it again", and you think "Oh no, they're not saying that at all!" It needs to be done in a more simplified manner.... I mean, neither of us are duffers, we know what we're doing, but it does help if you can understand their technical words, let's put it that way.'

(Male, 80, Derbyshire)

Linked to such complaints were negative attitudes towards the length and complexity of the forms they were required to fill in for disability-related claims. As discussed in Chapter 3, many older people sought support with such form filling because they felt unable to do it themselves. The issue of repetition was a particular concern and for some, led to a feeling that they were 'being tested' in some way or that the system was trying to 'trip them up'. This was illustrated in the following account:

'...for six years I had to be reassessed every two years, but I find that the forms repeat themselves and it's almost as if they're trying to catch you out, almost as if they're trying to make you make a mistake.'

(Female, above SPA, Leicestershire focus group)

However, there was also an appreciation that service providers have to be rigorous, especially in relation to potentially fraudulent claims which some older people felt justified the lengthy forms.

Importantly, some older people were put off completing disability-related forms because they were causing anxiety or confusion. This was a particular concern for those who did not have access to family, friends, neighbours or local networks (as discussed in Chapter 3).

In many cases, people's feelings about completing forms reflected the circumstances in which they had to complete them. For example, as discussed in Chapter 3, it could occur during a period in which they were experiencing considerable change in their lives (such as the death of a parent/partner, significant change in circumstances, etc.). For many, completing forms at such a time was often an upsetting distraction from the wider issues they were focused on. When such form-filling coincided with a traumatic and life-changing experience, as was the case in the following account, this could be enormously distressing:

'Because of me injury and being able-bodied right before and everything ... I got to the third page and ... I rang them [PDCS] up and I said "I can't do this.... I have depression".... I couldn't do it.... I just could not at that stage, because of everything I'd lost, me mobility and everything, and with the chronic pain and the medication, the morphine and everything, I just could not cope with filling that form in.'

(Male, above SPA, Leicestershire focus group)

More generally, there appeared to be confusion about how PDCS is structured and which organisations have responsibility for delivering which services, so that older people were sometimes unclear as to who was writing to them. In addition, a number of people mentioned that they had contacted PDCS by using a number taken from some written correspondence they had received and were told that they were speaking to the wrong department and that they needed to contact another part of the service to discuss the matter. They found this frustrating, as the following account illustrate:

Int: '... where do you get the first phone number from...?'

R: Take it off one of the forms you've got. And then they say, "oh sorry that's the wrong one". I said, "but you're there, aren't you?", "oh yes, but our office is in Northern Ireland".'

(Female, above SPA, Glasgow Pensioner's group)

4.3 Contact by telephone

Most older people had experienced at least some telephone contact with PDCS. As in the case of written communications, experiences were mixed. Overall, where simple transactions were all that was required, the telephone was viewed as an effective means of communication. However, for some older people, the telephone was not viewed as a particularly effective means of engaging with PDCS for a variety of reasons.

A common complaint related to automated services, with a desire being expressed to speak to a person, and for that to be the **right** person for their query. This frustration was exacerbated for some when they eventually did get through, by an unfamiliar accent, or by not knowing the identity/role of the person to whom they were speaking.

More generally, where people had to contact PDCS on a number of occasions, often in relation to an ongoing issue, a lack of continuity of contact with the same person – or to a person who had information about them readily to hand – was a common source of frustration. In this sense, people often felt they had to repeat their 'story' numerous times, primarily as a consequence of them having to deal with different parts of the service as if they were separate entities:

'I talk to people on the phone, but then next time you ring, there's somebody else, it's a different person...and then they'll say "Oh no, you'll have to tell me again", so you repeat it all again and then they get things wrong...and you can be going round and round in a blooming circle and getting nowhere.'

(Male, 80, Derbyshire)

For some, this lack of continuity was associated with the risk of mistakes being made, which could have significant negative financial and health impacts, as well as affecting their perception of PDCS itself. Not speaking to the same person and the resultant discontinuity had serious consequences for the following customer, who only received the benefits to which she was entitled through her persistence in accessing her original contact:

'I received a phone call from the man in the State Pension Office, and it was just unbelievable, he said to me you...should have been getting the full pension.... I then got thrown from pillar to post...a couple of months went past and I heard nothing, and he had told me it would be dealt with within the month. So I thought "No, I'm not going to let this go, I'm going to phone in" ... I was told he was no longer on the case...but I wasn't happy with that.... I asked to speak to that man...so he phones me back...and I said "I can't get anywhere with anyone, I've been phoning in", and he said, "I didn't know that had happened". I said, "They've actually stopped my pension"...he backdated all that money, right back to when I was 60. I got something like £8,000.'

(Female, above SPA, Glasgow Focus group)

There was also some evidence of dissatisfaction – not confined to communications with PDCS – with explanations given over the telephone. This dissatisfaction was often because older people did not feel that this form of contact allowed enough time for them to express themselves or to think about the issues that were being discussed in sufficient depth, in order to obtain the information they needed at that time.

For others, the telephone was not a preferred form of contact on the grounds of health conditions or impairments such as short-term memory loss, breathing difficulties and deafness. Over and above the frustrations described here, many people in pain or distress reported that they occasionally found a telephone conversation particularly challenging. This was in a context in which people felt PDCS staff were impatient with them, did not understand their needs or, on occasion, that they were rude or patronising:

'Some gentleman phoned me and he was very patronising, so I joined in. He said "Now, I'll try and explain this very carefully", and I said "Please do, because I'm thick as two planks!".... I often say "It's my legs that have gone, not my brain".'

(Female, 70, Leicestershire)

Furthermore, it was commonly mentioned that as a result of using the telephone, many older people were aware that they could be or appear impatient, frustrated or angry. However, this was explained in terms of them being in pain, in distress or of being anxious about the possible financial implications of getting things wrong. There was a commonly held view amongst older people that PDCS staff did not always show sufficient empathy with their circumstances during telephone conversations, as this account illustrates:

'You have to be even-keeled all the way through [the conversation]. But the fact that you're in pain and you're emotional about your situation – because sometimes when you ring you're quite desperate about things – and the operators don't allow for any of that disability or feeling of desperation.... They say "If you don't talk to me in a reasonable manner...", they have a certain term for it, "cutting you off" ... but when you're phoning, it's because your benefit hasn't arrived, and you need money to get food or you need to pay for care ...'.

(Male, over SPA, Leicestershire focus group)

4.4 The internet

Older people's views about online service delivery were explored in the context of their experience of using the internet more broadly. It is important to stress that, in common with the older population as a whole, only a minority of older people taking part in this research had internet access at home.

Amongst those who had internet access, the most common reasons for using it were to browse for information including the news; online banking and shopping; or to email. However, only two had used it to contact PDCS. Both these interviewees were in the younger (60-70-year-old) age group. Interestingly, they were very positive about this channel of communication for government-related contacts, in particular for completing online application forms.

However, some of the older people we spoke to expressed a disinclination for using the internet to seek benefit advice or to make an application. They tended to prefer more 'traditional' forms of communication, which they felt more familiar with, such as written or verbal communication.

'If I need to know something, I need to know verbally'.

(Female, 62, Derbyshire)

Among the majority who were 'excluded' from internet use, there were examples of 'involuntary' and 'voluntary' exclusion. The main cause of 'involuntary exclusion' from internet use was a feeling that they lacked the skills to be able to use it properly. Interestingly, older people often felt they had been 'left behind' suggesting that, for some at least, the barriers to using the internet to communicate with PDCS could be overcome:

'We feel as though we're being left behind and nobody has explained to us. You see, years ago things were so different...every time you look at things, they say "Well go online, go online". Well it isn't everybody who's got a computer, not everybody can afford to have one for a start off'.

(Female, 71, Leicestershire)

The impact of long-standing health conditions and impairment were specifically also cited as barriers to using the internet:

'It's good for some and on a good day it might be good for me, you know but I can't...because of my joints and that I can't use a computer for very long.'

(Female, 62, Derbyshire)

Those who 'voluntarily' excluded themselves mainly did so because of a lack of interest or a perceived lack of need, with some overlap between these two issues. In addition, in line with wider research evidence¹⁵, strong misgivings were expressed about the security of their personal data.

¹⁵ Whitfield, G., Perren, K., Stuart, D. and Norris, M. (2010) *Literature Review to Inform the Future Digitisation of Jobcentre Plus Service Delivery*. Commissioned by DWP.

There was some evidence that these misgivings were based on an awareness of online ‘scams’, which reduced people’s trust in the security of private information being given online.

While older people were generally averse to using the internet to access services themselves, there were instances of family and friends, who were more comfortable with technology, using it on their behalf. This again demonstrates the importance of the role of wider networks discussed in Chapter 3.

4.5 Key points

This chapter highlighted older people’s views on different methods of communication and on how they felt the service might improve the way in which it communicates with them:

- There was strong support for face-to-face contact, but little expectation this should be generally available other than for people with complex circumstances or particular health conditions or impairments.
- Written communication was valued, especially where it offered useful information or enabled people to keep information to hand. However, significant concerns were raised as a result of written communication not always being accessible or understandable.
- Telephone contact was viewed positively for simple transactions. However, difficulty getting through to the right person and having to provide and repeat information over the telephone caused problems and concern for many people.
- There was little appetite for internet-based services. This was mainly due to the cost of equipment and connection, the ability to use computers (for reasons relating to their impairments) and concerns about data security and privacy.

5 Experiences of contact with PDCS

This chapter builds on Chapter 4 and explores older people's views and experiences of Pension, Disability and Carers Service (PDCS) more generally. It sets out that the PDCS meets most people's needs and expectations of it most of the time. However, it also illustrates that the complex and fast-changing circumstances that characterise many older people's (and carers') lives can be made more distressing by 'inflexible' and 'unsympathetic' administrative requirements and processes. In so doing, this chapter highlights some ways in which PDCS services might better respond to the realities of older people's day-to-day lives.

5.1 From simple to more complex contact with PDCS

It is important to state that many older people recounted straightforward examples of contact with PDCS. These often involved a single contact or a series of simple exchanges and older people often felt that any issues that arose were dealt with very well. Others, however, reported more involved and protracted contacts with PDCS and of how this interacted with the complexities of their day-to-day lives. This section explores these two scenarios in turn.

5.1.1 Simple interactions with PDCS

Perhaps the most straightforward contact, experienced by many people, was when the service sent out the routine letter informing customers of annual upratings of benefit levels. This is also the letter in which customers are informed of their obligation to advise PDCS of any changes in their circumstances. Receipt of this letter was commonly seen as purely informative as in most cases it did not require, and did not lead to, further action.

The letter was generally considered to be a useful document in that it could be kept for reference if people did need to contact PDCS. Sometimes the letter did lead a recipient to inform PDCS of a change in their circumstances, either in response to the letter or at a later date when a change occurred.

Indeed, contacting PDCS about changes in circumstances was reported as being relatively simple if it was just a case of providing information to PDCS, for example, in relation to going abroad temporarily or to changing bank accounts. What seemed to be the key characteristics of 'simple and straightforward' contacts were that they related to a specific issue that could be dealt with in a single transaction, rather than as part of an ongoing chain of events, or that a series of exchanges were completed easily and with a clear outcome.

An example of a relatively simple process was one woman's experience of dealing with PDCS at the time of becoming eligible for her State Pension. This involved her:

- receiving notification of her State Pension entitlement in the weeks before reaching State Pension Age (SPA);
- receiving a form to fill in after she had contacted PDCS querying the amount;
- the form being completed over the telephone after she contacted PDCS due to her having difficulty understanding some of the questions; and
- her contacting PDCS after receipt of notification of the amended (higher) amount to confirm that the amount was correct.

A series of effective explanations by staff over the telephone meant that this customer understood how her pension had been calculated, and was clear about how the process worked.

It is worth highlighting, however, that a simple interaction may not necessarily result in a 'positive outcome' (such as an award of benefit). For example, one woman telephoned PDCS after receiving a leaflet about Pension Credit to see if she would be entitled to make a claim. After answering a series of questions she was told that she was not eligible and the reason was explained. While she was not necessarily 'happy' with the outcome, she felt satisfied that she had 'checked it' and with the way in which her enquiry had been dealt with by the service.

Even contact made in rather more difficult circumstances could be seen as straightforward if the matter was resolved in a satisfactory manner. One woman's interaction with PDCS upon the death of a relative who had been in receipt of Disability Living Allowance (DLA) illustrates this. This interaction involved:

- the woman writing to PDCS to inform them of the death and to enquire whether any DLA was owed or owing;
- PDCS sent a form out asking for National Insurance (NI) details for a range of family members;
- family members were concerned about this request for information and re-contacted PDCS by telephone to query; and
- PDCS advised this information was unnecessary and a cheque was sent for the final payment of DLA.

While initially the receipt of the form led to some anxiety, the fact that the information seemingly required was not actually necessary and that the matter was cleared up swiftly meant that this participant's concerns were allayed and the issue was satisfactorily resolved.

The evidence suggests that even when participants' experiences involve a number of interactions about a single issue the process would still be regarded as 'simple' if:

- the situation was resolved;
- people were left feeling that they understood what had transpired;
- no ambiguity remained; and
- no further follow-up was required.

5.1.2 More complex interactions

While the above section highlights the nature of the simple interactions that people experienced with PDCS, not all contact was as straightforward. The more complex interactions seemed to stem from a number of factors being 'in the mix'. In this respect 'complexity' was often a consequence of the interaction between the events taking place in people's lives and the nature of the dealings people had with PDCS services through these events. To illustrate this, this section sets out three examples of interactions with PDCS where an earlier decision was later reversed; assessments of means and needs were involved; and people had mental health conditions. These examples highlight the day-to-day experience of people's 'real lives' and of the potential negative impact when their circumstances or responses to them do not fit neatly into bureaucratic frameworks. In circumstances where people are dealing with, and making sense of, major changes in their lives and in which they do not fit neatly in PDCS' boxes, contact between PDCS and its customers can become complex for those administering claims and distressing for those attempting to navigate necessary processes and systems within the service.

Example 1: 'The reversal of an earlier decision'

One older man's dealings with the service were complicated by having to pay back benefits he had already received. As with a number of interviewees, the exact chain of events was difficult to document. This is partly because people cannot always remember chronology accurately. It is also because it is more difficult for people to recall events chronologically when they do not necessarily understand the reasons that have prompted each event or exactly how particular outcomes have transpired. The following man's dealings illustrate what he experienced as a complicated interaction. He:

- was contacted by the City Council in relation to Pension Credit;
- sent a 'very long informative letter' giving details of his and his wife's income and outgoings;
- had a telephone interview, as a result of which he received a letter informing him he had been awarded Pension Credit, including a back-dated amount;
- received a letter at a later date noting that he was not claiming for relief on his mortgage;
- visited the local office and supplied them with some documentation; and then
- was advised that, following another assessment, he had not after all been entitled to Pension Credit and may in fact have to pay it back.

This example illustrates a number of issues highlighted elsewhere in the report, such as different forms of communication (written, telephone, face-to-face) being more or less effective for particular purposes; dealing with different parts of the service, or with different individuals, in which information and decision-making does not appear to be 'joined-up'; and a lack of explanations which enable the customer to make sense of decisions and their outcome. In this case, the combination of these elements led to a reversal of an earlier decision, which resulted in a negative financial outcome for the customer, as well as an unsatisfactory experience of contact with the service.

Example 2: Assessment of means and needs

Another older man provided an illustration of having to return payment, this time connected to needs-tested benefits (rather than means-tested ones). In this case the man had been in receipt of Attendance Allowance (AA) and had subsequently had two hip replacement operations and a diagnosis of spondylosis. The interaction with PDCS was as follows:

- PDCS arranged a home visit to discuss the benefits he was receiving and potential eligibility for further financial assistance.
- A doctor was sent out to do an assessment.
- The man was advised of his entitlement.
- He was subsequently told that he had to repay £7,000 in AA payments.

The complication here lay in different perceptions of the assessment of his health status between himself and the doctor (who determined his needs according to PDCS criteria).

There was no indication of intent to deceive PDCS on this man's part, rather his account contained a series of confusing events. One issue was that he appeared to be unsure about whether the pain he continued to experience related to his hip operations or what he subsequently learned was

spondylosis. The doctor assessed his hip replacements as having been successful, which constituted a 'change in circumstances' that rendered him no longer eligible for AA. However, he understood that he had been awarded AA 'for life'. Furthermore, as far as he was concerned, he continued to have the same level of disablement as he was still suffering disabling levels of pain and limited mobility (despite the hip replacements) due to having developed spondylosis. This accounted for his 'failure' to inform PDCS of any change of circumstances. The case was further complicated by the fact that he could not locate any written proof of being made an award for life due to a series of major life events (bereavement and house moves) in which paperwork was lost.

This example reflects a situation that will be shared by many PDCS customers – that contact with the service happens in the context of a highly complex set of circumstances; an ongoing process of deterioration in one's health/disability, the assessment of which for determining 'needs' may not be properly understood by the customer, occurring at the same time as a series of life-changing events. When this is the case, normally straightforward 'administrative' matters can become much more complicated and stressful – and these can be difficult for both PDCS and their customers to deal with and respond to. There are implications here not only for PDCS decision-making, especially with older people who may not ask questions to enable them to fully understand the criteria on which they are being assessed and how their diagnosis/conditions meet or fail to meet these criteria.

Example 3: Complex interactions as a result of a mental health condition

Another couple reported that the complicated nature of their lives at a crucial point in time had prevented them from accessing additional support. Within this household, the husband had been in receipt of Incapacity Benefit since the age of 47 due to his mental health condition. At the time of the interview, they received AA. However, the wife felt that she had 'missed out on' receipt of Carers Allowance (CA) because the impact of his mental health condition had resulted in his refusing to sign any documents in relation to claiming qualifying benefits. In turn this meant that his wife was ineligible for CA and she was frustrated because she felt unable to act on his behalf on this issue.

A letter from the Council prompted her to review her situation, which resulted in an application for what she understood to be 'underlying Pension Credit' (but which was more likely CA). The initial application was turned down, but persistence on the part of a Welfare Rights officer resulted in this decision being reversed. However, this process was fairly protracted and was complicated by the husband's mental health condition which it was felt had prevented his wife from making an application for a benefit to which she thought she was entitled.

This example once again highlights the way in which the circumstances of older people's lives can impact on their ability to engage effectively with PDCS. It also highlights once more the critical role of agencies offering advice and support, as it was through the continued support of a Welfare Rights officer that this woman was eventually awarded Pension Credit and received several months of arrears.

These detailed examples reveal the diversity of experiences when interacting with PDCS. From a service delivery perspective it may seem that the main priority of PDCS is to simply deliver a package of benefits to eligible customers. However, for some customers, transactions with the service take place at a time in their lives when they are experiencing a range of challenging issues. People experiencing such challenges clearly felt that the ability of the service (and its staff) to recognise and respond in a more sophisticated way to these issues would result in a significant improvement in their contact with PDCS.

To summarise, what might be a straightforward matter of requesting and providing information by PDCS staff, can actually happen in the context of a complex set of attitudes, assessments,

interpretations and life-events, in which older people are sensitive to being accountable to those on whom they are now dependent for their income. At the same time, they may be confused about the criteria upon which assessments were being made, coping with mental health issues or deterioration in health more generally and taken up with major events like bereavement, house moves and new relationships.

5.2 Carers' experiences of contact with PDCS

Interviews and focus group discussions afforded much insight into carers' experiences, interactions and contact with PDCS. Some of the people who took part in this research were registered carers, while others were informal carers. Informal carers often talked specifically about the implicit mutual caring responsibilities that many older people undertake for their partners where both had health and care needs. For example, in the case of one older couple living in warden-controlled accommodation, the husband had suffered three heart attacks and had diabetes and restricted mobility whilst his wife had significantly restricted mobility:

'It's like a lot of people, you care for each other. [Name] just had a heart attack in February, so now we have to be careful about [name]. He cares for me, and I do what I can for him.... And that's how a lot of people work isn't it?'

(Female, over SPA, Leicestershire focus group)

Importantly, in mutual caring relationships there was evidence to suggest that couples operate as a single household unit, particularly with regard to the benefits package they receive. In this respect, they often saw their income as a joint income that was drawn into one financial 'pot' and it was difficult to unpack which person received specific benefits. Again, this echoes findings from wider research on the household economy and how couples regard their income and manage their net money. Of course, this is in contrast to the way in which the benefits system works, whereby people are generally considered as individuals, and this 'discrepancy' may impact on the nature of older people's dealing with PDCS.

Amongst the older people that we spoke with, some had a partner or relative with very complex care needs and amongst this group there were some that had power of attorney for their spouse or relative. Others undertook a less formal advocacy role, but nonetheless had experience of acting on others' behalf. Where carers fulfilling an advocacy role had had contact with PDCS on behalf of their partner or relative, some had found it difficult to navigate their way through the system. In particular, they were unsure about when they needed to contact the service and who to contact.

While these issues were also acknowledged by those that made contact with PDCS on their own behalf, these difficulties were exacerbated for carers by the complexity of their situation and the need to make contact with PDCS on behalf of somebody else. For example, in relation to not knowing when to contact PDCS, one man referred to the time his wife entered a care home:

'...you don't know, really, you don't know. For instance...my wife was in a nursing home since March, and the last kind of words the social worker said to me, "Now remember...as soon as she's in 28 days, you have to let the DWP know"...so that's something else you have to do...'

(Male, over SPA, Glasgow focus group)

The research found that for many with caring responsibilities, the complexity of their situation was often a source of considerable stress and many were juggling their own needs with the needs of

others. A particular concern in this respect was that PDCS staff lacked empathy due to a lack of understanding about the demands of the role of carer and the inherent stress associated with this role. For some carers, their experience of contacting PDCS about their spouse or relative was frustrating as they experienced what they perceived to be a distinct unwillingness to deal with them or even to explain what their options might be. One of the participants in the carers' discussion group talked in detail about an instance when he had telephoned PDCS in relation to his partner and they insisted on speaking to her directly. This was despite him informing them that she was unable to converse on the phone following three successive strokes.

While there may be very good legal and/or administrative reasons for this, carers who were already under considerable stress found it enormously frustrating. In particular, as noted above, there was considerable strength of feeling as to why the onus remained on them to overcome what they often felt to be administrative requirements rather than the service recognising their needs.

Another man talked about his experience of contacting PDCS on behalf of his mother. He was a carer for both his frail, elderly mother and his wife who had limited mobility, and his case illustrates a number of the more general issues carers experienced. He had contact with PDCS when his mother finally had to move into residential care as a result of a series of falls. He was visited at the home by a PDCS representative and had what he experienced as a very satisfactory meeting during which it was explained to him that he was now his mother's appointee and needed to open a new bank account for her benefits to be paid into.

Within a matter of days, having sorted out his mother's financial arrangements, he made a phone call to PDCS with a further query, but found himself speaking to someone who was not familiar with his circumstances, and who refused to speak to him on the matter. At this time he was managing his mother's admission to care, dealing with all the associated administrative changes; and looking after his wife, who then suffered a flare-up of her disabling arthritis, which he attributed to the increased stress they were under. His frustration is evident in the following account:

'That guy I rang in the afternoon, all he needed to say was "Look, thank you Mr X, I need to just talk to Mr S-, [PDCS representative he had seen at the home], get it sorted - I'll come back to you". But he had quite an aggressive attitude. He said "I can't talk to you, you're not an appointee".'

(Male, 68, Leicestershire)

In terms of service delivery, the carers that took part in the group discussion felt that PDCS should recognise their specific role and needs as carers. In particular, they felt it would be helpful if PDCS were aware of their advocacy responsibilities, the complexity of their situation and of the particular requirements they have of PDCS. One suggestion of how PDCS might address this was to 'streamline' the service and in this context, participants suggested that one point of contact would be useful, possibly even a dedicated line for carers.

In the context of dealing with PDCS, carers often talked about the importance of partner organisations and professional contacts in terms of helping them navigate the system. They mentioned a number of examples where local organisations had provided what was described as a 'lifeline', helping them to identify what support and benefits they might be entitled to. As with older people more generally, support from local organisations also included assistance with form filling. When carers discussed their contact with local organisations, they particularly valued having a single point of contact where they could access support with regard to contacting PDCS as the following account illustrates:

‘[Name of carer’s organisation volunteer] helps them fill the forms in and they never turn you away. She’s very knowledgeable, if she doesn’t know she’ll go round everybody she knows because she’s worked in this sort of area for over ten or more years, and she’ll get the help or advice, all the information to give to you, she’ll go well out of her way to do that’.

(Male, over SPA, Leicestershire focus group)

A further issue that arose during our discussions with carers was a lack of understanding about entitlement to CA. This was a concern for those who had reached SPA and lost the CA they were receiving up until this point. While those who had experienced this generally accepted that ‘rules are rules’ but, they did feel that issues relating to entitlement in general, and to this rule in particular, could be explained more fully:

Mrs Burleigh: ‘I would like to know why just because you’re retirement age a carer is deemed not to need the money, because once you turn that age your carer’s allowance stops, and it’s totally out of order.

Mr Watts: But you’re still a carer aren’t you.

Mrs Burleigh: You’re still a carer 24 hours a day.

Mr Cann: You’re not making any income are you.’

(Leicestershire focus group)

5.3 Key points

This chapter highlighted the experiences of people with complex circumstances and with needs that they felt had not been met. In particular, it details the experience of carers (including mutual carers). In so doing, it raises some specific issues that might assist PDCS in its thinking about meeting the needs of some of its most vulnerable customers:

- In respect of simple and straightforward transactions, most people’s expectations of PDCS were met and the perception of the service was positive. However, less straightforward transactions often resulted in confusion, frustration and disengagement due to complex forms, ‘technical’ letters, and having to repeatedly provide the same information to different PDCS staff; this often during times of significant change and distress.
- For some older people, the complexity of their everyday lives made engaging with the service more difficult. In this respect, people thought PDCS staff needed to have a better understanding of the nature of their lives and the impact of long-standing health conditions and that empathising with their situation would improve their interaction with the service.
- The experience of carers (particularly mutual carers and people caring for more than one person) was often stressful and frustrating and this was sometimes exacerbated by the lack of joined-up service delivery they experienced and staff not always being aware of, or sensitive to, their needs.

6 Conclusions

This concluding chapter aims to bring together the key findings from the study, including the findings from the Resources in Later Life (RILL) analysis, in order to provide The Pension, Disability and Carers Service (PDCS) with insight into issues that may help to consider how the service might:

- overcome the barriers people experience in becoming aware of and contacting the service, making claims and in understanding the information provided and required by PDCS;
- harness the key role of family/friends and local partners in raising awareness among, and providing support to, older people in accessing services;
- better understand and respond to customers' preferences and needs, and to manage and meet (potential) customers' expectations of the service; and
- review the way in which its services are delivered to respond to the particular pressures experienced by carers, in particular mutual carers.

6.1 Understanding the lives of older people and the role of PDCS

The complexity of older people's lives and the confusion caused by the way in which services are organised is often underestimated. It is often against the backdrop of rapidly changing and distressing circumstances – such as changes in health/disability status and financial circumstances, someone moving into care or a bereavement – that contact with organisations such as PDCS takes place. In addition, although contact with a number of organisations is a feature of everyday life for many older people, it is not always clear to them which organisation – or which part of an organisation – they are (or should be) dealing with at a particular time.

A key challenge for PDCS is to recognise that what might appear to be a relatively straightforward transaction or contact from a service delivery point of view, can often be complex and demanding for older people themselves. This is particularly the case for those whose health condition or impairment is not taken into account at the point of contact. Addressing this will require PDCS to review their approach to delivering services to older people, in particular recognising that their lives do not always fit into the administrative 'boxes' which underpin the way in which many existing services are organised. In many ways, this will require a shift in the way PDCS considers the nature of its relationship with its customers.

In practically addressing these challenges, the service might benefit from reviewing aspects of their staff training to ensure staff are aware of the complexity of older people's lives. For example, staff need to have an understanding of the wider responsibilities, commitments and experiences of PDCS customers and of the fact that many people's contact with the service is part of a broader process over time, rather than in respect of a specific single event. Of course, this will also require some attention to the processes PDCS staff work within, as adjustments will need to be made to enable staff to be more flexible in their approach. It would seem likely that this, along with recognition that older people particularly value continuity in provision, will result in a positive relationship between the service and its customers over a period of time. Ultimately, this should lead to an improved service. Further, in enabling staff to build relationships with customers in this way, contacts with PDCS are less likely to be traumatic for customers and, in turn, staff should be more adept at identifying and responding to older people who appear to be in distress or in need of a more flexible service.

6.2 Overcoming barriers

Issues around lack of awareness, pride and stigma and ‘not knowing where to start’ in the process of making a claim have a considerable impact on older people’s willingness to contact PDCS and other public services and their experiences of these interactions.

These represent real challenges to PDCS if they are to ensure that older people who are entitled to financial assistance, services and support that they are eligible for. This is of particular concern as many people experiencing financial difficulties or requiring other support are unlikely to contact the service as they do not know about what support is available or how to go about accessing it. In addition, overcoming the factors which may make older people reluctant to claim are, in some ways, a more fundamental barrier. Failure to address these issues ‘in the round’, risks PDCS expending considerable effort and resource but not achieving its aims, leaving older people without the support they are entitled to.

PDCS will need to consider how it might convince people that ‘the system’ is there to help, not hinder, their claim to their entitlements. While some of this can be done through simplifying claims forms, making letters less technical and making the overall process more transparent and understandable to customers, a wide range of other activity might also be necessary. This might include targeted campaigns and information provision for specific groups, albeit that there are resource implications on this kind of activity. It is clear that much of this activity needs to be done in conjunction with other agencies and local organisations if it is to be cost-effective for PDCS and help it achieve its aim of ensuring its most vulnerable customers get the support they need.

6.3 Harnessing the role of family/friends and local partners

The role of family, friends, neighbours and local networks is critical in raising awareness of services and in encouraging and helping older people overcome their reluctance to claim. Given the difficulties inherent in proactively contacting older people who have not claimed their entitlement, this research found that existing local networks offer a potentially invaluable resource for PDCS in its efforts to achieve its aims.

Engaging with local organisations which already successfully engage with older people provides real potential for PDCS as a strategy through which the service can advance its aims. It is evident that local community-based organisations, voluntary organisations and professionals in a range of organisations are an invaluable and (potentially) ‘already in place’ resource. These professionals can play a vital role in terms of being knowledgeable about benefits, validating the legitimacy of potential claims, and giving relevant practical support to older people in navigating ‘the system’. Where PDCS can engage with, and build on the existing work undertaken by local service delivery ‘partners’, it would seem likely to enhance service delivery of a range of organisations providing services to older people (not just PDCS).

Of course, it is important to stress that local networks may not be developed to the same extent in all areas and therefore PDCS will need to adopt a flexible local approach. It should also be noted that many community-based organisations are funded by ‘soft money’ and it is not uncommon for them to close. This clearly has implications, particularly in the current economic climate (although some of the principles of the ‘Big Society’ suggest that such organisations could take on a larger role in this kind of provision), for the ability of PDCS to develop sustainable local partnerships.

6.4 Managing and meeting expectations

Continuity of service provision is a key factor in the level of satisfaction with services. However, confusion and dissatisfaction is commonly a result of people being contacted by multiple methods and/or by multiple PDCS staff. It is also related to people being contacted by methods that do not meet their needs, do not enable them to provide PDCS with the required information or which require them to provide the same information several times.

In line with their expectations of other public services, PDCS customers generally expect a more 'joined up' interface in which information is shared between different parts of the service. These expectations are likely to have been formed in light of their experiences of other services (such as NHS Direct, for example) where electronic records are kept of discussions or transactions and thus avoid them having to repeatedly provide often complex or sensitive information to different members of staff. While it would not be appropriate (for both technical and cost reasons) for PDCS to simply adopt an existing system from elsewhere, there is clear value in the service exploring whether there are aspects of such provision that might translate into PDCS service delivery. This could, perhaps, be achieved through the introduction of a 'case-worker' approach for complex cases or through a more technical solution.

In respect of the day-to-day contact with customers, the evidence suggests that PDCS should adapt their approach to ensure that it more explicitly takes the needs and preferences of customers (and/or their partners or carers) into account. In most cases, this would not require special provision beyond ensuring staff (can) allow additional time, are patient with customers, ensure they explain things clearly and check they have been understood and ensure that people are communicated with in using a means with which they are comfortable. In the RILL study, it was notable that satisfaction with services was closely associated with people perceiving staff as having empathy with their situation, being helpful and sensitive to their needs.

While there may be a case for specialist staff to take ownership of cases identified as potentially complex or which may require additional contact, it may also be the case that PDCS, working more closely with or through local partners, might enable its services (particularly for complex cases or for people with high level needs) to be delivered more effectively. This may enable PDCS staff to deal with the administration of more straightforward transactions and have more of a focus on developing an oversight of quality of service.

6.5 Responding to the particular pressures experienced by carers

The day-to-day demands on carers (in particular mutual carers) are considerable and, as with other older people, their experience of the PDCS is that it is not joined up or responsive to their needs. Frustration, anxiety and distress with service delivery is particularly prevalent amongst carers who have to interact with the service on behalf of someone else.

Responding to the needs of carers would seem to be a clear priority for PDCS. In particular, it is evident that carers would benefit from specialist provision within PDCS, as the standard route does not seem to meet their needs. In addition, PDCS could usefully provide clearer information and assistance to help carers navigate the system and ensure that the process of establishing appointee, advocate or power of attorney status is highlighted to carers at an early stage. This latter point is important in that it would help overcome the difficulty carers experience when they contact the service during a period of 'crisis', only to find there are (understandable) legal barriers to PDCS being able to discuss matters quickly. Making provision of this nature would overcome the perception that PDCS adopt an administrative 'stance' on this issue rather than trying to help carers overcome any difficulties.

As in the case of more general provision, PDCS might usefully develop its engagement with local carers' organisations and groups. In some cases, the research found that such groups acted as a conduit through which carers could engage with a range of people who could provide them with support and advice and, indeed, support them when contacting PDCS. For a number of carers, such groups were considered to be an essential 'lifeline' which provided both emotional support and invaluable sources of information and advice. Building on this provision and working with/through these organisations would seem likely to assist PDCS in delivering their service to carers in a more effective way.

6.6 Some possible next steps

In addition to setting out PDCS customers' experience, this research has provided detailed insight into how they would like to experience the service. As supported by the RILL analysis, older people would like PDCS to:

- make its customers aware of how the organisation is structured;
- provide clear, accurate and timely explanations (both written and spoken);
- minimise the administrative burden on customers, in particular extensive completion of complex, repetitive forms;
- ensure continuity in service delivery, whereby whoever is dealing with a customer has access to details from earlier contacts on a particular topic or issue and records details of their exchange with the customer for future reference; and
- make a single point of contact such as a complex case worker available where appropriate.

In reviewing these findings, we have highlighted a broad range of issues for PDCS to consider. In thinking about how they might develop their services in the future, we have identified two suggestions for specific activities and further research that PDCS might wish to consider as part of its strategy to move forward, add value and gain additional detailed information.

6.6.1 Local mapping exercise

This research has identified the potential role of local organisations in helping PDCS improve delivery of its services. It is clear that PDCS harnessing the knowledge and expertise of local organisations and working more closely in partnership with them could enhance service provision. However, achieving this across the UK clearly presents challenges as the level of provision will differ by area.

In order to develop an awareness of the range of provision in local areas, PDCS might consider organising a series of stakeholder engagement workshops or conducting local case studies. These would have a clearly defined remit of establishing a detailed understanding of the range of organisations and agencies in a local area that are providing services to older people and which might be able to assist PDCS in achieving its aims and developing a two way relationship. This would need to include a wide range of organisations, both formal and informal and have an explicit focus on a specific local area, and would result in PDCS gaining a clear picture of how it might influence, develop or build on the current landscape of provision.

6.6.2 Further research with carers

The current research has only briefly touched on the experience of carers, and has particularly highlighted some of the complexities around mutual caring responsibilities, particularly where partners in a couple are both over SPA. This is a group which is often overlooked, especially in respect of their engagement with public services such as PDCS. In addition, further work with appointees or those with power of attorney would be particularly insightful in understanding the complex nature of the caring role. It is clear that in order to better think about how services might be tailored to meet their needs and preference, more detailed research is required.

Appendix A

Topic guides used in fieldwork

A.1 Depth interviews

Experiences of using the Pension, Disability and Carers Service (PDCS)

Topic guide

1 Introduction

- Introduce self/centre – independent research centre at Loughborough University.
- Check that they have project information sheet/give replacement if wanted.

Explain project

We'd like to discuss your experiences/views/expectations of the service you have received from The Pension Service (TPS) and/or the Disability and Carers Service (DCS) who are responsible for paying you a range of benefits and allowances.

We're interested in all aspects of your dealings with TPS/DCS – whether you feel your needs/wishes have been met, about the things they do well and the things you think they need to improve AND about how you would like to receive their service in the future (and why).

The aim of the research is to help TPS/DCS provide a service that meets their customers' needs and which is delivered as cost effectively as possible.

- Reiterate **confidentiality** and data protection arrangements – reassure that no personal information will be passed on to anyone outside the research team. Findings will be published in a report but in an anonymised and confidential form.
- Reminder of length of interview (around an hour).
- Explain tape recording and ask permission to record **Complete consent form**.
- Explain incentive payment (a 'thank you' for their time).
- Invite questions.

2 Background information

- Confirm **household type** verify owner occupier or tenant) and length of residence.
- **Household composition**: Single/couple with/without dependents, ages.
- **Work status/history**: Retired/currently working.
- Recent changes in **health/disability status**.
- Explore **social networks and regularity of contact** – employment; family contacts; friends, neighbours; groups such as day centre, formal/informal organisations.

- Explore **access to/use of internet**.

Do they have the internet?

What do they use it for?

How comfortable are they with it (e.g. data security/confidentiality)?

What is it good for/not so good for?]

3 Current benefit picture

- Confirm what benefits **currently** in receipt of:

PROMPT: State Pension, Pension Credit, Winter Fuel Allowance, Disability Living Allowance, Carers' Allowance, Attendance Allowance.

NOTE: If unsure, may be necessary to remind of these just in case/to remind them.

- **How long been receiving these benefits** – long time, last five years, only recently, etc. Explore BRIEFLY 'history' of benefit claims/receipt and how these came about.

PROMPT: Explore sources of information/help & reasons for claim/contact over time

- **Have they ever picked up/been given information from anywhere about the range of benefits might be entitled to? Have they done this recently?**

PROMPT: Libraries, doctor's surgery, hospital, hairdressers/barbers, day centres, clubs (e.g. WI, work or leisure), Citizens Advice Bureaux, etc. useful to gather others.

If so: Explore whether prompted/unprompted, and usefulness.

Explore what type of information/format

Explore whether they acted on it – if so, how & if not, why not.

- Ever sought/received any assistance/information in past [including pre-retirement] in relation to receipt of pension entitlement and/disability benefits? *If so, tell us a little about this – If not, why not?*

PROMPT: Who discussed this with or approached – Children, Family, Friends, Formal organisations (CABx), Informal organisations, internet – if yes – which sites

If so: Explore if information useful, acted upon – why/why not? How?

- **Thinking about now or in the future** – where might you go/who might you talk to, if you wanted to find out more about any benefits you might be eligible for?

PROMPT: Children, family, friends, formal organisations, informal organisations, internet

4 Triggers to recent contact (events and issues preceding contact)

NOTE: Most recent contact may have been minor, initiated by TPS/DCS and may not be readily apparent to interviewee. This section is about the **pathway to the most recent** (series of) contact/s. If respondent talks about **previous** contact rather than most recent, probe as much as possible to gain understanding of recent experience. If can only talk about another contact some months earlier, go with this if relevant to service delivery rather than outcome.

- Can you tell me when you last had contact with the TPS/DCS?
PROBE: Initiated by them or TPS/DCS, involve single or multiple contacts – gain as much background as possible (format, nature of contact/s etc.)
- In respect of this most recent contact, what led up to it/how came about?

Explore

- Significant life events.
 - Significant health/disability-related events or issues.
 - Significant expenditure-related events, e.g. rise in fuel/food prices.
 - Significant income-related events, e.g. learning about eligibility/entitlements.
 - Being advised by friend/family/neighbour/organisation about potential eligibility.
 - Seeing some information on TV/Internet/library.
- Explore how long after ‘trigger’ until contact with TPS/DCS initiated? [NB. ‘trigger’ may have been cumulative rather than a ‘single event’]
PROBES:
If major single event – when that happened, what did you do next and what happened then?
If a build up of events, explore if there was a ‘trigger’ event or what the ‘threshold’ was.
NOTE: Trigger may be simply being made aware of TPS/DCS or benefits rather than anything significant or new in their lives

The recent contact

- In relation to the most recent contact, **did you initiate the contact or did the TPS/DCS?**
- What was the **purpose** of recent (series of) contact/s?
- What **method/s** were used by them to contact TPS/DCS / by TPS/DCS to contact them
PROMPT: Letter, telephone call, online, face-to-face.
If >1: Gain understanding of combination/reasons for/views on this.
- Did you **receive any help** when dealing with the TPS/DCS on this occasion/during this period?
PROMPT: Children, family, friends, formal organisations, informal organisations.
- Has there been any subsequent contact between yourself and the TPS/DCS? [If so, explore/expand]
PROMPTS: Provision of information, explanation of process/outcome, appeal against a decision etc.

If they contacted TPS/DCS

- Who did you initially contact? How did you know who to contact?
- Were you clear about how the TPS/DCS might be able to help you?
- What did you expect to happen when you contacted TPS/DCS?

- What happened as a result of being in touch with them?
- Have there been/do they expect there to be any change(s) in the [pension/disability/other] benefits they're getting?

All

- Why did you choose to contact the TPS/DCS in this way?
- Were you happy with your method of contact? Why/why not?
- How effective do you think this mode of contact was?
- Did it meet your needs?
- Did you consider any alternative methods of contact? If so, what?
PROMPT: Letter, telephone call, online, face-to-face.
- If not, explore pros and cons of each/circumstances in which each more/less effective

5 Reviewing the process

NOTE: This is about the experience of the whole process of service delivery.

Help received from others/organisations

- Tell me how you've found it overall – the whole process of dealing with the TPS/DCS about your pension entitlements and benefits/allowances? NB: NOT JUST CLAIMING.
PROBE: Explore help received from other organisations, either directly or mediated by friends/family, e.g. if professionals /organisations were used, were they known previously or were they approached following contact with TPS/DCS?
- What was the impact on them of using a professionals/organisations?
PROMPT: Ease of access to information, timeliness of service response, treatment received and Outcome
- Explore any preferences for using professionals/organisations as avenue into TPS/DCS. How can TPS/DCS make this easier? Who should they be working with?

Overall views on contact with TPS/DCS

- Overall, how satisfied have you been with your contact/s with TPS/DCS?
PROMPT: Recent and previous (explore any differences)
Explore why dissatisfied AND why satisfied:
Try to ensure focus on process NOT outcome.
- To what extent did your contact with the TPS/DCS meet your **needs** and **expectations**?
PROMPT: Explore high/low expectations, levels of need, complexity of situation etc.
- And what about your **wishes** – what you wanted?

Improving the service

- Which aspects of the service did you find most useful/helpful?
PROMPT: Staff, information, mode of contact, flexibility.
What is it TPS/DCS did well and not well?

- Based on your experiences, are there areas where you feel the service could be improved? That is, what did they find not useful/unhelpful:

PROBE: Gain as much detail as possible – especially if respondent draws on wider knowledge/ experience of others. NOTE: Outcomes are not our focus.

- Explore issue of TPS/DCS being more proactive

PROMPT: What should TPS/DCS be doing to understand/ meet their needs.

Should they be left to contact the service if/when they need.

Should TPS/DCS contact them routinely/regularly/sporadically.

What about at different times in their lives/according to different needs.

- If think TPS/DCS should be taking the initiative more:

How might they to do this? Is the whole experience of getting your pension benefits different according to WHICH or HOW MANY benefits you receive? How? How might this be made more straightforward?

- Is there anything you can think of that might **simplify your dealings with the TPS/DCS?**

PROBE: Accounts Manager, single point of contact, better record keeping to prevent repeat provision of information.

- Are there other practical things the TPS/DCS might do to improve the way in which they deliver their services to you (people like you)?

PROBE: Ensure we get beyond initial statements. **Why, how might that improve, etc.**

What, in your experience, has been good/bad/easy/difficult about dealings with other forms of bureaucracy, such as local authorities?

PROMPT: How do these compare with the TPS/DCS. Are there lessons TPS/DCS can learn from others (or vice versa)?

6 Possible future changes

Only if not covered in interview so far (check time) due to lack of experiences/ views: this is hypothetical and mainly for coverage in focus groups.

TPS/DCS are constantly reviewing how they deliver their services. Both to ensure they deliver them in a cost-effective way and to ensure they meet the needs of their customers.

Probe views on processes mediated by face-to-face; online; telephone and postal contact – experiences of/preferences for each of these and reasons:

- Face-to-face services. When and for who is this desirable and is it always needed. What is good/ bad about this mode of provision.
- Of telephone services.
- On-line services.
- Postal services.

7 Closing

- Is there anything more they'd like to add?
- Close and thank.
- Give payment/get signed receipt.
- Would they be willing for us to contact them again, IF NECESSARY, in connection with taking part in a focus group? [Make clear what this involves and why it is different. ALSO mention payment and transport].

A.2 Focus group with older people

Focus group topic guide – Glasgow and Derby

NB – throughout, try to get at whether the group participants' have high or low expectations of the service(s).

Introduction ten minutes

Welcome the group – house keeping, etc.

Explain the project

Liz/Viet-Hai and I are based at the Centre for Research in Social Policy at Loughborough University and we have been asked by the DWP to carry out some research to get people's views and experiences of contact with TPS and the DCS.

Stress independence – we have been asked to do this because we are independent, whatever you tell us about the service, good or bad we are unbiased and therefore report back to the DWP fairly. We want to get your views so we can feed back to the DWP about real experiences from real people.

Background to research – we started this project earlier this year and we have done 30 one-to-one interviews talking to people about their personal experiences of contact they may have had with the service(s) and also what they might want from the service(s) in the future. What we want to do today is to explore some of the interview findings in more detail to try and get to the bottom of how service(s) should operate to best meet the needs of people like you.

About the group

We have got several issues we want to cover with you and hopefully we will manage to get through in the two hours available – help yourself to refreshments. We are interested in all your views and if you do have personal experiences you want to tell us about that's fine, if not, that's fine also. Also, it can be difficult running groups like this so you must let me know if you can't hear me or I am going too fast and try not to talk over each other. If there is anything you want me to explain at any point then just shout.

Reaffirm confidentiality and get permission to record the group discussion. Get participants to sign the consent forms.

Introductions – go round the group to tune the transcriber's ear.

General views about money matters and services – 15 minutes

Intro: In this section we want to think about the different state benefits that people above retirement age may receive and to explore whether people have an understanding of the service(s) that deal with these benefits...

Flipchart exercise

- To start with, I would like to get a feel for the different kinds of state benefits people are in receipt of so if we could just go round the table...
- Work through the list – where do these benefits come from?
 - Trying to get at whether people can identify which service is responsible for which benefit.

- Is it always clear where benefits/pensions are coming from? Why/why not? Does it matter?
- Do you think people see different benefits as being for specifically needs or requirements, or is it all just ‘money’ that goes into one pot?
 - E.g. someone in receipt of state pension and attendance allowance – do they see this as ‘an income’ or is the AA specifically for paying for caring responsibilities (trying to get at the difference between means tested and needs tested).
- When we did the one to one interviews we found that when people had been contacted about their pension or benefit they were sometimes confused about which service it was that had got in touch (either by letter or phone) with them? What is the experience of the group?
 - Does it matter?
 - Is it important – why/why not?
- If you had a query about any of the benefits we have discussed (run through in turn) – who would you talk to?
 - Explore how people know who to contact if they do?
 - How can service(s) promote themselves and let people know who to talk to?
 - If you didn’t know who to contact about your pension or disability benefits would you be concerned? Why – what would your concerns be?

Exploring the groups expectations about services – 15 minutes

Intro: In this section we would like to think about what type of things you expect from the service(s) – in terms of both what you feel people need and what they might want/prefer. So can we start by asking how many of you have had contact with the service(s) in the past six months – show of hands.

- Flip chart exercise – what do the group think services need to know about people to make contacting the service(s) easier? – write down ideas from the group (e.g. give examples that came from the interviews, e.g. family circumstances, benefits received, health or disability needs).
 - Is it essential that the service(s) have this information about people? Why is it important? Can we decide between us which bit of information is the most important?
- We were told by a number of people at the one to one interview stage that they would prefer services to be joined up (e.g. disability carers service working with the pension service/disability carers service with the blue badge scheme) – what do you think about this?
 - Why is it (not) important for service(s) to be joined up?
 - Does anybody in the group have an example of where a lack of joined up services has been a problem or examples of where services have shared information in a positive way?
- How important do you think it is for people to be told about other benefits they might be entitled to when they have contact with the service(s)? Why is this important/why not?
- Should the service(s) be proactive about getting in touch with people to tell them what benefits they might be entitled to?
 - How would you feel about getting a call out of the blue?
- If you speak to someone from the service(s), would you expect to be able to contact the same person again in the future should you have any questions?

- How important is this? Why is this important/why not? Would it affect people's views of the service (e.g. lack of trust, raised anxiety, etc).

Changes of circumstances 15 minutes

Intro: The DWP are interested in learning about what happens when people experience a change in circumstances and whether this has an impact in terms of the way they deliver their services...

Flipchart exercise – I think the starting point when talking about changes in circumstances is to first of all see if we share an understanding of what is meant by 'a change of circumstances' – what are your thoughts? What would you see as a 'change of circumstance'?

- E.g. change of address, change of health status
- How do you think people would know that they needed to contact the service(s) about a change of circumstances?
- Do you think people would know who to contact and how? – Explain.
- Would you have a preferred method of reporting your change of circumstances? – Explain.
 - E.g. phone, in writing.
- Do you think that if people's circumstances changed they would be concerned about that?
 - Trying to get at if this is associated with losing benefits, etc. What can the service do to reduce this anxiety?
- Does anybody have any examples of where you have experienced a change of circumstances and did you contact any of the service(s) in relation this – explore the process?
 - Was the process simple? If not, are there things that could have made it easier OR what was good about the process?

Channels of communication/complex transactions 15 minutes

Intro: In this section we want to look at the different ways of contacting the service(s), so for example in writing, by phone or face-to-face and to get some of your thoughts about that contact...

Flip chart exercise – brainstorm different kinds of contact experienced by people in the group.

- Out of the modes of contact identified, can we sort through and talk about how valuable each one is in turn (get views about what is positive and what is negative about each one).
- Can we talk about which method of contact people might prefer? – why is this mode preferred? Will other modes of contact not do the same thing?
- Face-to-face contact – why do you think people would want/expect this contact to take place?
 - Is it important for people to be in their own home?
 - Would people be happy to travel into town to visit a Local Authority Building, Age UK building or coffee morning that they might attend?
 - Is it appropriate to expect **all** people to travel to a face-to-face contact? Why/why not – explain.
- Can anyone in the group share an experience of where they have had contact with the service either face-to-face, by phone etc...did the form of contact work, would something else have been better or more appropriate?
- What works well and what doesn't?

Partners 15 minutes

Intro – In this section we want to talk about some of the other organisations you may have come into contact with/heard of and to ask you about whether organisations are a good source of advice and support for people when it comes to pensions and disability/carers issues.

Flip chart exercise – brainstorm organisations that people have come into contact with/heard of in recent years.

- From the list, do each of these organisations offer support/advice with pensions or disability related benefits – which ones narrow the list.
- As a group can we just think about how you know what support/advice is available?
 - E.g. already in contact with an organisation, seen leaflets, advertisements, word of mouth etc?
- Has anybody actually had any support/advice re. Pensions or disability related benefits from these organisations – if so how beneficial was this? – explain.
- Is it important for the service(s) to link with these organisations? If so why/why not?
 - Why would linking with these services be of benefit to people?
 - Are there some organisations it would be more important for the service(s) to link up with compared with others?
- How should service(s) work with these organisations? Why is this important?
 - E.g. someone from a local organisation going into someone’s home to support them with an application for attendance allowance.
- What do people think about approaching an organisation you have never dealt with before – is this something you think people would be comfortable with – why/why not? What are the barriers (e.g. transport, not knowing where to go)?
- Is there anything organisations can do to make people more aware of the services they offer? What sorts of things?
 - E.g. advertise, make sure all older people have a leaflet with contact details.
- Are there sources of advice/support that you think people would trust more than others? (E.g. is professional advice valued over the advice of friends/family) why/why not?
- In what ways do you think the pension service and the disability carers service might be improved by working with some of these organisations

End of group discussion

A3 Focus group with carers

Focus group topic guide – Leicester

Introduction

- 1 Welcome the group.
- 2 Explain the project.

Liz/Viet-Hai and I are based at the Centre for Research in Social Policy at Loughborough University and we have been asked by the DWP to carry out some research to get people's views on their experiences of contact with The Pension Service and the Disability and Carers Service. **Stress our independence** – We are an independent research centre and whatever you tell us today about the services, good or bad, we have no bias. We want to get your views so we can feed back to the services about real experiences from real people.

Background to research – We started this project earlier this year and we have done 30 one to one interviews talking to people about their personal experiences, specifically their contact with the service(s). What we want to do today is explore some of the interview findings in more detail to try and get to the bottom of how service(s) need to operate to best meet the needs of people like you.

We have got several issues that we want to cover today, focusing in particular on your role as carers, to get a sense of your experiences of interacting with The Pension Service and the Disability and Carers Service on behalf of others and to learn about the experiences you have had with the service(s) to date:

- Reaffirm confidentiality and get permission to record the group discussion. Get participants to sign consent forms.
- Not talking over one another, respect each other's views and experiences and respect each others' confidentiality.

3 Introductions

If we could just quickly go round the group and each say our name and where we live and a bit about the types of care you provide, for whom and how long you have been doing this?

Exploring the groups expectations about services

Intro – In this section we would like to get a sense of the kinds of contact you have had with the service(s) in the past and to start to think about what things you need from the service(s) in your role as a carer.

- Thinking about your role as a carer, have you ever contacted the service(s) on behalf of someone else? If so, can you give us some examples of why you needed to contact them?
- Did you feel the service(s) understood your position as carer?
 - Were they able to support you as a carer? Did you get the outcome you needed from the contact?
 - What was positive and what was negative about the interaction?
 - Was the level of information you received from the service(s) adequate? Were you able to digest it all? – are there any ways in which the service could have given you the information in a better way? E.g. perhaps bite size chunks rather than info all at once.

- Do you expect your dealings with the service(s) to be different as a carer, compared to if you contact them to do with your own personal circumstances? – if yes, why?
- Is it easy or difficult to deal with the service(s) on behalf of someone else? Get examples and explanations.
- How would you expect the service(s) to meet your needs as a carer? What could be improved?
- As a carer, would it be helpful for the services to be joined up? – why (why not) is this important?
 - Do you have any examples of where a lack of joined up services has been a problem or examples of where services have shared information which has been positive?
- Do you consider yourselves to have high or low expectations of the services? Why/why not? – trying to get at whether low expectations might be based on a prior experience of contacting the service(s) on behalf of someone else and a lack of ‘success’ in terms of their desired outcome.

Changes of circumstances

Intro – In this section we want to talk about whether you have contacted the service(s) specifically in relation to a change of circumstances on behalf of the person you care for and to look at your experiences of dealing with the service(s) in this respect.

- What do you think constitutes a change of circumstances for somebody? E.g. change of address, change of health status.
- Can you give examples of where you have contacted any of the services in relation to a change of circumstances for someone you care for – explore this process?
 - How did you decide/know you needed to contact the service/s – why did you think the change of circumstances would be important?
 - Did you know who to contact and how?
- Were you, or the person you care for, concerned about the change of circumstances in any way? If so, what kind of concerns did you have?
- Was the process simple? – if not, are there things that could have simplified the process OR what was good about the process? If the process was complex, do you think this was because you were contacting the service(s) on behalf of somebody else? If yes, do you have any thoughts about how the service(s) could improve things to meet your needs?
- How did you report the change of circumstances (mode of contact) and would you have preferred another means of reporting the change in circumstances? – Explain.

Channels of communication/complex transactions

Intro – In this section we want to look at the different ways in which you might have had contact with the service, so for example in writing, by phone or face-to-face and to get some of your thoughts about that contact.

- If you had to contact the service(s) would you have a preferred method of contact? Why is this the preferred method? Would other modes of contact do the same job – why/why not?
- From those people in the group that have had contact with the service(s) can we get examples of a simple/straightforward contact and a complex one?
 - What are the characteristics of simple or complex contact? What would make complex interactions simpler?

- What works well and what doesn't?
- Can we reflect on the person you care for and your role in dealing with the service(s) on their behalf? How essential is it that you deal with the service(s) for them? – e.g. trying to get at whether they would manage to do it themselves if they needed to, what would people struggle with, why do people need to rely on support from a carer in relation to contact with the service(s)
- We have focused so far on your contact with the service on behalf of others, have any of you had any contact with the service in your own right, in relation to carer's allowance for example? If yes, how did you find this process? How did it compare to contacting the service on behalf of somebody else?

Partners

Intro – in this section we want to talk about some of the other organisations you may have come into contact with in your role as a carer and to ask you about where you have received support or advice...

- What are your experiences of informal support/advice? – where did the advice come from and how valuable was it? (E.g. advice from friends or family who might have alerted them to the potential to claim carers allowance for example.)
- What are your experiences of formal support/advice? – where did the advice come from and how valuable was it? (e.g. advice from a professional)
- For those members of the group that have had formal support/advice:
 - How did you know support/advice was available? – does anybody have any examples of how they learned about the services on offer from any organisation/partner?
 - How did you seek support/advice?
 - Has anybody had any advice from hospital discharge teams in particular? If so, how effective was this – why/why not effective?
- Would you be happy to approach an organisation you have never dealt with before – why/why not?, (explore barriers to accessing services here e.g. transport, not knowing where to go etc.), what would make you feel comfortable approaching a partner/organisation for the first time?
- Is there anything partners/organisations can do to make people aware of the services they offer?
- Are there sources of support/advice that you would trust over others? (E.g. is professional advice valued over the advice of friends and family – why/why not?)
- Do you think the service you receive from either The Pension Service or the Disability Carers Service might be improved if they worked more closely with some of these organisations? If so, how?
- Which agencies do people think it would be most helpful for Pension and Disability Carers Service to work more closely with? Why? For what purpose and in what way?
- Is there anything you think organisations can do to support carers in particular? E.g. advice re. advocacy, etc.

End of group discussion

Appendix B

Sampling and the conduct of fieldwork

In terms of ‘customer group’, the sample included people from three categories of ‘overlapping customer’ who had made a claim for DLA/AA/CA:

- after becoming pensioners (group 1);
- before becoming pensioners, but who had reached SPA (group 2).

It also included people who had claimed both the State Pension and DLA/AA/CA around the same time, i.e., within six months of each other (group 3).

The characteristics of the sample of 30 interviewees are shown in the table below.

Table B.1 Achieved sample characteristics

Gender	
Male	15
Female	15
Age	
60+	13
70+	10
80+	7
Household composition	
Single	21
Married	9
‘Customer group’ (see above)	
1	17
2	6
3	7

Although the administrative database was ostensibly of people who had had some form of contact with PDCS within the previous six months, not all of those we interviewed had any memory of such recent contact. Nevertheless, all could readily talk about a variety of relatively recent contacts they had had with the ‘Pensions people’, and in fact appeared to value the opportunity to share their experiences of this.

Furthermore, although we sampled individuals, in couple, rather than single-person, households we were frequently presented, on arrival, with both members of the couple who were happy to be interviewed. Indeed, an important ‘finding’ of the study is that in their relationship and contacts with PDCS, couples operated **as a couple**, especially when they were mutual carers. This is consistent with findings from a substantial body of research on the household economy more generally¹⁶.

¹⁶ Pahl, 1989, 1995; Goode, 1998, 2009, 2010; Burgoyne and Sonnenberg, 2009; Rowlingson and Joseph, 2010.

Recruiting for the discussion groups was more of a challenge. The original intention was to do so predominantly from those with whom we had conducted in-depth interviews (that is, those in Derby/shire and Leicester/shire; we did not conduct individual interviews with people from the Glasgow database). Many of them expressed an interest in participating at the time of interview, but were unwilling to commit to this in advance. They were happy to be contacted nearer the time, but this often resulted in their telling us of their inability to attend, for a variety of reasons to do with health, mobility, family commitments, caring responsibilities and hospital appointments. This was indicative of the demands on people's time arising out of the pressures and commitments they had in their day-to-day lives. They may also have felt that they had told us all they had to say. This is borne out to some extent by the fact that we successfully recruited people for the Glasgow group from a database of those whom we had not previously interviewed, and who were keen to share their views and experiences. Consequently, we held one of the older people's groups at a local community centre which ran 'drop-in' sessions in Leicestershire.

Recruiting a carers' group also presented challenges. This was partly due to a reluctance on the part of those carers we had interviewed individually to participate in a group, this was due to logistical problems, despite resources being available to assist with transport; and partly due to difficulties in identifying potential recruits from the administrative data. The main issue for carers in terms of attending a focus group was not having access to care provision in their absence (we were unable to offer support or make a contribution towards this provision as part of the research). We therefore recruited the carers' group from a wider group of people who attended a local community centre group run for carers.

In all three groups, attendees participated very enthusiastically, and again, appeared to value the opportunity to share their experiences. In some cases, they were clearly learning from each other things they hadn't previously known: about entitlements; sources of information and so on, but there was another positive element of the groups, as participants expressed, and this was an appreciation of the opportunity to have their voices 'heard' – and hopefully attended to. This was particularly the case for the carers who took part in the group discussion, as they had specific needs and experiences. Despite the challenges of organising these groups, the data they yielded validated this as a research method for this group of customers – as long as the limitations of administrative data for this purpose are recognised and sufficient attention is paid to the demands on their time and energy that older pensioners face and the implications of this for the organisation and timetabling of research.

Appendix C

The resources in later life analysis

This appendix draws on a longitudinal research study, ‘Resources in Later Life’ (RILL)¹⁷, and provides context about the resources older people draw on at this time in their lives. It focuses on older people’s experiences of using a wide range of services, including the Pension, Disability and Carers Service (PDCS), and provides an insight into the main ‘triggers’ and barriers to their use, people’s needs, preferences, and their experience of receipt of services including dealing with changes in service provision.

Triggers to contacting/accessing (PDCS) services

Changes in personal circumstances

Deteriorating health was the main factor nudging some older people towards claiming new or higher-rate health-related benefits. However, this was sometimes in conjunction with an increased financial need or wanting to recompense family members for their additional support. Deteriorating health and concern over financial circumstances also acted as a spur for reapplying for health benefits where a claim had previously been unsuccessful.

A few older people who had stopped working or had cut down on the hours that they worked had contacted the service to claim means-tested benefits. Again, this was often related to a combination of increasing financial need and the impact of poor health when the demands of a physical job became too much.

Changing health and financial situations were also seen as reasons that people might contact the service in the future, or to find out about the effect of changing circumstances on their benefit entitlement – this included where savings were dwindling or where people were considering moving in with relatives.

Increased health-related need often resulted in extra financial outlay and could prompt people to seek more information about health-related benefits or adaptations to enable them to live independently. While some adaptations were obtained via social or housing services, people also bought mobility aids using their own funds. These included a stair lift, scooters, walkers, and rising chairs, often following a period of worsening health.

Proactive service intervention

A few older people in this study (even despite changing needs) only came to be in touch with a service about benefits after being actively contacted by PDCS or the Local Authority, although people were sometimes unclear as to which agency had contacted them. This pro-active contact was generally initially through a telephone call, followed up by a home visit. Another positive action that led to a few claims for means-tested benefits was a staff member initiating an application while

¹⁷ The RILL study consisted of two waves of in-depth interviews with 78 households of people aged between 65 and 84. See Hill *et al.*, (2009) for more information.

dealing with a health-related benefit claim. This demonstrates the value of proactive approaches by PDCS and of more general DWP moves towards linking benefit claims and exploration of ways of automatically paying benefits.

The role of informal support

Reasons for contacting a range of services tended to be cumulative and often gathered momentum after input from family and friends. Informal advice was generally ‘word of mouth’ and was often given about what grant or benefit was available in the first instance. Importantly, though, family and friends also provided encouragement as well as practical help to apply for a range of benefits, grants and services – without this ‘soft’ type of intervention, it is evident that some people may not have applied. Family also acted as a ‘sounding board’ for older people to talk through whether to adapt their home to help manage declining mobility. Family were again vital in initiating contact with social services or relevant agencies to instigate this.

It was important that older people were able to trust the informal information and advice that they were given. This could come in various forms – for example:

- the ‘expert’ friend or family member who was knowledgeable in a professional capacity, for example, worked at Age Concern/Jobcentre Plus/Citizens Advice Bureau (CAB); and
- where friends or family had ‘real life’ experience of claiming benefits or dealing with a range of services – from using community buses to banks to obtaining a window cleaner – here opinions were highly valued because of that direct experience.

Formal support

Occasionally, people had used third-sector organisations to help make a claim or provide advice about welfare provision, for example, CAB or Age Concern.

Public sector professionals also sometimes played a key role in accessing services for older people – for example, by obtaining grants for housing improvements. In relation to health needs, RILL participants had used specialist nurses as ‘go betweens’ or advocates, who set up appointments, and provided them with information and reassurance about their condition.

This type of support was particularly important for those with serious health conditions and when people were confused about what happens next. Such professionals were considered invaluable in co-coordinating the involvement of a range of services and were seen as operating in the older person’s best interests – again the issue of trust was paramount.

Barriers to contacting benefit services

Awareness

A key barrier to contacting services was lack of awareness or understanding about benefits, services and entitlement on several levels. First, participants were sometimes unaware of the existence of certain benefits (such as Pension Credit) or more widely grants that were available to help with repairs to the home. Second, even if they were aware of a benefit or service, people did not know that they may be entitled to it. Not realising that they might be eligible, or misunderstanding the eligibility criteria, could delay or inhibit people from making claims.

Attitudes to entitlement

The RILL research also highlighted how stigma and negative attitudes towards claiming benefits could deter some older people from making applications. Participants expressed feelings of guilt about claiming, stressed how they had not asked for anything, and how truthful they had been when making applications.

While these sentiments applied to both means-tested and health-related benefits, there were also some differences in the feelings they raised. People spoke of feeling ‘on the cadge’, embarrassed or belittled by claiming means-tested benefits. In contrast, with health-related benefits (and applying for a blue badge) issues people raised involved having to prove their frailty and that they were ‘disabled enough’ to claim – which effectively involved admitting increased vulnerability and loss of independence. Both can be seen as exposing personal areas of their lives to scrutiny, being assessed and having to ‘earn’ the benefit, mainly because people saw it as a hand out, rather than an entitlement. Furthermore, some people who had made unsuccessful claims felt as if their legitimacy had been called into question. Having their claim refused could put people off reapplying, or invoke anger at being questioned, particularly in relation to their health status.

A further point is that some participants remained unclear, either about the progress of an application, or the implications of receiving a benefit. Particular examples included how long they would get it for or if it affected other benefits. This indicates that, even after an application is submitted, or indeed successful, people can remain uncertain about their benefit status.

Experiences of different methods of service provision

Face-to-face service delivery

Participants who had received home visits from staff in relation to a benefit claim or home improvement grant saw these as useful. Underpinning these positive views was having confidence in the person visiting and the sensitivity of the staff involved.

Several people spoke of their satisfaction in how advisers had dealt with assessing their financial eligibility – being thorough, but without being intrusive – and also valued any reassurance that they had provided about making a claim. This is an important point for older people, who, as mentioned above, can be uncomfortable about claiming means-tested benefits. Being visited at home also meant that people could put their hand on the financial information required (in their own time). Furthermore, in relation to claiming health benefits, a face-to-face visit enabled an adviser to see for themselves a participant’s level of ability and need, which it was felt gave them the opportunity to demonstrate the legitimacy of their claim.

More broadly, face-to-face service provision was often valued by participants, from speaking to staff in a local bank branch, conversations with delivery people and local shopkeepers. This ‘personal touch’ seemed especially important to some older people who lived alone and were unable to get out as much as they used to. They were particularly appreciative where it was felt that a service provider took their time with them, went ‘the extra mile’, and had their best interests at heart.

Over the course of the research a few face-to-face services had been reduced. Following the closure of a local Housing Association Office one couple took a bus to a more distant office, rather than make contact by telephone which demonstrates the value they placed on dealing with this service personally. A reduction in the frequency of face-to-face warden contact was most keenly felt by a few sheltered housing residents with limited mobility and declining health who missed the regular human contact.

Telephone communication

As with face-to-face contact, participants often discussed the success of telephone service delivery in terms of how helpful the staff had been in dealing with them. Here people were positive about telephone contact in relation to claiming benefits or a housing grant where they felt they had been dealt with in a sensitive and professional manner (even where an enquiry or claim had been unsuccessful). Continuity was particularly valued, for example, where a participant was able to deal

with the same staff member, or a call was returned straight away. One participant whose claim was made via the telephone welcomed not having to fill in the forms themselves.

There were, however, some problems raised about telephone contact with services more generally. First was discontinuity and lack of communication on the part of service providers as some participants expressed frustration at repeatedly having to contact a company, having to recount the same information to different people and being passed from one person to another. Second was the difficulty some older people faced using automatic telephone services, for example, confusion with passwords for telephone banking systems, and the ‘nightmare’ of ‘getting nowhere’ with automated push button telephone services.

Using the internet/technology

A few participants in the RILL study (generally male, ex-professional/managerial occupations) used the internet to access services – for information, comparing prices and some very limited use of internet banking. Others used the computer for games, e-mailing and communicating with family abroad. Family members had often been instrumental in acquiring and setting up computers for participants and had showed them how to use the internet and e-mail. Sometimes participants’ families had used the internet to obtain information and access services on their behalf.

However, many of the older RILL participants could see no point in owning or using a computer. Some just did not want to learn how to use something new which was ‘not for them’ or too much trouble as they saw no reason why they would need it. In many cases lack of interest or expressions of ‘technophobia’ were because they had not used a computer before. Indeed, new technology in general was also perceived as a real source of frustration to some people, especially if they had difficulty operating devices, for example, a DVD player. Some of the older participants, particularly those whose eyesight or dexterity was impaired found mobile phones impractical and the small buttons ‘fiddly’ to use.

Barriers to using different services

The RILL research raised a variety of issues relating to dealing with bureaucracy generally that can impact on how older people view and use services.

Trust/mistrust

Many of the RILL participants expressed concern about not always knowing what help and advice is available to them, and if information is provided, whether it can be trusted. Older people sometimes felt vulnerable and in danger of being ‘ripped off’ when seeking help in their homes or gardens, or in their dealings with financial and mobility services.

One issue of major concern to older people was the extent to which they could trust having people they did not know to help them in the home. While, as outlined above, face-to-face service provision including home visits was valued by older people, especially sometimes those who are less able to get out, by the same token these people can be more vulnerable to ‘cold callers’ to the home. Several participants spoke of feeling uneasy about callers and under pressure in their homes from salespeople – occasionally being nearly relieved of their savings. Even by telephone people sometimes felt ‘badgered’ by insurance companies, electricity suppliers or mobility scooter services despite repeated refusals to take up or change a service. Again, the issue of trust was raised as the point was made that it was not always easy to know if a caller/service is legitimate or not. To combat this, many sought recommendations from trusted friends, or those with direct experience of employing cleaners and general home support.

People were also sometimes mistrustful about the ability of banks to operate in the customer's best interest and one even went so far as to suggest that their savings were safer in their own hands than with the banks¹⁸. Others were concerned about the extent to which the 'hole in the wall' system and PIN numbers were secure.

The RILL research also revealed some scepticism of government or local authority services or schemes. Occasionally participants were reluctant to use schemes such as Warm Front because of cynicism of the benefit of the scheme (that the equivalent cost would be put on the bill), or home helps provided through social services due to concerns about the rates charged and where the money was going. Several of these participants preferred to organise their own provision as they felt more confident about, and had more control over, how their money was spent. Such views demonstrate an underlying mistrust of 'official' services/provision and state bureaucracy as people questioned whether they were really serving their best interests. Again, the alternative sources of provision used highlights the value to older people of trusted sources of information and recommendation.

Difficulties in dealing with bureaucracy

Delays in accessing services were mentioned as problematic. Participants spoke of long waiting lists for sheltered housing, delayed or rejected applications for a shower via social services, and outstanding or partially completed work in social housing. As well as the difficulties to people's everyday life caused by such delays, a key issue was the perception of being overlooked, frustration at the lack of progress and inability to do anything about the situation. This frustration was amplified where people had come up against a 'brick wall' upon making enquires and were left feeling 'fobbed off' and powerless. This highlights the importance of service providers keeping people informed.

Some older people felt that they had to fight to get what they wanted and needed, for example, a replacement heater from the council, or getting doctors to acknowledge their views on their ill-health. 'Battling' to get their voices heard added to people's perception of an uncaring faceless bureaucracy that worked against, rather than with or for them. Sometimes family could step in to provide support, in other cases, people resigned themselves with no alternative but having to accept a situation.

A major cause of frustration among some RILL participants was not being listened to, taken seriously, or treated with respect in their dealings with various services, and sometimes this was thought to be because they were old. This ranged from unmet requests for aids/adaptations, to reporting a lack of police attention in neighbourhood disputes. While seeing people face-to-face was often regarded by participants as the best way of being able to explain and seek understanding of an issue, this could be a negative experience when those they were dealing with were unhelpful or dismissive. Participants' criticisms included perceiving that their concerns, views and needs had not been considered or addressed. In relation to health services this included questions not being answered, being talked over rather than to, impatience from staff, and lack of help at mealtimes. Some social housing tenants mentioned not having a say in work being done in their homes, and difficulties of living amid the mess and upheaval.

Dealing with changes in service provision

The RILL research was conducted over two years and therefore allowed an insight into how older people experience and manage change. This was relevant to several aspects of service provision.

¹⁸ It is worth noting that fieldwork took place during 2007, but mostly before the economic crisis and banking collapse.

Some participants were unhappy about changes to service provision – this was particularly the case when the changes were seen as detrimental to the service provided or how it affected the older person. In relation to banking, no longer being able to pay a bill at the local Post Office was more difficult for someone with limited mobility. Several participants were wary about switching to automated banking/payment systems, particularly where they had a limited budget and needed to keep tight control of transactions. Some were just content with the systems they had in place and therefore felt no need to make changes, however, resistance could occur if people felt that they were ‘being told’ to change. In some instances changes to people’s environments had implications for their day-to-day lives. For example, cutbacks in resident warden cover resulted in less face-to-face visits, and redevelopment work in the local area resulted in the closure of a bus station, lack of seating and lengthy diversions. A key issue is that these changes left older people feeling excluded, and to them, signified a lack of empathy of older people’s needs by the ‘powers that be’. The fact that such changes were imposed also meant that people felt that they had little choice or voice in what was being done. This highlights the need for service providers to think carefully about how changes are decided upon and implemented to avoid older people feeling overlooked and alienated.

Changes to benefit and pension payments were more acceptable where participants could see advantages in the new system. Some, whose pension was now paid into their bank account, now valued the convenience of paying bills by direct debit and security of not carrying around cash to pay large bills. The research also revealed how, over time, older people can adapt to change. Over the course of the research participants’ reservations about a using new pin/keypad system of pension payment diminished as people became more accustomed to using it. Furthermore, over time, a few participants found useful advantages in the new system of being able to draw money out anywhere, and using it as a mechanism to save money. These experiences indicate that older people can, like any other group, adapt to change in service provision – even if at first the change is not welcomed. The key issues are that people need time to adapt, and the most positive views were expressed when people experienced a real benefit of the change to their lives.

Conclusions from RILL

Older people’s routes to public services (including PDCS) include a combination of changing personal circumstances, direct approaches from services and the intervention of others. Formal and informal support, particularly from family, friends and local networks, is invaluable in raising awareness and for providing encouragement, reassurance and practical help in making a claim.

Different levels of support are required for people to successfully negotiate the claim process or access and use a service. This includes raising awareness of the benefit/service and entitlement, help with the application process/accessing a service, and also ensuring people understand what they are receiving and what should happen in the future. In addition, the vulnerability of older people unable to readily access support needs particular attention. This would reduce the risk of them being unaware of their entitlement in future, given that they will be in most need of advice, information and support should their health or financial circumstances change.

In terms of service delivery, it is often **how** the service is delivered, rather than the channel in itself that influenced people’s satisfaction, with continuity and staff helpfulness/attitude highlighted as key. Trust is also an important issue for older people in relation to advice or information about a service as well as in dealing with service providers.

The RILL research highlights that older people can adapt, over time, to changes in how services are provided. However, change is more readily accepted when people can see the benefit for them. Service providers need to give serious consideration to how changes are implemented – **with/for** older people, rather than to them – in particular providing clear explanations about the process and potential impact of change, and allowing plenty of time for people to get used to them.

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This research was conducted over a six month period with customers of the Pension, Disability and Carers Service (PDCS) in a context of government initiatives to increase levels of support to low income pensioners.

This study aimed to provide PDCS with detailed insights into what kinds of 'trigger' events encourage pensioners to make contact with PDCS; whether and how they are facilitated in doing so by others with whom they are in touch; what channels of communication they use; how they experience their contact with the service; and what PDCS might do to enhance the effectiveness of their service delivery.

The findings from this research are likely also to be relevant to other government departments and organisations with responsibility for delivering services to older people.

If you would like to know more about DWP research, please contact:
Paul Noakes, Commercial Support and Knowledge Management Team,
Work and Welfare Central Analysis Division, 3rd Floor, Caxton House,
Tothill Street, London SW1H 9NA.
<http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

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