

Casework with Carers: What Works and Why?

A Longitudinal Realist Evaluation

Elizabeth Victor

University of Nottingham

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Acknowledgements

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Abstract

Carers who look after family members on an unpaid basis often experience negative impacts from their caring role due to the lack of value placed upon care more widely in society. Casework with carers, 'the individualised support work undertaken by a practitioner with a newly identified carer', offers a means to support carers. This thesis considers the research question 'Casework with carers: what works and why?'. The study places an original focus upon the work of third sector carer organisations upon which there has been very little other research. A comparative perspective is taken to consider this together with the casework with carers undertaken by third sector condition specialist organisations and through statutory carer assessment. The study uses the realist evaluation framework, grounded in critical realism, to identify the outcomes of casework, the mechanisms explaining these and the contextual factors influencing this. A longitudinal research design involving thirty seven qualitative case studies of individual carers' experiences enabled original findings about change in outcomes over time to be identified and provided a unique insight into the long term impacts of casework. Separate carer and practitioner interviews at timed intervals, supported by audio-recording of the first main contact of casework, provided a comprehensive insight into casework.

The findings have been used to develop a new and original model of casework with carers. This identifies how outcomes can be achieved through a number of different types of mechanisms consisting of: psychological support to recognise the value of caring and carer needs; expression of feelings; development of knowledge and skills about caring and about resources and how to access these; and carer action including to access secondary services. It also identifies how a range of contextual factors, including carer characteristics and practitioners' characteristics and approach to casework, influence outcomes. The study illustrated that third sector carer and condition specialist organisations were potentially well placed as relatively accessible and visible services to achieve varied positive outcomes with carers. However, the findings also showed that casework was of limited help to some carers who continued to have serious unmet needs principally because of barriers in terms of the availability of appropriate secondary services or the reluctance of the person receiving care to use such services.

Interpreting the findings through the theoretical frameworks of the ethic of care and carer empowerment highlighted how the nature of the casework practised constrained its potential to support carers. The lack of integrated and ongoing support limited the ethic of care achieved, but perhaps the personalisation of services might help towards overcoming this. The mainly administrative approach of casework (rather than a therapeutic or empowerment based approach) limited the achievement of carer empowerment. Substantial changes in casework practice would be required to address this.

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Chapter One: Introduction

1.1 The focus of the research: casework

Feminist analysis has shown how care has been undervalued by western societies in recent history (Kittay, 1999; Tronto, 1993). Political campaigns arose to challenge the substantial difficulties experienced by women because of the lack of recognition and value given to the care they provide on an unpaid basis to family members or friends with a medical condition or disability. These campaigns have since expanded to seek improvements for all those providing care of this kind and have underpinned the social construction of those in society now known as 'carers' (Bytheway & Johnson, 1998).

In the UK, these constitute a group of 6.5 million people who care for a family member or friend on an unpaid basis (Carers UK, 2013). These people generally want to care and often derive important positive benefits from their role (Nolan, Grant, & Keady, 1996). However, a comprehensive body of research establishes the serious negative impacts caring can have (see page 23). Carers may also need and wish to develop their caring knowledge and skills as 'expert carers' (Nolan et al., 1996, p. 156). Thus, a challenge exists to support carers within their role (where they wish to continue) in order to limit negative consequences and also to enhance the positive aspects of caring.

The state has an instrumental motivation to support carers. Unpaid care has a considerable economic value to society estimated to be 132 billion pounds per year in the UK (Carers UK, 2016). Furthermore, the need for care is expected to increase with the continued growth of an ageing population and the accompanying increase in the number of people with age related long term medical conditions including dementia (Select Committee on Public Service and Demographic Change, 2013, p. Annex 9). In addition, carers who lack support are less likely to be able to contribute economically through paid employment to society and may face health problems which place additional demands upon the health service.

There is also an important moral case for supporting carers. Kittay argues that a true equality would recognise the connected nature of society and address 'nested dependencies' (1999). A first dependency exists where an individual is dependent upon another to care for them due to ill health or disability. The second dependency nested around this is the carer's dependency then upon society to support and care for them in this caring role. Kittay presents this as the concept of *doulia*, a public version of the concept of a *doula*, a person who looks after a mother's needs when she is caring for her newborn child.

To achieve this would require societal transformation at a structural level. Some progress has been made towards this as the later discussion of UK policy relating to carers shows (page 28). Carer support at an individual level is also important. This type of work may collectively contribute towards structural change. Even where it does not, it is helpful to understand how

carers can best be supported individually within the current structural constraints.

There has been considerable research looking at how carers have been helped or not through statutory carer assessment (the nature of this is discussed from page 109), the state gateway to support, and through various other specific carer services (Victor, 2009). What there has been relatively little focus upon, despite its substantial role in the current UK context, is the role of the third sector in carer support (Victor, 2009, p. 114). The UK has a widespread network of 118 local third sector carer centres and 63 third sector carer break schemes together reported in 2013 to have an income of £147.8 million and to reach over 426,000 adult carers in a year (Carers Trust, 2013). This network is facilitated by a national charity, Carers Trust, which aims to improve support, services and recognition for carers. There are also some other independent local third sector carer organisations which provide similar support but are not a part of the Carers Trust network. In addition, third sector condition specialist organisations such as MIND also sometimes provide carer support services for those caring for someone with a specific medical condition.

This research study arose from a partnership between Carers Trust (previously The Princess Royal Trust for Carers), the University of Nottingham and the Economic and Social Research Council to fund a PhD studentship to consider how interventions support carers. At the beginning of this study, a mapping of the nature of these carer services was conducted to help identify a more precise focus for this research. This mapping showed that a substantial part of the work of carer centres (in the Carers Trust network) involves carer support workers responding individually to newly identified carers.

The potential importance of this response to newly identified carers is underpinned by evidence of considerable unmet need for support and low take-up of existing support by carers (Yeandle, Bennett, & Buckner, 2007). This could be the first, critical step for carers towards positively sustaining their caring role and limiting any negative consequences of caring. There is considerable turnover in the carer population as people move in and out of caring roles over the lifetime (Carers UK, 2014b). Thus more people are constantly beginning new caring roles and may need support. The literature also suggests a number of potential barriers carers face in accessing support which this service response could potentially help to overcome (see page 26).

Consideration of this research question could have been restricted specifically to the work of local third sector carer organisations. However, this study has also included the two other principal carer specific forms of service which respond to newly identified carers in order to provide a more comprehensive understanding of how carers can be supported when they first contact services. The study has thus also examined the way that carer support workers at some third sector organisations specialising in particular medical conditions, for example, dementia or cancer, respond to newly identified carers. In addition, it has considered statutory carer assessment as the specific way in which local authority social care departments can first consider

any needs for support that a carer may have. Thus, the research is not simply an evaluation of one type of service but offers a wider consideration of what it is possible to achieve in responses to newly identified carers. There is already a body of knowledge considering statutory carer assessment and condition specialist support workers. This is reviewed in chapter 3. The study here has built upon the conclusions of this both in methodological terms and in extending consideration to third sector generic carer services.

The term 'casework' has been used here to cover the different forms of this work undertaken by the three different types of organisation. (More specific and detailed characteristics of the casework included within the sample of this research are discussed from page 109.) Whilst the services offered by these organisations may be presented differently (most commonly, as carer assessment or carer support work) and there are some differences in practice, there are important underlying similarities. Some of the essential similarities are captured in the summary definition used here of casework as 'the individualised support work undertaken by a practitioner with a newly identified carer'. Casework with carers has been developed as a concept in this study in order to examine beneath the surface of current practice approaches with carers. This is an original development in this area of research.

The term 'casework' captures the individually based nature of this work reflecting the historical use of the term 'casework' in social work practice. Most of the casework included in this sample was not principally undertaken as professionally qualified social work (page 100). 'Social worker' can only be used as a title by those meeting certain professional standards prescribed by a national regulator and professional social work practice is governed and directed by legislation and statutory codes of practice. However, some theoretical conceptualisation of casework is helpful and there has been little academic evaluation or theoretical consideration of such work in the third sector. There are similarities in the nature of the casework undertaken with the practice of social work which make it helpful to draw upon the theoretical literature on social work.

Within social work, the term 'casework' has historically differentiated work with individuals from that with groups or communities (Koubel, 2013a). This distinction is also being made here. However, casework with carers may involve work with the carer and the person they care for together (and potentially also wider family), and therefore could be individualised at the level of the family rather than always the carer alone. Whilst the casework services considered here were primarily focused upon the carer (see page 114), support for the carer could also involve helping the person receiving care and in some cases, the person receiving care was also present at the first main interaction of casework.

Casework is 'undertaken by a practitioner with a carer'. Thus, there is a relational aspect to casework. This has been a key focus of early literature on casework in social work (Biestek, 1957). Casework is undertaken within the context of, and potentially sometimes change is achieved through, the relationship between the practitioner and the carer. The generic term

'practitioner' is used here to represent somebody employed to support carers which could potentially be in a variety of roles including social worker, carer assessment worker and carer support worker. As noted on page 100, practitioners participating in this study had a variety of different types of qualification and backgrounds. Carers have been specified here as 'newly identified' in order to consider the impact of casework from the beginning of the interaction between the carer and the casework service.

Casework provides 'support'. This highlights that casework is about helping in some way. This reflects historical uses in social work, for example, 'an enabling service' (Bowers, 1949) and 'a way of helping people' (Biestek, 1957). The definition of casework used here has deliberately not specified the particular forms of supportive practice which might be undertaken within casework in order to enable the research to explore variation in practice and the impact this has. However, it is recognised that support could be offered directly by the practitioner and through the relationship they build with the carer but could also be achieved through the practitioner's facilitation of the use of other external resources and services. Casework could, in this way, lead carers to group or community based support as well as other secondary services. Casework constitutes the pathway to support here rather than involving group or community based work itself.

Social work theory raises further questions about the purpose of casework in terms of how it helps people (see page 33), including whether it is intended to offer therapeutic solutions for individuals, to mobilise resources for individuals within the existing system or to enable collective empowerment in the face of oppressive social structures (Dominelli, 2009). As the opening paragraphs indicate, carers currently experience oppression suggesting the need for an empowerment approach. Whilst in the current context, this might appear unrealistic or beyond the intentions of casework providers, this provides a framework for a critical evaluation of the success of casework. This is discussed further from page 34.

Thus, this study is then essentially concerned with evaluation, valuing the intervention's success, here in terms of carer empowerment. This leads to the research question, 'Casework with carers: what works and why?'. There are many different research methodologies for evaluating interventions and these rely upon different ontological and epistemological assumptions. The approach taken here, realist evaluation (Pawson & Tilley, 1997) seeks to explain change in outcomes occurring through interventions based upon solid philosophical foundations in critical realism (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Bhaskar, 1998). The nature of realist evaluation and the reasons for using this are explored further in chapter four (page 78). The realist framework seeks not just to identify outcomes (the change resulting from an intervention) but also to understand the mechanisms, the underlying processes which create this change, and the context within which this occurs. The importance of explaining the outcomes of casework by understanding its processes and recognising the influence of context also points to the potential value of a longitudinal approach. This would allow more insight into how processes developed over time and the influence of changing context. The longitudinal

approach used and the research design more generally are set out in chapter four.

To summarise, this study will address the question 'Casework with carers: what works and why?'. The realist evaluation methodology will provide a detailed linked understanding of the mechanisms which explain the achievement (or potentially absence) of outcomes, importantly set within an understanding of how context impacts upon this. The thesis will offer original findings on the previously neglected work of third sector carer support together with a comparative insight into other forms of casework with carers. The thesis also benefits from a rarely taken longitudinal perspective. The findings will be analysed within a theoretical framework using concepts of the ethic of care and carer empowerment in order to offer a critical perspective on casework with carers.

1.2 The organisational and personal context of the research

This research is set within its own micro-level organisational context. This includes the funding and organisation of the study as a PhD studentship in partnership with Carers Trust. The involvement in research of a third sector organisation focused upon both political campaigning work and on service delivery has potential benefits and drawbacks. Carers Trust has contributed to the development of the original research proposal, provided part of the PhD funding, participated in some PhD supervision meetings (particularly in the earlier stages) and supported with communication with local carer organisations. Several benefits have arisen from this. This has provided another perspective closely focused upon policy and practice concerns to feed into the development of the research. The involvement of Carers Trust has also been helpful in terms of advice about and support with gaining access to fieldwork sites. Perhaps most significantly though, their involvement provides a valuable opportunity for support with disseminating findings back into policy and practice. The value of this has already been evidenced in relation to an earlier, more comprehensive systematic review of the evidence on carer interventions conducted (Victor, 2009) from which the review within this thesis originates. This has been widely available to a range of stakeholders through its publication online by Carers Trust and it has been drawn upon in policy campaigning work. Advice from Carers Trust also informed the development of summaries in an appropriate format and language which were distributed to service managers. It is anticipated that this relationship will again be helpful with the dissemination of the thesis findings.

The principal danger with this type of relationship is that the integrity of the research may be compromised through the influence of the political body. Here, Carers Trust approved the specific focus and methodology of the study but have not altered this or proposed any amendments to the content of the thesis. However, evaluation research is already politicised through the framing of the issue to be evaluated (Taylor & Balloch, 2005). Carers Trust was involved in framing the original proposal for the research study to evaluate interventions for carers. This implicitly made the political assumption that

carers should be supported in some way. In the opening to this thesis, reasons have been set out for why this is considered to be important and necessary. However, some have argued against this and the underlying conceptual issues are considered in the review in chapter two.

After the development of the initial proposal, as the researcher, I have always sought to maintain a positive working relationship with Carers Trust. I also previously worked within third sector organisations, although these organisations did not work specifically with carers. As such, I have an understanding of the passion and intensive efforts of many working in this sector to make a positive difference to society. I am sympathetic to their work. I also recognise the difficult challenges such organisations often face in securing funding for their work. However, this study did not set out simply to legitimise and support funding for these services. Instead, I have been focused upon producing reliable and valid findings grounded in the data. Furthermore, this study has been about understanding casework in order to enable services to learn about and develop their work. This is very important given that it can be very difficult for such services to find the time, funds and expertise to assess and reflect upon their work themselves.

My other personal characteristics as the researcher may also be relevant context. I am a white, female researcher in my thirties. I have not been a carer myself but I do have some personal experience of close family members providing care. My grandfather cared for my grandmother and subsequently my mother and her sisters provided care for my grandfather. During the period of the research, I have been bringing up my three young children. Whilst this is a different form of care, there are many underlying similarities which have been apparent to me whilst conducting the research. Overall my attitudes are guided by respect and concern for carers.

All research is socially constructed knowledge. It is impossible to be objective and to understand entirely the influence my own characteristics or the partnership with Carers Trust has had upon the research. Nevertheless by being open about these, readers can make their own judgements.

1.3 Content of the thesis

The main body of the thesis is divided into chapters with the following content.

Chapter Two provides a conceptual review of theoretical and empirical literature concerning the key concepts underlying this study: care; carers; the third sector; social work practice and carer empowerment.

Chapter Three presents a systematic review of existing research evidence about casework in the form of information and support worker interventions for carers and also statutory carer assessment.

Chapter Four details the methodology used within this research study.

Chapter Five presents findings on the outcomes achieved directly through casework itself including in emotional well-being, caring skills and knowledge, employment and uptake of other secondary support services. It then explores the mechanisms generating these outcomes and the contextual factors which influenced whether or not these occurred. It concludes by presenting a realist model of casework with carers.

Chapter Six presents findings on outcomes achieved through the use of various secondary services to which casework directly supported access in some way. It also explores the mechanisms generating these outcomes and the contextual factors influencing uptake of these secondary services.

Chapter Seven presents an overall judgement of the success of casework for carers in a longitudinal perspective and considers how the context of casework and carer characteristics influenced this.

Chapter Eight reflects upon the success and limitations of the study. It considers the findings in terms of the ethic of care, carer empowerment and the role of the third sector. It finally presents the conclusion and recommendations for practice and future research.

Chapter Two: Care, Carers, the Third Sector, Social Work Practice and Carer Empowerment: A Conceptual Review

The chapter following this one examines and evaluates the existing empirical research into interventions offering a form of casework with carers. This provides insight into what is already known regarding the research topic. However, it is also important to give this study a theoretical underpinning by considering the key concepts underlying this research. Hence this chapter offers a conceptual review to explore key theoretical debates regarding: care, carers, the third sector, social work practice and carer empowerment. As in other conceptual reviews (for example, Hicks, 2016), this review uses political theory and empirical literature to identify key debates and theoretical understandings relating to the concepts concerned. This includes historical literature to illustrate the development of concepts over time and changes in theorisation. It can be helpful for a conceptual review to look more widely than the particular focus of the study (in this case, carers) in order to take a broader, critical perspective (Young et al., 2006). As noted in the introduction, it has been helpful here to turn to social work theory including particularly in relation to empowerment.

The first section (2.1) explores the concept of care and specifically how this has underpinned the historical development of the concept of carers and critical debates relating to this. It discusses how care has been reconceptualised and the theory of the ethic of care. The following section (2.2) considers how the concept of carers can currently be understood in terms of the diversity of this group, the impacts of caring, the carer service interface and in the recent UK policy context. The next section (2.3) examines the term 'third sector' and the particular recent manifestation of this in relation to carers in the UK. The fourth section (2.4) looks at analyses of social work practice to help develop a more theoretical understanding of casework and to consider how the success of this might be judged in relation to carer empowerment. The final section (2.5) identifies some of the key implications of the review for this thesis.

2.1 Understanding care

2.1.1 The gendered nature of care

Unpaid carers are now well recognised as a distinct group of people by policymakers and by third sector organisations in the UK who seek to improve the experiences of this group. However, 'carer' is both a constructed and a contested term. Its emergence and construction arose from the work of pressure groups and feminist academics responding to the disadvantages associated with caring in the welfare state (Bytheway & Johnson, 1998).

The National Council for the Single Woman and Her Dependants was founded in 1965 in the UK to campaign for the rights of single women who were

experiencing disadvantage through their roles as unpaid carers for other family members. This reflected the fact that many women were unmarried or widowed due to the First World War and that these single women were the first group within families expected to taking on caring roles (Bytheway & Johnson, 1998). This organisation in 1982 became the National Council for Carers and their Elderly Dependents, and then in 1986 formed the Carers National Association (later to become what is now Carers UK) through a merger with the Association of Carers (founded in 1981). These later organisations recognised that married women and some men were also disadvantaged through their caring roles for family members. They used the term 'carers' to mobilise campaigns to attach a higher value to unpaid caring work.

A body of early feminist academic work explained that the new policy focus upon care being provided *in* the community rather than in large scale residential institutions actually meant care *by* the community (Finch & Groves, 1980). Furthermore, this community of relatives and friends actually equated to women (Finch & Groves, 1980). Women were expected to and felt obliged to provide this care on an unpaid basis. There was a gendered kinship hierarchy influencing who would be expected to undertake unpaid care (Qureshi & Walker, 1989). Parental relationships where parents assume responsibility for children have been identified to be the kinship tie with the most fixed power for determining obligations (Finch & Mason, 1993). Spousal relationships have also been seen as a primary caring relationship, however, these can be cross-cut by gender where a daughter or daughter-in-law could replace a husband caring for a wife (Ungerson, 1987). Geographical distance between family members, material conditions such as the availability of accommodation for a relative and women's other commitments in terms of childcare and paid employment have also been shown to play a role (Ungerson, 1987). However, family responsibilities are fluid and negotiated on the basis of historical relationships rather than fixed obligations (Finch & Mason, 1993). The quality of previous relationships also influences who takes up a caring role (Ungerson, 1987). Whilst people expect to have a choice over the assistance they provide to family members (Finch & Mason, 1993), carers have often expressed that they feel obliged to take on roles.

Women have been socialised to be caring and to expect to undertake caring activities (Brody, 2006; Finch & Groves, 1980; Ungerson, 1987). Caring has been seen as a natural activity for women and undertaking care has acted as a key part of fulfilling a feminine identity (Graham, 1983). The expectations placed upon women to provide unpaid care made it difficult for them to seek equal opportunities through participation in paid employment and left them struggling to fulfil this obligation alongside other family responsibilities (Finch & Groves, 1983; Lewis & Meredith, 1988; Ungerson, 1987). These women consequently experienced financial hardship and social isolation (Finch & Groves, 1983). In this way, care could be seen as a burden. Patriarchal community care policies relying upon the female unpaid provision of care within families were a source of women's exploitation.

2.1.2 The social model of disability

A strong critique of the focus upon 'carers' has come from academics in the field of disability studies (for example, Morris, 1993). This critique argued that dominant conceptualisations of carers constructed the disabled people who receive care as essentially dependent, passive and a burden. These conceptualisations are seen to rely implicitly upon the medical model of disability. The medical model of disability focused on the abnormality or deficiency of the body which led to functional limitations or disability in terms of what a person can do. In this way, having a disability was seen as an individual problem or personal tragedy. This model was increasingly challenged in the 1970s and 1980s as disabled people reflected that the discrimination they experienced was due to the organisation of society rather than individual functional differences (Oliver, 2004). For example, a person using a wheelchair might not be able to use some public facilities because of a lack of ramps providing access rather than because of their medical condition itself. However, some disabled feminists have argued that the social model does not always provide a complete understanding because it focuses on public experiences and ignores private experiences of the impairment (Morris, 1991). In addition, the social model does not always highlight the different social locations, experiences and support requirements of groups with different impairments (Barnes & Mercer, 2010). However, the social model of disability usefully highlights where social structures limit the quality of life and participation of disabled people.

Using the social model of disability, the disability rights movement has argued that instead of considering carers' issues, the emphasis of social policy should be on removing social barriers and providing formal services to enable disabled people to live independently without the need to rely upon unpaid family care. There has been a particular focus upon paying personal assistants to provide the instrumental support disabled people need to exercise their autonomy (Barnes & Mercer, 2010).

However, what this approach sometimes fails to acknowledge is that some either prefer people they have a close relationship with to provide care rather than a professional support assistant (Parker, 1993) or might find it difficult to manage processes such as employing a paid worker necessary to sustain independent living. The independent living movement may also neglect the role of interpersonal relations by reducing the provision of support to mechanistic, instrumental activities (Watson, McKie, Hughes, Hopkins, & Gregory, 2004). Thus, whilst social structures which disable people need to be recognised and challenged, it is also necessary to acknowledge that the independent living model is not desired by, or possible, for all. Thus, there may continue to be some role for care. Furthermore, some of the objections to a focus upon care and carers may be overcome if the nature of this is carefully considered.

2.1.3 Reconceptualising care

A number of writers upon care have made statements similar to the following: *"The word 'care' has many different meanings, dimensions and values attached to it."* (Phillips, 2007, p. 14). As noted the particular associations that care has had with burden upon women and also the passivity of the care recipient have created negative understandings of care as well as resistance to use of the concept. However, some feminist theorists (Kittay, 1999; Sevenhuijsen, 1998; Tronto, 1993) have presented analyses of the nature of care which are more comprehensive and make visible other, more positive aspects of the concept.

One central understanding is that *"care implies a reaching out to something other than the self"* (Tronto, 1993, p. 102). In other words, it is relational or as Kittay (1999) says connection based. Tronto discusses that care can relate to other people but also to objects including our environment. Sevenhuijsen notes that care can be directed at other people and the physical environment but also at ourselves (Sevenhuijsen, 1998).

These theorists (Kittay, 1999; Sevenhuijsen, 1998; Tronto, 1993) also emphasise that care is a relationship between human beings in which we all participate at some point in the lifecourse. Everyone is dependent at the beginning of their life as a baby and young child, as Kittay points out *'we are all our mother's child'* (1999, p. 19). Dependency and a subsequent need for care may also reoccur later in life due to illness or frailty in old age. Human beings are inevitably and essentially interdependent due to their need for care. However, care does not necessarily have to be dyadic (Sims-Gould & Martin-Matthews, 2008; Tronto, 1993), there may be wider networks of people involved. It also does not have to be uni-directional but can involve reciprocity between the parties (Barnes, 2006; Henderson & Forbat, 2002).

Tronto discusses that *"Care is both a practice and a disposition."* (1993, p. 104). As well as being about carrying out particular tasks, it is an attitude and concern for others. A distinction can be made between 'caring for', providing practical care services to someone, and 'caring about' them, having emotional ties (Graham, 1983). However, it can be misleading to view these as separate entities. Good 'care for' somebody also requires affective care underlying this (Kittay, 1999). This is why caring has been conceptualised as a 'labour of love' (Graham, 1983). This latter term also recognises the labour or work involved in care as a practice. This has been broken down into three elements: physical labour, emotional labour and organisation (James, 1992).

Physical care can be the most apparent element of care. This has been categorised as potentially involving: personal care; the management of incontinence; medical and nursing care; and household tasks, for example, shopping and cooking (Twigg & Atkin, 1994). This can involve hard physical work (Finch & Groves, 1983).

Tronto highlights that as well as 'caring about' someone and the direct physical provision of care, 'caring for', care involves 'taking care of' (1993).

This is assuming some responsibility for an identified care need and determining how to respond to it. Similarly, James (1992) points out that the organisation of tasks is required to provide effective care either delivered by an unpaid carer or other sources. The actual provision of care may be separated from the organisation of this. Both authors suggest that separation of these functions may make it more difficult to provide good care, as it may be harder to recognise and to respond to the individual needs of those receiving care.

This also highlights the importance of the purpose of care as well as the activities involved. Tronto talks about this being *“to maintain, continue and repair our ‘world’”* (1993, p. 103). She also defines caring as being about meeting needs. Thus, there is a sense of looking after and addressing something, but care may also be about developing and enhancing well-being. Kittay refers to care as enabling another *“to grow, flourish, and survive or endure illness, disability and frailty”* (1999, p. 168).

Tronto (1993) identifies one other phase of care, ‘care-receiving’. This is important because it highlights the perspective and experiences of those who are dependent in some way. This can then involve reflection upon the standard and quality of the care provided and received. This also draws attention to the fact that caring relationships like all relationships involve power and potentially conflict (Brody, 2006; Tronto, 1993). There can be particular dilemmas in care arising from this. The person receiving care can be vulnerable to abuse through their physical or mental dependency. They may be subject to ‘paternalism’ whereby the carer makes decisions for them instead of allowing them to voice their own preferences (Tronto, 1993). How those receiving care can exercise their own autonomy is an important issue. The carer’s considerable responsibility and power for a potentially vulnerable person can in turn make them vulnerable to legal scrutiny and risk (Kittay, 1999). The person receiving care also has some power to assist or make the carer’s role more difficult. The carer may have difficulty identifying their own needs and avoiding entirely subordinating these to those of the care receiver. Thus there are likely to be inequalities of power within caring relationships which may be managed successfully within trusting, good relationships or turn into issues of abuse or domination (Kittay, 1999).

2.1.4 The ethic of care

The preceding analysis reveals the importance of care showing its universality and centrality to social life. Yet, the lack of value placed upon care as work and the cultural associations made between care and the feminine, emotions and the private realm have contributed to the inequality faced by women and other disempowered groups according to ethnicity and class (Kittay, 1999; Tronto, 1993). To overcome the exploitation of women and others, the normality of interdependency and the value of care need to be recognised. As discussed in the introduction, Kittay argues that society can be understood as connected through nested dependencies: people who provide care for those

who are dependent come to be secondarily dependent. Thus there is a political imperative to care for those who provide care.

Tronto (1993) argues that care should be a central part of moral philosophy guiding society. Gilligan (1982) earlier identified that men act within a moral framework of justice and rights subject to public and rational assessment, whereas women's moral framework related to responsibility for maintaining connections and caring within individual circumstances. The former governs political life and the latter is confined to the realm of private life. Tronto and Sevenhuisjen reject this dichotomy of the feminine ethic of care and masculine notions of justice. They argue that care should be taken from its place in the private realm to become a guiding concern in the public arena. The right to give and receive care is an issue of social justice.

Tronto and Fisher proposed an ethic of care as a guiding practice. This involves four elements: attentiveness, responsibility, competence and responsiveness (Tronto, 1993). These correspond to the four aspects of care identified by Tronto as discussed previously. Attentiveness involves identifying needs so that these might be met. This involves trying to suspend concern with one's own needs and preoccupations in order to consider others' needs. One's own needs for care may first need to be met before this can be done. 'Responsibility' is about taking action to care for those who need support. However, it is not the same as obligation and is not a set of fixed rules. It is a more flexible concept which needs to be understood and negotiated in its particular cultural context. 'Competence' draws attention to the importance of the quality of the care in meeting needs. 'Responsiveness' is to consider the perspective of the person receiving care as they express this. This recognises the vulnerability of those receiving care and the potential for abuse within inequitable power relations. Good care requires that these four elements of care are integrated together taking account of any conflicts involved.

This theoretical framework of the ethic of care can be applied in many situations and at different levels of analysis. It can be used to consider the micro-level interpersonal relationship between a carer and the person they care for. It is also argued that an ethic of care should be applied at the political level. Williams (2001) proposes that an ethic of care should be as central as the ethic of paid work to citizenship in the welfare state. Men and women should be able to consider how to prioritise paid work time and space, care time and space and personal time and space. It is only by valuing care, not just by women entering paid employment, that equality can be achieved. The ethic of care is a situated practice, it does not propose that all needs should be met but instead it provides a framework for negotiating and deciding how to approach moral problems.

Taking forward arguments for an ethic of care does not exclude the importance of independence, autonomy and empowerment for both those who receive care (Shakespeare, 2000) and carers themselves (Fine & Glendinning, 2005) whilst recognising the interdependence of human life. It can be understood that self-determinacy rather than self-sufficiency is key (Tronto, 1993, p. 134). Through an understanding of the ethic of care, autonomy may

also be reconceptualised as relational. In this way, individual choices and preferences are seen to be situated within interdependent relationships and may be influenced by mutual values (Fine & Glendinning, 2005; Keyes, Webber, & Beveridge, 2015).

Empowerment may depend upon an ethic of care to be achieved. Keyes et al (2015) present a concept of 'empowerment through care' in analysing their research into social care. They identified that the four elements of Tronto's ethic of care were present in the interaction between the social worker and those accessing services but a specific focus upon empowerment was also required to achieve service users' goals. They found that there is a significant role for interdependent relationships in realising relational autonomy and thereby enabling choice and control. Similar findings have been reported by other recent empirical social care research (Chapman & Tilley, 2013; Rummery, 2011; Scott & Doughty, 2012).

2.2 Carers

2.2.1 Diversity in caring

The next section explores how key socio-demographic factors mediate the nature of caring. Table 4.5 (page 104) gives a statistical overview of the profile of the national carer population in England by these characteristics.

- *Gender*

The association of women with care and of the feminine identity with caring have already been noted. However, some have labelled men 'the forgotten carers' (Arber & Gilbert, 1989) as the proportion of men taking on caring roles is actually not much lower than that of women. Dahlberg, Demack and Bambra (2007) have shown that caring by gender varies according to age: women are more likely to undertake caring under the age of 70 and men are more likely to do so after this age. Furthermore, they illustrate relationships between gender, age and the extent of caring responsibilities in terms of the number of hours committed. What this shows is that women may face particularly heavy caring responsibilities in middle age when they may also be trying to sustain paid work and have childcare responsibilities and that older carers, including men, also have particularly heavy responsibilities. More recent statistical analysis continues to illustrate these trends (Office for National Statistics, 2013).

Men may experience care in a different way. Ungerson (1987) found that men provide care generally out of love, not duty. In addition, some male conceptualisations of caring roles used occupational references and focused upon the skills involved (Ungerson, 1987). Twigg and Atkin (1994) found that women were more likely to have an 'engulfed' response to the caring role such that their life becomes almost entirely sub-ordinated to the caring role. Women were also more likely to view accepting help as a sign of failure than men. Men found it easier to set boundaries on their involvement in the caring role and

perceived themselves as 'professional carers' who should legitimately receive support (Twigg & Atkin, 1994). However, a collection of articles on male caring shows the diversity in the experiences and perspectives of male carers and the need to consider these in terms of other distinguishing characteristics such as the relationship to the person receiving care, the nature of the medical condition involved and ethnicity (Kramer & Thompson, 2002).

- *Ethnicity*

Incidence, experiences and perspectives upon caring generally are mediated by ethnicity. Reviews of empirical research upon caring amongst ethnic minority populations note that different ethnic minorities have their own experiences and cultures and also within distinct ethnic minority groups, there is diversity (Nolan, Grant, & Keady, 1996; Phillips, 2007). Furthermore, experiences are changing over time given the dynamic nature of the migration, settlement and integration of ethnic minority communities. Although the patterns across individual groups are complex, ethnic minority groups already often experience structural disadvantage in terms of suffering poorer health and economic disadvantage compared to the majority population (Nazroo, 2006). The disadvantage imposed by caring responsibilities can then combine to create a double jeopardy. It has also been claimed that ethnic minority communities have even more difficulty identifying with the term 'carer' than white carers. Some South Asian languages do not have a specific word for the concept (Williams & Johnson, 2010, p. 94). Assumptions about minority ethnic families being more supportive of carers than white families are not necessarily upheld by empirical data (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999; Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004).

A systematic review (Greenwood, Habibi, Smith, & Manthorpe, 2015) found that black and minority ethnic carers are less likely to use social care services despite evidence of greater need than amongst white carers. The review also found that many of the barriers to service access may be the same amongst carers of all ethnicities but there was also some evidence of barriers that were specific to black and minority ethnic carer groups. These included not taking up services because they were not perceived to be sensitive to particular religious or cultural needs and specifically wanting paid care workers of the same ethnicity. Language could also be a particular issue in terms of accessing information about services, applying for services and within service provision itself.

- *Age*

A review of evidence on older carers found that they are increasing in number, are most likely to be caring for older people, are likely to offer higher levels of physical and personal care than other carers and often have serious health problems themselves (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001). They may also have difficulty accessing support because the older people they care for may be particularly resistant to using formal services

because they do not want to feel that their independence is compromised (Arksey & Glendinning, 2007). Another group of carers who have been defined by age are 'young carers' (Aldridge & Becker, 1993). However, this thesis has focused upon adult carers.

- *Kin relationship*

The nature of the relationship, for example, whether it is spousal, a parent caring for their child or vice versa has been shown to influence experiences of caring. Parents of disabled children or children with learning difficulties may expect to continue to be carers for the rest of their lives. Todd and Shearn (1996) have labelled this 'perpetual parenthood'. As infants, there may be relatively little distinction made between general childcare needs and those relating to a medical condition but as children become older, parents start to recognise the particular caring contribution required as being distinct from general childcare (Beresford, 1994). Thus there is a particular temporal element to parent caring. In addition, a particular issue arises when older parent carers of adult children who have learning disabilities are no longer able to fulfil their role. In response to this proactive planning is required and recognition that these relationships may often be mutually dependent (Bowey & McGlaughlin, 2007).

Parker (1993) undertook a seminal study of caring within marriage. She found that the private nature of the spousal relationship may mean that spouse carers may receive and/or wish to receive less support compared to others. However, the particular bond of marriage does not necessarily mean that caring is easier. Caring within marriage prior to retirement age may be particularly difficult where this means that there is no main earner in the household. Like single co-resident carers of older people, spouse carers could be particularly socially restricted due to difficulties leaving the person they cared for and having no-one with whom to share the physical or emotional difficulties of caring. A study of older spouse carers noted the interdependency of many and how their caring roles could switch and change over time as each spouse's health needs changed (Ray, 2006).

Cavaye (2006) found that those who became carers through default were often co-resident with their relative, often a spouse, and felt they had no choice. The process of becoming a carer often occurred gradually as the relative's health deteriorated. In contrast, some non-resident adult children felt able to make a positive choice to care for their parent and tended then to feel more positively about their role. In this way, caring for an elderly parent is a more negotiated rather than assumed role. Many of those undertaking this role will have other nuclear family responsibilities (as well as potentially paid employment) competing for their time and affection (Lewis & Meredith, 1988; Ungerson, 1987). Studies have shown that this caring arrangement can lead to particular challenges in terms of the changing dynamics of power and dependency relationships between those involved because there is some element of role reversal. Studies show both examples of parents dominating their adult children in the caring role drawing upon their previous position of

parental power or becoming overly dependent and also examples of adult children inappropriately controlling the parent in their increasing dependency (Brody, 2006; Lewis & Meredith, 1988).

As well as the kinship form, the nature of pre-existing relationships is also likely to have an impact upon caring relationship. Carers who had previously had close and happy relationships and who continued to do so were more likely to feel positive about their caring situations (Lewis & Meredith, 1988; Parker, 1993; Ray, 2006).

- *Medical condition*

Some particular points can be identified in research relating to caring for people with specific categories of medical conditions. Twigg and Atkin (1994) discussed the particular experiences of carers of people with mental health difficulties. These included: greater difficulties in objectifying the condition and separating it from the relationship; the potential implication of the carer in the condition or its manifestation; and a greater emphasis upon being responsible rather than upon practical tasks. Reynolds and Walmsley also note the distinctive nature of the care provided by relatives of people with learning disabilities or mental health difficulties as *“usually quite diffuse, involving being available and responsible when they are needed, offering company, emotional support and often fighting for services.”* (1998, p. 68). They also review research showing that carers of people with mental health difficulties often felt the loss of their relative because of the medical condition. In addition, carers’ own emotional well-being could be closely related to that of the person with mental health difficulties. Care for people with learning disabilities (usually provided by parents) raises particular issues relating to autonomy and relationships of power. Twigg and Atkin (1994) note that carers may find aspirations for the person with the learning disability to lead a more independent life unrealistic or may feel these as a threat to their caring role.

The incidence of dementia is growing and also poses particular care challenges. As for mental health conditions more broadly, it creates particular emotional difficulties for carers and also often leads to behavioural problems which are difficult to manage (Newbrunner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). Newbrunner et al also identify stages relating to the progression of the condition which affect carers covering diagnosis and decline in the capacity of the person with dementia including in relation to their mobility, behavioural problems and incontinency.

- *Stages of caring*

A number of temporal models of the caring experience more generally have been developed (Burton, 2008; Cavaye, 2006; Lewis & Meredith, 1988; Nolan et al., 1996). The process of becoming a carer is the first stage of these. Burton (2008), in a small qualitative study of carers with various characteristics, found that when carers began their roles was a difficult stage

because of carers' inexperience, their lack of information and lack of support. This leads onto a stage of caring which Nolan et al (1996) and Cavaye (2006) discuss in terms of a process of gaining expertise. This is often achieved through trial and error, the accumulation of practical experience and intimate knowledge of the care receiver. The extent of caring can also change over time. Lewis & Meredith (1988) showed how caring could move from 'semi-care' where daughters felt a sense of responsibility even if little direct care was needed to 'part-time full-time care' where the daughter took full responsibility for the mother's care but also maintained some of her other responsibilities to 'full care' in which the daughter's time and responsibility was focused predominantly upon the caring role.

Cavaye (2006) and Burton (2008) show how different stages of caring may also be related to service use. Cavaye (2006) conceptualises these as stages of 'going it alone' (where no services are used) to stages of 'accessing services' (where carers go through the complex process of trying to access support) and 'carers as clients' (during which carers use services). The development of a carer identity often only comes through interaction with service professionals and other carers in the use of services (O'Connor, 2007; Twigg & Atkin, 1994).

Temporal perspectives on caring also recognise that caring roles end (Cavaye, 2006; Lewis & Meredith, 1988; Nolan et al., 1996). They may end in different ways: through bereavement, through the move of a disabled child to independent living or through admission into residential care. In the latter two cases, caring roles may continue but in different forms (Katz, Holland, Mitchell, Gage, Thein, & Sheehan, 2013). Research shows that when caring ends, as well as experiencing emotions of loss and guilt relating to bereavement or the admission of a relative to residential care, carers may feel there is a void in their life including a loss of purpose (Cavaye, 2006; Larkin, 2008).

2.2.2 Impacts of caring

This review now focuses upon the impacts of caring. The positives of caring were sometimes neglected in earlier literature because of the political focus upon highlighting the disadvantages often imposed by caring. However, Nolan et al (1996) review and categorise the different types of satisfaction that caring can offer. These can arise from a benefit either to the carer themselves (for example, the development of new skills), to the person receiving care (for example, maintaining their dignity) or to both parties together (for example, the development of a closer relationship). Satisfactions may also derive from different types of sources consisting of the interpersonal dynamic (for example, an expression of appreciation for the carer from their relative), the intrapersonal dynamic (for example, the carer's own sense of achievement) and an outcome (for example, avoiding the use of residential care).

Early feminist literature particularly noted the difficulties female carers found in engaging in paid employment and thus having material security (Finch & Groves, 1983). Census data from 2001 showed that both male and female

carers have lower full-time employment rates, but higher part-time employment rates, than all men and women of working age (Yeandle, Bennett, & Buckner, 2007). Employment rates also declined with the number of hours cared per week. A review of the literature upon paid employment amongst carers found that most carers want to continue to work but can find it difficult and stressful to sustain this alongside caring especially when they care for more than twenty hours per week and are co-resident with the relative receiving care (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005). Similarly Yeandle, Bennett, Buckner, Fry and Price (2007) found that amongst the group of carers who described themselves as looking after home and family full-time, over a fifth would have liked to be in paid employment but said that the services available did not make this possible. They also found that non-participation in paid employment can be associated with further negative impacts in terms of income and health.

Economic constraints for carers can arise from the difficulty of combining paid employment with a caring role but also because of additional costs that can be incurred through the caring role (Carers UK, 2014a). These arise through higher general household spending on items such as utilities as well as expenditure on items responding to ill health and disability such as equipment and cleaning products. As discussed on page 29, some carers are entitled to Carer's Allowance but the level of this is very low. It can also create a disincentive to work more hours or achieve a higher pay rate because greater earnings limit eligibility. Research evidence also shows that significant proportions of carers, possibly up to a third, have not accessed their benefits entitlements (Berthoud, 2010). The consequences of these financial restrictions can include carers facing difficulty paying for essentials, going into debt and experiencing ill health due to the anxiety created by this (Carers UK, 2014a).

Carers may experience 'restrictedness' (Twigg & Atkin, 1994) in terms of participation in leisure and social activities as well as in employment. This may relate to undertaking such activities independently but also with the relative they care for. Carers can find it difficult to maintain social networks of friends and family and this can lead to isolation (Carers UK, 2014a; Cavaye, 2006). Caring can also both improve and damage the relationship between the carer and the person they care for (Lewis & Meredith, 1988; Ungerson, 1987).

Caring can have a negative impact upon carers' physical health. Census data from 2011 shows that those providing unpaid care were more likely to report their general health as 'not good' compared with those providing no unpaid care (Office for National Statistics, 2013). The extent of the effect increased as the number of hours spent caring per week increased. Physical health problems related to caring can include physical injury due to caring tasks such as lifting and handling and problems associated with stress such as high blood pressure (Age UK et al., 2012). Hirst (2004) reported physical health inequalities particularly in terms of fatigue or lack of energy and health problems that limit social participation. Carers may also find it difficult to attend medical appointments (Age UK et al., 2012).

All of the potentially negative impacts of caring considered so far may ultimately have an effect upon overall psychological well-being. This can include experience of stress, anxiety and depression (Age UK et al., 2012; Singleton, Aye Maung, Cowie, Sparks, Bumpstead, & Meltzer, 2002). Increases in the extent of the caregiving role in terms of its intensity, length and number of episodes are associated with greater likelihood of psychological distress (Hirst, 2004). Raised levels of distress have also been identified particularly at the start of a caring role and at its end (Hirst, 2004).

Whilst this evidence illustrates the importance of objective stressors such as the extent of the caring role, other work has also highlighted how the experience of stress can be understood as a process (Pearlin, Mullan, Semple, & Skaff, 1990). Psychological outcomes are the complex result of the interaction of a number of factors including: background and context (for example, socio-demographic characteristics and caring history); primary stressors (for example, the cognitive status of the person receiving care); secondary role strains (for example, economic and social constraints); and secondary intrapsychic strains (for example, self-esteem). This model identifies the role of both objective and subjective stressors. A review by Nolan et al (1996) of work upon carer stress also concluded that the evidence supported a transactional model of stress in which an individual judges whether an occurrence is stressful according to their perception of the resources they have available to deal with this.

This points to the importance of understanding coping as a means for mediating and limiting psychological outcomes. Coping can be distinguished in terms of coping strategies, the ways in which people cope, and coping resources, the support available to assist a person (Nolan et al., 1996). Drawing upon the literature, Nolan et al (1996, p. 61) present a helpful conceptual categorisation of coping strategies. Coping strategies could be behavioural or cognitive and can have a number of aims: preventive action; direct action; reframing (creating alternative meanings of situations); and dealing with the consequences (where the difficulty cannot be avoided). A distinction can also be made between instrumental support (the availability of help with particular tasks) and expressive support (the availability of a person who is caring, trustworthy, uplifting and a confidant) (Pearlin et al., 1990). Resources can be internal (for example, skills, psychological disposition) or external (Nolan et al., 1996). External resources might include social support (including the extent, quality and supportiveness of social networks) and utilitarian support (for example, income, housing, formal services). The use of formal services by carers is now considered.

2.2.3 The carer service interface

Existing research shows that some of the most important help for carers may, in fact, consist of support directly provided for the person they care for (Pickard, 2004). However, carer support may actually help the carer to access services for the person receiving care (Cavaye, 2006). The beneficiary of services cannot always be clearly distinguished, for example, day care for a

person with learning disabilities can have educational value to them but also offer a break to their parent carer (Twigg & Atkin, 1994). A systematic review of existing research also found considerable evidence that carers can benefit from services specifically targeted at themselves including carer support groups, stress management, coping and counselling programmes and education and training (Victor, 2009).

National statistics show that local authorities reported that 374,000 carers were either jointly or separately assessed or reviewed in England in 2012/2013 (a further 37,000 declined an assessment or review) (Health and Social Care Information Centre, 2013). These statistics also identified that 354,000 carers received either carer specific services (169,000) or information only (185,000) following an assessment or review in England in 2012/2013. The Carers Trust network of local third sector carer centres and break schemes was reported to reach over 351,000 adult carers in England in 2013 (Carers Trust, 2013). Some other service providers including local third sector condition specialist organisations may also be reaching carers, although there may be some overlap in the group of carers who are reached by these organisations. Altogether it is unlikely that more than a million carers were accessing formal services in the period of a year. Yet 5.43 million carers were identified in the 2011 census in England including nearly two million who cared for more than twenty hours per week. This suggests that many carers were not interacting with formal services at the time data was collected for this thesis.

Not all carers may need support as some may manage their role without particular difficulties (Brodaty, Thomson, Thompson, & Fine, 2005). In a survey of working age carers (Yeandle, Bennett, & Buckner, 2007), a small proportion of carers (twenty per cent) in their sample (which had a relatively high proportion of carers caring for over fifty hours per week) did not want any services. About two thirds of carers would have liked a service that they did not have.

It has already been noted that specific carer groups (female carers, ethnic minority carers, spouse carers, those caring for older people and young adult carers) may be less likely to access services than others. It has also been suggested that working age carers, lesbian, gay, bisexual and transgendered carers and those caring for someone with an eating disorder or substance misuse problem may be particularly unlikely to approach services (Moriarty, Manthorpe, & Cornes, 2014). Some common themes and barriers to service use can also be identified across carers.

Carers do not necessarily perceive carer services to be for them. Many carers may not identify themselves as carers (O'Connor, 2007). They view themselves first as mothers, fathers, sons, daughters, husbands, wives and so on (for example, Henderson & Forbat, 2002). Carers often look for continuity in the relationships and identities of themselves and their family members during caring experiences thus positioning these as part of their wider lives (Barnes, 2006). Carers may even find the term 'carer' problematic because it can threaten the pre-existing nature of their relationship with the relative they care for (Molyneux, Butchard, Simpson, & Murray, 2010). This implies the potential

need for service professionals themselves to recognise and identify carers instead of expecting carers to seek help (Moriarty et al., 2014).

Carers may find it difficult emotionally to seek support. This may be due to ambivalence about their own adequacy and identity (Lewis & Meredith, 1988). Twigg and Atkin (1994, p. 122) developed a typology of carers' attitudes to the caring role (some of which echoes Lewis & Meredith's earlier work (1988)) and found that this influenced service use. As noted previously, in 'engulfment' where a carer's life was subordinated to the cared for person, carers were unlikely to use services due to difficulties identifying any of their own needs, the assumption of total responsibility for the caring role and a feeling that use of help would constitute failure. 'Balancing/boundary setting' involved some element of separation between the carer and the caring situation and these carers found it easier to accept some support as helpful to their role. Twigg and Atkin (1994) note that this approach sometimes occurred where carers assumed the identity of a carer, sometimes through the influence of contact with third sector organisations and carer support groups. The 'symbiotic' mode existed where carers gained in a positive way from their role such that they did not want to stop caring and were happy to use services as long as they did not threaten their caring role.

The nature of services can also be a barrier to use. In a study of carers of older people (without cognitive impairment), Cavaye (2006) found that the perceived authoritarian nature of services was the reason most often cited for not using services. Some believed that to interact with services would lead to a loss of control. Perceptions were based both upon experiences and anecdotal evidence. The potential intrusion of services was also feared because of the loss of privacy over personal space. Yeandle, Bennett and Buckner (2007) found that over forty per cent of the working age carers they surveyed said that their use of services was limited by services not being flexible or sensitive to their needs. Brodaty et al (2005) reported that the nature of services in terms of their availability, appropriateness, convenience of hours of operation and quality can impede use by carers of people with dementia. Burton (2008) identified that a lack of confidence in the perceived quality of services was often the most significant barrier for those who did not access support. Cost can also put carers off using services (Brodaty et al., 2005; Burton, 2008). Services may also often not be used because the relative receiving care did not wish to use them (Cavaye, 2006; Yeandle, Bennett, & Buckner, 2007).

Some of these barriers will be overcome where carers experience crisis or critical incidents in the caring role (Cavaye, 2006). However, support may still be difficult to access. A lack of information about services can be a barrier to service use by carers (Brodaty et al., 2005; Lewis & Meredith, 1988; Yeandle, Bennett, & Buckner, 2007). Cavaye (2006) found that once carers wanted to use social care services, they often encountered difficulties in the face of complex administrative procedures and poor communication. Unassertive carers easily gave up on the process of service access. Rand and Malley (2014) also found that carers trying to contact adult social care departments found the system difficult to navigate and received defensive or unresponsive interactions. A study of carers of people with dementia reported three key

themes encompassing the difficulties they faced in dealing with the formal health and social care service system: that navigating it was like a maze, that the response was often that the particular needs were 'beyond our remit' and a need to fight and battle for services (Peel & Harding, 2014). The systematic review detailed in the next chapter provides further evidence about the carer service interface.

2.2.4 UK policy relating to carers

This next section considers the wider policy context relating to carers when the casework evaluated within this study was undertaken. (This context has recently changed with the implementation of the Care Act 2014. The potential implications of this and other changes since the empirical work for this thesis was undertaken are considered in chapter eight.)

It is helpful to consider the policy context using a conceptual four-fold typology of ways in which service frameworks characterise and treat carers developed by Twigg and Atkin (1994, p. 12). Carers can be viewed as: resources; co-workers; co-clients; and superseded. In the 'carers as resources' model, carers are simply seen as care resources to be used. Community care reforms from 1990 which placed greater emphasis upon the role of family and friends in supporting those with social care needs effectively used carers as resources.

However, since this, the carers' rights movement has given carers prominence on the policy agenda. A National Carers Strategy was first developed in 1999, revised in 2008 and again in 2010, to set out national policy in relation to carers. In 2010, four priority areas were identified: early identification, recognition and involvement of carers; enabling carers to fulfil their employment and educational potential; personalised support for carers and those they support; and support for carers' mental and physical well-being (HM Government, 2010).

Emanating from the carers strategies, there has been concerted activity supported by injections of funding into the development of secondary support services for carers. The 1999 National Carers Strategy established the Carers Grant funding for local authorities to commission and develop local carer support services (HM Government, 1999). The 2007 New Deal for Carers and revised 2008 National Carers Strategy led to a range of national service developments. Funding was provided on a local basis to Primary Care Trusts for carer breaks and to local authorities for the development of schemes to support carers in emergency situations. The national Caring with Confidence course was established to help empower carers through training (Yeandle & Wigfield, 2011b). The Demonstrator Sites programme incorporated trials of new approaches to carer breaks, carer health checks and improved NHS support for carers (Yeandle & Wigfield, 2011a). The 2010 National Carers Strategy was also accompanied by funding for carer breaks, funding for national third sector carer organisations and a specific fund (£1 million) to

encourage condition specific organisations to consider how they could support carers as a first port of call.

These services may help carers to be 'co-workers', where social care professionals work alongside and support carers in order that they can fulfil their instrumental care role. They also enable carers to be considered as 'co-clients' where they have distinct needs of their own to be met. Whilst these services are there to help carers continue in their roles, as discussed on page 112, guidance on statutory carer assessment also explicitly states that carers have the right to choose whether, and to what extent, they continue in their role. Thus, there should exist the possibility of carers also being 'superseded', whereby the provision of formal services enables the carer and the person receiving care to become independent of one another.

However, pressures on government funding and society's economic reliance upon carers' contribution may also exert a covert influence to limit carers' choice over their roles (Harris, 2002). This is likely to be exacerbated by the 2010 Coalition Government's programme of deficit reduction. Substantial cuts (on average of 20 per cent) to adult social care funding were recorded between 2011 and 2014 (Age UK, 2014) in the face of increased demand for social care (Local Government Association, 2013). No statistical evidence has been identified specifically relating to the funding of third sector carer support. However, there is evidence that the general pressure on local authority budgets has led to cuts, possibly disproportionately large, in the funding they allocate to third sector organisations generally (Bhati & Heywood, 2013).

The benefits system is also important context in terms of understanding the potential of casework with carers. Caring can be considered a form of work, however, as analysis by Ungerson (2000) has shown, welfare states have organised payment for this in different ways. In the current UK context, carers receive Carer's Allowance, 'a care-giver allowance' in Ungerson's categorisation, a small, uncontractual, eligibility based payment. This is payable to those of working age caring for someone (who is themselves entitled to specific disability benefits) for at least 35 hours per week and who do not earn more than a small amount through paid employment (£102 after taxes per week in 2014). Carers may be entitled to other income based benefits but these may be reduced when Carer's Allowance is claimed. Carer's Allowance has been set at levels (£61.35 per week in 2014) which do not reflect the true economic value of carers' contribution. Instead, government policy has emphasised the need to support carers to undertake paid employment where possible (HM Government, 2010, p. 15).

It might be expected that access to suitable services (for the carer and the person receiving care) would be facilitated in the wider context of the personalisation agenda in social care policy in recent years (Department of Health, 2007). The personalisation agenda intends to maximise the choice, control and power that service users have in social care. A key element of this is control over resources. The long term vision has been for all service users (including carers) to have access to a personal budget (Department of Health, 2007). This is a specific amount of money available to the individual either to

be accessed as a cash direct payment or to be managed by the local authority or another third party but spent according to the individual's choices.

The specific form of personalisation being implemented in social care with its focus upon individual self-determination and control of resources has been critiqued because of its reliance upon an individualistic view of society (Ferguson, 2007) and lack of recognition of the relational elements of care (Lloyd, 2010). This perhaps also partly explains the relative lack of attention in empirical research upon personalised support in relation to carers. Larkin and Mitchell (2016) review the existing limited knowledge about personalisation and carers particularly in relation to choice and control. They find that personalisation can give carers greater flexibility in the amount of caring they undertake. This can allow them more choice in how they spend their non-caring time including with other family members and in social activities. This can lead to a better quality of life, an improved relationship with the person they care for and greater enjoyment of the caring role. However, they also note that there are a range of issues where carers themselves become paid assistants for the person receiving care including change in the nature of the relationship, limits upon other aspects of their lives and financial restrictions. The review also identifies a range of contextual factors constraining the intended choice provided by personalisation. These include the potential extra demands placed upon carers to help manage personalised support for the person they care for (with few services available to assist with this), the limited availability of support in the context of financial capping and the greater difficulties realising personalisation for people with particular types of need.

There has also been very little research into personalised support schemes aimed directly at carers (rather than the person they care for). The little evidence there is (Campbell, Pyer, & Turner, 2012; Silburn, Elwick, & Becker, 2011; Yeandle & Wigfield, 2011a) suggests that this can have positive impacts for carers in terms of having a break and also sometimes in respect of their health. Again, the processes involved in organising such support potentially influence its success. A study found that carers could require time and assistance to consider how best to use funds (Campbell et al., 2012). Personalised support directly for carers may also be restricted by financial capping and regulations on how resources may be used by carers (Carers Trust, 2012; Larkin & Mitchell, 2016).

2.3 The third sector

2.3.1 Understanding the third sector

The third sector has alternatively been known as the voluntary, voluntary or community and not-for-profit sector. These different terms primarily relate to variation in the role and form of organisations in the sector in specific historical and cultural social contexts. The organisations considered in this study are located in a context in which the concept of the third sector is dominant (Alcock, 2010) and this term is accordingly used here.

Kendall and Knapp (1996) termed the voluntary sector 'a loose and baggy monster' because of its internal diversity and the indistinct nature of its external boundaries. Third sector organisations may take a variety of forms including community groups, mutual associations, social enterprises and charities. The third sector organisations taking part in this research were legally constituted as charities. The 2006 Charities Act made 'demonstrable public benefit' a requirement for all charities. The third sector generally has made claims to being distinctive in terms of pursuing particular values, for example, empowering people or pursuing equality. However, empirical research suggests that these distinctive features are contingent and variable (Macmillan, 2013b). Another claim has been that the sector offers innovation and distinctiveness in service provision. However, again empirical research suggests that practice varies (Osborne, Chew, & McLaughlin, 2008).

Another approach to understanding the third sector can be to consider its organisational features. Kendall and Knapp (1996) identified four distinctive features of voluntary organisations. They are voluntary, that is a substantial part of their resources of time, effort and funds are provided by the choice of members. (This first criteria, however, did not apply to those taking part in this research.) They are non-party political and non-sacramental, they do not seek election or provide the main infrastructure of a religious body. They have a formal organisation, that is the use of structures and rules beyond the scope of informal and self-help groups. They are also independent of government such that they determine their own policy and practice, although this may be influenced by government through the provision of funding and regulation of consequent services delivered.

These latter two characteristics relate understandings of the third sector to other types of institution: the state and civil society. Alcock (2010) notes that third sector organisations have commonly been defined in terms of their non-governmental nature and non-profit motive, in other words, as distinct from both the state and market. Evers (1995) develops a sophisticated conceptualisation of the position of the third sector by likening the location of the third sector to a 'tension field' in between the state, market and civil society. In this, inter-organisational relationships are often more precarious and contingent than stable and predictable. Third sector organisations can also exist along the boundaries of these distinctions. Young (2000) also highlights how the third sector can exist in different relationships to the state. He discusses three different positions: independent as supplements to government; as complements to government in a partnership relationship; and engaged in an adversarial relationship of mutual accountability with government. Salamon (1995) considers how the third sector and state work together in partnership and explains how the state can compensate for failure in the third sector potentially including: insufficiency (it is small scale and typically insufficient to meet need), particularism (it focuses on some groups rather than others), paternalism (it focuses on the interests of funders rather than social needs as a whole) and amateurism (a pervasive lack of professional skills).

2.3.2 Third sector carer organisations

The particular nature and role of the third sector in the UK is considered here specifically in reference to carers organisations up to the time of data collection (more recent developments are considered in chapter eight). As discussed previously, the third sector carer movement began from the grass roots in the sixties as a campaigning effort to highlight how the welfare state was not meeting the needs of a particular group. Third sector carer organisations in this manifestation were occupying an adversarial position with the state in Young's typology (2000).

In subsequent decades, the third sector carer movement also began to develop in other ways with the establishment of local Crossroads schemes from 1974 to provide respite services to carers and of local carer services to provide advice and support to carers within a national network, The Princess Royal Trust for Carers, from 1991. These organisations, set up as independent charities, were thus service providers. In Young's typology (2000), they can be seen to offer supplementary provision to the state on an independent basis.

New Labour placed a new emphasis upon partnership with the third sector (Lewis, 2005). Commitment to the third sector included infrastructure building and its involvement at all levels of government leading Kendall (2009) to talk of the 'mainstreaming' of the sector. This can be understood as the 'complementary' relationship to which Young (2000) refers. This change can be seen in the development of third sector carer services in this period. Much of the Carers Grant funding for local authorities to develop local support services for carers established through the 1999 National Carers Strategy (HM Government, 1999) was allocated to local third sector carer organisations (Fry, Price, & Yeandle, 2007, p. 40). These organisations were also heavily involved in delivering further service developments outlined in the revised 2008 National Carers Strategy (HM Government, 2008) including carer emergency planning schemes (Elwick & Becker, 2011, p. 7), new approaches to carer breaks, carer health checks and improved NHS support for carers (Yeandle & Wigfield, 2011a) and the Caring with Confidence training course (Yeandle & Wigfield, 2011b). In a piece of research which considered the provision of carer services in six local authorities, carer strategies were developed through local partnerships between local authorities and third sector organisations and services were then often provided by local third carer and condition specific organisations (Yeandle, Bennett, & Buckner, 2007). In this way, considerable funding has been provided to the third sector to expand service provision for carers thus counteracting a potential 'insufficiency' failure of third sector provision (Salamon, 1995).

A concern was raised by some local authority respondents in the Yeandle, Bennett and Buckner (2007) research that third sector carer organisations had become part of the local authority system and were less able to articulate the grass roots views of carers. The outsourcing of statutory carer assessment by some local authorities to third sector carer organisations has also raised this fear (Moriarty & Manthorpe, 2014). Here the third sector is acting in a

partnership relationship with the state but with the risk of being dominated. This risk could potentially be limited by a potential change of policy again under the Coalition government from 2010 (Macmillan, 2013a). The deficit reduction programme potentially limited funding for the third sector. In addition, the 'Big Society' concept, initially a key part of the Conservative agenda, instead argued for at least a partial 'decoupling' of the third sector from the state, instead viewing its role as important in developing a strong civil society (Macmillan, 2013a). In this way, the third sector is potentially becoming more of a supplementary independent provider again or even an adversary. Reflecting these trends, in 2014, the government set up a Carers Social Action Support Fund to be used for projects to support carers predominantly involving people working upon a voluntary basis.

2.4 Social work practice and carer empowerment

2.4.1 The purpose of social work

The next section considers the concept of casework drawing upon the theoretical literature on social work as proposed on page 8. There are many considerations of what social work broadly is and should be (Payne, 2005). It is argued by some that social work should be focused upon working with communities rather than individuals (as in a casework model) in order to challenge the social structures that disempower people (Koubel, 2013a). However, the predominant model currently operating in practice and investigated in this research involves working with individuals as a starting point. As explained later, this may constitute a starting point for generating wider social change. A number of key distinctions in the form and purpose of casework are elucidated in similar categorisations given by Dominelli (2009) and Payne (2005).

One approach, the therapeutic approach focuses upon problem solving and therapy with individuals to enable well-being and self-fulfilment. Counselling theories underlie such an approach. Change occurs within the individual as they develop ways of managing difficulties they face. However, analyses of the development of managerialism in social work practice (for example, Harris, 2003) have shown how social work has increasingly involved a greater focus upon gatekeeping and resource management at the expense of therapeutic work. Following the community care reforms of the NHS and Community Care Act 1990, then embedded in further reforms under New Labour, a key role in modernised social services became that of the 'care manager' focused upon assessing need, eligibility and risk and then allocating individualised support available from a range of care providers (Koubel, 2013b). Care managers did not necessarily require professional social work qualifications and had a more managerial, administrative role rather than being concerned with relationship based practice (Harlow, Barry, & Chandler, 2012).

A second approach to understanding the aims and practice of social work fits better with the current managerialist, modernised context. This categorisation has been labelled 'maintenance' by Dominelli based upon the work of Davies

(1994). Davies views the social worker's task as helping individuals within the existing social order which is considered to be benign. Similar approaches are discussed as 'individualist-reformist' (Payne, 2005) and 'administrative' (Lymbery, 2005). Lymbery (2005) talks about mobilising resources particularly through liaison and coordination to help people within the current social system.

A different, third approach, labelled as 'collectivist' or 'emancipatory' argues that social work should do more than this. This sees the task of social work as being about developing cooperation and mutual support within society so that those who are oppressed and disadvantaged can gain greater power over their lives. Such approaches seek to transform society and power relations at a structural level to achieve a more equal, just society. This is the view taken by those promoting anti-oppressive practice (Dominelli, 2009). Given the recent managerialist context of social work, this is not necessarily what would be expected from casework with carers. However, the recent development of the personalisation agenda is concerned with the empowerment of service users, albeit in an individualised rather than collective form. Even if an empowerment approach is not intended or may be constrained, thinking about casework in terms of carer empowerment offers a means of critically reflecting upon this work.

2.4.2 Empowerment through social work

Key theorists writing upon empowerment in social work (Adams, 2008; Smith, 2008) argue that a collective, transformational approach of power structures is required. It might be difficult to envisage how casework as an individually based practice can achieve this. However, these theorists also recognise that empowerment can involve working at different levels including the individual, social or community group and society as a whole. They argue that a 'self-help' approach where individuals are empowered to help themselves cannot be wholly effective in the context of wider disempowering social structures but individual work can be a starting point for wider empowerment. This also accords with the critical realist understanding that individual actors have power but this is constrained by social structures. The following discussion first considers the implications of an empowerment approach for the form of casework undertaken and then proceeds to consider what the intended outcomes of this might be.

The empowerment statement by Lee (2001) has been drawn upon particularly because this offers a detailed, holistic model of empowerment work with individuals. This is centred upon empowerment work with ethnic minority groups. Shera and Wells note in relation to empowerment that: *"While the overall strategies and techniques are similar, the priorities, context, the particular strengths and challenges faced by each population and their unique history of stigma, discrimination and oppression require particular knowledge and skills."* (1999, p. 468). As yet, there is no clear theoretical framework for conceptualising carer empowerment (Larkin & Milne, 2013). How some of

Lee's ideas might be interpreted specifically in relation to carers is considered in the next section.

Lee's work is based upon an idea of empowerment defined by Solomon: *"a process whereby the social worker engages in a set of activities with the client ... that aim to reduce the powerlessness that has been created by negative valuations based on membership in a stigmatized group. It involves identification of the power blocks that contribute to the problem as well as the development and implementation of specific strategies aimed at either the reduction of the effects from indirect power blocks or the reduction of the operation of direct power blocks."* (2001, p. 33). Lee notes that: *"empowerment resides in the person, not the helper"* (2001, p. 33). This notion is found more widely in empowerment movements, for example, the disability rights movement (Oliver, 2004). In an empowerment model the practitioner should act in a partner role rather than as an expert. *"People empower themselves: social workers should assist."* (Lee, 2001, p. 60).

From this, it follows that interactions should be a dialogue and an exchange. Social workers should encourage the client to express themselves and their perspective. Yet, they can also help clients to recognise internalised oppression and to reject feelings of victimhood. Lee talks about helping clients to take up their rights and responsibilities in the process of empowerment rather than the social worker always undertaking work for the client.

For Lee and others as noted above, group work is also a key part of empowerment practice. This is not just about sharing experiences and catharsis, but also about critical consciousness raising through dialogue between group members. Lee, drawing upon Freire's work, argues that consciousness raising and critical education take place most effectively within groups. This then creates the energy and resources to enable collective action to challenge oppressive structures at the political level.

In terms of what empowerment is seeking to achieve, Lee identifies three interlocking dimensions of empowerment: *"1) the development of a more positive and potent sense of self; 2) the construction of knowledge and capacity for more critical comprehension of the web of social and political realities of one's environment, and 3) the cultivation of resources and strategies, or more functional competence, for attainment of personal and collective goals."* (2001, p. 34). The next section considers how these might be understood particularly in relation to carers.

2.4.3 Carer empowerment

Lee's first element of empowerment, developing a more positive and potent sense of self, poses some challenges in relation to carers because of the challenges surrounding carer identity. As noted on page 26, many carers do not identify themselves as carers. The establishment of the term 'carer' has been shown to be a means to improve the position and power of carers. O'Connor (2007) identified three benefits which could be seen as empowering

through identification with a carer identity. The first was the development of a sense of connection and mutual understanding with other carers. The second was increased access and use of services because this led to awareness that these were available and that it could be acceptable to use other forms of help. The third benefit was carers' recognition of their contribution as a carer and of the skills they had developed within their role.

However, a carer identity is not fixed but socially constructed and thus the particular form this takes is important. As noted in relation to policy, carers can be constructed as 'resources, co-workers, co-clients or superseded'. All of these would have different implications to the power carers have in relation to their role and resources to support this. It has been noted that carers can take different perspectives on their role from being 'engulfed' to having a 'balanced/boundary setting' approach (Twigg & Atkin, 1994). This can influence carers' perspectives on the acceptability of taking help and the importance of maintaining other aspects of their lives and identities, for example, in relation to paid employment, leisure and other relationships. Changes in carer identity can be understood as mechanisms of reasoning or carer choices in the realist evaluation framework.

It has been identified (page 15) that the political focus upon carers may be disempowering to those who need care. Similarly, at an individual level, the development of a carer identity can be problematic in terms of its impact upon the relationship between the carer and person they care for. O'Connor (2007) reported that the development of a carer identity could depersonalize or objectify the person receiving care. It could also lead to the carer taking greater control potentially disempowering the relative receiving care.

Lee notes that a principle of empowerment practice is recognising all different forms of oppression (2001, p. 60). Casework could also be about responding to disadvantage that a carer experiences together with the person they care for as a family unit where they are not receiving adequate support resources and/or about helping counter disability or age based discrimination faced by the person receiving care. A key outcome in this would then be carers' and their families' power in their interactions with service providers. Lee's second element of empowerment 'the construction of knowledge and capacity for more critical comprehension of the web of social and political realities of one's environment' would involve understanding discrimination against carers but also how this may be connected to disability and age related discrimination.

Lee's third element of empowerment was 'the cultivation of resources and strategies, or more functional competence, for attainment of personal and collective goals'. As well as external resources, carers' own expertise is likely to be important here. Established carers are likely to have this already through their longstanding ties with and experiential knowledge of the person they care for (Allen, 2000). The increasingly prominent notion of 'expert carers' can have different meanings. There is a danger that this can be interpreted in a narrow sense to focus upon training carers to perform technical duties (Sadler & McKevitt, 2013). A broader definition would also recognise the potential to help some carers with coping skills as well as their understanding of a medical

condition (Nolan et al., 1996). This expertise and other resources and strategies can be understood as mechanisms of capacities in the realist evaluation framework.

In terms of personal and collective goals, Larkin and Milne (2013) outline some key outcomes which carer empowerment could be expected to involve including: less stigmatisation and discrimination; rights to work, education, leisure and a decent income; greater choice and control over the nature of the support services they, and the person they care for, receive; greater access to services; choice over the caring role and recognition of carer knowledge. Better physical and mental health for carers is also critical as the earlier review here of the impacts of caring notes.

Individual carers' goals will differ but these can be considered in terms of Sen's capability approach to human development (1999). The basic concepts of this approach are not context specific and so they can be applied to other contexts concerned with human well-being such as carer empowerment. Sen argues that social welfare should be assessed in terms of people's 'functionings', "*the various things a person may value doing or being*" (1999, p. 75). Sen does not identify one set of basic functionings because these will depend upon the context and what is valued by those concerned. In relation to carers, functionings could include some more widely applicable to other populations, for example, participating in leisure activities and others perhaps more specific to the context of caring, for example, being able to provide skilled care. The functionings achieved by people in any given context are not a sufficient understanding of social welfare, the concept of freedom is also critical and is encapsulated in Sen's concept of 'capabilities'. A capability is a person's freedom to achieve valued functionings and these must be real, not just held theoretically or legally. This is not about valuing choice for itself but in terms of what it can achieve. The capability approach offers a way of considering carer's attainment of goals. It may also be necessary to think about this in relation to the person receiving care and/or together with the carer. This is where the concept of freedom or autonomy may need to be thought about as relational (see page 19).

In terms of the process of empowerment, the importance of group work could be harnessed through casework with carers where it connects carers to carer support groups and other collectives that might fulfil this purpose. However, there are some specific characteristics of carers that might make this difficult. The transient nature of membership of this group in that people move in and out of the role (Carers UK, 2014b) presents one challenge. In addition, the relational aspect of being a carer, in that it fundamentally involves another person, also raises questions about how it can be ensured that the perspectives of those receiving care are not overshadowed.

2.5 Implications for the research

The findings of this conceptual review have implications for the design, conduct and interpretation of findings of this research study. Some key points are noted here.

The relationship between the carer and the person they care for is critical. The research does not need to focus equally on both the carer and the person receiving care, but it must recognise and consider the implications of the caring relationship. Great complexity and diversity characterises carer experiences. This suggests that realist evaluation which places the contingent nature of outcomes and the importance of context at its heart offers an appropriate framework for the research. The diversity of carer experience was also important in decisions about sampling. The analysis will need to explore any indicators of the influence of important distinguishing carer characteristics such as gender, ethnicity, age, kin relationship, medical condition and stage of caring.

The conceptual review provides theoretical frameworks which will be useful to interpreting the findings of the research. The ethic of care and Kittay's concept of doulia focus attention upon considering this research in terms of how society meets its responsibilities to unpaid carers. The ethic of care framework can also be used at a micro-level to consider how individual practitioners and services care for carers and potentially their families. A framework for considering carer empowerment has also been identified. It may also be useful to consider the findings concerning third sector organisations in light of the different positioning these can have in relation to the state. Another key consideration is the nature of casework itself and how this affects the achievement of outcomes for carers and carer empowerment.

Overall, this chapter draws a complex picture of often conflicting forces and developments in the context of the UK in recent years surrounding the provision of unpaid care. Growing awareness and recognition of carers may be countered by the limited availability of resources to support carers and cultural expectations that people, particularly women, should provide unpaid care. The focus on individual carers and personalised service provision is in tension with the social relationships of and interdependence underlying care. Calls for therapeutic work and empowerment in social work practice sit uneasily in the reality of the managerialist context. The third sector potentially addresses needs unmet by the state but may be insufficient without financial support. The findings of the research will be interpreted in light of these tensions.

Chapter Three: A Systematic Review of the Evidence upon Carer Information Services, Carer Support Workers and Statutory Carer Assessment

The previous chapter examined the nature of the key concepts underlying this study to establish a theoretical foundation for it. This chapter now moves on to consider what is already known empirically about the research question in terms of whether and how casework supports carers. This is achieved through a systematic review of the empirical literature concerned with interventions for carers offering forms of casework. Section 3.1 details the review methodology and section 3.2 provides the findings of the systematic review.

3.1 Review methodology

3.1.1 Scope of the review

The following thesis adds to and builds upon existing knowledge about the outcomes and processes of casework with carers in the form of carer information services, carer support workers and statutory carer assessment. This chapter presents a systematic review of the existing evidence on these interventions. This was conducted to address the following questions:

- What is known about the outcomes of these interventions?
- What explanatory evidence exists about how these interventions support carers and the contextual factors which influence outcomes?

A systematic review, a specific method of identifying and synthesising existing research evidence originating in the medical field (Petticrew & Roberts, 2006), was undertaken rather than a traditional literature review. This was because the following specific features of a systematic review allow greater validity and reliability to be attributed to the synthesised findings. As far as possible, a systematic review is comprehensive in its coverage of the literature; pays careful attention to the quality of included evidence; takes a clear, systematic approach to the synthesis of the data; and generally follows transparent and rigorous processes.

Different methods of systematic reviewing in the social sciences have been developed (Victor, 2008). The traditional method of systematic review originating in medical science focuses upon assessing the impact of particular interventions and organises evidence in a hierarchy in which randomised controlled trials, followed by quasi-experimental designs, are prioritised because they provide the most reliable statistical estimates of the effect of an intervention. The findings of such reviews in the social sciences may be limited because of the difficulty of conducting randomised controlled trials for practical and ethical reasons. Furthermore these can only be used to answer the specific 'what works' form of review question. A second set of review methods extend the original methodology to widen its use and applicability within the

social science (for example, EPPI-Centre, 2007). A wider range of types of evidence can be included whilst their limitations are recognised. They are also likely to cover other types of question including those relating to understanding intervention effects, 'why' something works.

The questions of the systematic review addressed here required an extended approach to the traditional systematic review methodology that included explanatory evidence about how and why interventions work and under what circumstances, as well as considering their outcomes. Given that outcomes are contingent upon many factors and differ amongst carers, explanatory evidence about the context and processes which influence the success or otherwise of interventions is important.

Studies were included in the review if they had a substantial, distinct focus upon either:

- the outcomes of a relevant intervention for carers; or
- explanatory evidence which considers how interventions support carers or the contextual factors which influence the achievement of intervention outcomes for carers.

Studies using any outcome measure that could be considered to relate to the carer's well-being or ability to care were included. The review only included studies based upon empirical research. All types of empirical study designs were included if the work met the other criteria set out here.

This thesis is focused upon casework with carers defined as 'the individualised support work undertaken by a practitioner with a newly identified carer' and occurring in practice as detailed from page 109. Studies of interventions of the following kinds provided relevant evidence about this type of work: information services; support workers; and statutory carer assessments. Existing studies into interventions offering this type of support often did not specify whether or not carers were new to the service. This needs to be borne in mind in comparing the findings reported here and those identified in the data collected for this thesis. The review only includes studies focused upon specific interventions developed for carers. Interventions which were jointly targeted at the person receiving care and the carer (for example, stroke family support workers) could be included if they met all the other criteria for inclusion and separate findings for carers were reported. The review excludes studies of interventions targeted primarily at the person receiving care. Studies were only included if they were conducted within the context of the UK since 1990.

Studies were included if they were concerned with services for adult carers defined as: people over the age of 18 who care for family members, friends or neighbours on an unpaid basis. The carer could be caring for someone with any type of health condition, for example, mental health difficulty, terminal illness and so on and could have varying kinds of relationship to them, for example, parent, child or spouse.

3.1.2 Search strategy

A comprehensive search strategy was used. Relevant evidence could take a number of forms as indicated in the left hand column of Table 3.1. Sources (mainly bibliographic databases) for each type of data were therefore searched as listed in the right hand column. Searches were updated and completed between March and September 2013.

Table 3.1: Data sources for search strategy

<i>Type of data</i>	<i>Source(s) searched to identify evidence of this type / in this field</i>
Systematic reviews and randomised controlled trials	• Cochrane Database of Systematic Reviews • CRD register – DARE, HTA and NHS EED • C2-SPECTR (Campbell Collaboration) • CCTR (Cochrane Clinical Trials Register)
Evidence from the medical / health care field	• Medline • British Nursing Index • HMIC
Academic social science research	• Applied Social Sciences Index and Abstracts • International Bibliography of the Social Sciences • Social Services Abstracts • Sociological Abstracts
Grey literature	• Social Policy & Practice (combines Social Care Online, AgeInfo, ChildData, Planex and Ubadoc) • Carer organisations (via the websites of Carers Trust, Carers UK and all local carer centres via e-discussion list and local authority carer leads via e-discussion list) • Government department websites
Material that is poorly indexed on databases	• Citation tracking and above grey literature searches

3.1.3 Quality appraisal

The different types of data included in this systematic review (outcome measurement and explanatory) required two different approaches to quality appraisal. Those used are outlined below. Where a single study included both outcome measurement and explanatory evidence, both types of quality appraisal were undertaken. Reasons are given below for the approaches used here. However, it is recognised that the most appropriate approach to quality appraisal of social research is still a matter of debate. Thus, the appraisals given here should be considered as a guide on quality assessment rather than offering definitive conclusions. The details of the scores for individual aspects of quality for each included study are given in Table 3.2 (from page 47).

- *Quality appraisal of outcome measurement*

The number of high quality randomised controlled trials of interventions identified for this review was expected to be limited. It was therefore decided to include a wide range of study designs whilst recognising the potential bias of estimates of effect from some of these. A systematic review of methods for considering bias in non-randomised intervention studies identified six quality appraisal tools which could potentially be used in systematic reviews (Deeks et al., 2003). These were selected from a much larger collection of tools because they met certain important criteria concerning internal validity. One of these six tools (Thomas, n.d.) has been selected for use here because it: covers a range of study designs; considers key quality criteria; is relatively user-friendly and provides clear guidance about how to assess each criterion; and offers a summary conclusion about the strength of the evidence.

This tool considers quality in eight respects:

- A. *Selection bias*: whether the participants selected to participate were likely to be representative of the target population.
- B. *Study design*: randomised controlled trials and controlled clinical trials are considered strong; cohort analytic, case control, cohort and interrupted time series studies are considered moderate; and all other designs are considered weak.
- C. *Confounders*: whether there were important differences between the groups compared and if so, whether these were controlled for.
- D. *Blinding*: whether outcome assessors and study participants were aware of participant allocation to the intervention or control group when they were measuring outcomes.
- E. *Data collection methods*: whether these have been shown to be valid and reliable.
- F. *Withdrawals and drop-outs*: whether participant withdrawals from the study were reported and their level.
- G. *Intervention integrity*: how many participants actually received the intervention; consideration of the consistency of the intervention; and the possibility that participants received other unintended interventions.
- H. *Analyses*: whether the units and methods of analysis were appropriate and whether analysis was conducted on an intention to treat basis.

The tool provides guidance for scoring each study as strong, moderate or weak in each of these categories. An overall score is then arrived at through summing the individual scores for categories A to F. (The ratings for G and H are given separately and are not included in the overall score.) Cross-sectional surveys and qualitative studies containing outcome evidence were automatically given an overall rating of weak for outcome measurement.

- *Quality appraisal of explanatory evidence*

Explanatory evidence about how interventions produced outcomes and the relevant contextual factors which influenced outcomes required a very different

kind of quality appraisal tool. Most of these studies were qualitative, although some quantitative research also included relevant data. There is no definitive agreed framework for assessing the quality of qualitative research but a number of different models have been proposed. The approach and tool used here (Harden et al., 2001, pp. 62-63) was based upon the common themes identified through a review of a range of approaches to quality appraisal of qualitative evidence.

The tool assesses quality on the basis of the inclusion of the following seven items.

1. An explicit account of the theoretical framework used and/or inclusion of a literature review.
2. Clearly stated aims and objectives.
3. A clear description of the context in which the research was undertaken.
4. A clear description of the sample.
5. A clear description of the methodology including data collection and analysis methods.
6. Evidence of attempts made to establish the reliability and validity of data analysis.
7. Sufficient original data to mediate between data and interpretation.

A yes/no answer was allocated for each question. An overall score was also given to each study: a strong rating was given for studies which included six or more of the above items; a moderate rating was given for studies which included five; and a weak rating was given to those which included less than five.

3.1.4 Data extraction and synthesis

Data from included studies was extracted to cover the following: study aims; intervention type; sample; research methods; and findings. Mixed methods of synthesis were used. Summaries of the evidence on the outcomes of interventions is presented in a narrative form in the body of the report (Popay et al., 2006). Statistical meta-analysis has not been used because the diversity of the interventions considered would have rendered this problematic. Explanatory evidence has been synthesised thematically (Pope, Mays, & Popay, 2007, pp. 96-97). The synthesis has been undertaken within the realist framework for understanding intervention outcomes (Pawson & Tilley, 1997). This framework is detailed further in the next chapter (from page 78). Using this framework each section of the review findings is divided into evidence on outcomes, the mechanisms explaining outcomes and contextual factors influencing the achievement of outcomes.

3.2 Review findings

The findings of the systematic review are now presented beginning with a consideration of the nature of the evidence identified (section 3.2.1). This is

followed by the findings on the outcomes of interventions for carers (3.2.2), the explanatory evidence on the mechanisms generating outcomes for carers (3.2.3) and the explanatory evidence on the contextual factors influencing the achievement of outcomes (3.2.4).

3.2.1 The nature of the evidence identified

Summary background information on each of the studies included in the systematic review is given in Table 3.2 at the end of this section. Numbered study references are given on page 74.

- *Studies of information services*

Both support worker interventions and carer statutory assessment include the provision of information but four studies considered interventions which were primarily centred upon informing carers about support [1-4]. The interventions evaluated were quite diverse as described in Table 3.2. The evidence measuring outcomes in these studies of information services is weak in quality as it is based upon small sample sizes and/or retrospective measurement. There is some limited explanatory evidence about the mechanisms and contexts which explain and influence outcomes. This was rated as weak in two studies [1,4] and strong in one study [3].

- *Studies of support workers*

Twenty studies of support workers were identified. These support worker services were primarily located within health services and third sector condition specialist organisations. Accordingly the interventions evaluated principally focused upon carers of people with particular conditions: stroke (seven studies) [5-11]; mental health (three studies) [12-14]; dementia and older people with mental health difficulties (four studies) [15-18]; cancer (three studies) [19-21]; and severe disabilities (one study) [22]. The majority of the interventions considered in these studies worked with a mix of carers in terms of their relationship to the person receiving care. There were two exceptions: one study focused upon parent carers of disabled children [22] and another upon spouse carers [17]. Two studies [23,24] focused upon support workers based in GP surgeries who worked with all types of carers.

Nearly all of the outcome evidence reported by these studies was rated as weak on the quality appraisal tool used with the exception of three studies. One study of a stroke family worker service was rated high in quality for outcome measurement [10]. Another stroke specialist study [5] and the study of a service for carers of people receiving palliative care for advanced cancer [21] were rated moderate in quality for outcome measurement. The low quality of outcome measurement evidence is unsurprising given the stringent requirements for higher ratings which can be difficult to meet on practical and ethical grounds in social research.

Just over half (twelve) of the studies of support workers used longitudinal designs which allowed change in outcomes over time to be assessed. Two thirds of these (eight) also included a control group permitting more rigorous comparisons to be made. The other studies used a cross-sectional or qualitative research design to identify outcomes. The use of qualitative assessment of outcomes (included in nine studies of support workers) should also not be dismissed lightly. These can say little about the extent to which outcomes might be achieved across a population. However, the spontaneous qualitative feedback from carers has a particular validity in terms of capturing the nature of the outcomes experienced.

Just over half (eleven) of the studies of support workers included explanatory evidence. The quality of this was mixed: five were allocated a strong rating [8,15,19,20,22]; five were rated as moderate [6,12,13,21,23]; and one received a weak rating [14].

- *Studies of statutory carer assessment*

Thirteen studies of statutory carer assessment were identified [25-38]. The majority (nine) of these studies considered carer assessment conducted with a wide range of types of carers in terms of the condition of the person they cared for. One specifically looked at carer assessment with carers of people with learning disabilities [34,35] and one with carers of older people with mental health difficulties [33]. One study included data from practitioners working with a range of types of carers but only included data from carers of older people with dementia [36]. All studies considered assessments conducted with a mix of carers in terms of their relationship to the person receiving care.

One small scale study considered assessment where this was carried out by a third sector carers organisation on behalf of the local authority [32]. The same statutory guidelines about the purpose and form of carer assessments apply whoever conducts them. However, there may be some variation in the interpretation of and compliance with guidelines by organisation and by individual practitioner. This was particularly apparent in one study of assessment where an explicitly outcomes-focused approach was taken [31]. Change could also be expected over time as legislation and guidance has developed in relation to carer assessment. However, it has not been possible to assess any change related to this satisfactorily because study designs differ and generally involve small samples.

The studies of carer assessment identified consist of cross-sectional surveys and qualitative studies. The evidence in terms of identifying outcomes is accordingly weak given the small samples used and/or reliance upon retrospective assessment of change. However, as noted previously, qualitative assessment of outcomes has a particular validity in capturing the type of outcomes achieved. The majority of these studies (ten) offer high quality explanatory evidence with the exceptions of one study rated as moderate [28] and one as weak [30]. This evidence is rich in terms of suggesting contextual

factors which may influence the outcomes of assessment and in providing insight into the mechanisms of change operating through assessment.

Table 3.2: Details of the systematic review studies

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
<i>Information services</i>					
1. Carers UK help-line set up for a nationwide carer awareness day in 2005.	Cross-sectional survey and some follow up telephone interviews.	n=265 carers (survey).	Post-intervention knowledge of and applications for various benefits and carer assessment.	Weak.	Weak. 1:y;2:y;3:n;4:n; 5:n;6:n;7:n.
2. One day social services training workshop for carers providing information on opportunities for involvement and services available.	Uncontrolled longitudinal outcome measurement.	n=18 carers.	Psychological empowerment: perceived control at individual, organisational and community level (scales used); self-efficacy (unstandardised, carer specific scale used); self-esteem (Rosenberg's 1965 instrument) and self-perceived knowledge of involvement methods, services and rights. Measures at 2 weeks prior to the intervention and on completion.	Weak. A:w;B:m;C:w;D:w; E:w;F:s;G:s;H:s.	
3. A carer information pack about services for carers, benefits and advocacy provided to carers identified via a GP surgery.	Cross-sectional survey.	n=12 carers.	Satisfaction.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
4. An information mailing service and phone and advocacy service provided by a local third sector carer centre.	Cross-sectional survey.	n=63 carers.	Satisfaction, knowledge, use of services and feelings.	Weak.	Weak. 1:n;2:y;3:y;4:y; 5:n;6:n;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
<i>Stroke specialist support workers</i>					
5. A stroke family care worker.	RCT.	n=246 carers of people who had had a stroke in the last 30 days.	Social activities (Frenchay activities index); emotional health (GHQ and HADS); social adjustment scale; caregiving hassles scale; and carer satisfaction questionnaire. Follow-up measures at 6 months.	Moderate. A:s;B:s;C:w;D:s; E:s F:s;G:s;H:s.	
6. Specialist nurse stroke support worker. Considers the same intervention as study 7.	Qualitative interviews.	n=15 carers of people who had had a stroke and been discharged from hospital 13-15 months previously.	Retrospective qualitative feedback on use of services and satisfaction.	Weak.	Moderate. 1:y;2:y;3:y;4:n; 5:y;6:n;7:y.
7. See study 6.	RCT.	Carers of people who had had a stroke. (n=240 patients, carer sample size not given.)	Emotional well-being (GHQ-28). Follow up measures at 3, 6 and 12 months.	Weak. A:m;B:s;C:w;D:m; E:s;F:w;G:m;H:s.	
8. Stroke Association stroke family organiser. Considers the same intervention as study 9.	Qualitative interviews.	n=14 carers of people who had had a stroke 9-24 months previously.	Retrospective qualitative feedback on the services received in the previous 9 months.	Weak.	Strong. 1:y;2:y;3:y;4:n; 5:y;6:y;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
9. See study 8.	RCT.	n=159 carers of people who had a stroke within last 4 weeks at recruitment.	Emotional health (GHQ-12); strain (Caregiver Strain Index); tailored questionnaires covering knowledge of condition and services and satisfaction with information and services. Follow up measures at 4 and 9 months.	Weak. A:m;B:s;C:w;D:w; E:w;F:w;G:m;H:m.	
10. Stroke Association family support worker.	RCT.	n=267 carers of people who had had a stroke in previous 6 weeks.	Knowledge about stroke and use of services (tailored questionnaire); social activities (Frenchay Activities index); emotional health (HADS, GHQ-28 and the Caregiver Strain Index); quality of life (Dartmouth co-op charts and SF-36); satisfaction with services (existing questionnaires). Follow-up measures at 6 months.	Strong. A:s B:s;C:s;D:s; E:s;F:s;G:s;H:s.	
11. Stroke Association family support organiser.	RCT.	Carers of stroke patients. (n=340 patients, carer sample size not given.)	Caregiver Strain Index; emotional health (HADS); also questions about social life and life after stroke; and satisfaction with stroke care (the carer version of the Pound Satisfaction Scale). Follow-up measures at 3 months and 1 year.	Weak. A:m;B:s;C:w;D:m; E:s;F:w;G:m;H:m.	

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
<i>Mental health specialist carer support workers</i>					
12. Carer support workers based in the community mental health team. Referrals from carer assessment.	Qualitative interviews.	n=11 carers of people with mental health difficulties.	Retrospective qualitative feedback covering emotional health and social inclusion.	Weak.	Moderate. 1:y;2:y;3:n;4:y; 5:y;6:n;7:y.
13. A nurse led family and carer service on three adult acute psychiatric wards.	Cross-sectional survey plus qualitative interviews.	n=25 (for qualitative feedback) carers of people on acute psychiatric inpatient wards. n=8 professionals: 3 ward managers, 3 family nurses; 2 consultant psychiatrists.	Carers' retrospective qualitative feedback in form of written questionnaire.	Weak.	Moderate. 1:y;2:n;3:y;4:n; 5:y;6:y;7:y.
14. Third sector carer-focused family mental health support workers.	Non-randomised controlled design plus qualitative interviews.	n=62 carers of people with long-term mental health problems, mainly schizophrenia. Comparison of those who were new cases (n=25) and those who had been supported for at least 6 months (n=37).	Quality of life (Lancashire Quality of Life profile); burden (objective burden scale from the Social and Behavioural Assessment Schedule); and satisfaction.	Weak. A:m;B:m;C:w;D:m; E:m;F:w;G:w;H:m.	Weak. 1:y;2:y;3:y;4:y; 5:n;6:n;7:n.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
<i>Support workers for carers of older people with dementia or psychiatric problems</i>					
15. Dementia Adviser (worked with the carer and the person with dementia).	Non-randomised controlled design plus qualitative interviews.	Number of carers and people with dementia completing ASCOT outcome measurement not given separately. n=62 carers (qualitative interviews).	Well-being (ASCOT needs); health related quality of life for people with dementia (DEMqOL); and qualitative feedback.	Weak. A:w;B:m;C:w;D:w; E:s;F:w;G:w;H:m.	Strong. 1:y;2:y;3:y;4:n; 5:y;6:y;7:y.
16. A pilot of the Admiral Nurse Service for carers of people with dementia.	Uncontrolled longitudinal outcome measurement.	n=20 carers of people with dementia.	Carer needs assessment. Follow-up measures 3 months later.	Weak. A:w;B:m;C:w;D:w; E:w;F:w;G:w;H:w.	
17. Mental health key worker intervention for the couple (carer and their spouse with a psychiatric illness).	RCT.	n=44 spouse carers of older people: 29 with dementia, 12 with depression, 2 with anxiety and 1 with schizophrenia.	Psychological morbidity (GHQ-28, Geriatric Mental State for those over the age of 65 or the Clinical Interview Schedule plus additional questions for those under the age of 65); and severity of difficulties in housing, finance, marriage and social life (shortened Social Problems Questionnaire). Measures at baseline, 12-14 weeks later (the control group were then offered the intervention) and then final assessment another 12-14 weeks later.	Weak. A:w;B:s;C:w;D:m; E:s;F:s;G:w;H:m.	

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
18. Admiral Nurse Service for carers of people with dementia.	Controlled longitudinal outcome measurement.	n=128 carers of people with dementia.	Emotional well-being (GHQ). Follow-up measures 8 months later.	Weak. A:m;B:m;C:s;D:m; E:s;F:s;G:w;H:m.	
<i>Cancer specialist carer support workers</i>					
19. Individualised carer support programme delivered by a hospital support nurse for 12 weeks initially.	Uncontrolled longitudinal outcome measurement plus qualitative interviews.	n=25 carers of people recently diagnosed with lung cancer.	Emotional well-being (GHQ-12); quality of life (Quality of Life Family Version Instrument); and meeting of needs (Family Inventory of Needs). Follow-up measures at 12 weeks.	Weak. A:w;B:m;C:w;D:w; E:s;F:s;G:m;H:m.	Strong. 1:y;2:y;3:y;4:n; 5:y;6:y;7:y.
20. Third sector lung cancer carer support workers.	Qualitative interviews.	n=20 carers of people with new diagnosis of lung cancer. Details of professional sample not given.	Retrospective qualitative feedback.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:y;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
21. Six week palliative cancer care carer support worker service.	Randomised controlled trial plus qualitative interviews.	n=271 carers of people receiving palliative care for advanced cancer of various types.	Emotional well-being (above threshold GHQ-28 and GHQ score, Carer Strain Index, and where bereaved, Core Bereavement Items); quality of life (CareGiver Quality of Life Index); and satisfaction where bereaved (satisfaction with care 4 months after death). Follow-up measures at 4 weeks, 9 weeks and 12 weeks.	Moderate. A:m;B:s;C:w;D:m; E:s;F:s;G:m;H:m.	Moderate. 1:y;2:y;3:y;4:n; 5:y;6:n;7:y.
<i>Specialist ethnic minority carer support workers</i>					
22. Third sector advocacy service for Pakistani and Bangladeshi families with children with severe disabilities.	Longitudinal qualitative interviews with carers and qualitative interviews with practitioners.	n=19 families with children with severe disabilities. n=5 advocates.	Retrospective qualitative feedback including coverage of service access and uptake, empowerment and emotional support. Follow up interviews 10 weeks later; at 9 months; and at 11 months.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
<i>Carer support workers based in GP surgeries</i>					
23. Comparison of a pilot GP surgery employing a carer support worker with two control GP surgeries with no carers' register or specialist provision for carers.	Mixed methods comparative study including qualitative interviews with carers and practitioners, carer survey and documentary analysis.	n=47 carers (30 in the pilot surgery and 17 in a control surgery). n= all 10 staff from pilot surgery; all GPs from control surgeries.	Retrospective carer self-report of services received and satisfaction.	Weak.	Moderate. 1:y;2:y;3:y;4:n; 5:y;6:n;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
24. Carer support workers based in GP practices.	Uncontrolled longitudinal plus cross-sectional survey.	n=68 carers (GHQ measures). n=191 carers (satisfaction survey).	Psychological well-being (GHQ-12). Assessed an average of 9 months apart. Satisfaction (by cross-sectional survey).	Weak. A:m;B:m;C:w;D:w; E:s;F:w;G:m;H:s.	
<i>Statutory carer assessment</i>					
25. Statutory carer assessment.	Longitudinal qualitative interviews with carers and single qualitative interviews with staff.	n=51 carers. n=20 staff (4 senior managers and 16 practitioners involved in carer assessment).	Qualitative feedback from carers. Follow-up measures at 6 months.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
26. Statutory carer assessment.	Documentary analysis plus qualitative interviews.	n=10 carers. n=13 assessors.	Retrospective qualitative feedback from practitioners and carers.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
27. Statutory carer assessment.	Documentary analysis plus qualitative interviews.	n=11 carers. n=16 staff (mix of social services staff who carried out carer assessments).	Retrospective qualitative feedback from practitioners and carers.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
28. Statutory carer assessment.	Cross-sectional postal survey.	n=1,276 carers.	Retrospective satisfaction and service receipt.	Weak.	Moderate. 1:n;2:y;3:y;4:y; 5:y;6:n;7:y.
29. Statutory carer assessment.	Cross-sectional postal and telephone surveys.	n=1,655 carers (postal survey). n=98 carers (telephone survey).	Retrospective services offered and used and satisfaction.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
30. Statutory carer assessment.	Cross-sectional survey plus qualitative interviews.	n=1,695 carers.	Change in number of community care services accessed (with comparison to expressed need for support). Retrospective carer views of outcomes.	Weak.	Weak. 1:n;2:y;3:y;4:y; 5:n;6:n;7:y.
31. Statutory carer assessment using newly developed outcomes focused tools accompanied by staff training in this approach.	Documentary analysis plus qualitative interviews.	n=12 carers. n=37 assessments reviewed. n=14 practitioners: 5 home care organisers and 9 social workers/care managers conducting assessments.	Retrospective qualitative feedback from assessors and carers (within a year of assessment).	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:n;6:y;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
32. Statutory carer assessment conducted by a voluntary carers organisation in a rural area.	Qualitative interviews.	n=9 carers.	Retrospective qualitative feedback on needs met.	Weak.	Strong. 1:y;2:y;3:y;4:n; 5:y;6:y;7:y.
33. Statutory carer assessment. (The study compares areas where carer assessments were said to be available (68.6% of areas) and those where they were not said to be available despite the fact that there was a legal duty to provide these in all areas of England at this time.)	Cross-sectional postal survey.	n=5,391 carers of older people with mental health problems.	Carers' self report of: whether they were asked if they needed any help; informed about various aspects of support; given a contact; and whether they were receiving the help needed to have a break.	Weak.	
34 & 35. Statutory carer assessment.	Longitudinal qualitative interviews.	n=20 carers of people with learning disabilities.	Qualitative feedback after assessment and approximately 1 year later.	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.
36. Statutory carer assessment.	Qualitative interviews.	n=64 carers, all spouses or adult children of older people with dementia. n=32 care managers.	Retrospective qualitative feedback (relating to an assessment conducted within the previous six months).	Weak.	Strong. 1:y;2:y;3:y;4:y; 5:y;6:n;7:y.

<i>Study number and intervention evaluated</i>	<i>Research design</i>	<i>Sample size (at baseline)</i>	<i>Outcome measures and timing of these (where given)</i>	<i>Quality appraisal for outcome measurement</i>	<i>Quality appraisal for explanatory evidence</i>
37. Statutory carer assessment.	Secondary analysis of 9 previous studies including data from surveys, qualitative interviews, focus groups and documentary analysis.	n=2,000+ carers across the 9 studies. n=376 professionals across the 9 studies at strategic and operational level, in different types of organisation.	Retrospective qualitative feedback.	Weak. A:s;B:w;C:s;D:m; E:m;F:w;G:s;H:m.	Strong. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:n.
38. Statutory carer assessment.	Qualitative interviews.	n=6 carers.	Retrospective qualitative feedback on access to work, leisure and education (assessment had taken place within the previous six months).	Weak.	Strong. 1:n;2:y;3:y;4:y; 5:y;6:y;7:y.

3.2.2 Outcome findings

Findings on the outcomes reported to be achieved by the interventions evaluated in the existing literature are presented below by outcome type. The quality rating of the evidence referred to for outcome measurement was weak (the majority of studies) except where other quality ratings are specified.

- *Knowledge of and empowerment to liaise with services*

The weak outcome evidence of four studies of information services [1-4] based upon small samples suggested that these could make carers aware of:

- assistance available if needed in the future [1,3];
- services [2,4];
- opportunities for involvement with service providers [2];
- their rights [4];
- who to contact in a medical emergency and in a care crisis [4]; and
- carer assessment [4].

One study found that the information service did not make carers feel any more empowered in their contact with service providers [2].

There was mixed, conflicting evidence from two stroke support worker studies [9,11] about whether carers' satisfaction with knowledge of and actual knowledge of different types of services and support increased. One stroke study of moderate quality [5] found higher satisfaction in the intervention group compared to the control group in relation to the following statement "I know who to contact if I have problems relating to caring for him/her" after six months. Evidence from qualitative studies [6,8] suggested that this intervention may help some by providing information in a systematic and proactive way in contrast to leaving this to carers' own efforts which may be more or less successful.

Other support worker services (specialising in dementia [16] and mental health [13] and GP based [23]) may help to improve communication between carers and services. The study of advocacy workers for Pakistani and Bangladeshi parent carers [22] found little evidence of success in empowering carers to deal with service providers themselves after the intervention finished.

There was a little qualitative evidence that carer assessment included the provision of helpful information to carers [25,27]. Another study of carer assessment [33] reported better knowledge amongst carers in areas where needs assessment was available compared to areas where it was not. However, this categorisation should be treated with caution as carers in all local authorities in England had a legal right to request an assessment of their needs at this time.

- *Service use*

Information services could lead to: requests for carer assessment [1]; greater take up of carer assessment [4]; and greater use of alternative care services [4].

There was mixed evidence from studies of a number of types of support worker about whether this led to improved service support for carers. A study of a GP based service [23] reported mixed findings. A study of stroke support workers [10] rated strong for outcome measurement compared the family's use of a range of services at six months but found only one statistically significant difference. The control group used physiotherapy services more than the intervention group. Qualitative evidence [6,8] on this specific intervention suggested that this improved access to practical support. Studies of dementia specialist support worker services [15,16] also indicated that these helped carers to access practical support for their caring role.

Most studies of carer assessment [25,26,27,28,29,30,31,34,37,38] considered consequent service use. However, some studies found it difficult to distinguish services provided as a result of carer assessment rather than any other assessment or process [25,27,34]. Two studies found that about two thirds of carers *accepted* the services offered to them [28,29]. Generally low proportions of carers, below half, received additional services following assessment [25,28,30,34]. In some cases, this was despite evidence of unmet need [30,34]. In addition, where services were provided, there was variation in carers' satisfaction with them [25-27,38]. The study of outcomes focused assessment [31] reported a higher level of changes in services, for about three quarters (76%) of carers.

- *Caring related knowledge and skills outcomes*

Improvements to caring related knowledge in terms of the condition and symptoms, treatment, medication and prognosis of the person receiving care were reported across studies of support workers with different types of specialism covering dementia [16], mental health [13] and cancer [19]. A qualitative study [8] and two randomised controlled trials [9] including one rated of moderate quality [5] of stroke specialist support workers reported improvements in satisfaction with or actual knowledge of stroke. However, the one study [10] rated strong for outcome measurement did not identify any improvements in relation to stroke related knowledge (despite improved satisfaction with knowledge).

There was some qualitative and uncontrolled longitudinal evidence of improved caring related skills specifically in terms of coping with challenging behaviour and the management of medication within studies of an acute psychiatric ward family service [13] and of the Admiral Nurse service [16]. There were also some general qualitative reports of improved ability to care from a study of mental health support workers [12] and a support nurse intervention for carers of people with lung cancer [19]. Three studies (two of

mental health specialist workers [12,14] and one of a lung cancer support worker [19]) included qualitative evidence of improvements to the relationship between the carer and the person with the condition as a result of increased caring related knowledge.

- *Social and leisure participation outcomes*

There was a weak indication that information services could lead to a more positive attitude towards accessing paid work, leisure or education [4]. Studies of support workers reported mixed, inconclusive outcomes relating to social and leisure participation. The quantitative findings of support worker studies in this outcome domain showed some improvements but most of these were not statistically significant [15,16,19]. Two other studies reporting statistical significance found no differences [11,17]. The one study rated of strong quality for outcome measurement [10] reported mixed findings on a stroke specialist service. There was some qualitative evidence in support worker studies of achievements in terms of increased social support through attendance at support groups [15] and generally greater participation in social opportunities [12]. Just one study of carer assessment [25] indicated that assessment can lead to improvements in social and leisure participation through the use of alternative care services.

- *Paid employment outcomes*

There was a weak indication that information services could lead to a more positive attitude towards accessing paid work, leisure or education [4]. Within studies of support worker interventions, there was just one consideration of outcomes relating to paid employment [14] where a positive impact was reported in respect of the impact of the patient's illness upon the carer's work life. There was mixed evidence from three studies of carer assessment about outcomes relating to paid employment. It was possible for assessment to lead to outcomes in this domain [30] particularly through the arrangement of alternative care services [25,38]. However, there was also evidence of unmet need [25,30,38] and a lack of consideration of paid employment concerns [25,30]. This occurred even in a more recent 2011 study [38] where it might have been anticipated that the requirement to consider carer's needs and wishes in relation to paid employment would have been more embedded in practice. There was also some mixed qualitative evidence about whether assessors provided sufficient information about the social security benefits available and the financial implications of ending paid employment for some carers [25].

- *Emotional well-being outcomes*

One study of an information service reported that the information commonly helped carers to feel less alone [4].

Nearly all the studies of support workers considered emotional well-being in some way. However, the findings were quite mixed. There was weak quantitative evidence of improvements to emotional well-being in studies of GP based support workers [23,24], dementia specialists [16,17] and a cancer specialist service [19]. No statistically significant changes were identified in studies relating to carer services specialising in mental health [14] and stroke [7,9]. Mixed findings were reported in other studies of a dementia service [18] and of a stroke service [11]. Amongst the few quantitative studies of support workers with higher quality ratings for outcome measurement, there was limited evidence of benefit to emotional well-being. A study of moderate quality of a six week cancer carer service found no evidence of improvements [21]. A study of moderate quality of stroke specialist support workers did report some quantitative evidence of improvements to emotional well-being [5]. The study rated strong of stroke specialist workers [10] reported predominantly neutral impacts.

However, the qualitative evidence on carer support workers consistently reported often quite widespread and important benefits to carers' emotional well-being. This was the case across all the different types of support workers. Reports covered:

- general receipt of emotional support [13,22];
- a feeling of reassurance about the availability of support [6,8,13,15,19,20] (specified as the most important outcome in one study [19]);
- feeling recognised by the support worker [6,8,19,23];
- having an improved outlook on their situation [6,8,12];
- being more relaxed [12];
- feeling more confident [12,15]; and
- the benefit of having someone to talk to [13,19].

The specificity and importance of improvements to emotional well-being reported within the qualitative data provide some grounds to believe that this intervention does contribute somehow to emotional well-being even though there is not yet definitive statistical evidence. As some authors have noted [21], the nature of the quantitative evidence may explain the difference. Outcome measures may not be sufficiently sensitive or there may be too much variance within the dataset.

The predominantly high quality qualitative literature on carer assessment similarly shows improvement to carers' emotional well-being. This was reported in a number of forms.

- Most strongly, it was reported that carer assessment can provide carers with recognition and validation of the care they provide, their experience and identity [25-27,30,34,36-38].
- Carers can also find it useful emotionally to have this time to talk about and reflect upon their situation, coping strategies and needs [31,37,38].
- Practitioner contact through assessment can help carers to feel less alone as they feel there is someone they can turn to if they need help [25, 26] and even sometimes to have a sense of shared responsibility [25].

There is some evidence that these outcomes can be achieved and important even when service provision is not satisfactory [25,34]. However, there was

also some evidence that carers still had unmet needs in relation to emotional well-being following carer assessment [25,30,36,37].

- *Physical health outcomes*

There was limited, mixed evidence about the impact of support worker services upon carers' physical health. There was qualitative evidence of better health in a study of mental health carer support workers [12] and (not statistically significant) quantitative evidence of this in two studies, one of a dementia specialist [16] and one of a lung cancer service [19], but the opposite was found in another study of mental health support workers [14]. One study of a stroke family worker [10] rated strong for outcome measurement quality reported mixed evidence in terms of changes to carers' physical health after six months. Just two studies of carer assessment considered outcomes relating to carers' physical health. These suggested that assessment can lead to improvements [25,30] but there are often unmet needs [30] and support may only be implemented at the point of crisis [30].

- *Financial outcomes*

There was some evidence that information services led to applications for carer benefits and for Pension Credit (or a reassessment of this) [1] and to benefits checks [4]. The outcomes of these were not reported.

A quantitative study of a stroke specialist support worker [9] found no difference in satisfaction with information on benefits or in knowledge about benefits. Another similar study found that a significantly lower proportion of carers in the intervention group were satisfied with the information they received about benefits than in the control group [11]. Conversely, in a qualitative study of the same type of service [6], carers reported that they had found out about benefits from the support worker and had been given the encouragement they needed to apply for them.

Four studies of support workers reported evidence on ultimate financial outcomes. One reported positive outcomes in terms of securing significant additional benefits income for families as well as grants from the Family Fund [22]. Two studies reported an improvement in the level of financial need (not statistically significant) [14,16]. One other study [17] found no clear evidence of impact.

Two studies of carer assessment [25,27] noted that information was provided about financial benefits but no studies reported upon the ultimate outcomes of this.

- *Housing outcomes*

Three studies of different types of carer support worker services reported improvements in the level of housing needs but statistical significance was not considered [15,16,22]. One found that it was easier to secure household adaptations than a transfer to a new council property [22]. Another study found no statistically significant changes in respect of housing [17].

- *Overall impact*

Two studies of information services reported high levels of satisfaction with their services [3,4]. Two quantitative studies of support worker services did not identify any statistically significant findings in relation to satisfaction for interventions specialising in mental health [14] and stroke [9]. However, another stroke study [5] rated of moderate quality for outcome measurement found higher satisfaction in the intervention group compared to a control group. Other studies of support workers reported qualitative evidence of high levels of satisfaction for services specialising in mental health [12,13], cancer [21] and stroke [6,8]. Three studies of carer assessment reported varying levels of carer satisfaction: 70 per cent [28] and 76 per cent [29] satisfied with the process; 59 per cent satisfied with the outcomes [29]; and 56 per cent generally satisfied [34].

A quality of life improvement was reported in two studies of support workers at a GP based service [24] and a mental health specialist service [14]. A study of moderate quality of a six week cancer carer support service [21] did not find any evidence of quality of life improvement (within a twelve week period) but a study of high quality of stroke specialist support workers [10] did report a quality of life improvement (after six months).

Mainly based upon qualitative evidence, studies of different forms of support worker, specialising in dementia [15,16], stroke [6], South Asian advocacy [22] and GP-based [23], showed that this intervention could positively address carer needs but that this did not occur for some carers. The South Asian advocacy study noted that housing issues were most difficult to address [22]. A study of the Admiral Nurse Service reported that emotional needs could be more difficult to meet than practical and informational needs [16]. Mixed outcomes were also reported in terms of whether carers' needs had been met overall or not as a result of carer assessment [27,30,31,37] including in a more recent 2011 study [38] and the study of carer assessment conducted by a third sector carer organisation [32].

- *Outcomes for the person receiving care*

There was little consideration of outcomes for the person receiving care in most of the studies of support workers where the intervention was not also directly targeted at them with the following exceptions. The pilot study of the Admiral Nurse Service for dementia found an improvement in the person with

dementia's generic health and mental health needs but did not consider statistical significance [16]. A wider evaluation of this service [18] found no difference in terms of the proportion who remained at home, had entered a residential home or who had died at eight months. Qualitative evidence in a lung cancer support worker study [20] reported that in some cases, the service enabled the patient to stay at home longer and even to die at home in accordance with their wishes. Qualitative evidence in a mental health support worker service indicated that the person receiving care was appreciative of the support for their carer [12].

One study of stroke specialist workers (targeted at both the carer and the stroke patient) suggested that there might be some negative outcomes in terms of rehabilitation and social adjustment from this intervention for stroke patients [11]. However, the stroke studies rated of moderate [5] and high quality [10] for outcome measurement reported some beneficial outcomes and no difference respectively. Other studies of stroke specialist workers found: very little difference [7]; no difference in mood or independence but some benefits in terms of satisfaction with and knowledge of stroke and support services [9]; and mixed findings on satisfaction and some greater use of services [11]. The qualitative studies of stroke support workers [6,8] suggested that patients experienced some of the same benefits as carers. This included: having the reassurance that there was someone to turn to for support if needed although there was some reluctance amongst patients (as well as carers) to make a call if needed [8]; great appreciation of the worker's involvement [6]; and the beneficial effect of knowing someone was interested in them [6]. A higher proportion of people with dementia who used dementia adviser services (aimed at both the carer and the person with dementia) [15] had no needs on the ASCOT measures of wellbeing (covering accommodation, personal cleanliness, food and drink, social participation, occupation, control and dignity) compared to people in areas with no dementia adviser but where usual services were available (with the exception of the measure of personal safety). Statistical significance was not considered throughout. There was also some qualitative evidence of people with dementia living at home for longer and accessing social support groups [15].

3.2.3 Explanatory evidence: Mechanisms

- *Emotional support mechanisms*

A number of mechanisms of emotional support were identified in studies of support workers and carer assessment as follows.

- The provision of moral support, validation and recognition by the practitioner [6,8,19,23,25,26,27,30,34,36,37,38].
- Knowing that there was somewhere to turn for help if necessary [4,6,8,13,15,19,20,25,26].
- The discussion and expression of their situation and feelings [13,19,31,37,38].

There was some very limited evidence that emotional support also supported access to other secondary services and outcomes as follows.

- Support and 'permission' for carers to make more time for themselves was important as well as this time itself [12].
- The stroke support worker had given carers the encouragement they needed to apply for benefits [6].

- *Informational mechanisms*

Studies of information services provided weak evidence of a link between the mechanism of the provision of information to outcomes in terms of knowledge of services [1-4] and some use of services [4]. There was some limited evidence that this also contributed to outcomes in emotional well-being by leaving carers feeling less alone [4]. Several studies of support workers included reports of different types of information (relating both to the condition and to support services) being provided to carers [12,19,20,24]. Qualitative studies of stroke support workers [6,8] suggested that the proactive, systematic provision of information about services by support workers could be more effective than the individual efforts of carers in the control group to access information. Information about the condition was linked to the outcomes reported relating to improvements in carers' caring related knowledge and skills. It is not clear how, if at all, information about services was linked to other outcomes. There was a little qualitative evidence that carer assessment included the provision of helpful information to carers [25,27]. However, it is not clear *how* this information helped.

- *Secondary services as resource mechanisms*

Aside from emotional support and the provision of information, the main resource mechanism was the subsequent use of secondary services. The take up and use of such services has already been considered. There was limited evidence about how use of these services contributes to other outcomes for carers.

A study of dementia advisers [15] noted that this service could enable social support through facilitating participation in support groups. In one small scale qualitative study [12], the mental health support worker service was judged to be most successful where additional support was also being provided for the person receiving care and was also perceived as unsuccessful in one case where the services requested for the person receiving care were not available. This study also noted a particular link between additional support for the person receiving care and the carer being able to enjoy social opportunities.

Some studies of carer assessment [25-27,35] provided some qualitative case examples of how additional services supported and sustained the caring role (and also where they did not). There was also some limited evidence that services were significant in relation to improved emotional well-being [25], physical health [25,30], social and leisure participation [25] and paid

employment outcomes [25,38]. Service provision was found to be linked with satisfaction [34], with dissatisfaction identified where this was not sufficient, not appropriate or too costly [29]. Unmet needs were also related to a lack of services [37] or inappropriate services [31].

- *Active assistance mechanisms for access to secondary services*

There were also some indications that active assistance with accessing secondary services might be a significant mechanism in outcomes of casework. However, the evidence upon this is very limited. Some studies of support workers reported the provision of assistance with accessing services. This included referrals made to and assistance with accessing support from various different organisations and services including health services, social care, occupational therapy, counsellors, third sector organisations and for benefits help [13,19,20,24]. However, there was very little consideration of the links between this and service use or other outcomes. A qualitative study of stroke specialist workers noted that other agencies were more likely to respond to requests for assistance when they were aware that a support worker was involved with the case [8]. Two studies of carer assessment hinted at the potential significance of active assistance with access to secondary services. One study [25] reported the benefit of assessors being ready to help and advise on the process (such as form filling) and recognising the need for encouragement and guidance. Another study [34] found that carers were most satisfied where the assessor was described as a kind of advocate.

3.2.4 Explanatory evidence: Contextual factors

There was evidence that a number of contextual factors could influence the likelihood of these mechanisms occurring and outcomes being achieved. These can be divided into those relating to: the characteristics of the interventions; practitioner skills and approach; the availability and nature of secondary services; and carer characteristics.

- *The characteristics of the interventions*
- *Intervention type.* There was evidence that condition specialist support worker services could improve caring related knowledge and skills amongst carers in contrast to the absence of evidence on this outcome domain in studies of statutory carer assessment, information services and non-condition specialist support workers. Overall, there was evidence of higher satisfaction with support worker interventions than there was with statutory carer assessment. However, there was mixed evidence about the extent to which both types of intervention managed to meet carers' needs.
- *Preparation for assessment.* Providing relevant information to prepare the carer prior to assessment could be helpful [25,27,36] whilst bearing in mind that handing out the assessment tool beforehand might make some carers

anxious [27]. Some carers found it helpful to be supported by carer support groups or condition specific organisations in their preparation for the assessment [25].

- *Presence of others.* Carers likely to want a private discussion without the person they cared for [25] supported younger people with learning disabilities or people with mental health problems associated with advancing age (also noted in [36]) and/or have poor or less close relationships with their partners. Some parent carers of people with learning disabilities wanted a private discussion without their partner present [34]. The presence of the person receiving care could limit the discussion of caring risks [27]. However, there was an example of how discussion of carer outcomes with the user present had helped to receive a conflict of interest between the two parties [31].
- *Allocation of time.* More than one assessment visit [27] or less time pressure [36] could be beneficial.
- *Assessment focus and scope.*
 - Some carers felt that too much focus on the person receiving care was unhelpful [25].
 - The more comprehensive the scope of the assessment the more it was appreciated [34]. For some carers, their main issue of housing was not addressed [34]. Generally carers would have appreciated greater recognition of their need for emotional support [25] (and relational issues with people with dementia [36]) as practitioners primarily focused on practical support. Some carers suggested that offering assistance with benefits for new carers could be helpful [24].
 - Satisfaction increased when the expertise and knowledge of carers in relation to the individual's needs was recognised by the assessor [34,36].
 - A needs-led approach was appreciated by carers in contrast to approaches which began with a tick list of services [34,37]. An outcomes-focused approach [31] was also particularly successful.
- *Assessment tools.* The nature of assessment tools could be relevant [26,27,31] including not being too long and complex [36], but covering a wide range of potential needs [27], including open questions [27] and having an outcomes focus [31].
- *Self-assessment.* No link was found between the use of self-assessment and satisfaction with the services provided consequently [25]. Some carers felt constrained by self-assessment [37], some (particularly older carers) found it difficult and this did not provide the recognition and validation of going through the form with the assessor [25]. Self-assessment could be useful preparation for a face-to-face interview though [25].
- *Ongoing contact.* Ongoing contact from support workers of different types, specialising in dementia [18], cancer [20], stroke [6,8] and GP based [24], and from carer assessment workers could be important [25,34]. A specific

link was made between ongoing contact (in contrast to a one off assessment only) and emotional well-being outcomes [18]. Ongoing contact after carer assessment was needed for as long as the implementation of the carer's plan required further action [27]. Being kept in touch with assessment progress could compensate for delays or problems in service provision in the eyes of carers [34]. Families with whom contact had been maintained were more likely to feel able to re-contact the practitioner if needed, whereas others felt they no longer knew how to access support [34]. Where contact was not maintained, carers could feel very let down [34,38]. Some carers would value a more proactive approach from practitioners contacting them occasionally to see if their needs had changed [30].

- *Length of service.* Similarly a specific link was made between a greater amount of intervention time and emotional well-being [17]. In three other studies, carers felt that it would be beneficial to provide the service for a longer period [12,21,22].
- *Timing of support.* The majority of carers of people receiving palliative care for cancer (57 per cent) felt that the sessions came at the right time (new referrals to the palliative care team) but about a fifth felt they were too late in the patient's illness and a small minority felt they were too early [21]. Carers of stroke patients particularly seemed to experience anxieties upon the patient's discharge from hospital, thus this was an important time at which to offer support [8]. Information may be more helpful once carers of people with dementia have had some time to accept a diagnosis rather than immediately upon diagnosis [15].
- *Flexibility.* A number of studies of different types of support worker noted that the flexibility and individualised approach of the intervention was important [6,8,12,19]. Similarly, a study of carer assessment [34] found that the provision of information about different service options and a choice were more likely to lead to satisfaction with services following assessment.
- *Mode of contact.* Individuals had different preferences for face-to-face, telephone or a combination of methods of interaction with a cancer support nurse [19]. Some preferred to receive information verbally rather than in written format [19].
- *Links to other services.* Cancer workers' links with the medical teams were very important to the success of their work [20]. Communication with social care was improved through having a support worker (employed by the local authority social care team) in place at the GP surgery [23]. The involvement of health professionals in carer assessment as well as social services was highly valued [27,34]. Assessment referrals with clear intended outcomes led to a more successful mental health support worker intervention [12].

- *Accessibility.* Being able to contact a practitioner easily was important [4,14] and with calls returned to save costs [6]. Flexibility in the timing and location of meetings was also appreciated [15,19].
- *Nature of the information provided.* Particular features of information noted as important were: the extent of the information - not too much [3] or too little [4]; relevance [3]; and that information is well laid out [4].
- *Practitioner skills and approach*

There was evidence that interventions were more likely to be successful in a context where the practitioners had the following skills and approaches.

- *Good interpersonal skills and empathy.* This included specifically: not using jargon [25], high levels of motivation and a conscientious approach [14], and professionalism [6]; being a good listener and being someone with whom it was comfortable to talk [25]; and being friendly [4,6], caring [14], reassuring [4], tactful [6] and empathetic [14].
- *Relationship building and familiarity.* The creation of a relationship of trust with carers was necessary [27,34]. A new worker needed to read the file beforehand rather than asking the carer to repeat the entire history [27,34]. The lack of an existing relationship was felt to limit the topics covered [27] but some preferred a fresh start with someone specifically concentrating on their own needs [34].
- *Personal experience as a carer* was mentioned as an advantage by practitioners [26].
- *Similar characteristics to the carer.* Carers found it easier to talk to an assessor of the same gender as them [25].
- *Training and/or experience in carer assessment* was noted as important by practitioners [26,27]. To deliver a specifically outcomes focused approach, practitioners need to be skilled, to have time to develop their understanding and skills in the use of these tools [31].
- *Knowledge.* This was mentioned as potentially important in relation to: carer services and support [27,34]; the law [26]; the 'system' or social care support and services generally [25,26]; and generally [14].
- *Carer specialism.* It was beneficial to have an assessor whose role was specifically carer support [27]: to establish longer term relationships with carers; to facilitate access to services; and to limit the paperwork involved.
- *Response and follow-up.* It was important to respond and undertake follow-up work quickly and reliably [4,25] and that assessors were efficient [34]. It was preferable to have one person co-ordinating support with whom the

carer could maintain contact [26]. It was valuable to be able to communicate well with other services [34].

- *Availability and nature of secondary service provision*

The availability of resources and suitable services to meet identified carer needs was important to outcomes [4,12,25,26,27,30,38]. Even where some resources and services were available for carers, the following factors affected use of and satisfaction with these.

- *Flexibility.* In general, flexibility, personalisation and choice contributed to satisfaction [25,27,38]. In one study, 25 per cent of respondents did not have the support they needed because services were not available at the times they wanted [30].
- *Cost.* Cost could deter carers from accepting services [25,27,29,30].
- *Quality.* In relation to breaks for the carer (where the person receiving care was cared for outside of the home), potential issues were the appropriateness and quality of the provision for the individual receiving care [25,27,30,38]. In terms of alternative care and practical support provided in the home, potential issues influencing satisfaction were the reliability and timing of provision [25-27,30], poorly trained staff [30] and continuity of staff [25,30].
- *Transport.* A lack of transport provision could be a barrier to use of services [25,38].

- *Carer characteristics*

There was also some limited evidence about carer characteristics that could influence outcomes as follows.

- *Carer attitude* [25,34]. People who clearly and forcefully articulated their needs for help or services, were persistent, confident and not deferential, were more likely to receive support. It could also be important to be well informed about service provision and the social services system. Making staff feel appreciated could help to ensure progress. Some elderly carers had asked their children to be present in meetings and some carers had approached more senior people, including a local councillor, and/or made formal complaints. Some of the carers of people with learning disabilities had drawn on their networks with other families of people with learning disabilities to keep informed and know when to push for support. Some carers felt that they needed to communicate the worst case scenario to ensure they received support.

Some carers viewed a stroke support worker as just someone else from social services and this appeared to affect uptake of the service offered

and restricted the type of support requested [8]. In addition, whilst the importance of knowing there was someone to turn to if things became overwhelming was mentioned by all, approximately half of both patients and carers reported a reluctance to make a call to the support worker even when it was needed [8].

- *Culture.* The qualitative study of advocacy workers for Pakistani and Bangladeshi parent carers [22] included the following findings about the influence of carer culture. Impact was limited where the work of the service did not fit with some of the existing cultural and family dynamics. Parents did not understand or relate to the service providers' concept of self-advocacy and intention to work towards empowering parents to advocate for themselves. Female advocates found it difficult to engage and work with fathers. There was one exception with a worker specifically supporting Bangladeshi parents. She thought that this was because she was older and because no-one in these families spoke English and thus they relied upon her to negotiate with English-speaking service providers. More generally, language was seen as the major barrier to achieving empowerment and self-advocacy in cases where the parents did not speak English.
- *Characteristics of the person receiving care.* The proportion of carers who received services [30] and who had unmet needs following assessment [30,37] varied according to the type of condition which the person they cared for had. However, the statistical significance of these differences was not considered. There was some evidence that dissatisfaction [34] and unmet needs [32] were likely to be particularly limited for carers of people with the most complex needs. Carer outcomes could also be limited where the person receiving care did not want to accept alternative support [6,30,38].

3.3 Conclusions of the systematic review

The reviewed bodies of knowledge upon information services, carer support workers and statutory carer assessment lead to a number of conclusions relating to gaps in the evidence base, issues concerning research methodology and knowledge to guide and build upon in the study presented here.

Only one study [4] of an information service and another [38] of statutory carer assessment considered casework provided by third sector generic carer services. Thus, there has been very little consideration of the role and outcomes of the substantial casework services provided by third sector generic carer services such as carer centres. Thus, this forms the main focus of this study. As yet, there has also been little research into the outcomes and underlying process of statutory carer assessment undertaken by the third sector. There has also been very little comparison of different forms of casework services. This study therefore takes a comparative perspective.

There is a lack of outcome measurement evidence rated strong in quality. This is not unexpected given the practical and ethical difficulties involved in using research designs such as randomised controlled trials in social policy. Using this type of method is also particularly difficult with interventions in which the approach of the individual practitioner can make a potentially very important difference (as the existing evidence, particularly upon carer assessment, suggests it can in casework). Thus, it is difficult to achieve true intervention fidelity within a trial. Furthermore, there is likely to be considerable variation in carer needs and desired outcomes (which is again already apparent in some of the existing explanatory evidence) which also complicates the use of such approaches. This may partly at least explain some of the conflicting findings of quantitative and qualitative evidence, particularly the relative lack of evidence of improvements to emotional well-being in quantitative studies compared to widespread reports of benefits within qualitative data. It may be difficult to capture such outcomes with quantitative methods. This indicated that a qualitative approach would be the most appropriate design for this research study.

There is a good body of high quality explanatory evidence, particularly in relation to carer assessment. This offers important insight into what types of factors are likely to be important to outcomes in casework and this has informed data collection in this study. These can be divided into categories covering: the nature of the casework service itself in terms of its processes and scope; the individual practitioner's skills and approach; the availability and nature of secondary service provision; and the carer's characteristics. Whilst they were recognised as potentially relevant, there was relatively little evidence about how the carer's characteristics (including socio-demographic factors and the nature of their caring role) influenced outcomes. Qualitative evidence also did not often make direct links about how exactly contextual factors influenced the operation of mechanisms and the achievement of outcomes to build up an explanatory model of interventions. A better understanding of this could help to explain the often mixed findings reported here on the achievement of different types of outcomes across and within studies. That this has not occurred is perhaps not surprising given that these studies were not undertaken in a realist framework. A focus in this thesis has consequently been to build this type of linked understanding through realist evaluation.

The existing body of evidence is also quite limited in the knowledge it provides about how outcomes change over time. Quantitative studies of support workers sometimes took outcome measures at a number of points of time. However, analysis of this was not revealing other than showing that improvements in emotional well-being could be related to the length of input of the intervention over time. Comparison of the findings of different studies which took outcome measurements at different points in time was also not productive because of the extent of variation in these studies otherwise. Longitudinal analysis within qualitative studies was also limited. Mainly this involved data collection at two points in time, generally immediately, where analysis focused upon reflections upon the process of assessment (rather than outcomes) and between three and twelve months later. None of the

existing studies considered outcomes beyond twelve months. This study has sought to add original longitudinal understanding of how the outcomes of casework changed over time including in the long term.

There is a reasonable body of knowledge relating to outcomes concerned with emotional well-being, knowledge and service use. However, there is very little consideration of wider outcomes relating to domains such as physical health, financial situation, social inclusion and paid employment. There is also very little understanding about how outcomes are achieved in these domains. For example, just four of the thirty seven studies reported on financial outcomes for carers (in contrast to several studies that noted that relevant information or support was provided but with no indication of the outcomes of this) and none of these provided any indication about what contextual factors influenced outcomes in this domain. This study has sought to consider all ultimate outcomes of casework as fully as possible.

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Chapter Four: Methodology

Having reviewed what is already known about the outcomes, mechanisms and contexts of casework with carers and having established a theoretical foundation for this study, this chapter moves on to present the methodology of this study. This builds upon the conclusions of the previous two chapters, particularly those of the systematic review. The chapter begins by specifying the research focus (4.1). This is followed by explanation of the realist evaluation framework used (4.2). An overview of the qualitative longitudinal case studies used in the realist evaluation framework is then provided (4.3). The following sections discuss particular methodological aspects of the case studies covering: the longitudinal form of data collection (4.4); the observational evidence gathered (4.5); and the semi-structured interviews undertaken (4.6). The sampling strategy and the characteristics of the sample achieved are presented (4.7). The approach to analysis is then considered (4.8) and the presentation of the findings explained (4.9). Finally, ethical issues are discussed (4.10).

4.1 Research focus

The overarching research question is:

‘Casework with carers: what works and why?’

This has been broken down into a series of more specific questions in response to the conclusions of the systematic review as follows.

To address the lack of research upon third sector generic carer services:

- *What are the outcomes of the casework of third sector generic carer services?*

And to incorporate this with and compare understanding of other approaches:

- *And how does this compare to the context of the work of third sector condition specialist organisations and statutory carer assessment?*

To add new longitudinal understanding:

- *How do the outcomes of casework change over time?*

To extend understanding of a full range of carer outcomes:

- *What are the ultimate outcomes of casework for carers, including potentially those concerning emotional wellbeing, knowledge, physical health, financial situation, social inclusion and paid employment?*

To build an explanatory, linked understanding of how outcomes result from mechanisms and how this is influenced by contextual factors in the realist framework:

- *What mechanisms produce which outcomes? How?*
- *What contextual factors influence these processes and how?*

As suggested by the existing literature on carer assessment, this should include but not be limited to consideration of the following:

- *What is the influence of:*
 - *the nature of the casework service itself in terms of its processes and scope?*
 - *the individual practitioner's skills and approach?*
 - *the availability and nature of secondary service provision?*
 - *the carer's characteristics?*

4.2 Realist evaluation

The research question is essentially concerned with the evaluation of casework. As noted in the introduction, different approaches to evaluation have been developed relying upon different ontological and epistemological assumptions. The classic approach to evaluation is the experimental method (Campbell & Stanley, 1963) which uses randomised controlled trials to measure statistical differences in outcomes between subjects randomly allocated to an intervention and a control group. The statistically robust design enables precise measurement of the impact of an intervention. However, in practice, experimental trials of social programmes often do not meet the particular requirements of this method and achieve the high quality standards sought. This is because there are practical and ethical difficulties with taking this approach, particularly in allocating people randomly to a control and intervention group. In addition, the findings of trials are often inconclusive. This is likely to reflect difficulties with their underlying ontological assumptions. They may have difficulty adequately controlling for the diversity and contingency of the social world. It is also difficult to standardise interventions based upon social interaction and responding to varied needs. Even where trials do offer conclusive findings, they provide information only about what happens in a very particular set of circumstances and cannot account for change in the social context. This experimental approach would seem particularly inappropriate for evaluating casework with carers given that this work is individualised not standardised and takes place in a wide range of contexts in terms of the intervention itself and also the diversity of the carer population.

Addressing some of the difficulties of the experimental approach and emanating from the wider development of interpretivist and constructionist perspectives, naturalistic evaluators (Guba & Lincoln, 1989) prioritise social context, individual agency and interpretation in understanding social programmes. In evaluation, they collect the constructions of all the different

intervention stakeholders and then compare and consider conflicting reports through a process of negotiation with all stakeholders. Epistemologically they argue that there are multiple different individual interpretations of events and no particular account should be privileged in any way. However, a negotiated consensus may be difficult to achieve in practice and the process of negotiation may influence the constructions themselves. This leaves the evaluative knowledge gained limited. Some interpretivist approaches are also criticised for often focusing upon what has occurred, the process or practice, but without linking this to an evaluation of the impact this has had (Kazi, 2003).

Theory driven approaches to evaluation have been developed in order to try and understand the process of what happens in order to explain changes in outcomes (Chen, 1990). This has been referred to as opening up the 'black box' of the intervention (Scriven, 1994). This is what this study has set out to do in relation to casework. The research question posits 'what works' firstly, seeking to understand the outcomes or difference made by the intervention to carers, but also 'why' to understand how effects are achieved. This provides insight that can help to inform the development of future interventions.

There are different approaches to theory driven evaluation (Blamey & Mackenzie, 2007). The approach taken here, realist evaluation (Pawson & Tilley, 1997) seeks to explain change in outcomes occurring through interventions based upon solid philosophical foundations in critical realism (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Bhaskar, 1998). Realist evaluation has been chosen because it is based upon my preferred ontological and epistemological understanding of the social world generally. It was developed by academics assessing interventions in crime prevention. It has since been used successfully in social work research (Kazi, 2003) and particularly in health care interventions (Marchal, van Belle, van Olmen, Hoérée, & Kegels, 2012).

When the realist approach is considered in light of the nature of the casework explored here, it also seems particularly appropriate. There is likely to be considerable diversity to take into account in terms of carer and intervention characteristics which implies the potential importance of context and the realist concern with 'what works for whom in what circumstances'. Due to its focus on mechanisms (discussed below), realist evaluation has also been identified to be potentially particularly useful in evaluation where micro level processes are of interest (Blamey & Mackenzie, 2007). This is likely to be the case at the individual level of casework.

Realist evaluation considers there to be a social reality as in the experimental method but also recognises the role of context, agency and interpretation. Critical realism responds to the ontological dilemma of structure and agency by understanding that we have the capacity to act but within multiple, sometimes conflicting, pre-existing social structures which constantly evolve as humans transform them whilst being guided and constrained by them. Within this process of social change, actors' meanings and motivations play an important role, hence it can be important to understand these in research studies.

Epistemologically, research participants' accounts and researchers' observations and analysis are the only ways through which we can try to understand the social world. These are necessarily individual subjective interpretations influenced by current social structures. However, unlike the extreme interpretivist position, a critical realist approach to evaluation believes that there is a social reality and views the researcher's task as to try to assess the limits and bias of the data gathered to develop as valid a picture of that social reality as possible. The researcher is also influenced by social structures and ultimately the knowledge built must always be considered as an interpretation rather than an absolute truth. However, the use of particular research methods and strategies to enhance validity and reliability mean that the researcher's account can be argued to offer more insight than other individual interpretations.

The realist approach to evaluation seeks an understanding of 'what works' as 'what works for whom in what circumstances' through building theory which explains the differential outcomes of interventions with different participants and in different contexts. Outcomes, context and mechanisms are the three elements to understanding how interventions work identified by Pawson and Tilley based upon a critical realist foundation.

Outcomes are the social regularities or patterns which result from the action of certain mechanisms. The outcomes considered in this research are those resulting from casework with carers which have included change in the caring role, in carers' lives outside caring and in carers' well-being. These can then be considered through the lens of carer empowerment.

"Mechanisms refer to the choices and capacities which lead to regular patterns of social behaviour" (Pawson & Tilley, 1997, p. 216). Explanatory mechanisms could incorporate individuals' decision making processes and reasoning (choices) and their resources to achieve something (capacities). Example mechanisms underlying casework which lead to the outcome of a carer participating in leisure activities might include: the recognition by the carer through the practitioner's encouragement that it is acceptable to take a break (a mechanism relating to choice) and learning about funding for leisure activities through information provided (mechanisms relating to capacities). Mechanisms explain how outcomes are achieved. In this way, critical realism offers the insight of a generative view of causation, explaining the mechanism of change.

Context is the existing set of social relationships which mechanisms act within and work upon. Different contexts may act as a barrier to or a facilitator of certain mechanisms. In this research, at the macro level, context could cover the prevailing culture about carers' right to support and the level of funding available to resource support for carers. At the micro level, this includes, for example, the social identity of the carer, for example, their ethnicity and gender and the nature of their relationship with the person who receives care.

The task of realist evaluation is then to explore various configurations of mechanisms, contexts and outcomes to develop theory about 'what works'. Critical realism understands society as being an open, evolving system. In an open system, many mechanisms affect outcomes, sometimes in different directions, and these may change quickly and over time and in different locations, that is different contexts. The changing and complex nature of society as an open system means that we cannot predict outcomes but can understand that there are tendencies. Relationships between outcomes, contexts and mechanisms are contingent rather than necessary. Research must try to make sense of an open, evolving social reality. Consequently, it is important to try and understand and explain the social world and its processes rather than simply measuring specific outcomes.

There are potential disadvantages to using realist evaluation. As realist evaluation is still a relatively young methodology, those using its methods have encountered some difficulties in applying the particular concepts of context, mechanism and outcomes and in developing configurations of these as theory (Byng, Norman, & Redfern, 2005; Marchal et al., 2012). Partly, this is because the explication of these terms is simpler in theory than when implemented in the messy world of social reality. However, returning to the ontological and epistemological foundations of critical realism can help to understand more complicated findings (Byng et al., 2005). The approach taken here consequently in analysis was to be flexible about the use of these elements. Something could potentially be coded as one element of the realist framework in one part of the analysis but as another elsewhere (Byng et al., 2005). For example, feeling more positive could be an initial outcome but could also potentially act as a mechanism explaining an outcome of providing better care. In addition, the aim was for the analysis to be flexible in the form of context, mechanism, outcome configurations. For example, a single outcome configuration might involve several mechanisms and contexts at a micro or macro level.

Porter and O'Halloran (2012) criticise realist evaluation because it aims to generate knowledge to enable piecemeal development of social programmes. They argue that this can lead to neglect of the wider political and social context of interventions. They propose a return to the wider emancipatory aims of critical realism (Bhaskar, 1998). Its role was not just to understand the structures and mechanisms explaining outcomes in the social world but also to challenge these where they are oppressive (Houston, 2005). In this thesis, wider political concerns about the role and value of care have been responded to by considering the findings in the light of the theories of carer empowerment and the ethic of care (Tronto, 1993).

4.3 Research design

4.3.1 Using longitudinal qualitative case studies in a realist evaluation

Qualitative case studies have been used in this study within the realist evaluation framework. The realist approach is not prescriptive about the type

of methods that should be used in evaluation. Instead, it advocates selecting research methods and participants according to the information they can contribute to understanding outcomes and developing intervention based theory. The selection of methods is also likely to depend upon the extent and nature of existing knowledge. A qualitative design was used for the following methodological (rather than epistemological) reasons: because it is well suited to an exploratory approach, to understanding context, to examining process and to considering actors' meanings (Becker & Bryman, 2004, p. 92).

A qualitative approach allows concepts and theory to emerge inductively where there is little initial existing theory. A realist evaluation would ideally begin with hypotheses about which mechanisms would generate which outcomes in which contexts through the intervention concerned. However, as noted previously, there was limited existing knowledge about the casework conducted by third sector generic carer services. In addition, whilst there is a good body of high quality explanatory evidence particularly in relation to carer assessment, this does not often make direct links about how mechanisms achieved outcomes and how contextual factors influenced this.

This would potentially involve quite complex and varied processes. As Shaw (2003) notes, qualitative research is particularly helpful for looking at links between outcomes and processes and pinpointing the micro-processes that operate within the broader context of particular services or programmes. This sort of knowledge was necessary here to understand the mechanisms of change operating in casework. The systematic review identified that a considerable number of contextual factors might also be important to understanding casework. Thus the study was likely to require considerable contextual understanding which is difficult to gather adequately through quantitative means.

Critical realism views actors' meanings and motivations, as well as wider social structures, as having causal properties in their own right (Houston, 2010). In this research, casework outcomes in terms of carers' emotional well-being, in particular, might depend upon their subjective interpretations, for example, of their caring situation. Qualitative methods offered the opportunity to gain insight into these.

Many qualitative researchers would argue that qualitative research should concentrate only upon producing 'thick' description and the interpretation of meaning and discourse rather than providing explanation or causal analysis (Cooper, Glaesser, Gomm, & Hammersley, 2012). Generally this would be underpinned by other philosophical positions such as constructionism and would lead to a design involving a small number of participants or cases and an in-depth exploration of the subject concerned. Yet, qualitative research is now used in many different fields and there is "*a considerable amount of epistemological and methodological plurality*" (Moriarty, 2011, p.5). As Cooper et al (2012) and realists more widely argue (Maxwell, 2012; Porter, 1993), qualitative methods need not be tied to a constructionist philosophy.

The particular epistemological and ontological framework is likely to influence the type of qualitative research design used. The realist evaluation framework used here focused upon gathering and analysing data particularly about outcomes, contexts and mechanisms and the configuration of these. Thus the approach taken was more structured than much other qualitative research. The successful use of such an approach has been demonstrated in other realist evaluation (for example, Clark, Whelan, Barbour, & MacIntyre, 2005; Kazi, 2003) where qualitative data of different types was gathered and analysed but within a clear structure based upon the realist evaluation framework. In this work and here, the realist framework of mechanisms, outcomes and context structures data collection and analysis but within this, qualitative methods allow participants' own meanings to be captured and understood.

Qualitative research also often involves small samples in order that the subject can be investigated in depth with this small number of participants. However, there are classic examples of qualitative work which use a reasonably large sample (Cooper et al., 2012). As Cooper et al note, what matters in deciding upon this matter is the purpose of the data.

There were two reasons here why a reasonably large sample was sought. Firstly, breadth in the sample would be needed to consider all the different contextual factors identified in the systematic review as potentially of relevance. In order to build some theory about the links between context, mechanism and effects, it would be necessary to compare cases as well as identifying linkages within cases. This would provide depth in terms of explanatory power. However, due to practical time constraints, this would have to be balanced against the level of depth achieved within individual cases. This was also appropriate given the nature of casework. Casework could have many strands in terms of the way it supported carers, for example, considering the need for alternative care services, leisure activities, caring knowledge and so on. However, it was not itself generally an intensive intervention in that it did not, for example, offer counselling or in-depth training, but rather offered a route to such support (see page 109).

4.3.2 Methods responding to the nature of casework

The particular methods used in the research design also needed to respond to the nature of casework (see page 109). Casework centres around individual carers and so the research design reflected this. It would have been difficult within focus groups to manage and record the anticipated diversity in experiences of an intervention responding to the individual needs of different carers.

Casework involves a first main meeting between the carer and the practitioner which could be anticipated to constitute a key beginning to this. Thus, each case study would include observation of this meeting. This offered an opportunity to capture data on casework that was 'naturally occurring', it had not been generated artificially through the research, for example, in an

interview, although it may still be framed or influenced by the researcher depending upon how this is accessed (Silverman, 2013). This acted as a key foundation for data collection. This is discussed further in section 4.5.

The interactions and process of casework after the first main meeting could be quite varied. This was the beginning of a potential web of interactions and service use. There were no further obvious options for observing this. Documentary analysis to explore later activity would have prioritised practitioners' viewpoints. In addition, in the third sector, the documentary records kept were anyway minimal. These varied but often consisted of keeping brief basic registration details about the carer and sometimes, but not always, a brief record of contacts. Thus, a series of semi-structured interviews with the carer and the practitioner individually in a longitudinal design were planned to collect data about the outcomes, processes and context which followed the first main meeting. These also provided the opportunity for exploration of the underlying motivations and meanings of carer and practitioner actions and views which might not be apparent through observation.

4.3.3 Reliability and validity

The reliability and validity of the research are critical issues. These terms originated in relation to quantitative research and have a very specific application in that context. However, these can be adapted to consider the quality of qualitative research (LeCompte & Goetz, 1982). External reliability in quantitative research is about being able to replicate a study. This is difficult in qualitative research where a particular social context is likely to change and the researchers themselves exert an influence. To respond to this a key concern in qualitative research can be setting out the procedures that have been used and being reflexive about the researcher and their influence (Seale, 1999). This has been undertaken throughout this chapter of the thesis. Internal reliability considers whether data is consistent, for example, in participants' accounts and in the coding of this data. Validity can also be understood in two ways. Internal validity is concerned with the extent to which theoretical interpretations and conclusions are supported by the empirical data. External validity considers the extent to which a study's findings can be generalised to other settings. The reliability and validity of the research are considered throughout this chapter in relation to specific aspects of the methodology. However, some specific points are now made in relation to the overall design of the study.

The reliability and validity of cross-sectional data gathered about events and activities over time is threatened by discrepancies in participants' memories. Casework could involve change over a considerable period of time. Longitudinal qualitative research provides a means to gain a rich and detailed understanding of changes over time (Molloy, Woodfield, & Bacon, 2002). The use of multiple data collection points in a longitudinal design allowed more reliable and valid data to be collected about changes in outcomes but also the processes creating this. Undertaking a series of interviews with the same

respondents also has the advantage that the researcher has a record of their earlier views and circumstances and is not entirely dependent upon the respondent's ability to identify change (Molloy et al., 2002, p.150). Thus the original longitudinal approach undertaken here enhances reliability.

Having three different data sources (observation, practitioner interviews and carer interviews) also enhanced the validity of the study in terms of ensuring that there was quite comprehensive coverage of the outcomes, context and mechanisms involved in casework. Silverman (2013) cautions against assuming that mixed methods will provide a more complete picture and that data from different sources can be triangulated. However, the different methods used here had particular purposes. Interviewing both carers and practitioners (separately) enabled access to different types of knowledge. Carers had personal experience of outcomes and mechanisms and also reflected upon relevant contextual factors in their own circumstances. Practitioners had some specific knowledge about mechanisms and contextual factors relating to their own characteristics, their own services and secondary services that influenced outcomes. Practitioners also provided some insight into how individual cases compared to their work more widely helping to provide some understanding of whether it would be possible to generalise about some findings. This helped to extend the external validity of findings. There was also some limited use of triangulation where different data sources offered information on the same aspect of casework (page 117).

4.3.4 Pilot cases

Four pilot cases were carried out and reflected upon before the main phase of data collection in order to try and improve the value and quality of the study. These were undertaken with two practitioners from two different third sector carer organisations (one of whom undertook a statutory carer assessment on behalf of the local authority). The four participating carers consisted of one man and three women of varying ages, with different kin-based relationships to the person they cared for who had various different medical conditions. Hence, there was reasonable diversity within this small sub-sample. The first main interaction of casework was observed and audio-recorded in December 2008 or January 2009. Interviews were then undertaken immediately after the first main contact of casework and approximately six months later where possible (see Table 4.6, page 107) with both the carer and practitioner individually.

A number of issues were identified during the process of conducting the pilot cases and in analysis of the data collected. Changes made to the research design to account for these are discussed on the following pages in relation to: the longitudinal design, page 86; the potential involvement of the person receiving care in the first main contact, page 122; sampling pages 97 and 100; arrangement of the first practitioner interviews, page 93; and interview content page 92 and conduct page 94.

4.4 Longitudinal data collection

This study took an original longitudinal approach to investigating casework. Longitudinal evaluation research can consider change potentially arising within a number of different domains: service; individual; policy; and structural (Lewis, 2007). Understanding of the 'service domain' underpinned the use of the first three points of data collection in the longitudinal research design. The first point of data collection consisted of the first main contact itself as a potentially key interaction and immediate reflections upon this. This first contact is then followed up by practitioner and/or carer action, arrangement of any necessary secondary services and possibly other, generally shorter, follow up practitioner and carer contacts. It was anticipated that most of this activity would occur within the first six months. The four pilot case studies were therefore conducted with a second series of interviews at six months. However, upon review of the pilot case studies, it was found that much of the activity relating to casework occurred relatively soon after the first main contact and that by six months, carers' recollections of this could become hazy. Consequently, for the main phase of data collection (not in the pilot), it was decided to add another series of carer interviews approximately two months after the first main casework contact to improve the reliability of the study. The two month interviews were conceptualised as capturing 'short term' outcomes and the six month interviews as considering 'medium term' outcomes.

This study also included a long term point of data collection approximately two and a half years later. This provided a new opportunity to extend the understanding of the service level change created by casework. This also allowed more consideration of how the outcomes of casework could be affected by change relating to the other domains identified by Lewis (2007): individual, policy and structural. In terms of individual change, carers' circumstances and needs change over time (Nolan, et al., 1996) and thus this approach also enabled some long term consideration to be made of this and its relationship with the outcomes of casework. Whilst this research was not specifically focused upon assessing the impact of specific government policies or wider structural changes in society, the long term perspective taken also enabled some consideration of how this context influenced the outcomes of casework to be included. This study is unique in that none of the studies in the systematic review considered outcomes beyond twelve months

The longitudinal design of this study raises a question about whether the term 'outcome' is appropriate where multiple points in time are being considered. 'Outcome' implies that an end point has been reached and possibly also that this is the point where an intervention has had its full effect. However, casework is not a time bound intervention. It may be delivered over different periods of time (see page 113). Its effects may also last for varying lengths of time including, for example, where carers might continue using secondary services accessed through casework for weeks, months or years. Even the final long term point of data collection could not be seen as a definitive end to casework as some change would have continued to occur after this. Whilst there was a rationale for the use of the four different points of data collection

as set out above, it was never anticipated that there could be an exact correspondence between data collection points and the impacts of casework.

Consequently, terms such as 'effects' or 'impacts' might be considered more appropriate to capture the changes occurring as a result of casework because it avoids the implication of an end point. However, the term 'outcome' is dominant in the evaluation literature and is also a key term in the language of the realist evaluation framework (Pawson & Tilley, 1997) used in this study. The term 'outcomes' is also used in other research evaluating casework interventions including where these assess change at multiple points in time (for example, systematic review references 9 and 11, page 74). Thus, it was decided to continue to use the term 'outcomes' to be consistent with this body of work and the realist evaluation framework. The long term data collection point alone could have been considered the outcome. Yet, as noted above, this was not necessarily an end point either (other than of the research) and it was not wanted to ascribe this particular point of data collection a privileged status. In addition, where outcomes at more than one point in time are being discussed together using different terms would make the language of the thesis more difficult. However, to mitigate the difficulty with the term 'outcomes', where outcomes at a particular point in time are being discussed in the presentation of the findings in chapters five, six and seven, these have been specified as 'immediate', 'short term', 'medium term' and 'long term' outcomes (relating to the four different points of data collection, immediately after the first main contact of casework, approximately two months later, approximately six months later and two to three years later).

Whilst data collection was pursued at particular points in time, interview timings had to be flexible to an extent to respond to participants' other commitments. The mean time and range of times at which interviews actually took place are shown in Table 4.1 overleaf. This shows, for example, that the carer short term interviews, which were intended to be held approximately two months after the first main contact of casework, took place on average nine weeks after this. This table also shows, for example, that the earliest of these carer short term interviews took place seven weeks after the first main contact of casework and the latest was conducted fourteen weeks after the first main contact of casework. The main phase of data collection was staggered with first observations undertaken from January 2010 until March 2011 and all final long term interviews completed by March 2013.

Table 4.1: Timing of interviews

		<i>Categorisation of data collection point</i>			
		<i>Immediately after the first main contact of casework</i>	<i>In the short term (intended to be approximately two months later)</i>	<i>In the medium term (intended to be approximately six months later)</i>	<i>In the long term (intended to be two to three years later)</i>
<i>Carer interviews</i>	<i>Mean timing of actual interviews after the first main contact of casework</i>	8 days	9 weeks	6.4 months	2 years 7 months
	<i>Range (minimum and maximum timing of actual interviews after the first main contact of casework)</i>	2 to 25 days	7 to 14 weeks	5.5 to 8 months	1 year 11 months to 3 years 2 months
<i>Practitioner interviews</i>	<i>Mean timing of actual interviews after the first main contact of casework</i>	7 days		7 months	
	<i>Range (minimum and maximum timing of actual interviews after the first main contact of casework)</i>	0 to 35 days		5 to 9 months	

4.5 Observational data

4.5.1 Observational data collection

I collected observational data upon the first main meeting between the carer and practitioner through audio-recording. This was not intended to be a traditional ethnography centring upon participant observation in order to immerse oneself in and understand deeply a particular culture and/or community. Instead, this was a part of a wider data collection strategy and acted as a foundation for the interview stage of data collection. I acted as an 'observer as participant' rather than a participant observer. I was involved in the initial introductions including seeking consent for and beginning audio-recording of the meeting and at the end of the meeting. I was also occasionally drawn into the content of the meeting briefly. However, I generally sought not to be involved as I was not seeking to achieve an 'insider' view but instead to collect data upon the interaction between the practitioner and carer. The potential influence of my presence is discussed further in the next section.

The observation had two purposes. Firstly and critically, the observational data acted as an important foundation for the subsequent interviews undertaken with carers and practitioners. It helped facilitate and improve the reliability of these in a number of ways. Some previous research into carer assessment [25,26,27] encountered difficulties because carers had trouble remembering even having an assessment, let alone what this had involved and any outcomes achieved. This severely limits the evidence that can be presented. Collection of data at this point was critical to address potential difficulties that carers and practitioners might have had recalling exactly what occurred in this contact. Topics including particular services and needs brought up in the first main contact were followed up at later stages even where the carer or practitioner had forgotten about or did not raise these.

Collection of information during the first main contact also meant that the carer and practitioner did not need to repeat certain things within research interviews. In addition, being present before and after this first main contact provided some opportunity for myself, as the researcher, to become acquainted with the carer and practitioner and to build some rapport to facilitate subsequent research interviews. This was particularly important given that later interviews were to be conducted on the telephone, a mode of contact in which it can be more difficult to build rapport (Irvine, 2012).

Secondly, the observation provided some data used within the analysis in its own right covering evidence of direct, immediate outcomes occurring within the first main contact and of the contextual characteristics of this first main contact and mechanisms at work. Detailed notes were made through listening to this recording in accordance with this structure. The notes were coded into the categories summarised in Table 4.2 which also provides the purpose of these and example data. The recordings were not transcribed because of the large volume of data involved alongside the considerable body of interview data. Full transcription and use of a method of analysis such as conversation analysis probably would have generated some further insight here. However,

the time required for this would have made it impossible to fulfil the broader data collection strategy which was judged to be more important in providing a comprehensive picture of casework, its impacts and how these were achieved. This reflected the understanding of casework in which this first main interaction was one (important) part of a wider web of interactions and activity that overall constituted casework rather than this first main meeting being a complete activity in itself.

Table 4.2: Coding of observational data

<i>Categories of code</i>	<i>Example data</i>
For use in data analysis	
Context of meeting	Home visit, person receiving care present
Background detail	Carer works part-time, Practitioner has been in role for 2 years
Topic covered in first main contact	Paid employment
Participant actions (achieved verbally)	Practitioner raised topic, Practitioner offered reassurance, Carer expressed thanks
Outcomes	Application for Blue Badge completed, Carer expresses relief from talking
For use in future interviews	
Needs and interests identified	Carer needs help with benefits claim
Planned actions	Practitioner to refer to OT

4.5.2 The impact and influence of the researcher

Critical realism is concerned with understanding the underlying reality of the social world and this includes recognising that the research itself takes place within a real context. Consequently, there is a need to be concerned with how the researcher and the research processes impact upon the knowledge gained (Maxwell, 2012). At the beginning of the observation of the first main contact, practitioners and carers were asked to behave as if I was not present and to continue as they would otherwise do. However, this does not mean that this necessarily occurred in practice. Accordingly, practitioners were directly asked how, if at all, my presence at the first main contact influenced what they did or said and carers were also later asked about any influence their participation in the research had. Some practitioners and carers also made comments during the first main contact itself or elsewhere in interviews which suggested the research had had some impact upon casework.

In a minority of cases (three), quite a substantial change in the context of the intervention was reported. In one case, a home visit was used when the practitioner thought otherwise she might have just made a phone call initially. In another case, a different room was used to ensure there was space for the researcher as well. The practitioner perceived the room used to have a more

formal feel than the usual space. She thought this was perhaps less conducive to encouraging the carer to be open, although there was no evidence of this impact in the carer's interview responses. In another case, the practitioner did not have a colleague accompanying him as usual because my presence fulfilled safety requirements for conducting visits in pairs. He thought this made some difference as the colleague would normally add anything he might have forgotten and this made it harder for him simultaneously to continue the conversation and make some notes. The conclusions of the research suggest that the context of a home visit may be conducive to improvements in emotional well-being and so this may have had an influence in this way. There was no evidence linking other features of the physical environment to outcomes. The influence of the last contextual factor is unknown as this form of casework where two colleagues attend together was not otherwise included in the research.

There was evidence that practitioners sometimes also modified the content of their approach to casework. Practitioners commonly reported feeling slightly self-conscious to begin with and aware of being recorded in the first main contact but they said they quickly forgot about this. There is no evidence that this feeling had a substantial impact. What was likely to be of greater importance was evidence from some practitioners that they had attempted to provide the best possible service because the case was being externally evaluated. This was evident in a number of forms. Three practitioners reported trying to ensure particularly comprehensive coverage of topics within first main contacts. One practitioner reported making more follow up contact with the carer than they otherwise would have done. Another said she had made more thorough notes about what had happened in order to facilitate reporting back to me. These practitioners were very candid about the influence of the research. It is perhaps reasonable to assume that there may have been some additional efforts more widely. This suggests that the practice included within the research is likely to tend towards being relatively good practice. This does not invalidate the findings as the intention was to build knowledge towards models of good practice rather than necessarily a naturalistic assessment of all practice. However, it is important to be aware of this.

There were some indications that the carer's input to the first main contact of casework was influenced slightly by my presence or by being recorded. There were occasional signs within the first main contact that the carer wanted to explain their situation more fully to me as well as to the practitioner. It was twice suggested by practitioners that my presence and being recorded might have caused carers to be less open in the first main contact of casework. There were five specific cases within the research where the practitioner felt the carer did not open up. However, in two of these cases, there was conflicting evidence from the carer who expressed that they did do so. In the other cases, a range of reasons were suggested relating to this as well as the possibility that my presence and being recorded might have influenced this. In one case, the practitioner felt the carer might open up over time as they built a relationship and later reported that this did occur. In another case, the practitioner suggested that the carer did not have needs of this kind and the carer also reflected this. In the final case, the carer had a negative attitude

towards and low expectations of support before the meeting which may have influenced this. The practitioner also considered whether this was partly the carer's personality or the influence of being recorded. Thus, there was not any clear evidence that my presence or being recorded substantially altered the carer's involvement in the first main contact of casework.

4.6 Semi-structured interviews

4.6.1 Interview design

A series of semi-structured interviews was undertaken individually with carers (at all four points in time) and practitioners (immediately and in the medium term) as shown previously in Table 4.1. Interviews were all digitally recorded (with participants' consent) and were transcribed with the exception of the long term carer interviews (see page 117). Interviews took the form of what Rubin and Rubin term 'topical interviews' in that they focused upon particular events and processes and thus they needed to be reasonably structured and directed (2005). This follows other examples of qualitative research taking a critical realist approach (Longhofer, Floersch, & Hoy, 2013). The interview guides were specifically designed to find out about and to some extent, to try and link together the outcomes achieved through casework and the mechanisms and relevant contextual factors explaining these. Thus, at each stage of data collection they asked questions about this in accessible language. The basic interview guides are provided in Appendices 2 and 3. These were individually tailored for each interview prior to its conduct to take account of preceding data collected about the particular case and sometimes additional questions were also added where review of the previous interview transcript noted a particular gap in information. This tailoring of interviews thus improved the overall reliability and validity of the dataset.

The interview guides asked separately about the impact of the different aspects of casework in order to distinguish these thereby improving the validity of the conclusions drawn about these. The first interview and a section of the short, medium and long term interview guides therefore asked about the impact that contact with the practitioner had. Another section of the short, medium and long term interview guides asked about any secondary support services used. This specifically asked how each was arranged in order to establish the role of the practitioner in this and hence establish the validity of claims about these outcomes of casework. This then asked about the difference this secondary service made. In the interviews, the carer was also asked about the overall impact of *all* the practitioner support and secondary services used to gather an overall indication of impact. It was recognised from the pilot interviews that carers may not segregate feelings and outcomes so this provided an opportunity to respond to this. In addition, it recognised that outcomes also do not necessarily exist entirely independently and may influence each other (Byng, Norman, & Redfern, 2005). This also enhanced the reliability of the data collected by providing an opportunity to bring together earlier responses. Carers and practitioners were asked initially for their unprompted responses on outcomes, but they were later also prompted to

consider the outcome domains identified within the systematic review to ensure that data collection was comprehensive and reliable. The systematic review findings were also used in the questionnaire design to ensure data on contextual characteristics (carer, practitioner and service based) potentially identified as relevant was collected. This construction of the interview guides meant that interviews could feel a little repetitive at times with respondents sometimes feeling that they had little more to say. Whilst this could occasionally feel a little awkward, this also suggested that the topics had been exhausted rather than important information being missed.

Within qualitative research, it is important that interviews are not too rigid to ensure that issues and perspectives of importance to participants are adequately covered (Jones, 2004). Thus, whilst the interview guides included quite a lot of questions focused upon specific areas of concern, questions were phrased in an open manner to encourage participants to talk about what was of significance to them. Participants were also given the opportunity to raise any other matters and where this happened during conversation, these issues were also pursued. Questions were also framed to try and avoid presuppositions about what had occurred, for example, by asking 'what effect, if any, has contact with the service had upon X outcome?'. Some questions were also included to help make judgments about the nature of the evidence collected. For example, practitioners were asked to comment on how the particular cases studied might differ to their usual work.

Table 4.3 overleaf shows the number, average length and mode of the interviews conducted for the study. The majority of the interviews were undertaken by telephone. However, some of the first set of practitioner interviews were undertaken face-to-face just after the observation of the first main contact. The pilot interviews had indicated that this would probably often be a time efficient approach for both the researcher and the practitioners involved rather than trying to identify a separate suitable time slot. Some practitioners participated in more than one case (see page 100) which meant that sometimes they discussed more than one carer, in turn, within a single interview. However, in Table 4.3, practitioner interviews discussing more than one carer have been divided in length by the number of carers considered and counted as separate interviews in order to ensure that the scope of the interviews of different modes (face-to-face or telephone) compared was similar.

All carer interviews and the remaining and later stage practitioner interviews were undertaken by telephone. Conducting interviews by telephone made the process of data collection manageable given the number of interviews to be conducted (170 were ultimately undertaken). This enabled the valuable longitudinal approach to be taken by making it practically manageable. It is questionable whether carers would have been willing to receive four face-to-face visits. Given that carers are very busy and often have to change their plans to accommodate the requirements of caring, telephone interviews also offered more flexibility in terms of the timing of interviews and in re-scheduling where necessary.

Table 4.3: Interview length and mode

<i>Interviewee and time point of interviews</i>	<i>Number of interviews</i>	<i>Mode</i>	<i>Average length</i>
<i>Carer interviews</i>			
- immediately after the first main meeting	33	Telephone	39 minutes
- in the short term	26	Telephone	29 minutes
- in the medium term	28	Telephone	33 minutes
- in the long term	23	Telephone	18 minutes
<i>Practitioner interviews (per carer)</i>			
- immediately after the first main meeting	12	Face-to-face	32 minutes
- immediately after the first main meeting	23	Telephone	36 minutes
- in the medium term	25	Telephone	26 minutes

It has been noted that participants may talk less in telephone interviews and there have been some indications that communication between participants may not be as clear as in face-to-face interviews (Irvine, Drew, & Sainsbury, 2010). However, empirical research studies have also found that telephone interviews can be used to gather qualitative data of similar quality to that collected in face-to-face interviews (for example, Sturges & Hanrahan, 2004). The importance of the mode of contact is likely, at least partly, to depend upon other characteristics of the research study and participants. It was felt that the focused nature of these interviews and their relationship to an event (the first main contact of casework) that the researcher and interviewee had both attended would help facilitate the conversation. The telephone interviews undertaken with practitioners actually turned out to be slightly longer on average than the face-to-face interviews conducted with practitioners. Care was also taken within the telephone interviews to provide verbal indications that the researcher was listening and finding the responses helpful to encourage full participation. However, it was more difficult to judge how respondents were feeling during the interview without being able to see facial reactions or body language.

4.6.2 Interview construction

Interview data is constructed through the interaction between the researcher and interviewee (Maxwell, 2012; Rapley, 2007). Thus, the nature and quality of this data depends upon the interviewee and also the researcher's skill, approach and personal characteristics. The pilot interview transcripts were reviewed to consider how, I, as the researcher might improve the quality of the data collected. This highlighted that I needed to probe more fully in interviews particularly where a respondent was not very forthcoming.

My own personal characteristics also influenced the relationship and interactions I had with participants. My perception was that my characteristics as a relatively young woman (younger than nearly all of the participating practitioners and many of the carers) in the role of a student with a fairly quiet

personality probably acted to limit perceptions that I was a threat. This was probably particularly helpful in terms of my interactions with practitioners who might have been concerned about judgements being made about their practice.

The position I aimed to take within interviews was of being empathetic but not over involved (Rubin & Rubin, 2005). I was happy to offer some personal information where it arose naturally. For example, in the arrangement of interviews, it often became apparent to participants that I was either pregnant or had a young child/children. This led to some natural conversation and appeared to help build rapport. However, aside from being a mother and from seeing others in my family provide care, I did not have direct personal experience of care to share or to influence the interaction of the interviews. Equally the fact that I have not worked in similar roles to the practitioners also meant I did not share this type of experience with practitioners during interviews. This limited the particular preconceptions I had but also potentially limited the potential insight I had into respondents' viewpoints. The fact that I was not a practitioner may also have been helpful in that it limited the likelihood of carers perceiving me as another source of information rather than a researcher during interviews.

What somebody says to another depends upon what they think the other is 'up to' (Jones, 2004). A particular difficulty with evaluation research is that participants are aware that a service is being evaluated and may wish either to provide a particularly positive or negative view on the service to support or damage the provider. An interview account can be seen as offering one particular meaning of the subject (Silverman, 2013). For example, a carer may present a particular account of casework to a researcher, but a different one to a friend or family member (where there is not the same perceived consequence arising from the viewpoint given). The relatively structured nature of the interview guide focused on specific experiences, rather than general views of the service, aimed to overcome this to an extent.

The satisfaction level of those using a service will depend upon an array of contextual factors (for example, expectations about support and whether the service is perceived as a favour, an entitlement or sanction) (Shaw, 1999, p. 161-162). This was likely to influence carer responses, even though the intention was to focus upon outcomes rather than satisfaction generally. This was borne in mind in analysis and questions were also included within the interviews about carers' expectations and their pathway to casework. This helped to understand underlying motivations for the ways in which carers might construct interview accounts.

Different motivations underlay practitioners' accounts in the research interviews. As noted in relation to the observations, generally and understandably, practitioners were keen to demonstrate the positives of their work. However, this did not generally appear overstated or unjustified. Practitioners also noted limitations to their work and questioned particular actions they had taken as they reflected upon their work during interviews. It may still be that overall, they were more likely to focus on the positives than

the negatives. Some practitioner accounts about later carer outcomes were speculative because practitioners had not had further contact with carers. This type of information was excluded from the analysis. In contrast, some practitioners referred to quite detailed notes (and sometimes correspondence) they had kept on a case which provided more confidence in consequent detailed answers about activities.

A number of specific impacts of the research interviews upon carers were identified. Over time, the research interviews evidently reminded three carers of the organisation they had had contact with and the availability of various secondary services. However, there was no evidence that this actually led to additional contact or use of services. As discussed in the findings (page 128), some carers found the research interviews provided a useful opportunity to talk indicating an unmet need of this kind. Five carers also reported valuing the fact that their issues were being recognised and hoped that this would make a difference to other carers. Thus participation in the research did have some impact upon carers but there is no clear evidence that this specifically altered the outcomes of casework, their mechanisms or influential contextual factors.

4.7 Sampling

The approach to sampling was purposive (Silverman, 2013). It was intended to include interventions and carers with a range of characteristics to facilitate comparisons to generate greater insight into casework and responding to the potential importance of these indicated in the systematic review. This would enhance the external validity and use of the findings. Sampling also necessarily had to be pragmatic to an extent and respond to the willingness of services and practitioners to participate.

4.7.1 The sample by intervention characteristics

The sampling strategy began by inviting different organisations providing casework to carers to participate. Organisations were approached in accordance with key intervention differences identified through an initial mapping of interventions in order to sample purposively. Table 4.4 on page 99 provides details of the forms of casework included in the final sample of case studies.

The first key difference related to the organisation type (local authority, third sector carer organisation or condition specialist organisation) providing casework. A list of local authorities acted as the sampling frame for these organisations. The list of third sector carer organisations belonging to the Carers Trust network was used as the sampling frame for this type of organisation. (Thus, the third sector carer organisations included were all members of the Carers Trust network and were registered charities run by paid employees, not volunteers.) There was no known list of third sector condition specialist organisations offering casework with carers to use as a sampling frame. Instead a list of such organisations was compiled through

internet research. Using these sampling frames, organisations to approach were then also prioritised according to how easily accessible they were to the researcher in terms of their geographical location for reasons of practicality. This meant that sites were primarily in the West Midlands region but with some also in the East Midlands and South East regions of the UK. These included organisations serving primarily city populations and others serving mainly rural populations.

The focus of the study was primarily upon third sector generic carer services as a service provider neglected within existing research. Accordingly, over half of the thirty seven cases (twenty one) centred upon this type of intervention. Six case studies where casework was carried out by third sector condition specialist organisation were included to compare and contrast their specific approach. Ten case studies of local authority work were also included as a comparator. These cases all consisted of a statutory carer assessment with one exception where information, advice and support were given informally. During the pilot case studies, it was learnt that some third sector carer organisations were beginning to conduct statutory carer assessments on behalf of the local authority. This potentially constituted an interesting new form of casework and efforts were made to include this within the study. Subsequently three cases of this type were included. Another interesting opportunity arose during the fieldwork and was taken to include a case which involved both a statutory carer assessment worker and a third sector condition specialist worker working in partnership to conduct casework together with a carer within one appointment.

An initial mapping of third sector generic carer services showed that these services were organised in different ways in terms of the mode and location of the first main contact of casework. This included home visits, drop-in and appointments at service offices and telephone help-lines. It was hypothesised that this might be relevant to outcomes and so the aim was to include a range of interventions in this respect. Home visits and appointments and drop-in visits at centres were well represented. However, it was difficult to find telephone help-line services and practitioners willing to ask carers if they were happy for their initial phone call to be recorded because of concerns that carers would find this off-putting. One service was identified where it was possible to seek initial consent prior to carers' first main telephone contact with the service. This service distributed their own promotional material to locations such as GP surgeries which carers could complete and return to express an interest in hearing from the carer service. They were then first sent an information pack before receiving a phone call. A research information leaflet was included in this information pack for carers to return to indicate if they would be willing to participate in the research. A low response rate within the timeframe of the research meant that it was only possible to include two cases of this type.

As chapter two notes, the personalisation agenda has been a key development in social care policy recently. It was known that some, but not all, local authorities (and some third sector organisations as noted in the pilot case studies) had begun to offer carer one off direct payments. Hence, it was

intended that at least a third of the sample should consist of cases where this type of personalised support was available to carers (given that at the time of data collection, the target for local authorities was for at least 30 per cent of all service users to receive Personal Budgets). This was easily achieved with more than half of the sample (twenty four of thirty seven cases) being offered some kind of one off carer payment.

Table 4.4: Sample characteristics by intervention

<i>Organisation type</i>		<i>Type of intervention</i>	<i>Mode & location of first main contact</i>	<i>Practitioner specialism</i>	<i>Number of case studies</i>
Third sector	Carer service(7)	Information, advice and emotional support	Telephone help-line	Generic carer worker(1)	2
			Face-to-face: 7 home visits, 3 service appointments	Generic carer workers(5)	10 (including 3 pilot)
			Face-to-face, service appointment	Carer mental health specialist(1)	1 with no follow-up
			Face-to-face, drop-in service	Generic carer workers(4)	5
	Condition specialist service(4)	Statutory carer assessment on behalf of the LA	Face-to-face: 1 home visit, 2 service appointments	Generic carer workers(2)	3 (including 1 pilot)
		Information, advice and emotional support	Face-to-face home visits	Condition specialist carer workers(4) BME specialist(1)	6
Local authority(3)		Statutory carer assessment	Face-to-face home visits	Carer specialists within older people(1), learning disabilities(1), younger adults with disabilities(1) teams, BME carer specialist worker(1)	9 (including 2 with no follow-up)
		Information, advice and emotional support	Face-to-face home visits	Older people specialist with a carer interest(1)	1

4.7.2 The sample by practitioner characteristics

As a result of a review of the pilot case studies, individual practitioners were asked to participate in no more than three case studies (and generally not more than two) in order to include practitioners with a range of characteristics and approaches to casework. In total, twenty two practitioners took part in the research. Eight participated in one case study, twelve took part in two case studies each and two practitioners participated in three case studies.

As a preference, where possible, all practitioners within a service were invited to participate. However, in some cases, managers requested that certain practitioners were approached to take part due to service preferences in terms of workload and availability (and possibly other uncited reasons). It is difficult to know how this may have influenced the nature of the practitioner sample. In addition, many practitioners themselves chose not to take part. Service managers were first approached about participating in the research and generally once contact was made, they were interested. Practitioners were less willing ostensibly because they felt the presence of a researcher at their first main contact with the carer could be off-putting for the carer. Consequently a considerable amount of time and effort was spent recruiting sites and practitioners. Some practitioners were very happy to take part which perhaps suggests an attitudinal difference between practitioners who did and did not participate. It seems likely that those who took part were more confident practitioners with a more open attitude to research and practice development. It might reasonably be suspected that this might tend towards representing better practice within the field.

A variety of practitioners were included within the research in terms of their specialisms. These related primarily to the type of organisation for which they worked (as shown in Table 4.4). It had been hoped to include some non-carer specialists within local authority social care departments and also condition specialist carer workers employed by third sector generic carer services. This was not achieved because of the difficulties encountered in recruiting practitioners generally. It is important to note that the statutory carer assessments included within this sample were conducted by carer specialists, given that many statutory carer assessments will not be undertaken by carer specialists. Those included within this research could consequently be expected to represent relatively good practice with carers.

Practitioners had varied backgrounds in terms of their training and qualifications. Four practitioners had qualified as social workers (two of these were now working for third sector organisations rather than in roles specifically for qualified social workers). The largest group, eight practitioners, had some other form of social care qualification. Three practitioners had some training in counselling. Two practitioners had a health background, one as a psychologist and one as a nurse. Four other practitioners had no particular training or qualifications relevant to their role (other than personal experience as noted below).

Most of the twenty two practitioners who participated were female (nineteen), over the age of fifty (seventeen) and had been working in this role for some time (eighteen for at least two years). Hence they were generally experienced, older women. The majority of practitioners were of white British ethnicity. One practitioner was white from another European country. A reasonably sized minority (five) were from ethnic minority groups including: Black British (one), Pakistani (one) and Indian (one). (The ethnicity of the remaining two was not specified because they did not take part in the interviews, see page 105 on sample attrition.) Nearly all the practitioners talked about having some personal experience of caring or at least of a close family member caring for another family member. Two of the practitioners working for condition specialist organisations did not have personal experience of caring but did have personal experience of the relevant medical condition. Given the level of experience and also the personal empathy practitioners could be expected to have with carers, again it seems reasonable to anticipate the sample would represent relatively good practice in this field. That said, the researcher's wider experience of meeting staff teams offering casework to carers suggested that these demographic biases within the sample reflected general biases within this group of employees rather than being specifically related to those willing to participate in the research.

4.7.3 The sample by carer characteristics

Once services and practitioners had agreed to participate, carers were initially randomly invited to participate. The one exception was the two cases who self-selected to participate by returning an expression of interest to the telephone help-line service through the process of recruitment explained previously. Some criteria were used to exclude certain types of carers from participation covering: those involved in terminal care; where adult or child protection issues had been identified; where there was very strong suspicion of outside bodies by the carer or their family; and anyone unable to give informed consent. A minority of carers approached chose not to participate (and three withdrew following their first main contact with the service). The characteristics of the minority who chose not to participate are not known but as discussed below a wide range of characteristics was present amongst the participating sample.

As recruitment progressed, key socio-demographic and caring characteristics were monitored (as listed in Table 4.5) to ensure that a diverse sample was achieved and thus to enhance the external validity of the findings. Some specific efforts were later made as necessary to recruit carers of a particular type. For example, some carers from black and minority ethnic communities were specifically recruited via the participation of a specialist black and minority ethnic carer assessment worker. Ultimately four carers from the following black and minority ethnic communities participated: Bangladeshi (one), Pakistani (two) and Black British (one).

Details of the characteristics of the carers included in the sample are provided in Table 4.5 alongside national statistics on the carer population. The carer

survey data for England is taken from the 2011 Census for gender, age, ethnicity and employment and from the 2009/2010 Carers in Households Survey for length of caring role, hours spent caring per week, condition of the person receiving care and relationship of carer to the person they care for. The wider population of carers who used casework may obviously not have the same characteristics as the national carer population as a whole. Given that the sample used here was a small qualitative sample, it was not intended that it would be entirely representative. However, it was intended that all of these categories would be represented where possible to achieve breadth in the sample. This was broadly achieved but there were some differences in the breakdown of the research sample and survey profiles of carers which it is useful to be aware of as now discussed in more detail.

As Table 4.5 shows, in relation to key socio-demographic characteristics of gender, age and ethnicity, the sample was broadly representative of the national carer population. However, no carers were recruited within the 18-24 age bracket. The 2011 census only provides data for the 0-24 age bracket where 7 per cent of the population were identified as carers, thus a smaller number than this would be expected to fall within the 18-24 category. This lack of representation may also relate to the fact that other research has noted that these carers can slip through a gap between young carer services and adult carer services (Becker & Becker, 2008). Two carers were recruited within the 25-29 age bracket which enabled some inclusion of the perspective of younger adult carers.

The proportion of carers who were employed was lower within this sample than in census statistics. The majority of working carers included within this research were working part-time rather than full-time. Other research has found that higher proportions of carers outside paid employment have had carer assessments than working carers (and higher proportions of part-time employees have compared to full-time employees) (Yeandle, Bennett, Buckner, Fry, & Price, 2007). In addition, given that the services included within this research primarily operated during normal working hours, it would have been more difficult for carers in full-time paid employment to access them compared to other carers.

A higher proportion of carers in this sample (21 percent) had begun their caring role in the last six months compared to nationally (4 percent). This is probably again to be expected given that the focus on this study was upon carers' first contact with a service. Carers who are new to their role can be expected to have particular needs, for example, accessing new benefits entitlements. There was also a higher proportion of carers in this sample who were caring for over fifty hours per week, about half, compared to nationally where just under a quarter of the carer population were reported to do so. Again this is not necessarily surprising given that those with more intensive caring roles may have greater needs for support.

The sample used here included a mix of carers in terms of the condition of the person they cared for and their relationship to the person receiving care. This differed somewhat to the national breakdown. There was a higher proportion

of carers caring for a parent in this study compared to nationally and conversely a slightly lower proportion of carers caring for a child in this study compared to nationally. This may also have some relationship to the slightly higher proportion of carers caring for someone with dementia in this study compared to nationally.

Table 4.5: Carer sample characteristics compared to survey data

	<i>Carer survey data for England</i>	<i>Research sample</i>
<i>Carer gender</i>		
Male	42%	38%
Female	58%	62%
<i>Carer ethnicity</i>		
White	89%	89%
Black and minority ethnic	11%	11%
<i>Carer age</i>		
0-24	7%	0%
25-49	35%	41%
50-64	36%	35%
65+	22%	24%
<i>Carer employment</i>		
Employed	53%	30%
Not employed	47%	70%
<i>Length of caring role</i>		
Less than 6 months	4%	21%
6 months to less than 5 years	45%	26%
5 years or more	52%	53%
<i>Hours spent caring per week</i>		
1 to 19 hours	64%	35%
20 to 49 hours	13%	14%
50 or more hours	23%	51%
<i>Condition of the person receiving care</i>		
Dementia	10%	22%
Learning disability	11%	19%
Mental health difficulty	13%	8%
Problems connected to age	17%	16%
Other	49%	35%
<i>Relationship of carer to the person they care for</i>		
Parent	33%	19%
Spouse/partner	26%	32%
Adult child	13%	32%
Other	28%	17%

Practitioners were asked if there was anything unusual about the cases they worked upon which were included within the research. This provided some opportunity to gauge if there were any other factors relating to representation that needed to be borne in mind. Practitioners were only commenting on the small number of cases that they were directly involved with rather than upon the sample as a whole. Some comments were made which related directly to individual cases and did not have a wider representation. However, six practitioners commented that they felt the carer had relatively limited needs compared to the wider carer population with whom they worked. There were also two practitioners who conversely thought that the carers they worked with in the research had particularly extensive needs. It needs to be borne in mind that you might expect practitioners to want to evidence positive outcomes and thus to highlight that other cases might generate more extensive outcomes. In other conversations within the interviews, practitioners also commented that needs varied considerably with some carers having quite simple, straightforward requests. It may then be that there is slight under-representation of the extent of carer needs and of the outcomes that casework can achieve but it seems unlikely that this is a serious bias.

The sample included sufficiently wide a variety of caring situations and contexts to consider the influence of this upon outcomes. The variation noted between the research sample and the national carer population seems most likely to be explained by differences between casework services' wider user population and the national carer population. Thus, there is no clear evidence of any particular bias in this sample of carers as casework service users, although as a small qualitative sample, it is obviously not possible to claim it is entirely representative.

4.7.4 Sample attrition

Considerable efforts were made to collect as full a dataset as possible to enhance the quality of the data including: making multiple contacts at different times; being flexible about interview timing; and writing letters where contact was not achieved through telephone. Table 4.6 on page 107 shows the number of carer and practitioner interviews successfully completed at different stages of the research. Sometimes some of the gaps were filled to an extent by data collected in subsequent interviews. There were a number of different reasons why it was not possible to collect complete interview data for all the cases explained below.

- Fewer data collection points were used in the four pilot case studies.
- Following observation of the first main contact of casework, three carers and one practitioner decided not to participate in the interviews despite having expressed initial willingness to do so.
- One practitioner (in the one case where two practitioners from different organisations worked in partnership) chose only to participate in the observation and not in the interviews.
- Three carers had been recently bereaved at different points in the research and so it was not appropriate to request further interviews.

- It was no longer possible to make contact with five carers and two practitioners at different points in time either because of changes in their contact details or a lack of response indicating they did not wish to continue to participate.
- On two occasions, a carer chose not to take part at specific points in time because they did not have anything they wanted to report.

Table 4.6: Interviews successfully completed

	<i>Carer interviews</i>				<i>Practitioner Interviews</i>	
<i>Case study</i>	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>1</i>	<i>2</i>
1 (pilot)	√	X	X	X	√	X
2 (pilot)	√	X	X	X	√	X
3 (pilot)	√	X	√	X	√	X
4 (pilot)	√	X	√	X	√	√
5	√	√	√	√	√	√
6	√	√	√	√	√	√
7	√	X	X	X	X	X
8	√	√	√	√	√	√
9	√	√	√	√	√	X
10	X	X	X	X	√	X
11	√	√	X	X	√	X
12	X	√	√	√	√	√
13	X	X	X	X	√	X
14	√	√	√	√	√	√
15	√	X	√	√	√	√
16	√	√	√	√	√	√
17	√	√	√	√	√	√
18	√	√	√	√	√	X
19	√	√	√	√	√	√
20	√	√	√	√	√	√
21	√	√	√	√	√	√
22	√	√	√	X	√	√
23	√	√	X	X	√	√
24	√	√	√	√	√	√
25	√	√	√	X	√	√
26	√	√	√	X	√	√
27	√	√	√	√	√	√
28	√	√	√	√	√	√
29	√	√	√	√	√	√
30	√	√	√	√	√	√
31	√	√	√	√	√	√
32	√	√	X	X	√	√
33	X	X	X	X	X	X
34	√	√	√	√	√	X
35	√	√	√	√	√	X
36	√	X	√	√	√	√
37	√	X	√	√	√	√
<i>Total interviews</i>	33	26	28	23	35	25

4.7.5 Sub-samples by intervention type

The research includes some comparison of the outcomes and processes of the different forms of casework with carers offered through generic third sector carer organisations, condition specialist organisations and statutory carer assessment. Given the small sub-sample sizes, it was not possible to ensure that each of the sub-samples covered by these different intervention types was entirely representative or balanced. However, it is useful to be aware of any notable differences between these sub-samples when making comparisons.

Analysis of the sub-sample of carers within the research who had an appointment with a generic third sector carer organisation found the following. Compared to carers in contact with other types of organisation, more of these carers proportionately were: caring for less than fifty hours per week; did not have any existing support in place for the person receiving care; and approached the service with an open attitude towards, but few expectations of support. These carers mainly approached the organisation themselves for support (of various kinds) rather than vice versa.

Analysis of the small sub-sample of six carers within the research who had an appointment with a condition specialist organisation found the following. Compared to carers in contact with other types of service, more of these carers proportionately were: over the age of 65 (and therefore retired); the spouse of the person they were caring for; and were caring for more than fifty hours per week. In all of these cases, contact with the organisation had either been instigated by the professional via health services or the carer had been referred by health services.

Analysis of the sub-sample of carers within the research who participated in a statutory carer assessment conducted by the local authority found the following. Compared to carers in contact with other types of organisation, more of these carers who had an assessment proportionately were: male, under the age of 65; of black and minority ethnic ethnicity; caring for over fifty hours per week; already had some support services in place for the person receiving care; and had low expectations of support having had some previous negative experience of contact with services. Their carer assessment was also more likely to have been suggested by another professional to consider their general needs rather than initiated by themselves.

These differences are mainly what might be expected. Those who participated in a carer assessment had often been offered this because the person they cared for was already receiving some services via the local authority. This was also likely to reflect the fact that the person they cared for had more extensive needs leading to a relatively intensive caring role. The direct relationships the condition specialist organisations had with health services enabled practitioners to approach carers directly to offer support more frequently within this sub-sample. Carers with less extensive roles might be more likely to approach a third sector carers organisation (who publicise themselves to the general public) for support rather than to go to the local

authority. These differences have been borne in mind in the following analysis.

4.7.6 Understanding the practice of casework in this sample

The following discussion provides some further contextual understanding of the nature of the casework undertaken within the particular sample in this research. This draws upon documentation collected during the study on overall organisational and service aims, the job descriptions of the practitioners delivering casework, practitioners' interview responses and recordings of the first main meeting between practitioners and carers.

There were a number of key dimensions of difference in the context and form of casework for carers as delivered by the three different types of organisation: third sector generic carer organisations, third sector condition specialist organisations and local authorities (in the specific form of statutory carer assessment). These are summarised in Table 4.7 and then discussed in turn. There was some blurring of these boundaries in four specific cases. The research sample included three cases of statutory carer assessment conducted by a third sector carer service on behalf of the local authority. In these cases, the nature of casework conformed to that of statutory carer assessment with the exception that practitioners were also able to offer direct access to the secondary services that their own third sector organisation directly provided. The sample also included one case where a local authority practitioner did not undertake a statutory carer assessment but instead offered informal information, advice and support. This case was closer to the third sector carer service form of casework but without direct access to the secondary services directly provided by third sector carer organisations.

Table 4.7: The nature of casework

	<i>Third sector generic carer organisation support work</i>	<i>Statutory carer assessment</i>	<i>Third sector condition specialist organisation support work</i>
<i>How the nature of the service is determined</i>	By individual services and practitioners.	National legislation and statutory practice guidance, interpreted by services and practitioners.	By individual services and practitioners.
<i>Scope of casework</i>	Not proactively comprehensive but open to supporting carers in any area of their lives to improve carer well-being, to support the caring role and to enable a life outside caring.	Proactive comprehensive topic coverage including consideration of the carer's willingness to care, the sustainability of the caring role and the carer's wishes to undertake paid employment, education and leisure activities.	As for third sector generic carer services but including a particular focus upon increasing knowledge and skills relating to the medical condition.
<i>Use of documentation</i>	Basic carer details collected, some services used registration forms.	A comprehensive assessment form is completed.	Basic carer details collected, some services used registration forms.
<i>Temporal nature</i>	Predominantly one main face-to-face interaction with some proactive practitioner telephone follow-up in six months and consistent follow-up by mailings.	Predominantly one main face-to-face assessment interaction with occasional telephone or email follow-up to arrange agreed secondary support.	Mix of one or two face-to-face interactions with consistent proactive practitioner telephone and mailing follow-up until no further support is identified.
<i>Client focus</i>	Carer.	Carer.	One carer specific service, two primarily carer services, one service for the carer and the person receiving care.

	<i>Third sector generic carer organisation support work</i>	<i>Statutory carer assessment</i>	<i>Third sector condition specialist organisation support work</i>
<i>Direct provision of secondary services</i>	All provided complementary therapy, support groups and leisure activities/trips (some of these were also open to the person receiving care). Some also directly provided one-off carer payment schemes, emergency planning schemes and training.	The local authority's legal power to provide carer services was manifested in consistent provision of one-off carer payment schemes and occasional direct provision of other services. The local authority also had a duty to provide certain community care services for the person receiving care.	Limited direct provision of carer services. These organisations mainly provided support groups, sometimes exclusively for the carer but also for both parties.

At the time of data collection, statutory carer assessment was governed by several pieces of legislation: the 1995 Carers (Recognition and Services) Act, the Carers and Disabled Children's Act 2000 and the Carers (Equal Opportunities) Act 2004. Carer assessment was supposed to be undertaken within the framework of statutory practice guidance accompanying this legislation (Cass, 2005; Department of Health, 2001b, 2005a). Within this there were specific stipulations as to the content, form and aims of statutory carer assessment. However, practitioners may find ways of exercising discretion in the application of apparently prescribed procedures (Lipsky, 1980). In addition, the carer also exerts an influence upon the interaction (Twigg & Atkin, 1994).

The legal framework for statutory carer assessment sets out that this should be a holistic process focused upon *"the outcomes the carer would want to see help them in their caring roles and maintain their health and well-being"* (Department of Health, 2001a, p. 11). Carer assessments must consider the sustainability of the caring role in terms of the carer's ability to provide and to continue to provide care. The willingness of the carer to continue caring, or to continue providing the same level of support, should not be assumed. The assessment must consider the sustainability of care in light of the carer's health and safety and ability to manage daily routines and maintain involvement in other areas of their lives. The assessment must specifically consider any wish on the part of the carer to undertake paid employment, education, training or leisure activities.

The legal framework for carer assessment contrasts with the freedom that third sector organisations have to develop and provide the service they offer to newly identified carers. Whilst the third sector generic carer services which took part in the research were all members of the national Carers Trust network committed to recognising and supporting carers, they were all independent locally based charities with their own individual aims and services. The third sector condition specialist carer services which participated in the research were in three cases, local services of national condition specialist charities, and in one case, a local independent charity affiliated to a national condition specialist charity. Again each service had its own aims and functions.

Third sector carer services and the individual practitioners working within these were open to supporting carers on an individually tailored basis in any areas of their lives either immediately or as part of an ongoing relationship. However, they did not necessarily proactively seek to take an entirely comprehensive approach. This meant that not all potential topics, needs or available support were necessarily discussed in the first interactions of casework.

Whilst third sector organisations did not have particular duties to consider in terms of carers' well-being or willingness to care, they did have overarching aims. These varied by individual organisation but some key themes were identified. They were generally concerned with identifying and responding to carers' needs for support. This was in order to improve carer well-being

(potentially in a variety of ways including in terms of their mental and physical health and financial situation), to support and sustain the caring role and to allow carers to have a life outside of the caring role. They also sometimes referred to carers' control of their lives. However, there was a less explicit focus than in statutory assessment guidance upon the need to consider the carer's willingness to continue in their role. Third sector condition specialist services also had an explicit focus upon support to add to carers' knowledge and skills relating to the relevant medical condition and managing this. This latter role was not referred to by third sector generic carer services.

In line with the comprehensive approach of statutory carer assessment, assessment practitioners were required to seek information from carers in order to complete lengthy forms in the assessment meeting. In contrast, whilst third sector practitioners all gathered some basic details about the carer to keep on file, only some used registration forms to help structure the first main contact between the carer and practitioner. These forms were much shorter and less comprehensive than those used in statutory carer assessments. This allowed the first main contacts to take the format of a more free flowing conversation. However, depending upon the carer's emotional state and the existence of any particularly pressing dominant issues, third sector practitioners still tended to want to cover particular topics. They wanted to ensure that they found out generally about the carer's situation and the carer's well-being and that they gave information about possible support including that provided through their own organisation, other service providers and financial benefits.

Practice guidance indicated that assessment may be a one off or an accumulative process depending upon the particular needs and characteristics of the carer (Department of Health, 2001a). Within this study, the carer assessment was the main interaction used to identify any needs and the practitioner and/or carer would then take various actions to meet these needs. In just two cases of statutory carer assessment, a second face-to-face meeting occurred to consider further particularly difficult issues that the carer was facing. In another four cases of statutory carer assessment, a further one or two contacts were made by telephone to confirm the arrangement of support considered in the assessment (two of these comprised of cases where a third sector practitioner was conducting the assessment). In another case, the (third sector) practitioner made further later telephone calls to check on the well-being of the carer. Otherwise, there was no further contact between the carer and the assessment practitioner. Thus assessment was primarily centred upon one main face-to-face interaction.

Guidance suggests there should be a review of a carer assessment three months after a new care package is introduced or otherwise after six or a maximum of twelve months later or at the carer's request if their needs change (Department of Health, 2001a). In three cases, carers were told they would be proactively invited to have a review in twelve months but none of these carers reported having had one. All the other carers were told that they could request a further carer assessment in twelve months or if their circumstances

changed. Just one carer reported having had a second assessment almost two years later as a result of changes in the family's needs.

Nearly all of the third sector generic carer services also worked in this way with a first face-to-face meeting constituting the main interaction of casework. In two cases, this first main meeting occurred over the telephone as part of a telephone based helpline service. In two other cases, there were two main initial face-to-face contacts. In one case, this was because the completion of a benefits form took a long time. In the other case, this was because of the complex nature of the difficulties faced by the carer. In seven cases, there were also one or two phone or email contacts between the carer and the practitioner to follow up on particular needs or issues discussed in the first main contact.

There was more ongoing contact between the third sector generic carer practitioners and carers compared to in carer assessments. In two cases of third sector generic carer services, there was another face-to-face contact for a purpose unrelated to the initial contact. In one case, the practitioner was simply checking on the carer's well-being and in another, the carer was seeking some new support. In five cases, the practitioner made an occasional proactive phone call to check on the carer's situation in the first six months. In two cases, the carer also contacted the carer service again over time about a new matter in the first six months. Third sector carer services all also offered to send the carer a newsletter and other mailings regularly over time so this type of contact was maintained.

The expectation of practitioners in third sector condition specific organisations was that they would continue to be in contact with carers and offer support over a more extended period of time from a few months to a couple of years, although cases would be closed where they felt they could not offer any further support. In two of these six cases, a second face-to-face meeting was held about matters first discussed between the carer and practitioner. In one additional case, a second face-to-face meeting was held at the carer's request relating primarily to new matters. In all cases, the practitioners (or in one case, a colleague) made one or two further proactive telephone calls to check on the carer's situation and needs over time. In two cases, the carers themselves also contacted the practitioner again by email or telephone about new matters. These included one case where some contact had been maintained beyond six months. These organisations also all offered carers the opportunity to be sent mailings about service activities over time. Thus the condition specific form of casework with carers provided the greatest level of contact both initially and over time.

Whilst local authorities potentially also have legal responsibilities towards the person receiving care, the carer assessment is focused upon the carer. However, this may involve exploring and considering support for the person receiving care in order to support the carer. Third sector generic carer services were also focused upon the carer whilst recognising that sometimes consideration of support for the person receiving care would offer a route to supporting the carer. One condition specialist service was also aimed at the

carer. Another two of these services were primarily for the carer but support could also be offered for the person with the medical condition where there was no conflict of interest. In the final case, the service was intended for both parties.

With one exception, practitioners working for condition specialist organisations wished to meet the person receiving care as well as the carer. They consequently did so in the first main meeting of casework except for in one case. Guidance on statutory assessment practice states that the carer should always have an opportunity to have a discussion without the person receiving care being present (Department of Health, 2001a). Within third sector generic carer services, there was also generally a preference to have the opportunity to talk to the carer without the person receiving care being present. However, in some of these cases, (four statutory carer assessments (one carried out by a third sector employee), the one informal local authority interaction and five third sector generic carer service cases), the person receiving care also attended the first main meeting. In about half of the cases, this was because the carer chose to have the first main meeting of casework together with the person they cared for despite the offer of a private meeting. In the other cases, there had been no consideration of having a private meeting. Where this occurred at a third sector drop-in service there was obviously no opportunity for prior discussion of this.

Local authorities had a power to provide carer services through carer assessment under the Carers and Disabled Children Act 2000. In all the assessments in the research sample, a one-off carer payment scheme was available to enable carers to fund support of their choice to achieve agreed outcomes. There was some limited other direct provision of carer services by local authorities with two directly offering emergency planning schemes for carers and one of these also offering complementary therapy and training for carers. For other carer services, local authorities would need to refer carers elsewhere. All local authorities also had a duty to provide services under community care legislation for the person receiving care where necessary in line with its eligibility criteria when carers did not wish to provide certain care.

Third sector generic carer organisations all chose to provide directly complementary therapy services, carer support groups and leisure activities and trips. Some of the latter could sometimes be attended by both the carer and the person they cared for. Third sector generic carer organisations sometimes also directly provided carer training courses, emergency planning schemes and one-off carer payment schemes. Third sector condition specialist organisations directly provided fewer secondary carer services. One of these four organisations offered a small grants scheme and another provided complementary therapy. Two services offered carer support groups or organised leisure activities for the carer alone and one of these and another organisation also offered support groups or leisure activities for both the carer and their relative to attend together. These organisations all offered some services directly for the person receiving care, for example, rehabilitation services and leisure activities reflecting the condition specialist focus of their organisation.

Across all three organisation types, in summary, three key activities were undertaken within casework: emotional support; information and advice; and assistance to enable carers to access other secondary services. Emotional support was informal and part of the wider interaction rather than being delivered formally as counselling or the main purpose of the interaction. Some services and practitioners specifically stated that they did not provide counselling or befriending but carers could instead be referred to other secondary services for this type of emotional support. Information and advice could take two forms. The first was information and advice given directly about the caring role and the carer's situation. The second was information and advice about accessing secondary support services. Practitioners also assisted carers to access other secondary services in a variety of ways, for example, through completing application forms or making referrals.

4.8 Analysis

The knowledge sought through this piece of research was relatively specific as with much other applied qualitative research in social policy. Hence, a relatively structured approach to data analysis was required rather than a more open technique such as grounded theory or analytic induction, whilst ensuring that this was not too rigid. The longitudinal case based nature of the data collected for this study meant that the method used had to permit analysis of the data either by theme or case relatively easily. Framework matrix analysis (Ritchie, Spencer, & O'Connor, 2003) fitted these requirements. This proposes the development and use of a template to structure interrogation of the data. The template offers a way of indexing and presenting the data in a manageable format to facilitate interpretation and analysis.

The matrices consequently developed here responded to the realist evaluation framework to include outcomes and enabling and disabling contextual factors. The matrices were also determined by the structure of the case study data collection in terms of the different points of data collection and the topics covered within these. Electronic software in the form of Excel spreadsheets was used to help manage the large volume of data. The data was organised to facilitate analysis both by theme (moving down the columns) and by case (reading across rows). Separate worksheets were used for data collected at distinct points in time. The clear display of data facilitated valid analysis by making it easier to see and understand the data and its linkages (Miles, Huberman, & Saldana, 2014).

The whole dataset after the medium term point of data collection was reviewed and entered into the matrices. At this stage, interview data was entered as far as possible in the participants' own language and interview and page references were given so that the original data could be returned to easily when necessary. Descriptive and explanatory analysis (Ritchie et al., 2003) of the data organised in the framework matrices was conducted. Descriptive analysis involved identifying the content and nature of the phenomena

covering outcomes, mechanisms and contextual factors and categorising these. An index of codes was produced as a result of this. This index of codes was then used after completion of the long term interviews to enter the data from these directly into the matrices.

After coding, the data was then explored to develop explanations as to how specific outcomes were produced through different mechanisms and within different contexts. This involved consideration of: direct links made by carers and/or practitioners within individual cases between outcomes and mechanisms and/or contextual factors; general reports by practitioners of associations in their wider work; and associations within the whole sample between particular characteristics or mechanisms and outcomes. Analysis also compared and contrasted where outcomes were and were not achieved. Wider empirical evidence and theoretical understanding were also drawn upon to identify potential relationships to consider. Longitudinal analysis was conducted to explore how outcomes, underlying mechanisms and contextual factors of influence changed over time.

This research is based upon the work of one postgraduate researcher and so has not included the opportunity for several researchers to compare and test insights. However, a number of approaches were used to try and ensure the reliability and validity of the data analysis as far as possible. During analysis, to increase reliability, frequent reference was made back to the original transcripts to check that coding was consistent and that identified associations were reliable. Careful attention was also paid to indicators of the reliability of accounts, for example, carer expressions of difficulty in recollections.

The frequency with which categories and relationships are identified within qualitative research has no statistical validity and hence ability to indicate how widespread a finding is likely to be in a wider population. Nevertheless, it can be useful to indicate the numbers involved in key findings to guard against anecdotalism (Seale, 1999). Accordingly this has been done within this thesis. Some simple counting was also used within this analysis to consider any patterns of association between certain outcomes or mechanisms and different contexts (for example, different intervention or carer types). Again this is not statistically valid, but the likely validity of indicated associations could then be explored through consideration of other data such as interview responses and also findings in wider literature.

This latter approach was one example of how greater validity was achieved through the use of multiple sources of data. Where possible, different sources were compared and contrasted in relation to particular findings. This could include comparing observational evidence, individual practitioner reports on individual cases but also on their wider experience of casework, individual carer reports and patterns across cases within the dataset. A constructionist perspective would view different accounts of the same things as different social constructions themselves which do not represent a single phenomenon (Silverman, 2013). However, underpinned by critical realism, this analysis was based upon the belief that there are real social structures, processes, powers and events even though individuals may have different perspectives upon this.

In this way, considering these together helped to improve the validity of the data analysis. In some cases, where reports supported each other this meant greater confidence could be felt in findings. In other cases, contradictory reports were given. In these cases, careful judgements were made about the likely reliability of different perspectives. For example, where a practitioner thought a carer had taken up a particular service but a carer reported that they had not, it was considered that the carer's perspective, based upon personal experience in contrast to records of others' actions, was more reliable.

4.9 Presentation of findings

Findings are presented in sections relating to the three key elements of the realist evaluation framework: outcomes, mechanisms and contexts. These have been distinguished in terms of outcomes achieved directly through casework (chapter five), those achieved through the use of secondary services accessed with support from casework (chapter six) and overall impact (chapter seven). Longitudinal change is considered throughout the analysis. The nature of each particular instance of the different components of the realist framework, outcomes, mechanisms and contexts is explained separately for clarity. However, the links between these are key. These can be difficult to capture clearly in a narrative form. Hence, tables have been used to show the links in a summary form.

Throughout the presentation of the findings, the nature of the evidence is detailed in terms of sources (for example, practitioner interviews) and extent (the number of reports). Given the qualitative nature of the data, it has also been important to provide quotations to illustrate the evidence upon which claims have been made. These have been taken from as many different participants as possible to indicate the breadth of the data. These have also been chosen as exemplars of common themes or commonly expressed views. In addition, selection of quotations has taken account of how easily presentable these are with a preference for those where points are made succinctly within a single section of conversation in order to make the thesis easier to read. Cases are described narratively where evidence from across interviews needs to be summarised.

As a qualitative piece of research, more extensive use of quotations and case studies might be expected, perhaps in a narrative form. However, the primary aim here has been to present clearly the findings on outcomes, mechanisms and contexts in the realist evaluation framework with the data providing a supporting role to illustrate and evidence this. There is a danger that this fragments and depersonalises narratives of very affecting lived experiences. To mitigate this, some case studies are given to illustrate the overall impact of casework in chapter seven.

4.10 Ethical issues

4.10.1 Research governance approval

The research proposal was first approved via the ethics assessment processes of the School of Sociology and Social Policy at the University of Nottingham (University of Nottingham, 2015, 2016). The chief executives of local third sector organisations were then contacted to invite their service to participate in the research. It was explained that the research had been approved through the University's ethics procedures. Chief executives were also asked if they had their own procedures which would need to be completed. However, the third sector organisations which participated did not have these and accepted the oversight of the University in this respect.

In order to undertake research with local authority social care departments, I completed a Midlands Research Governance application (Birmingham City Council, 2015). Sixteen local authorities from the Midlands region were members of a network which had agreed this common research governance process. Thus completing this process once allowed me to work with multiple local authorities in the Midlands region. This application was a comprehensive process based upon the Department of Health's research governance framework for health and social care (Department of Health, 2005b). I addressed two lists of concerns from the research governance committee covering a wide range of issues including sampling, content of the consent forms and interview guides and data handling, storage and retention before final approval to proceed was granted.

It was also recognised that unforeseen ethical issues might arise during the process of the research (Miller & Bell, 2012). Some of these are considered in the next sections discussing and reflecting upon specific ethical issues: informed consent, confidentiality and harm to participants. It can also be argued that efforts to ensure the quality of the research (as discussed elsewhere in this chapter) also constitute an ethical approach in terms of ultimately providing rigorous research evidence as the researcher's first responsibility (Hammersley & Traianou, 2012).

4.10.2 Informed consent

Informed consent was sought separately in sequence from the organisations acting as research sites, from individual practitioners and from carers. In all cases, as well as explaining the research verbally, potential participants were given a tailored written project information briefing. (These were tailored to the different types of participant, see Appendix 4 for an example.) Potential participants were given the opportunity to ask any other questions before deciding whether or not to participate. Willing participants completed a consent form (see Appendix 1 for an example).

As discussed in relation to sampling (page 100), the managers of organisations providing casework were first approached, then with their

permission, practitioners were invited to participate in the research. Managers were then acting as 'gatekeepers' whose power may have implications for the ability of research participants to choose to take part in the study or not (Miller & Bell, 2012). In some cases, the manager was involved in suggesting practitioners who might take part and even where this was not the case, the manager's approval of the research might have created some pressure upon practitioners to participate. This was clearly often not the case as many practitioners successfully declined to be involved. I always sought consent individually with practitioners but on reflection, it is possible that this may not always have removed all pressure they might have felt to participate.

Practitioners then effectively acted as gatekeepers in helping to provide access to potential carer participants. The researcher discussed with practitioners how carers would be selected (at random, aside from the exclusion criteria) in light of the way in which appointments were arranged in the different organisations to try to avoid any other practitioner influence upon selection. The practitioner was asked to explain that there would be no negative consequences arising from non-participation to avoid the carer feeling pressure to participate. This included clarifying for carers that the researcher was independent of the service provider and that their decision would not affect the support they received from the service provider. This was also repeated separately by the researcher verbally and was included on the carer information leaflets. It was also explained that carers could choose to withdraw from the research at any point in time.

As the research progressed, the majority of carers expressed that they were pleased to take part in the research and to share their experiences. A small number of carers said that they did not wish to participate in the research but attended a first main contact with carer services without participating in the research. Thus it clearly was possible for carers to decline to participate. On the other hand, the fact that three carers initially agreed to participate in the research but subsequently chose not to participate in the interviews suggests that they may have felt they should agree but rescinded this once they had had contact with the service. However, it still seems that in these cases, no harm was done. There was one case where a carer who had initially agreed to participate in the research subsequently chose not to attend the service. It is not possible to know if this was because of the research. They were given the option to attend without participating in the research but still declined. Practitioners reported that people do change their minds when there is no research to consider. Thus on balance, there was not any clear evidence that carers felt obliged to participate or that the research caused harm in terms of deterring carers from attending support services.

In order to recognise their contribution and the time carers had given to the research, participating carers were sent a ten pound gift voucher as a token of appreciation. There is a danger that the use of monetary payments can tempt people to participate in research against their initial judgement (Silverman, 2013). Whilst this could have been the case here, there was no evidence of this. No carers actively requested their gift voucher. The voucher was sent after the first interview. If this was a significant motivation for participation,

carers might then have chosen not to participate in further interviews. Only two of the thirty seven carers participated in the first interview but not in further interviews and their participation did not appear to be motivated by this token in any way.

Difference in the mode of the first main contact of casework in the sample meant that slightly different approaches had to be developed for recruitment and achieving informed consent with carers depending upon this. In most cases, the casework provider initially asked potential carer participants on the phone before their first main contact if they were happy for the researcher to contact them directly to explain about the research project. I then explained the project in detail on the phone and carers' consent was sought and if it was given, I attended the first main contact. The advantage of this was that carers had time to find out fully about the research project without this impacting upon their casework appointment.

In the five cases included of the drop-in service where there was no prior contact between the organisation and the carer, the researcher was briefly introduced by the practitioner and initial consent sought at the beginning of the first main contact. At the end of the first main contact, I explained the research in more detail and completed the consent form with the carer if they were willing to participate. In the cases included of telephone help-line work, carers were sent a leaflet about research in the information pack they received from the service prior to their first main contact. If they returned this indicating their willingness to take part, then their first main telephone call with the service was audio-recorded and a consent form was completed with them afterwards. Hence, in these latter cases, *full* informed consent was achieved retrospectively at the end of the first main contact between the carer and the service. This was justified because the carer's *initial general* consent was achieved prior to the contact. There was also the opportunity for the carer to withdraw their participation completely when the full process of informed consent was being conducted. The advantage of this was that the initial consent process did not take too much of the carer's attention at a point when they were seeking support from the casework service. The potential disadvantage was that the carer might feel pressure to continue to participate having allowed the first main contact to be recorded despite preferring to withdraw once they had a more detailed understanding of the research and the nature of participation. However, one carer was able to decide not to participate in this way and all of the other carers subsequently continued to participate in the research interviews (albeit in one case, in only one interview).

Within a longitudinal study, it is important to ensure that consent is maintained over time (Miller & Bell, 2012). This was perhaps particularly important with carers because some might find it difficult to find the time and energy to participate in the research because of the impact of their caring roles. Hence at the beginning of each interview at the different points in time, participants were asked if they were willing to take part again. The researcher also checked at the first meeting when the best times to contact a participant might be and tried to arrange interviews to suit participants.

During the pilot case studies, it became apparent that in some cases, informed consent would also need to be sought from the person receiving care if they also participated in the first main contact between the carer and the casework provider. In cases where this person did not have the mental capacity to give informed consent, their contribution was not included within the research in order to avoid the considerable ethical difficulties involved in this scenario. This affected two observations of the first main contact of casework and so had a limited impact upon data collection.

Consent to audio-record meetings and interviews was requested from all participants at the beginning of each interaction. Once transcripts were produced, copies of these were returned to participants to provide them with the opportunity to make any changes if they wished. This was to show respect to participants, allowing them to retract anything they regretted revealing in the free flowing conversation or to make any corrections. Four practitioner participants chose to make some minor corrections.

Informed consent is based upon an understanding of what participation involves which may not always be entirely clear initially (Miller & Bell, 2012). Here, participation was expected to be confined to the first main contact of casework and subsequent interviews. However, I spent other time with the practitioner where we travelled together to carers' homes for appointments. Inevitably some informal conversation during this time would be of relevance to the research. This had not been specified as part of the research and was not recorded. However, where something seemed particularly of interest, I tried to raise this with practitioners within subsequent interviews.

4.10.3 Confidentiality

Confidentiality was guaranteed to all participants apart from where there was disclosure or evidence of illegal activities, significant harm, abuse, neglect or danger. It had been planned that if I identified an issue of this kind which was not being dealt with by the relevant practitioner then I would contact the appropriate person or organisation after taking advice from my supervisors. In the event, this did not arise.

Confidentiality had to be carefully considered where sometimes it was helpful to draw upon information given in interviews with one type of respondent (practitioner or carer) in an interview with the other party involved in a case (carer or practitioner). This was done through careful use of wording to avoid reporting directly what each party had said to another to ensure that confidentiality was not compromised.

Following on from this, anonymity was important. When transcripts were constructed, basic identifying details, for example, names and locations were excluded and/or changed. Fictional names have been used in the quotes and case examples used within the written thesis. As Hammersley and Traianou note (2012), the extent of anonymisation required depends upon who could

see the evidence presented from the research. In this study, all participants would potentially have access. This meant that extra care was required because many details of the cases would be familiar to both the carer and the practitioner involved in each case. Yet, the promise of confidentiality meant that they should not be able to recognise each other's contributions. Therefore, some details, for example, age and ethnicity have not been included unless they are required to support a particular point. Some other details, for example, the specific form of support used in a case have also sometimes been changed to obscure identities. There can be a tension here between anonymisation and providing a detailed and accurate account of what has been studied (Hammersley & Traianou, 2012). This is slightly lessened when the purpose is to illustrate more general points and explanations rather than to provide an in-depth description of a particular case (Hammersley & Traianou, 2012). Details have been changed carefully here in order to ensure that the nature of the points being illustrated remain consistent.

To preserve confidentiality, data has been stored both electronically (password protected) and in hard copy in secure filing cabinets at the researcher's home and at the university. Data saved on memory sticks has been kept on the researcher whilst it is being transferred from one site to another. Only the researcher has had access to the data. All hard copies of data and data collection tools which enable identification of participants will be destroyed upon completion of the research.

4.10.4 Harm

Considering harm from research (which can take various forms) involves potentially difficult assessments of the likely risk of this and its severity to be weighed alongside potential benefits (Hammersley & Traianou, 2012). A number of issues have been considered in relation to ensuring this research did not cause harm to participants. Probably most important in this respect was a concern expressed by some practitioners during initial conversations about participation that my presence and recording of the first main contact might either deter some carers from attending that first main contact or from fully participating in casework. (The latter concern has been considered previously on page 91.) Equally there were practitioners who did not have this concern. Other research of this kind had previously been conducted without negative reports of such effects (for example, Stanley, Manthorpe, Bradley, & Alaszewski, 1998). It was felt that the process of informed consent undertaken should minimise these risks. The discussion of informed consent previously suggests it is unlikely that harm of this kind occurred.

Harm can be caused in research interviews where the topics covered invoke difficult emotional experiences in participants (de Laine, 2000). This was potentially an issue here because of the psychological impact caring can have. Within research interviews, occasionally some carers did find it difficult talking about their experiences because of the emotions this raised. If this was apparent, they were asked if they would like to end the conversation but they chose not to do so. Another potential unintended negative consequence arose

that sometimes through asking a series of questions about whether carers had taken up various support services available, carers gave the impression that they might start to feel some obligation to do so or to evaluate themselves negatively for not having done so. To mitigate this, I was careful to use phrases such as 'I'm not expecting you to have' in such conversations.

Another ethical dilemma concerns the role of the researcher and the potential difficulties of separating this from that of counsellor or friend (de Laine, 2000). As noted, some carers did find the research interviews a useful opportunity to talk and rapport was developed. The longitudinal design also meant that a relationship was built over time. This was still limited in that it consisted of a maximum of five contacts, mainly by telephone, generally of less than an hour, over a period of up to three years. I chose not to extend relationships in any way and was careful not to raise any expectations in this regard. However, I still felt a slight sense of guilt and/or sadness that these relationships ended, perhaps particularly because carers were often relatively isolated and struggling.

Another potential role dilemma was whether carers would confuse my role with that of a practitioner. I was occasionally asked specific questions by carers in response to research interview questions about their use of support. I generally advised carers to ask the practitioner instead unless it was a straightforward question which it made sense to answer. By the very nature of the research, the carer was already in touch with a practitioner who should have been able to offer them support. I did not therefore initially offer any other particular details to participants about sources of information and advice. (Some general contact information for sources of help was provided at the end of the research.)

Another ethical concern arose where, in five cases when I telephoned carers to request follow up interviews, it was learnt that the person receiving care had passed away. In these cases, condolences were offered and the interview was not requested out of respect and to avoid harm through intrusion at a time of grief. In two of these cases, this involved the final long term interview and occurred about a year after the person receiving care had passed away. In both of these cases, the carer chose to take part in another interview despite my suggestion to end participation to avoid topics that might cause distress because of the bereavement. Both of these carers were able to talk without becoming upset.

Thus, overall, steps were taken to limit the risk of harm and there was no evidence that the research did cause harm. The repeat contacts made with participants through the longitudinal design of the study provided several potential opportunities to note this if it had occurred. Some limited direct benefits for participants were noted (page 128) in terms of carers having an opportunity to talk and for their experiences to be recognised. Some carers also hoped that the research would make a difference to other carers in the future. The intention was that the research will have some positive benefits generally for carers and society more widely through helping to develop policy and practice to support carers. However, ethical concerns might be expressed

that a single research study is unlikely to have the far reaching impact that participants might desire (Miller & Bell, 2012). However, equally this may not really be a prominent concern for research participants (Miller & Bell, 2012). Generating robust knowledge in itself is a general benefit of research (Hammersley & Traianou, 2012).

Chapter Five: Direct Outcomes of Casework, their Mechanisms and Context

The next three chapters present the findings of the study. The first of these, chapter five, reports on the evidence gathered of the outcomes achieved *directly* through the practice of casework with carers, the mechanisms underlying these and the contextual factors influencing these. This includes the outcomes which consisted of *use* of a secondary service where casework was the mechanism leading to this use. For example, use of a complementary therapy service was achieved through the casework practitioner booking the appointment for the carer. The further outcomes then generated through use of these secondary services, for example, the improvements in emotional well-being achieved through use of complementary therapy, are discussed separately in the next chapter (six). The final data presentation chapter (seven) then brings this together to provide an overall evaluation of the impact of casework in a longitudinal perspective.

In the following chapter, section 5.1 reports upon the nature of each outcome achieved directly through the practice of casework with carers including quotations and/or case studies exemplifying these. It includes understanding of the importance of individual outcomes to carers and the longitudinal nature of these. It also provides evidence of identified unmet needs. This is then followed by an examination of the findings on the mechanisms which generated outcomes (section 5.2) and then of the contextual factors which influenced whether mechanisms generated outcomes or not (section 5.3). The realist aim is to develop understanding of configurations of outcomes, mechanisms and context. Relationships between outcomes, mechanisms and context are discussed narratively in the text but are brought together in the outcome tables (pages 167 to 178) to provide an overview of the evidence linking outcomes, mechanisms and context. This is then further developed in a model of casework (section 5.4).

5.1 Direct outcomes of casework

Outcomes were identified in the following domains as discussed in turn: change in emotional well-being (5.1.1); behavioural change (5.1.2); development of caring knowledge and skills (5.1.3); employment (5.1.4); and use of secondary services (5.1.5).

5.1.1 *Change in emotional well-being*

- *Reassurance (Table 5.1)*

Many carers (about half of the sample) proactively reported feeling reassured immediately after their initial main contact of casework. This was also mentioned by several practitioners (six) as being important generally. Reassurance was described as being achieved through the mechanism of

learning that someone could be contacted for help or that support was available generally. Three carers specifically said that this was the most important immediate outcome of the initial contact for them. Mavis reported: *"If ever I need somebody at the end of the phone to ask something, then I know she's there, that was the main thing."* (Mavis, carer, interview 1, page 4). In three cases, this outcome was also reported as being achieved for the person receiving care. John discussed this: *"Dad feels more positive because if we get forms that I'm not sure about, things like that, I take them down."* (John, carer, interview 2, page 12).

In many cases (nine), the reassurance of having somewhere to turn and the importance of this to carers continued in the short to medium term. Reassurance was again noted as the most important short to medium term outcome by two carers. In the long term, four carers continued to express that they felt some reassurance that there was somewhere to turn for support. Paul commented, *"It is nice to know that it's there should you ever need it."* (Paul, carer, interview 4). This was expressed less emphatically than previously as might be anticipated given the decrease in contact over time.

- *Relief (Table 5.2)*

The mechanism of talking and expressing their feelings in the first main contact with carer services was reported to make carers feel better including offering a sense of relief. Just under a third of carers in the sample actively reported this either during or immediately after the first main contact with casework and several practitioners (seven) highlighted the importance of this. Towards the end of her appointment, Becky commented, *"Just letting me rabble on has so helped."* (Becky, carer, observation, page 18). For some carers (five cases), the experience of discussing their situation generated mixed emotions. Charlotte described this *"I found it quite hard to start talking first of all, so that was emotionally, it was quite draining emotionally. [...] I felt better at the end."* (Charlotte, carer, interview 1, page 3).

In the short to medium term, there were two proactive reports by carers of having further useful opportunities to talk and express their feelings. Stanley said *"I would say that's the most important thing actually just to have somebody to talk to about things."* (Stanley, carer, interview 2, page 4). In addition, three practitioners gave examples within the research of carers requesting further meetings in the short to medium term with an apparent practical purpose but where they thought afterwards that principally the carer had just needed the opportunity to talk. *"There were other things he wanted me to look at, some forms and things he'd had to do with his Council tax and things but I think really he just wanted to talk to somebody out of the house and was probably feeling a lot more stressed out and although they had a lovely relationship, it's the usual traumas if you're with somebody 24-7."* (Shirley, carer assessment worker, interview 2, page 1). In the long term, very few carers (two of twenty three followed up) had had any recent contact with the same service. Hence there had been little further direct input from practitioners to support carers emotionally in this way.

Three carers specifically cited this as an unmet need within research interviews. *“What I would have liked but this is going back on a hypothetical thing, you know, to be able to talk to somebody knowing that they’re not judging, just to be at the end of the phone.”* (Nishan, carer, interview 2, page 10). The existence of unmet need in this respect over time was also suggested by two carers’ reports that they found the research interviews a useful opportunity to talk. When asked how, if at all, participating in the research had had an influence upon him, Ryan responded: *“You’re about the only person I talk to about it, so you’re a bit of an agony aunt as well! So that’s a positive if I talk.”* (Ryan, carer, interview 3, page 6). Some other carers did not voice this need or experience but seemed keen to talk about their role during the research interviews. Together this indicates that this may be a reasonably widespread need.

- *More positive outlook (Table 5.3)*

Five carers reported feeling better from a change in their perspective on their situation achieved through the first main contact of casework. Four carers mentioned coming to the realisation that they were not the only carer and that their situation and feelings were normal. In response to a question about how the meeting affected her emotionally, Becky commented *“It kind of perked me up a bit.”* She then continued: *“Yeah, I’m not naïve I know I’m not the only person in the world that does this, but sometimes you feel like that.”* (Becky, carer, interview 1, page 3).

In three cases, carers reported the value of the practitioners’ recognition of their contribution and competence as a carer. *“It made me sort of think well, I’m doing the best I can.”* (Charlotte, carer, interview 1, page 4). Five practitioners emphasised the importance of providing this recognition. Three carers reported change in the way they felt about their caring role including experiencing a greater acceptance of their role and feeling more confident and able to manage through their discussions with practitioners. This could be very important. Jane commented *“It does as I say give you an identity as a carer and as a role, as opposed to just somebody that’s just getting up and just trawling through the day you know.”* (Jane, carer, interview 1, page 6).

Two carers who had ongoing contact with a practitioner continued to report benefits relating to a change in their perspective in the short to medium term. One reported that he found it easier to look after his Dad as a result of emotional support which helped him to accept and be more positive about his caring role.

You think I’m waiting to die now. When you start talking to people who’s been there, like [the carer support worker], who knows a few of the ropes and because of that, your heart opens and your eyes open and you think wait a minute, you haven’t got such a bad life have you? [...]

It's no longer a burden to get up and do things. Dad watches the TV and I get up and get him a bit of supper, I get him a cup of tea and I make sure he's alright when he goes to bed.

(John, carer, interview 2, page 9).

Another carer also reported new benefits of this kind through his ongoing contact with a practitioner. *"She does back me up, she says I'm doing a great job and all that, so that's a confidence booster, yeah."* (Jim, carer, interview 3, page 8).

- *Disappointment, frustration, negativity (Table 5.4)*

There was a slight sense of disappointment about the extent of the support available immediately after the first main contact of casework in two cases. Another carer who was shortly afterwards faced with potential cuts to the family's care package felt frustrated at the juxtaposition of this with the offer of help via her carer assessment. In four cases in the short term and another in the medium term, carers felt disappointed or sometimes even resentful over time when they did not receive any further contact through casework. Philip commented at the beginning of the research interview almost two months after his first main contact with the local authority: *"I'm a bit disappointed there. She hasn't rung me back yet."* (Philip, carer, interview 2, page 1). In two cases, this later changed positively when helpful support was put into place or contact later made. In the long term, two carers continued to express disappointment at the lack of ongoing contact through casework.

There was one unusual case where the carer reported that discussing her situation had a negative impact. This was because this was within a context where she did not have hope that she would be able to access support following the meeting because the person she cared for was not willing to try alternative support. The carer described the impact of discussing her situation: *"It's like if you've got toothache, you try not to think you've got toothache, but if you think you've got toothache it becomes worse, you know. You then feel well, yeah, we are in a pretty poor situation."* (Angela, carer, interview 1, page 4).

- *Anxiety*

Two carers experienced some anxiety immediately after the first main contact of casework. This consisted of anxiety about the contact having an impact upon other aspects of their life including benefits receipt and job applications and general anxiety about the involvement of professionals in their private lives. When she was asked about how, if at all, the meeting affected her emotionally, Linda responded: *"Well, I thought after am I doing the right thing? Am I signing these things? It's things like that what get to me more. Have I done the right thing, should I sign these forms? Should I do this? Should I let people right into my life?"* (Linda, carer, interview 1, page 4). These feelings did ease over time in these cases.

- *Undermined*

Two carers reported feeling undermined immediately after their first main contact by the practitioner's attitude towards them or their actions. These examples were quite different. In one case, the carer thought the practitioner was undermining her aspirations to a particular employment role. In the other case, the carer felt he was almost being chastised for not taking the necessary action to maximise the family's benefits receipt when he was too overwhelmed to do so. He explained:

"It's not the fact that I can't be bothered, it's the fact that, she [referring to the practitioner] made this thing go over her head. I've got so many responsibilities, for instance, like being a dad [...]. It's not the fact that I can't be bothered to fill in forms, it's the fact that sometimes you have to say no to things and that is one of those things my brain can't cope with, so therefore I have to delegate it to somebody else. I can't take full responsibility for everybody and I think she was undermining me there and I didn't like that. She made me feel uncomfortable with that."

(Nishan, carer, interview 1, page 2)

These carers had no further contact with the practitioner over time.

5.1.2 Behavioural change to address health or leisure needs (Table 5.5)

Outcomes of behavioural change were reported by a small number of carers after the first main contact of casework in respect of two aspects of their lives: health and leisure. There were two cases of carers who reported changing their behaviour to improve their health as a result of practitioners' encouragement to do so. In one example, this involved seeking medical help (actually in the medium term as a result of ongoing contact with the casework practitioner). In the other example, in discussion about what she had learnt from the first main contact, Mavis said: *"I think I've got to take more care of myself so that I'm able to cope better. I think I've got to sit back a little bit and relax more and eat more and rest more so that I'm fit. I think that was one of the points that came over."* (Mavis, carer, interview 1, page 4).

There were three examples reported here directly by carers of action taken to address some leisure needs themselves as a result of the practitioner's input but without any further secondary service support. These involved the carer changing their routines around caring to extend and/or enhance their leisure time. One carer simply made time during the day to have a rest or read a book instead of always looking for jobs to do. Another carer went out more. In the quotations below, another carer explained changes she had made to the way she spent time caring to incorporate a leisure activity and enhance the enjoyment of this partly through encouragement from the practitioner.

Researcher: *Did it [her first main contact with the carers service] affect or influence your behaviour at all, in terms of how you care or lead your life more generally?*

Sarah: *I have done more, I have gone out and because obviously Grace, she, we're spending quite a lot of time in and being sat which is completely alien to anything I do in my, what would be classed as my normal life, so I've gone out and invested in little care packages which are things that, like I do a lot of knitting now and that kind of stuff that I can take to Grace's so that I don't feel like I'm having a portion of my day stolen from me. So yeah, I've done that.*

Researcher: *Was that related to anything [the Carer Support Worker] said or was it more your own initiative?*

Sarah: *Well, I did do, it's sort of almost like an occupational therapy type thing and I did it when I was quite ill [...] So you know that and just sort of [the Carer Support Worker's] reinforcement of are you ok? You need to look after yourself, you know, that sort of encouragement, you know. It sort of gives you the permission to go and spend fifty quid on stuff because actually that's important as well. I need not to think I've got so much to stuff to do and I'm sat here. It's turning it on its head. It's like that's fine, me and Grace sit and I knit and she does TV and chat and so it makes the whole experience a lot easier.*

Researcher: *Yeah. That sounds good, that sounds very positive.*

Sarah: *Yeah, and it does, that caring for the carers that comes from the carers centre.*

(Sarah, carer, interview 2, page 6)

5.1.3 Development of caring knowledge and skills (Table 5.6)

A small number of carers reported immediate outcomes in terms of developing their knowledge and skills in relation to the medical condition of the person they cared for through the first main contact of casework. Two carers learnt from both verbal and written information provided by the practitioner about the medical condition of the person they cared for in a number of ways. They reported being better informed about the medical condition. In one case, other family members also learnt from information that was passed onto them. Two carers also specifically sought understanding of the potential for rehabilitation or cures from illnesses. Information could offer hope. Responding to a question about any ways in which she found information booklets provided useful, Sue explained:

Just the fact that you know people had had the condition and some of them had come through it, they're obviously not going to be the same as they were before but it's just the fact, my main concern with my aunt is her mobility so you know, it's nice to hear from other people that had had that issue and how, if and how they cope with that.

(Sue, carer, interview 1, page 1)

One carer discussed how learning about particular aspects of the medical condition enabled her to take a different perspective, to be more understanding and patient with the person she cared for. One carer explained that discussing specific behavioural issues had helped her to adjust her approach and attitude.

“It occurred to me, you know, I was saying to my husband, to do anything with my aunt takes ages and obviously like working mum with kids and stuff you’re sort of used to going ‘right, der der der der’, that realisation of how I approach things and that came out of the meeting. So it’s more of an acceptance that these things are going to happen, rather than fighting it, trying to go with it.”

(Sarah, carer, interview 1, page 4)

Further knowledge about the medical condition and managing this were also achieved in two cases in the short to medium term. No specific long term outcomes in this domain were identified due to changes in caring circumstances as discussed on page 154.

5.1.4 Employment outcomes (Table 5.7)

The direct input of casework enabled one carer to return to paid employment in the short term by providing information about how benefits eligibility was affected by paid employment. The carer then used his own initiative to secure a job. This provided additional financial income and improved quality of life. In the long term, this carer was no longer undertaking this paid employment role due to changes in his caring circumstances.

John talked about the impact of the income earned from his new employment.

Well, it’s good because I’ve got x money to play with. It’s easier to run the car, help run the car. I buy myself more personal things like clothes and more toiletries you know and I’ve got a little bit saved up now, not a great deal because I don’t earn a great deal but I’m getting money you know and this, that and the other and a bit later on this year my son wants me to go to the Lake District, they’ve got a place to stay up there, [...] so I wouldn’t have done that.

(John, carer, interview 2, page 10)

5.1.5 Use of secondary services

Casework helped carers to access secondary services in a variety of ways, for example, through the provision of information and assistance with application forms as discussed in section 5.2. The uptake of each different type of secondary service achieved through casework is now discussed in turn. The outcomes then achieved through use of these secondary services are discussed in chapter six.

- *Use of alternative care services (Table 5.8)*

A serious need to relieve some of the pressure of the caring role was reasonably widespread within the sample (eleven cases, two of whom were already in the process of requesting support from statutory services). These carers required some kind of alternative care services for the person receiving care in order to reduce or ease their caring role. In three cases, carers were not anticipating that appropriate support would be available to meet their needs. The reasons for this are discussed later in terms of contextual barriers to support (section 6.3).

There were mixed short to medium term outcomes in terms of whether alternative care services had been accessed to ease or reduce the caring role. Two carers could not be followed up. In four families, some alternative care services were now being used. These included adaptations to the home of the person receiving care including to the bathroom and installation of stair rails. Alternative care services used also included a meals on wheels service and regular visits from a paid care worker (either on an ongoing basis or whilst the carer was on holiday). Two carers were still waiting for services to be arranged. Five carers had unmet needs to reduce or ease the caring role and another two were not taking breaks because of the unsuitability of the available alternative care services. One of these carers did receive an aid which was helpful but overall they had serious unmet needs.

In the long term, in three cases where alternative care services had been arranged previously, changes in the caring situation meant that these were no longer required. Three carers were only able to report at the long term stage that some practical support originally identified as required in the first main contact of casework had finally been put into place. It had taken a very long time for statutory services to implement this. The support used included installation of a ground floor wet room, a laundry service and educational courses and support worker intervention with a person with learning difficulties. In the cases where alternative care services had been arranged at an earlier point in time, casework had played a role in arranging this. However, in these cases where alternative care services were only accessed in the long term, the carers interacted with the organisations directly providing these services and it is not clear that casework played a role.

Deterioration in the condition of the person receiving care also meant that in three cases, new needs for alternative care services had emerged in the intervening period. When this happened, carers contacted another relevant organisation (rather than the original casework provider), for example, local authority social care or health services and directly arranged services. The cases in which originally carer needs for alternative care services were identified as being unlikely to be met for reasons relating to the nature of services continued to be unmet. In the one case where the reluctance of the person receiving care to use alternative care services had prevented the carer from reducing her role, this eventually changed and alternative care services were arranged through the local authority which had previously undertaken the carer assessment.

- *Use of a peer support service (Table 5.14)*

In an exceptional case, one carer used a peer support group for those applying for personalised support from statutory services.

- *Use of practical support for the person receiving care (Table 5.9)*

In just under a third of the total sample, a specific need for some kind of practical support principally for the benefit of the person receiving care (rather than the carer) was identified in casework with carers. Whilst the support was principally for the person receiving care, they may need help from their carer to organise and access their own support. In addition, the carer themselves is often particularly concerned with enhancing the quality of life of the person receiving care. In practice, distinguishing who the support is for is not always clear cut, but it is useful to make a distinction to help understand the different types of carer needs. In this sample, these needs were not presented as critical needs for any of the parties involved but were potentially of some benefit. Practical support for the person receiving care could theoretically be accessed directly by this person via services aimed at them, for example, community care assessments. However, in all but two of the cases considered here, the person receiving care had not had a community care assessment and was not intending to do so.

There were six instances of support being successfully accessed for the person receiving care in the short to medium term (amongst cases that could be followed up). These included use of chiropody and a transport service for disabled people and successful receipt of a RADAR key to enable use of accessible public toilets, a Blue Badge and a walking frame. Some support of this type was not taken up. The reasons for this are discussed in later sections. In one case, better medical care was achieved for the person receiving care in the short term through the practitioner's intervention to remedy difficulties accessing this. In the cases followed up here, the practical support accessed in the short to medium term was no longer required in the long term due to changes in caring circumstances. In the long term, one carer used information previously provided to take the person they cared for to some social activities but they then chose not to continue this.

- *Use of emergency planning schemes (Table 5.10)*

Four carers, just over a third of those who expressed an initial interest, went on to register with an emergency planning scheme for carers in the short to medium term. In the long term, two carers continued to be registered or hold cards for emergency planning schemes. Emergency schemes were no longer needed by the two other carers.

- *Participation in training courses (Table 5.11)*

Ten carers (eight of whom were followed up) expressed interest in the Caring with Confidence training courses. Two carers fully participated in a course, one other carer began a course but did not continue. Two carers expressed interest in other types of training courses, one in moving and handling, and one focused on learning about a particular medical condition and related behaviour. These were not taken up for reasons explored elsewhere.

- *Participation in carer leisure activities and support groups (Table 5.12)*

Planned leisure and social activities for carers included day trips to places of interest such as museums, gardens or cities and social events such as wine tasting, bowling and regular coffee mornings. Some of the latter were organised on a regular basis to function partly also as a support group. There were nine expressions of interest but only three carers ultimately attended provision (two arranged leisure activities and one a support group) and they did not continue to use this provision beyond the medium term.

- *Use of complementary therapies (Table 5.13)*

Complementary therapies were taken up by one carer in the short term only. Another two carers in the sample intended to use complementary therapy services (one of whom had an actual appointment booked the following week) but could not be followed up.

- *Use of a specialist employment service (Table 5.14)*

One carer visited a specialist employment service to explore opportunities for doing some voluntary work.

- *Use of a welfare rights service (Table 5.14)*

Five carers had an appointment with a welfare rights service either to check the family's potential entitlements generally or to provide support with an application for Attendance Allowance.

- *Receipt of financial support (Table 5.15)*

Ultimately about a quarter of the carers followed up were known to have successfully accessed a benefit using some support through casework. Thus, this was a substantial area of support. Over half of the benefits claimed via casework were received within the short term. This included two carers who were awarded Carer's Allowance and two carers who accessed Attendance Allowance for the person receiving care (payable to those aged 65 and over

who need help with personal care). Another carer and his family accessed Carer's Allowance and Attendance Allowance at the higher rate (it had previously been awarded at a lower rate) in the medium term. In two cases, casework practitioners ensured that Attendance Allowance claims were made from the earliest date permitted to maximise the income received. Two other carers had made an application but could not be followed up. There was also one example where a carer benefited financially from casework by learning to ask for carer discounts when visiting any leisure venues. In the long term, of the carers that could be followed up, one carer and his family continued to rely upon this benefits income originally accessed through casework. There were also two new cases of carers accessing a benefit (Attendance Allowance) through casework in the long term.

- *Receipt of one-off carer payments (Table 5.16)*

A substantial number of the carers followed up (ten) received one-off carer payments via casework (of £100 to £400) for one or more items in the short to medium term. In three of these cases, the funding was used for a break or leisure activity which the carer would have undertaken anyway and in another case, the carer extended their participation in an existing social activity. In all other cases, the funding was used for something which the carer had not otherwise anticipated being able to fund. The use of previous payments ended in the long term as would be anticipated given that these were one-off payments. However, two carers received further payments for new purposes in the long term. The varied uses of these payments and their outcomes are discussed in the next chapter.

5.2 Mechanisms of casework

Mechanisms of different types were identified. Section 5.2.1 discusses emotional support mechanisms underpinning changes in emotional well-being and also some use of secondary services. Different mechanisms of learning are considered in section 5.2.2. Mechanisms to arrange use of secondary services are examined in section 5.2.3. The carer's own action as a mechanism is considered in section 5.2.4. Secondary services also acted effectively as a resource mechanism of casework. This included those secondary services such as welfare rights services which effectively replaced other mechanisms of casework to enable carers to use other secondary services. However, to avoid confusion about the direct outcomes of casework and those achieved indirectly through the use of secondary services arranged through casework, these are discussed separately in the next chapter.

5.2.1 Mechanisms of emotional support

- *Mechanism: Expression of feelings*

The improvements in emotional well-being in terms of a feeling of relief were achieved through the mechanism of carers having the opportunity to talk and express their feelings. Joan, a carer support worker, commented “*you see some people, it just makes them feel better if they can talk things through but they’re not better because the situation hasn’t changed but emotionally they’ve offloaded.*” (Joan, carer support worker, interview 2, page 9).

- *Mechanism: Normalisation, recognition and valuing of caring contribution and competence*

Discussion with the practitioner led to improved emotional well-being through a change of perspective for some carers on their situation as noted. This occurred through understanding that others were in similar situations to theirs, a normalisation of their role and circumstances (see Becky’s quote page 128). A more positive outlook also occurred through practitioners’ recognition and valuing of carers’ contribution and competence. Marlene said: “*In terms of actually speaking about their caring role and people understanding actually what they do, I think that’s a very important exercise for them, to feel that, you know, what they’re doing is a very important role.*” (Marlene, carer assessment worker, interview 2, page 5). In the minority of cases where a carer reported feeling undermined by a practitioner, a mechanism of the opposite nature was effectively operating. Practitioners were perceived not to be recognising carers’ competencies or otherwise how these were limited by the carer’s circumstances.

- *Mechanism: Accepting the importance of considering and responding to the carer’s own needs*

Carers’ acceptance of the importance of considering and responding to their own needs through the practitioners’ encouragement acted as a mechanism leading to a number of varied outcomes consisting of: carers making changes to extend or enhance their leisure time and to improve their health and being willing to use alternative care services to reduce or ease the caring role and using complementary therapy.

Some carers experiencing serious negative impacts from caring had reached a point where they wanted to seek help. However, some also expressed feelings of doubt and guilt about letting their relative down. Within the first main contact with carers, whilst recognising carer feelings of guilt, duty and love, practitioners emphasised the importance of carers looking after their own health and other needs, reinforcing or providing a rationalisation for and validation of support use. In three cases, there was evidence that this helped carers psychologically to continue with seeking support. There were also four cases of practitioners encouraging carers to consider support to reduce or

ease the caring role in the future if circumstances changed. Two carers later did so. The following extract provides an example of discussion with the carer in the first main contact and then the carer's report of how this helped her progress towards accessing support.

June: I know it sounds horrible, but just thinking one day, I haven't got to go to Mum's today but I'd feel guilty if I didn't.

Helen: Right. Yeah, I think carers, a lot of carers, I don't think you're alone there, I think it's that balance isn't it? Between feeling that you've got to do something and feeling guilty if you don't do it, it's really important that you do look after your own health. So you've taken the right step being here today, hopefully we'll be able to move things forward and seek some additional help for you

(June, carer, observation, page 6)

In the research interview after the first meeting, June commented *"I felt relieved actually when I came away that somebody had pushed me to do more, not pushed me but coaxed me if you like"* (June, carer, interview 1, page 3).

Practitioner encouragement of carers to look after themselves also contributed to the outcomes of changes in carers' behaviour in relation to their health needs and also their leisure participation. In addition, in the case of use of complementary therapy services, the carer support worker encouraged the carer to use this to respond to her need for stress relief. The carer support worker reported: *"I encouraged her to have an urgent appointment to see our therapist at the centre. I felt like she needed some help with her stresses. She agreed to that and I rang the therapist who said she would offer an urgent appointment at home."* (Shefali, carer support worker, interview 1, page 4). This carer reported she accessed the therapies because *"Shefali thought, she said I think you need something."* (Alison, carer, interview 2, page 4).

- *Mechanism: Fear of service involvement*

The anxiety reported by two carers was an outcome of the fear they felt about the potential consequences of their interaction with casework upon their lives. This fear was also referred to by practitioners in terms of general reluctance by older people and black and minority ethnic groups to use alternative care services (see page 153). In another case where there was a history of difficulties between the carer and statutory services, the carer was unwilling to bring up emotional well-being needs in his carer assessment because of the fear that this might lead them to have concerns about him.

- *Mechanism: Feeling supported by an independent organisation*

Another carer reported that she had been more assertive in her contact with social services about a planned care package for her mother because she had the potential back up generally of a third sector professional.

Jane: I did contact social services again and I did chase up the appeals. There is a decision back so you know it's looking more positive as far as a care package goes and I probably, to be quite honest, I probably wouldn't have bothered, not even chasing it if I hadn't really had the visit [from the voluntary sector carer support worker]. I felt more proactive really probably.

Researcher: Right, ok, that's interesting. Could you say anymore about why that was?

Jane: I think it's because I knew I could get advice from an independent organisation to really push what I felt I needed. I really felt that I need, things have sort of gone on for quite a while. I just felt more confident to push for something to be resolved. I needed additional help with mum, it had been quite a hard week and I really felt that, you know, as her situation had deteriorated. I felt, it's really been quite a struggle the past week and I felt that, you know, I couldn't do it much longer really and I just felt maybe sort of clear, I felt more confident to actually deal with it.

(Jane, carer, interview 1, page 5)

5.2.2 Mechanisms of learning

- *Mechanism: Learning about the medical condition and how to manage this*

Carers reported learning about the medical condition of the person they cared for through both verbal information and written booklets provided by the practitioner. Practitioners empathised with the difficulties and made suggestions about how to deal with particular behaviour exhibited by the person receiving care. Carers tried to use some of this advice. For example, Margaret gave Tracy a number of suggestions for dealing with the sometimes difficult attitude of the person she cared for as the quotes below illustrate.

Margaret: Do you say to him, but that would be at a well time, what am I best to do if you're feeling low or high or? How am I best to be with you?

Tracy: I haven't actually. I haven't really had that conversation.

Margaret: That might be a good one. Obviously pick your times just so that you know, because I think, he might say 'I don't know' but by asking somebody, they're taking ownership of it and they're expressing to you how they feel.

Tracy: *Perhaps I should when he's feeling normalish.*

Margaret: *You might want to consider it because you don't know how to be with someone do you when they become unwell?*

Tracy: *No and I just tend to be the same all the time.*

(Tracy, observation, page 3)

- *Mechanism: Learning about secondary services*

The important feeling of reassurance discussed in section 5.1 was gained through learning that there is someone to turn to and/or that support is available generally. Conversely where carers were disappointed, frustrated or had a more negative outlook on their situation, this mechanism was absent because they were not satisfied that the support they needed was available.

Learning through the provision of information about the existence of and how to access specific secondary services for carers and the people they cared for also enabled some outcomes to be achieved in the uptake of some services. There was one example of a carer acting directly herself upon information provided to arrange alternative care services to ease the caring role. Maureen was given a list of sitting services with one particular recommendation and successfully arranged use of a service herself. (In another case, a carer planned to do so but the case could not be followed up.) In addition, in four cases, carers successfully pursued information themselves provided about secondary services and how to access these primarily for the benefit of the person they were caring for.

Two carers successfully followed up information provided about a welfare rights service. Information was often also provided about a range of carer specific services including carer leisure activities and support groups, complementary therapy services, the Caring with Confidence course and carer emergency planning schemes. In this sample, with the exception of the latter (carer emergency planning schemes) discussed below, learning about the existence of these services alone did not lead to uptake of these services. Proactive invitation and booking was also involved where use was achieved as discussed later. The number of carers who used these services was generally relatively low compared to the number who were informed about and who expressed interest in these activities. Partly this is explained by the existence of contextual barriers (explored in section 5.3.1) inhibiting participation. However, this also raises the possibility that other mechanisms are required to enable use of these services as discussed in section 5.2.3.

This is also suggested in the evidence relating to the provision of information to carers to enable them to contact another agency to register for emergency planning schemes. This had mixed success. One carer proactively registered with a service. However, another forgot to do so. *"I've got this literature stored away but I haven't got through it. A key fob, I'm glad you prompted me on that."*

I should follow that up really shouldn't I?" (Neil, carer, interview 2, page 3). Two carers took up support where this simply involved them completing a card with details of who to contact in an emergency and putting this in their wallet. At one service, practitioners did not mention emergency planning in the meeting but a leaflet was included about this within the printed information pack given to carers. However, there was no evidence of any interest or uptake of provision stimulated via these leaflets. In fact, the approach was later changed at this service as a practitioner explained. *"I think what was happening we were giving out leaflets but people weren't referring themselves. We can refer anyway now because that was something that was picked up by the provider, that people weren't using the leaflets to refer themselves."* (Pat, carer support worker, interview 2, page 6). In all cases where information was provided and carers were left to complete application forms by themselves, these were not used.

- *Mechanism: Learning about financial support*

Information and advice provided by the practitioner about potential entitlements to benefits within the caring situation had made three carers newly aware of potential entitlements. Valerie, who had taken on a new role caring for her grandson, had made an enquiry about his disability benefits. *"It was those that put me on the track that I'd, I would have to claim Child Benefit as well, you know, which I didn't realise."* (Valerie, carer, interview 1, page 6). In two cases, information and advice and the provision of an application form constituted sufficient help and carers were able to make the application themselves. Information and advice about the rules concerning Carer's Allowance and paid employment sought and received in the first main contact acted as an effective first step from which another carer was able to make further enquiries and subsequently to secure paid work himself. There was one example of use of information about discounts by a carer. Stanley had received a carer leisure concession card but mislaid the list of places where this could be used but commented *"basically I've just learnt as a matter of course wherever you go you ask for a discount for being a pensioner and then you also ask if there's any discount for carers."* (Stanley, carer, interview 2, page 6).

Practitioners across all intervention types raised the topic of benefits where carers did not enquire about financial support. This led to three of the cases of families receiving a new benefit or income being maximised through the backdating of payments to an earlier date.

There was also some evidence that information was sometimes possibly insufficient in relation to taking up benefits entitlements. In the short to medium term, it was apparent that a small number of carers (four) were not going to pursue potential benefits entitlements. In all but one of these cases, the practitioner had made a recommendation to carers to contact another organisation for benefits support. Other contextual factors relating to carers' characteristics also played a role in the lack of uptake in these cases. It is difficult always to disentangle entirely the contribution of each of these.

- *Mechanism: Learning about carer rights*

Practitioners sometimes needed to ensure carers understood that they did have entitlements to support, that other services did need to respond to them, in order to enable them to progress to accessing support. Two carers were successfully supported to understand that, contrary to their perceptions (based upon negative previous responses from other statutory health and social care services), they were entitled to some support. In one case, a carer support worker specifically emphasised to the carer that she had a choice over her caring role in order to encourage the carer to have further contact with statutory services. The practitioner made it clear to the carer that she had a right to choose not to continue to provide care to the same extent and that statutory services had a duty to respond to this.

Pat: You have a right, an absolute right to say that you cannot continue doing this, yeah? You have an absolute right to say that.

Maureen: I know I've got a right but it's still my Dad isn't it?

Pat: It doesn't mean that you're going to pull away from Dad and never, ever see him or never do anything. You have a right to say I cannot continue to do the amount of stuff I'm doing, it's affecting my health, I'm under an awful lot of stress. However, my Dad is at risk because he's not able to care for himself and he isn't by what you're saying.

(Maureen, carer, observation, page 11)

This arose in a specific context in which the carer was feeling defeated and that it was impossible to access support because her father had refused the statutory services offered and arranged and statutory services had expressed that they could not help any further. This argument from the practitioner alongside emphasis upon the carer's need to look after her health and have her own life was used during the first main contact to reach a point where the carer was willing for referrals to be made again to statutory services. Another practitioner talked about using a notion of entitlement to support in efforts generally to encourage older carers to consider using support. Sylvia commented "*perhaps they need to be reassured this is a service for them, it's their right that they can take it up.*" (Sylvia, carer support worker, interview 2, page 3).

In a case where this mechanism was not present, the carer's rights were not raised in the face of strong resistance from the person receiving care to the use of alternative care services, these services were not accessed (until about two years later). This depends upon the context of the practitioner's approach (page 156). The opportunity to consider other options was also potentially limited by the presence of the person receiving care in this instance of casework (considered on page 158).

- *Mechanism: Learning how to liaise with statutory services to improve the chances of their needs being met*

Third sector casework practitioners had also sometimes advised carers about how to liaise with (and sometimes potentially challenge) statutory professionals to improve the likelihood of successful outcomes. This included emphasising the particular difficulties of their situation and ensuring that the carer's point of view was heard as well as that of the person receiving care. One carer reported following some of this advice and having a private conversation with other professionals before seeing them with the person receiving care. It is not clear if this directly improved outcomes but it may have played a role. In another case, the practitioner provided advice about a local authority financial assessment to help limit any charges required for care services. No contributions were later requested. One carer also reported following advice that they could request an earlier appointment with the consultant if the person receiving care was struggling with their medical condition.

- *Mechanism: Learning how to express carer needs to negotiate with the person receiving care*

In two cases where the carer was having serious difficulty with their caring role and their relative was reluctant to try alternative support and/or physical aids or adaptations, practitioners advised carers to use the same kinds of arguments that practitioners used to encourage carers themselves to consider alternative care services. These related to reducing the strain on carers, protecting their health and enabling them to have a life outside caring. For example, Pat explained *"Maureen told me she was going to try the bath lift, Dad had agreed for eight weeks. We discussed how the carer could motivate him to continue using this. We talked about positive things she could say to her Dad about how it improved her health and how there was less strain for her."* (Pat, carer support worker, interview 2, page 1). There was evidence of these carers putting this into practice effectively. June talked about discussions with her Mum: *"At first, she was, I think her words were 'I don't want this, all this crap, everybody coming in. What are they all coming for?' I said 'they're coming to help me, Mum, to help me look after you'. 'Why?' 'Because I can't carry on like I am' and I think I got that through to her. 'Oh, as long as it's helping you then.' She accepted the meals and that a lot, lot better than I thought she would."* (June, carer, interview 2, page 3).

5.2.3 Mechanisms of the arrangement of secondary services

- *Mechanism: Referral to a secondary service*

In two cases, alternative care services to reduce or ease the caring role were accessed where practitioners made referrals for carers. The need for this additional input from the practitioner was linked to the context of carers experiencing considerable stress as discussed on page 148. In another case

where information was provided but without any further input or follow up, outcomes to reduce or ease the caring role were not achieved. This carer would have liked more help at home but did not follow up information provided about a third sector service that could help her to organise personalised support. Again, however, this may be influenced by the context of the caring situation. Partly she expressed this was because she was able to manage *“maybe because I could be more proactive in sitting down seeing what’s out there and making phone calls but because it’s not too terrible at the moment.”* (Rachel, carer, interview 1, page 5).

Use of other types of secondary service was also achieved by practitioner referrals in a small number of other cases. In one case, a referral by a practitioner had facilitated contact between the carer and a secondary service to arrange a walking frame, although this later required further practitioner intervention to ensure this was successfully followed up. In one case, a direct referral for a home visit to register a carer with an emergency planning scheme was successfully made for them. Casework referrals also led one carer to access a specialist employment service, another carer to use a peer support group for those applying for personalised support and three carers to have contact with welfare rights services.

However, in many cases, there was some kind of breakdown in the referral process which meant that secondary services were not used. This occurred in relation to: three referrals to emergency planning schemes; a referral to a specialist employment service; two referrals to complementary therapy services; three referrals to a Caring with Confidence course; and one referral to a welfare rights service. A referral to occupational therapy also broke down but in this case, this deficit was remedied by the carer’s own initiative to contact occupational therapy herself as she had not heard anything.

- *Mechanism: Practitioner booking of a service*

For three different types of secondary service provision (organised leisure activities, complementary therapies and the Caring with Confidence course), proactive invitation to and booking of an event or activity by a practitioner was one of the mechanisms leading to service use. In the cases where therapies were taken up or booked, the practitioner directly contacted the therapist who was commissioned by and worked at their carer centre to arrange an appointment. Where the Caring with Confidence course was attended, carers had been proactively invited and booked onto the course by a casework service.

In the two cases where organised carer leisure activities were taken up, the practitioner proactively invited and booked the carer into the activity or event. Conversely in three other cases where there was an interest but this did not lead to attendance, the carer said they had not been proactively invited. For example, in relation to potentially taking his mum on a trip organised by the carers service, Stanley reported *“I haven’t actually chased them but they haven’t told me either, you know. I would have taken her on that”* (Stanley,

carer, interview 2, page 6). It is difficult to know if these carers would really have taken up this provision if they had been booked onto it, particularly given the evidence that some carers were not that interested in this type of provision (see page 149).

- *Mechanism: Assistance completing applications*

In some cases, practitioners provided some assistance with an application process to enable receipt of a secondary service. Two carers contacted a carer service specifically because they were having trouble completing a benefits claim form. In these cases, the practitioner completed the majority of the form with the carer in their first meeting. Practitioners' help was very important because carers were struggling to progress these applications appropriately alone. Talking about entitlements she had accessed previously, Norma explained: *"We wouldn't have got anything done if the right people hadn't come and filled the right forms in."* (Norma, carer, interview 2, page 3). The data suggest that, alongside other factors (see page 149), the absence of this support may have contributed in part to some other carers not pursuing potential benefits entitlements.

Practitioners also enabled the successful receipt of a Blue Badge for two families by helping carers who were not confident about the paperwork to complete this. One assessment worker sometimes gave direct assistance with applications for the emergency planning scheme to improve the likelihood of take up. She explained:

If you just hand the form to them, it will just either stay in the envelope or they don't have the time to actually fill the form out or haven't got the confidence to fill out that form. So I basically get the form out and say shall I just fill in some of the details already, then put a star where they just need to sign it, so it just makes the process a bit quicker.

(Karen, carer assessment worker, interview 1, page 5)

- *Mechanism: Practitioner intervention in service access difficulties*

In four cases, practitioners contacted a secondary service directly themselves to intervene to remedy a difficulty in access (for practical or medical support for the person receiving care and benefits). For example, a carer received a letter awarding a lesser entitlement to a benefit than he had anticipated and he sought advice from the practitioner about this. The worker's knowledge of the system enabled her to understand the problem and she liaised directly with the agency to remedy this quickly. In another case, the practitioner advised speaking to the doctor about a difficulty and when she heard that the person receiving care would not attend the appointment, she arranged a home visit. After this, the condition was better supported with additional medication with a positive effect for both the carer and the person receiving care as reported by the practitioner.

There were indications in other examples that a practitioner had made some efforts to try and resolve a difficulty or wait involved in access to secondary services but without outcomes being achieved. The potential need for this was also suggested by another case in which a carer was struggling to find someone in statutory services to provide a definitive response to his request. He was feeling resigned to the lack of help and responded that what he would like was *“Someone to know the answers about the bed wetting and stuff like that, who’s going to grab the bull by the horns and not let it go and just keep, go to the end whether it’s an answer of no or an answer of yes. Like I said earlier I feel as if there is something out there but no-one knows who.”* (Ryan, carer, interview 3, page 4).

- *Mechanism: Identification of uses for one-off carer payments*

The purpose of a one-off payment has to be decided before this form of support can be arranged. In three cases, practitioners did not directly provide information about the availability of one-off carer payments but assessed themselves whether they thought these would be of use. In one case where funding was given for short breaks away that would not otherwise have been taken, the practitioner identified the need for breaks away through discussion with the carer about her situation in the carer assessment. She then recommended allocation of funding without previously informing the carer about the availability of the payment scheme. In this case, this meant the funding was used in a way that made a considerable difference to the carer. There were also two cases where practitioners taking this approach did not mention or allocate any funding because they had not identified any relevant needs. Here the carer did not have any opportunity to consider if they could use these funds helpfully.

In four other cases, carers were already aware of the existence of one-off payment schemes and made specific requests about how they wished to use these. In another five cases of use of one-off payments, the practitioners informed the carer explicitly about payment schemes and encouraged them to consider how they could utilise these. However, just straightforwardly informing carers about the availability of one-off payments was not necessarily sufficient to achieve use. Three practitioners noted the difficulty of identifying carer needs. A practitioner explained that in terms of considering one-off payments:

It’s not easy to get people to think, to be creative about it. I mean I turn up out of the blue with a form they’ve never seen before, it is asking quite a bit of them to go from perhaps thinking they’re talking about the person they’re caring for to actually thinking about themselves in the space of an hour, an hour and a half or two hours, sometimes so I do make a positive effort to try and push that side of it.

(Richard, carer assessment worker, interview 1, page 7)

This quote indicates the potential importance of the carer having time to consider how best they might use one-off payments. The carers who already knew about the schemes had had more time to consider how to use these.

One other potential solution to difficulties identifying uses for these funds is to identify an existing activity which could be funded as in some cases (see page 190). In four uses of one-off payments, carers took up specific examples of support suggested generally by practitioners. In another single example, a carer (Carol) proactively asked if a one-off payment could be used to pay for private chiropractor services to help with a physical health problem. It appeared that this followed the practitioner mentioning that these funds could be used for therapies on a previous occasion. She had wanted this treatment for a while but had been unable to afford it.

5.2.4 Mechanism: Carer action

The preceding sections have already indicated a number of ways in which carer action enabled the achievement of outcomes. This occurred where a carer arranged to use secondary services directly themselves using the information provided through casework about what was available and how to access this. Carer action was also involved in securing paid employment, in organising the support funded by one-off payments and in making behavioural changes to carers' lives.

Sometimes the carer also acted to remedy a deficiency in the processes or outcomes following casework. In one case, where there was a breakdown of some kind in the referral process to occupational therapy, the carer contacted them directly herself because she had not heard anything. In two cases, where a secondary service did not provide the support sought, the carer took their own action to achieve their desired outcome. In one such case, where occupational therapy had not been able to provide adaptations in the way the family wished, the carer found a way of altering things themselves to meet their needs. Angela explained: *"They decided they couldn't do that, so I said 'well, forget it'. So I went out and bought a secondhand chairlift and put it in myself."* (Angela, carer, interview 3, page 2). However, the carer will not always remedy such issues. In three other cases of this type, the need was not met.

5.3 Contextual factors influencing the direct outcomes of casework

Contextual factors influencing the direct outcomes of casework have been grouped into four categories relating to: carer characteristics (5.3.1); practitioner characteristics (5.3.2); casework characteristics (5.3.3); and the structural context (5.3.4). Other key contextual factors which influenced the uptake of secondary services were the nature, funding and accessibility of these. This is discussed in the next chapter where the outcomes of these secondary services are also examined.

5.3.1 Context: Carer characteristics

- *Context: Caring commitments and pressures*

The pressures and time involved in caring acted as a contextual barrier preventing or limiting the impact of a wide range of outcomes. This acted to limit the impact of some of the direct earlier outcomes of casework. Four carers mentioned that the positive impact of emotional support lessened over time because this was overcome by the daily pressures of the caring role or other issues arising such as periods of illness. Vera reported: *“your tension gets back up again as soon as, within an hour or so of carrying on.”* (Vera, carer, interview 2, page 8). For one carer, the fact that he was busy and stressed from caring meant he was less likely to consider changing his lifestyle habits as result of advice from the practitioner on smoking. One carer reported that she found it difficult to maintain her patience with her husband gained through improved understanding of his condition over time. In six of the eight cases where carers did not report experiencing any improvements to emotional well-being through casework itself, it seemed that the pressures of the caring role were probably acting to prevent this.

Some secondary services were not taken up and the use of some was not continued over time because of the commitments and pressures of the caring role. In three cases a leisure activity was not attended because a competing medical need (or anticipated need) relating to the carer or the person receiving care was prioritised. For example, a carer explained *“They go out for lunch quite often and there was one, I think the wife had got a hospital appointment and I couldn’t make it, you know.”* (Paul, carer, interview 3, page 1). In another case, the carer had not found the time to attend a complementary therapy service and the carer who did originally use this type of service also did not continue to do so in the medium or long term because of time pressures despite recognising the benefits of the provision. Another carer who was interested in moving and handling training did not attend because she was too busy. In two cases, carers did not find time to look at detailed, specialist written information about conditions provided by practitioners in any detail. Two carers who were also booked on to a Caring with Confidence course did not eventually participate because they were ill or too busy at the time. June explained *“I didn’t manage it. [...] I was shattered.”* (June, carer, interview 3, page 4).

Another carer did not pursue a potential benefit entitlement because of the time involved. The practitioner had offered to help with paperwork generally but the carer, who had a busy life combining her caring role with a part-time paid employment position, turned down this offer. She still thought the burden would fall upon her and felt the forms were too complex and required detailed information about medical history that she would have to try to find. The complexity of the system is also important here as discussed on page 196.

The pressure and stress of caring was also cited as a reason why practitioners would sometimes provide additional assistance in arranging alternative care

services for carers. A practitioner explained this in the following quote. *“That carer was in quite ill health and off work because she was so stressed, so in that situation I would try and help her as much as possible because I would feel that if I gave her too many things to do, she would feel unable to do them at the moment.”* (Helen, carer support worker, interview 1, page 8-9). Two other practitioners talked generally about the need to provide this additional support where carers were particularly stressed. In the case of use of complementary therapy services, the carer support worker had put in effective additional effort to encourage the carer to take these up because the carer had been recognised as experiencing mental distress. Conversely, in one case, a carer did not pursue support herself (see page 144) because she was managing at the time.

- *Context: Carer lack of interest*

Whilst the pressures of the caring role limited the ability of carers to take up some secondary services, in some cases, the carer also, or alternatively, expressed a lack of interest in doing so. One carer eventually decided that complementary therapies were not really for him as a man even though the practitioner had suggested otherwise. Two carers even expressed a sense of obligation to attend organised carer leisure activities. Paul commented *“I do feel that they send these invitations and this, that and the other and I think really you ought to make the effort and go to one even if the prospect of it doesn’t exactly make you want to dance for joy.”* (Paul, carer, interview 3, page 2). A practitioner also reflected that this might not have been that important to a carer. *“She’s not indicated that she’s too bothered in missing support groups.”* (Matt, support worker, interview 2, page 3). In another case, a carer did not appear to want to focus on the medical condition of the person receiving care despite the efforts of the practitioner to provide information.

In the short to medium term, it was apparent that a small number of carers (four) were not going to pursue potential financial entitlements. It is difficult always to disentangle entirely the contribution of different reasons for this. None of these carers expressed a strong need or desire to take up these benefits. Evidence in three of these cases suggested that because of this, they were unlikely to pursue a claim without direct support from a practitioner which was not provided in these cases. The evidence suggested that the complexity of the benefits system may also be a relevant factor.

- *Context: Reluctance to enter an unfamiliar social setting*

There was evidence that two carers were hesitant about attending social provision they were not familiar with initially. Linda discusses this: *“Once all the limelight’s gone and you’re just enjoying yourself with everybody, that’s what I like then. I just don’t like to be centre of attention, if I went and he said ‘oh this is Mrs Dean, she’s new here today’. I’d hate that. You know what I mean?”* (Linda, carer, interview 2, pages 6-7).

- *Context: Preference of the person receiving care not to use services*

There was evidence of the preference of the person receiving care not to use secondary services influencing outcomes of this kind. Two carers were supported to overcome this to access alternative care services to ease the caring role as discussed on page 143. However, in one case, this acted as a barrier which was not overcome until two years later.

In four cases, part of the reason the carer did not attend organised leisure activities (intended for the carer and the person they cared for together) appeared to be because the person receiving care was not interested. Norma commented in relation to her husband and the invitation to a coffee morning: *"He'd just sit there and wouldn't sort of take part. So you know, he said I'd sooner not be going and that's good enough for me."* (Norma, carer, interview 1, page 1). In another case, the person receiving care chose not to continue attending social activities. In two cases, aids and adaptations were not pursued because the person receiving care decided they did not want them.

Researcher: *When I spoke to you last as well you were also thinking about talking to an occupational therapist about maybe getting a scooter for your Dad?*

John: *That's it, we didn't. Dad didn't like the idea of that so we didn't approach that, I still think it's a good idea but I can't force Dad to do what he doesn't want to do because then he feels.. He has to do his own thing, the best he can, he does his own thing, then he's got his independence. So no, I don't want to take his independence off him.*

(John, carer, interview 2, page 5)

- *Context: Sense of carer entitlement*

The mechanisms informing carers about their rights (page 142) and encouraging carers to consider their own needs (page 137) are effectively about giving carers a sense of entitlement to support. The extent to which carers already have a sense of entitlement and also practitioners' view of this is a contextual factor which potentially influences use of secondary services. This was particularly apparent in relation to one-off payments. Talking about carers, Christine, a carer support worker, reported *"There is an element, a very small element but there is an element of people who think 'ah I'll just go and get my £100. It's April. Can I have my entitlement please?'"* and talking about colleagues, she commented *"I've heard conversations where it's 'oh I'll just pop a form in the post' and it's like, well, you haven't discussed their situation yet. It's almost like some of the workers have become like that, you know 'oh, it's time for the £100 or whatever'."* (Christine, carer support worker, interview 2, page 5). Prior carer knowledge of entitlements also effectively gave carers time to consider how to use these which the data suggests is important (page 146). This is explored further in relation to gender on page 152.

- *Context: Carer support networks*

There was some limited evidence about how the carer's wider support networks might influence the uptake of emergency planning services. In two cases, carers expressed that they did not feel a strong need to be registered with a scheme because they believed that they had adequate informal support networks to deal with emergencies. One carer had been going to join the scheme and was unclear about what had happened about the intended referral visit but had decided not to pursue it for the following reasons.

"Because if I really needed anybody, I think his mate would come round or his sisters, that would be alright and I have got quite a bit of family in the area and they're only, I mean they're just there if we need them." (Linda, carer, interview 2, page 7). Conversely, another carer had not registered for the emergency service despite interest because she could not identify any personal contacts to nominate.

- *Context: Nature of the caring role*

A relatively high proportion of carers caring for someone with dementia or another kind of mental health difficulty reported outcomes and needs relating to the opportunity to express one's feelings. There are particular challenges involved in dealing with difficult behaviour and interactions where a person has a mental health condition which may cause these carers to have greater needs in this respect. A large proportion of the cases where needs for information and advice about the medical condition were apparent also involved carers caring for someone with dementia. These cases included both carers who were fairly new to their role and those who had been doing it for a number of years.

The majority of carers who successfully claimed a benefit were either relatively new to their caring role or had had some change in circumstances which led to new eligibility for a benefit.

Most of the carers who needed help to reduce or ease the caring role were in established caring roles lasting for more than two years. They were all within caring roles with a high impact which generally also correlated with a full-time caring role of over fifty hours per week. It could be expected that these carers would need to reduce or ease their substantial roles. In addition, those carers who had unmet needs for alternative care services were more likely to be co-resident with the person they cared for, a parent carer, to be caring for someone with a condition other than being elderly and frail or having dementia and not to be in paid employment.

- *Context: Carer gender*

There was some indication that female carers particularly had considerable needs in relation to easing the caring role. All eleven of those requiring help to ease the pressure of the caring role in the first main contact of casework apart

from two were female, although at later stages in the research, other male carers had similar needs. In addition, the three carers who did not anticipate being able to access appropriate alternative care services to meet their needs right from the beginning were all female carers (mothers of those they were caring for and not in any paid employment).

The potential importance of gender was occasionally raised by research participants. Three practitioners suggested that men, in particular, could sometimes find it difficult to open up and express their feelings. Christine commented: *"Sometimes men do find that quite difficult to talk about intimate subjects. You know, there's a thing about men being brave and strong and there's a woman in front of him talking to him about carers' issues but he seemed quite comfortable in the end."* (Christine, carer support worker, interview 2, page 6). However, no direct evidence of a gender pattern was found in this sample. The five cases in which practitioners felt that carers did not open up (where this was not related to the presence of the person receiving care) all involved female carers except for one case. There was also no evidence of gender based differences in participants' willingness to open up during the research interviews. As noted previously, one carer did not feel that complementary therapy services were for him 'as a man'.

The data suggested that the attitude of carers may have an influence upon the uptake of one-off payments and this may have some relationship with gender. Seven (of thirteen) female carers were interested in taking up a payment when this was suggested. Three female carers were reluctant to consider such payments because they did not see themselves as a carer, they thought others could benefit more and/or they would only do so if they had a very specific need. Susan said *"to be honest if I don't need it, why have it?"* (Susan, carer, interview 3, page 8). Three other female carers also could not identify any particular use for a one-off payment. Amongst the six men who were invited to consider using a one-off payment, one took this up for the practitioner's suggested idea and two postponed use to a later date. Three men appeared keen to ensure that they found some way of using this (and did so). *"I did get the maximum and I did think I'm not getting finance in any other shape or form, I might as well take advantage of that."* (Neil, carer, interview 2, page 1).

There was some possible further evidence of a different sense of entitlement according to gender. The two carers who expressed a slight sense of disappointment immediately after the first main contact of casework at the extent of the support available generally happened both to be men. (One of these and another male carer also expressed disappointment that they did not qualify for any financial benefits despite their caring contribution.) The three cases in which there was evidence that practitioners helped carers psychologically to continue with seeking support by emphasising the importance of recognising their own needs despite carers' feelings of doubt and guilt about letting their relative down all involved women.

- *Context: Carer ethnicity and age*

A small number of black and minority ethnic carers (four) took part in this study (one of whom could not be followed up). There was some suggestion from their participation and practitioners' general comments on ethnicity that this was a relevant contextual factor in some ways. There was evidence that black and minority ethnic carers were less likely to achieve some outcomes. All three black and minority ethnic carers who were followed up did not report any benefits to their emotional well-being. However, no evidence could be identified here linking this in any particular way to their ethnicity. Two of the four carers who did not pursue potential benefits entitlements were from black and minority ethnic communities. Within the two cases considered here, in one, cultural factors may have played a role alongside other factors. This carer (who was British Bangladeshi) also did not pursue an application for a direct payment to fund the care he was providing as suggested by the practitioner. The family did not wish to formalise their care arrangement in this way. The carer explained this with specific reference to their culture. *"Asian people they feel a bit sensitive, you know, because traditionally, culturally our younger generation just look after us no matter what, so to employ somebody is quite offensive sort of thing."* (Nishan, carer, interview 2, page 3).

Two practitioners talked about older people and another two practitioners mentioned black and minority ethnic carers as particular carer groups who may have limited awareness, or generally negative perceptions, of alternative care services which acts as a barrier to use. Anna said of older people: *"they've got this whole, this whole social services will come in and put you in a home sort of thing and that is very common with older people, very common."* (Anna, carer support worker, interview 1, page 12). No particular pattern of attitudes could be related to socio-demographic characteristics including age and ethnic group in this sample. However, those carers most reluctant to use services may not have been represented by virtue of this characteristic.

Amongst the Afro-Caribbean community, Marlene thought carers were less likely to use services because *"sometimes it's fear of the unknown"* and *"I don't think they always understand the systems and how to go about things"* (Marlene, carer support worker, interview 1, page 8). Karen related reluctance to use services to specific concerns about the nature of support amongst the Asian community.

They know in the back of their heads, that the services are not going to meet their needs really, like the flexible breaks voucher schemes which I have talked about and about the sitting service but they know they won't get an Asian paid care worker coming in so you know.

(Karen, carer assessment worker, interview 2, page 5)

One practitioner mentioned using referrals to alternative care services specifically in relation to black and minority ethnic carers because of their particular reluctance to use alternative care services. In addition, one carer, Nas, twice asked if the carer assessment worker could help her with a form rather than referring her to another organisation. This may partly have been

because she had already met the practitioner previously and established a relationship of trust. It can also be speculated that this may have been partly related to her South Asian ethnicity and the fact that the practitioner was also South Asian (albeit from a different specific ethnic group). There is not enough evidence to conclude.

- *Context: Longitudinal change in caring circumstances*

The context of many carers' roles changed considerably in the long term. Predominantly the changes involved related to deterioration in the condition of the person receiving care such that they moved into residential care or bereavement except where specified below. This had two main effects. This often limited the achievement of earlier outcomes particularly in terms of use of particular secondary services previously accessed. This also led to the development of new carer needs as discussed at the end of this section.

The earlier outcomes achieved in relation to improving carers' knowledge of the medical condition involved were no longer relevant in the long term due to changes in caring circumstances. In the long term, carers who had returned to employment with some assistance from casework (one via the use of alternative care services) were no longer in these positions due to changes in their personal circumstances. One carer was on sick leave but this was not related to their caring role at that time. The other carer had ended his paid employment role because he could not rely upon other family to support with the caring role.

In three cases where alternative care services had been arranged earlier for carers, changes in the caring situation meant that these were no longer of relevance in the long term. Practical support accessed primarily for the person receiving care in the short to medium term was also no longer used in the long term due to changes in the caring circumstances. In one unusual case, where a solution was only finally being reached for practical support for the person receiving care (for a disabled parking space and access), deterioration in the condition of the person receiving care meant outings were no longer an option anyway. Emergency schemes were also no longer needed by two carers where there had been a change in their caring circumstances. Apart from one case, in the long term financial benefits accessed previously also no longer continued to be received because of a change in caring circumstances (and in one case, because the carer was then receiving his pension which removed his eligibility for benefits).

Deterioration in the condition of the person receiving care also meant that in three cases, new needs for alternative care services to reduce or ease the caring role had emerged by the long term. When this happened, in these cases, carers contacted another relevant organisation (rather than the original casework provider), for example, local authority social care or health services directly to arrange alternative care services. Whilst these carers did manage to secure support through generic statutory services, they expressed that this was difficult both practically and emotionally. These three carers reported that

they could have benefited from emotional support to help them through periods of transition. Charlie said *"You've given all this time to caring for your parents, then they're gone. You're too low to pick yourself up."* (Charlie, carer, interview 4). These needs were not met because of a lack of ongoing contact with the service (page 163) and the closure of casework services (page 165). In this latter case, the caring role had become more limited in the long term enabling the carer to consider paid work again. However, he expressed some difficulty with this and the lack of continued contact from the carer service meant he was not offered any support as discussed on page 164.

In the one case where the reluctance of the person receiving care to use alternative care services had prevented the carer from reducing his role, this eventually changed in the long term. This occurred because of change in the attitude of the person receiving care and also the physical health problems the carer was experiencing.

5.3.2 Context: Practitioner characteristics

- *Context: Outside the carer's family*

In two cases, it was noted that it was specifically helpful to talk to someone that was not a member of the family.

- *Context: Practitioner knowledge*

In all the cases where learning from the information provided verbally by the practitioner was a mechanism contributing to an outcome (section 5.2.2), the context of the practitioner's knowledge underlay this. Two casework practitioners' specific knowledge about Attendance Allowance applications enabled this to be claimed from the earliest possible date and also meant that comprehensive information about the needs of the person receiving care was included to improve the chances of receiving the benefit and at the highest rate where appropriate. In addition, in three cases, carers linked the reassurance they felt from the practitioner to the practitioner's knowledge of social care systems. For example, Philip talked about the practitioner: *"We have every faith in the fact what she is trying to do for us. When you think of it, she's been in that service what 25, 30 years, she should know her job by now. I'm sure she does as well."* (Philip, carer, interview 1, page 3).

- *Context: The practitioner's supportive manner*

The practitioner's supportive manner was also indicated to be an important context to achieving outcomes of improved emotional well-being. Two carers noted the importance of practitioners having a supportive manner in relation to feeling reassured. Claire discussed why she would turn to the carer assessment worker rather than the colleague who had conducted the review of her son's care: *"she was very knowledgeable but I felt like she was just*

doing a job whereas, [carer assessment worker], I know he's doing a job but he seemed more approachable." (Claire, carer, interview 1, page 5). In relation to feeling relief through having the opportunity to talk, two carers specifically mentioned the following practitioner characteristics as helpful: listening; being non-judgmental and non-condescending; understanding, supportive and friendly. For example, Mavis commented: *"She was a friendly person. She's down to earth, she seemed natural, she didn't seem above her station or anything. I felt I could talk to her."* (Mavis, carer, interview 1, page 6). More widely, carers who reported the value of having the opportunity to talk also identified practitioners as having these characteristics whilst not proactively making a specific link between these.

- *Context: The practitioner's personal experience of caring*

Two practitioners commented that they felt their personal experience of caring underlay the characteristics of a supportive manner. Maggie explained: *"I'm a carer myself, I know exactly what sort of issues they're going through. We just want them to know that we're there for them and the support's always here for them."* (Maggie, carer support worker, interview 1, page 2). Two carers also made some links between the feeling of reassurance they had gained to the practitioner's personal experience of caring. Jane discussed the implications of the practitioner's personal experience of caring: *"She was aware of the difficulties that I probably am going through and will go through and I think that gave me confidence that she could sort of almost gauge what lay ahead and if I was having trouble you know in future or particular things I'm struggling with, I'm probably more likely to talk to her about it."* (Jane, carer, interview 1, page 3). Nearly all of the participating practitioners had personal experience of care so this may have had a wider influence even though this connection was not proactively reported more frequently.

- *Context: The practitioner's approach to casework*

It was previously noted that one practitioner challenged difficulties arising from the reluctance of the person receiving care to use alternative care services by informing the carer about their legal rights (page 142). In contrast, this reluctance was not successfully challenged in another case, where the practitioner did not seem to consider there to be any other options whilst the person receiving care was not willing to use services. He explained that he would pass on information about services available but could not go much further. *"Really I have to sort of give her the information for him to, I just pass information on and I don't feel I can be as proactive as I want to in some ways in terms of trying to get him to be involved because I'm always aware it's not really my place to do so."* (Richard, carer assessment worker, interview 1b, page 5).

The discussion of the mechanisms of casework relating to the uptake of one-off payments (page 146) has also indicated that the practitioner's approach

may influence this in terms of whether they proactively inform carers about the existence of this support.

There was also some limited evidence that practitioners' approach in terms of emotional support might influence outcomes. Two practitioners noted that they allowed the conversation to deviate from the specific forms that were being completed during the meeting to enable carers to talk freely. The absence of improvements to emotional well-being was found across different types of casework. However, observational evidence suggested that in two cases the nature of the practitioner's approach to the first meeting may have been influential. In one case where there was no reported emotional impact (and another with little reported impact), the practitioner was very focused on factual information and did not comment positively on the carer's contribution or facilitate a general discussion of their role and situation as other practitioners did. In one of these cases, the presence of the person receiving care also potentially limited the opportunity for this.

There was some evidence that practitioners differed in terms of whether they perceived needs relating to caring skills as something with which they were able to help. As noted previously, some practitioners did support carers with learning about the medical condition of the person they cared for and how to deal with difficulties arising from this. This related to whether practitioners specialised in particular medical conditions. In three cases with generic carer practitioners (not specialising in particular medical conditions) where carers were talking about dealing with a particular medical condition and/or behaviours, practitioners empathised and generally validated the carer's approach (without offering information and advice). In one case, a carer (looking after his wife who had dementia) asked about whether he was taking the right approach and the practitioner validated this. She commented: "*you know, you're the one who best knows her needs and how you prefer things to be done because we're all different aren't we? So I wouldn't worry too much about that, you're doing a grand job.*" (Shirley, support worker, observation, page 5). However, there were further indications in subsequent research interviews that he could have benefited from some more specific advice on managing behaviour arising from his wife's dementia. He reiterated the wish for some input.

David: I just wanted to be helpful, to know that I was doing the right thing and if there was anything else I could do to help it, you know, really. It's all brand new.

Researcher: When you say doing the right thing, what do you mean in terms of?

David: Do I go along with everything that's going on in the house or do I stop and say no this is wrong, you've got to do it this way or something like that really. You don't know whether you're doing the right thing or not.

(David, carer, interview 1, page 3)

The practitioner did inform this carer about a specialist carer support group which may have fulfilled this function, although she did not specifically explain that it might help in this way. The carer was subsequently bereaved but he did not previously seem likely to participate in this type of support.

A similar attitude amongst practitioners was displayed by the hesitancy of two asking standard questions from assessment forms about whether the carer had any training needs. When asked about her hesitancy about enquiring about carers' training needs, Marlene explained: *"I think training is something for somebody who's never done it before. When somebody's been caring for somebody for so long, it's like treating somebody like they don't know what they're doing."* (Marlene, carer support worker, interview 1b, page 4).

5.3.3 Context: Casework characteristics

- *Context: Casework service opening hours*

One of the carers in full-time employment who participated in this research noted that he had difficulty accessing the casework service which was only open during standard working hours because he was working during these hours. Many of these casework services are only or predominantly accessible during standard working hours. This is likely to limit the potential outcomes these services can achieve particularly for carers in full-time paid employment.

- *Context: Home visit*

The achievement of relief through talking about your situation was reported by carers accessing all the different forms of casework but reports of these benefits were relatively more frequent amongst those whose first casework appointment took place at their home rather than at the organisation's office or on the telephone. Direct feedback from carers and practitioners also suggests that carers feel more at ease and comfortable talking in their home environment compared to elsewhere. Helen commented, *"the carer certainly feels more relaxed in their own home so they're more likely to speak more openly and feel relaxed and if they feel a bit emotional then they feel able to let those emotions out perhaps more in their own home."* (Helen, carer support worker, interview 1, page 4).

- *Context: The presence of the person receiving care in the first main contact*

A higher proportion of the carers who reported benefiting from the opportunity to talk about their situation met practitioners without the person receiving care being present compared to across the sample as a whole. The relevance of this was reinforced by acknowledgement from practitioners and carers that the presence of the person receiving care could limit the opportunity for the carer to talk openly. Neil regretted his decision to have the assessment with the

person he cared for present and said *“perhaps I would have said more and opened up more if he hadn’t been there.”* (Neil, carer, interview 1, page 4).

However, some ways of mitigating this inhibiting contextual barrier were also suggested by the data. One possible mechanism for coping with this difficulty is intervention within discussions to try to facilitate the opportunity for the carer to talk openly. For example, when Linda was discussing some of the difficulties she faced in having a break, her husband for whom she was caring joked *“Are you depressed yet?”* The practitioner responded: *“Give her ten minutes, give her ten minutes.”* (Linda, carer, observation). Sometimes, further contact was later made with the carer without the person receiving care present which allowed a more open discussion to take place.

The data also showed that it was possible that the presence of the person receiving care could have benefits. Susan said *“I’m glad he was there because he would, like he did, he would put forward about me which I might not have bothered saying about myself.”* (Susan, carer, interview 1, page 6). This could help with the identification of carer needs. Some practitioners also reported some benefits to meeting the person receiving the care, for example, to help provide some insight into the carer’s situation and also for the person receiving care to hear the carer’s perspective. A practitioner explained *“the carer asked me to do it with his mother there. Actually that opened up quite a bit and he was able to say things that he wouldn’t normally have been able to say in front of his mother, so it kind of released him to do that.”* (Pat, carer support worker, interview 2, page 4). This might help with negotiation between the carer and the person receiving care.

- *Context: Third sector carer organisation visibility and publicity*

The number and proportion of carers reporting the different outcomes has been compared in relation to the type of organisation the practitioner conducting casework was employed by: third sector generic carer organisation; local authority; and third sector condition specific organisation. This has led to a number of findings about contextual factors relating to organisation type which are discussed in the next few sections.

This showed that third sector generic carer organisations were particularly successful in achieving outcomes in terms of improvements in emotional well-being, behavioural change, employment, use of alternative care services and practical support for the person receiving care and receipt of financial benefits. The difference in outcomes is discussed in turn below. These numbers have no statistical significance. However, it is useful to consider whether there is any other evidence or reason for thinking that any patterns in outcomes are explained by organisation type in some way.

The achievement of improvements in emotional well-being of various kinds (reassurance, relief through expression of feelings and a more positive outlook) were more frequently and were proportionately more likely to be reported by carers who had had contact with a third sector carer organisation

rather than casework conducted by a local authority employee. This pattern was particularly clear for the outcome of reassurance. There was also an association between reporting reassurance and having a caring role which had a more moderate impact upon the carer's life compared to others. In addition, carers who initially had low expectations of support based upon previous negative experience (more common in statutory carer assessments) were less likely to feel reassured. Thus, these differences seem likely to relate to the different characteristics of the sub-samples of carers participating in each type of casework (see page 108).

The five examples where carers had taken some action to change their behaviour to address leisure and/or health needs as a result of the casework practitioner's input were all cases of third sector casework (one of which was conducting a statutory carer assessment on behalf of the local authority and one of which was condition specialist). The carer who returned to paid employment did so via learning achieved through third sector casework. The carers who accessed alternative care services or aids and adaptations to ease the caring role in the short to medium term all had some support from third sector casework (in one, this involved a statutory carer assessment carried out by a third sector employee). However, there was no apparent necessary link to organisation type.

There was greater uptake of practical support primarily for the person receiving care amongst cases conducted by practitioners from third sector generic carer organisations compared with statutory carer assessments. Third sector generic carer services fulfilled these needs well where they were presented with the unproblematic exceptions of where the person receiving care decided they did not want the support on offer. However, in the cases where use was not achieved (statutory carer assessment and one condition specialist case), this was because occupational therapy services were unable to fulfil these needs appropriately. Thus the nature of the secondary service was a key barrier here. In addition, the support and needs involved could be argued to be more complex and difficult to resolve than in the cases of third sector casework.

Within this sample, outcomes of successful benefits receipt did not occur through statutory carer assessment (with one exception where this was delivered in partnership with a third sector organisation which provided direct support with the benefits claim). Third sector organisations, both condition specialist and generic carer, did enable carers either to receive new benefits entitlements or to maximise their entitlements in some way. This is partly explained by the fact that a substantial minority of the sample (six carers) proactively made contact with third sector generic carer services because they were seeking information or support related to benefits applications. In addition, in two cases, a condition specialist practitioner achieved this with carers of people who had suddenly experienced a particular illness and who were accordingly relatively new to the role and therefore newly eligible for financial benefits. The practitioner's proactive approach to these carers through their links with health services may mean they are particularly likely to be able to achieve this type of outcome. The limited achievement of this type

of outcome through statutory carer assessment may also be explained by the fact that these carers were more likely to be from families who already have some service support and who were therefore likely to have already had their welfare eligibility checked.

No evidence was found suggesting particular reasons relating to the nature of the casework undertaken to explain why the third sector was more successful than statutory carer assessment in relation to these outcomes. However, it does seem likely that the pathway to contact with the different forms of casework influenced this. As already noted, the characteristics of the different carer sub-samples varied. This included the fact that third sector carer organisations were mainly approached by carers themselves who did not already have any service support, third sector condition specialist organisations were contacted through links with health services and most contacts with the local authority were the result of a recommendation from another professional to carers in families who often already had service support. Over half of the carers who approached a third sector carer organisation did so either following a personal word of mouth recommendation, through coming across the organisation's promotional materials or from noticing their physical premises in their local area. (The remainder was informed about the organisation via another service professional.) This suggests that these third sector carer organisations were a relatively visible, accessible first port of call for these carers, thus enabling them to access casework with the potential to achieve outcomes.

- *Context: Direct booking of carer secondary services by third sector carer organisations*

Emergency planning schemes were taken up by carers through all the different organisational forms of casework. All the other forms of secondary services specifically for carers (Caring with Confidence course, complementary therapies, carer leisure activities and support groups) were used by carers who participated in casework with a third sector generic carer organisation. The numbers involved here were small as discussed on page 135. This may also be partly explained by the nature of the sub-samples and the publicity and visibility of third sector carer organisations as discussed in the preceding point. However, this pattern seems also likely to relate to mechanisms previously discussed which are used differently according to organisation type.

Third sector generic carer organisations directly booked carers into this provision. Some of this (complementary therapies and carer support groups and leisure activities) was also provided directly through their own organisation and so quite specific information was given about the activities on offer. The Caring with Confidence course was delivered by another organisation but carers were booked directly into this by the third sector organisation. In contrast, statutory carer assessments referred carers to the Caring with Confidence course, but these referrals had broken down (and this also occurred in two cases of interest in complementary therapies). In local

authority casework, practitioners informed carers generally about the existence of third sector carer organisations whose provision included social events and activities for carers. This did not lead to any take up of these.

- *Context: Statutory carer assessment direct allocation of one-off carer payments*

The majority of one-off carer payments were made through a statutory carer assessment (including a number which were conducted by a practitioner from a third sector carer organisation on behalf of the local authority). This could relate to the extensive caring roles of carers in the sub-sample who had a statutory carer assessment conducted by a local authority. Alternatively it could reflect the fact that one-off carer payments were available in all statutory carer assessments but not in all cases of third sector casework. Four of the eleven participating third sector organisations offered these directly, and in some cases, these organisations informed carers about the availability of these through the local authority.

- *Context: Strained relationship with the local authority*

The context of a strained relationship with the local authority where there were difficulties around the provision of statutory social care services for the person receiving care meant that carers' potential mental health needs were not considered fully in two cases of carer assessment.

- *Context: Third sector condition specialist organisations' focus on medical condition and skills*

Increased carer knowledge of the medical condition of the person receiving care and improved skills for responding to behaviour arising from this was most apparent in cases involving contact with a condition specialist third sector practitioner (and one practitioner from a generic carer organisation who specialised in a particular condition). This is explained by their direct, proactive provision of this form of support.

- *Context: Third sector condition specialist organisations' links with health services*

Contact between third sector condition specialist organisations and carers had been made via links with health services. As noted previously, this can help some condition specialist practitioners to reach carers when they are likely to need help with benefits entitlements. In addition, a condition specialist practitioner's links with the health service facilitated outcomes in terms of practical support primarily for the person receiving care as the following quote discusses.

I think it's good that I'm based in the hospital because I was able to liaise with hospital issues, like whether she was going to have more physiotherapy, that's the second one and the first one with Sue, I could easily speak to people about the walking frame. You know I can liaise on their behalf quite easily.

(Joan, carer support worker, interview 2, page 8)

- *Context: Ongoing contact with the casework practitioner*

As discussed on page 113, the nature and frequency of ongoing contact between the casework practitioner and carer varied according to organisation type. Condition specialist practitioners made more proactive ongoing contact with carers over time than practitioners from other types of organisation. This contributed to later outcomes of various types in a range of ways. It enabled some new needs that developed later to be identified and met, it enabled breakdowns in the route to some secondary support to be remedied and it allowed a relationship to be built over time that facilitated some later outcomes. However, there was also evidence that the more limited ongoing contact made by practitioners from third sector generic carer organisations did contribute to maintaining some improvements to emotional well-being.

Proactive ongoing contact by condition specialist practitioners enabled some new or changed carer needs to be identified over time, and in most cases addressed. These included the provision of advice on the need for health support and possibly alternative care services, uptake of a financial benefit, the provision of information about some equipment to address a difficulty in the behaviour of the person receiving care and discussion about options for social activities for the person receiving care. For example, in one case, in a general check on the carer's well-being in a phone call, a carer support worker heard that he had not been well for a couple of weeks and was struggling. She was then able to encourage him to go to the GP and also made a referral to social services to discuss potential support. *"I asked how he'd been managing with his wife and he felt that it was actually time for a little bit of support and a bit of help. He agreed that I could make contact with the GP about a possible visit or somebody ringing him up to see how he was doing and also that I could contact the social work team for input."* (Lesley, carer support worker, interview 2, page 7). Her phone call meant that support was offered at an earlier point in time than probably otherwise thus potentially preventing more serious difficulties occurring. The carer who received support from a peer support group for those accessing personalised support also found this support particularly useful because of the proactive email and phone contact from group members to check on her progress.

The importance of this is further supported by evidence that some carers did not contact anyone for support when new needs to reduce or ease the caring role emerged. This is despite other findings reported earlier that carers derive great peace of mind from knowing there is somewhere to turn for support. Unfortunately this does not always translate into picking up the phone and asking for help. In the example below, the caring role had become more

limited in the long term enabling the carer to consider paid work again. However, he expressed some difficulty with this and the lack of continued contact from the carer service left him unwilling to seek help generally as the discussion below illustrates.

Charlie: To be honest, it's afterwards you need the help, when I've now got the time, when I'm now left redundant really. What do I do with myself now? I've given my life to them. I'm still having to go in and care. I can't get any financial help. I haven't got a job. I'm still stressed out with worry. I could probably do with going in and getting a cut price massage or something but you know, it [refers to contact from the carers service] stopped. I mean I don't know, I haven't phoned them in all honesty to find out.

Researcher: Is there anything that stops you doing that do you think?

Charlie: I feel a little bit bitter towards the whole system really. A bit like well, I'm not going to go begging there for help. I survived it on my own really. I sort of can't be bothered.

(Charlie, carer, interview 4)

Conversely, there was also one case of a carer proactively getting back in touch with a carer organisation to request further information to organise new support to benefit the person receiving care.

The ongoing proactive contact made by a condition specialist practitioner enabled difficulties in the process of accessing secondary services to be remedied. Sue had expected a walking frame to arrive in six weeks but it was still not there three months later. She mentioned this to the support worker and reported *"she got in touch with my aunt's physio at the hospital and within a week really, you know, after speaking to her so she had it within the week"*. (Sue, carer, interview 3, page 2). In another case, the practitioner also intervened to help the carer liaise with medical professionals to manage the medical condition of the person receiving care after learning that they had not attended appointments as planned. This was absent in Ryan's case referred to on page 146 where he had considerable difficulties accessing the support he wanted to ease the caring role.

There was also some evidence that the building of a relationship over time between the carer and practitioner facilitated the later achievement of improved emotional well-being and better understanding of the medical condition. A practitioner reported that the carer who initially was reluctant to discuss her husband's condition began to do so over time. In later contacts, they discussed particular challenging behaviours and the practitioner provided information to try to improve the carer's understanding of this. In another case, the practitioner felt that the carer might express herself more over time as they built a relationship and reported later that this did occur.

In the majority of the reports of ongoing reassurance, there was some ongoing contact between the carer and the third sector carer service even if this only

involved receiving service mailings. In two cases, carers specifically linked this ongoing contact to the reassurance they continued to feel. When asked how, if at all, a follow up phone call from the practitioner affected her emotionally, Sarah responded: *"It was just, it was very reassuring I think, yeah, you know and it's nice to be thought of. [...] again it's just a reinforcement that they're there if I need them really."* (Sarah, carer, interview 2, page 5). There were also two proactive reports of carers having further useful opportunities to talk and express their feelings where there was further ongoing contact from the practitioner in third sector cases.

Some benefits to emotional well-being were maintained where there was no further contact. Three carers continued to report feeling reassured in the medium term even where there was no proactive ongoing personal contact from practitioners. In addition, three practitioners gave examples within the research of carers requesting further meetings in the short to medium term with an apparent practical purpose but where they thought afterwards that principally the carer had just needed the opportunity to talk. However, as noted on page 129, in four cases in the short term and another in the medium term, carers felt disappointed or sometimes even resentful over time when they did not receive any further contact from the service. In one case, the carer's expectations were more than the service intended or expressed that it offered in terms of making proactive repeat contact. In the other cases, the practitioner had offered more contact and also support with other services which did not materialise or not as quickly as the carer expected. This led to disappointment. In two cases, this later changed positively when helpful support was put into place or contact later made. Feelings of disappointment were predominantly identified in cases of statutory carer assessment. However, it is difficult to draw conclusions about any reasons for this association because of individual variation in these cases. Such feelings of disappointment can have implications as to whether carers will seek help in the future if necessary as in the example given above of Charlie.

5.3.4 The structural context

The wider structural context also acted as a barrier to achieving outcomes. In particular, the availability and nature of secondary support services such as alternative care services and occupational therapy constituted a barrier to use and further outcomes. This is discussed in chapter six. In one case, the wider context of a carer's employment setting limited the use of information provided through casework about how to manage the competing demands of caring and paid employment roles. The carer felt unable to implement strategies for balancing shifts with her caring role faced with a shift system that was not very flexible. Consequently, she chose instead to reduce her working hours. The lack of particular legal rights (to take time off to attend medical appointments with the person she cared for) also contributed to this decision.

In the long term, two third sector carer services were no longer in existence due to funding cuts emanating from the deficit reduction programme, although an alternative form of support was available locally. Two carers who had

previously used these services had new needs that developed in the long term. They did manage to secure support through generic statutory services but they expressed that this was difficult both practically and emotionally. Whilst these carers' responses appeared genuine, it is possible that they may have also wanted to make a political as well as a personal point in the research interviews about the need for the service.

Outcome Table 5.1: Reassurance

Mechanisms	Contextual factors of influence			
	<i>Immediately (after the first main contact of casework)</i>		<i>Over time</i>	
	<i>Enabling</i>	<i>Inhibiting</i>	<i>Enabling</i>	<i>Inhibiting</i>
Learning that there is somewhere to turn for support or that support is available generally	<i>Practitioner characteristics</i> - experience of caring - knowledge and expertise - supportive manner <i>Caring characteristics</i> - caring role with moderate impact	<i>Carer characteristics</i> - low expectations of services based upon previous negative experience	<i>Casework design</i> - ongoing contact	<i>Practitioner approach / nature of secondary service</i> - lack of/ slow follow up of actions/ contact (sometimes carer expectations higher than service aims) <i>Casework design</i> - lack of ongoing contact

Outcome Table 5.2: Relief

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Expression of feelings through talking	<i>Practitioner characteristics</i> - outside the carer's family - facilitates discussion - supportive manner - personal experience of caring <i>Casework design</i> - home visit	<i>Carer characteristics</i> - under too much pressure - closed personality? - negative previous experiences? - male? <i>Research</i> - recording? <i>Casework design</i> - presence of the person receiving care in the first main contact <i>Practitioner characteristics</i> - factual approach, little general discussion of the caring role	<i>Casework design</i> - ongoing contact including carer seeking practical help and proactive contact from the practitioner	<i>Casework design</i> - lack of ongoing contact <i>Carer characteristics</i> - under too much pressure <i>Structural</i> - closure of third sector casework services due to funding cuts

Outcome Table 5.3: More positive outlook

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Normalisation, recognition and valuing of caring contribution and competence		<i>Practitioner approach</i> - factual approach, little general discussion of the caring role or positive comments on the carer contribution	<i>Casework design</i> - ongoing contact	

Outcome Table 5.4: Disappointment, frustration, negativity

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Carer dissatisfaction with support available		<i>Carer characteristics</i> - person receiving care unwilling to try alternative support <i>Nature of secondary services</i> - insufficient	<i>Casework design</i> - follow-up of actions <i>Nature of secondary services</i> - successfully arranged	<i>Casework design</i> - lack of ongoing contact - lack of follow-up of actions <i>Nature of secondary services</i> - not yet implemented, slow process <i>Carer characteristics</i> - higher expectations than service aims

Outcome Table 5.5: Behavioural change to address carer health or leisure needs

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Carer accepting the importance of considering and responding to their own needs <i>and</i> Carer action to make changes		<i>Carer characteristics</i> - under too much pressure	<i>Casework design</i> - ongoing contact with practitioner	

Outcome Table 5.6: Development of caring knowledge and skills

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Learning about specific medical conditions and how to respond to particular difficulties Learning how to liaise with statutory services to improve the chances of needs being met <i>Leads to</i> - Better care (also in one case through intervention to remedy difficulties in medical service access) - Reassurance about rehabilitative potential	<i>Casework design</i> - proactive focus upon specific medical conditions and arising caring difficulties including provision of verbal and written information <i>Practitioner approach</i> - allows general discussion of caring role and issues - completion of application form raises issues - offers advice upon caring difficulties <i>Caring characteristics</i> - caring for someone with a mental health condition including dementia (these carers more likely to have needs)	<i>Practitioner approach</i> - recognises carer expertise and does not perceive a need for practitioner input <i>Caring characteristics</i> - carer lack of interest	<i>Casework design</i> - ongoing contact from practitioner to build a relationship	<i>Caring characteristics</i> - time pressures - carer under too much pressure - change in circumstances (long term)

Outcome Table 5.7: Participation in paid employment

Mechanisms	Contextual factors of influence			
	<i>Immediately</i>		<i>Over time</i>	
	<i>Enabling</i>	<i>Inhibiting</i>	<i>Enabling</i>	<i>Inhibiting</i>
Learning about paid employment and benefits Carer action in job seeking			<i>Carer characteristics</i> - caring role reduced	<i>Casework design</i> - breakdown in referral, no follow-up - lack of ongoing contact <i>Carer characteristics</i> - caring role too intensive <i>Structural</i> - lack of employer flexibility - lack of legal rights to attend caring related appointments

Outcome Table 5.8: Use of alternative care services

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Carer accepting importance of considering and responding to their own needs <i>and sometimes</i> Learning of state responsibility to meet care needs where carer does not wish to continue <i>and sometimes</i> Learning about alternative care services and how to access these <i>and sometimes</i> Learning how to liaise with statutory services to improve the chances of their needs being met <i>and sometimes</i> Learning how to express carer needs to negotiate with the person receiving care <i>and sometimes</i> Feeling supported by an independent organisation <i>and sometimes</i> Carer arrangement of services <i>or sometimes</i> Arrangement of service through practitioner referral	<i>Caring characteristics</i> - in caring role for more than two years, generally providing 50+ hours of care per week - pressure of caring leads to needs and practitioner to make referral	<i>Caring characteristics</i> - person receiving care prefers not to use services - fear about alternative care services particularly amongst older people and BME groups - perception that appropriate support is not available (including culturally appropriate for BME groups) - caring situation manageable so no action taken <i>Practitioner characteristics</i> - no further intervention where the person receiving care expresses preference not to use services <i>Nature of secondary services</i> - not perceived to be available / appropriate - carers refuse to take on the burden of organising personalised services	<i>Casework design</i> - ongoing contact from the practitioner identifies further needs	<i>Casework design</i> - lack of ongoing contact <i>Carer characteristics</i> - change in circumstances, change of needs (long term) <i>Practitioner approach</i> - lack of assistance with organisation of support - lack of ongoing contact to remedy issues in arrangement of services <i>Nature of secondary service</i> - lengthy waiting period - not of satisfactory quality - insufficient support available (exacerbated by funding cuts) - difficult to access - too expensive (to justify carer taking paid employment)

Outcome Table 5.9: Use of practical support for the person receiving care

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Learning about services and how to access <i>and</i> Arranged through: carer action <i>or</i> - practitioner assistance to complete application forms, <i>or</i> - practitioner referral (not always successful), <i>and sometimes</i> - practitioner intervention to remedy service access difficulties			<i>Practitioner approach</i> - ongoing contact - condition specialist links with health services <i>Carer characteristics</i> - proactively seeks help with further needs	<i>Caring characteristics</i> - person receiving care prefers not to support - change in circumstances, no longer needed (long term) <i>Nature of secondary services</i> - support available not appropriate - slow processes - funding not available

Outcome Table 5.10: Use of carer emergency planning schemes

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Learning about schemes and how to access Arrangement of service, through: - carer action, <i>or</i> - practitioner referral to a scheme (not always successful), <i>or</i> - practitioner assistance with applications	<i>Carer characteristics</i> - interest <i>Nature of secondary service</i> - simple wallet card for carer to complete	<i>Carer characteristics</i> - carer cannot identify emergency contacts - lack of interest because of good informal support networks <i>Nature of secondary service</i> - physically unsuitable to be carried by carer		<i>Casework design</i> - breakdown in referral process, no follow up <i>Carer characteristics</i> - change in circumstances, no longer needed (long term)

Outcomes Table 5.11: Participation in training courses

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Arrangement of use through: - practitioner booking of the service	<i>Casework design</i> - direct booking of service (third sector carer organisations)			<i>Casework design</i> - breakdown in referral process <i>Carer characteristics</i> - male? - health problems - time pressures (also in relation to a moving and handling course) - not prioritised <i>Nature of secondary service</i> - funding not available for a condition specialist training course

Outcomes Table 5.12: Participation in carer leisure activities and support groups

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Arrangement of use through: - practitioner booking of the service	<i>Casework design</i> - specific information provided and direct booking of own provision (third sector carer organisations)	<i>Nature of secondary service</i> - not to carer's taste - timing or location not easily accessible for carer - carer not anticipated to fit with the normal demographic of attendee - not open to the person receiving care <i>Carer characteristics</i> - time pressures - lack of interest - hesitant about first visit - person receiving care not invited or prefers not to attend joint provision		

Outcomes Table 5.13: Use of complementary therapy

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Acceptance of importance of considering and responding to carer needs Arrangement of use through: - practitioner booking of the service	<i>Carer characteristics</i> - under too much pressure, therefore practitioner encourages use and makes booking <i>Casework design</i> - direct booking of own provision (third sector carer organisations)	<i>Carer characteristics</i> - time pressures	<i>Nature of secondary service</i> - flexible timing and location	<i>Casework design</i> - breakdown in referral process <i>Carer characteristics</i> - male - health problems - time pressures - not prioritised <i>Nature of secondary service</i> - inflexible timing

Outcome Table 5.14: Use of an access support service (for personalised support, employment support, welfare rights)

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Learning about services and how to access Arrangement of use through: - carer action, or - practitioner referral		<i>Case work design</i> - breakdown in referral process, no follow-up		

Outcome Table 5.15: Receipt of financial support

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Learning about potential benefits entitlements (sometimes via proactive practitioner enquiry about benefits receipt) <i>and</i> Arranged through: carer action <i>or</i> referral to welfare rights service (not always successful or desired by the carer) <i>and sometimes</i> practitioner assistance completing application form <i>and sometimes</i> practitioner intervention to remedy service access difficulties Learning about availability of carer discounts	<i>Carer characteristics</i> - relatively new to role or change in circumstances creating new benefits eligibility <i>Practitioner approach</i> - expertise in benefits <i>Casework design</i> - condition specialist links with health services enable identification of carers likely to require help with benefits entitlements	<i>Carer characteristics</i> - time pressures - lack of interest - possible ethnic minority cultural objection to receiving financial support for care (in the form of a direct payment) <i>Casework design</i> - breakdown in referral to welfare rights service, no follow-up <i>Nature of secondary service</i> - complexity of benefits eligibility and applications	<i>Casework design</i> - ongoing contact to identify needs	<i>Carer characteristics</i> - change in circumstances, no longer needed/eligible

Outcome Table 5.16: Receipt of one-off carer payments

Mechanisms	Contextual factors of influence			
	Immediately		Over time	
	Enabling	Inhibiting	Enabling	Inhibiting
Identification of a use, through: practitioner assessment of need or carer idea or identification of an existing activity suitable for funding or consideration of examples of use Carer action to organise support	<i>Practitioner approach</i> - identifies a need - informs about availability of one-off payments - views as a carer entitlement <i>Carer characteristics</i> - aware of payment scheme, has time to consider needs - sense of entitlement (possible link to male gender) <i>Nature of secondary service</i> - available (more frequently through statutory carer assessment than via third sector organisations)	<i>Carer characteristics</i> - limited sense of entitlement (possible link to female gender)	<i>Nature of secondary service</i> - reimbursement design	<i>Nature of secondary service</i> - insufficient funds available

5.4 A model of casework

Critical realism makes a distinction between the empirical (what we observe and experience), the actual (what occurs in practice, whether experienced or not) and the real (the structures, powers and mechanisms which generate events) (Houston, 2005). The outcomes tables (from page 167) show the researcher's considered interpretation of the *actual* manifestation of context mechanism outcome configurations in the casework sample included here according to the empirical evidence gathered. Using insight gained through this, Figure 5.1 (page 182) then seeks to illustrate the *real* mechanisms and context of casework to show what could potentially be involved in any individual case. In individual cases, specific mechanisms are likely to be generated (or not) and to lead to particular outcomes depending upon the formation of the range of contextual factors shown. As noted previously, these relationships should be considered as tendencies rather than as necessary. The aim of realist evaluation is to provide a more abstract theory that can potentially be used in the future to offer insight in an open and evolving social reality. Thus, Figure 5.1 has been developed to offer a more theoretical understanding of casework. Each element of this model of casework is now briefly discussed.

Realist evaluation is concerned with the outcomes of interventions based upon an understanding that the role of an intervention is to try and change some pre-existing social regularities or outcomes. Here, this begins with the carer and negative impacts of caring or other needs. The conceptual review (page 23) explored these. These needs (and potential outcomes addressing these) will depend upon the nature of the caring role, socio-demographic factors and carer interests as this research has further evidenced. For example, carers of people with dementia appear more likely to need support to understand the medical condition and how best to respond to challenging behaviours arising from this. Carer characteristics will also influence the nature of the intervention mechanisms required to achieve outcomes. For example, some (possibly predominantly female) carers will require emotional support to recognise and respond to their needs before accessing secondary services to address these needs.

A number of mechanisms may be generated through the processes of casework to address negative pre-existing social regularities experienced by carers. The first key mechanism was psychological support. This can be seen to have two elements. The first was concerned with normalising and valuing the carer's experience and contribution and also attaching priority to their own needs. This can be understood to respond to a context in which care is not valued and is associated with the private realm of kinship relations rather than the public sphere as analysed in key feminist theory (page 17). This mechanism improved emotional well-being directly but also contributed to carer behavioural change. It also effectively gave carers permission to use public sources of support. Thus, this mechanism was sometimes required before others could be generated. The other psychological support mechanism involved carers having the opportunity to express themselves thereby experiencing relief and improved emotional well-being.

The development of caring knowledge and skills led directly to some outcomes. Learning about secondary services and how to access these through the provision of information could enable carers to access the resources of secondary services to achieve outcomes. Yet, often this was not sufficient. In a context where service access is difficult (page 27) and also given that carers are under considerable pressure, practitioner assistance with arranging secondary services was often also required.

The resources of secondary services then in turn acted as a mechanism enabling carers to achieve a wide range of outcomes as discussed in the next chapter. Occasionally, these secondary services effectively substituted for casework or a part of it by generating the same mechanisms. Thus the casework provision examined here is not necessarily the only way of generating these mechanisms and achieving outcomes for carers.

Individual mechanisms were only generated in particular contexts of casework in terms of the characteristics of the participating practitioners and the organisations they worked for. Casework is likely to be most successful where practitioners are knowledgeable and have a supportive manner (potentially based upon their own personal experience of caring). Some mechanisms will only be generated depending upon the practitioner's approach in terms of whether they offer emotional support or input to help carers develop their caring knowledge and skills where required. In addition, the expression of feelings is likely to be facilitated where a home visit is provided and the person receiving care is not present in the first main contact. The impact of casework over time will be limited unless there is ongoing contact because carers' circumstances and needs change. In order to achieve any outcomes, the carer first has to make contact with a casework provider. Some factors that were noted as potentially relevant here were the public visibility and promotion of carer services, links with health services and service opening hours.

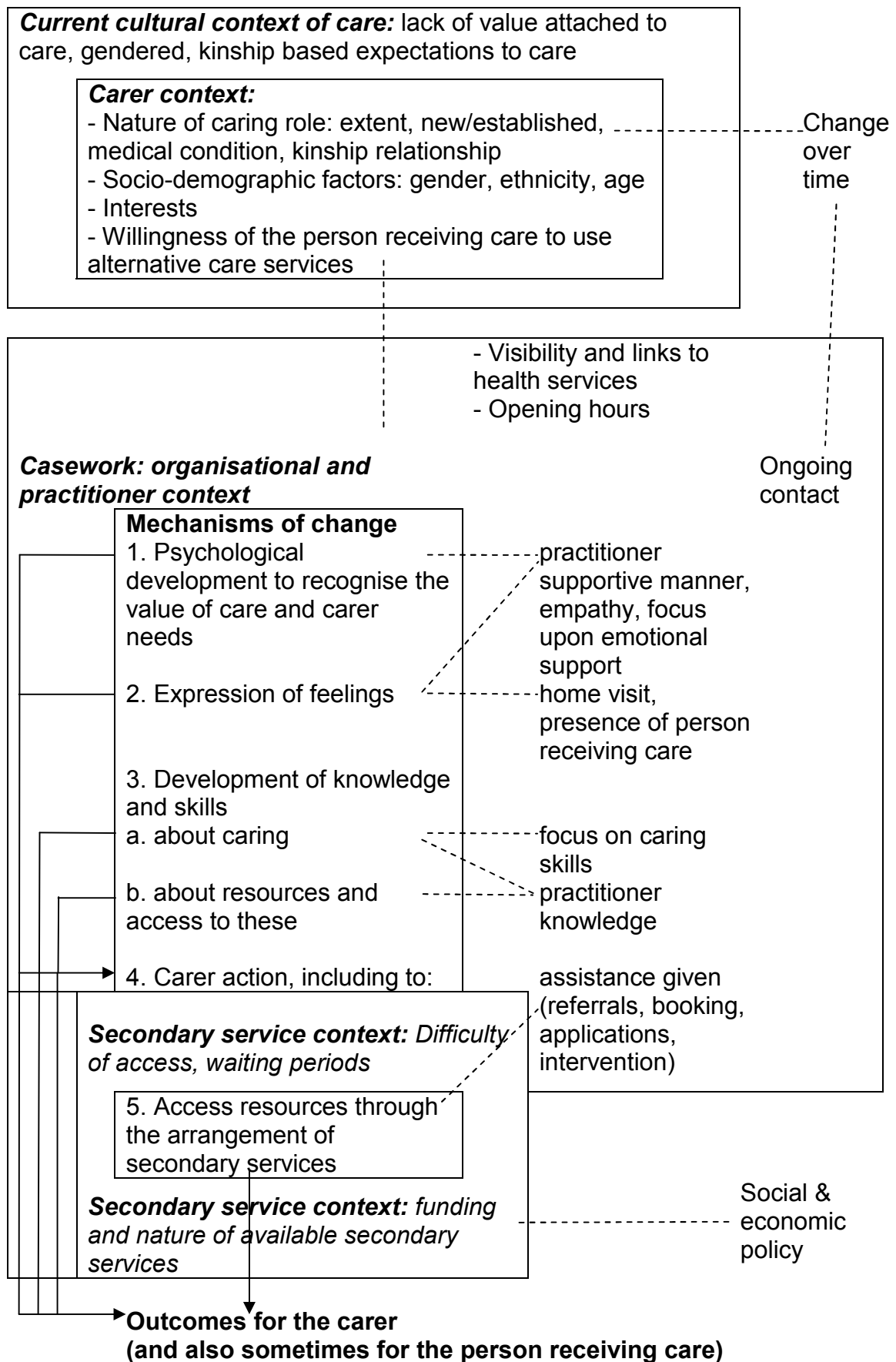
There are interactions within the model of casework. Emotional support improved emotional well-being itself but also facilitated the generation of other mechanisms including carer action to make behavioural changes and to access secondary services. Table 6.1 (page 191) also illustrates some identified links between the outcomes of secondary services, for example, a return to paid employment leads to increased income.

This model of casework takes a slightly different form in relation to the use of personalised one-off carer payments to achieve outcomes. Here, the identification of uses for this support was key. This depended upon the practitioner's approach in terms of informing the carer about the availability of these, the time the carer had to consider use and the carer's sense of entitlement and consequent interest in using these.

The context of secondary services can act as a key barrier to casework successfully achieving outcomes with carers. This concerns the funding available for these, the nature of the services available, waiting periods and difficulty of access. Part of the function of casework was to overcome barriers

in terms of the difficulty or complexity involved in accessing secondary services. With this exception, in this sample, mechanisms of casework were not identified which successfully challenged the barriers of this context. This was critical for a particular group of carers with very demanding, intensive caring roles experiencing negative impacts.

Figure 5.1: Casework mechanisms and context



Chapter Six: Outcomes of Secondary Services Accessed through Casework and Context Influencing Uptake

The previous chapter presented evidence on the outcomes achieved directly through the practice of casework, the mechanisms underlying these and the contextual factors influencing these. This included identifying the use of secondary services accessed with some form of support from the casework practitioner. The timing of use of these services was specified in the previous chapter but was mainly identified in the short and medium term. This chapter now presents evidence on the outcomes achieved through use of these secondary services. These secondary services may be provided by the same organisations and practitioners who conduct casework or by other entirely separate organisations. These secondary services effectively acted as a resource mechanism of casework to achieve further outcomes for carers. Table 6.1 (page 191) summarises the outcomes achieved by carers through the use of each type of secondary service and the mechanisms underlying these. These outcomes are detailed in section 6.1. Mechanisms underlying these secondary services are discussed in section 6.2. Contextual factors influencing the use of these services are reported upon in section 6.3.

6.1 Outcomes of use of specific secondary services

6.1.1 Outcomes of use of alternative care services

The use of alternative care services ultimately provided important benefits to two carers (June and Maureen – see case example page 201) in a range of ways including improving their mental health, physical health, financial situation and life outside caring including through participation in paid employment and in social and leisure activities. June responded about the extent of the difference overall that the alternative care services had made to her: *“A lot, a lot, it’s been a great help.”* (June, carer, interview 3, page 9). For two other carers, alternative care services had a more moderate impact because the caring role continued to be extensive and stressful. In one case, some issues with the quality of the service also limited its benefits. One other carer who had serious unmet needs of this kind did receive one aid which helped reduce the strain of the caring role.

Good services reduced the pressure upon carers by allowing them to relinquish certain responsibilities. They could also allow them to spend time doing other things including household jobs, being with other family members and enjoying more quality time with the person receiving care. Regular visits from paid care workers also provided reassurance and peace of mind through knowing that the person receiving care was being checked upon regularly. Aids and adaptations could also improve the safety of the person receiving care and through this gave the carer greater peace of mind. These also alleviated physical strain upon the carer which had sometimes been damaging their physical health. For example, use of special equipment to help the person receiving care to get back up after having a fall reduced the physical strain placed upon one carer. This was reported as very important. The

implementation of alternative care services (meals on wheels) had also removed the financial costs for June of providing meals for her mother.

June also successfully began a phased return to paid employment once appropriate alternative care services had been implemented. However, over time, she was unable to continue her return to paid employment because the condition of the person she cared for deteriorated and she continued to struggle to combine the two roles whilst further support was being considered.

These carers reported that once this support was in place, there were some benefits for the person receiving care despite initial reluctance to use alternative care services. As noted above, physical aids and adaptations could improve the safety of the person receiving care. The carers also reported that the person receiving care enjoyed the company provided by paid care worker visits. June commented: *"Well, yeah, I say she enjoyed the people coming in eventually although she's like old school and it was all this 'noseying and I don't know why, I can do this on my own' but no, then sort of when, if I was there when the carers came in, her face would light up and you know, I'd see my old Mum."* (June, carer, interview 3, page 9). June also talked about alternative care services helping to provide a daily routine for her mother.

This discussion of the outcomes of use of alternative care services indicates their importance to carers. This can also be seen in evidence about the impact and severity of unmet needs amongst carers who had to wait or who did not access any or sufficient alternative care services despite having serious needs to reduce or ease their caring role.

Three other carers did eventually achieve some new long term outcomes when practical support for the caring role was finally put into place. As noted previously, it is not clear in these cases that the eventual use of alternative care services can be attributed to casework. Two of these carers had continued to experience considerable strain throughout the period they had been waiting for support.

In the short to medium term, as well as those waiting for support to be implemented, five other carers had important unmet needs for practical support to ease or reduce the caring role. They did not anticipate that these needs would be met either because of the reluctance of the person receiving care to use such services or because they did not think that the appropriate services were available. In two of these cases, carers continued to experience serious health problems in the long term which might have been alleviated to an extent if they had taken up further support with the caring role. In one case, this was part of the reason why a carer did not pursue his interest in returning to paid employment. This also prevented four carers from having a much needed break. Two other carers mentioned a specific need for a holiday within their first main contact which would necessarily involve the use of alternative care services for their relative. However, again, contextual barriers in the form of a lack of appropriate secondary care services and the reluctance of the person receiving care to use these prevented outcomes from being achieved. There was also some evidence of increasing needs for a break in the medium

term as two carers (who had been relatively new to the role) became more worn down by the demands of their caring role. However, again barriers in the lack of available, appropriate alternative care services prevented these carer needs from being met. The importance of alternative care services as a contextual barrier to leisure and social outcomes continued in the long term. Some of these carers did receive some other secondary support, for example, one-off carer payments. However, within the context of these carers having other more serious unmet needs, these had limited impact.

6.1.2 Outcomes of a peer support service

The carer who used a peer support service for people applying for personalised support through statutory services found this very helpful. It encouraged her to seek support and also enabled her to learn about what to include upon application forms, how support could be used and to be aware of problems others had had. She specifically drew upon others' personal knowledge developed through experience. Ultimately she did secure personalised support for both the person she was caring for and for herself in relation to her own disability. She commented on the importance of this support to her application for statutory service support:

Probably what I would have put on the form probably would have been rejected really because I wasn't thinking about other things that I can put on the form, what needs to be included, things that would have been considered. And if I hadn't spoken to the group itself I'd be none the wiser really. As I say, I probably, if I was rejected by the board, I probably wouldn't have reapplied, I probably would have thought well, I wasn't eligible for it and that's it. I wouldn't have pursued it.

(Jane, carer, interview 2, page 3)

6.1.3 Outcomes of support organised for the person receiving care

Where aids and services were secured primarily for the benefit of the person receiving care, these enhanced the well-being of the person receiving care and fulfilled the carer's aims. For example, Sarah reported the benefit of accessing a physiotherapy service for her aunt via information from the carers service "*it does make a huge difference to her.*" (Sarah, carer, interview 3, page 4). Use of the Blue Badge, RADAR key and local transport for disabled people made it easier for the person receiving care to go out with the carer, enjoying leisure time together and this improved their quality of life.

6.1.4 Outcomes of emergency planning schemes

The use of carer emergency schemes provided reassurance for carers. Philip said "*it's nice to know there's a back up for me*" (Philip, carer, interview 2, page 2). This was reported by users of two different forms of schemes including a simple wallet card with the carer's emergency contacts and a more

extensive scheme where a plan was made for alternative formal care services to be available for up to 72 hours. No carers reported any need for actual emergency use of the back up support provided by emergency schemes during the period of the research. In the long term, two carers continued to be registered or hold cards for emergency planning schemes and received reassurance from this. In one example, it was noted that this provided reassurance for the person receiving care as well. *"I think it reassures my wife."* (Bob, carer, interview 4). Whilst this was not proactively reported more widely, this benefit may have extended more generally to the person receiving care.

6.1.5 Outcomes of the Caring with Confidence course

The two carers within the sample who fully participated in a Caring with Confidence training course both felt more confident generally about their caring role as a result of this. Susan discussed an example of how she had put skills she had developed into practice:

So like the other week we had to deal with the rental agreement renewal and they wanted us to go to the office. And I said "well I can't go to the office, we'll either do it by phone or you'll have to come to us, you know, because my husband can't get there and the contract's in his name." So they came to us and helped us sort it out, you know.

(Susan, carer, interview 3, page 5)

She also mentioned benefiting from developing her caring knowledge and skills from this provision by learning from other carers. *"You learnt things about what other people would do that you didn't think of doing"* (Susan, carer, interview 2, page 5). The other carer generally reported that the course helped make him feel better just through having a break, meeting other carers and also learning that others were in worse situations than his.

6.1.6 Outcomes of leisure activities and support groups

The two carers who attended arranged carer leisure activities reported that these improved their emotional well-being at the time and also provided social contact with other carers. Bob commented *"I enjoyed it very much. It was strange because there were carers there and you'd think that away from our care we would talk about anything else but we didn't, we all spoke about the people we were caring about. [...] It was an opportunity to get away, [...] and I came back sort of totally relieved."* (Bob, carer, interview 2, page 2). The one other carer who had attended a support group (without accompanying leisure activity) reported a benefit to emotional well-being: *"it's psychologically supportive"* (Stanley, carer, interview 2, page 4).

6.1.7 Outcomes of complementary therapy services

The one carer who reported using complementary therapy services found this beneficial to her emotional well-being: *"It's been absolutely brilliant. [...] they just made me feel a little bit more relaxed."* (Alison, carer, interview 2, page 5). This also helped relieve a physical problem. *"She did my shoulder. Nobody can cure that, it's an operation but it did help."* (Alison, carer, interview 2, page 4).

6.1.8 Outcomes of a specialist employment service

In the single case of use of a specialist employment service, the service provided some contacts for the carer to approach about voluntary work but this did not lead to any outcomes in this case.

6.1.9 Outcomes of welfare rights services

In two cases, a welfare rights service helped families complete application forms for Attendance Allowance. In one case, this was successfully received in the short term. The other case could not be followed up. In three other cases, a welfare rights service checked families' entitlement but no further benefits applications were made.

6.1.10 Benefits support outcomes

Four families specifically reported that benefits receipt helped them to meet particular costs arising from the condition of the person receiving care and/or the caring role. Sue explained *"it's going to help with his, getting him to and from the hospital obviously because we're getting taxis and things like that."* (Sue, carer, interview 2, page 3). Two carers reported that the additional income helped to free money for other things and five stated that this generally eased their financial situation.

Three carers also reported that improvements to their financial situation led to reduced stress, accompanying better physical health and/or improved leisure time and better quality of life. Another carer who received Attendance Allowance in the long term reported that this enabled him to visit his wife in a nursing home if other family members could not take him and to have a better quality of life. All these benefits helped to establish the caring role on a more sustainable footing. For example, Paul talked about the money helping them to go out sometimes, to pay people to do jobs such as gardening and the effect on his well-being:

I was worrying, I was getting a bit obsessed about the money, you sit there this, that and the other. But now, you know, I just, the dog gets walked a lot more and you know, I don't seem to mind so much going shopping because we've sort of got the money, you know. I'm eating

better, you know and stuff like that and not worrying and sleeping better so you know, it's physically and mentally.

(Paul, carer, interview 2, page 6)

The award of benefits also reduced the pressure upon three carers to work, either at all or for longer hours which helped to sustain the caring role. For example, when asked what the impact would have been if her benefits claim had not been successful, Sarah gave the following response.

It would have been really difficult and I would have to, I would have continued, have to take more work so that would have squeezed my time with my aunt and it would have made my life more stressful and it just would have spiralled on.

(Sarah, carer, interview 2, page 9)

As benefits were always to some extent (and generally wholly) pooled within the family, positive outcomes were also sometimes proactively reported as present for the person receiving care as well. In two cases, where the person receiving care had been awarded Attendance Allowance, they felt better that they could contribute to the household income or were providing replacement income where a carer had reduced their paid employment to care. Sarah explained: *"She's happy that somebody somewhere is paying me to look after her, you know, and she doesn't have to feel guilty that I'm not working."* (Sarah, carer, interview 3, page 6).

Carers expressed satisfaction themselves and also on the part of the person receiving care about potentially accessing their legitimate entitlements. *"This is something that he's entitled to, he has worked so he has paid in his contributions and things like that. So no, I'm happy that he's getting what he's entitled to you know."* (Sue, carer, interview 1, page 5).

The impact of additional benefits income varied according to the wider financial context of carers' lives. In one case, unusually the carer expressed that the family did not really need the additional benefits income claimed. Where carers had some other income from paid employment, benefits helped them to live comfortably. However, in one case (and for other carers who were already depending solely upon benefits income), the level of benefits income left them trapped in quite a restrictive lifestyle. In this case, additional income received through benefits accessed through the first main contact of casework continued to be relied upon two to three years later in the long term. This illustrates how a relatively small input initially through casework can have a very long term effect. These benefits were critical to sustaining the caring role albeit leaving the family facing a very restricted lifestyle. Jim reported that receiving benefits meant they were *"just about keeping our heads above water"* (Jim, carer, interview 4).

Two carers who were not entitled to Carer's Allowance or other benefits because of the income they earned from paid employment felt some

disappointment about the lack of financial recognition for their care contribution. Neil explained his expectations and feelings about this.

I thought there would be some financial help to be honest. I mean because I do a lot of running around, you have to go here there and everything, make appointments, get medical help, visit different people, the hospital and things like that. It is time consuming on my part and I have to sort of combine it with work and everything else. So I thought well, I think I'm out of pocket, I'm out of pocket that doesn't bother me, but I thought I shouldn't be missing out if there are any financial rewards for being a carer because I hear like you can be a full-time carer, you can be a part-time carer. From what I can gather, there's nothing which I'm basically disappointed about.

(Neil, carer, interview 1, page 2).

6.1.11 Outcomes of one-off carer payments

There were two examples where one-off carer payments were used to ease the caring role. One carer used a one-off payment to have some changes made to the garden to make this more accessible to reduce the physical strain upon him in helping his relative to access the garden. The other purchased a piece of equipment to help her with her practical caring role. These involved small amounts of funding which could make a considerable difference to carers who did not otherwise have the income to fund such support. However, in both these cases, this impact was limited because it was set within the context of broader unmet needs.

Two carers used one-off carer payments to have decorating done to help improve their emotional well-being. A carer reported that this had helped both himself and the person he cared for emotionally *"it's helped to brighten up the house and help our moods"* (Rob, carer, interview 3, page 4). However, he had other serious unmet needs. Another carer did not report benefits from this support because of the wider context of her other serious unmet needs.

In four cases through one-off carer payments, carers undertook some kind of physical exercise, for example, going to the gym, and consequently also reported improved physical well-being (although two may have undertaken this activity without the funding). In one case, the carer did not continue with this beyond the medium term due to health concerns. In another case, this was undertaken together with the person receiving care thereby also potentially benefiting them. Angela reported on the impact of receiving a contribution towards a gym membership: *"I go and have an hour at the gym in the belief it will get me fit, but it keeps doing my knee in. [...] It gives you a purpose to go out."* (Angela, carer, interview 4).

Two carers who were supported to go on breaks would have done so anyway. The other carer in an intense caring role who would not otherwise have taken a break benefited substantially. *"That's made a big difference because financially I couldn't afford to do those things. It's been really brilliant."*

(Charlotte, carer, interview 3, page 1). She felt this helped her to care better as well (hence potentially also benefiting the person receiving care).

The carer who sought funding for chiropractic services reported that this gave her physical pain relief enabling her to perform her paid employment and caring roles better (thus potentially again benefiting the person receiving care). Responding to a question about the difference this made, she said: *“less pain, I’m not so stiff, I’m able to do things better work wise and at home. [...] so it’s made quite a difference and with probably two more sessions that should be it and then top it up every so often.”* (Carol, carer, interview 2, page 4). Here the carer also explains that having some initial sessions improved her health condition so that she could then just have occasional treatment to ensure her health was maintained in the long term. In this way, the initial investment provided an ongoing benefit for the carer.

There was also an interesting example of the potential for empowerment within the carer’s organisational role being created through use of a one-off carer payment. A carer had used this to purchase a laptop and through this, had developed his previously very limited IT literacy. Whilst he currently used this primarily for his own purposes generally, he said that he would use this in future to research any support he might need for the person he cared for.

There were three examples (out of thirteen payments) within the research where applications were made for carer one-off payments for items or activities which the carer had already planned to pay for or had actually paid for. A specific justification was given for allocating funding to carers’ existing social and leisure plans in terms of increasing the carer’s motivation to continue an activity. Karen explained *“it is ok to fund something that they’re already doing because that will give the motivation for her to carry it on next year”* (Karen, carer assessment worker, interview 1c, page 5). This was borne out by evidence from one carer. *“It just helped me, it made my life easier not worrying about finding the money here or there or how to, you know, fund it so that’s really helped me and has put my mind to rest that for X amount of sessions I can go and do the class so that’s fine.”* (Nishan, carer, interview 2, page 1). Otherwise in these cases, this payment (of varying amounts from £100 to £400) then functioned primarily as additional income which carers could use for other purposes. Mavis commented *“it’s nice to have this money for other things.”* (Mavis, carer, interview 3, page 5).

Table 6.1: Outcomes and mechanisms of secondary services used by carers

<i>Outcomes</i>	<i>Mechanisms</i>	<i>Secondary services</i>
<i>For the carer:</i>		
Improved emotional well-being:		
- Reduced stress	Removed or eased caring task(s)	Alternative care services, aids and adaptations to the physical environment (one-off payments)
	Fewer financial worries due to additional income	Benefits receipt
	Physical pain relief	Complementary therapy
- Reassurance	Knowing the person receiving care is being cared for in the carer's absence	Alternative care services
	Knowing contingency plans are in place	Emergency planning schemes
- Developed confidence, positive outlook	Learning, social interaction with other carers	Caring with Confidence course
- Generally:	Having a break, social interaction with other carers	Caring with Confidence course, carer leisure activities, holidays (one-off payments)
	Satisfaction at receiving entitlements	Benefits receipt
	Improved environment	Decorating (one-off payment)
Improved physical health	Removed or eased caring task(s)	Alternative care services, adaptations to the physical environment (one-off payment)
	Reduced stress through additional income	Benefits receipt
	Physical pain relief	Complementary therapy, chiropractor (one-off payment)
	Participation in exercise (new or increasing motivation to continue)	Swimming, gym membership (one-off payments)
Return to paid employment (also leads to increased income)	Removed or eased caring task(s)	Alternative care services

<i>Outcomes</i>	<i>Mechanisms</i>	<i>Secondary services</i>
Improved performance in paid employment	Physical pain relief	Chiropractor (one-off payment)
Improved caring knowledge and skills	Learning (from other carers)	Caring with Confidence course
Improved social and leisure participation	Removed or eased caring task(s)	Alternative care services
	Removal of barriers to leisure participation of the person receiving care	Practical support for the person receiving care
	Participation in social and leisure activities	Carer leisure activities
	Additional income (to fund social and leisure activities including holidays and exercise)	Benefits receipt, One-off payments (swimming, gym membership, holidays)
Additional income (meets costs of caring, eases pressure to participate in paid employment and sustains the caring role)	Removed caring task(s)	Alternative care services
	Benefits receipt	Benefits receipt, Welfare rights service
	One-off payment funding existing activity	One-off payment
Better able to care	Having a break	Holiday (one-off payment)
	Physical pain relief	Chiropractor (one-off payment)
	Development of IT skills to enable future research related to caring	Laptop purchase (one-off payment)
	Additional income (see this outcome)	
Uptake of other secondary services	Emotional support, learning how to liaise with statutory services to improve chances of needs being met	Peer support service
	Arrangement of service (benefits) through assistance completing application	Welfare rights service

<i>Outcomes</i>	<i>Mechanisms</i>	<i>Secondary services</i>
<i>For the person receiving care:</i>		
Improved safety of the person receiving care	Use of aids and adaptations	Alternative care services
Improved social and leisure participation	Interactions with paid care workers	Alternative care services
	Quality time with carer due to eased caring role	Alternative care services
	Practical support removing barriers to leisure participation of the person receiving care	Practical support for the person receiving care
	Participation in exercise	One-off payment
Improved emotional well-being of the person receiving care	Making a contribution to household income	Benefits receipt, Welfare rights service
	Knowing contingency plans are in place	Emergency planning schemes
	Improved environment	Decorating (one-off payment)
Better care received	Improved carer health	Break (one-off payment), Chiropractor services (one-off payment)

6.2 Mechanisms of secondary services

Table 6.1 (page 191) identifies the mechanisms explaining all the identified outcomes of the various secondary services used by carers. These mechanisms are wide-ranging. Two particularly concern the caring role and the first may lead to the second: removed or eased caring task and having a break from the caring role. A number of other quite varied mechanisms underlay the outcomes of secondary services which were quite different to those generated directly through casework. These covered: an improved environment; physical pain relief; participation in exercise; additional income; knowing the person is being cared for in the carer's absence; knowing contingency plans are in place; social interaction with other carers; and some others specifically relating to the person receiving care.

The same mechanism could lead to a range of outcomes. For example, a removed or eased caring task could lead to improved emotional well-being, physical health and a return to paid employment. Some mechanisms could be understood as outcomes in themselves, for example, physical pain relief. Yet, they also explained the achievement of other outcomes, for example, physical pain relief enabled a carer to perform their paid employment and caring roles better. A wide range of mechanisms were generated through one-off payments reflecting the very varied uses of these.

Two secondary services (the peer support group for those applying for personalised support and a welfare rights service) which, like casework, are also concerned with helping carers to access secondary services generated some of the same mechanisms as casework. These included: emotional support, learning how to liaise with statutory services to improve the chances of needs being met and arrangement of secondary services (benefits) through assistance completing application forms.

6.3 Contextual factors influencing the use of secondary services

The following sections explore four contextual factors which influenced the use of secondary services (and thus, the potential for outcomes to be achieved through these). These are included in the outcomes tables (pages 167 to 178). These create a context in which casework operates.

6.3.1 Context: *The nature of secondary services*

Three carers did not use secondary services to ease the negative impacts of their caring role because they did not think that appropriate support was available. In one case, the carer related this to the particular unusual medical condition of the person she cared for. In another case, the carer had tried support previously and it had not met her needs. At least part of the issue in two cases was the personalised form of support available. Within this sample, two carers specifically expressed reluctance to take on the administrative and organisational burden of organising support themselves. Kelly explained "I've

never wanted to do it because I think to myself social workers are paid to do their job, I'm paid to do my job. If you make me do the direct payments or personal budgets then I'm doing the work of a social worker!" (Kelly, carer, interview 2, page 2). However, conversely, two families were more willing to consider alternative care services because of the option for personalised support.

The nature of the secondary services available also prevented some carers using these to enable them to enjoy more leisure time. For example, Linda was dissatisfied with the previous respite provision she had used and was frustrated at the difficulty of finding somewhere more appropriate for any future breaks she would like to take.

It's just when I had a break, ... trying to get somewhere suitable for him, trying to get somewhere that wasn't old, where he'd be comfortable, I mean he was looked after well but it was a nursing home and I don't want him in a nursing home. ... I just feel if there's just somewhere else they could go where there's a bit of activity rather than sitting around and that's what I don't seem to be able to find, people who are ill, but he is, he has got his faculties, I know he can't do a lot but I think if he was in an environment where even if people were doing it and he could watch if you know what I mean? That's the only thing I feel sad about that there's not enough places.

(Linda, carer, interview 1, page 5)

In four cases, an inability or unwillingness on the part of statutory occupational therapy services to provide the form of support sought prevented the use of practical support primarily for the person receiving care. In her discussions with occupational therapy about a lift and bathroom adaptations, Angela reported: *"I said 'yeah, that is a bog standard sort of disability lay out'. I said 'but it wouldn't work for him' and he was like 'well, that's all we do'."* (Angela, carer, interview 3, page 10). In this case, the carer found a way of altering things themselves to overcome this barrier. For the others, the need was not met. Another carer had been unable to access social activities for the person he cared for because of inflexibility in the provision available.

For the following three other secondary services for carers, the form of the provision was given as a barrier to use but lack of use was not presented as a critical issue. In one case, the carer felt that the form of the aid, a key fob, for carers to carry with details to be used in emergency planning was not suitable for use because *"It's just too bulky. They should put it on a card."* (Kelly, carer, interview 2, page 4).

In relation to leisure activities for carers, in the cases where carers did attend, the specific type of leisure activity planned happened to be of interest to them. Conversely, barriers to attendance were raised in relation to the nature of the provision in two cases including that the activity was not to the carer's taste or the timing or location made it difficult to attend. *"The other thing wasn't really me, and the event being late I think and the distance really."* (Linda, carer, interview 2, page 2). One carer also expressed concern that she might not fit

in with other attendees. *“Maybe it is quite a lot of quite elderly women. I don’t know if that’s a preconceived idea, you know, not that there’s anything wrong with that. It’s just that sometimes when you’re already looking after an elderly parent, do you really want to go to a meeting full of other.. I’m desperate for something a bit younger!”* (Jane, carer, interview 1, page 7). There was also an example where the carer’s perception that the person receiving care was *not* invited to attend leisure activities meant that he preferred to organise their own activities instead.

In a case where therapies were not taken up despite interest from the carer, the therapies were just on offer through a one day relaxation event such that when the carer could not make that event, the opportunity effectively ended. In the cases where there was uptake or a booking was made, the service was very accessible and flexible. A therapist worked at the same carers service on an ongoing basis and the practitioners proactively made a direct appointment that suited the carer and in at least one case, which took place at the carer’s home.

There was also some evidence that the specific nature of one-off payment schemes could influence use and the outcomes achieved. Some schemes required carers to claim back money already spent rather than distributing funds upfront. One carer had only taken a break after negotiating another way around this through using quotes to illustrate her intended expenditure as she could not afford to pay for her holiday before being reimbursed.

6.3.2 Context: Waiting periods

In two cases where carers had to wait until the long term for statutory service support to reduce or ease the caring role, the practitioner indicated that there were reasonably long waiting periods for this type of support. Olivia said *“the [...] service asked her to be patient if possible, because they have a backlog and it could take months before they come back but they know and could I please reassure the carer that they will come and visit.”* (Olivia, carer support worker, interview 1, page 8). There was evidence that an extensive wait created a risk in all these cases that carers gave up seeking support despite having substantial needs. Julie made the following comments after six months: *“It’s taken so long to sort it out, well, you know, I wish I’d never started it. I could have gone on the way I was and left it until something happened.”* (Julie, carer, interview 3, page 4). It was sometimes difficult to disentangle entirely the influence of this alongside other contextual barriers, particularly, the nature of the secondary service and complexity of access, in understanding use.

6.3.3 Context: Difficulty of access

A number of the mechanisms discussed in the previous chapter in terms of learning (about carer rights, about how to liaise with statutory services to improve the chances of their needs being met, about benefits entitlements and one-off payments), making referrals (to secondary services) and assistance

completing applications all potentially help carers to access secondary services where there may be a difficult process involved in this. Sometimes this seemed to reflect the possibility that social care services might not be sufficiently concerned with the carer's perspective and needs (page 143). In other cases, this appeared to be about the difficulty of getting a final response to a need or enquiry. This was suggested to be a factor in Ryan's difficulty accessing a particular support to reduce or ease the caring role (page 146). Access may also be difficult because the application process or system is complex. This was apparent particularly in relation to benefits. In one case, this put a carer off from claiming a potential benefits entitlement as the quotation below illustrates. The evidence suggests that this was also possibly a factor in some of the other cases where carers did not take up potential benefits entitlements alongside other factors.

Becky: I just can't be bothered with all that paperwork, it's like taking an exam! It's one big booklet and they're asking all sorts of questions from years ago and this, that and the other. I really just can't be bothered with it at the moment.

Researcher: Would it, if someone offered to do it with you, do you think that would help?

Becky: Well, I've still got to dig through all papers and stuff like that and what with working, I just can't be bothered at the moment to be honest with you.

(Becky, carer, interview 3, page 2)

6.3.4 Context: Service funding

There were two examples where funding was not available for specific support which carers were seeking (home adjustments and a condition specialist training course). In another case, the carer was able to take limited breaks but needed more activities available for the person he cared for to enable him to have more of a break. One carer also reported that the cost of alternative care services acted as a barrier requiring him to secure paid employment with a high salary which he could not find at that time. *"As yet, I can't find something that can afford me to go and pay somebody to stay here."* (Jim, carer, interview 3, page 2) This case illustrates how both alternative care provision and the labour market may act as barriers to paid employment. In addition, the extent of the funding available through one-off payments could limit outcomes. Some carers required more support than was available because one-off payments were capped at a certain level for a specific period, for example, two hundred and fifty pounds over two years.

There was also some evidence that changes in the macro level context in terms of the government's deficit reduction programme and the consequent tightening of local authority budgets during the period of the research were restricting the availability of services needed by carers. Two third sector carer services were closed. There was also some evidence that funding cuts were

putting increasing pressure on the funding of alternative care services by local authorities. One carer reported a reduction in a service: *"It's terrible. ... His incontinence pads have all changed. He now, instead of having six pads a day, it's now dropped down to three to four a day."* (Lee, carer, interview 4). Another carer had had to fight to continue to receive the support the family was already using. Another carer, Kelly, was still awaiting the outcome of planned reductions to her family's care package. Very soon after the carer assessment, Kelly received notice that new charges were anticipated upon her son's existing care package due to budgetary pressures on the local authority. This posed a very serious risk to the carer's health (she was already experiencing health problems arising from her caring role) and the sustainability of her caring role. The carer could not afford the proposed charges and said: *"I have written to Number 10 and I have told him that my back won't last more than 6 months and he'll have to move into residential care."* (Kelly, carer, interview 1, page 5). One local authority changed its charging policies such that families were expected to contribute benefits income towards the cost of alternative care services. This meant that a carer had to contribute some of his Carer's Allowance towards the cost of local authority funded care workers when his relative started to use this service despite the fact that he was still undertaking a substantial caring role.

In addition, this climate could cause anxiety. Two carers continued to receive support but were concerned about whether this would be cut in future. Talking about potential funding cuts, Jane said: *"now we're benefiting from that support, how long is that actually going to be in place? That's the worry now. You know, maybe we've just had a taste of how things can be but is the carpet going to be pulled from underneath us?"* (Jane, carer, interview 4).

Chapter Seven: Overall Evaluation of Casework

The preceding two chapters have considered the impact of casework in relation to individual outcomes. This has provided a comprehensive understanding of the outcomes of casework and the details of the evidence in terms of how these were individually explained by mechanisms and influenced by contextual factors. However, carers' experiences are not necessarily neatly fragmented in this way. This chapter aims to present the evidence in another way to provide a more rounded perspective in terms of the following.

- a) How different outcomes (or unmet needs) were experienced together by individual carers and their overall importance. This gives an important insight into the relative significance of different outcomes, how these influenced each other and what difference they made overall to carers' lives. Some case examples of individual carers' experiences are provided to bring to life these findings.
- b) How this can be understood in terms of groupings of carers across the sample. This gives an indication of the extent of particular overall patterns of outcomes. The groupings are necessarily a simplification of the data but these are useful as a way of understanding key distinctions. Some proportions and numbers are given to provide an indication of the extent of particular experiences. (It should be noted that the size and composition of the group of carers followed up at each stage changed, see page 107). These groupings are then explored further in section 7.5 to consider whether carer or intervention characteristics are likely to provide some explanation of this.
- c) How this changed longitudinally. This chapter presents a clearer picture of how individual carers' experiences changed over time. To achieve this, the evidence is discussed narratively in longitudinal sections considering overall success: immediately after the first main contact of casework (7.1); in the short term (7.2); in the medium term (7.3); and in the long term (7.4).

7.1 Overall success immediately after the first main contact of casework

Immediately after the first main contact of casework, almost two thirds of the sample (twenty of thirty three) reported that a positive start had been made. This generally consisted of a cluster of immediate outcomes which sometimes positively reinforced each other. The immediate outcomes achieved included primarily the receipt of emotional support and formulation of some plan of action towards accessing other types of support. Achievement of some progress towards accessing some kind of practical support could offer carers relief and a sense of hope. Equally, emotional support could help carers to take the first steps towards accessing secondary services. Most commonly progress towards use of secondary services related to accessing financial support and to using alternative care services or aids and adaptations to support the caring role. Knowing where to turn for help in the future gave

carers an important underlying reassurance. Occasionally other immediate outcomes were achieved for some carers through the direct provision of information, for example, help to care through a better understanding of the condition of the person they cared for.

Within this group, the extent and severity of the needs identified varied quite considerably so that greater or lesser achievements would be anticipated at a later date. For a minority of carers (two), little was identified to benefit them in the longer term but they did report some emotional support and reassurance from the first main contact. For some though (five cases), these immediate outcomes were already very important even at this stage and even where they were still awaiting additional support in the future.

Case example: Immediate positive outcomes for John

John reported a cluster of immediate positive outcomes generated very quickly from his first main contact with the carers service. He had received help to complete an application for support and also used other information provided by the practitioner to access a piece of equipment for his Dad. He was better informed about how his benefits eligibility could be affected by employment putting him in a position to consider his employment options further. He felt much better emotionally for a number of reasons. He had found it useful to have the opportunity to talk about his caring role. He also felt better about his caring role from learning that others were in similar situations to him and from knowing that the service was available to him in future if needed. He reported that this support was very important to him even at this early stage. This case illustrates how casework can generate a number of outcomes very quickly through a combination of emotional support, information provision and active assistance with accessing other services.

For another small group of carers (five), no substantial outcomes had yet been achieved and they were reserving judgement about the value of the service to them. As with the first group, practitioners had identified some steps towards providing support. However, the hope and positive reassurance generated amongst the majority of carers was not present in this group. Two carers were coping well and did not appear to have the need for emotional support or reassurance that other carers had. Equally, they had little interest in any of the generic secondary carer services that the practitioner informed them about. In addition, all of these carers reported having either negative, or at least ineffectual, experience of other services providers in the past. This led them to have limited expectations of casework. However, in all these cases, potential was identified for important outcomes to be achieved for these carers in future.

For another small group of carers (six), there was evidence that a specific need of primary importance to the carer was unlikely to be met. These needs all depended upon some kind of support with the caring role of different kinds. This was required to address different ultimate needs of carers including to facilitate a break to meet leisure and social needs, to manage the demands of

the caring role itself or to reduce the strain on their physical health. The main reason these were not anticipated to be met was that carers did not think the right type of secondary service support was available. Difficulty accessing support also played a role as did the reluctance of the person receiving care to use alternative care services.

The perceptions of carers with serious anticipated unmet needs varied quite considerably. Most (four) were fairly indifferent about the service seemingly because their expectations of support had been limited. One was very negative. Another carer also felt this way due to anticipated reductions in the funded care package of the person receiving care. These two carers' needs were great and they experienced little hope of receiving the necessary support. Their interaction with the service also seemed to have exacerbated their feelings about their situation. They required a behavioural response, some direct action, to support their caring role. However, in addition to having trouble accessing this, their cognitive perception of their situation and/or of services worsened.

In a minority of cases (two), there were mixed feelings about the intervention. In one exceptional case, the carer had mixed feelings about her assessment because she had felt undermined by the practitioner. In another case, the carer felt that the contact had not considered his situation in a holistic way. In both cases, there was still considerable potential for outcomes to be achieved in the coming period.

7.2 The short term overall success of casework

In the short term (about two months after the first main contact of casework), carers could be categorised into four broad groupings of similar size in terms of the overall success of casework at this stage. The first grouping (nine carers) reported a very important positive impact upon their lives. In about half of these cases (four), this was primarily the result of carers now having accessed some particular secondary support service that they found very helpful. The nature of this varied but most often included practical support for the caring role. This practical support was very important to a minority of carers who had been reaching crisis point in their caring role.

Case example: Positive short term outcomes for Maureen

Maureen had been in great distress at her first appointment with the carers service. She felt she could not manage her current caring role but that no help was available as other services had not implemented any support due to the unwillingness of her father to accept any services. The first appointment may have helped her emotionally a little but it was clear that any improvements were very limited whilst she was not able to access any practical support.

Two months later, Maureen reported extensive benefits as a result of support accessed through support from casework: *"It's a great help."* (interview 2, page 9). She had accessed some equipment to use in her caring role which reduced

the physical strain she experienced and also gave her greater peace of mind about her father's safety. She had also booked a sitting service to use whilst she was away on holiday which she anticipated would provide her with considerable reassurance. She had attended a carers' leisure activity which had relaxed her and had found it useful to talk about her situation to the practitioner.

This case study illustrates how immediate benefits may not occur in situations where a carer is experiencing considerable difficulty and needs practical support for their caring role. The practical support provided within the first two month period made an important difference to her.

Amongst the other half of the grouping of carers (five) who reported a very important short term impact, this was due to a combination of the direct support of the practitioner, particularly emotional support and reassurance, and some secondary support (often receipt of benefits). Thus, again there was a positive cluster of short term outcomes which had an impact on several aspects of carers' lives together. These carers were generally experiencing less difficulty with their caring role than those in the previous group and thus did not have the same intense need for practical support with the caring role. They were also at an earlier stage of their caring role. Thus this support was acting in a more preventive manner to establish their caring role on a more stable, sustainable basis. It was also not so much about limiting serious negative impacts of caring. More often it enhanced the positive aspects of caring, for example, improving the quality of the time that carers spent with the person receiving care or enabling carers to have a more positive outlook on their caring role.

In one exceptional case, a cluster of substantial positive short term outcomes based upon emotional support and accessing practical support were achieved primarily through a secondary support service rather than through casework itself. The carer used a peer support group for people making applications for personalised social care support. It is possible for these types of outcomes principally achieved through casework to be attained through such alternative services.

For a second grouping of carers (six), casework had had a positive short term effect of more moderate or minor importance to their lives. The support used seemed to make a more peripheral change to their lives rather than a fundamental one. In all cases, this was also balanced against unmet needs in other areas. For example, Norma had had a request for a specific piece of equipment turned down by occupational therapy but this was not critical to her. However, she had been reassured by the availability of support through the service if it was needed. She summed up: *"The way I look at it, it's nice to think that if the carer needs anything, there's someone to turn to, but if the carer is managing, you know, and everything's running nice and smooth, don't alter it, you know."* (Norma, carer, interview 2, page 6).

The third grouping of carers (six) was principally still awaiting support. These carers felt differently about casework at this stage according primarily to their expectations about future support. Two carers had had some communication such that they still thought that support would materialise and so were positive. Two carers who had expected or hoped that support would already have materialised, seemed disappointed (including one who consequently declined to participate any further in this interview). Denise commented: *"I haven't heard from him since you came. Not very happy about it really."* (Denise, carer, interview 2, page 1). Two continued to have limited expectations of future support. This had a greater or lesser impact upon them depending upon the perceived importance of the support and their ability to try and resolve this through other means.

The final grouping of carers (five) continued to have outstanding serious unmet needs as had been anticipated at an earlier stage. Two carers received some helpful secondary support in other domains. However, this was still outweighed overall by the carer's other primary unmet need which limited their quality of life. An additional serious unmet need for emotional support was identified for another carer. This was not being considered or addressed through casework because the carer did not have ongoing contact with the practitioner.

7.3 The medium term overall success of casework

In the medium term (approximately six months after their first main contact of casework), the same broad groupings of carers in terms of the impact of casework could be identified with some changes in their relative size. The grouping of carers who reported quite an important impact upon their lives grew slightly (to eleven carers) in comparison to this at two months. Again, for some (five carers), this was primarily due to the receipt of some kind of secondary support service through casework. For some, this continued to avert a crisis generally. For others, it addressed an important need in a particular aspect of their life. For the other six carers, a substantial positive medium term impact resulted from a combination of secondary support plus the emotional support and reassurance provided by the practitioner directly through casework. Three of these carers had accessed some further secondary support and also help from the practitioner in the last few months. The three other carers continued to receive the same secondary support, for example, benefits and continued to feel the same emotional benefits with little or no additional input since the two month stage. As in the short term, this often acted in a preventive manner to make carers' positions more sustainable, often at the early stages of their caring role. However, as noted on page 188, in one distinctive case, casework helped a carer to access benefits to sustain the caring role but this also effectively trapped the carer in a restrictive lifestyle given their lack of other financial means.

Case example: Positive medium term outcomes for Susan

After six months, Susan had benefited from casework in a number of ways. She had successfully claimed Carer's Allowance improving the family's financial situation. She reported that her contact with the practitioner had enabled her to have a more positive outlook and to feel more confident. She had also used some secondary services attending both a one-off organised carers' leisure activity and the Caring with Confidence course. She had found the latter particularly useful. She had learnt from it and felt more confident. This was put into practice in an example where she was more assertive with another organisation to ensure that they took more account of the family's situation. Overall, the combination of the practitioner's input together with the secondary services had made an important difference to this carer, particularly in relation to her emotional well-being.

Referring to the staff at the carers centre, she commented: *"they're all lovely people and it does make you feel confident when you've got someone that you can talk to at the other end, when you're at the end of your tether and you think you can't go on with what you're doing, which luckily at the moment, I'm not that bad. It was bad when you saw me because it was all new, you know, but since then, in the last six months, I've got really more confident about myself."* (interview 3, page 9)

A grouping of five carers continued to report some overall positive medium term impact of moderate or minor extent. This was often just in one or two outcome domains rather than having a more widespread general benefit to their life. For example, Miriam had received some information which helped confirm some things she already knew relating to the legal and financial aspects of her relative moving into residential care. She also continued to feel reassured that there was somewhere to turn for help if she needed it. Positive medium term outcomes in certain domains could be mixed with unmet needs in other domains. For example, Neil had received a one-off carer payment which he anticipated would be useful but felt disappointed at the lack of contact from the local authority over time.

By this stage, just two carers were still awaiting other support. This outstanding support depended upon responses from secondary statutory services. These carers continued to experience negative impacts whilst awaiting support.

By six months, a group of eight carers continued to have serious unmet needs. The number of carers with serious unmet needs had grown slightly because it had become apparent that some serious needs for two other carers were unlikely to be met now through casework. One of these arose again because of a lack of suitable secondary service provision and another because of insufficient emotional support. This group constituted about a quarter of the sample. Three of these carers had received some other helpful secondary support in the medium term through casework as the following case illustrates.

Case example: Kelly's unmet needs in the medium term

During her carer assessment, Kelly initially agreed to a number of actions being taken to support her including an application for a one-off carer payment to fund support to improve her emotional well-being. However, in the days immediately after the carer assessment, other staff at the local authority informed her of anticipated funding reductions in the social care support provided for her son due to the deficit reduction programme. She subsequently cancelled her carer assessment in protest at this. Her case illustrates the total irrelevance of the potential carer support to her faced with insufficient social care support for her son enabling her to sustain her caring role. She summed this up:

Well, I think carers need practical help, they don't need fluff. They don't need going to have massages and stuff like that, that's not practical help is it?

[...]

What's the use of looking after my well-being when they're not helping me practically? It's like they're giving you something with one hand and then they punch you in the face with the other.

(interview 1, pages 3-4)

In this case, the carer assessment worker tried to clarify the situation through talking to colleagues but was unable to offer any conclusive information. Whilst waiting, the carer expressed that she had felt anxious and alone. During this time, this carer was also continuing to suffer serious physical strain from her caring role and was restricted in her lifestyle. This was initially not being addressed because she did not feel appropriate alternative care services were available to assist her and she was reluctant to take on the burden of organising personalised support. The ongoing threat to her existing support made it possible that this strain would increase rather than decrease. Kelly was still waiting for a decision over two years later.

For four carers, the earlier impacts of casework changed at this time due to change in their own circumstances. For three carers, some earlier positive outcomes ended because their circumstances had changed and they no longer required the support previously accessed or sought. These included two cases where the person receiving care had recently passed away and also one where the health of the person receiving care had deteriorated such that the carer had sought other additional support from other services. In contrast, in another case, where casework had had little impact at the earlier points in time, this changed when the carer experienced ill health and the practitioner then helped to link him into other support. In this case, ongoing contact with the practitioner was critical in enabling these later outcomes to be achieved.

7.4 The long term overall success of casework

In the long term (two to three years after their first main contact), carers had very rarely continued to have contact with the casework provider. Just two carers (of twenty three) had had any recent contact with the same service. At this stage, three carers newly reported substantial positive long term outcomes from the receipt of long awaited statutory care services to support the caring role. Once this was in place it was extremely important and helped to avoid the otherwise real potential of crisis. In these cases, it is difficult to attribute the achievement of this to casework because these carers had also sought this support through other means.

Five carers reported an ongoing more moderate or minor long term impact upon their lives. This occurred in different ways. In some cases, it was through the continued ongoing reassurance of having somewhere to turn for help. Carol commented: *"It's just knowing that it is there if I needed it."* (Carol, carer, interview 4). In other cases, this occurred through continued receipt of a secondary service, for example, a financial benefit. In some of these cases, the impact of casework had lessened over time for carers compared to previously. This occurred for various reasons. Quite simply, sometimes the impact of earlier support was now spread over a longer period of time. Some carers no longer either wanted or were entitled to certain support. One carer no longer received (or needed) Carer's Allowance because he was now in receipt of a good pension. Another carer had attended some carer service leisure activities but over time chose to access this type of support through a condition specialist organisation instead. Earlier outcomes were no longer achieved for a further two carers because deterioration in the health of the person receiving care leading to use of residential care meant that previous support was no longer required.

Those carers in the grouping who had serious unmet needs at this point in time had changed from previous stages. Two of the carers who previously noted serious unmet needs over the first six month period after their contact with a carer service no longer had these due to bereavement. In two cases, these needs had been eventually met to an extent firstly through other service support and secondly as a result of a change in personal circumstances. This had taken a very long time.

Overall, however, the proportion of carers who had serious unmet needs had grown. Five carers continued to have serious unmet needs albeit with some change in the nature of these over time. In addition, another carer had new substantial needs and another's needs had intensified over time. Two carers also discussed having important unmet needs within the intervening period since the previous interview. At this stage, the reasons for the serious unmet needs in these additional four cases included that there was no apparent available secondary service to meet the need in one case, as noted in earlier cases of serious unmet needs. The three other carers did not have contact with services to consider or receive any help with their new unmet need. In one case, this was because neither they nor the carer service initiated ongoing

contact. In two cases, the third sector service had closed due to funding cuts. These carers did seek support elsewhere but this still left some needs unmet.

Amongst some of these cases, some positive outcomes had been achieved alongside these unmet needs. As the preceding analysis shows, the overall achievement of outcomes was quite complex for some carers. At particular points in time, there could be some positive outcomes of certain kinds alongside other types of unmet needs of differing importance to carers. This could also change over time creating quite a complex dynamic of outcomes. The following two case examples provide some illustration of this.

Case example: Mixed outcomes of casework for Jim

During the first six months after the carer support worker made contact with Jim, she supported him to meet a number of needs. She proactively assisted him with benefits claims enabling the family to receive their full entitlements. This made it possible financially for the carer to continue in his caring role as he wished. She encouraged him to register with the carer emergency service which he subsequently did which gave him greater peace of mind. She also advised him helpfully about his interaction with statutory care services. Jim felt great reassurance from knowing that the support worker was available to help if necessary. Overall, Jim thought that the practitioner's input had made an important positive difference to his life and also consequently indirectly to the person he cared for as well. *"Otherwise in this minefield now which I think it is, I would have been pulling my hair out trying to do it all myself not knowing what's what anyway. I think that would have been absolutely disastrous."* (interview 2, page 11).

However, there were also areas in which Jim would have liked more support. From the beginning he expressed an interest in returning to paid employment at some point. He was given some advice about this and services that could support this. After six months, he was also expressing that it was becoming increasingly difficult for him to take any breaks from the caring role. The lack of funded alternative care services that he and the person he cared for would have been happy to use prevented this. This was still the case over two years later. He felt that returning to paid employment would have been an even harder task given this context.

In the long term, Jim had had little contact with the practitioner but he continued to feel reassured that she was available. The family also continued to depend upon the financial benefits the practitioner had earlier helped him to access. Thus the input continued to make an important difference to the carer. However, his lifestyle and freedom was very restricted due to his dependence upon benefits (which provided a small income) as a result of his caring role.

Case example: The mixed impact of casework for Angela

In her carer assessment, Angela's most prominent need was to ease her caring role by having a break. However, her husband was unwilling to accept alternative care services to facilitate this. As discussed elsewhere, whilst the practitioner did try to encourage use of services ultimately he did not intervene further. At six months, Angela was still not able to take a break from her caring role and was feeling quite disappointed at this. Her need was already serious but in addition, her feelings about this were exacerbated by the frustration of knowing that services were available but not being in a position to access these.

"You sort of strive thinking we can do this, then the realisation is well, I can't. I suppose it's a bit like kids being promised a party and then not. You're at that sort of level sort of thing, which is, you know, you're grown up, you just have to suck it up."

(interview 3, page 7)

She had expressed an interest in a carer's course and complementary therapies but the referral process broke down such that she did not hear anything further about these. Some other helpful support had been put into place at six months. The couple had received an aid to help them to deal with falls which improved the safety of the husband and reduced the physical strain upon the carer. They were also awaiting a one-off carer payment to help make adaptations to the garden to make this more accessible and to help reduce the physical strain upon Angela. This support was valuable but did not reduce the need for a break.

About two years later, Angela's circumstances had changed. Her husband had begun using some alternative care services due to change in his attitude possibly arising from deterioration in his condition and her need to stay in hospital for her own health needs. This had enabled Angela to have regular short breaks, although she still wanted but had not managed a week long break. In addition, Angela had accessed a further one-off carer payment to join a gym again to have a break and improve her physical health. However, Angela still felt that the level of support, particularly financial help, was very limited. Commenting on the support, she said *"it was good but you know, it is very limited. It is still unbelievably limited."* (interview 4).

7.5 The relationship between overall success and carer and casework characteristics

When the overall success of casework was considered through a breakdown of the type of casework provider involved, two related patterns were found. Carers who reported that casework had made an important positive difference to them within six months had all had contact with a third sector organisation. (This group consisted of eleven carers, of whom one had participated in a statutory carer assessment conducted by a third sector practitioner on behalf

of the local authority.) A much higher proportion of those who had had a statutory carer assessment had ongoing serious unmet needs compared to those who had general contact with a third sector organisation. (Five of the seven carers who had originally had a statutory carers assessment conducted by the local authority had ongoing serious unmet needs at six months.)

This overall success is built upon some underlying patterns in individual outcomes discussed in chapter five. Two contextual factors identified there in terms of the nature of third sector organisations seem likely to continue to be influential in explaining their success. A relatively high proportion of carers who reported that casework had made an important overall positive difference at six months had either been approached directly by a third sector condition specialist organisation or had been able to make proactive contact with a third sector carers organisation as a result of its publicity or visibility in the local community. The relative accessibility of these organisations is thus likely to enable carers to make contact and achieve these outcomes. In addition, the ongoing proactive contact made by third sector organisations was beneficial in some of these cases of overall positive difference.

Some additional patterns underlying overall success have been identified relating to carer characteristics. As the preceding analysis discusses, carers who reported an important positive difference could be considered in two groupings according to how this was achieved. For the first group, the carers had accessed some particular secondary support which was very helpful. In the second group, the impact was due to a combination of the direct support of the practitioner, particularly emotional support and reassurance, and some secondary support, often receipt of benefits. Amongst the second group, a relatively high proportion of carers had begun their caring role quite recently and had not had contact with any services in relation to caring before. This meant that they often had certain needs arising from their new role (frequently for support with benefits claims) which it was relatively straightforward for practitioners to address. This sub-sample also tended to have less intensive caring roles (as was noted generally for carers in touch with generic third sector carer services). This meant these carers were not facing some of the more difficult problems that some other carers encountered. Thus some of the characteristics of these carers and their needs created a reasonably promising starting point from which casework could potentially make a difference.

The other group of carers who benefited substantially from a third sector form of casework did so via the use of a specific secondary service. There was considerable variation in the type of secondary support which made a substantial difference including one-off carer payments (for health and leisure purposes), a peer support group and practical support to reduce or ease the caring role itself. This included support both that the third sector provided directly and from the statutory sector to which third sector organisations supported access. This small sub-sample of carers had some characteristics in common. They were all female, had been caring for a long period (over five years) and were all caring for an elderly parent (all but one of whom had dementia) generally in a role with a high impact. It is understandable that carers with these characteristics would benefit particularly from specific

secondary support to reduce or ease the caring role or to address particular difficulties they were experiencing.

Other carers with substantial needs for support with the caring role did not successfully access the support they required. This occurred more commonly (but not solely) in statutory carer assessments (five out of eight cases). However, no particular reason was identified linking this outcome to the form of casework. These carers had a slightly different profile in some respects. They were disproportionately likely to be under 45, to have been in their caring role for over five years, not to be in paid employment and to be either the partner or parent of the person receiving care and co-resident with them. They were caring for people with learning disabilities, mental health difficulties or other specific conditions including brain injury, stroke and multiple sclerosis but not for people because they were elderly and frail or had dementia.

It could have been hypothesised that the explicitly comprehensive approach of statutory carer assessment would have led to more and a wider range of outcomes being achieved for carers through this form of casework compared to others. Yet, within this sample, practitioners' efforts to cover a wide range of topics through carer assessments were not key to achieving outcomes. A wider range of types of outcome (for example, improved emotional well-being, financial situation and caring related knowledge) occurred within more individual third sector cases of casework compared to statutory carer assessment.

It could also have been hypothesised that more and a wider range of outcomes might also have been achieved in the small number of cases where a third sector practitioner carried out a statutory carer assessment (three) or in the single case where a third sector practitioner participated in a statutory carer assessment together with a local authority assessment worker in a partnership arrangement. The direct access to both the services and resources of the third sector and the local authority might have offered a wider range of services and easier access for carers. The observational data from these cases suggested the potential for this and practitioners also referred to this. For example, talking about referrals for a local authority short breaks service, Pat commented that via carer assessment "*probably we can do it a lot quicker*" (Pat, carer support worker, interview 2, page 2). However, the potential for improved or wider outcomes was not realised in the evidence relating to individual carers' experiences within this sample. This suggests that other factors are more important in the achievement of outcomes.

Chapter Eight: Reflections, Discussion of the Findings, Conclusions and Recommendations

This chapter now brings the thesis to a close through reflections, interpretation of the findings, conclusions and recommendations. The chapter begins with reflections upon this study in terms of the specific research methods employed (8.1) and the use of the realist evaluation framework (8.2). The findings of the study are then interpreted through some of the theories discussed in the conceptual review. Firstly, whether casework is achieving an ethic of care is considered (8.3). The next section then explores the extent to which carer empowerment is being facilitated by casework (8.4). The role of third sector casework in the changing policy context is then considered (8.5). The chapter finishes with the conclusion of the thesis (8.6) and recommendations from the research (8.7).

8.1 Reflections on the research design

The research design of this qualitative study had a number of distinctive features: its longitudinal design; the relatively large sample included; the use of multiple sources of data; and the relatively structured approach taken to both data collection and analysis. The value of these design features is now reflected upon in the light of the research process and findings.

A four stage longitudinal approach was taken to gain insight into outcomes over time and the process of change in a reliable and valid way. Important findings have been reported showing that outcomes (and contexts) changed considerably over time and why. In particular, the importance of ongoing contact from practitioners (or its absence) has been shown. This also relates to the significance of temporal changes in carer circumstances which reflects findings in the review of chapter two about how caring can be seen to have stages. A unique insight has also been provided into the long term outcomes of casework, particularly how limited these are over time. Yet, it was also found that a small number of cases showed how a relatively small input of resources through casework could continue to have important benefits over the long term. In addition, the staged process of data collection allowed data to be collected at a later point from two carers who were not initially willing to participate in an interview because they felt they had little to say until they received some secondary service support.

A reasonably large sample was sought to cover the diverse range of contextual factors anticipated to be of influence and to allow comparison of cases to achieve explanatory depth. The relatively large and diverse sample did allow a lot of different contextual factors to be explored. This was important because the diversity of carer experiences meant that some findings still relate to a relatively small number of carers. A smaller sample may well have missed several of the findings identified here. However, a considerable amount of time and energy was invested in recruiting different sites and practitioners to achieve this.

Overall, the disadvantage of a large sample together with a longitudinal design was that this was resource intensive. Thus this limited the resources available for other aspects of the study. It was therefore preferable to conduct the majority of the interviews by telephone which potentially limited the depth and quality of the communication. However, the main limitation created by the efforts focused upon achieving a relatively large sample and a longitudinal design is felt to be that more use could have been made of the observational data collected. This observational data proved very valuable in the way it was used. As noted, carers' recall of assessments can be poor (page 89). It was noted in responses here, particularly in the first round of interviews (those intended to be undertaken as soon as possible after the first main contact of casework) that where these took longer to arrange, respondents struggled more with recollecting events. In addition, occasionally practitioners confused one case with another. Undoubtedly, using the observational data to prompt respondents in interviews was very important to the completeness and reliability of the data collected overall.

However, the observational data may also have been able to add more insight into some other findings. For example, this may be the case with the findings on the potential importance of practitioners' interactions with carers in terms of changing their perspective on their caring role, developing a carer identity and encouraging them to consider their own needs. Transcribing the data and using some kind of discourse or conversation analysis might have been useful in considering how these changes were achieved. Analysis of the observational data relied upon the detailed notes made through listening to the audio-recording of the first main meeting between the carer and the practitioner. This meant that the use of non-verbal and embodied interaction was not considered. This might have added further insight, perhaps particularly into the understanding of emotional well-being outcomes.

Multiple sources of data were used together in the study in ways which strengthened the quality of the research. The role of the observational data in this has already been noted. Carer interviews were the primary source of information upon outcomes and their mechanisms. However, practitioner interviews were useful in adding further support for carer assertions (for example, on achieving reassurance, page 126) thus enhancing the confidence that can be felt in some findings. Practitioner interviews also combined with other data to provide a fuller picture of casework in some instances. For example, a practitioner (using detailed notes kept on the case) explained that she requested a home visit from the doctor for the person receiving care in response to the carer's concerns about his behaviour and his unwillingness to attend an external appointment (page 145). The carer had mentioned the home visit but not the practitioner's involvement in this in her interview. Practitioners also provided information about contextual factors particularly relating to their approach and the service context. In addition, practitioners gave some insight from their wider experience which helped where the information available from the carer sample was limited, for example, in relation to the relevance of ethnicity. One limitation in terms of the data sources used was that there were no first person reports of the outcomes and experiences of the person receiving care.

The relatively structured nature of both data collection and analysis enabled a comprehensive picture to be built of the outcomes, mechanisms and contexts of casework meeting the requirements of the research questions and the realist evaluation framework. A key concern in evaluation research is establishing the validity with which outcomes can be attributed to an intervention rather than any other source of change. The close questioning on outcomes and their relationship to casework helped to achieve this. The advantage of this was borne out by the insight generated through the use of the realist framework as discussed in the next section.

The realist position asserts that all knowledge is necessarily an interpretation. The conclusions presented here are based upon my interpretations as a researcher, which are also founded upon the interactions of and the interpretations presented in interviews and the first main meeting of casework. However, overall the various design features discussed have helped to enable me to present a relatively valid and reliable analysis of the reality of casework.

8.2 Reflections on using realist evaluation

The key advantage of realist evaluation is that it seeks to open up the 'black box' of an intervention and provide explanation of how the intervention works. This has been achieved here. This produces a different kind of evidence to that identified in the systematic review. Despite the extensive number of studies included in the systematic review, the section reviewing the existing understanding of the mechanisms of casework (from page 64) contains very little insight. The realist approach of this study has enabled an initial model of how casework with carers functions to be developed.

The realist approach argues for the need to go beneath the surface of intervention activities and identify the mechanisms of change. The search is for mechanisms based on the interplay between structure and agency and the social embeddedness of change (Marchal et al., 2012). This study has helpfully highlighted underlying mechanisms of change in terms of psychological change and learning as well as of secondary services as resources. Use of the realist framework has also provided important insights into the influence of context in terms of carer characteristics, practitioner and organisational differences and the wider availability of secondary service resources. It provides an understanding of casework in terms of 'what works, for whom, in what circumstances'.

It was noted on page 81 that one of the potential difficulties of realist evaluation is identifying exactly what each element of the framework (contexts, mechanisms, outcomes) consists of. This was difficult here. Some intervention activities involved in arranging secondary service use have been included as mechanisms. Some intervention features have been included within context. (It is intended that context should be understood as separate to the intervention (Marchal et al., 2012).) This approach was taken because it has been important to show how some intervention processes lead to outcomes

and how differences at both the organisational and practitioner level are a key influence upon the generation of mechanisms and achievement of outcomes. This difficulty seems particularly to have arisen because of the very variable nature of casework according to the individual practitioner, organisation and carer.

It was also recognised from the outset (page 81) that context mechanism outcome configurations might not neatly consist of one of each element. The outcome tables included here show that multiple mechanisms may be required in order to achieve an outcome. In addition, for each outcome, a number of contextual factors have often been identified, potentially that either inhibit or enable the generation of mechanisms. Thus, the outputs are not as neat or tightly specified as realist evaluation sometimes appears to be intended to achieve.

Ultimately realist evaluation is intended to be an iterative process of theory development and testing. The study here has taken a more exploratory approach given the absence of any existing explanatory models of carer casework. However, the model of casework developed here (page 182) could be considered in more specific contexts in future research. For example, given the importance of the personalisation agenda, further research into context mechanism outcome configurations in the use of personalised payments for carers would be useful. It would also be useful arguably to focus upon developing the model in relation to specific groups of carers, perhaps particularly where the data indicates that their characteristics are likely to be influential, for example, carers of people with dementia and black and minority ethnic carers. In this way, the realist approach means that evaluation findings can be used more widely.

As noted in the introduction, Porter and O'Halloran (2012) critique realistic evaluation for its focus upon piecemeal social engineering and neglect of the broader emancipatory aims of critical realism. This criticism could have been applied here. It is relatively straightforward to identify small improvements to casework using the realist framework, for example, that the progress of referrals needs to be checked. The interpretation of the findings through the use of wider theories of care and carer empowerment is also needed to enable a more critical perspective to be taken.

8.3 To what extent are casework providers achieving an ethic of care?

As noted in the introduction, there is a moral case for society to care for the carer or 'doulia' (Kittay, 1999). Tronto and Fisher's ethic of care (1993) (page 17) is used here to reflect upon the findings in terms of whether casework was able to provide care for the carer. Each element of the ethic of care: attentiveness, responsibility, competence and responsiveness is considered in turn before an overall assessment is made.

8.3.1 Attentiveness

Attentiveness is about being aware of and recognising the needs of others from their own perspective. Within casework, many and varied needs were identified both for the carer and often also for the person they cared for as well. There was some evidence that attentiveness was not being fully realised in specific respects. This was particularly apparent in relation to the lack of attention given to carers' needs relating to their knowledge and skills concerning the medical condition of the person they cared for and any difficult behaviour arising from this. As noted in chapter two, the process of gaining expertise in caring can be seen as a stage of caring (Cavaye, 2006). This is often achieved through trial and error, the accumulation of practical experience and intimate knowledge of the care receiver. This understanding of carer expertise can mean that this is perceived as something with which a casework practitioner is not necessarily qualified to support. However, some carers did want support with this to which some practitioners were not attentive.

Practitioners were often attentive to needs of emotional well-being, for carers to express themselves and to consider their situation. The practitioner offered a supportive manner and listened to the carer. The importance of this was also apparent in the occasional cases where this was not present and accordingly outcomes of improved emotional well-being were not evidenced.

The study has also shown how practitioners sometimes encouraged carers to be attentive to their own needs. Tronto argues that to care for others, one first needs to be attentive to one's own needs. As in other research (Keyes et al., 2015), the relationship between the social worker and service user enabled the identification of needs.

Whilst casework was mainly effective at attending to carer needs in the first main interaction, the evidence shows that over a longer period of time, this was less the case. With exceptions, the lack of ongoing practitioner contact reduced the opportunity for attentiveness to later or changed carer needs.

Tronto also discusses the relationship between ignorance and inattentiveness and raises questions about considering the needs of those who are not known to us. Third sector organisations where they proactively approach carers and also where they display and distribute promotional material are seeking to be attentive to carers not necessarily in contact with services. As the conceptual review notes, a key concern in relation to carer support is whether carers identify themselves as carers and consequently seek support. Thus, this is important.

8.3.2 Responsibility

Responsibility is about taking the decision to meet the need for care identified. By virtue of their existence, providers of casework for carers are seeking to take some responsibility for the care needed by carers. They can do this either by providing care and meeting needs directly themselves or by helping carers

to access other secondary support to do this. The findings suggest that mainly casework was taking responsibility through supporting carers to access other secondary services. One exception was the responsibility taken by some condition specialist practitioners to support carers directly with understanding the medical condition of the person they cared for and helping them to respond to this. Some other outcomes were achieved directly through casework, particularly emotional support, but these were time limited and there was not a sense of overall responsibility being taken for responding to this directly. This shows that, as intended, casework was not proactively taking a therapeutic approach (Payne, 2005). Instead it consisted more of an administrative approach (Lymbery, 2005) of mobilising resources with the current social system.

Taking responsibility to enable carers to access secondary services involved a range of assistance. Responsibility is not about fixed obligations but will be negotiated in the particular context in which care occurs. Two particular aspects of the context here meant that practitioners needed to offer additional assistance to enable carers to use secondary services. The fact that carers were often busy and overwhelmed by the caring role meant that their capacity to take action to access other services was limited. In addition, the difficulties often involved in accessing particularly statutory secondary services meant that practitioner support would be required to do so successfully. Thus, responsibility here meant providing active assistance with access to secondary services. This could involve providing information of various kinds, making referrals, directly booking provision, completing application forms and giving advice about how to negotiate with services and the person receiving care. Carers also sometimes required help to consider the use of and to arrange personalised support.

However, again, responsibility was mainly time limited. If further contact was not made by practitioners, then they were unaware and did not act to remedy breakdowns in the process of accessing secondary services which meant that these were not ultimately used.

8.3.3 Competence

Competence, the quality of the care, is an important moral aspect of care. Generally, whilst it was time limited, the quality of casework itself was good. There were some exceptions where some negative impacts in terms of emotional well-being were noted of disappointment, anxiety, being undermined and having a more negative outlook. The more significant issue in terms of the quality of care received by carers was apparent in relation to the availability, flexibility and quality of secondary services and the length of any waiting period. This is a wider contextual issue that impacts upon the potential of casework to care for carers. A question is raised of whether casework can do anything to limit these issues.

8.3.4 Responsiveness

Responsiveness involves considering the perspective of the person receiving care (in this case, the carer primarily but also sometimes potentially the person they care for) and what the care provided means to them. Chapter seven on overall findings provides a summary of this. There were quite different overall responses depending primarily upon the carer's specific circumstances. Again, a key barrier to positive care is the availability and quality of alternative care services.

The personalisation agenda has been intended to make services more responsive to carers. Where more personalised services for the person receiving care were an option, this could offer both advantages and disadvantages for the carer. More flexible, personalised services were more acceptable to the person receiving care and the carer. However, carers were sometimes unwilling to take on the potential organisational burden involved.

In terms of personalised support directly for carers (rather than the person receiving care), one-off payments were shown to be an effective means of achieving outcomes in a flexible and personalised manner for carers in terms of leisure, social and health needs particularly. The flexibility of this support can be particularly important to carers as a group of people who have difficulty committing to the fixed times of other standardised social and leisure provision. One-off carer payments also offered some benefits in terms of reducing or easing the caring role but this impact was limited in comparison to the contribution of, or unmet need for, alternative care services. The more standardised carer services such as the Caring with Confidence course and arranged leisure activities had limited reach within this sample.

8.3.5 The integrity of care

These four moral elements of care (attentiveness, responsibility, competence and responsiveness) must be integrated into a whole. When Tronto discusses the corresponding nature of care, she argues that it is best provided when its different elements (caring about, taking care of, care giving, care receiving) are undertaken together. Casework can be attentive and take responsibility for carers (although the longitudinal extent of this is limited where ongoing contact is not maintained). It can also provide some competent, responsive care in the domains where it directly provides care and meet needs. However, if carers require the use of secondary services which are independent of casework, the care of casework is critically limited by the wider context of the availability, quality and responsiveness of secondary services for carers and those they care for. The separation of casework from secondary services then limits its ability to meet the moral elements of an ethic of care. However, interestingly, personalisation may offer an opportunity for the re-integration of the different elements of care if casework supports the carer to access resources in this way.

8.4 To what extent is casework achieving carer empowerment?

The preceding section has considered the extent to which casework was able to care for carers. However, this does not explore the achievement of particular goals for carers, in particular, that of carer empowerment. As noted in the conceptual review (page 18), a specific focus upon empowerment may be required within the context of an ethic of care to achieve individuals' goals. This is considered here using Lee's model of empowerment (page 35). As noted previously, this framework is used as a means of assessing the reality of casework against an ideal of carer empowerment. It was not anticipated or expected that practitioners would have intended, or have been able, to deliver this entirely.

8.4.1 The development of a more positive and potent sense of self

The first element of empowerment identified by Lee (2001) was 'the development of a more positive and potent sense of self'. For a small number of carers, there was some evidence of a positive change in their perspective on their identity and role as a carer. This involved seeing caring as a normal experience and a valuable contribution. It also consisted of carers accepting their role and recognising their own competence. A more positive sense of self might also reasonably be inferred to be occurring where carers were supported to recognise and give some priority to their own needs. In this way, carers are seeing themselves as 'co-clients' in Twigg and Atkins' typology (1994), not just as resources or co-workers. They are also taking action to take a 'balanced/boundary setting' approach to their role (page 36).

It has been indicated that gender may mediate this. There is evidence in the literature (page 19) and some in this study that women are more likely to be engulfed by the caring role than men and thus to sub-ordinate their needs to those of the person receiving care. Conversely, men may be more likely to perceive themselves as professional carers who are entitled to support.

A potential difficulty with the development of a more positive identity as a carer is the impact this may have upon the relationship with the person receiving care (page 36). There was no evidence identified here of a negative impact of this kind but this does rely upon the perspectives of carers and casework practitioners, not those of the person receiving care.

Whilst the evidence shows that casework could facilitate this aspect of empowerment, this was not that widespread. In addition, small numbers of carers effectively identified the opposite when they reported a negative outlook, anxiety and/or feeling undermined.

8.4.2 Knowledge and critical comprehension of one's environment

The second aspect of empowerment that Lee identifies is 'the construction of knowledge and capacity for more critical comprehension of the web of social

and political realities of one's environment'. Through casework, carers often achieved improved knowledge of their environment in terms of learning about the availability of casework and a range of secondary services for carers. The simple act of learning through the process and experience of casework itself that support was potentially available in future was a very important outcome for many carers. In addition, learning about the existence of specific secondary services and financial support was a starting point for accessing these.

To a limited extent, there was some evidence of carers possibly achieving a more critical comprehension of their environment too. This is implied where practitioners helped carers to learn about their legal rights and how to liaise with statutory services to improve the chances of their needs being met. Whilst in theory, carers (and the person they cared for) had entitlements, the reality was that it was not always easy to access these. Casework sometimes helped carers to understand how to assert their needs within the system implying a more critical understanding of this. Similarly, it may be inferred that some carers developed a more critical understanding of their relationship with the person they cared for through learning ways in which to negotiate within this relationship to address some of their own needs.

In addition, where there was evidence of disappointment and frustration about the contact or support available, this reflects an understanding that carers already felt there should be more support available. Whilst this is not a desirable outcome, it indicates that there is some critical comprehension of the existing environment and its deficiencies in relation to carer support.

Lee (2001) proposes that consciousness raising and critical education takes place most effectively in groupwork. Whilst in some cases in this research, there was encouragement for carers to participate in support groups and other collective forms of support, there was very limited uptake of this. Where carers did participate, this had a positive impact upon carers' perspectives in increasing their confidence, feeling supported and encouraging them to seek support. It also enabled learning from each others' experiences. Thus, personal strength and knowledge were gained through collective interaction. There was no evidence of critical education or building upon this, of challenges to social structures through collective action.

8.4.3 The cultivation of resources and strategies for achieving goals

The third aspect of empowerment identified by Lee was 'the cultivation of resources and strategies for achieving personal and collective goals'. The main type of resources used in this sample was those provided through secondary services. In particular, these often acted as a substitute for the carer enabling them to reduce or ease their caring role which was critical to carers who were under a lot of pressure. Another key resource was income either through benefits receipt or carer one-off payments. Interaction with peers through, for example, training courses constituted another resource which was occasionally used.

A small number of carers also created their own strategies sometimes drawing upon their own resources to achieve outcomes. For example, this occurred in the cases where carers made changes to their routines or approach to caring to address leisure and/or social needs. The development of caring knowledge and skills is another way in which carers can then achieve outcomes through their own resources. This can also extend to skills for liaising effectively with other organisations, for example, statutory carer services. The extent to which this occurred was relatively limited. There is necessarily a concern to provide additional support on carers' behalfs where they are under considerable pressure rather than expecting them to go through complicated applications or access processes themselves. However, there is perhaps the possibility that sometimes the development of carers' own resources and strategies could be considered and used more widely.

Chapter seven on the overall success of casework discusses the extent to which personal goals (or outcomes) were achieved and how this varied amongst carers. It is useful to reflect upon the extent to which these were just 'achieved functionings' or also 'capabilities' in Sen's theoretical framework (1999) (page 37). 'Achieved functionings' are those outcomes that have been successfully pursued and realised at a given time. 'Capabilities' are a person's valued functionings in a context of free choice. Thus, this is about judging whether the outcomes achieved by carers are those that would be freely chosen by carers (possibly together with, or with consideration of, the person receiving care).

Casework could be seen in some cases to be opening up the choice that carers had by enabling them to realise that they did have some choice to address their needs and to use secondary services. However, the evidence of unmet needs reported in this thesis shows that capabilities are not always being achieved. As noted in chapter seven, there was a key group for whom important needs were not met through casework. There was some variation in these but some themes can be identified in terms of key capabilities which were often not met and the barriers often responsible for this. Some carers experienced poor physical health, poor mental health, limited social and leisure participation and exclusion from paid employment through their intensive, established caring roles. Whilst these carers wanted to choose to continue with their caring role, they did so in a context which imposed the negative impacts of this upon them. This was often because of barriers in the availability, funding or suitability of alternative care services. In addition, they were also often subject to financial restrictions through their reliance upon a small benefits income. In their context, non-participation in paid employment could hardly been seen as a positive choice. The data showed (for example, in the case example of Jim on page 207) that sometimes casework may achieve a number of positive outcomes for a carer but within a context of wider, significant unmet needs. The provision of a basic income through receipt of a benefit was an important achieved functioning supported by casework. However, this was certainly not the preferred capability of a more generous income achieved through paid employment whilst high quality alternative care services met some of his relative's care needs.

There was also some evidence of unmet needs, and thus that capabilities were not achieved, in other specific domains, for example, caring skills and the need to talk. The choices involved in some other decisions can also be seen to be constrained. For example, the carer who chose to reduce her working hours in order to make it easier to attend medical appointments with the person she cared for did so because she was constrained by an inflexible shift system and a lack of legal rights in this regard. Choices about whether to take up potential benefits entitlements and personalised support for the person receiving care were constrained at least in part by the difficulty or organisational burden involved in access to these. In addition, there were examples of carers not taking up alternative care services and practical support for the person receiving care because of a lack of choice involved in this. The evidence suggests that one-off carer payments as a form of personalised support do offer some potential in enabling better achievement of capabilities through the greater choice they offer carers in comparison to more standardised provision such as arranged carer leisure activities.

Many capabilities related to the carer and the person receiving care together. In this way, the freedom or autonomy that carers are concerned with is relational (see page 18). This is apparent in the desire to provide high quality care. Capabilities in terms of social and leisure participation were also often about the carer and the person receiving care being able to enjoy this together. The one potential key area of conflict was where a capability for the carer, for example, physical or emotional health depended upon the person receiving care to use other services against their preferences.

8.4.4 Empowerment and the form of casework

Overall, this consideration of the findings through the lens of carer empowerment highlights that the extent to which this is achieved is influenced by the form of casework practised and also by the wider political context. The mechanisms in the model of casework developed as illustrated in Figure 5.1 (page 182) correspond quite well with each element of empowerment identified by Lee. However, the extent to which these were achieved was quite limited in the context in which this study was undertaken. The form of casework practised could generally be argued to be closest to the administrative approach (Lymbery, 2005). There was not a strong emphasis upon a therapeutic approach thus limiting the potential for developing internal psychological resources to empower carers. Equally there was not an explicit focus upon empowerment which limited the focus upon critical comprehension of the environment or on collective action. However, given the limited uptake of collective forms of support by carers in this sample for various reasons, this may not be that easy to achieve. Furthermore, there are currently significant barriers in the wider context in terms of the resourcing and nature of social care services which limit the resources available to carers.

8.5 The role of the third sector in a changing context

The preceding two sections illustrate that the form of casework and the wider political and economic context of social care support influence the potential of casework to care for carers and to achieve carer empowerment. Following on from this, it is worth reflecting upon the role and context of third sector organisations as providers of casework and as the primary focus of this research. It is also important to do this in light of the changing context of carer policy.

Since the data was collected for this study, the 2014 Care Act has come into force bringing in important new rights for carers. For the first time, this provides for carers to be supported on the same basis as people receiving care in terms of their rights to an assessment and to support. This removes the requirement for carers to be providing 'regular and substantial care' in order to qualify for a carer assessment. Local authorities now have a new duty to meet carers' eligible needs. The new Act also includes a general duty to provide a range of preventative services including to prevent, delay or reduce the needs of carers for support. The Care Act also enshrines personalisation into statute for the first time.

The conceptual review showed that third sector carer organisations have occupied various and changing roles in relation to the state using Young's (2000) typology of adversaries, complementary partners and independent supplements. Through the casework analysed in this research (just one element of their work), third sector carer organisations were operating as complementary partners to the state. They were undertaking preventative work and supporting some with more intensive needs to access secondary support. They were effective as an accessible, visible first port of call. These organisations can potentially continue in this complementary role to help fulfil the new provisions of the new Care Act. The practice guidance to this legislation particularly notes the likely role of the third sector in relation to prevention and in the provision of information and advice (Department of Health, 2014).

In terms of the personalisation agenda encapsulated within the Care Act, the casework within this study was fulfilling some of the wider aims of this in terms of providing personalised information and advice to carers, again in a complementary role to the state. In addition, there were examples of third sector carer organisations beneficially allocating one-off carer payments to achieve personalised support. The practice guidance (Department of Health, 2014) also suggests a role for the third sector in helping carers to organise personalised support for the family. This did not occur directly through the casework considered here but was apparent in the referral to and use of a peer support group for this purpose. This could possibly be a service that third sector organisations of the types included in this research might want to consider providing. This was also suggested by the analysis of the findings using the ethic of care which found that the non-integrated nature of the care provided through casework limited the value of this. Providing a more

integrated form of care through support with implementing personalised support may help to address this.

Whilst it seems then that third sector organisations could play an important complementary role in helping to meet the new provisions of the Care Act 2014, a considerable threat to this is the continued budgetary restrictions for social care (Local Government Association, 2016). The impact of earlier funding restrictions under the deficit reduction programme was already evidenced in the research by the closure of some participating third sector organisations. Funding constraints may threaten the existence of third sector carer organisations but they also create the need for such organisations to act in an adversarial role, campaigning for carers' legal rights to be translated into practice in this difficult context.

Previous legal rights in relation to carer assessment have often not translated into good practice (Seddon & Robinson, 2015). Some of the cases of unmet need identified in this research were arguably illegal under the legislation of the time. Whilst additional funding has been provided to support the implementation of the Care Act, using a statistical analysis of carer data, Pickard, King and Knapp (2016) conclude that the anticipated extra number of carer assessments (and accordingly support) has been underestimated by the Government and thus insufficient funding has been allocated. Early reports on the implementation of the Care Act suggest that the impact has been limited (Bennett, 2016; Carers UK, 2016). More widely, reductions in benefits income for carers and their families through various changes to the system including the 'bedroom tax' Housing Benefit reductions, the localisation of Council Tax reduction, changes in disability benefits and reductions in disability and carers benefits due to changes in the way annual increases are calculated (Carers UK, 2014a; Carers UK, 2016) also threaten carers' well-being. This research has indicated how restrictive benefits income could be previously for some carers and their families, let alone after these further reductions.

This context suggests the need for third sector organisations to act in an adversarial role for carers. The previous analysis has shown, however, that casework achieved little in this sample in the face of challenging barriers concerning the availability and nature of secondary services and lengthy waits for these. Thus, it may be necessary to think about new ways in which casework or these organisations more widely can challenge this. The empowerment model suggests that collective action may be an important part of this. This potentially coincides with arguments for a third sector focused upon developing civil society. This research found limited evidence of this. However, it only included third sector carer organisations within the Carers Trust network and did not examine collective forms of carer support.

It is also worth considering if the research suggests that the state needs to address any failures in the third sector as identified in Salamon's analysis of the relationship between the two entities (1995). The first possible failure is the third sector's insufficiency. The main way in which casework was insufficient was in the lack of ongoing contact. Resources would be needed to address this but, as noted, this is an issue generally. Possibly a voluntary collective

form of support might offer a means of meeting this need. Particularism is another potential failure of the third sector. The specific focus upon carers alone could constitute this. The evidence shows that casework practitioners and carers also often consider the needs of those receiving care but there still remains a question as to whether this is sufficient.

The third sector may also be subject to the danger of paternalism where it focuses on the needs of funders rather than social needs more widely. Much of the funding of Carers Trust network members currently comes from local authorities and local health bodies. This is where a conflict of interest arises if, as suggested, the third sector potentially needs to take a more adversarial position in relation to the state to address carers' needs.

Even if this is not an issue, the needs of funders (local authorities) may affect the nature (if not the aims) of third sector casework where they specify that this must take the form of statutory carer assessment. The practice guidance to the new Care Act (Department of Health, 2014) suggests that local authorities may need to consider using alternative providers including the third sector to meet the potential extra demand for assessments. Undertaking statutory assessments is more time consuming and involves more paperwork than the generally more informal approach of third sector casework, thus potentially limiting the number of carers who are supported or the potential for ongoing work. Whilst the difference in sub-samples by organisation type prevents definitive comparisons, there was no positive evidence in this study that a statutory assessment model (in terms of using standardised forms which comprehensively cover a range of topics) achieves better outcomes for carers. What were important were the skills, responses and supportive and empathetic manner of practitioners. However, statutory carer assessments may have a particular benefit if they are the main or only route for carers to establish eligibility for certain resources, for example, one-off carer payments for personalised support.

The final potential failure of third sector organisations identified by Salamon (1995) is amateurism. This was not highlighted as an issue in this study, although as discussed in the methodology, it was anticipated that the sample included here would represent relatively good practice in casework. However, if casework was to be developed to offer a more therapeutic or empowerment based approach, then this would potentially be enhanced by further skills development and appropriate supervision.

8.6 Conclusions

In response to the overarching research question of this study: '*Casework with carers: what works and why?*', this thesis has shown that this varies according to many factors. Thus, an original realist model to understand casework with carers has been developed on page 182. This identifies the key mechanisms of change potentially generating outcomes through casework with carers and the contextual factors which influence the generation of, or need for, different mechanisms and outcomes. This is an original and important development

which addresses the previous lack of a conceptual understanding of casework with carers. Conclusions in relation to the more specific research questions of the thesis are now presented.

- *What are the outcomes of the casework of third sector generic carer services? And how does this compare to the context of the work of third sector condition specialist organisations and statutory carer assessment?*

The thesis has provided new understanding of the impact of third sector carer casework services addressing a substantial gap in the existing literature. A key finding was the positive outcomes achieved by the third sector in the short to medium term for the majority of carers, relative to those of statutory carer assessment. Third sector generic carer organisations were successful in achieving improvements in emotional well-being, behavioural change, employment, use of alternative care services and practical support for the person receiving care and receipt of financial benefits. The difference in outcomes by organisation type was seen to relate partially to the nature of the sample of carers participating in casework with different organisation types. However, this also appeared to reflect the visibility and accessibility of third sector carer organisations to some carers and also the way in which third sector condition specialist organisations could reach carers through their links with health services. Thus, the third sector may be well placed to support some carers not already in contact with services.

The comparative focus of the study highlighted that non-condition specialist forms of casework may sometimes overlook carers' needs in relation to their knowledge and skills concerning the particular medical condition of the person they care for. This thesis has also added further evidence that ongoing contact provided by third sector organisations, particularly condition specialist organisations, positively influenced the achievement of outcomes over time.

- *How do the outcomes of casework change over time?*

The longitudinal design of this study has enabled important and original findings about how outcomes changed over time to be identified. This research has shown that some important immediate outcomes were achieved for some carers very quickly (and with relatively few resources) through the direct interaction between the carer and the practitioner. The importance of this interaction in itself should not be overlooked. As other research has shown, short to medium term outcomes were often achieved through enabling carers to access secondary services. The research also provided a unique insight into long term outcomes not captured in the existing literature. The main finding here was that there was little impact in the long term due to changes in carers' circumstances and a lack of ongoing contact with casework over time.

- *What are the ultimate outcomes of casework for carers?*

A wide range of types of outcomes were achieved for carers covering: improvements in emotional and physical well-being (but there were also some negative impacts upon emotional well-being); improved caring knowledge and skills; participation in paid employment; increased financial income; improved social and leisure participation; and being better able to care. Positive outcomes for the person receiving care were also achieved. However, a group of carers had serious needs that were left unmet. Furthermore, when outcomes were considered in terms of carer empowerment, the achievements could be seen to be limited. There was a limited impact in terms of carers' development of a more positive and potent sense of self or critical comprehension of their environment. In addition, where outcomes were achieved, there was evidence to suggest that these were not always necessarily those that would have been chosen in a context of free choice.

- *What mechanisms produce which outcomes? How?*

A strength of this research has been the detailed investigation of the mechanisms underlying the generation of outcomes for carers through casework. Five key groups of mechanisms were identified in the model of casework on page 182. In particular, this study has provided insight into important psychological mechanisms concerned with valuing care and recognising carer needs which are hardly noted in the existing literature. This study has also provided a much more detailed and nuanced understanding of how developing carer knowledge and different forms of assistance to arrange access to secondary services relate to use of these. The role of carer action was also not highlighted by the systematic review but is potentially very important. Casework is not a simple matter of arranging services for carers but involves a number of different types of mechanisms which can interact with each other.

- *What contextual factors influence these processes and how?*

The thesis has provided further validation of the relevance of a number of contextual factors noted in the systematic review as well as highlighting some new factors. In particular, the practitioner's supportive manner and knowledge were further validated as important. The practitioner's approach in terms of considering the medical condition, providing emotional support and informing about carers' rights was also influential. The provision of a home visit may be helpful. The presence or absence of the person receiving care in the first main contact of casework was also potentially influential in varied ways.

Consideration of the findings in light of the theories of the ethic of care and carer empowerment identified particular contextual factors which limit the achievement of these. These suggest that a more profound consideration of the nature of casework with carers would be required to try and achieve a

complete ethic of care and carer empowerment. The provision of some ongoing support is a key consideration here. Personalisation could offer a means towards achieving an ethic of care in terms of creating an opportunity for casework to deliver a more integrated, holistic service. Personalised support requires particular attention to be paid to identifying the purposes of support and carers' sense of entitlement. To achieve carer empowerment, there would also need to be a greater focus upon psychological development and critical education potentially through peer support. The potential of casework with carers was also constrained by external structural factors including the nature and availability of secondary services such as alternative care services and occupational therapy. This raises a question for casework providers in terms of whether they might be able to find ways of challenging this.

8.7 Recommendations

8.7.1 Recommendations for practice

It is recognised that those involved in casework with carers face many real constraints in their work particularly in terms of resources. However, the research findings raise some interesting and important questions for service managers, planners and practitioners to consider in casework practice with carers.

1. Continued provision of emotional support. The research has shown the considerable value of emotional support in a number of different forms within casework. This occurs informally interwoven with the administrative tasks of casework. It can be enhanced through home visits and ensuring carers have the opportunity to have a private discussion. Practitioners should view this as an important aspect of their work. They also need to maintain an awareness of this element of their practice particularly to guard against cases where there may unintentionally be a negative emotional impact. There may be scope for greater therapeutic work and outcomes if carers are interested and willing to commit to this and practitioners are suitably trained and supervised.

2. Drawing on carer strengths and resources. There have been examples of simple and effective behavioural changes carers have made following discussion with casework practitioners. A more explicit focus upon how carers' own resources and routines could be used to their benefit could be helpful.

3. Extension of information and advice relating to the medical condition of the person receiving care. Practitioners should ensure they are open to recognising and responding to carers' needs for input on caring skills. This applies particularly to carers of people with dementia. There also needs to be recognition that new needs of this type may emerge over time. There is a careful balance to be maintained with also recognising carers' existing expertise. Practitioners who do not specialise in particular medical conditions may need to draw upon other secondary services to meet this need. This also

suggests the value of having specialist practitioners in particular conditions, for example, dementia.

4. Continued provision of information about and assistance with accessing secondary services. The study has shown that the provision of assistance with accessing secondary services, not just information, makes a difference to the use of these by carers (and thus achieving outcomes through this use). This raises questions for services and practitioners to consider about what assistance to provide directly and where to refer to other organisations (in which case, the progress of referrals needs to be checked). This also needs to respond to the circumstances of individual carers, for example, in terms of the pressures upon the carer.

5. Greater ongoing support. More ongoing support would improve outcomes, particularly for carers caring for someone with a progressive condition where needs are likely to change over time. The issue of resources makes this a challenge. Peer support might be an option here as discussed further below.

6. Service visibility and accessibility. It is important that services and practitioners continue to consider different ways in which they can make themselves known to carers, particularly those who might not identify themselves as carers or who have reservations about service use, for example, older people and members of black and minority ethnic groups. This includes considering how to make casework services accessible to those in full-time employment.

7. Organisational delivery of casework. At the level of service design, managers need to consider how best the mechanisms of casework might be generated. This might involve new forms of working as considered in the next recommendations. In terms of local authority commissioning, as noted on page 224, use of statutory carer assessment may not be the most efficient and effective means of supporting carers, particularly those in less intensive caring roles, who come into contact with third sector organisations.

8. Assistance to organise personalised support. It is clear that some carers require assistance to organise personalised support for the person they care for and also that they may need help to consider how they personally can use such support. This potentially offers an opportunity for casework to be more successful through providing more integrated care for carers rather than losing influence once referrals are made to other secondary services. The research has also raised questions about the nature of any assistance provided with personalised support. Carers need to have time and information to consider how to use this type of support. There needs to be recognition of and consideration of carers' and practitioners' different views and approaches in terms of entitlement. The design of schemes themselves is also important.

9. Supporting collective action. Although there was evidence of the opportunity for carers to join support groups or participate in organised group leisure activities or courses, the uptake of this was relatively low in this study. However, where this was used it had value and in some ways, extended the

benefits of the time limited form of casework. If the form of this was developed further, it could also potentially be important to carer empowerment. It may be that other means of doing this need to be considered, for example, through the use of online communities and social media. These forms of support would possibly also limit to an extent the problem of carer time restrictions and pressure preventing participation.

10. Challenging failures in the provision of secondary services. The funding of and nature of the available alternative care services are likely to continue to be critical issues for carers with more intensive roles. There was little evidence that casework with carers as it was practised in this sample was able to influence this much. Some development of the preceding two forms of support may offer some scope to address this. This also raises a question about whether practitioners could take a more adversarial role on behalf of or with individual carers in some way. This is likely to be just one strand of any successful effort to change outcomes for carers more radically.

8.7.2 Recommendations for research

11. More research on the third sector. The limited research on the role of the third sector in carer support should be extended further. It would be useful to have an overview of how, if at all, the provision of the sector is changing in relation to carer support as a result of wider policy developments particularly the personalisation agenda and reduced public expenditure. It would also be interesting to look at other forms of third sector support for carers, for example, carer run voluntary groups which might take a different positioning in relation to the state.

12. Research into peer support. One case in this research suggested considerable potential for peer support to act as a replacement or at least a complementary service to casework. Further research should be undertaken into the existence, outcomes and processes of such initiatives.

13. Research on carers' pathway to contact with services. The research has suggested that the third sector is well placed to act as a first port of call for carers. Given the lack of identification with a carer identity and barriers to service use amongst carers, it would be helpful to explore carer pathways to support further.

14. More research on the actual interactions between carers and services. The research has highlighted the importance of psychological support and the reframing of carers' perceptions and identity in carer support. It would be useful to consider this further, perhaps through discourse or conversation analysis of interactions between carers and professionals.

15. Further consideration of the process of accessing personalised support. This research has provided some interesting evidence about the process of accessing personalised support for carers in the form of one-off payments and contextual factors influencing the use of these. Given the prominence of the

personalisation agenda, further research is required in order to maximise the value of future practice in this area.

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Appendix 1: Carer Consent Form

School of Sociology and Social Policy, University of Nottingham

Research project: *Initial case work with carers: what works and why?*

I have read the research information leaflet and the nature and purpose of the research project has been explained to me and I am satisfied with the answers given to any questions.

Yes ☐ No ☐

I understand the purpose and nature of the research project and my involvement in it.

Yes ☐ No ☐

I understand that my participation is voluntary and I may withdraw from the research project at any stage. I do not have to give a reason and withdrawing will not disadvantage me in any way.

Yes ☐ No ☐

I understand that while information from the study (including quotes) may be published, any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published.

Yes ☐ No ☐

I understand that the researcher will also interview the worker about their contact and work with me.

Yes ☐ No ☐

I understand that the interviews will be audio-recorded.

Yes ☐ No ☐

I understand that data will be securely stored. Electronic files will be password protected and hard copy data will be kept in locked files. All materials which include any personal details will be destroyed at the end of the research.

Yes ☐ No ☐

I understand that the information provided can be used in other research projects which have ethics approval. In this case the data will be fully anonymised before it is available to other researchers.

Yes ☐ No ☐

I understand that I may contact the researcher (Liz Victor, Tel: 07811 831 414, School of Sociology and Social Policy, The University of Nottingham, University Park Campus, Nottingham NG7 2RD) if I require further information about the research, and that I may contact Professor Saul Becker Tel: 0115 951 5403 (at the same

Yes ☐ No ☐

address) if I wish to make a complaint relating to my involvement in the research.

I agree to take part in this research project.

Yes

☐

No

☐

Participant's name (BLOCK
CAPITAL)

Participant's signature

Date

Researcher's name (BLOCK
CAPITAL)

Researcher's signature

Date

Appendix 2: Practitioner Interview Guides

Practitioner Interview Guide 1

Aims:

- To add to my understanding of the intervention undertaken by finding out about the intended approach and the motivations, guidance and organisational context underlying this and the practitioner's characteristics;
- To find out about any outcomes they felt have been achieved and any processes or contextual factors that influenced these.
- To gain insight into how these appointments might compare with their wider experience;
- To understand expectations of future outcomes;

This guide is to be reviewed and tailored prior to each use to take account of points noted in the preceding observation.

Introduction

- Check happy to take part again, thank.
- Introduce interview (30 minutes or so background to and feedback on appointment, also seeking to draw on their wider experience, emphasise confidentiality).
- Check permission to record again.

1. Background to appointment(s)

Could you describe a bit about your overall approach to these appointments. Probe on: aims, structure, topics covered, direction by the carer /practitioner, presence of others eg person receiving care.

What has led you to use this approach? What sources or experience have you drawn upon?

(Where possible, some of this will be collected informally previously.)

Can you explain to me how this appointment(s) has come about? For example, how was it allocated to you? *(Where relevant)* How was it decided to do a home visit?

What, if any, particular materials did you have with you for this appointment? Does this differ from your usual practice?

What information, if any, did you already have about this carer and their needs? Does this differ from your usual practice?

How, if at all, did you prepare for this appointment? Does this differ from your usual practice?

2. Reflection on the appointment(s)

I'm going to ask some specific questions about the meeting(s). But first I wondered if you could tell me a bit generally about what you thought of the meeting last X and how it went?

(Outcomes)

Of course the meeting may be a first step towards achieving outcomes at a later stage but I wondered if there is anything specific that you feel has been achieved through the meeting already?

Was there anything you wanted to achieve in the meeting that you felt you were not able to or that was difficult?

(Processes/context)

I'd also like to try and understand whether you think various factors might have influenced how helpful the appointment was (might need to combine these for time).

Firstly do you think there was anything about the carer's input that might have influenced the outcomes? *If appropriate* - The presence of the cared for?

What about the organisation of the meeting?

What about the processes of the assessment? *Prompt on the nature of the documentation involved.*

What about your own approach?

Was there anything unusual about this appointment compared to other first appointments you've had with carers?

3. Next steps

What, if any, particular needs for support did you identify?

Which of these do you think you/ the Carers Centre will be most able to help with?

Which, if any, support needs will be most difficult to meet? Why?

What, if anything, do you expect to do to follow up this appointment?

Overall how, if at all, did my presence influence what you did and said?

4. Practitioner background

I'd like to just ask a few questions about your background if you don't mind because sometimes it influences the approach practitioners have.

How long have you been working with carers? In this role?

Could you tell me a little bit about your background? For example, any relevant professional training?

Do you have any personal experience of caring or other relevant situations?

Socio-demographics to be noted – age, gender, ethnicity

Can I get back to you if I have forgotten anything or need to clarify anything?

Thank and close.

Practitioner Interview Guide 2

Aims:

To gain insight into:

- The practitioner's perspective on outcomes achieved through intervention (since the previous interview) in particular, relating to a) service receipt and b) its impacts. Also any outcomes achieved through the process of support including emotional support and receipt of information and advice.
- Processes or contextual factors influencing the achievement of outcomes.
- To gain insight into how these appointments might compare with their wider experience.

Interview to be undertaken ideally at about 6 months.

This guide is to be reviewed and tailored prior to each use to take account of points noted in the preceding observation and interviews.

Introduction

- Check happy to take part again, thank.
- Introduce interview (30 minutes or so follow up on appointment outcomes and processes, also seeking to draw on their wider experience, emphasise confidentiality).
- Check permission to record again.

1. Service use

I understand from the carer that they have received the following services (list these) since the meeting I attended. Are you aware of anything else that they might have forgotten to mention? Take details.

I'd also like to ask for your perspective on these in terms of:

- Was there anything particularly helpful and/or problematic about *the nature of the services* they received (go through services individually)
- How do you think the service (go through services individually) has made a difference (positive or negative) to the carer?

What, if any, difficulties, frustrations or disappointments have you experienced in the provision of services to this carer? Please give any reasons for your answers.

Have you been able to provide access to all the desired support and services for the carer?

2. Outcomes from your contact with the carer

I'd also like to ask how, if at all, you think any contact you have had with the carer since the appointment has done any of the following:

- affected them emotionally?
- led to them learn anything in particular?
- made them think differently about their caring situation or themselves as a carer?
- affected or influenced their behaviour, for example, the way they care or lead their lives more generally?

For each response, follow up by asking: Can you say a little bit about how this happened or what helped with this?

3. Other outcomes

Overall, what effect, if any (positive or negative), do you think your contact with the carer and/or any of the services or support they have received subsequently has had upon the carer's:

- emotional well-being;
- ability to care;
- physical health;
- financial situation;
- employment situation;
- social life and networks;
- relationship with the person receiving care and other close networks.

(Where relevant refer to any instances already given by the carer and ask if there is anything to add.)

For each effect noted, ask: Can you say a little bit about how this happened or what helped with this?

Overall, are there any additional ways in which you would say your work with the carer and any services they've consequently received have made a difference to the carer?

Of all the services and support we've talked about, which do you think has made most of a difference to the carer? Please can you explain why.

What difference, if any, do you think any of this support has made to the person receiving care (positively or negatively)?

4. Processes

a. Is there anything about the context within which you work that you think has been particularly significant in helping to support the carer or that has made it more difficult to support the carer?

b. Is there anything about your approach to your work that you think has been particularly significant in helping to support the carer or that has made it more difficult to support the carer?

c. Is there anything about the carer's situation that you think has been particularly significant in helping to support them or that has made it more difficult to support them?

Background on the service

I also wanted to try and understand a little more in terms of the background of the service if possible.

Could you just describe for me how you see your role?
(Prompt on: Aims? Boundaries? Directed by the carer's needs at that time rather than necessarily ongoing? You don't do any scheduled reviews?)

I wondered if you have any documents on this, for example, setting out the purpose of the service/ service policy and/or job descriptions that you would be able to pass onto me as well

Fill in any gaps on their use of paperwork and any copies I am missing.

How, if at all, do they keep up to date or informed about ways to support carers and their rights? Do you have enough time to do this?

Do carers get back to you proactively? How does this vary?

5. Final comments

a. Do you have any other comments about your work with this carer?

b. Do you feel your work with this carer has differed from your general work with other carers in any particular way? If so, please elaborate.

c. Do you have any comments about your participation in this research project so far? All feedback welcome!

Can I get back to them if I have forgotten anything or need to clarify anything?

Thank and close.

Appendix 3: Carer Interview Guides

Carer Interview 1 Guide

Aims:

- To identify the pathway (events and motivations) leading to the appointment;
- To identify outcomes already achieved as a result of the appointment;
- To identify processes and contextual factors which they feel influenced the achievement of these outcomes;
- To capture their expectations of future outcomes;
- To gather any background details not already collected;

This guide is to be reviewed and tailored prior to each use to take account of points noted in the preceding observation.

Introduction

- Check happy to take part again, thank.
- Introduce interview (20 minutes or so feedback on appointment, no right or wrong answers, emphasise independence and confidentiality).
- If there is anything you don't want to talk about, please just say and I'll move on.
- Check permission to record again.

1. Pathway to the appointment *(NB Probe carefully to ensure a full understanding)*

I want to start by going back to what happened before the appointment. So can you tell me how you first heard about the carers centre?

How did you contact the carers centre?

Can you tell me a little bit about that telephone call/drop in etc? What happened?

What, if any, specific help did you receive at that stage?

Was there anything particularly helpful or unhelpful about the response you received at that stage?

Did you try to contact any other organisations for the same purpose before contacting the carers centre?

If yes, what happened?

What was your reason for contacting the carers centre now?

Why had you not done this before do you think? Explore any relevant background in terms of their caring situation and the history of this.

2. Reflection on the appointment

Expectations

If you can think back to before the appointment, what were your expectations of the appointment? How did the appointment actually compare to your expectations?

What was your attitude to or feeling immediately before the meeting? Were you nervous at all? Why do you think this was?

How did this change, if at all, during the meeting? Why was this?

Outcomes

I'm going to ask some specific questions about the appointment. But first I wondered if you could tell me a bit generally about what you thought of the appointment last X?

How, if at all, did you find the appointment useful or helpful?

Which of these was most important to you?

What, if anything, from the appointment did you find unhelpful?

What, if anything, do you think you learnt from the appointment?

How, if at all, did the appointment affect you emotionally do you think? How did it make you feel – during? And afterwards? Why?

How, if at all, did the appointment make you think differently about your caring situation?

Did you think that your situation and needs had been understood?

How did you find the process of being registered as a carer? What did you feel about being asked the questions you were asked? Amend as appropriate for use of other relevant documentation..

What, if any, particular action did you take as a result of the appointment? Why?

What, if anything, did you hope that the appointment would achieve that it didn't?

How significant would you say these outcomes (specify those discussed) are to your life?

Processes and context

So we've talked a bit about what came out of the appointment for you, for example, you mentioned... (*go over any outcomes identified by the carer*). I'd now like to ask a bit about what might have helped to make this possible.

Firstly, what, if anything, about *name's (practitioner)* approach helped with this do you think? Or was there anything about his/her approach that didn't help?

What, if anything, about the way the appointment was organised helped? Or what about this didn't help?

What, if anything, about the process of the appointment helped? Or what about this didn't help?

How easy or difficult did you find it to understand the information or advice that the support worker was giving you? Why did you think that was?

What, if anything, would you suggest could be done differently or better when other carers are met for the first time? *Probe on why if necessary.*

3. Expectations of future action

I'd like to contact you again in a few months to see what has happened following this appointment, but I wanted to ask quickly now as well:
What, if anything, do you hope will happen following this appointment? Follow up with probe: in terms of getting any particular help or using services?

Would you contact the carers centre or practitioner name again if something new came up which you wanted some help with? Is there anywhere else you would turn first? If so, would you want to speak only to practitioner name or would you be happy to speak to somebody else?

Do you have any other comments about your experiences with or feelings about the carers centre up to now?

What kind of support, if any, did you think would be available to carers?

4. Background characteristics

To be asked if not already gathered:

- Carer age, gender, ethnicity, employment status, family status
- Person receiving care – age, gender, relationship, condition, co-resident
- Caring situation – hours per week, how long been caring, nature of care, history of caring

Closing

- Can I get back to them if I have forgotten anything or need to clarify anything?
- Clarify next stages of research, follow up in 2 and 6 months on telephone
- GET ADDRESS to send voucher.
- Any questions?
- THANK and close.

Carer Interviews 2 and 3 Guide

Aims:

To gain insight into:

- Outcomes achieved through intervention (since previous interview) in particular, relating to a) service receipt and b) its impacts. Also any outcomes achieved through the process of support including emotional support and receipt of information and advice.
- Processes or contextual factors influencing the achievement of outcomes.

Interview to be ideally undertaken at about 2 months and again at about 6 months.

This guide is to be reviewed and tailored prior to each use to take account of points noted in the preceding observation and interviews.

Introduction

- *Check happy to take part again, thank.*
- *Introduce interview (20 minutes or so feedback on change since appointment, no right or wrong answers, emphasise independence and confidentiality).*
- *If there is anything you don't want to talk about, please just say and I'll move on.*
- *Check permission to record again.*

1. Service use since previous appointment

As a result of the appointment I attended and your subsequent contact with *practitioner's name* can you tell me what services have you used?:

Prompt specifically on: carers centre services (social/leisure activities, advocacy, training, counselling, support groups, breaks); local authority services; statutory carer assessment; benefits claims; other organisations' services.

Prompt specifically on any mentioned in the assessment or previous interviews.

Have you arranged any other services yourself as a result of information provided by the practitioner?

Have you been offered any other services which you have declined to use? If so, why did you decline this?

For each service, ask:

Could you tell me a little bit about the service please?

How was this service arranged? What was the role of practitioner in helping you to use this service? (for example, provided information, encouraged use, contacted the service on their behalf, advocacy)

What, if anything, has been helpful about the way in which this service has been provided to you?

What, if anything, has not been helpful (or frustrating or disappointing) about the way in which this service has been provided to you? (*Press on this*)

What difference, if any, do you think this service has made to you (in a positive or negative way)?

If appropriate, probe as to how the service has achieved this.

Is there any support or services which you had hoped to gain from your contact with the carers centre which you have not received? Or which you would receive from any service provider in an ideal world? (*Press on this*) And if so, please can you tell me a bit about why you think this has not happened? And what have been the consequences of this?

2. Other outcomes of contact with the practitioner

(If not covered, ask about what contact there has been with the practitioner since the appointment) Include whether they have received a newsletter or any other mailing or approach?

I'd now like to find out a bit about how any contact you've had with the practitioner has affected you. How, if at all, has this:

- affected you emotionally?
- led you to learn about anything?
- made you think differently about your caring situation or yourself as a carer?
- affected or influenced your behaviour, for example, the way you care or lead your life more generally?

For each, follow up by asking: Can you say a little bit about how this happened or what helped with this?

Also ask about the maintenance of any outcomes since the previous interview – for example, has improved emotional well-being been maintained?

3. Other outcomes

Now I'd like to ask overall, how, if at all, positively or negatively, your contact with the practitioner and/or any of the services or support you have received subsequently have affected you:

- emotional well-being;

- ability to care;
- physical health;
- financial situation;
- employment situation;
- social life and networks;
- relationship with the person receiving care and other close networks.

(Where relevant refer to any instances already given by the carer and ask if there is anything to add.)

For each effect noted, ask:

Can you say a little bit about how this happened or what helped with this?

Also ask for each: Have any other changes in your life contributed to this? If so, how?

Overall, are there any additional ways in which you would say your contact with the carers centre has made a difference to you?

Of all the services and support we've talked about, which has made most of a difference to you? Please can you explain why.

How much of a difference overall have these services and support made to you?

What difference, if any, do you think any of these services and experiences you have had have made to the person you care for (positively or negatively)?

4. Final comments

Do you have any other comments about your experiences since you contacted the carers centre?

Can I get back to you if I have forgotten anything or need to clarify anything?

Thank and close.

Carer Interview 4 Guide

Aims: To gain insight into:

- Outcomes achieved through intervention (since previous interview) in particular, relating to a) service receipt and b) its impacts. Also any outcomes achieved through the process of support including emotional support and receipt of information and advice.
- Processes or contextual factors influencing the achievement of outcomes.

This guide is to be reviewed and tailored prior to each use to take account of points noted in the preceding observation and interviews.

Introduction

- *Seek consent to take part again, thank.*
- *Introduce interview (10 minutes or so feedback on change since we last spoke, no right or wrong answers, emphasise independence and confidentiality).*
- *If there is anything you don't want to talk about, please just say and I'll move on.*
- *Check permission to record again.*

1. When I last spoke to you 6 months after your first contact with *service name*, you had received the following support – *list*.

For each service:

- Have you continued to use this support?
- What difference, if any, do you think this service has made to you?
Probe for any further outcomes, positive or negative
- What, if anything, has not been helpful (or frustrating or disappointing) about the way in which this service has been provided to you?

2. Have you used any other support as a result of your contact with *service name*?

- What difference, if any, do you think this service has made to you?
Probe for any further outcomes, positive or negative
- What, if anything, has not been helpful (or frustrating or disappointing) about the way in which this service has been provided to you?

3. Have you had any further contact with the carers service? *If yes, probe.*

4. Do you have any other needs for support as a carer that have not been met?

5. Overall, how has your contact with *service name* made a difference to you? How significant has this been to you?

6. Do you have any other comments you would like to make?

Many, many thanks!

Appendix 4: Project Information Sheet Example

School of Sociology and Social Policy, University of Nottingham

Information Sheet for Carers Centres

Research Project: *Initial case work with carers: what works and why?*

This research project will examine the outcomes and processes of initial case work undertaken with newly identified carers.

There is currently very little evidence about this work, yet it is potentially very significant in terms of helping carers to access further support. The findings will address this gap in the research and inform service development for carers.

I am looking for carers centres who are interested in participating. This would provide you with information which could help with your own service development.

I (Liz Victor) am a PhD researcher based at the University of Nottingham. My research is funded by The Princess Royal Trust for Carers and the Economic and Social Research Council.

What would be involved for your organisation?

With your consent, I would like to conduct up to ten case studies of initial case work with carers at your organisation. The case studies will explore in detail the experiences of carers and front-line practitioners in initial case work.

I am proposing that the case studies would work in the following way.

Upon first contact from a carer with your service

- Your practitioner would briefly explain the research to the carer (information to be provided).
- If the carer is interested, I would send a leaflet and speak to them on the telephone.

Practitioner's first appointment with the carer

- I would come along to this. At the beginning, I would spend a few minutes going through a consent form with the carer and answering any queries. I would then sit in on and audio-record the appointment.
- Shortly afterwards, I would spend about 30 minutes with your practitioner discussing their views of the initial appointment.
- I would also seek some feedback from the carer via telephone in the following few days.

Follow-up

- After about six months, I would ask for a follow up telephone interview of about 30 minutes with your practitioner.
- I would also contact the carer for a follow up telephone interview.

How will the research be used?

The findings of this research will be published in various outlets. They will be used by The Princess Royal Trust for Carers and others to inform service development. A summary of the research findings will be sent to all research sites and participants. The work will also contribute to a PhD being undertaken by the researcher.

Ethical issues

The research design and ethics have been approved by the School of Sociology and Social Policy at the University of Nottingham. I will be happy to complete any internal research governance and ethics procedures your organisation has itself in addition if required.

Participation is entirely voluntary. Informed consent will be sought on an individual basis from all the practitioners and carers who are invited to participate. The information collected will be stored in line with current data protection legislation. Personal data will be anonymised to obscure identities. Participating carers will be offered a £10 voucher to thank them for their time.

Contact details

I will be happy to discuss the research in more detail with you and to answer any questions.

I (the researcher, Liz Victor) can be contacted as follows: Tel: 07890 419 867, email: lqxejv@nottingham.ac.uk.

You may also contact my supervisors either:

- Professor Saul Becker at the University of Nottingham: Tel: 0115 951 5403, email: saul.becker@nottingham.ac.uk or by post at: School of Sociology and Social Policy, The University of Nottingham, University Park Campus, Nottingham, NG7 2RD.
- Alex Fox, Director of Policy and Communications, The Princess Royal Trust for Carers: Tel: 0113 268 8817 , email: afox@carers.org or by post: The Princess Royal Trust for Carers, Unit 14, Bourne Court, Southend Road, Woodford Green, Essex IG8 8HD.

Complaint procedure

If you wish to complain or have any concerns about the research, then in the first instance please contact either of the supervisors identified above. If this does not resolve the matter to your satisfaction then please contact the School's Research Ethics Officer, Professor Bruce Stafford, Tel: 0115 846 7439, email: bruce.stafford@nottingham.ac.uk.