Facilitating family engagement in older people's home-based reablement: A realist inquiry

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Abstract

An ageing population brings pressures and opportunities. Since 2010, the UK Government has invested substantially in reablement, to release pressure in health and social care services and to promote wellbeing. When a deterioration in an individual's health results in increased difficulty with everyday activities, reablement offers them short-term help to start doing things for themselves again. Current policy and guidelines for reablement emphasise a person-centred approach to delivery, making no differentiation between a service user with family and one with none. This exposes gaps in knowledge about family engagement in reablement.

Aim

The aim of this thesis is to build theory-led explanations about what works and does not, when engaging families in their relative's home-based reablement.

Methods

Realist methods were used to develop and refine theories. Preliminary consultation with stakeholders led into a review and synthesis of existing literature. This resulted in initial theories that were then refined through fieldwork (within a Local Authority reablement service in England). Data were collected through interviews and a focus group with study participants. A group of members of the public contributed their expertise as family carers. Data were analysed using a realist approach to identify what contexts are relevant to engaging families in reablement, how different people might respond to resources aimed at engaging them, and how, as a result, outcomes might be affected.

Findings

The findings explore four areas: instilling an understanding of reablement, the additional skills and support required by the workforce to engage families, customising service delivery to family circumstances, and empowering families to use a reabling approach themselves. They identify and link mechanisms associated with applying a reabling approach to different family contexts. They show how, for example, families can be encouraged to adopt the core mechanism of standing back with empathy in different circumstances. Considering reablement as a mindset that needs to be instilled actively in service users and their families during service delivery, the findings show that if this mindset is only introduced in a superficial way, there is a risk that families will revert to doing things <u>for</u> their relative, rather than helping them to maximise their capabilities in the longer term.

Implications

This research provides new insights into how reablement can either be enhanced or threatened by family members. It identifies considerations to take into account in future development of guidelines, policy and practice to optimise and sustain the benefits of reablement beyond its immediate delivery. It contributes to the field by reframing reablement as a relationship-centred service and mindset so as to empower families to enhance its success.

Acknowledgements

I have drawn on the support and encouragement of very many people to help me get through my PhD journey. My supervisory team, Professor Jane Powell, Dr Ailie Turton and Professor Praminda Caleb-Solly have coached me skilfully from start to finish. Dr Justin Jagosh has assured me and brought clarity to my thinking. Realist colleagues (especially Nicky Harris and Lisa Dibsdall) and the wider realist community have been generous with their time and patience when I have felt befuddled. My mother, sisters, niece and friends have helped me to persevere and have endured a considerable amount of unintelligible ranting and rambling. I have used their names as my participants' pseudonyms in recognition of their support. Special mentions go to my father-in-law, Vincent Sumpter, who helped me to type when I had an eye and a hand out of action simultaneously, and to my sister Susan Gillingham for her eagle-eyed reading of the entire lot. As for the person who suggested I do a PhD in the first place, Dr Jak Lee, I am grateful that she did, and know that I could not have done it without her unwavering support and friendship.

I would like to express my gratitude to all the study participants for giving their time and ideas so generously. It has been inspiring to work alongside people who are so committed to improving older people's lives. Particular thanks go to the Team Manager and to the Patient Public Involvement Group volunteers.

Finally I would like to acknowledge the love of my husband and children which underpins everything, always. I know that I am very lucky to have you.

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Acronyms

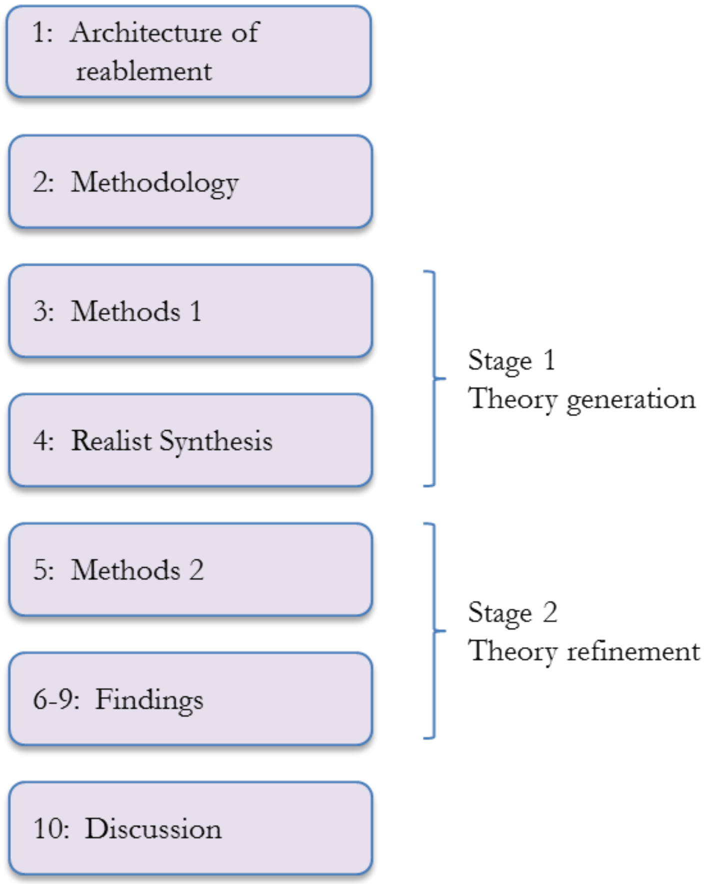
ADL	Activities of Daily Living
BCF	Better Care Fund
CCG	Clinical Commissioning Group
CMO	Context, Mechanism, Outcome
CMOC	Context, Mechanism and Outcome configuration
CSED	Department of Health's Care Services Efficiency Delivery Programme
DToCs	Delayed Transfers of Care
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
LA	Local Authority
NAIC	National Audit of Intermediate Care
NHS	National Health Service
NICE	National Institute for Care and Health Excellence
NIHR	National Institute for Health Research
OT	Occupational Therapist
PPI	Patient and Public Involvement
RCOT	Royal College of Occupational Therapists
RW	Reablement Worker
SCIE	Social Care Institute for Excellence
UWE	University of the West of England, Bristol
VICTORE	Volitions, Implementation, Contexts, Time, Outcomes, Rivalry and Emergence

Introduction

This thesis explores what works and does not work when engaging family members in the reablement of a relative. It focuses on home-based reablement services delivered for up to six weeks by Local Authorities in England, where the service user is over the age of 65. The service user's family members encompass a wide range of people including partners.

Structure of the thesis

The thesis is organised into 10 chapters:



Chapters one and two introduce and contextualise the research area and the research methodology used. Chapters three and four describe the approach to generating theories through formative research and by searching existing literature. Chapter 5 provides the reader with a description of the methods used to refine these theories through fieldwork. Chapters 6 to 9 represent the findings of the fieldwork over four theory areas. Chapter 10 is a discussion of the findings, bringing together theories across all four areas. It includes implications for guideline, policy and practice development, proposals for future research and a critical appraisal of using the research methodology.

Personal motivation and background

In order to provide context for the reader, I believe it is essential to start by identifying my own positioning within this study. This is important as it demonstrates that I have worked with and for older people in a professional capacity and have also engaged personally in supporting an older relative. Neither of these roles was within the field of reablement, meaning that I do not have any allegiances within the field. Rather, they encouraged me to attempt to understand different perspectives and increased my interest in taking a realist approach to the study.

I arrived at a PhD following many years' working in project management. Many of my projects have been in charities, working with and for people whose choices about their independence are compromised in some way. The most recent of these was with a UK charity that works to enrich the lives of older people living in care. My job was to create a programme to empower care staff to provide effective and meaningful activities for care home residents. I learned about the importance of training staff to start with the individual and work with them to identify activities that would capture their imagination and enthusiasm. I gained knowledge about living with dementia and saw how families and friends could contribute to the creation of meaningful activity for and with them.

When my father's cognitive abilities started to decline as a result of dementia, I decided to give up my work and put my knowledge to personal use by contributing more actively in my parents' daily lives as they were adapting to my father's condition. I like to think that alongside the extremely impressive adaptation that my mother made, the support my siblings provided and my father's gentle humour, my contribution helped us all in some way to make the most of the last phase of his life. These elements of my professional and personal background have provided different perspectives to draw on in my study.

Background to the formulation of the research questions

The first months of the PhD were concerned with identifying and honing a research question relating to enhancing workforce efficiency within rehabilitation and reablement. The first decision made was a pragmatic one. This was to focus on reablement only, as delivered by Local Authorities (LAs) in England. It was clear that the research base for reablement was limited and that there was scope to address gaps in understanding about how to develop it as an intervention intended to bring about positive change. This provided breadth of choice in terms of paths to follow in the thesis. A large-scale English study contributed to my decision to focus on facilitating family engagement in older people's home-based reablement. This study had identified gaps in understanding about how carers can contribute to, and benefit from reablement (Glendinning et al., 2010). A final scoping decision was to focus on the period during which reablement is delivered only and not on referral into or transition from it.

In order to exploit fully the outcomes of the research, it was important to me that the findings could inform both policy as well as practice. For this reason the primary audience for the research was considered to be service commissioners, heads of adult reablement services and reablement service managers. These groups were therefore considered to be the primary stakeholders who could contribute to an understanding of the logic and architecture of the intervention and to locating existing theories about how it works.

Overall research question

The overall research question for the study is:

What are the causal explanations for the ways in which reablement teams engage families in older people's home-based reablement?

Contribution to new knowledge

The Discussion Chapter (Chapter 10) describes how this thesis contributes to new knowledge, by providing fresh insights into how engaging families in reablement can reinforce the positive impacts of reablement both during and beyond the period of its delivery. The thesis findings have implications for future development of reablement guidelines, policy and practice, reframing reablement as a relationship-centred service and mindset.

Chapter 1: The Architecture of Reablement

Key aspects of the architecture of reablement in England are identified in this chapter. "Architecture" is used as a metaphor to describe the building blocks of reablement as an intervention. "Clarifying the architecture of a programme or policy is a building block toward understanding how initiatives are meant to work based on the resources implemented in contexts and how people respond to those resources" (Jagosh, 2019a). It will be seen that many aspects of the architecture of reablement are not clearly conceived. The lack of a standard model for its delivery, the complexity of its composition and its reliance on social contingency all combine to create a number of blind spots, obscuring a clear vision of how to optimise it.

Pawson's VICTORE checklist is used as a means of structuring this chapter (Pawson, 2014). VICTORE (an acronym for Volitions, Implementation, Contexts, Time, Outcomes, Rivalry and Emergence) was proposed by Pawson as a means of mapping the "contours of complexity as they envelop the intervention under study" (Pawson, 2014 p43); in other words, the architecture of an intervention. Applying VICTORE mapping is an activity recommended to evaluators, systematic reviewers and policy analysts as an initial step before entering a field of enquiry. Pawson did not intend for VICTORE to be adhered to rigidly. It has been adapted here to help define the characteristics of the architecture of reablement as they apply to the study. Following an introduction and a short section on defining reablement, VICTORE is mostly used in the order in which it comes, starting with stakeholders' volitions. It introduces in particular the stakeholders of interest in this study – family members. Contexts and Time are combined in section 1.6 and include aspects of the pre-existing policy landscape. Rivalry is recast as related initiatives in section 1.8.

1.1 Introduction to reablement

The political, economic and social climate in England has been ripe over the last decade or so for the emergence of interventions that hold potential to offer financially sustainable solutions to the pressures presented by our ageing population. Reablement has been argued to be such an intervention (Glendinning et al., 2010). An early reference to reablement as a service in England appears in an evaluation of a pilot project in which it is referred to as "Services for people with poor physical or mental health to help them accommodate their illness by learning or re-learning the skills necessary for daily living" (Kent et al., 2000). This project provided a foundation for a subsequent Government-funded evaluation of home based reablement services in England (Department of Health and CSED, 2007).

Since then, definitions of reablement and models for its delivery have developed rapidly and continue to do so. During the course of this doctoral study, the National Institute for Health and Care Excellence (NICE) published its first guidelines on reablement (NICE, 2017) and its first quality standard for reablement (NICE, 2018a); a major NIHR-funded research project examining reablement in England was published (Beresford et al., 2019); the first textbook on reablement was published (Ebrahimi and Chapman, 2018) and ongoing implementation of the Care Act was in evidence (Department of Health, 2014a). These publications and developments are all an indication of how topical and timely research into this evolving intervention is. This status provides opportunities to contribute to its ongoing development.

1.2 Defining reablement

Since early references to reablement and the publication of a series of reports into reablement resulting from the CSED evaluation (Newbronner et al., 2007; Jones et al., 2009; Rabiee et al., 2009; Pilkington, 2012), a multitude of definitions of reablement have been produced by agencies, Local Authorities, practitioners and researchers, and continue to be produced (Doh, Smith and Gevers, 2019).

The Social Care Institute for Excellence (SCIE) definition below is a broad definition that could apply to a range of models of reablement. It provides a starting point for this overview of definitions. It includes an indication of the time-limited nature of the intervention and encompasses some of what distinguishes it from other interventions.

> Reablement is generally designed to help people accommodate illness or disability by learning or re-learning the skills necessary for daily living. These skills may have been lost through deterioration in health and/or increased support needs. Reablement services are generally provided for a period of up to six weeks although people often meet their goals in a far shorter period of time. The focus is on promoting and optimising independent functioning rather than resolving health issues. It is about helping people do as much for themselves as possible rather than doing things for people that they cannot do.
>
> (SCIE, 2013)

The challenge of defining reablement is recognised and ongoing (Ebrahimi and Chapman, 2018; Beresford et al., 2019). High-level definitions of reablement used by agencies across the UK refer to reablement variously as a service, an assessment, an intervention and an approach (See Appendix A). They differ over the inclusion and exclusion of several aspects of service provision. Recent analysis indicates why this is the case, highlighting enormous variation in the way that reablement is implemented in terms of where services are located and who delivers them (Beresford et al., 2019).

This lack of uniformity extends to how the aims of reablement are defined. Although the notion of learning or relearning skills is commonly expressed, the reasons for doing so are not expressed in a consistent way. Maximising or optimising independence is frequently expressed as an aim. Although remaining at home is frequently part of the definition, independence is sometimes referred to in more abstract terms and is not linked specifically with the home (NI Health and Social Care Board, 2012; SCIE, 2013; Social Services Improvement Agency, 2013). Another thread that runs through definitions of reablement is that of self-reliance; people doing things for themselves rather than relying on others. In some instances this distinction is made by contrasting reablement with traditional homecare, where the emphasis is on doing things for people (Royal College of Occupational Therapists, 2015). Unusually, in Age UK's definition, the idea of reablement and traditional care running alongside each other in a service user's home is mentioned (Age UK, 2018). Some organisations frame reablement as "person-centred" in their high-level definitions (NI Health and Social Care Board, 2012; Royal College of Occupational Therapists, 2015).

These differences in definition are important and will be explored in particular in Chapter 6 with respect to instilling an understanding of reablement among the families of service users. At this stage it is sufficient to identify the SCIE definition as a starting point and to suggest that the dynamic that arises out of different perceptions of what reablement is based on and how it is defined, can impact on engagement with it.

The term "restorative care" is used instead of reablement in the USA, New Zealand and Australia as well as in some documents produced in English by Scandinavian researchers (Tinetti et al., 2002; Parsons et al., 2013; Lewin et al., 2014).

1.3 Stakeholders and their volition

Service users represent the primary stakeholder group for reablement. Although initially conceived as a service for older people, increasingly Local Authority services do not identify a minimum age limit for acceptance. Models of inclusion vary over factors such as mental ill health or learning disabilities, long-term conditions or impairment, disability and people living with dementia. In general terms, people with long-term, progressive conditions, with a need for ongoing care are more likely to be referred to traditional forms of care.

As awareness of reablement among the general public is low, reablement service users are likely to have been referred to reablement rather than actively seeking it out themselves. In terms of volition, this means that they are not approaching the intervention with a full understanding of its parameters and how it differs from traditional care services. In some cases it might be offered as a means of assessment in advance of identifying other packages of care. In these cases the service user might regard it as a stepping stone to other care services rather than an end in itself. It appears that the practice of setting goals with service users is fundamental to all services. This is intended to be based on the volition of service users. Goal-setting is typically revisited during the course of reablement alongside ongoing assessment of capability. As reablement is concerned with encouraging people to do more for themselves, motivation (both intrinsic and extrinsic) is key and is likely to fluctuate during delivery.

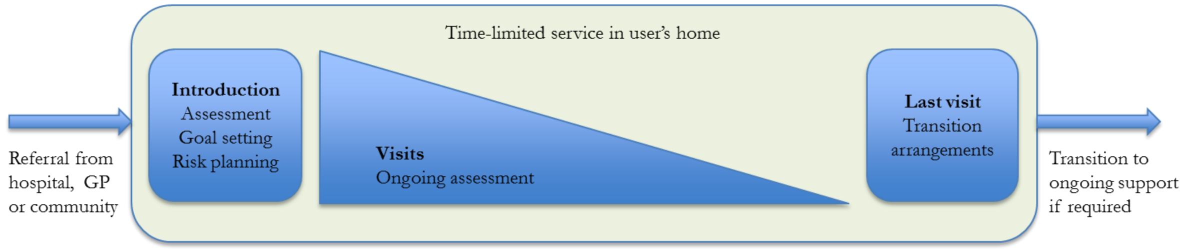
A second stakeholder group is represented by the people mostly closely involved in the life of the service user, typically family, friends and/or neighbours. From among this group it is the volition of families that is at the centre of the research and how families in particular are facilitated to engage with the intervention. Section 1.5 introduces this group more fully.

Members of the reablement team represent the third stakeholder group. They guide and support the service user through the reablement service. The composition of reablement teams varies around England and can be made up of different combinations of Reablement Workers (sometimes called support workers), occupational therapists, physiotherapists, nurses and social workers, along with their managing teams and administrators. Reablement Workers undertaking the majority of home visits in Local Authority reablement services typically come from either a traditional care background or come to reablement without experience in other care environments. This has potential to impact on their volition towards the reabling approach and will be explored in the thesis. Interpersonal exchanges between these three groups of stakeholders are fundamental to reablement and are at the heart of this study.

1.4 Implementing reablement

The study focuses on home-based reablement services provided for up to six weeks by Local Authorities in England and Figure 1 provides an initial broad overview of its key stages.

Figure 1: Overview of the key stages of home-based reablement



The referral process into reablement is beyond the scope of this study. It is sufficient here to identify the fact that routes into reablement vary between Local Authorities but that people are generally referred directly from hospital, by their GP or through community-based organisations such as other care organisations or referral services, some of which are commissioned or managed by Local Authorities. There is no single body in England that determines how reablement should be delivered and as a result there are marked differences in the way that services are run, with varying interfaces and degrees of involvement with health services, other social care services, the private, voluntary and community sectors.

Generally, the first visit or visits made by the reablement team focus on assessment of capability and the identification of reablement goals. Beresford et al. categorise reablement services as either functional or comprehensive (Beresford et al., 2019). Goals in services that provide functional reablement are identified by them as restoring functional ability associated with activities of daily living in the service user's home; whereas goals in services that provide comprehensive reablement extend to activities outside the home and social engagement. Clearly the latter requires service providers to have knowledge of and possibly links with local community and voluntary groups.

There is variation across Local Authority services with regard to functional and comprehensive models of reablement. However, as a person-centred intervention (see section 1.6), it is intended that the service user always plays an active role in identifying goals, regardless of the model. Aspects relating to goals are risk planning and the provision of equipment where needed. During the course of reablement, multiple visits are made which vary in duration and content. Goals are revisited and revised in light of assessments made by the reablement team during these visits. The wedge shape on the figure above indicates the aim of gradually reducing the number of visits during reablement as the service user becomes better able to undertake tasks without assistance. The team members who visit at different junctures varies by service, as does the way in which the team communicates among itself. Generally, a care record that logs details related to visits and progress remains in the service user's home.

Some high-level definitions of reablement refer to the time-limited nature of the intervention. Reablement services are generally provided for a period of up to six weeks. However, people can be discharged in a shorter period of time at the discretion of the service, if they have met their goals. The service is normally provided free of charge for however long it is delivered, up to a maximum of six weeks, although this is also subject to variability. Arrangements for transition from reablement are typically made during the last visit or visits. Although this study will not focus on ongoing support beyond reablement, the sustainability of what has been achieved during reablement will be considered.

A final word here relates to the locus of reablement. Although this study focuses on home-based reablement, it is noted that reablement services are not provided exclusively within a service user's home. Sometimes reablement is offered in care homes or in a specialist secondary care setting where people might go, for example, as a stepping stone between hospital and home. In addition, some independent homecare providers offer an approach to homecare that is reabling or restorative in its approach. These can be referred to as reablement services too.

1.5 Family members as stakeholders in reablement

This study is concerned with what works and does not work when engaging family members in the reablement of a relative. Naturally, it is not the case that every reablement service user will have a partner or family involved in their lives. The study focuses only on those who do, and family members are taken to include partners. A partner could be living with them or not and could be a spouse or an unmarried partner. Family members can be from any generation, for example, a grandchild, adult child, daughter- or son-in-law, niece, nephew, sibling, or parent. Some of these might be sandwich generation carers - people who look after older relatives in some way alongside looking after their own children. A great deal of thought was given to terminology for stakeholders during the course of the study. As a result, in most cases the term "carer" is avoided when referring to family members in the thesis. More detail on this can be found in Appendix B. This section, however, draws on a number of sources which use a variety of terms for family members such as family carers, infomal carers and unpaid carers.

There are formal imperatives that support considering family members as stakeholders in reablement. They are regarded as stakeholders by both SCIE, the national social care improvement agency, and NICE, the provider of national guidance, standards and advice to improve the wellbeing and care of people in England (SCIE, 2013; NICE, 2017). More fundamentally the Care Act, that was introduced in 2014 (Department of Health, 2014a), and is the most significant piece of legislation affecting reablement, requires Local Authorities to consider both the cared for and the carer. The Care Act represents a shift in terms of offering reablement to all relevant referrals into adult social care and one of its critical provisions relates to the obligation it places on Local Authorities to make an assessment of a carer's needs for support (Department of Health, 2014a Provision 10). In this context a carer means an adult who provides or intends to provide care for another adult, and a carer's assessment covers current and likely future support needs. It must take into consideration: whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care; whether the carer is willing, and is likely to continue to be willing, to do so; the impact of the carer's needs for support; the outcomes that the carer wishes to achieve in day-to-day life; and whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes.

In broader terms, the importance of considering family members as stakeholders in their relative's reablement is reflected in the pivotal role that they are known to play with regard to care in general. In 2010, Carers UK stated that "the bulk of care is and has always been provided within families, with twice as many unpaid carers – nearly 6.5 million - as there are paid staff in the health and social care systems combined." (Carers UK, 2010). A more recent estimate puts this figure at 7.6 million (Social Market Foundation, 2018). Table 1 shows highlights from the latest Carers UK digest and analaysis of research and statistics. These demonstrate how critical the support of family carers is to older people as well as to the economy (Carers UK, 2019).

Findings from the Beresford et al. study cite informal carer involvement in reablement as one of a number of factors that may moderate or mediate the effectiveness of reablement and that is potentially amenable to change from the perspective of service structure and practices (Beresford et al., 2019). The study found that "service user and family member (mis)understandings of reablement could present a barrier to engagement" (ibid p113) and goes on to recommend "the development/identification and evaluation of feasible interventions, delivered prior to/on the point of entry into reablement, to improve understanding and expectations of reablement, both on the part of potential service users and family members" (ibid p114). Instilling an understanding of reablement in family members is the subject of Chapter 6.

Table 1: Selection of Carers UK statistics, 2019

Current profile of family carers

- Almost 1 in 3 people aged 80+ provide vital, unpaid care for someone else despite many having their own severe health issues.
- The carer population is not static: 3 in 5 people are carers sometime in their lives.
- 40% of carers care for parents/parents-in-law, 26% care for their spouse/partner.
- Around half of carers live with the person they care for.
- In 2016-17 per week, 36% were caring for over 100 hours; 13% for 19 hours or less; 15% between 20 and 49 hours and almost 15% between 50 and 100 hours.
- BAME carers struggle to access culturally appropriate services.

Increasing need for care by people over the age of 65

- Between 2007 and 2032, the number of people aged 65 and over who require unpaid care is projected to have grown by more than one million.
- The hours of care provided by relatives is increasing.
- The proportion of adults helping parents with activities of daily living is increasing.
- The number of carers aged 65+ is increasing more rapidly than the general carer population. 2 million people aged 65 or older are estimated to be carers.

Economic impact

- The care provided unpaid by carers is worth an estimated. £132bn per year - considerably more than total spending on the NHS in England.
- Estimated annual public expenditure costs of carers leaving work (England): £2.9bn.

Personal impact of caring

- The pressures of caring can take a toll on carers' physical and mental health and 61% of carers report being worried about the impact of caring on their relationships with friends and family.
- Over 2.6 million people have given up work at some point to care for loved ones, 2 million have reduced working hours.
- In 2017, the majority of carers felt that their contribution is not understood or valued by the public and society more broadly.

1.6 The context in which reablement is delivered

This section examines some of the macro-contextual factors behind reablement implementation.

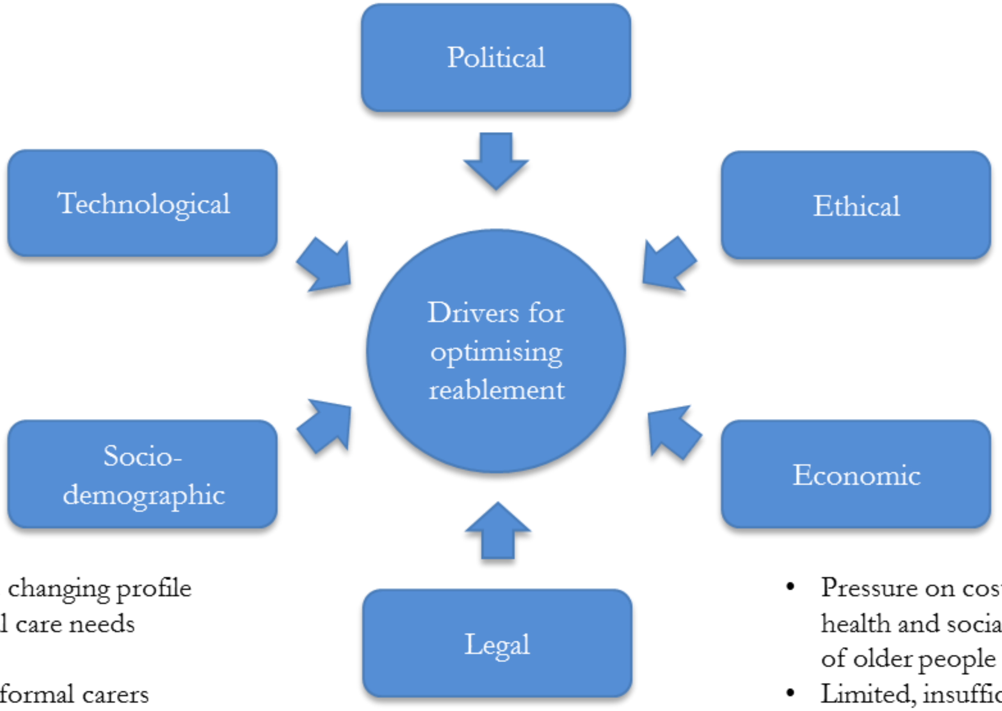
1.6.1 Drivers for reablement in England

A range of pressures have driven support for reablement as an intervention for older people in England since 2005. These are summarised in Figure 2. At a policy level, there has been a growing recognition that current approaches to health and social care services are rapidly becoming unsustainable and pressure for their reform continues to build. In response to this, the potential of services that focus on preventing health emergencies have become increasingly prominent. The 2005 Green Paper (Department of Health, 2005) and subsequent White Paper (Department of Health, 2006) illustrated this shift towards prevention as a potential long-term means of reducing demand for high-cost services. Reablement is positioned within this agenda.

The personalisation of services has risen up the policy agenda alongside prevention. The Government's 2007 Putting People First concordat placed a focus on independent living for all adults, supported by a high quality, joined up, responsive care system. (Deptartment of Health, 2007). In a shift away from reactive care, its commitments included the promotion of person-centred planning, with a greater emphasis on self-assessment, self-management and access to direct payments for all service users to enable them to choose and control their own care. It emphasised early intervention, enablement and the involvement of relatives and carers in care planning. Although the term person-centred care is now widely used and is seen in many definitions of reablement, its meaning is not understood in a uniform way, as a recent scoping review of the person-centred literature in rehabilitation demonstrates (Jesus et al., 2019). Broadly speaking, a person-centred approach recognises that individuals are both participants and beneficiaries, and have responsibilities for their own health and wellbeing.

Figure 2: Drivers for reablement in England

- Focus on prevention to reduce demand on costly services
- Personalisation / person-centred care / wellbeing agendas
- Promoting independence, self-management, self-determination in health and social care
- Promoting community-based care systems



- Growth in healthcare technology and assistive technology

- Stereotyping older people
- Older people's autonomy
- Consent for people with cognitive impairment

- Growth in ageing population and changing profile of older people's health and social care needs
- Isolation and loneliness
- Increasing demands on unpaid informal carers
- Increasing demands on ill-paid care workforce
- Changing family structures
- Cultural mix with variety of norms concerning care in old age

Care Act
2014

- Pressure on cost, delivery, sustainability of health and social care services to meet the needs of older people
- Limited, insufficient resources
- Depleting workforce
- Growing demand for evidence-based outcome measures

The economic pressure on meeting the health and social care needs of an ageing population, with rising numbers of people living with long-term conditions is increasing all the time. The aspiration to deliver health and social care services for older people that are both sustainable and individually tailored has significant economic implications. It has led to a growing demand for evidence-based outcome measures that can demonstrate the value of services. This is taking place against a backdrop of inadequate funding and a depleting workforce. The consequent policy focus has been on reducing demand on acute services, nursing homes and long-term residential care in favour of increased care in the community. Connected to this are impacts related to NHS discharge-to-assess policies (NHS England, 2016) which aim to reduce the time that people spend in hospital at the point at which they no longer need acute care, by supporting a return to home for assessment. This sometimes results in services having to accept into reablement people who would not usually be considered appropriate.

Finding more sustainable ways to deliver care that meets the needs of older people is driving innovation in health and social care policies, strategies and practices. Supporting family and other unpaid carers to balance competing responsibilities, particularly work, is among the priorities set out in the Government's "Future of an Ageing Population" report (Government Office for Science, 2016) that are relevant to reablement. Finally, underpinning all considerations of adapting to an ageing population, are ethical considerations relating to how older people are viewed by the general public as well as by those working in health and social care professions. In terms of reablement, alongside who is involved in making decisions about their care, perceptions about what older people can and cannot do are also relevant.

1.6.2 Funding reablement in England

Reablement first received policy support in England in 2010 with the announcement of a £70 million investment by the Department of Health (Department of Health, 2010). In the context of supporting preventative services, this investment was aimed at developing the capacity of reablement to prolong or regain independence and support recovery. Initially channelled through the National Health Service Commissioning Board, ongoing funding was subsequently transferred to Local Authorities in 2013-14. With the advent of the NHS Five Year Forward View in 2014 (NHS, 2014) setting out a new vision for the future of the NHS based around new models of integrated care and support, further investment was made in reablement. This came via the Better Care Fund (BCF). Consisting of funds reallocated from existing budgets, the BCF initially pooled £3.8 million in 2015/16 into a single budget for health and social care services to work more closely together, with £300 million for Clinical Commissioning Group (CCG) reablement funding. (Department of Health, 2014b). Regarded now as a core element of intermediate care (NICE, 2017), reablement appears likely to continue to attract government funding. Intermediate care is discussed more fully in section 1.8.

1.6.3 Published guidelines and quality standards for reablement

NICE guidance, standards and advice apply to the wellbeing and care of people in England. Decisions on how NICE guidance applies in other parts of the UK are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive (NICE, 2014). In September 2017 NICE published its first guideline for reablement, Guideline NG74 "Intermediate care including reablement" (NICE, 2017). Its publication was in response to a request by the Department of Health and was based on a review of the evidence available at the time. This indicated that "Long-term savings are anticipated because of reduced use of home care and reduced admissions to hospital in the first two years following reablement. Costs are higher in the short-term because of the increased cost of reablement compared to standard home care" (NICE, 2018b). It is notable that much of the evidence informing the guideline relates to rehabilitation at home after acute injury rather than to reablement specifically.

The guideline states that it was developed for: health and social care practitioners who deliver intermediate care and reablement in the community and in bed-based settings; other practitioners who work in voluntary and community services, including home care, general practice and housing; health and social care practitioners in acute inpatient settings; commissioners and providers; and adults using intermediate care and reablement services, and their families and carers. For the last of these, the guideline provides an idea of what they can expect from reablement. It sets out recommendations for referral and assessment for intermediate care (including reablement) and for how to deliver the service. A number of recommendations relate explicitly to the involvement of families and carers and are fundamental to this study. They are set out in Appendix C.

In August 2018, NICE published its first quality standard for intermediate care and reablement (QS173) to accompany the guideline (NICE, 2018a). I met the analysts who were devising the quality standard a month before its publication in order to gain an insight into their consideration of family involvement. The senior technical analyst explained that a key requirement was to ensure that the quality statements specified in the standard were quantitatively measurable and were primarily designed to assist service commissioners to drive up standards. Three of the four quality statements are relevant to home-based reablement and these contain frequent reference to the inclusion of "family and carers as appropriate". These are attached in Appendix D.

NICE guidance and quality standards are supplemented by the Social Care Institute for Excellence (SCIE). SCIE uses funding from agencies including the Department of Health and Social Care to develop resources to help improve the knowledge, skills and practice of practitioners and commissioners. SCIE's Guide 49 "Maximising the Potential of Reablement", published in May 2013, is based on research published between January 2011 and November 2012. It is aimed at "people who plan, refer to and provide reablement" and includes a section on "The role of families in supporting the reablement process". It advises that family and informal carers should be involved when appropriate to the delivery of reablement. (SCIE, 2013). This guide is complemented by other SCIE resources which will be referred to in the realist synthesis section of the thesis. It sets out a number of recommendations in relation to the role of families in supporting the reablement process. These recommendations are attached in Appendix E. The NICE and SCIE guidelines will be referred to throughout this thesis.

1.7 Reablement outcomes

This section of the chapter concerns mapping the architectural contours of reablement as they relate to outcomes. Pawson suggests mapping monitoring and evaluation systems that have been applied and are likely to be applied to the intervention using the VICTORE checklist (Pawson, 2014). Mapping these systems for reablement is complex due, in part, to the lack of homogeneity in reablement delivery models. The NIHR-funded comparative evaluation of reablement services in England study (Beresford et al., 2019) was published two years after this doctoral study started. The findings from this far-reaching study inform much of what is set out in this section. The study was commissioned in recognition of the variety of delivery models for reablement and "a lack of consistency in patterns of association of service characteristics" (ibid p103). Furthermore, the commissioning brief for the Beresford et al. study noted in relation to impact on the individual and their carers that "previous research has tended to focus on the outcomes that services were originally set up to meet rather than whether they substantially enhance patients' lives" (NIHR, 2013). Examples of these outcomes are not given.

Among many other aspects of reablement, the evaluation examined outcome measures over a range of reablement delivery models. In common with other evaluations of reablement, it found a "dearth of existing evidence" to draw on for the outcomes evaluation part of the analysis. Particularly lacking was evidence relating to the impact of the intervention on the service user, the impact of intervention and service characteristics on outcomes, and findings regarding the different outcomes that were being assessed. It found that standardised outcome measures were only used by a small minority of services, presenting difficulties in comparing outcomes across and even within services.

In order to set out this aspect of the architecture of reablement, it is necessary firstly to articulate what the desired objectives of reablement are. Based on an analysis of evaluative literature, policy and practice guidance documents, these are succinctly expressed by Beresford et al. (ibid) as being to achieve some or all of the following:

- Help people regain everyday living skills
- Reduce the need for ongoing (social) home care
- Prevent longer than necessary stays in hospital
- Prevent admission to long-term care when at risk
- Prevent hospital admission during acute illness

I created the following table to give an indication of the range of measures used in evaluations of reablement to date. It draws on a critical review of international reablement literature (Doh, Smith and Gevers, 2019) which identified the most common focus of outcome measures for reablement in studies and evaluations of reablement, as well as the Beresford et al. study. Measurement tools are only included where they exist for family level outcomes.

Table 2: Sample measures used in reablement evaluations

Focus	Measure
Service level	Proportion of older people (65+) still at home 91 days after leaving hospital to go into reablement services
	Destination following discharge from reablement (e.g. discharged without an ongoing care package, referred on for assessment of eligibility for other social care, transferred to homecare services)
	Moved into long-term care, independent living (possibly with the involvement of informal carers), ongoing care but at a lower level than before reablement
	Rates of unplanned hospital admissions
	Delayed transfers of care (DToCs)
	Time between referral to and starting reablement
	Inappropriate admission to residential care
	Cost and resource allocation, cost-effectiveness
	Service usage
Service user level	Locally-developed measures to capture service user experience: satisfaction, quality and continuity of care, choice and control, dignity and independence, involvement in decision-making
	Progress against personalised goals (assessed individually using professional judgement)
	Physical functioning (e.g. mobility using Timed Up and Go test)
	Change in dependence in terms of functional skills: ability to perform daily activities (ADLs) and instrumental activities of daily living (IADLs)
	Self-perceived health and Self-perceived mental health
	Perceived quality of life and Health-related quality of life
	Social care-related outcomes
	Self-perceived performance in everyday living
	Service-user engagement
	Intervention fidelity

Focus	Measure
Family level	• As above, locally-developed measures to capture service user experience sometimes include the view of the family or are completed by a family member • National Audit for Intermediate Care (NAIC), Reablement includes one category relating to families "Staff gave my family or someone close to me all the information they needed to help care for me" (PREM Q12) • Self-report measure of quality of life of unpaid carers, not specific to reablement (e.g. ASCOT-Carer) • Health-related quality of life of informal carers, not specific to reablement (e.g. selected parts of the 36-item Short Form questionnaire SF-36) • How caregivers perceive their caring role (e.g. Caregiver Reaction Assessment Instrument)

In terms of evaluating the overall impact of reablement, the Beresford et al. findings suggest that a range of outcome measures should be used. These should include a measure of mental well-being; a finding that is supported by the Doh et al. review. The findings also indicate the validity and value of capturing longer-term outcomes (ibid p104).

1.7.1 Family level outcomes

The brief summary of outcome measures for reablement in general provided above gives an indication of what appears to be an emphasis on quantitative, service-level outcome measures. These measures are aimed at providing insights both within and between social care services. It is notable, and of direct relevance to this study, that in the absence of a measure for service user engagement in reablement, the Beresford study team adapted the Hopkins Rehabilitation Engagement Rating Scale. This rating of the service user's engagement with reablement was completed immediately post discharge by a member of the reablement team participating in that study and captured the domains set out below. Although this was not adapted for gauging the engagement of family members, the domains could be considered as having equal relevance to them. The domains were: prepared for intervention; impairments affecting participation, attitude towards intervention, acceptance of need for intervention and participation in intervention. The team also developed a measure of intervention fidelity completed by service users. This yes/no answer checklist comprised statements referring to the understanding of the reablement approach, experience of a goals-focused approach, user involvement in identifying goals, working towards achieving independence potential and reviewing progress. This was completed within a week of discharge. Again, this was not designed for family members, although the variables included a category relating to informal carer involvement. The question used for this was "Have you received help from friends or family in the last two weeks?" with response options being Yes or No.

Although families were not the focus of the Beresford et al. study, two family members were interviewed and some other aspects of the study related to the families of service users. A small number of findings relate to families and impacts associated with their engagement in reablement. In accordance with a randomised controlled trial of reablement versus usual care (Lewin et al., 2013), it was found that not having family or friends as informal carers was associated with greater improvement in some outcomes (ibid p104). Interviewees referred to the way reablement removed a possible pressure or burden on families. In terms of the impact of upskilling families only one reference was made to Reablement Workers upskilling a family member to support reablement. This was reported by a service user and related to the use of equipment (ibid p74). The difficulties and negative impact of working with "resistant families" were emphasised by staff participating in the study. The main issue was expressed as a lack of awareness and understanding of the reablement approach. This was perceived as affecting effectiveness because of its impact on "engagement with reablement and the therapeutic relationship" (ibid p108). These issues are explored further in this thesis.

It was not a specific aim of the Beresford et al. study to identify and explore what successful outcomes for reablement might be from the perspective of families, nor to explore outcomes related to the engagement of families in reablement. It is therefore possible that reablement teams, service users and families might differ from each other in how they would interpret attempts to measure the impacts mentioned above. It is also possible that different contexts would affect their interpretations in different ways. For example, there is no further insight into whether there are any differences between outcomes for families who were already actively involved in the service user's life and care before the delivery of reablement, those who have not been involved before but demonstrate a willingness to be involved and those whom the team seeks to involve but who do not demonstrate a willingness to be involved.

There appear to be very few measures in use relating to how families value outcomes during and after reablement, or relating to the impact of families' engagement with reablement. The family level measures used in the studies mentioned here are not specific to reablement. Table 2 above includes a reference to the National Audit of Intermediate Care (NAIC). NAIC is an annual collection of data from providers of intermediate care services including reablement in England, Wales and Northern Ireland. I spoke to the Programme Manager for the NHS Benchmarking Network who manages the validation and analysis of NAIC, to establish in what way the audit could add to an understanding of family engagement. The manager explained that a survey (Patient Reported Experience Measure – PREM) is completed by service users and/or their family post discharge. There is no way to indicate which of these completed the survey.

Finally, there is little emphasis on the longer-term impact of reablement on the individuals who experience it; both service users and their families. Service users' personal outcomes are measured by progress against individual goals during reablement, and often relate to functional independence. It is possible that measures of self-efficacy of the service user and family regarding independence and coping would be more appropriate. Self-efficacy concerns an individual's belief in their own capability. Measures of this sort might give an indication of whether and how the behaviour change aimed at by moving to a reabling approach is sustained.

1.8 Related initiatives

The "R" in VICTORE stands for rivalry and the focus here is on interactions (if any) with existing programmes or interventions. Rather than reablement having rival interventions, it is important to note here its positioning within intermediate care and to comment briefly on the distinction between reablement and rehabilitation. The NICE Guideline for Intermediate care including reablement (NICE, 2017) identifies reablement as one of four core elements falling under the umbrella of intermediate care. The other three are identified as crisis response, home based intermediate care and bed-based intermediate care. Reablement is distinguished from the other three categories in the guideline by its aim to assist people to regain their abilities, with a focus on supporting self-care and everyday life skills.

In spite of many attempts, there is no consensus on how to define rehabilitation (Meyer et al., 2011). A recent investigation of systematic reviews examined the key features of rehabilitation and resulted in the development of an evidence-based description of effective rehabilitation (Wade, 2020). The description of the goals, patients and places and content of rehabilitation is extensive and shares much in common with reablement. The two diverge in the areas of pain and long-term disability as well as in procedural detail. Wade's description of the goal of rehabilitation includes "minimizing pain and distress" and identifies the beneficiaries or patients as being people with a "long-term disabling illness". Neither of these descriptions are likely to appear as critical to a description of reablement, whereas, unlike rehabilitation, the time-limited nature of reablement is crucial to its definition.

1.9 Emerging ideas associated with delivering reablement

This section maps emerging ideas about the process and practice of delivering reablement in England. This theme will be returned to in the discussion chapter of the thesis.

Reablement is referred to variously as a service, a model for practice, a policy approach, a philosophy and an ethos. This variation compounds confusion over what it is. For example, in a relatively early discussion paper, Pitts et al. proposed that reablement should be conceived of as a critical policy approach to explore and assess how reablement affects the life of older people, rather than as a service model (Pitts et al., 2011). A couple of years later, a SCIE report observes that reablement is sometimes seen as a distinct service and sometimes as a philosophy for the provision of all adult social care and support (SCIE, 2013). In the same year, a NICE working group considering guidance for home care social care and reablement's positioning within it, agreed broadly that "reablement ought to be considered as an outcome and philosophy that should underpin all aspects and stages of homecare" (NICE Collaborating Centre for Social Care, 2013). These ideas all appear to suggest that viewing reablement purely as a service model undervalues its potential to have broader societal impact. Yet regarding reablement predominantly as a philosophy that underpins all adult care services also presents a potential danger in terms of undermining the knowledge base associated with its delivery as a service. A 2013 study (Miller and Allen, 2013) identified emerging characteristics of delivery models at that time. All but the last have subsequently become common features of reablement in England:

Table 3: Contrasting emerging models of reablement in 2013 with initial models

Initial	**Emerging (2013)**
Focused on a particular transition	Act as the 'entry' point to all adult services
Older people only	Open to all adult user groups
In house home care act as sole/ lead provider	Independent Sector also provide reablement
Occupational Therapy input	Other therapies and nursing input
Social work referrals only	Multi-professional pathways / open access
Local Authority funding only	Contribution from health

A factor that had perhaps not been foreseen with respect to reablement in 2013 (pre-dating the 2014 Care Act) was the impact of pressure to discharge hospital patients to be assessed at home, combined with difficulties in moving them on effectively at the end of reablement. The strain on service capacity in the traditional care sector, both private and public caused partly by steadily worsening staff shortages, has meant that transition from reablement into other care services is subject to delays. In some Local Authorities, service users stay longer with a reablement service in these instances, thereby reducing the capacity of the service to take on new referrals. These factors can combine to give an impression of reablement as an eleborate clearing or holding house. This is at odds with current notions of strengths-based social care and movement away from underestimating service users' capacity towards encouraging the growth of capacity and self-determination.

Naturally, the varying contexts of those who are interested in the emerging development of reablement will affect their perspectives on it. In the course of this thesis, I explore ideas related to conceptualising what reablement could be as it relates specifically to families. In particular, reablement will be framed as a mindset that could be consciously applied and sustained in the lives of service users and their families following delivery of the intervention.

1.10 Terminology used in this study

A full description of the reasons behind the choices made about terminology can be found in Appendix B. Terminology relating to the methodology will be discussed in Chapter 2. Decisions made about terminology relating to service users, carers and families were made in collaboration with the study Patient and Public Involvement group. To summarise, the following terminology will be used to refer to the stakeholders of reablement:

- Service users (the people being reabled)
- Reablement Workers (the people who make the bulk of the reabling home visits)
- Families and family members (relatives of the service user, including partners)

People over the age of 65 are referred to as older people. "Traditional homecare" is used to mean other types of homecare that are focused on supporting people by doing things for them rather than supporting them to do things for themselves. Finally, "engage" is used consciously as a verb that is both transitive and intransitive, as opposed to either "involve" or "participate". This means that it can encompass the activity of practitioners in engaging families in reablement as well as the action and volition of families engaging in reablement themselves. This was deemed to provide a wider scope for an examination of causal factors.

1.11 Chapter summary

This chapter has set out some of the key aspects of the architecture of reablement in England in general, drawing attention to aspects relating specifically to the families of reablement service users. These aspects will be referred to throughout the thesis as they constitute macro context for much of what is explored. For example, defining reablement feeds in particular into the findings in Chapter 6 (Instilling an understanding of reablement). The published guidelines and quality standard highlighted in this chapter are critical to theory generation in the thesis and are discussed more fully in Chapter 4 (Realist Synthesis). Broader ideas relating to emerging ideas associated with outcomes and delivery are explored in Chapter 10 (Discussion), along with their potential implications for policy and practice development in the field.

All of the areas covered in this chapter are of significance to addressing the core research question: What are the causal explanations for the ways in which reablement teams engage families in older people's home-based reablement? The next chapter introduces the choice of a realist methodology to explore this question.

Chapter 2: Methodology

2.1 Introduction

The choice of methodology for this study was led by the research question:

What are the causal explanations for the ways in which reablement teams engage families in older people's home-based reablement?

There is a gap in knowledge about these causal explanations that, if addressed, might help reinforce the positive effects of reablement both during and beyond the period of the intervention. However, the process of identifying and articulating causal explanations presents challenges. The research question is not concerned simply with whether reablement teams engage families or not, or how they go about it. Rather, it seeks to elucidate what it is about the way that reablement teams facilitate engagement in different circumstances that causes it to work or not. The following serves as an example of the complexity of the challenge and will be referred back to throughout this chapter:

While ageing is an inescapable reality, the meaning that different people attribute to it depends on their own understanding and experience of it. Two children of an ageing mother might react to her approach to living an active older age very differently, according to:

- context (such as their proximity to her, which is readily observable)
- resources (her ownership of a panic alarm, which is not necessarily readily observable to them when not in use)
- response (such as their individual attitudes towards risk-taking, which is not observable and which they might not have articulated to themselves or anyone else)

In addition, the way these two individuals react to their mother's active ageing might differ to the way they react to their father's or an aunt's active ageing[1]. These differences will impact on how members of a reablement team interact with them.

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[1] Acknowledgement is made here to Sonia Dalkin who uses a similar example based on reactions to the death of a relative (Dalkin, 2014).

The example indicates the necessity of selecting a methodology capable of identifying and working with abstract concepts. Furthermore, this methodology needed to assist in translating both observable and hidden aspects of these concepts into articulated theory which could ultimately lead to new knowledge. Realist methodology is suited to exploring causal explanations for complex social interventions. A theory-driven approach, it is concerned with producing a contextualised understanding of the functional means by which interventions result in different patterns of outcomes. Rather than seeking to isolate what usually works in order to estimate the general effectiveness of an intervention, the methodology embraces the intervention's inherent complexity. I sought to employ the methodology in order to expand understanding about engaging families in reablement, seeking to build theories about what works, for whom, in what circumstances and how (Pawson and Tilley, 1997).

This chapter sets out the anatomy of realist methodology and describes its relevance to the research question. It starts with a short consideration of reablement as a complex social intervention. It then moves on to describe the philosophical position of realist inquiry before considering its ontological and epistemological standpoints. It sets out what contexts, mechanisms and outcomes mean in a realist inquiry and how realist logic assists in their configuration. The chapter ends with an account of an alternative methodology considered. The research methods used in the course of the two stages of the study are described separately in Chapters 3 and 5.

2.2 Reablement, a complex social intervention

Social interventions are delivered into existing social systems in order to address a particular problem, such as difficulty in managing tasks associated with daily living. Their introduction is expected to improve patterns of behaviour, events or conditions via changing and rebalancing the system (Pawson, 2006b). However, what can be known about any type of social intervention is not definitive. Social interventions are active and fluid and are affected by contexts which in themselves are changeable. This means that no two applications of the same social intervention will ever work in the same way as each other. As described in the previous chapter, home-based reablement can be considered a social intervention. It is a complex intervention that relies on interaction between a service user, their family members or other unpaid carers (where they exist), and a multidisciplinary team of professionals. These stakeholders all bring something to, take something from and have an impact on the service. There are therefore a number of causal factors that might be interacting at once and these relate to people's behaviour as well as to organisational behaviour.

Pawson and Tilley, the founders of realist evaluation, refer to social interventions as "social programmes" and characterise them as "theory incarnate" (Pawson and Tilley, 1997). This characterisation captures the idea that if the intervention (used synonymously with programme in this thesis) is delivered in a certain way, it will improve outcomes. Each time the intervention is delivered, there are underlying theories about what might cause change as a result. It is these theories that are being examined in a realist inquiry. However, they are not necessarily easily identifiable and the researcher(s) needs to make them explicit by interrogating the data. Referring back to the earlier example, an underlying theory in reablement may be: if reablement teams improve an adult child's appreciation of the health benefits to their parent of doing things for themselves, then that adult child could feel encouraged to help their relative remain living in their own home, because they support a degree of necessary risk-taking.

2.3 Philosophical positioning of realist inquiry

Realist inquiry is based in realism which sits in philosophical terms between positivism and constructivism. The following table devised by the contemporary realist inquiry expert, Gill Westhorp, provides a useful overview of this positioning (Westhorp et al., 2011):

Table 4: Philosophical differences: Positivism, Realism and Constructivism

	Positivism	**Realism**	**Constructivism**
Ontology	There is an objective reality, which exists independent of us	Material and social reality – we interact with reality	Subjective reality – we "create" reality
Epistemology	Truth and final knowledge exists	No final truth or knowledge, but improvement in knowledge is possible	No way to choose between interpretations. What we jointly believe is true
Implications for evaluation	Evaluators "tell facts" Context factors should be eliminated: Randomised Control Trials/Quasi-experimental methods	Evaluators explain how and where programs generate outcomes Mixed methods (qualitative and/or quantitative)	Evaluators describe stakeholder interpretations Qualitative methods

A positivist philosophical paradigm is commonly used within healthcare research in order to determine whether or not an intervention works, based on an association between cause and effect (Greenhalgh, Thorne and Malterud, 2018). A constructivist paradigm on the other hand facilitates the description of multiple interpretations of how the intervention is experienced. Occupying a middle ground between positivism and constructivism, realist philosophy draws on both in order to reach an improved understanding of what causes the intervention to work or not in particular circumstances. This study adopts a realist paradigm in order to create testable theories about the causal explanations for the ways in which reablement teams facilitate family engagement in this complex social intervention.

The following sections provide a backdrop for the chosen research approach by examining its position within realism; the meaning of ontology and epistemology in realist inquiry and the defining principles of the approach.

2.4 Realism

The term "realism" has a vast range of meanings and applications within different disciplines. Sayer, a prominent theorist in the field, identifies the most basic idea of realism as follows:

> *"The nature of the world is largely independent of an observer's ideas about it, and it is this that explains both the adequacy and fallibility of our knowledge, such as it is." (Sayer, 1992)*

He provides a clear example of a real world existing independent of our knowledge of it: whether climate change is happening or not, does not depend on an individual's view on the matter (Sayer, 1992 p. viii). In addition to this notion of mind-independent reality, a key feature of realism is its emphasis on "the mechanics of explanation, and its attempt to show that the usage of such explanatory strategies can lead to a progressive body of scientific knowledge" (Pawson and Tilley, 1997 pp55-56). Embracing these two concepts is critical to unpicking the causal query expressed in the research question.

Ray Pawson illustrates the transdisciplinary nature of realism and the most prominent thinkers associated with it by means of a family tree (Emmel et al., 2018 p207). He divides the main proponents of realism into philosophers, sociologists, evaluators and "other disciplines" and discusses how they identify their branch of realism and the extent to which they use qualitative and quantitative methods in their approaches. It is beyond the scope of this thesis to set out all the branches of realism or contemporary debates about them. Rather, it is necessary to site realism in the field of social science inquiry and explanation.

Realism argues that all social systems are open systems. The boundaries of open systems "are porous and flexible: people, ideas, information and resources flow in and out of social systems. Social systems themselves interact and influence each other" (Westhorp, 2014 p4). Westhorp adds that social interventions are open social systems in themselves, without clear boundaries and that these systems are not static but morph over time, irrespective of the introduction of policies or procedures. Furthermore, the outcomes of social interventions are influenced not only by the intervention itself but also by interactions within and across systems. As described in the previous chapter, reablement is positioned within broad prevention and personalisation agendas alongside the more specific health and social care needs of an ageing population as well as those of their unpaid carers.

In siting realism in the field of social science and open systems, it is important for the purposes of this thesis to identify and draw a distinction between two strands of realism: critical realism and scientific realism. Broadly speaking, critical realism is philosophically oriented, and is concerned with a series of philosophical positions on ontology, causation and forms of explanation. Scientific realism on the other hand is a methodological paradigm. Pawson points out that a number of the thinkers that he places on his family tree would identify themselves with critical realism (e.g. Archer and Bhaskar). He emphasises the crucial role of thinkers who would, by contrast, be identified with scientific realism (e.g. Popper, Campbell, Hedström and himself). Scientific realism (also sometimes referred to by other terms such as empirical realism or emergent realism) can be considered a methodological paradigm using concepts from critical realism. It is the paradigm of scientific realism that forms the backdrop to the choice of approach in this study, as it provides a pragmatic approach to the formulation and development of theories intended to evaluate and develop interventions.

These two stands of realism diverge in their response to the dilemmas about open systems in social science as expressed above. Pawson, citing Archer and Bhaskar, identifies the guiding assumptions of critical realism to be that "there will always be an overabundance of explanatory possibilities, that some of these will be mistaken, and that the primary task of social science is to be critical of lay thought and actions that lie behind the false explanation" (Pawson, 2006 p19). This puts the social scientist in the position of a "privileged standpoint" or a critical, "moral high ground" (ibid p19). In the same work and by contrast, he identifies the guiding assumption of scientific realism to be that it is "still worth trying to adjudicate between alternative explanations even in the knowledge that further explanatory possibilities remain untapped in the unrelentingly open systems in which we live" (ibid p19).

In order to address the research question's search for causal explanation for the ways in which reablement teams engage families in home-based reablement, adjudication between possible explanations is a useful approach. I have undertaken what can be considered a scientific realist "explanatory quest" (ibid p19); formulating and refining theories using procedures associated with realist methodology and concepts from realism. The next section looks more closely at ontology, epistemology and causation in realist inquiry.

2.5 Realist ontology

Ontology is concerned with the nature of being, reality, and how it works. In its most basic form, a positivist ontology asserts that there is an objective reality which exists, independent of us. A constructivist ontology asserts that reality is subjective and is filtered and created differently by us as individuals. At the core of realist ontology is the idea of mind-independent reality: the world exists, independent of our perception of it. A realist ontology asserts that "both the material and the social worlds are "real", at least in the sense that anything that can have real effects is itself real" (Westhorp, 2014). The examples that she provides of this are gender, culture and class. Furthermore, thoughts and feelings are "real" as they have effects that are real and we interact with them.

A key feature of realist ontology is the concept of understanding reality as being stratified in layers, giving it "ontological depth" (Bhaskar, 1975). This depth is made up of a combination of successively deeper layers of reality – an empirical layer at which elements of reality are manifest and observable, a deeper layer at which elements of reality are manifest, regardless of individuals' ability to observe them, and deeper layer still at which some elements of reality might not be manifest – they exist as a possibility, and might be hidden, latent or dormant. The attempt to unpick complex problems and understand how interventions operating in open systems might impact on them, requires the researcher to bring some of those abstract elements that might not be manifest into view. This is achieved through theorising and theory testing.

The example set out at the beginning of this chapter showed layers of reality: at an observable level (geographical proximity); at a deeper level, regardless of visibility (possession of a panic alarm) and at a deeper level still, existing as a possibility (attitudes towards risk-taking). A recognition of these layers of reality means that any theory that is devised about engaging family members with their relative's reablement will generate an understanding of the topic, but this understanding will not be definitive. It will be partial (meaning incomplete as opposed to prejudiced) and contextually dependent.

The concept of ontological depth is crucial to this study, not only in terms of levels of engagement with reablement, but also in terms of how reablement itself is regarded; as a service, an approach, an ethos and/or a mindset.

2.6 Realist epistemology

Epistemology is concerned with the nature of knowledge, how it is defined, what can be known and what its limits are. Positivist epistemology asserts that truth and final knowledge exists, whereas constructivist epistemology asserts that there is no external reality independent of human consciousness and that what we jointly believe is true (Robson, 2002). At the heart of realist epistemology is the belief that no final truth or final knowledge exists. Rather, knowledge can be constantly added to and accrued in order to get to a closer understanding of reality.

Researchers taking a realist approach to understanding how interventions work, therefore, are concerned with the accrual of knowledge about how those interventions work (Pawson and Tilley, 1997). They are concerned with uncovering the root causes of an intervention's outcomes rather than focusing solely on the outcomes themselves (i.e. whether the intervention worked or did not) or how people experience the intervention. This is frequently referred to as opening up the "black box" of programme or intervention implementation (Pawson and Tilley, 1997). The epistemological foundation of this is the belief that the black box can be opened up by researching different views of how an intervention works, determining the causal relationships within it and building an explanation. This explanation in itself creates knowledge that illuminates the intervention under investigation. It could also potentially inform explanations about other programmes where similar theories are at play.

I believe that applying realist thinking and a realist approach to the study of how reablement teams engage families in older people's reablement enables abstract concepts about this aspect of the intervention to be articulated. It enables both observable and hidden aspects of reality to be brought into view through theorising and theory refinement in a way that could lead to new knowledge, pertinent to the field. Although this knowledge is not definitive, I believe that it, in turn, could form a basis from which further knowledge could be accrued. The approach allows for opposing explanatory theories to be built and refined within the scope of this study and further refined and tested outside it in order to improve aspects of the way that reablement teams work with families. The next section discusses how the methodology enables this.

2.7 Realist methodology

Methodology is taken to mean the overall approach to the research process (Silverman, 2011), and, as described above, in the case of realist methodology it is linked to the paradigm of scientific realism. A defining feature of the way that realist methodology has developed is its focus on the evaluation of programmes, services and policies (Jagosh, Harris and Dorling, 2019). It is common to see realist methodology referred to as an "approach" or a "logic of enquiry" (Pawson et al., 2004; Rycroft-Malone et al., 2012; Dalkin et al., 2015). The methodology is applied by means of realist synthesis (also referred to as realist review) and realist evaluation. Wong summarises both as follows:

> *"Realist review is a theory-driven approach to evidence synthesis. Data from documents (e.g., studies, other reviews, policy documents, etc.) are used to develop and test theory.*
>
> *Realist evaluation is a theory-driven approach to evaluation that uses data that is collected by the evaluators for theory development and testing" (Wong, 2018).*

Some of the defining principles of realist methodology (causation, retroduction and its theoretical framework) are discussed below before moving on to a closer examination of the realist methods used in this realist inquiry.

2.7.1 Generative causation

Several aspects of Westhorp's explanation of how causation works in realist inquiries (Westhorp, 2014) are used in this section, combined with examples specific to reablement. The idea behind causation in realist terms is based on the ontology and epistemology of realism as described above. It asserts that what we experience or can observe is caused by deeper processes that cannot usually be observed. Referring back to the example given at the beginning of this chapter, over the course of reablement visits, the team might observe that family members increasingly stand back and leave their relative to do things, such as making their own cup of tea. What cannot be "seen", however, is how the family member has taken in and stored, for example, information about how reablement differs from traditional homecare, or information about ways of standing back while being alert to risk. Nor can the team see how this knowledge provokes family members to stand back or not. This underlying causal process which takes place at a different level to its observable outcomes is referred to in realist inquiries as a "mechanism".

Mechanisms operate within a wider system. In the case of the reablement example above, the reablement team operate in relation to the service user and their family member or members, in the service user's home, possibly using equipment such as a kettle tipper, and employing the techniques and policies that guide the practice of their particular reablement service. If any of these elements of the system were removed or changed, then the causal process would change too. Another aspect of mechanisms is that they exist, irrespective of whether they are operating at a particular moment or whether they are hidden, latent or dormant. This means that a Reablement Worker has the potential to teach family members about how reablement differs from traditional homecare; and family members and service users have the potential to apply this learning, whether or not that is currently happening. The mechanism is already there as potential, but it will only operate when the circumstances are right.

In their work that first applied this conceptualisation of mechanisms to programme and policy evaluation, Pawson and Tilley asked what the "causal powers" of programmes themselves might be (Pawson and Tilley, 1997). They argued that programmes provide something – a resource, an opportunity or a constraint of some kind – that is intended to influence the target person's decision-making. Social policies often aim to shift the proportion of a population that can or will make a desired decision, such as older people striving to remain living in their own home rather than moving into residential care. In Westhorp's words, however, "ultimately, it is the target person's decision that determines whether the desired outcome is achieved (e.g. a reduction in the number of people moving into residential care). That is, *it is the interaction between what the programme provides and the reasoning of its intended target population* that causes the outcomes. This interaction, therefore, constitutes a "programme mechanism". The implication is that the evaluator (or researcher) needs to identify what resources, opportunities or constraints were in fact provided, and to whom; and what "reasoning" was prompted in response, generating what changes in behaviour, which in turn generate what outcomes". It is through describing the various ways in which reasoning and resources interact in different contexts, that hypotheses about how programmes work can be built.

In the case of this study, the mechanisms under scrutiny relate to one aspect of the reablement intervention; family engagement. To date there has been no detailed specification of mechanisms relating to facilitating families to engage with reablement, nor a description of a theoretical framework underpinning it.

2.7.2 Retroduction

In a realist enquiry, the process of accruing knowledge is accomplished through an exploration of underpinning causal mechanisms by means of retroduction. Whereas a positivist approach to articulating how you know what you know is based on deductive reasoning (demonstrating knowledge by testing it against evidence), and a constructivist approach is based on inductive reasoning (demonstrating knowledge by showing evidence); a realist approach adopts more "pragmatic theorizing with a focus on creativity as a logic of inference" (Tavory and Timmermans, 2014). This abductive approach configures evidence, expertise and common sense to arrive at a hypothesis through a creative, imaginative process. Retroduction builds on abduction by going back from, below, or behind observed patterns in order to discover what produces them (Lewis-Beck, Bryman and Liao, 2003). Through the process of exploring causal explanations, retroduction enables theories to be built, refined and ultimately tested.

In terms of the examination of what works when engaging families in reablement, a deductive approach (seeking to test theory against evidence) might, for example, have sought to answer the question "Does the involvement of families in reablement reduce subsequent reliance on formal care?". An inductive approach (seeking to derive theory from evidence) might ask "What reduces reliance on formal care following reablement?". The retroductive approach adopted here (seeking to identify and explore theory inspired by evidence), is asking "What is it about the way that reablement teams engage families that causes them to adopt the approach, if it does?".

While recognising that what can be known about any type of social intervention is not definitive, the retroductive approach allows opposing explanatory theories to be built in relation to facilitating family engagement in reablement. These theories could contribute to opening up the "black box" linking outcomes to potential explanations that encompass contextual difference as well as factors peculiar to the individual stakeholders. Once articulated, these theories could subsequently be tested in order to improve certain aspects of the way the intervention works. Although reablement guidance encourages the involvement of families in reablement (NICE, 2017), this is a lesser-explored aspect of reablement in England. This approach therefore holds potential to provide novel insights in the field.

2.7.3 Theoretical framework

In both realist syntheses and evaluations, initial or candidate programme theories are typically formulated using a varying combination of background expertise, stakeholder consultation, existing literature and retroductive thinking. These theories are then refined iteratively in order to produce an idea of causation within the intervention. This is achieved by identifying the mechanisms that are likely to operate, the contexts in which they might operate and the outcomes that will be observed if they operate as anticipated. This process is known as developing Context-Mechanism-Outcome (CMO) hypotheses or CMO Configurations (CMOCs) (Pawson and Tilley, 1997). The meaning of context, mechanism and outcome in this study is set out here.

2.7.4 Contexts

Context refers to elements outside the parameters of the formal programme architecture that have causal impact on the outcomes of the programme. Context can be anything in the physical or social environment such as cultural norms/values, participant characteristics (e.g. age, gender, illness type), economic conditions, geographic aspects (e.g. rural, urban), public policy (e.g. laws, regulations) and pre-existing outcomes from a previous stage of programme intervention (Jagosh, 2018). The causal impact of context can be positive, negative or neutral.

As discussed in Chapter 1, reablement can still be considered to be in its infancy, is highly heterogeneous as an intervention and there is a paucity of policy and practice guidance related specifically to it. This created difficulties in the study in defining background contexts and led to the need to theorise some of them as discussed in the ensuing chapters. Examples of contextual factors relating to family members include their geographical proximity to the service user and their history of providing them with support. For reablement staff examples include their experience of working in reablement and in other care environments (if any). As the intervention typically takes place over an extended period of up to six weeks, a further complicating factor is that context can change rapidly during reablement. If something such as a change in health of either the service user or their family member or both occurs, then the context will immediately change. This, and other changes of context, can happen several times during the course of reablement. Other aspects of context such as inherent cultural values and beliefs are less likely to change during that period.

2.7.5 Mechanisms

As described above, mechanisms are the underlying generative forces or influences that lead to the intervention's outcomes. They are often hidden and can be triggered or not by contextual factors. They can be linked to but are not synonymous with the programme strategy. The term refers to the cognitive process or what "turns on" (or not) in the minds of participants when they are offered, or asked to engage with an intervention. How people react or respond is brought to the fore as the most important data to understand (Jagosh, 2018).

Dalkin et al. advocate explicitly disaggregating two components of mechanisms (resources and reasoning) in the course of realist analysis (Dalkin et al., 2015). This helps to differentiate between resources which are introduced within a particular context and responses to them in that context; responses which cause a change in a participant's reasoning and behaviour, leading to outcomes. This approach to disaggregating mechanisms has been adopted where possible during the study. Whereas Dalkin et al. use the terms "resources" and "reasoning", this study uses "resources" and "responses" as Pawson and Tilley do; "responses" being considered to encompass both considered, as well as more instinctive, reactions (Pawson and Tilley, 1997). Dalkin et al. use the following figure to illustrate the disaggregation of mechanisms:

Figure 3: Disaggregating resources and reasoning

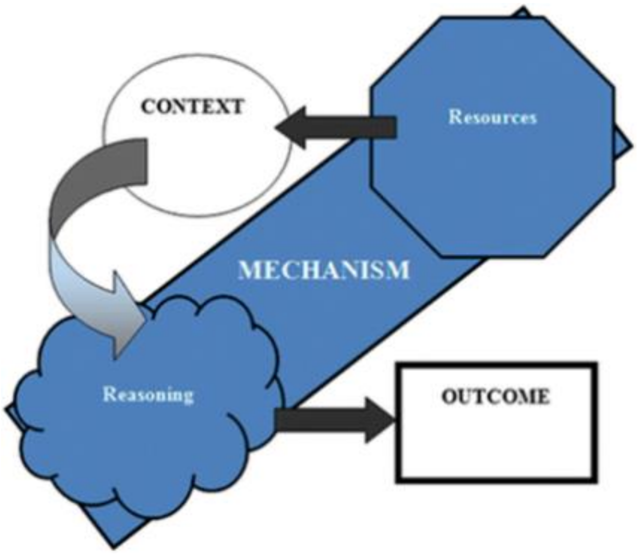


Figure from Dalkin, S.M., Greenhalgh, J., Jones, D. et al. Implementation Sci (2015) 10: 49. https://doi.org/10.1186/s13012-015-0237-x CC BY 4.0

In this thesis the disaggregation is represented in tabular form, with the colour coding indicating the unity of the mechanism for example:

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Reablement Workers actively demonstrate to families how to stand back safely		Family is concerned about the risk that reablement might present to their relative		Family becomes reconciled to the fact that a degree of risk-taking is necessary and manageable		Family has increased confidence in standing back

2.7.6 Outcome patterns

Ultimately, in evaluating an intervention, its results or outcomes provide the key evidence for recommendations. In the course of a realist inquiry, multiple mechanisms are explored which have multiple potential effects on different stakeholders in different contexts, producing multiple potential outcomes. Patterns of outcomes are proposed and examined in a realist synthesis through theory refinement. They are inspected not in order to simply identify whether or not the intervention works, but are analysed in order to discover if the conjectured mechanism/context theories might be confirmed (Pawson and Tilley, 1997 p217). Outcomes can be intended or unintended, expected or unexpected, frequent or rare. They can be arrived at through qualitative, quantitative or mixed methods data collection or can be conjectured. They can be final or intermediate outcomes. Finally, an outcome can in itself produce a new context.

In his chapter concluding a recent publication about applying realist approaches, Pawson refers to the fact that many realist inquiries have succeeded in demonstrating differential impact across individuals, groups and institutions. He goes on to note, however, that "durability and sustainability are prized assets of an intervention but are seldom tracked or well understood. As such, they represent a crucial opportunity for realist thinking"(Emmel et al., 2018 p213). This is the case for reablement as discussed in Chapter 1. The durability and clarity of intended outcomes for reablement and their relevance to different stakeholder groups will be a recurring theme in this thesis and have had implications for the application of the methodology.

2.7.7 Context-Mechanism-Outcome Configurations (CMOCs)

Pawson and Tilly's CMOC heuristic is used to capture the ways in which different people respond to the same resource in different ways, generating different outcomes. Because programmes work differently in different contexts and through different change mechanisms, it cannot be assumed that they can be replicated from one context to another or that they will automatically achieve the same outcomes if they are (Westhorp, 2014 p7). Therefore, articulating contexts, mechanisms and outcomes enables the realist researcher to analyse and ultimately communicate differences in context that influence both whether or not mechanisms operate, as well as identify which mechanisms operate. This knowledge "can then inform choices about which programmes to trial in which contexts, how to refine policies and programmes to improve their effectiveness, and how to adapt programmes to new contexts" (ibid p7).

It is notable that Pawson and Tilley originally set out the configuration as a summative equation ($C + M = O$) (Pawson and Tilley, 1997). Pawson has recently urged flexibility in ordering these items, favouring MCO as more representative in the analysis of interventions. He points out that "theory and research invariably start with mechanisms before moving to investigations of contexts, which then combine to help us understand outcome patterns", suggesting that "it is generally better to begin by asking why an intervention might work (i.e. what is the mechanism?) before thinking about the contexts that might support or stifle its action" (Emmel et al., 2018 p209). This is particularly relevant to the way in which the approach has been applied in the realist synthesis part of this study which focused on identifying mechanisms. Further consideration of this is given in Chapter 4. It noted here that Dalkin et al.'s extension to the equation, disaggregating the mechanism, also reorders it in this way (Dalkin et al., 2015):

$$M\ (\text{Resource}) + C \rightarrow M\ (\text{Reasoning}) = O$$

2.7.8 Middle range theory

As described above, realist researchers describe their theories about how an intervention works using context-mechanism-outcome configurations. A realist programme theory usually uses multiple context-mechanism-outcome configurations to explain how the intervention operates and these require descriptions of context, generative mechanisms, implementation processes and outcomes. Theories are understood to sit at different levels of abstraction and stratification (Pawson and Tilley, 1997, Pawson 2006, Shearn at al., 2017). Pawson and Tilley were influenced by Merton's concept of "middle-range theory", advocating for integrating existing formal theory into realist evaluation (Merton, 1968; Pawson and Tilley, 1997). A middle-range theory can have explanatory power beyond the setting in which it was developed, meaning that knowledge generated elsewhere can be useful in a different setting. Although this study is not a realist evaluation, the idea of middle-range theories will be mentioned.

2.8 Consideration of alternative methodologies

The choice of a realist approach was grounded in the following considerations:

- the search for causal explanations as articulated in the research question, rather than asking whether or not the intervention works more generally
- the need to investigate different factors relating to the same intervention as it applies to different stakeholder groups and how differential outcomes are thought to be achieved
- the apparent lack of theory relating to reablement and in particular how families engage with it that examines the mechanisms that might explain differential outcomes at both micro and macro levels

Consideration was given to combining a realist approach with a case study approach (Stake, 1995; Yin, 2014). A case study approach could have used multiple research methods to elicit data from different data sources including from the different stakeholder groups. This might have given descriptive insights into the complex inter-relationships between these groups within one or more settings, possibly illuminating aspects of how and why families engage, rather than simply whether they engage or not. However, the case study approach in itself would not specifically have sought to make a link between how and why reablement teams engage families in reablement and the particular micro contextual circumstances nor wider macro contexts in the way that a realist approach does. This might have led to issues related to the portability of theories formulated in the course of the study. Furthermore, I favoured the positionality of the researcher in a realist approach as both teacher and learner (Pawson, 1996; Pawson and Tilley, 1997) over the more typically dominant positionality of the researcher in case study approaches. For these reasons I chose a realist approach.

2.9 Chapter summary

This chapter has outlined the core elements of realist inquiry and has justified its applicability to exploring the research question. Realist approaches are increasingly being used and funded in order to develop thinking and practice relating to health and social care interventions (Emmel et al., 2018; Wong, 2018). Yet as the RAMESES standards and techniques associated with applying the approach are still evolving, flexibility is required when employing it. A comment made by Professor Trish Greenhalgh, proponent of the approach, and contributor to the development of methodological standards for it, resonates as much for investigating reablement as a complex intervention as it does for using a realist approach to do so:

> "As ever with these complex initiatives, there are successes and disappointments – and nothing happens quite the way it was planned. Adaptive, collaborative learning is key!" (Nuffield Trust, 2019).

As the forthcoming chapters will demonstrate, a series of adaptations were made to utilising realist methodology for the purposes of this study. These will be discussed further in a critique of the approach in the Chapter 10 (Discussion). The next chapter describes the methods associated with the first stage of the research – a realist synthesis.

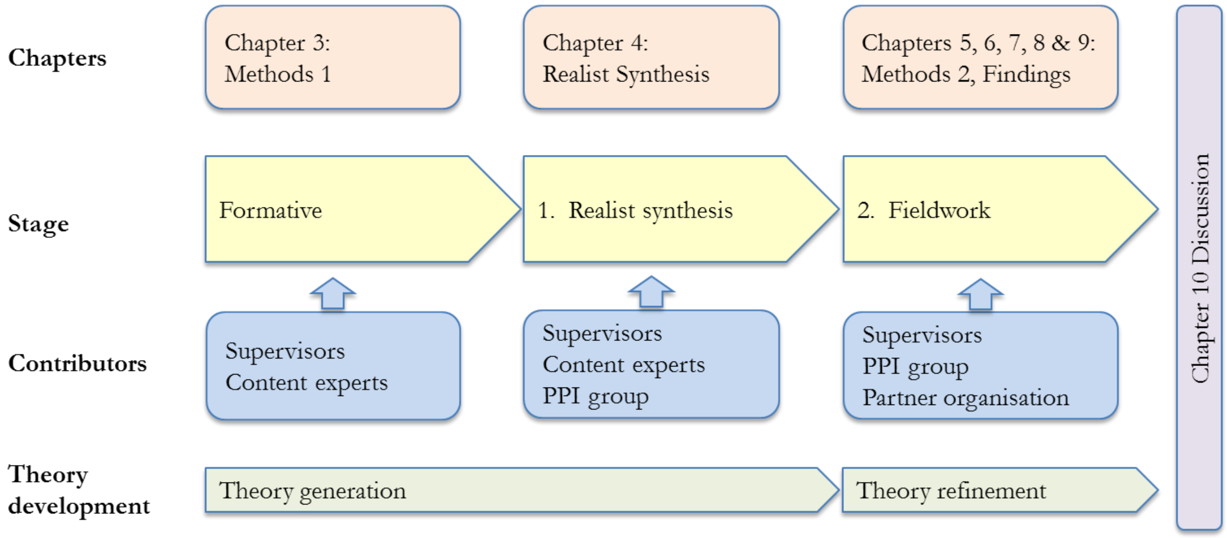
Chapter 3: Methods 1 - Formative research and realist synthesis

3.1 Introduction

As with any research inquiry, the choice of methods follows from the data required to answer the research question. In the case of this study, the research question was formulated during the first months of the study. This formative stage involved input from the supervisory team and a range of stakeholders, combined with an informal literature search. The decision to use a realist approach, starting with a realist synthesis in stage one of the study, was made towards the end of this period.

This chapter introduces three distinct groups whose contribution was critical to the study: the supervisory team (a constant throughout the study), content experts (who contributed to the formative stage of the study) and the Patient Public Involvement group (which contributed to stages one and two). Methods associated both with the formative stages of the research and with the realist synthesis are described here. A second methods chapter (Chapter 5) introduces the research partner organisation that participated in fieldwork during the second stage of the study and describes the methods employed in that stage. The following map provides an overview of the stages of the study, who contributed to them and which chapters cover them.

Figure 4: Stages of the study



3.2 The research team and reflexivity

3.2.1 Supervisory team

This PhD study was supervised by a multidisciplinary team at the University of the West of England, Bristol: Professor Jane Powell is an economist and social scientist specialising in public health, and is the Director of the University's Centre for Public Health and Wellbeing; Dr Ailie Turton is an Occupational Therapist and senior lecturer specialising in stroke rehabilitation and recovery with experience of supervising another PhD study that used a realist approach to explore a different aspect of reablement; and Professor Praminda Caleb-Solly who specialises in assistive robotics and intelligent health technologies and is theme leader for Assisted Living at the Bristol Robotics Laboratory. The supervisory team played an active part throughout the study by means of frequent meetings which I arranged and minuted. Dr Justin Jagosh, an independent consultant, mentor and trainer for realist methodology provided one-to-one guidance on methodological issues.

3.2.2 Researcher and reflexivity

As a researcher's personal and professional characteristics and experiences have the potential to influence study findings (Berger, 2015), reflexivity was applied throughout the study. Critical reflection was facilitated through regular meetings and communication with the supervisory team, annual reviews with other academics at the University and through a diary of researcher reflections written on an ad hoc basis (excerpt in Appendix F). The diary is a reflexive account and is written in the first person, like the whole thesis. Reflexivity will be considered again in Chapters 5 and 10.

3.3 Working with content experts

In the formative stages of the research, I consulted a range of content experts in the field. These informal consultations took place before the realist approach was formally adopted, before a Patient Public Involvement (PPI) Group was established, and before the research partner organisation was formally recruited. The content experts provided specific knowledge of reablement and its architecture. The consultations with them informed the research question and initial ideas that guided the study.

Content experts were identified through different sources and were representative of a range of reablement service models: three Local Authority (LA) reablement services, a reablement service housed within a care home and an independent provider of home care operating with a reabling ethos. All three LAs appeared to present potential to be future partners for the study. I approached the care home which was known to have a strong reputation locally for its innovative approaches. I approached the independent provider following an inspiring presentation that the manager gave at a conference, which illustrated how her company's approach to reabling older people emphasised the importance of relationships and staying connected to others in the community as a key aspect of wellbeing.

I had discussions within each of these environments separately, shadowing a Reablement Worker from Local Authority A on four home visits and accompanying a wellbeing worker from the independent provider on a visit to a client and their partner which took place in a café. I also helped to facilitate two focus groups at Local Authority B as part of a university colleague's related project. These were with occupational therapists and physiotherapists operating within Local Authority B's reablement service. Table 5 lists the content experts consulted in the formative stage of the study.

In the course of these meetings and observations, content experts discussed some of the strengths and weaknesses of reablement as an intervention; their own ideas and concerns. These contributed to the description of the architecture of reablement as described in Chapter 1 and also served to shape some of the choices about language used in the research. Although some of these choices could be considered small, subtle shifts in semantics, they proved to be extremely important in terms of respecting equally the views of staff, families and service users.

Another aspect of these discussions with stakeholders that contributed to theory development was in relation to the timescale within which outcomes for reablement were considered. From the perspective of the service provider, service delivery outcomes were expressed in terms of the duration and immediate aftermath of reablement, whereas from a service user's perspective, outcomes could be considered in the longer term. An example of the latter was given by the manager of the care home with an in-house reablement service. She referred to a positive outcome of reablement in relation to a particular service user who returned to the care home as a long-term volunteer, following reablement there.

Table 5: Consultation with content experts

Organisation	**Role**	**Method of consultation**
Local Authority A	Director of Adult Social Care	1:1 meetings
	Head of Service – Reablement, Intermediate Care and Regulated Service	1:1 meetings
	Reablement and Intermediate Care Team Manager	1:1 meeting
	Reablement and Intermediate Care Team Leader	1:1 meetings
	Reablement Worker	Accompanied on home visits
	Service users and family members	Home visits (immersion rather than consultation)
Local Authority B	Strategic Planning Manager	1:1 meetings
	Group Manager Adult Care and Commissioning with responsibility for reablement	1:1 meeting
	OTs and Physios working in home-based reablement	2 focus groups (immersion rather than consultation)
Local Authority C	Adult Social Care Principal Occupational Therapist – Reablement Service	1:1 meetings
Care Home with in-house reablement service	Manager	Joint meeting
	Care assistant / reablement lead	Joint meeting
Independent Homecare Provider	Founder / Manager	Joint meeting
	Senior Team Member / Wellbeing Worker	Joint meeting and accompanied on visit
	Client and client's partner	Accompanied on visit (immersion rather than consultation)

The visits on which I accompanied Local Authority A staff served to provide early examples of Reablement Workers' contact with service users and their families. These included:

- a service user whose co-habiting adult son had agreed to engage in certain parts of reablement only
- another service user whose adult son was helping in the garden at the time of the visit but who was not known to engage with her reablement visits at all
- a service user without family
- a service user whose partner (who had his own care needs) attended the meeting

There were clear differences in the way the idea of reablement was translated into practice within the three settings (LAs, care home, independent provider) but also within the three LAs. The supervisory team advised that focusing on one LA would be most manageable within the constraints of a PhD. Local Authority B's reablement service was in the throes of a large-scale transformation programme and Local Authority C had only recently finished a commitment to participate in another PhD study. As Local Authority A was enthusiastic about participating and was in a position to do so, it was subsequently selected as the research partner organisation. A series of formal meetings were held with stakeholders at that LA throughout the period of the synthesis and subsequent fieldwork. These meetings were conducted as semi-structured discussions based around evolving programme theory and the logistics of implementing the fieldwork. The selection and recruitment of Local Authority A will be described in greater detail in Chapter 5 (Methods 2) alongside a description of how I worked with their reablement service.

3.4 Recruiting and working with a PPI Group

In addition to and distinct from consultation with content experts, I established a Patient Public Involvement (PPI) Group during the synthesis stage of the study. The National Institute for Health Research (NIHR) national standards for public involvement in research (NIHR, 2018) informed my approach to establishing and working with the group, alongside guidance provided by People in Health West of England. These are both summarised in Appendix G. Notes on how NIHR terminology about engagement differs from that used in this study are set out in Appendix B. It is noted here that the description Patient Public Involvement is more relevant to health care than to social care, nonetheless the term is in common use and is used throughout the thesis recognising that "patient" refers instead to service users and their families.

There are a number of ways in which a PPI group can contribute to research studies. I was primarily interested in drawing on a PPI group as expert carers to discuss and refine programme theories as well as to help shape the research approach, including approaching families and service users. A conscious choice was made to frame PPI meetings as meetings rather than focus groups. This captured the idea that the relationship with PPI group members was intended to be agile and reciprocal, and that they would have direct involvement in some of the decisions made about how to proceed with the research. Considering the role of a PPI group in these terms fits very well with the teacher-learner cycle used in realist approaches (Pawson, 1996) which is described in Chapter 5 (Methods 2). It also builds on basic realist epistemology in terms of considering that we each have a partial truth based on our own experience. Through interviews, or in this case group discussion, these separate truths can be brought together by the researcher into a larger truth (Jagosh, 2018).

3.4.1 Information session for potential PPI group members

I recruited the PPI Group with the assistance of the Carers Engagement and Involvement Lead at a local Carers Support Centre. More detail about the information session that I ran for recruitment and the process in general can be found in Appendix H. Two points raised by attendees are mentioned here. The first is that during the question and discussion time, a number of people expressed dislike for the term "carer", saying that they did not associate themselves with it. This caused me to reconsider the term. Subsequently, as a result of further discussions with the PPI group, I decided to avoid the term as far as practical in the study. Secondly, attendees queried the extent to which NICE guidelines for reablement take into consideration the provisions of the Care Act, particularly with respect to people choosing to provide only the care that they are willing to provide and regarding them as expert care partners. Both of these areas are addressed in the thesis, in particular in Chapters 4 (Realist Synthesis) and 8 (Customising service delivery to family circumstances).

As a result of the meeting, five people were recruited to the PPI group. This information session and subsequent meetings of the PPI group proved an invaluable source of guidance for the study and a source of representation for the voice of families in the intervention.

3.4.2 PPI group and group meetings

The first PPI group meeting was held six weeks after the information session at the same location. All five people recruited (three women and two men) attended. They all had caring responsibilities for family members; three for partners over the age of 65 and two for their children. Two had direct experience of reablement specifically. One worked for a different branch of the carers' organisation that had assisted with recruitment. As a result of their role there they had a good overview of current issues in care. The aim of this meeting was to establish the group as expert care partners, to share some of the initial theories to be explored in the realist synthesis and to get their insights into them. This would serve to bring together their knowledge with my developing knowledge. I had not anticipated how useful the insights and involvement of the PPI group would be. All five members engaged fully for two hours and expressed a desire to attend a second meeting of the same length five months later.

The next chapter (Chapter 4) focuses on the realist synthesis and will describe in more detail how the PPI group contributed to the refinement of aspects of the initial theories. The second PPI group meeting fed into ongoing theory development as well as the design of the fieldwork and is described in Chapter 5 (Methods 2) and the following findings chapters. I facilitated both these meetings in order to ensure that everyone contributed and was able to express their ideas. Each two-hour meeting started with an update of progress on the research and an explanation of what the purpose of the meeting was. A log of PPI group activity was kept which included a record of meeting aims, content, anticipated and unanticipated outcomes and, where relevant, impacts and reflections. A sample is shown in Appendix J.

3.5 Informal literature search

In the formative stages of the study and alongside the consultation with content experts, I undertook an informal search of reablement literature, using the university library's search function as well as Google Scholar. This was in order to determine broadly the volume and range of evidence available in the field of reablement. It appeared from this preliminary search that there had been very little academic research published to date which focused explicitly on the role or voice of families in reablement. Exceptions to this were two Norwegian studies (Hjelle, Alvsvåg and Førland, 2016 and Moe and Brinchmann, 2016) as well as an English study protocol (Mann et al., 2016). Further reference is made to these in the next chapter. The preliminary search of grey literature relating to reablement across the UK revealed guidance documents published by SCIE (SCIE, 2012a, 2012b, 2013). It also revealed that many LAs only referred to their reablement service in very general terms on their websites. Some provided a link to a leaflet about reablement (e.g. Leeds City Council Reablement brochure (Leeds City Council, 2011). Few of these websites appeared to refer specifically to families. An example of one that did was that of Flintshire County Council which provided a link to its leaflet

"Reablement: A Guide for Carers" (Flintshire County Council, 2017). There is neither a single body representing the interests of reablement professionals in the UK, nor a central point for the collecting and sharing their knowledge and expertise.

While the preliminary informal search for literature was underway, NICE published its first ever guideline for reablement; part of a broader guide for intermediate care (NICE, 2017). As described in Chapter 1, this new resource subsequently paved the way for the first quality standard (NICE, 2018a). The evidence base underpinning the guidelines was examined[2]. It was found that much of the evidence related to rehabilitation at home after acute injury rather than to reablement specifically. None of the three research studies identified in the preliminary search were analysed in the NICE review of evidence. It is likely that they had not yet been published at the time of the review. NICE and SCIE guidance proved core to the subsequent synthesis as described in the next chapter.

3.6 The realist synthesis method

Realist synthesis is a method of evidence synthesis designed for explanation building. "The purpose is to articulate underlying programme theories and then to interrogate the existing evidence to find out whether and where these theories are pertinent and productive" (Pawson, 2006 p74). It is by means of a realist synthesis combined with further theory refinement with stakeholders that this study contributes new ideas to the field of reablement. Theory-building takes "pride of place as the prime activity" in realist synthesis (Pawson, 2006b p73). In the first stages of a realist synthesis preliminary or "candidate" hypotheses are created in order to formulate speculative ideas about what works, for whom, in what circumstances and how. Driven by these theories, existing evidence (qualitative and/or quantitative) is sought, interrogated and synthesised from a range of sources including academic as well as grey literature. Grey literature can encompass any type of literature outside the academic sphere including, for example, policy documents, briefing notes, reports, web pages and promotional material.

The main strength of a realist synthesis is in its explanatory power. In order to build explanations about how and why an intervention works, emphasis is placed on exploring the mechanisms within it which bring about particular outcomes; the contexts that influence how those mechanisms work; and ultimately how different contexts can influence outcomes. During

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[2] https://www.nice.org.uk/guidance/ng74/evidence/appendix-a-pdf-4600707950

this synthesis process, evidence is concurrently interpreted through retroduction in order to develop the candidate theories. Overall, these theories contribute to the creation of an abstract model of how and why the intervention works. This can be used to provide advice on the implementation and targeting of any innovation to the intervention (Pawson, 2006b).

The study takes account of RAMESES quality and publication standards for realist synthesis (The RAMESES Project, 2014; Wong, Greenhalgh, et al., 2013a). These standards are still evolving but in the face of the acknowledged complexity of applying the methodological process of realist synthesis, they assisted me in achieving rigour and transparency. Pawson identifies characteristics of various approaches to realist synthesis. The approach adopted for this research accords with what he describes as "Synthesis to question programme integrity" (Pawson, 2006b p94). The aim of this approach is to discover weaknesses in the implementation of the intervention under review. It is suited to circumstances in which implementation relies on the actions of several stakeholders. The power of the analysis lies in using primary sources to identify data that will facilitate a deeper understanding of "vital points of strain" in implementation (Pawson, 2006b p95), ultimately with the aim of supporting fresh thinking. The detail of how the method was applied for the purposes of this study, including how pragmatic adaptations were made to it, is described in the next chapter, Chapter 4.

A final note is made here with respect to the choice of a realist review over a systematic review. The primary purpose of a systematic review is to find out whether an intervention works "on average". On the other hand, realist reviews explore the inner workings of an intervention, looking beyond its outcomes. All types of data relating to how, why, for whom and in what circumstances, including outcomes data, are integrated in a realist review. From the point of view of policy makers and practitioners operating in health and social care, knowing the average effects of a single intervention is arguably less useful than having an understanding of which interventions work for whom and how, as this understanding is likely to have wider applicability across other interventions and issues.

3.7 Chapter summary

This chapter has introduced the supervisory team and has described the method of involving content experts in the formative stages of the study and the establishment of a PPI group. It has described the realist synthesis method and how, through its adoption, I aimed to start to contribute to an understanding of theories in the research field. The next chapter describes the realist synthesis in detail.

Chapter 4: Realist Synthesis

4.1 Introduction

This chapter will describe the aims of the realist synthesis and how it was approached. It will present and discuss how Candidate Programme Theories (CPTs) were generated and how these were refined during the course of the synthesis. It will demonstrate how the synthesis resulted in new theory-driven insights that fell within four themes:

1. Instilling an understanding of reablement
2. Customising service delivery to family circumstances
3. Empowering families
4. Skilled workforce

These themes guided the next stage of the study in which a selection of theories were refined through fieldwork with reablement managers, reablement practitioners, families and service users combined with input from the PPI group.

This realist synthesis is registered as PROSPERO CRD42019127614.

4.2 Aim and objectives of the synthesis

At the beginning of the realist synthesis process it was apparent that there was a gap in understanding causal explanations for what works when engaging families in older people's home-based reablement. The aim of the synthesis was to contribute insights that would begin to address this gap by generating theories based on a study of existing and available sources.

The objectives of the synthesis were:

- To explore existing documentary evidence on the engagement of families in older people's home-based reablement in order to understand notions about what is thought to work in facilitating engagement, for whom, how and in what circumstances.
- To synthesise the most relevant documentary evidence, using realist methods, in order to build and refine programme theories for facilitating the engagement of families.
- To use the findings of the synthesis to inform further refinement and validation of the programme theories with reablement practitioners, family members and service users.

The synthesis needed to explore how the responses of reablement teams, families and service users, to the resources offered to them during the intervention (mechanisms), are triggered in certain circumstances (contexts), in order to generate particular outcomes. I therefore set out to explore evidence relating to the core research question and the following three subsidiary questions through the synthesis:

1. What contexts are relevant to explanations for the ways in which reablement teams engage families in older people's home-based reablement?

2. What mechanisms can be identified that act at the level of the family, service user and reablement service in these contexts?

3. What outcomes are sought for the engagement of families in home-based reablement and which contexts and mechanisms are thought to affect them?

4.3 Approach to the synthesis

The process of undertaking a realist synthesis is recognised for its complexity (Pawson et al., 2004; Emmel et al., 2018). Although, as mentioned in the previous chapter, standards and materials are evolving to facilitate this process, the particular needs of the research question and the availability of relevant sources play a large part in determining how any synthesis is approached. In the case of this study, the intervention was still at a relatively early stage of development and there was not an abundance of relevant sources. The impact that these factors had on the approach taken to the synthesis is described in this chapter. Around half of the chapter is concerned with the process of locating, searching, appraising and synthesising the evidence. The other half, starting at section 4.10, is where it is analysed.

The following process diagram (Figure 5) illustrates the approach taken and is used as a structure for this chapter. It is an adaptation of a model used by Wong et al. and is based on Pawson's broad stages that inform the structure of a synthesis (Pawson, 2006). The main iterative cycles have been indicated by dotted lines in the diagram, however, it should be noted that all realist inquiries are highly iterative and that retroduction involves a constant cycle of drawing initial conclusions, refining and analysing them during a realist synthesis.

Figure 5: Realist synthesis process

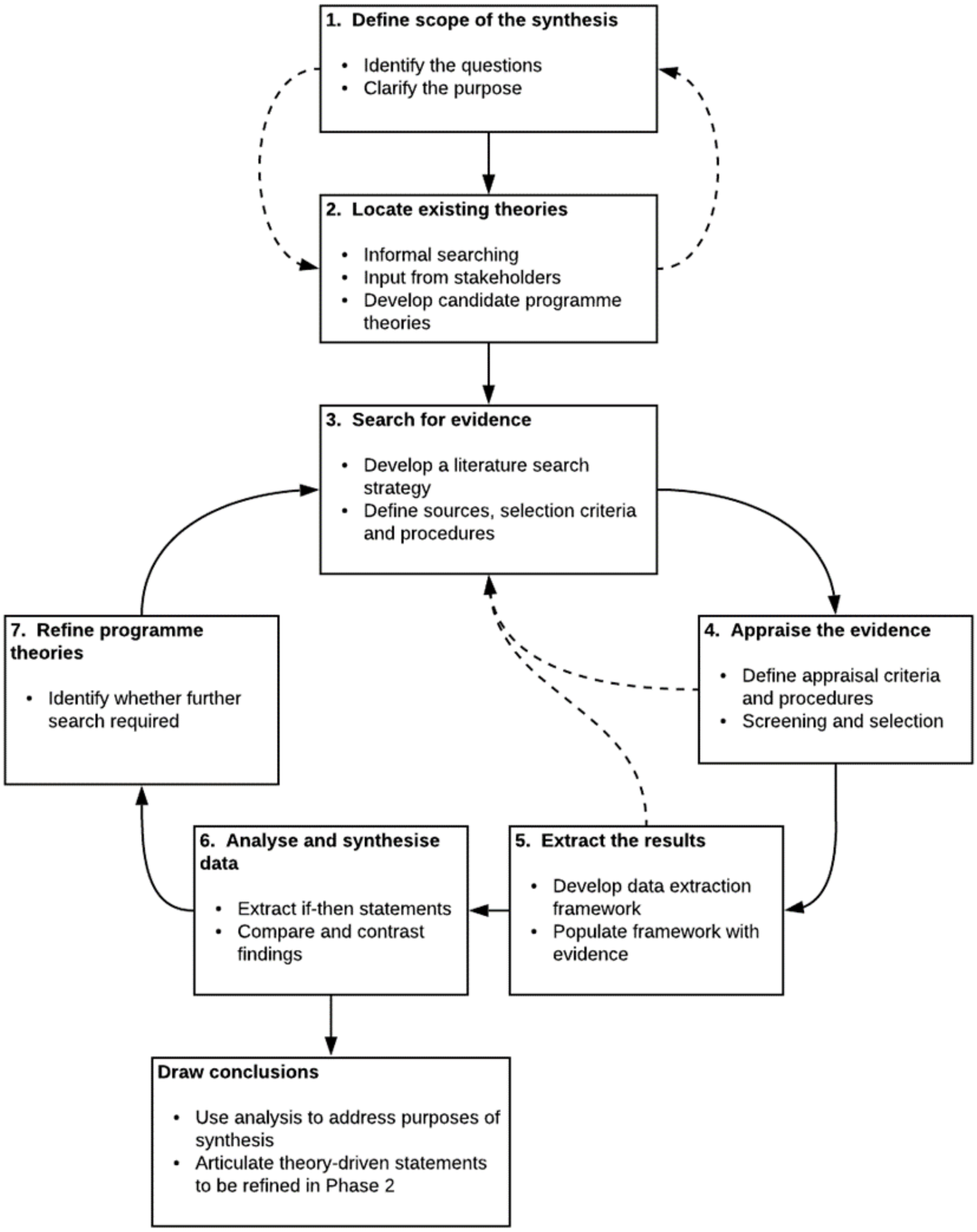


Figure adapted from Wong G, Brennan N, Mattick K, et al., Interventions to improve antimicrobial prescribing of doctors in training: the IMPACT (IMProving Antimicrobial presCribing of doctors in Training) realist review. BMJ Open 2015;5:e009059. doi:10.1136/bmjopen-2015-009059 CC BY 4.0

4.4 Defining the scope of the synthesis and locating existing theories

The first two stages of the synthesis as identified on this diagram are shown as iterative. In the study these stages pre-dated the decision to use a realist approach. They were described in the previous chapter as being achieved for the most part in the formative stages of the research through working with content experts and conducting an informal literature search.

The scope of the synthesis was based on achieving the aims and objectives set out in section 4.2. It was identified as concerning reablement once it commences within the service user's home, rather than referral into, or transition on from it outside the home. The purpose of locating existing theories in the first stages of a realist synthesis is to provide a means of establishing the underlying assumptions about why it is deemed to be a good idea and the best explanation of how it works. Alongside establishing an appreciation of the architecture of the intervention (as described in Chapter 1), this stage provided clarity about theories that already existed in relation to its implementation.

4.5 Developing Candidate Programme Theories

As well as honing the scope of the realist synthesis, these first two stages helped to inform the articulation of initial Candidate Programme Theories. Early questions developed from discussions with content experts, combined with questions arising from the preliminary literature search, related to theory integrity and adjudication.

- Theory integrity – do families engage in a way that reablement managers and workers anticipate? It was clear from these early discussions and from the accompanied visits that families engage with reablement in a wide variety of ways. From the instances observed and discussed, some people engage fully, some are clear about what aspects they would like to engage with and what not, some prefer to observe rather than take an active part and others are only heard from if they would like to make a complaint.

- Theory adjudication – do some theories about the engagement of families in reablement seem to fit better than others? Very few potential theories were expressed by stakeholders at this stage about what causes some people to engage and others not. Staff at the independent home-care provider, however, emphasised their belief that relationships are key to wellbeing and reported that they work actively with clients to identify how to build and maintain connections with family and others in the community.

The process of refining Candidate Programme Theories is highly iterative and involves constantly revisiting them as they evolve. The next section focuses on the development of Candidate Programme Theories from NICE and SCIE guidance.

4.5.1 Rationale for using NICE and SCIE guidance

The publication of the first NICE guidelines on reablement presented an opportunity for my study and was an indication of its topicality. In view of the fact that there was variation in service delivery models for reablement in England, as well as variation in the definition of reablement itself, the guidelines presented a central source of thinking on the architecture, aims and application of reablement. It was therefore decided to use the NICE guidelines as a starting point for the location of existing evidence-based theories.

Based on the informal literature search and discussions with the content experts, I recognised that it would be useful to supplement the NICE guidelines with guidance on reablement that had been published by the Social Care Institute for Excellence (SCIE) (SCIE, 2013). Whereas the NICE guidelines conceptualised reablement in a largely linear way, the SCIE guidance offered a more holistic conception of the intervention. Together, these two guidelines, combined with learning from stakeholders to date, provided the core sources for the development of a set of Candidate Programme Theories to refine through the synthesis process.

Using the NICE and SCIE guidance in this way meant that the research had potential to contribute to their usability and application. Through identifying and exploring gaps and unquestioned assumptions in the guidance and understanding the mechanisms by which engaging families in reablement works, the research might have the capacity to provide insights into how the intervention could be optimised and how its benefits could be sustained in the longer term. I discussed this approach with a group of realist researchers and experts (many of whom had a background in professional health and social care practice and policy) at a course for advanced study in realist methodology facilitated by Justin Jagosh of the Centre for Advancement in Realist Evaluation and Synthesis (CARES). I also discussed it with my supervisory team. It was agreed that this approach served the purposes of the study aims while also adhering to the philosophy of the realist approach.

4.5.2 Working with NICE and SCIE guidance

Based on where family engagement is advised in NICE Guideline NG74 (NICE, 2017) and SCIE Guide 49 (SCIE, 2013), combined with the discussions with stakeholders, eight Candidate Programme Theories were eventually developed to guide the search for evidence. They are expressed in the form of "if-then" statements (e.g. IF reablement teams have an ongoing understanding of what support family carers are willing and able to offer, their attitudes towards their caring role and their own needs for support, THEN they will be able to devise a reablement plan that works for everyone). These theories were discussed with and agreed by the supervisory team. As described earlier, the process of defining Candidate Programme Theories is highly iterative. Initially, six theories were identified. However, it became apparent during the synthesis that one of these was too broad. The PPI group contributed to dividing this area into three theories as described in section 4.8.2.

In the NICE Guideline, reference to "family" or "families" is made in eleven points falling under sections 1.1, 1.3, 1.5, 1.6 and 1.7. These are set out in full in Appendix C. Two of the points were excluded as out of scope as they related to assessment for intermediate care in general rather than reablement specifically (i.e. before the identification of reablement as the most appropriate service). Closely linked points were grouped as described below. SCIE Guide 49 "Maximising the Potential of Reablement" includes a section focusing on the role of families in supporting the reablement process. The eight recommendations made in this section of the SCIE guide were also used to inform the Candidate Programme Theories and are set out in full in Appendix E. Although they are bulleted in the publication, they have been numbered for ease of reference in this study.

Although the two sets of guidance provided enough information to develop the "if" part of these Candidate Programme Theories, the desired outcome (the "then" part) was seldom identified. In order to work with this limitation, the guidelines as a whole were used to derive the "then" part, along with discussions with stakeholders (for example, recommendations made in the NICE Guidelines refer to what should be discussed at the start of reablement, without articulating the intended outcome of these discussions). At this stage of the process, it was not necessary or productive to detail the anatomy of context, mechanism and outcomes within the statements. These were developed through the next stages of the synthesis by selecting, analysing and synthesising the sources.

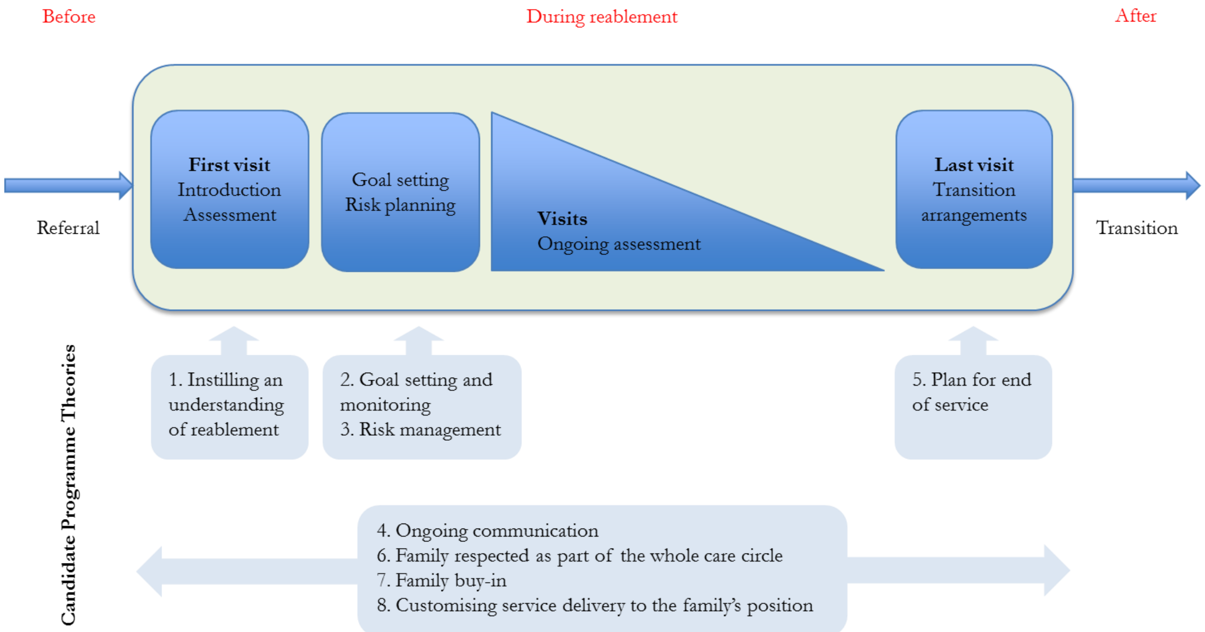
4.5.3 Candidate Programme Theories

The eight Candidate Programme Theories relate to the following areas:

1. Instilling an understanding of reablement	5. Plan for the end of the service
2. Goal setting and monitoring	6. Family respected as part of the whole care circle
3. Risk management	7. Family buy-in
4. Ongoing communication	8. Customising service delivery to the family's position

In the course of the synthesis these theories underwent further significant refinement. For this reason they are not set out in further detail here. Appendix K provides a fuller description of each Candidate Programme Theory (CPT) expressed as an if-then statement, along with an identification of its sources within the NICE and SCIE guidance and questions that it raised at this stage of the synthesis. This stage (locating existing theories) provided insight into where further critical thinking would be required in the research. I conceptualised the reablement journey in the following way and mapped the Candidate Programme Theories onto it:

Figure 6: Candidate Programme Theories mapped onto the reablement journey



4.6 Searching for Evidence

Sources are searched in a realist synthesis in order to develop, confirm, refute or refine the Candidate Programme Theories. All study designs are eligible for inclusion, in order to understand the context in which the intervention works. All sources are considered of potential value to theory development without a hierarchy of evidence. Having established a set of Candidate Programme Theories and a range of questions relating to them, I was in a position to conduct a theory-led examination of evidence relating to the core research question and subsidiary questions set out at the start of this chapter in section 4.2.

It is recognised as "entirely legitimate for the synthesis' objectives, question and/or the breadth and depth of the review to evolve or be refined as the review progresses" (Wong et al., 2013b p18). As the preliminary informal literature search suggested that there were likely to be only a small number of studies focusing explicitly on families in reablement, a pragmatic approach to focusing the synthesis and refining theories was required. In consultation with the supervisory team, I decided to match concepts identified in the literature to all eight Candidate Programme Theories initially. This was anticipated to result in the production of further theories, some of which would then be selected for refinement following the synthesis in stage two of the study.

4.6.1 Developing a search strategy

This section describes the strategic approach taken to searching the literature purposively. A combination of the widely used tools PICOS (CRD, 2009) and SPIDER (Cooke, Smith and Booth, 2012) were used to determine the broad search terms.

Table 6: Literature search tools

SPIDER	**PICOS**	**Search Terms**
Sample	Population	Older people, family carers
Phenomenon of Interest	-	Involvement in reablement
-	Intervention	Reablement
Design	Comparison	N/A
Evaluation	Outcomes	Independence
Research Type	-	N/A

4.6.2 Defining Sources, Selection Criteria and Procedures

Working with the assistance of an expert academic librarian, the broad search terms were broken down into detailed search terms shown in Appendix L. The search was conducted in November 2017 and was restricted to items in English only for practical purposes but not to any particular country. All study designs and evidence types are eligible for inclusion in a realist synthesis as they all have the potential to contribute to building programme theory. Documents included, for example, qualitative, quantitative and mixed methods evidence, process evaluations, systematic reviews, editorials, opinion pieces, commentaries, reports, and LA and specialist bodies' web pages with embedded videos and online leaflets. Searches were conducted on the full text of documents rather than abstracts alone. The search was conducted across all dates, even though it was thought most likely that UK publications of most relevance would appear after 2010 when the intervention started to attract more funding.

The following electronic databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINHAL), The Allied and Complementary Medicine Database (AMED), MEDLINE, Psychinfo, Embase, Social Policy and Practice (including Social Care Online), British Nursing Database, Humanities Index, International Bibliography of the Social Sciences (IBSS), Social Science Database, Social Science Premium Collection, Social Services Abstracts, Sociological Abstracts, Sociology Collection, Sociology Database and ASSIA.

4.6.3 Search results

When the term rehabilitation was included in the searches, 22,216 results were returned. This high number of hits was not entirely surprising as rehabilitation covers a vast array of services across the fields of imprisonment, addiction and health. In order to focus the searches, they were run again without using the term rehabilitation. This returned 819 results which was deemed to be manageable for the early stages of the synthesis. A separate search of the Cochrane Database of Systematic Reviews was subsequently undertaken in order to identify potential additional research of interest. Two studies met the eligibility criteria for inclusion in a Cochrane 2016 review comparing home-based reablement with usual home-care. These two studies had already been located but neither proved sufficiently relevant to the study (Lewin et al., 2013; Tuntland et al., 2015).

4.7 Appraising the evidence

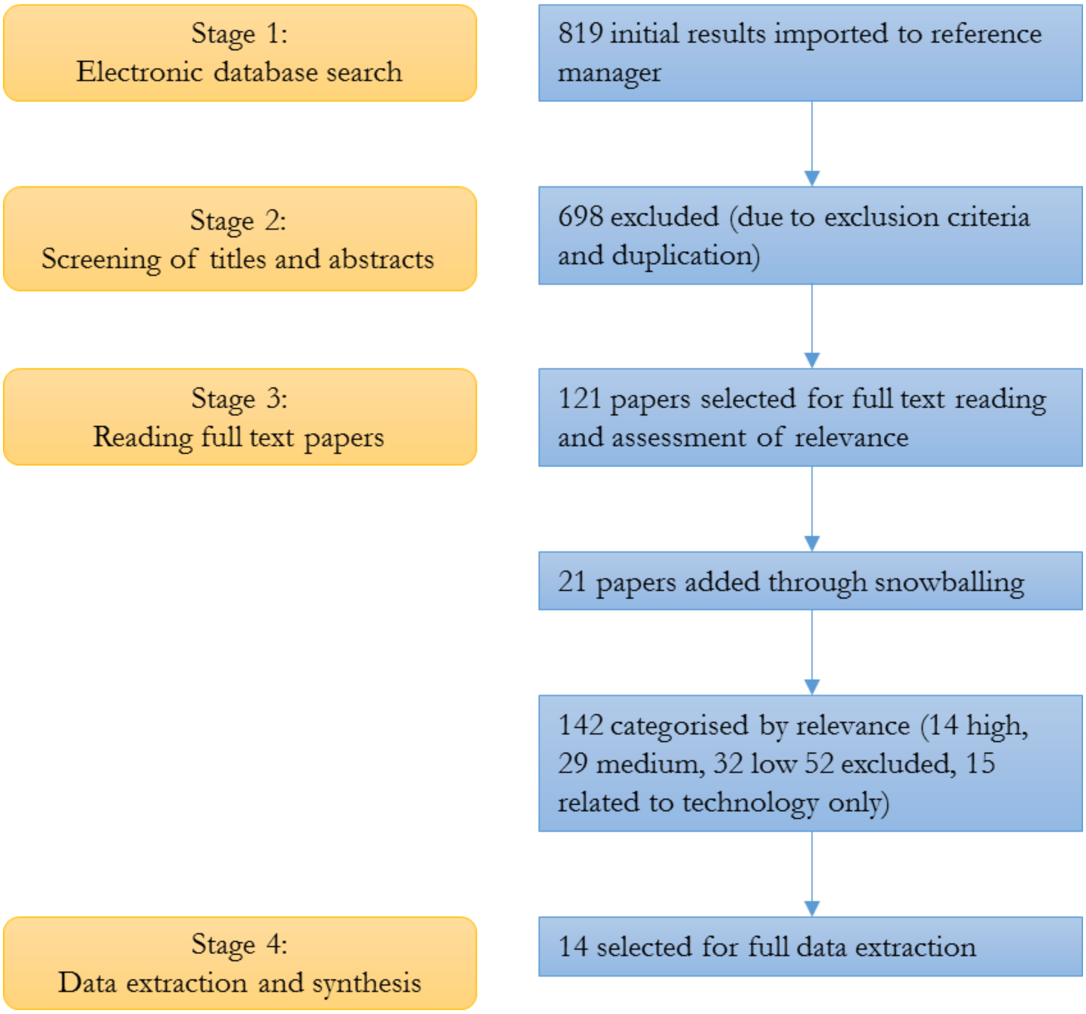
At the heart of a realist synthesis, available sources are interrogated in order to unpack the mechanisms by which an intervention works or fails (Rycroft-Malone et al., 2012). Contexts, mechanisms and outcomes (CMOs) are identified from all the relevant literature searched. The CMOs are then analysed systematically and accumulatively, to inform the development and refinement of Candidate Programme Theories. This section identifies the appraisal criteria and procedures used to identify a core set of sources to appraise in detail.

4.7.1 Study appraisal criteria and procedures

I reviewed the abstracts of the 819 documents returned from the search in order to determine their relevance. A large number of these documents related exclusively to mental health. These were excluded along with documents that appeared to be highly condition-specific (e.g. with a focus on dementia) and those which related to care settings that were not community-based. Any duplicated documents were removed at this stage. This left a longlist of 121 documents which were downloaded into Mendeley. These were read in full and an additional 21 papers were also read as a result of forward and backward citation tracking. Each of these 142 papers (listed in Appendix M) was assessed for its potential to provide evidence to inform the synthesis. They were identified as having high, medium or low relevance, or were excluded. The definitions of these categories, based on an adaptation of an unpublished Realist Review Appraisal Form developed by Justin Jagosh for use in his CARES training courses, are set out in Appendix N. Potential middle range theories emerging from the documents were also noted at this stage.

Documents were included based on their relevance, regardless of the type of evidence. This was an iterative process. As the review progressed and theory developed, decisions about the degree of relevance were influenced by what had already been reviewed. This meant that documents that were reviewed late in the process sometimes provided data that supported existing ideas but did not generate new insights. This is a common feature of realist synthesis and indicates a degree of saturation of emerging concepts (Pawson, 2006b). An assessment of rigour for the purposes of realist synthesis is determined alongside the analysis and Pawson emphasises the value that “trustworthy nuggets of information” within a study can hold for the overall synthesis, regardless of the overall technical strength of a study (Pawson, 2006 p90). For this reason, documents that were categorised as having medium and low relevance were retained and revisited as the synthesis progressed. The screening process and results are summarised below:

Figure 7: Summary of screening process and results



For the 14 sources identified as having high relevance to the synthesis, a core set of descriptors was collected. These captured information about the source's aims, its strengths and weaknesses for the purposes of the synthesis, the country or countries it applies to, the type of reablement and service user group it examined. For research studies, information was captured about the research methodology and research methods (theoretical approach, data collection method, participants, sampling and data analysis) along with a summary of the findings. (See Appendix O for an example). At this stage it was decided not to follow up the medium relevance sources. These did not focus on reablement specifically but on related interventions. They could be drawn on later in the research if required.

Although presented here as sequential, reviewing and assessing the sources was an iterative process that took place alongside ongoing refinement of the Candidate Programme Theories. This iterative approach enabled me to develop a fuller understanding of where knowledge already existed in the field of reablement. However, as the review of the literature progressed and my understanding of both the intervention and realist approaches developed, it was acknowledged that some of the 14 sources selected for the synthesis were not sufficiently rich conceptually in themselves for detailed data extraction. This led to each of the 14 sources which had been selected for their relevance to the synthesis being assessed additionally for their conceptual richness.

Criteria for conceptual richness based on a hybrid appraisal tool proposed by Ritzer and Roen et al. and used in other realist syntheses (Pearson et al., 2012, 2013; Brennan et al., 2014) were adopted (See Appendix P). It is noteworthy that discussions about how to consider richness among leading thinkers in realist methodology are ongoing. Ray Pawson, Justin Jagosh and Gill Westhorp all responded to an email posted on this theme by Andrew Booth on the RAMESES discussion group in September 2019 (Booth et al., 2019). In this, Justin Jagosh refers to an assessment of richness as adjudicating "on the existence and quality of causal insights found in the relevant literature"; and Ray Pawson talks in terms of assessing the soundness of the evidence being examined and extracted for the purposes of the particular study. My approach to richness concurs with these two contributions.

In some cases, sources were deselected because they mostly summarised other work which was represented more fully in other sources. In other cases, although the sources provided a good understanding of reablement in its entirety, the detail on the involvement of family carers aspect of reablement did not provide any additional insight that would illuminate thinking about context, mechanisms and outcomes that had not already been detailed more fully in another source or sources. This purposive sampling strategy resulted in the supervisory team agreeing a reduced number of seven sources for full data extraction, while retaining a small number of fragments or "nuggets" from the other seven sources. These will be referred to repeatedly in the analysis section of this chapter (Section 4.10).

Table 7: Core sources for full data extraction

Authors	**Title**	**Year**
Glendinning, C, Jones, K, Baxter K, Rabiee, P, Curtis, LA, Wilde, A, Arksey, H, Forder, JE	Home Care Re-ablement Services: Investigating the longer-term impacts (prospective longitudinal study)	2010
Hjelle, KM, Alvsvåg, H, Førland, O	The relatives' voice: how do relatives experience participation in reablement?	2016
Jakobsen, FA, Vik, K	Health professionals' perspectives of next of kin in the context of reablement	2018
Pearson, M, Hunt, H, Cooper, C, Sheppard S, Pawson, R, Anderson, R	Providing effective and preferred care closer to home: A realist review of intermediate care	2015
SCIE	Maximising the Potential of Reablement	2013
SCIE	Role of Carers and Family – online video	2014
Wilde, A, Glendinning, C	'If they're helping me then how can I be independent?' The perceptions and experience of users of home-care re-ablement services	2012

For further detail on the characteristics of the core sources and which theories they informed, please see Appendix Q. For a list of papers that were deselected at this stage and the reasons for deselecting them, please see Appendix R.

4.8 Extracting and organising the data

The purpose of extracting data from the seven core sources was to bring to the surface ideas about what is thought to work and not work when engaging families in reablement. These data were organised according to the eight Candidate Programme Theories (CPTs) with a view to then exploring the context, mechanism and outcomes elements within them.

4.8.1 Developing a data extraction framework

Using an approach adopted by Pearson, Pawson et al. in a realist review of intermediate care (Pearson et al., 2013 p27), emerging, explanatory ideas relating to the research questions were extracted in the form of if-then statements. These were ideas drawn inductively from the original text and encompassed anything relating to what works well, what does not work well, how and why, when engaging families in reablement. Extracting the ideas in this manner allowed for further consideration of them as aspects of context, mechanism and/or outcomes. An Excel spreadsheet was constructed to record the data extracted inductively from the sources. This provided a number for each if-then statement, a record of its source, columns for each of the CPTs (allowing each statement to be associated with more than one theory) and a column to capture any theories that were not encompassed by the CPTs.

4.8.2 Populating the framework with evidence

I extracted 251 if-then statements with potential to bring to the surface understanding about the CPTs from the seven sources. Their selection relied on my implicit judgements. It is acknowledged that another researcher might have made different choices about which ideas to extract. However, unlike the process undertaken in a systematic review, in which criteria are defined stringently at the beginning of the review, the aim of the approach was to select ideas in an intentionally inclusive way, regardless of how simple or complex they appeared to be. It was critical that the origin of the statements could be traced back to their sources in the literature.

I then allocated the if-then statements to one or more of the eight CPTs. When a realist synthesis is undertaken by a team of researchers, it is common at this stage for individual researchers to allocate propositions to CPTs independently of one another, and then compare their choices in order to reach agreement. In order to accomplish this as a researcher working predominantly alone, the three members of the supervisory team agreed to verify a sample of 10% of the statements (#=25). The sample was taken across all studies in approximate proportion to the number of statements arising from that study. The supervisors all examined the same 10% independently of one another and allocated them to the CPTs. These allocations were then discussed in a meeting. In the majority of cases there was consensus (72%). The remaining cases were discussed further in order to reach a shared understanding and agreement. The following table gives examples from the 251 statements. The full spreadsheet is attached in Appendix S, including a table showing the total number of statements matched to each CPT.

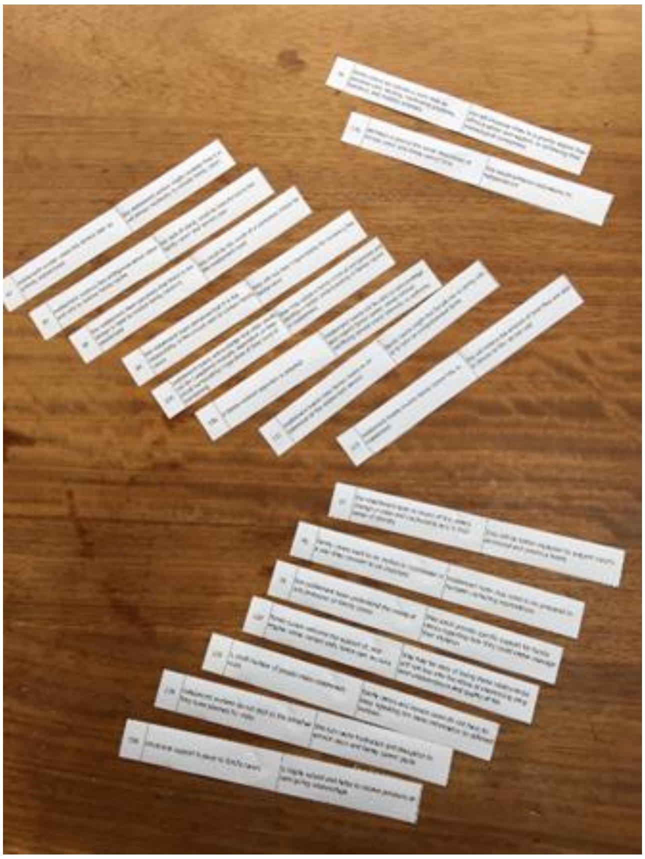
Table 8: Examples of if-then statements matched to Candidate Programme Theories

#	**If…**	**Then…**	**Candidate Programme Theory #**
69	family carers are not familiar with the parameters of reablement	they will have unrealistic expectations	1 (instilling understanding)
130	family carers have the opportunity to chat to reablement workers on a daily basis	they will have valuable opportunities to address areas of unmet need in a relaxed manner, reinforcing the reablement process	4 (ongoing communications) and 6 (family respected as part of care circle)

An example of one of the statements that the group initially disagreed on and which was discussed in order to reach a shared agreement is shown below:

Statement 182: If service users are in a vulnerable state then it might not be possible to expect negotiation about the objectives of care [with family] to take place on an equal footing.

The researcher had matched this to candidate programme theory 2 (goal setting) as well as 6 (family respected as part of care circle). One of the supervisors who has a background in occupational therapy matched it against theory 3 (risk management). Her reasoning for this was that if people are in a vulnerable state they may not be able to negotiate objectives, either because they do not have the confidence to speak out and express their goals if they think this might lead to conflict with a family carer or a health care professional, or alternatively because they lack capacity to determine realistic goals. In such instances it would be imperative as a health and social care professional to either advocate for the person or to protect them. A discussion with family about balancing and managing risk alongside building independence would be imperative. It was agreed to allocate this statement to the risk management theory.



As described earlier, the PPI group met during the synthesis and contributed to it. They helped me to divide the very dense SCIE guidance into three more manageable separate theories by means of a teacher-learner approach (Pawson, 1996). This approach was used extensively in the second stage of the study and is described in Chapter 5. I printed out 17 if-then statements from the sources that related to the SCIE guidance and facilitated discussion of them with the group. The photograph here shows how the group divided them up. One of the potential challenges of the teacher-learner process is pitching the theories to be shared at the right level. I explained that the statements had been taken as direct quotes from existing literature and therefore some might need elucidation. It was recognised that the group might not get through all 17 statements. Pairing up, they read through and discussed the statements before returning to discuss them as a group. Initially the group interpreted the if-then statements as items to simply agree or disagree with rather than discussing them. This was possibly due to the fact that some of the group had former experience of involvement with research studies adopting different methodologies. Although I had had some concerns about asking the group to engage with the theories in the spirit of discussing and refining them, once this had been explained, everyone engaged with them extremely deeply and willingly.

4.9 Synthesising and analysing the data

The aim of synthesising and analysing data in a realist synthesis is to explain the labyrinthine relationships between the contexts, mechanisms and outcomes of the intervention. This process is acknowledged for its complexity and there is no prescribed approach to it. It is by necessity highly iterative and relies on a retroductive approach to conceptualising ideas. However, the methodological process applied in a realist synthesis should still endeavour to be rigorous and transparent (Pawson et al., 2004).

I engaged in ongoing fortnightly discussions with the supervisory team on the emerging theories as well as discussions with co-opted expert on realist methodology, Dr Justin Jagosh, and the PPI group. In the interests of transparency, the following two sections of the chapter serve to help the reader navigate the complexity of this stage of the synthesis process. Ultimately, four theoretical themes were created and Section 4.10 presents and analyses the synthesis findings according to these.

Where there is a wealth of highly relevant literature to draw on for a realist synthesis, it is possible at this stage to begin to set out context, mechanism and outcome configurations (CMOCs). In this case however, where there was a dearth of relevant literature, it was necessary to take a different approach. An examination of the 251 if-then statements drawn from the literature revealed that they related predominantly to mechanisms. Insights into the contextual factors that affect the engagement of families in reablement and intended or unintended outcomes of doing so were scarce.

Following Pawson's suggestion as described in section 2.7.7 (Emmel et al., 2018), I started by analysing the statements that I had identified as mechanisms. This was with a view to moving the analysis towards the potential creation of CMOCs at a later stage, providing insight into how the resources offered during service delivery might influence the reasoning of the family members, the service user and reablement staff. This was a highly iterative process.

As there was a considerable amount of overlap in ideas among the statements, the following criteria were developed and used to rationalise the 251 statements:

1. Statements that had the characteristics of a mechanism (including either or both reasoning and resource elements) were identified for inclusion in the analysis at this stage.
2. Statements that were excluded were coded as below, for consideration later in the study.
3. Mechanism statements that expressed the same idea as each other were amalgamated and one selected that expressed the idea most fully.
4. These were coded as resource or reasoning.
5. The level at which the mechanisms could be triggered was identified (i.e. family members, reablement staff and the service user), based on whether any effort or absence of effort on the part of these stakeholders could trigger the mechanism to fire.

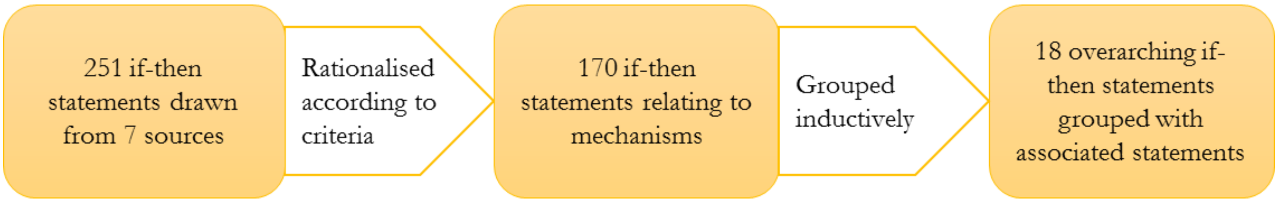
At this stage the following categories were identified but not included in the analysis: potential contexts, outcomes, middle range theories, statements that lacked a causal link or had a weak causal link to context or outcomes, and those which had appeared to have potential earlier on to inform that analysis but which were subsequently deemed of insufficient relevance to families specifically.

The result of this rationalisation was 170 if-then statements relating to mechanisms that had potential to illuminate causal factors.

4.9.1 Synthesising if-then statements into 18 groupings

Working with a considerable amount of data and ideas is a common feature of a realist synthesis. This section describes how, having rationalised 251 if-then statements drawn from the sources down to 170 statements, I then grouped the 170 inductively into a more manageable set of 18 overarching if-then statements.

Figure 8: Process for synthesising 251 if-then statements into 18 groupings



Firstly if-then statements among the 170 that related to an idea in common were grouped together. This resulted in 18 groupings. One statement from each of the 18 groupings that most fully represented that grouping was then selected to represent it (its "overarching" if-then statement). It was acknowledged that the selection of only one statement to represent a group generally, would not fully represent the detail of related statements. For this reason, statements within the group that appeared to have potential to contribute to an understanding of the causal mechanisms beyond what was expressed in the overarching statement were not discarded. They were retained and referred to in the analysis. Opposing or "rival" theories within the groupings proved useful in subsequent discussions with stakeholders. This process resulted in a more manageable set of statements while retaining potential for causal explanation. Table 9 shows an example of this process.

Table 9: Process for grouping if-then statements

Original data extract:

The relatives also expressed a wish to be informed about how to support and motivate their family members to engage in physical exercise and perform everyday activities. This desire was expressed as "I am dependent on the information about what and how I can contribute." (Hjelle, Alvsvåg and Førland, 2016)

Overarching if-then statement:

IF family carers are informed about how to support and motivate their relative, THEN this will support them in their role (if-then statement 11).

Examples of other if-then statements from other sources grouped under this overarching if-then statement:

IF family carers engage fully with the reablement process, THEN they can learn more structured ways of approaching their relative's needs and new skills in helping with practical tasks (Glendinning et al., 2010).

IF family carers are given support, information and education linked to their role, THEN they will be better equipped to support reablement (Jakobsen and Vik, 2018).

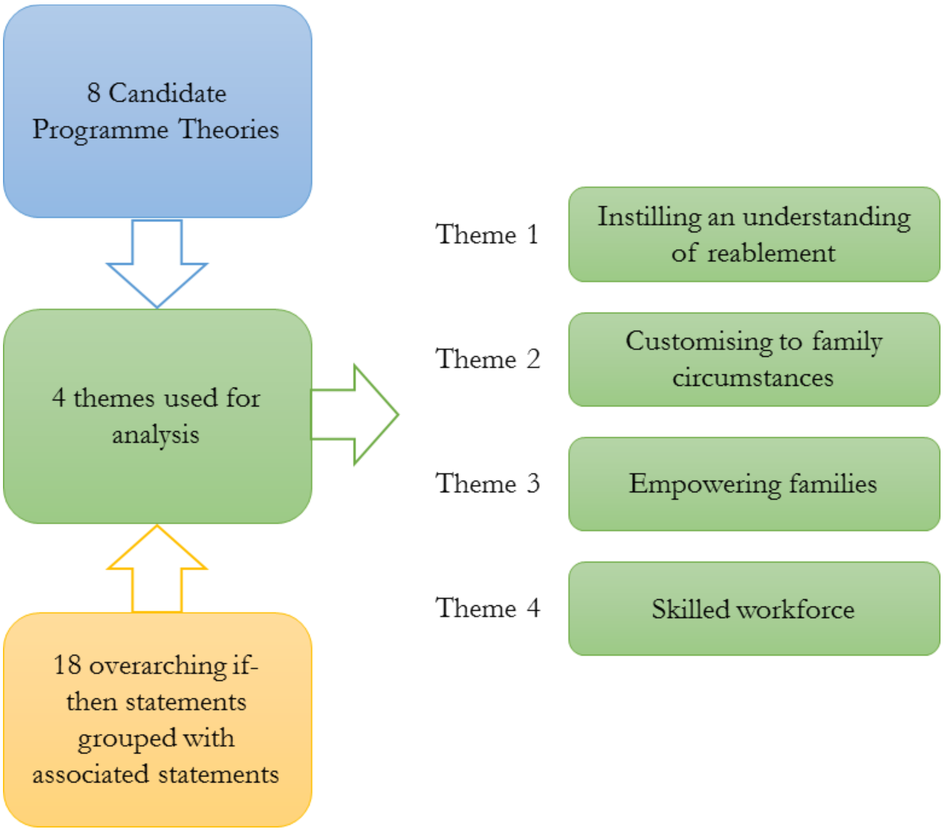
Related Candidate Programme Theory:

Candidate Programme Theory 6: Families and partners respected as part of the whole care circle.

4.9.2 Refining the Candidate Programme Theories into four themes

The Candidate Programme Theories were revisited and consolidated as part of the process of synthesising the if-then statements. Over the course of fortnightly meetings with the supervisory team, and informed by earlier discussions with the PPI group, the Candidate Programme Theories were consolidated into the four themes identified at the start of this chapter. These themes will be used throughout the thesis. They are analysed in turn in Section 4.10 of this chapter and each of them is represented by a findings chapter (Chapters 6-9).

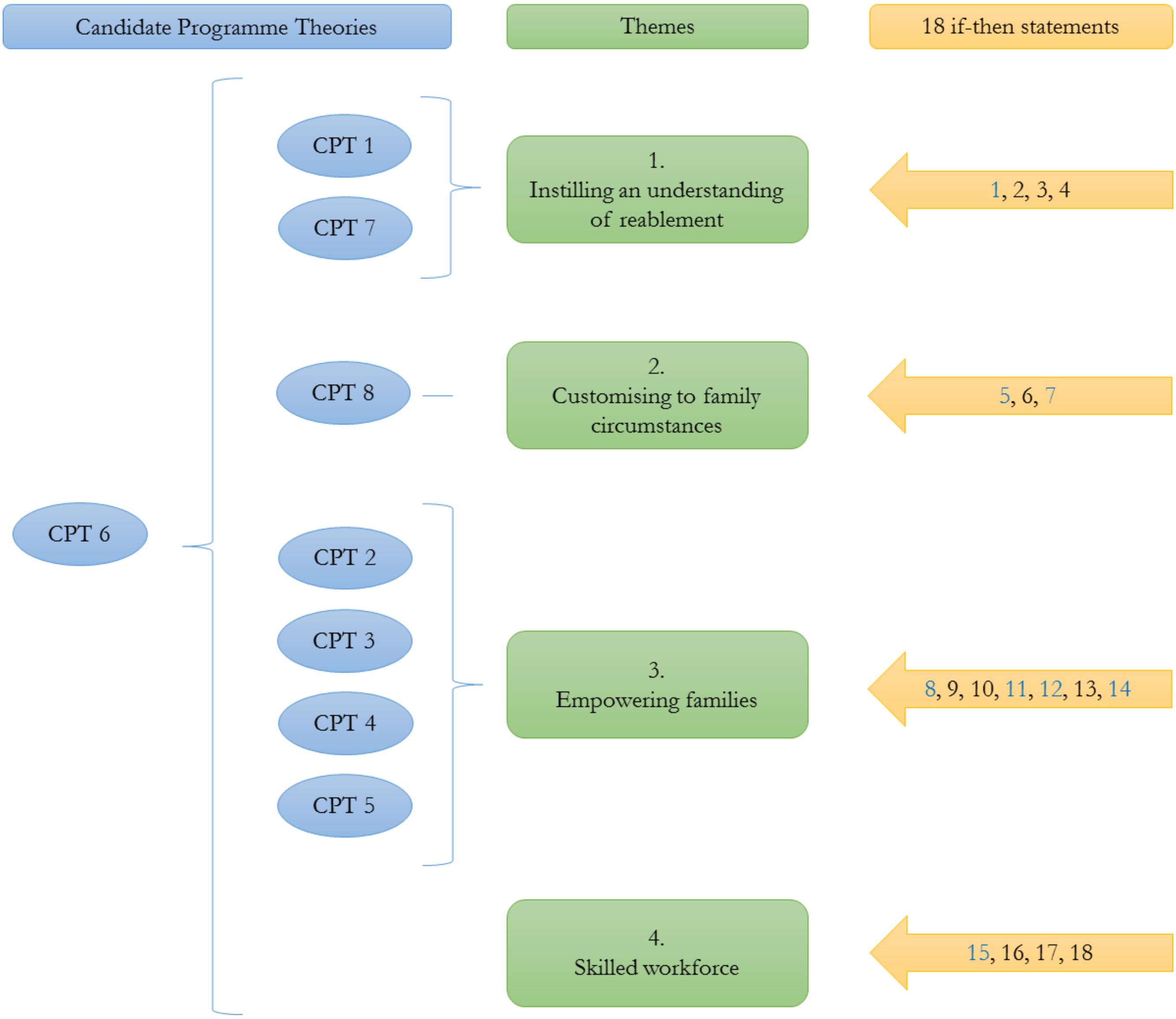
Figure 9: Four themes used for analysis in the realist synthesis and to guide fieldwork in Stage 2



Before moving on to the heart of the synthesis, the analysis of its findings (Section 4.10), it is important to provide an overview of how the Candidate Programme Theories were consolidated into the four themes and how these relate to the 18 overarching if-then statements. Figure 10 represents this and is followed by an explanation of the consolidation which includes a restatement of the Candidate Programme Theories for ease of reference.

A selection of if-then statements were ultimately taken forward for further refinement in Stage 2 of the study. The blue numbers represent these. They will be stated in full in the analysis section of this chapter (Section 4.10). They can also be found in full in Appendix T grouped according to the four themes.

Figure 10: Overview of themes and their corresponding Candidate Programme Theories (CPTs) and 18 if-then statements



Candidate Programme Theory 7 (Family and partner buy-in) was understood as a potential outcome of Candidate Programme Theory 1 (Instilling and understanding of reablement) and these two were therefore combined under the theme "Instilling an understanding of reablement". Overarching if-then statements 1, 2, 3 and 4 corresponded to this theme.

Candidate Programme Theory (CPT)	**Theme 1**
CPT 1: Instilling an understanding of reablement IF reablement teams involve families and partners in discussions with the service user explaining what reablement is at the start of the intervention THEN families and carers can understand what reablement can and cannot achieve and how it differs from traditional homecare. **CPT 7: Family and partner buy-in** IF families and partners are completely "signed up" to the concept of reablement, THEN they can help to motivate the service user throughout and beyond reablement.	Instilling an understanding of reablement

Theory 8 (Customising service delivery to family's position) was renamed Customising service delivery to family's circumstances. Overarching if-then statements 5, 6 and 7 corresponded to this theme.

Candidate Programme Theory (CPT)	**Theme 2**
CPT 8: Customising service delivery to family's position IF reablement teams have an ongoing understanding of what support family carers are willing and able to offer, their attitudes towards their caring role and their own needs for support, THEN they will be able to devise a reablement plan that works for everyone.	Customising service delivery to family's circumstances

Candidate Programme Theory 2, 3, 4 and 5 were drawn together as theories relating to operational aspects of empowering families. Overarching if-then statements 8, 9, 10, 11, 12, 13 and 14 corresponded to this theme.

Candidate Programme Theory (CPT)	**Theme 3**
CPT 2: Goal setting and monitoring IF the reablement goals are shared with families and partners, in agreement with the service user, THEN families and partners will understand the goals and may be able to help the service user to achieve them. **CPT 3: Risk Management** IF reablement teams involve families and carers in a discussion about balancing risk and building independence at the start and during reablement as well as in risk planning, THEN families will understand the risks implied in aiming to achieve the goals that are set and the strategies for managing and mitigating them. **CPT 4: Ongoing Communications** IF reablement teams ensure that families and partners have access to a record about what has been provided and any incidents or changes, are able to answer questions and concerns and contact families if they have to change visit arrangements, THEN families and partners will benefit from good communication and will feel fully informed about the provision of the service. **CPT 5: Plan for the end of the service** IF reablement teams agree and document a plan for when reablement ends, encourage families and partners to consider continuing to provide social support, encourage them to consider the sustainability of the support they can offer and give them information about other sources of support including support for carers, THEN an effective transition from the service will be made.	Empowering families

Theory 6 was made up of many different elements each of which were picked up in different themes (e.g. giving them practical tips and techniques for providing support was associated with Empowering families (Theme 3)).

CPT 6: Families and partners respected as part of the whole care circle

IF reablement teams respect families and partners as an important, active part of the whole care circle, encourage them to contribute to the process as partners, giving them practical tips and techniques for providing support, and maintain good communication with them, THEN families and partners will be empowered to help to contribute towards the service user's independence throughout the process and will be empowered to reinforce the approach with the service user after the end of reablement.

An additional theme was created in the process of synthesising the if-then statements. This had not been represented in the Candidate Programme Theories and related to workforce skills. This appeared to be a distinct and critical element of facilitating family engagement and was named “Skilled workforce”.

4.9.3 Selecting if-then statements to refine further with stakeholders

All 18 if-then statements were analysed in the course of the study and represent a significant move on from the original Candidate Programme Theories. They provided a great deal of scope for further investigation of the mechanisms relating to many aspects of facilitating the engagement of families in reablement. I selected eight of the overarching if-then statements to refine further in Stage 2 of the study (the numbers shown in blue in Figure 10). This selection was achieved with assistance from the PPI group by means of discussion and consensus-building facilitated by me. Naturally there are ideas encompassed in the other if-then statements that would benefit from being scrutinised but those chosen were considered to offer the greatest potential to explain how to optimise the engagement of families in the short as well as the longer term, applying across all four themes. There was also sufficient detail in the if-then statements clustered under these overarching if-then statements to encompass ideas about potential barriers as well as rival theories. The level at which the mechanisms could be triggered in these statements was predominantly at the reablement team level. As the study’s focus was on teams facilitating family engagement this was appropriate. Due to the restrictions of word count for the thesis, only the eight statements chosen for further refinement in Stage 2 are presented in the next section.

4.10 Analysis of synthesis findings

The synthesis set out to explore and analyse existing documentary evidence on the engagement of families in older people's home-based reablement in order to understand notions about what is thought to work in facilitating engagement, for whom, how and in what circumstances. As described earlier in this chapter, it started by identifying mechanisms. The analysis is based on the core sources listed again below. Two of the seven sources are studies based in Norway. It is acknowledged here that the way that people respond to reablement in Norway might be different to the way they respond in England due to different cultural and organisational factors. Nonetheless, the insights that these studies provided have helped to build theories that are subsequently refined in Stage 2 of the study which is conducted in an English context.

Authors	**Title**	**Year**
Glendinning, C, Jones, K, Baxter K, Rabiee, P, Curtis, LA, Wilde, A, Arksey, H, Forder, JE	Home Care Re-ablement Services: Investigating the longer-term impacts (prospective longitudinal study)	2010
Hjelle, KM, Alvsvåg, H, Førland, O	The relatives' voice: how do relatives experience participation in reablement?	2016
Jakobsen, FA, Vik, K	Health professionals' perspectives of next of kin in the context of reablement	2018
Pearson, M, Hunt, H, Cooper, C, Sheppard S, Pawson, R, Anderson, R	Providing effective and preferred care closer to home: A realist review of intermediate care	2015
SCIE	Maximising the Potential of Reablement	2013
SCIE	Role of Carers and Family – online video	2014
Wilde, A, Glendinning, C	'If they're helping me then how can I be independent?' The perceptions and experience of users of home-care re-ablement services	2012

The if-then statements that were taken forward for further refinement with research participants in Stage 2 of the study are analysed in four sections that correspond to the four themes:

Theme 1: Instilling and understanding of reablement (Section 4.10.1)

Theme 2: Customising service delivery to family circumstances (Section 4.10.2)

Theme 3: Empowering families (Section 4.10.3)

Theme 4: Skilled workforce (Section 4.10.4)

Following an analysis of the sources, each section concludes with a summary of aspects of Context, Mechanism (Resource and Response) and Outcome where these were apparent. At this stage in a realist synthesis it is sometimes possible to set explanations out as complete Context, Mechanism and Outcome Configurations (CMOCs). Although I experimented with doing this, it was agreed with the methodology consultant that it would not be productive to pursue this at this stage of the study. This was due to the high number of questions that remained regarding context in particular, limiting the possibility of identifying clear interactions between contexts and mechanisms and thus patterns in outcomes. Nonetheless, the process adopted proved to be a productive way of moving the conceptual framework on in order to explore causal links in greater depth in the next stage of the study. Each section of the analysis ends with some questions provoked by the gaps in evidence. The Findings Chapters that follow take up these questions and address them through fieldwork with study participants.

4.10.1 Theme 1: Instilling an understanding of reablement

The idea that families need to understand and know what to expect of reablement is a common thread that runs through the core sources considered under this theme. The following overarching if-then statement that relates to this theme is analysed here:

Statement 1

IF the principles of reablement are understood by service users and their family carers, THEN they will welcome or accept a more observational and encouraging approach, in spite of initial reluctance.

All of the core sources contributed evidence to add causal explanation to this statement. Evidence concerned families understanding the difference between reablement and traditional care, how, when and who instils that understanding and how families perceive their role in reablement.

Ensuring a good understanding of how reablement differs from traditional (doing for) homecare was cited as important (Glendinning et al., 2010; SCIE, 2012b). Understanding the difference can provide families with an appreciation of the fact that standing back provides service users with the opportunity to practise new skills. Standing back also allows the team and family to observe the service user's capability, providing an opportunity for ongoing reassessment and resetting of goals during the intervention. Additionally, gaining an understanding of the parameters of reablement was deemed to contribute towards avoiding unrealistic expectations (Wilde and Glendinning, 2012; Jakobsen and Vik, 2018), particularly for people who have had direct or indirect experience of traditional homecare but not of reablement itself (Wilde and Glendinning, 2012). For example, if reablement is considered by service users and their family to be an opportunity for respite and support for the family member or partner, then these expectations will not be met (Glendinning et al., 2010) and might result in a sense of abandonment at the end of the intervention (SCIE, 2012b).

The stage at which this information is imparted and its format is referred to in the literature. There is the suggestion that grasping the nature of reablement takes time. It might be unrealistic to expect people to understand it in one visit, or from written information alone (Wilde and Glendinning, 2012; Jakobsen and Vik, 2018). Receiving an explanation of the intervention prior to the first home visit might help some people to manage their perception of reablement as a risky intervention (Glendinning et al., 2010) but people who are still preoccupied by the stress of a change in the health of their relative might not be receptive at this stage (Wilde and Glendinning, 2012). Furthermore, confusion about the aims of reablement might be compounded if service users and their families have contact with large numbers of health and social care staff during discharge from hospital or following referral to reablement (Wilde and Glendinning, 2012).

There is some variation in the literature in terms of who is responsible for ensuring that families understand reablement. Sometimes the family is placed initially in the role of a somewhat passive recipient of information: having been given information, they can then move on to actively helping advise the service user on how to use the service (SCIE, 2012a; Hjelle, Alvsvåg and Førland, 2016). By contrast, the SCIE video suggests that families need to devote sufficient time and effort to understanding how reablement works in order to play a key role in assisting with the process (SCIE, 2012b). This source goes on to suggest that it is important for families to understand the time-limited nature of the intervention and that they may subsequently have to pay for services that follow it. Understanding these aspects might help families to make the most of the service during its provision. Conversely, there is the possibility that if families are concerned that effective reablement might lead to the removal of other services or reduce eligibility for other services, they might be motivated to resist reablement (Jakobsen and Vik, 2018).

Other contextual factors referred to in the literature relate to how families see their role in relation to their relative. The reabling process might be undermined if the family member perceives a need to care by “doing for” as opposed to “enabling” (SCIE, 2012; Pearson et al, 2015; Jakobsen and Vik, 2018). Related to this is the idea that some family members (in particular adult children) might be seeking from reablement the reassurance that their relative will receive traditional care and that this is more important to them than the idea of helping their parent to live independently (Hjelle, Alvsvåg and Førland, 2016). Jakobsen and Vik report circumstances in which the aim of reablement is emphasised to families as being to achieve increased independence, yet the importance of ongoing interaction between the service user and family member is not emphasised (Jakobsen and Vik, 2018).

Although the sources displayed a wide range of ideas on this theme, there was little examination of the ideas in depth. Aspects of Context, Mechanism (Resource, Response) and Outcome apparent in the sources are set out here:

Context	• Prior understanding and/or experience of reablement before delivery • Initial openness or resistance to the approach
Mechanism Resource	• Communication of the principles of reablement including: – how it differs from traditional homecare – that it is time-limited – that payment for ongoing services might follow
Mechanism Response	• Understanding the benefits of encouraging the service user to do things for themselves • Having realistic expectations of what reablement will achieve • Maximising or resisting the approach
Outcome	• Family gains an understanding of how supporting in a reabling way benefits the service user

Questions provoked by gaps in the evidence:

- What other contextual factors are important to consider?
- What is it about reablement that needs to be communicated to families?

Summary of Theme 1: Instilling an understanding of reablement

Instilling in families an understanding of reablement can be considered as an aspect of empowering them to engage with the intervention. Although there is a general acknowledgement across the sources of the importance of families understanding reablement, there is very little specification of different contextual conditions that might provide insight into what causes understanding to be achieved. What is more, the articulation of the intended and unintended outcomes of families achieving an understanding of the principles of reablement for both the short and longer term is largely absent. There appears to be potential to optimise this aspect of family engagement with reablement if it is understood in greater depth.

4.10.2 Theme 2: Customising service delivery to family circumstances

The engagement of families in reablement is often couched in what could be considered discretionary terms in the NICE guidelines. For example point 1.3.4 reads "Actively involve people using services (and their families and carers, as appropriate) in assessments for intermediate care and in decisions such as the setting in which it is to be provided" (NICE, 2017). When it is not expressed in discretionary terms, the advice relates to giving family information and providing them with opportunities to express their wishes and ask questions. It is possible that the expression involve family "as appropriate" is intended to recognise the very common situation in which the service user does not have relatives or friends who can be or are involved in their everyday life, rather than meaning only involve families and carers in certain situations. It is not clear which of these two interpretations of "as appropriate" is intended but either way, the recommendations do not extend as far as to suggest that family might be regarded as part of a wider care circle or part of the team itself. Two overarching if-then statements that relate to this theme are analysed here (5 and 7).

Statement 5

IF professionals respect families and carers and recognise their role as part of the whole care circle, THEN their role will be maximised.

In addition to ideas from the PPI group, four sources contributed to this overarching if-then statement (SCIE, 2012b, 2013; Hjelle, Alvsvåg and Førland, 2016; Jakobsen and Vik, 2018). Apart from the evidence derived from the Jakobsen and Vik study (which was by far the richest source of evidence for this area), the sources suggested very little contextual variation in terms of reablement teams valuing family. This meant that they predominantly focused on situations in which reablement teams do value family engagement, resulting in positive outcomes. They demonstrated very little examination of what happens when reablement teams do not value family engagement. These sources added less explanatory depth to the area than the Jakobsen and Vik study; an indication of how little in-depth analysis has been conducted into this aspect of reablement.

Some of the literature suggests that when reablement teams respect and empower families, recognising them as part of a whole care circle, this triggers family members to function as a valuable resource, contributing towards the independence of the service user (SCIE, 2012b; Hjelle, Alvsvåg and Førland, 2016). Another source suggests that it is important for this respect to be genuine (SCIE, 2013) and further, that if families perceive a lack of genuine recognition and appreciation of their role from the reablement team, this will prevent them from feeling engaged (Hjelle, Alvsvåg and Førland, 2016). An unintentional outcome, however, of regarding families as an extension of the reablement service, could be that some families might feel forced into a caring role (Jakobsen and Vik, 2018).

Jakobsen and Vik explore how health professionals perceive their collaboration with next of kin in reablement and include a consideration of circumstances in which the professionals consciously choose not to collaborate with families. Their study revealed a paradox:

> *Even if health professionals regard next of kin as important partners and useful to collaborate within reablement, they are concurrently not always sure there is a need to collaborate with or include them. One possible interpretation could be that the health professionals emphasise reablement as a person-centered intervention. This view of reablement involves showing respect to older adults by ensuring that they have the knowledge and information they need to make their own decisions in everyday life.*

Connected to this idea of respecting the service user primarily as autonomous, these researchers provide another potential explanation for why Reablement Workers might not always consider it necessary to collaborate with families. They suggest that Reablement Workers might not regard service users as dependent on their family or partner. In these cases, they might view involving family as taking autonomy away from the service user. Further to this, if the workers regard it as the responsibility of the service user to contact family, rather than theirs, they will not take responsibility for ensuring that the family is involved. The Jakobsen and Vik study suggests that if the Reablement Workers feel less certain or ambiguous about when and why to involve family members, then this lack of clarity could be transferred onto both the family and service user.

It was noted in the Jakobsen and Vik study that if reablement teams do acknowledge that families can support the service user, then they will feel more inclined to involve them and consequently families will be more likely to feel as though they are part of the team. The PPI group discussed these ideas. They made a distinction between working in collaboration with the reablement team and acting as an extension to the team. The latter was viewed as undesirable. They emphasised the importance of understanding the service user in the context of their family and social relationships and linked the idea of the reablement team adopting a family-centred approach to a suggestion that was made in the Jakobsen and Vik study:

> *Our suggestion to health professionals is to acknowledge that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning. A family-centered perspective may enable health professionals to develop a better understanding of next of kin in reablement.*

Aspects of Context, Mechanism (Resource, Response) and Outcome that were apparent in the sources are set out here:

Context	Reablement teams believe in the value of engaging families
Resource	Demonstrating respect Empowering families
Response	Family feels valued and empowered
Outcome	Family supports the process

Questions provoked by gaps in the evidence:

- What causes reablement teams to deem it desirable or undesirable to engage families in reablement?
- What can contribute to easing tension in cases where Reablement Workers do not believe in the value of engaging families?
- How do differences in the perception of independence between service user and family impact on reablement teams and outcomes?

Statement 7

IF the content of the intervention is designed with the family carer's needs as a crucial factor, THEN this will encourage their active participation.

Evidence was derived from six of the seven core sources for this overarching statement as well as discussions with the PPI group. Interestingly, the source that did not provide any evidence here was the SCIE video. Although this source focuses on the role of carers and families in reablement, it does not feature the voice of any carers or families themselves.

Under the provisions of the Care Act (Department of Health, 2014a), LAs must not presume that individuals are willing or able to take on a caring role. It is the LA's legal duty to offer carers a free carer's assessment if it is apparent that they need support. This assessment examines the sustainability of the caring role, including the carer's practical and emotional support needs. There is a danger that if the reablement team and the service user assume that a family member is willing and able to take on a particular role during and potentially after reablement, then discussions about goals could proceed without the family member's conscious assent and could lead to a sense of unease about their role (Pearson et al., 2015). The PPI group highlighted that it is the right of a family member to decide not to undertake a care role and that this should be recognised and acknowledged during the course of reablement. One of the studies found that if families are given the option to attend visits or not, then they are less likely to feel burdened by their involvement (Hjelle, Alvsvåg and Førland, 2016).

The literature refers to the practical and emotional support needs of families. It recognises that if the reablement team understands the needs of and pressures on family carers, then they can provide specific support for them in order to help them better manage their situation (Jakobsen and Vik, 2018). This could take the form of referrals to specific carer support services (Wilde and Glendinning, 2012). Moreover, if the team is alert to the fact that the support that family members are willing and able to offer could change over time, then expectations could be managed accordingly (SCIE, 2013). The PPI group discussed the fact that it is common for family to experience a shift in their role towards caring and suggested that this is something that might be difficult for them to both identify themselves and to articulate. In situations where family members are able to share with the team the feeling of being emotionally or physically burdened by their caring role however, then they could experience the service as a relief to them personally (Hjelle, Alvsvåg and Førland, 2016), as well as a relief to their relationship with the service user (Glendinning et al., 2010; Wilde and Glendinning, 2012). There was the suggestion that this might impact positively on concerns that families might have for what their role might entail after reablement too.

Receiving physical support as a family member during reablement is related but different to receiving emotional support. Glendinning et al. found that for some families, the work of the reablement team was perceived to be indispensable in providing physical help which would otherwise have been beyond their own capability. There is the suggestion here that this might lead to a sense of relying on the team in a way that would not be sustainable after the end of the intervention. Furthermore, the same study highlights the concern that if families welcome the support and regular social contact that they experience with Reablement Workers, then there is the possibility that they may be wary of losing these relationships and consequently may not "buy into" the reabling ethos.

This if-then statement relates in particular to the needs of families. The Glendinning study considers the ramifications of this, highlighting the fact that, if Reablement Workers understand that different family members have different needs, then information and support for them can be targeted to their particular needs. The study points to examples in the interviews conducted jointly with service users and their family carers in which male and female carers have different needs to one another. It also emphasises that reablement interventions that are designed to meet the needs of service users as well as family carers, in particular when the family carers have their own significant health problems, can be regarded as invaluable by all concerned. The study highlights the pitfalls of not supporting the needs of family carers:

> *Informal carers who received direct support or guidance from the re-ablement workers found this very helpful. Conversely, informal carers who were unsupported expressed significant worries about their own welfare and their diminishing capacities to provide for the service user or other family members and would have welcomed more advice on how to maximise users' independence and meet their own needs.*

The identification of a link between greater confidence on the part of families and having their needs met is an idea also expressed in one of the Norwegian studies (Hjelle, Alvsvåg and Førland, 2016). This study also identifies something that would be considered a context variation in realist terms; the fact that families might experience reablement as a change in their role towards and relationship with the service user, which might in turn impact on their sense of identity. The Norwegian researchers suggest that if reablement teams are aware of this, then they will be better placed to support families' emotional and practical needs.

> *Several [family] carers who had received advice about managing a service user's daily routines, or about their own carer-related needs, reported feeling more confident in their own roles as a result of re-ablement.*

Although participation in goal setting will be discussed more fully under if-then statements 11 and 15, it is noted here that one of the studies (Wilde and Glendinning, 2012) puts priority setting within reablement into a broader context of what independence means to individuals; both service users and family members. This study concludes:

> *Understanding service users' and carers' own priorities for recovery and the aspects of daily life that they consider central to their independence appears fundamental to successful reablement.*

Contextual factors cited in the literature that relate to this statement include the state of the family member's or partner's own health, the family's willingness and ability to take on a potential role within reablement, and how they perceive this role, as well as the degree to which they expect support for themselves from the reablement team. These are noted below alongside the family's own priorities for their everyday life both with and without the service user. Although the idea of independence meaning different things to different people was mentioned in one of the sources (Glendinning et al., 2010), it was not explored specifically in relation to family members. This is included as a hypothesised contextual factor below, alongside other aspects of Context, Mechanism (Resource, Response) and Outcome, apparent in the sources:

Context	Family's health and own support needs Family's ability and willingness to engage in reablement Hypothesised: What independence means to family and service user
Resource	Service design capable of taking into consideration family's needs, offering options for engagement
Response	Families feel their role is understood and recognised Families feel supported in undertaking the role they have chosen
Outcome	Enhanced level of trust and collaboration between team, family and service user

Questions provoked by gaps in the evidence:

- The context of willingness and ability of family is subject to constant change during reablement and might also differ between different family members. What characterises the different contexts of family willingness and ability?
- What sorts of resources can reablement teams introduce into the different contexts identified and to what effect?

Summary of Theme 2: Customising service delivery to family circumstances

The if-then statements in this group relate to the reablement team customising the way that they approach their delivery of the service based on an understanding of and respect for the service user's family, their needs and their willingness to engage with the intervention.

There was very little England-specific evidence found in relation to this aspect of family engagement in reablement. The discretionary terms in which the NICE guidelines suggest involving families "as appropriate" place an emphasis on the judgement of Reablement Workers to make decisions about when is appropriate and not. The synthesis of the sources points to a need to investigate how this judgement is made and applied. It also points to the need to understand more about contextual factors such as the degree to which Reablement Workers believe in the value of engaging families in reablement and what it is about this belief that triggers them to customise the way they work.

4.10.3 Theme 3: Empowering Families

This group of if-then statements is affected by what is prescribed in the particular service delivery model (such as formal processes that are in place to support family engagement in the various stages of reablement) and how families might respond. Sources relevant to the idea of facilitating engagement through the processes of service delivery were analysed. Many of the if-then statements under this theme were also discussed with the PPI group. If then statements 8, 11, 12 and 14 relate to this theme and are analysed in turn here.

Statement 8

IF there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties, THEN family carers would have an opportunity to provide input on the content of the reablement process.

Four of the seven core sources contributed evidence to this statement (Glendinning et al., 2010; Wilde and Glendinning, 2012; Hjelle, Alvsvåg and Førland, 2016; Jakobsen and Vik, 2018). Although it was only the two Norwegian studies that made an explicit link between process and action: having a formal process in place to facilitate input from families, and Reablement Workers translating this into action.

Families interviewed in the Hjelle study (which examined a 3-month reablement intervention) suggested formalising information and knowledge sharing with families in the architecture of the intervention:

> *The relatives in our study called for a system, a routine, a culture, and an attitude for sharing information and knowledge. We argue that such a system and routine could move collaborative practices forward.*

The Hjelle study researchers suggest that such a system could be characterised by a number of resources such as a telephone call to families to initiate collaboration, a process to invite them to the first and subsequent reablement meetings, and routine contact from the reablement team, with the option to communicate with the team by telephone. They consider that these resources provide the potential to enable families to share and discuss information and knowledge about their relative and how they are progressing, even if they live some distance away, thereby strengthening their involvement in the process. They perceive that this dialogue between the reablement team and the family (separate from and/or in addition to discussions held in the presence of the service user) would lead families to feel confident that the service user had told the team everything of relevance. Routine contact of this sort could also give reablement teams an idea of how the family sees their relative's situation and could generally enhance collaborative practices. They recognise, however, that if families feel obliged to be at all meetings, they might experience collaboration as a burden. The PPI group echoed the potential benefit of providing families with opportunities to speak to Reablement Workers when the service user is not present.

If there is no system in place to include families as partners in reablement in this way, there is the possibility that even if reablement staff are aware that families are involved in some way in the reablement process, this will not translate into active collaboration (Jakobsen and Vik, 2018). Hjelle refers to Glendinning et al.'s observation that the form that communication takes is important. For example, if information about reablement is given initially in written form, then this could easily be overlooked, mislaid or forgotten. It is theorised that language barriers and literacy levels might also mitigate against this as an effective means of communication for some family members. If for this reason, or for other reasons, the family relies on the service user for information about the service and their progress with it, then they might not get a full understanding (Glendinning et al., 2010). On the other hand, if they have opportunities to chat to Reablement Workers on a regular basis, this could provide them with valuable opportunities to address areas of unmet need in a relaxed way, ultimately reinforcing the reablement process. They suggest that this sort of interaction could help Reablement Workers in turn to communicate with service users. SCIE suggests that the presence of relatives during Reablement Workers' visits presents an opportunity to resolve any uncertainties about the aims of the intervention.

Aspects of Context, Mechanism (Resource, Response) and Outcome apparent in the sources were:

Context	Where and when information exchange takes place – when families are physically present or not and whether service users are present at the time How consistently processes for information exchange are applied Reablement Worker belief in the value of family input
Resource	Formal organisational processes that support Reablement Workers to implement information and knowledge exchange
Response	Reablement Workers feel encouraged to value the family's input Families feel knowledgeable about reablement and feel confident to input into it
Outcome	Families engage with opportunities for information and knowledge exchange

As much of the evidence here is from Norway, questions provoked by gaps in the evidence need to be addressed in an English context:

- What is it about routine communication that can trigger Reablement Workers to involve families in the reablement process?
- What is it about routine communication that can trigger families to provide input into the reablement process?

Statement 11

IF family carers are informed about how to support and motivate their relative, THEN this will support them in their role.

All of the sources except one (Pearson et al., 2015) contributed to this overarching if-then statement, including the PPI group. It was clear that what is considered to be relevant input in terms of information, advice and training will vary. For example, if families are given advice on safer ways of accomplishing tasks, then their concerns about risks could be allayed (Glendinning et al., 2010). If they are used to doing things for their relative, then they could be trained how to stand back (SCIE, 2012b). If the support, information and training is targeted to the role that the family is undertaking in reablement, then this could equip them to support and maximise the capabilities and independence of the service user (Glendinning et al., 2010; Wilde and Glendinning, 2012; Jakobsen and Vik, 2018), and if families are included in discussions about how to apply the approach, then they might be able to learn new ways of coping (Glendinning et al., 2010).

In Norway there is an emphasis on physical training in reablement which does not feature to the same degree in services in England. The Jakobsen study refers to the characteristics of the service studied as follows:

> *The professionals collaborated and assisted the older adult (65+ years) with an individual physical training program and practising everyday activities important to helping the older adult towards their goals. The reablement intervention often lasted for 4–6 weeks, and during this time, the older adult received reablement from either a therapist or health professional from the home care services, often called a home trainer, up to five times a week.*

The Hjelle study worked with a service that was characterised as having the following standard features (Hjelle, Alvsvåg and Førland, 2016 p4):

- Minimum one hour/week physiotherapist and/or occupational therapist-assisted training
- Repetitive training and multiple home-visits by health care personnel, who were present during daily training for the purposes of building confidence and relearning skills
- All health care personnel stimulated the participant in self-management and self-training
- Practising exercises and undertaking the daily living skills tasks were all considered "daily training"

Personalised features included:

- Training in daily activities, such as dressing, food preparation, vacuuming, bus transport, visiting friends at a club, or being able to knit
- Adaptations, such as advice on appropriate assistive technology or adapting the activity itself or the environment to simplify activity performance
- Exercise programs, such as indoor or outdoor walking with or without walking aids, climbing stairs, transferring, and performing exercises to improve strength, balance or fine motor skills. The exercises were incorporated into daily routines and the person was given a manual explaining each of the exercises and encouraged to train on their own

In this context, where training is an overt part of the resource offered, and where families are educated in how to support that training, then the Hjelle et al. study concludes that the family will feel more involved in the process and will consequently feel part of the team. This study identifies examples of skills training as including personal care, feeding, swallowing, transfers and mobility activities and suggests that receiving training relating to these skills will empower families to a greater degree than receiving advice or support, or enhancing their psychological competence. The English sources, by contrast, suggest that it is helpful for family members to be present when equipment is installed in order to develop an understanding of how to operate it (SCIE, 2013). If this equipment can only be used with the assistance of a Reablement Worker, then feelings of dependency will result (Wilde and Glendinning, 2012). The desirable outcomes in the English studies focus on supporting the service user rather than on family becoming part of a team alongside the reablement practitioners, or on preparing them for their role once reablement is over. There is little detail in any of the studies about information, support and training that could be offered to families.

Aspects of Context, Mechanism (Resource, Response) and Outcome that were apparent in the sources are set out here:

Context	Not explicit other than identifying family's care role at the time of reablement delivery
Resource	Providing individualised information, advice and training to families in line with reablement goals
Response	Families feel confident, capable and motivated to support reablement routines while looking after their own welfare
Outcome	Families support the service user's daily routines

Questions provoked by gaps in the evidence:

- What contextual factors are important to consider in relation to empowering families to engage with reablement?
- What sorts of resources to empower families are relevant in England?
- Into what contexts can the different resources be applied and to what effect?
- To what degree is a good understanding of a reabling ethos necessary in order to make the most of these resources?

Statement 12

IF family carers are regarded as a resource by the reablement team, THEN they will be able to reinforce the reablement team's work by supporting and motivating the service user.

Contextual data for this statement was weak in the literature. However, some circumstances that were described helped to theorise contexts. One such example is the circumstance in which culture plays a key role. Families can be used to explain choices to service users, contributing towards a richer understanding of cultural preferences and what service users understand by independence (Wilde and Glendinning, 2012). In fact, the consideration of cultural factors was weak throughout the literature. Another contextual variation is when reablement teams experience frustration due to lack of time to carry out and follow up the intervention. In these circumstances, it is proposed that regarding family as a resource might be helpful (Jakobsen and Vik, 2018). An Operations Manager for a reablement service that was featured on the SCIE video suggests that a trigger for families to become involved as a resource might be when they witness the positive results of reablement (SCIE, 2012b):

> *If we can get somebody's engagement, then normally it's a pretty smooth process in moving people on. And I think that's where families also, once they see their relative's improving and actually doing things that perhaps they hadn't seen them do for some time, they also get very engaged and they then also take some responsibility for actually encouraging them to do things.*

This suggests a link between families seeing the benefits of reablement before being able to consider contributing to it as a resource themselves. Aspects of Context, Mechanism (Resource, Response) and Outcome that were apparent in the sources are as follows:

Context	Unclear from sources Time pressure felt by reablement team on achieving aims within time limits of reablement
Resource	Reablement teams draw on the family's knowledge of the service user's preferences including cultural preferences Reablement teams treat family as a useful resource to help achieve reablement goals both during and after reablement
Response	Families are stimulated by seeing their relative make progress to become more involved themselves
Outcome	Family becomes motivated to encourage and support the service user in a reabling way

Regarding the family as a resource appears to span a number of the if-then statements under themes 2, 3 and 4. The evidence, however, is very patchy and questions provoked by gaps in it include:

- What causes or prevents Reablement Workers from regarding families as a resource and in what contexts?
- If families are regarded as a resource for reablement, what factors contribute to establishing them as such?
- What if any link is there between demonstrating to families what is achievable by involving them as a resource and their motivation to support the service user in a reabling way?

Statement 14

IF family carers are advised on how to carry out routines after reablement is finished, THEN their confidence in their own ability to provide care and safeguard their own welfare will be increased.

Two of the sources contributed to this overarching if-then statement (Glendinning et al., 2010; Wilde and Glendinning, 2012), although neither examine it in great detail. Neither of these sources seek to unpick contextual factors that could impact on the way families experience transition from reablement. The first (Glendinning et al., 2010) provided these reports:

> *Several carers felt more confident about their caring responsibilities after re-ablement, especially where information about managing daily routines was passed on from the re-ablement team, or advice relating to their own needs was given. However, some carers were disappointed that they received no support or advice.*
>
> *A third man reported that he felt much more confident in his abilities to provide care for his wife and safeguard his own welfare after being advised on how to carry out their morning routine after re-ablement finished.*

This study concludes with recommendations relevant to this statement:

> *The role and contribution of informal carers to re-ablement warrants further consideration. Several carers who had received advice about managing a service user's daily routines, or about their own carer-related needs, reported feeling more confident in their own roles as a result of re-ablement. Others found the provision of equipment like hoists was also helpful. Most of the small sample of carers interviewed in this study would have liked more involvement in re-ablement and advice on how to maximise the service user's independence.*

The second study cites confidence derived from learning more structured ways of meeting their relative's needs and learning new ways of carrying out daily care routines as a perceived benefit of reablement for families.

Aspects of Context, Mechanism (Resource, Response) and Outcome apparent in the sources were as follows:

Context	Unclear from sources
Resource	Teaching families how to meet their relative's needs during and after reablement
Response	Families feel confidence in applying newly learned support skills, while looking after their own welfare
Outcome	Families continue to support daily routines after reablement

Questions provoked by gaps in the evidence:

- What is it about the way that learning is passed on to families that is likely to improve the chances of its adoption during and after delivery of the intervention?
- It is notable that outcomes expressed in the sources do not refer to continuing to apply a reabling approach beyond reablement. How are outcomes for empowering families to adopt the approach articulated if at all?

Summary of Theme 3: Empowering Families

The if-then statements under this theme relate to actions that can be taken to facilitate family engagement in reablement in different ways. Many of the statements refer to procedures that might or might not be explicitly prescribed by the service. Some of these can result in the exchange of information and knowledge between reablement teams and families; others might result in upskilling families.

There were gaps in evidence, particularly in relation to evidence specific to England for this group of if-then statements. Notably, there is little consideration of either intended or unintended outcomes of facilitating families to engage in reablement. This not only relates to articulating what the benefits and impacts of facilitating engagement might be during reablement but also to what the benefits and impacts of engaging families might be in the longer term.

Related to this is the idea of regarding families as a resource for the reablement team to draw on. There are gaps in the evidence about how reablement teams regard families; as a resource during reablement, as co-workers during reablement, as a co-client or as a source of potential future support for the service user.

There was insufficient detail in the sources about the everyday practice of involving and engaging families; how Reablement Workers motivate families to motivate service users; how they elicit useful information to assist in goal setting and assessment; and how they facilitate families to engage in a reabling way rather than in a hands-on way. Although ideas about contexts, mechanisms and outcomes have been sketched out for this group it is clear that theories need further investigation and refinement with input from reablement practitioners and families. This would serve to suggest what might work for different people in different circumstances, to what end and how.

4.10.4 Theme 4: Skilled Workforce

The final group of overarching if-then statements relates the reablement team's skillset, particularly in relation to negotiation and mediation with families. It also encompasses the balance between respecting service user autonomy whilst also involving family in decision-making. The PPI group's valued contributions to ideas falling under this theme are included. Statement 15 is the focus of the analysis here.

Statement 15

IF the reablement team is able to negotiate and manage different expectations and opinions, THEN this will enhance collaboration.

This statement is derived from data drawn from four of the sources (SCIE, 2013; Pearson et al., 2015; Hjelle, Alvsvåg and Førland, 2016; Jakobsen and Vik, 2018). Differences of opinion and conflict can arise in any situation where judgement is used. In times of stress, where poor health is evident, it is likely that emotions will affect that judgement. Although the potential negative impact of unresolved conflict on integrated working is alluded to in the sources (Pearson et al., 2015; Hjelle, Alvsvåg and Førland, 2016), the causes of differences of opinion are not examined in detail in any of the sources reviewed.

One study asked health professional participants in a focus group how they experienced dilemma with next of kin in reablement (Jakobsen and Vik, 2018). The study reports:

> *The health professionals experienced how they assessed the need for assistance differently from the next of kin. This was seen particularly when the health professionals perceived the older adult's everyday performance as better than their next of kin did. One registered nurse from the rural home care group said that in such cases: "It was difficult to disagree with next of kin". Several of the participants from the focus group discussions pointed out that the consequences of these situations could be exhausting and unpleasant for them. They had to spend extra time persuading and negotiating with next of kin concerning whether reablement was the right type of assistance for their older adult.*

This question is not unpicked further in the source but raises a number of issues, such as varying perceptions of performance and need (which could potentially be gauged differently by all three parties), the time and skills required to negotiate with family, and the strength of influence of family. The last of these points in particular is echoed in another study which looks at home-based intermediate care in general rather than reablement specifically (Pearson et al., 2015):

> *The nature of existing relationships within a person's home is such that a professional cannot simply 'over-rule' a carer's input (Martin et al., 2005). Professionals may find this mismatch in expectations highly frustrating and hard to deal with, resulting in some carers being labelled as difficult, resistant or obstructive (Dow and McDonald, 2007). Providing ways for professionals to address these frustrations and subsequently engage with carers and collaboratively develop care plans is therefore vital for the delivery of integrated working. Of course, this process may differ substantially depending on the agreement or otherwise between the initial expectations of carers, service users and professionals.*

Another aspect of the strength of family influence is the impact that this might have on service user autonomy. If there is disagreement between the service user and their family member on the content or delivery of reablement, then it is important that the reablement team can manage this, while respecting the service user's autonomy (Jakobsen and Vik, 2018), ensuring that they do not experience reablement as disempowering (Hjelle, Alvsvåg and Førland, 2016). SCIE refers to this potential difficulty in relation to goal-setting specifically (SCIE, 2013 p13):

> *Where appropriate, the individual's family and friends should also be involved in goal-setting. Any conflicting or opposing views about suitable goals must be negotiated sensitively and with professional judgement.*

Elsewhere in this source (ibid p21) there is reference to drawing on the judgement and mediation skills of social workers in dealing with conflict between service users and family:

> *If family and friends provide regular support to the individual, they should be invited to participate in the assessment process and development of the care plan. This is usually undertaken by a social worker prior to referral to the reablement service. Where conflicts arise, social workers will use their professional judgement and skill to mediate the individual's and the families' views and needs.*

It should be noted, however, that although social workers are sometimes involved prior to reablement, or at initial goal-setting in some services, it appears to be relatively uncommon in England for social workers to be a formal part of the reablement team in an ongoing capacity (Beresford et al., 2019). The Jakobsen study, which explores family involvement in reablement from the perspective of the reablement team, endorses the need to set aside time to manage different perceptions. In particular, the professionals involved as participants in the Jakobsen study expressed the view that family have a tendency to underestimate their relative's capability and that time needs to be devoted to addressing this difference in estimation. The PPI group, by contrast expressed the same idea but from the relatives' point of view. They determined that service users are inclined to overestimate their own ability. Furthermore, they stated that it is not uncommon for the service user to lack a full appreciation of the amount that family members generally do. It is therefore important for Reablement Workers to regard families as the "experts in their own experience". They pointed out that in situations where families want to be involved in reablement, if they are involved in goal-setting then this difference of perceptions might be minimised. The group categorically stated that if service users make decisions without the involvement of their family, then the family will not "buy into" the process and are likely to be disruptive. This discussion provided some causal insight into conflicting expectations, but pointed to a need for further analysis of these mechanisms. In terms of finding ways to avoid or deal with conflict, one of the Norwegian studies (Hjelle, Alvsvåg and Førland, 2016) recommends having a process and structure for decision-making that allows for the voices of all involved in reablement to be heard. It suggests that such a process could work to strengthen collaborative practice.

Contextual detail was weak for this theory. It could be theorised that the nature of a family member's relationship to the service user, both their affiliation (spouse, sibling, adult child), as well as the dynamics of their existing relationship - could impact on how conflicts arise and are resolved. In addition, if there is more than one family member involved in the service user's life at the time of reablement, the potential for conflict between these members could be an additional level of complexity for Reablement Workers to manage. There was the suggestion that some family members underestimate their relative's capability, but the reverse might also be possible. This, combined with the way that the families view their role (for example as "doing for" rather than "re-enabling"), might or might not be a significant aspect of context but requires deeper exploration and richer sources of evidence.

Aspects of Context, Mechanism (Resource, Response) and Outcome apparent in the sources area set out as follows:

Context	Unclear from sources. Likely to be highly varied but include: Family underestimate the ability of the service user Family provide too much hands-on care
Resource	System to support decision-making that allows all voices to be heard Staff applying skills in negotiation and mediation Time to devote to addressing issues
Response	Frustration and exhaustion felt by Reablement Workers Feelings of mutual trust and respect
Outcome	Time taken away from working with the service user Differences of opinion persist or dissipate

Questions provoked by gaps in the evidence:

There are a great many gaps in evidence here. There appears to be a great deal of potential to unpick this statement further as the sources touch on a number of issues between them but do not go into enough detail to innovate practice on any of them. If differences of opinion are not resolved during reablement, there is the danger that disagreement could easily disrupt and undermine the intervention during its delivery and impact on the likelihood of its benefits being sustained after delivery. Core questions are:

- What contextual issues typically give rise to conflict with families?
- What resources do reablement teams introduce to situations of conflict and to what effect?
- What are the outcomes of resolved and unresolved conflict with families?

Summary of Theme 4: Skilled Workforce

The if-then statements under this theme related largely to the expertise of reablement teams in negotiating with families and service users when disagreements or resistance arise. Although there is an identification of the need for this expertise (typically within the core skillset of a social worker), there are gaps in the evidence regarding its importance for Reablement Workers, and gaps regarding how negotiation skills might be acquired, supported and applied. Equally, there are gaps in the evidence about what causes families to experience frustration and the longer term impact that frustration might have on sustaining the benefits of the reabling approach beyond service delivery. The lack of evidence presented difficulties for identifying aspects of context, mechanisms and outcomes for this group. Several ideas were identified, however, that if explored in greater depth with stakeholders, could result in more refined theories. These related in particular to tensions presented by keeping a focus on the service user's autonomy, while respecting the family, and the role of negotiation in managing these tensions. Chapter 7 presents the findings of fieldwork that examined this theme in more detail.

4.11 Refining programme theories – next steps

In the course of iterative refinement of programme theories in a realist synthesis, a decision needs to be made with regard to when and whether further searching of the literature is required. I was aware from published protocols that further studies were underway scrutinising reablement, for example a large-scale mixed methods evaluation of reablement in England, subsequently published in 2019 (Beresford et al., 2019) and a multicentre investigation of reablement in Norway, also published in 2019 (Langeland et al., 2019). As the synthesis had produced a high number of potential theories in the form of if-then statements before the publication of these studies, I decided to conclude the synthesis at this point and to move on to further refinement of the selected theories with input from stakeholders, rather than conduct a further search of the literature to inform the synthesis.

4.12 Chapter summary: drawing conclusions

The final stage of a realist synthesis uses the results of synthesising and analysing the data from the sources to address the aims and objectives set out at the start. As well as summarising the chapter, this section reflects back on the aims and objectives, the degrees to which they have been met, how this was achieved and how the results informed the next stage of the study.

As described at the start of this chapter, the aim of the synthesis was to contribute insights that would begin to address a gap in understanding causal explanations for what works when engaging families in older people's home-based reablement.

The objectives of the synthesis were:

- To explore existing documentary evidence on the engagement of families in older people's home-based reablement in order to understand notions about what is thought to work in facilitating engagement, for whom, how and in what circumstances.

- To synthesise the most relevant documentary evidence, using realist methods, in order to build and refine programme theories for facilitating the engagement of families.

- To use the findings of the synthesis to inform further refinement and validation of the programme theories with reablement practitioners, family members and service users.

With a view to framing causal explanations based on the sources, the following three questions were explored through the synthesis:

1. What contexts are relevant to explanations for the ways in which reablement teams engage families in older people's home-based reablement?

2. What mechanisms can be identified that act at the level of the family, service user and reablement service in these contexts?

3. What outcomes are sought for the engagement of families in home-based reablement and which contexts and mechanisms are thought to affect them?

The synthesis started by combining input from stakeholders in the formative stages of the research with current guidance on delivering reablement as it refers to families (SCIE, 2013; NICE, 2017) in order to formulate eight Candidate Programme Theories. The Candidate

Programme Theories threw up a number of questions about what sorts of assumptions lay behind the guidance that had informed them. These were unpicked during the course of the synthesis by referring to a range of academic and non-academic evidence sources. By means of a highly iterative process of data sourcing and extraction from the literature, the eight Candidate Programme Theories led to the identification of 18 if-then statements which were analysed in four thematic groups. This approach allowed for the relationships between and within a very broad range of factors to be examined. The realist approach involved juxtaposing sources, adjudicating between and/or reconciling them, consolidating findings into provisional explanations, and identifying rival explanations (Pawson, 2006b; Pearson et al., 2013). Using the "if-then" structure was a useful means of working with the mix of abstract ideas and concrete examples that were located in the sources. The 18 if-then statements and their analysis represent a considerable step forward in refining the initial 8 Candidate Programme Theories. They span the entirety of the reablement journey and beyond it, offering a more holistic view than had previously been possible.

Although it did not prove productive to formulate full CMO configurations at this stage, mechanism resources and responses in particular were identified. Some of the mechanism resources related, for example, to processes and skillsets. Some of the mechanism responses describe aspects such as feeling understood, recognised and supported. There are suggestions in some of the statements that contextual factors can have a key influence on how families are facilitated to engage (e.g. whether the Reablement Worker values involving family). Additionally, in circumstances with constantly changing contextual factors, the impact of trying to engage families may be limited (e.g. changes in the willingness and ability of families to act as a resource for reablement teams, combined with changes in the health of the service user).

Rather than producing a final judgement on what works or size of effect, the synthesis gave rise to a rich set of new theory-driven insights and a range of questions about existing understanding that could direct further investigation. As far as I am aware, this is the first realist synthesis exploring what works when engaging families in reablement. It exposed gaps in understanding about contextual and causal factors associated with facilitating family engagement. It also exposed gaps in thinking about how engaging families might contribute to optimising the impact of the intervention as a whole, in the short and longer term. The products of the synthesis, 18 if-then statements and their analysis, provided a conceptual framework that appeared to hold potential to contribute to reablement guidance and practice, if scrutinised further. Due to time and resource restrictions of the PhD study, a pragmatic decision was made to select eight if-then statements for further exploration.

The synthesis suggests that mechanisms relating to four conceptual themes might have an important part to play in optimising the engagement of families in reablement. These themes cut across the if-then statements as well as the Candidate Programme Theories and provided a means of structuring the next stage of the research. The next chapters represent Stage 2 of the study. Following a chapter describing the methods employed in this stage (Chapter 5: Methods 2), are four findings chapters organised according to the conceptual themes:

Chapter 6: Instilling an understanding of reablement (Theme 1)

Chapter 7: Skilled workforce (Theme 4)

Chapter 8: Customising service delivery to family circumstances (Theme 2)

Chapter 9: Empowering families (Theme 3)

Chapter 5: Methods 2 - Fieldwork

5.1 Introduction

This chapter introduces the second stage of the study, in which fieldwork was conducted. It presents the design and methods associated with this stage including the selection and recruitment of the research partner organisation and participants as well as the data collection, coding and analysis methods.

The realist synthesis had produced a set of theory-driven insights relating to instilling an understanding of reablement, customising service delivery according to family circumstances, ways of empowering families to engage and the skills required of the workforce to work with families. However, gaps in explanations remained in understanding contextual and causal factors associated with these areas, meaning that the full realist CMOC heuristic had not been used at that stage of the analysis. In order to explore the causal factors behind the explanations more deeply, I devised a means of refining a selection of the if-then theory statements with input from a range of perspectives within a single reablement service. In keeping with a realist approach, this provided an opportunity to identify contexts relating to the circumstances of different families, to explore resources introduced into the contexts by reablement teams and to seek to explain responses to them.

Sometimes a realist synthesis leads directly into a realist evaluation. Realist evaluation is a theory-driven approach to evaluating an intervention that uses data collected by the evaluators. These data relate to the implementation of the intervention and are used for further theory development and testing. Ideally, contexts, mechanisms and outcomes are all made explicit in advance of designing a realist evaluation in order to focus the data collection on testing interactions between all three. In some circumstances, CMOs can be developed concurrently, in which case they become a product of the evaluation, as opposed to being used as a design tool. However, it is not possible to undertake a CMO analysis with no outcomes data (Westhorp, 2014). Facilitating the engagement of families in reablement is not yet established as a distinct aspect of implementing reablement. There is no set of resources that are applied to any systematic degree in engaging families, nor a widely accepted specification of the intended outcomes of engaging them. For this reason, undertaking a full realist evaluation would have been premature at this stage. Instead, and in discussion with the supervisory team, I followed the realist synthesis with fieldwork intended to collect data to refine further the theories developed through the synthesis, paving the way for potential future research.

The fieldwork was undertaken with a Local Authority reablement team and this chapter explains the selection and application of the methods used. As described in the first Methods Chapter (Chapter 3), realist approaches do not rely on a rigid set of associated methods or prescriptive methodological guidance. Although the fieldwork was not designed as a full realist evaluation, the data collection and analysis methods described and justified in this chapter cohere with the RAMESES quality standards for realist evaluations (The RAMESES II Project, 2017). I used realist interviewing which is explicitly consistent with realist methodology as well as a group format which is less commonly used.

5.2 Ethics

Ethical approval was granted by the University of the West of England, Bristol on 18 July 2018 for Phase 1 of the fieldwork and on 18 July 2019 for Phase 2. Approvals for undertaking the research with the Local Authority were granted through its research governance process on 28 November 2018 for Phase 1 and 7 October 2019 for Phase 2 by the Adult Principal Social Worker, Head of Service for Mental Health and Area Services. Please see Appendix U.

5.3 Research team and reflexivity

I made efforts to reflect critically on the influence of my own experience on the study as described in Chapter 3. Reflection was supported in particular by regular supervisory team meeting discussions, consultations with Dr Justin Jagosh and discussion with a network of realist researchers. Regular contact with the research partner organisation in the development of the approach to the fieldwork also contributed to reflexivity. I continued to use a reflective journal to capture reflections on both progress and process during the fieldwork. Some reflections chartered the emotional journey of the research and show my increasing resilience, others provided observations about research participants, adding contextual insights to their data.

5.4 Selection and recruitment of the research partner organisation

As described in Chapter 3, I had established contact with three Local Authorities in the formative stages of the study. One of these was selected as being in the best position to partner with. The relationship with this Local Authority's Director of Adult Social Care and Head of Service for Reablement, Intermediate Care and Regulated Services had been established through a series of meetings in the early stages of the research. None of the relationships with the research team or research partner pre-dated the study.

The fieldwork was undertaken as a single centre study in this Local Authority's area - an English city with a population of over 460,000, with people aged 65 and over representing 13% of the population (ONS 2019 mid-year population estimate). The Local Authority's reablement service is delivered in three geographical areas of the city and forms part of a broader intermediate care service. Service users can be referred to the service from hospital or through an intermediary agency by means of self-referral or referral by a friend, relation or a health professional.

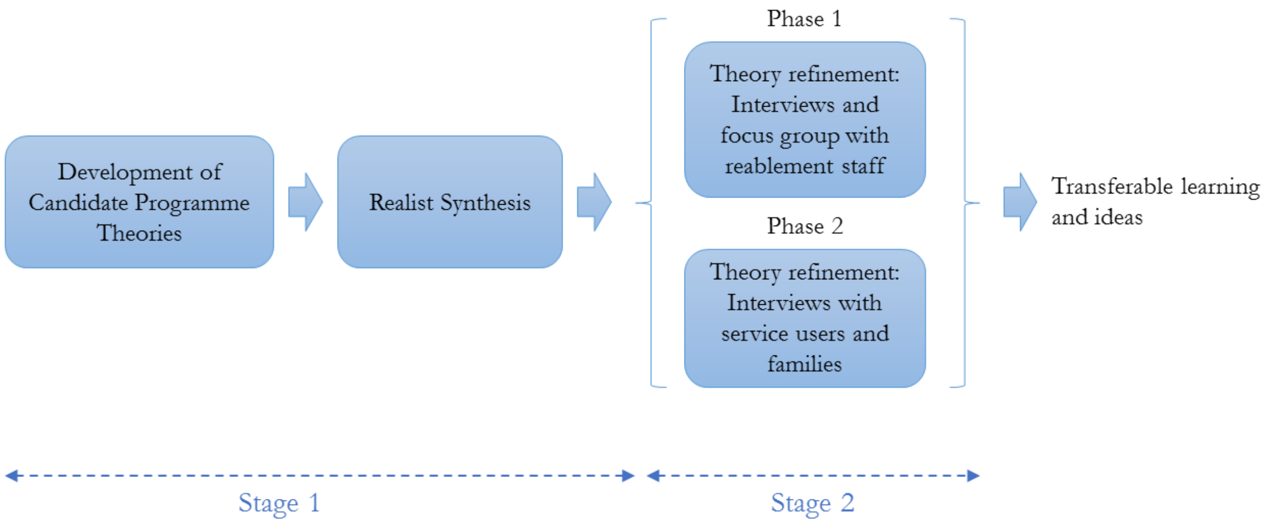
The Head of Service for Reablement, Intermediate Care and Regulated Services provided access to the research site - one of the city's three service delivery areas. This area includes some of the city's most deprived neighbourhoods. It has a below-average Black, Asian and Minority Ethnic population for the city. The approach to the fieldwork and the recruitment of participants at this site was designed and agreed with the site's Service Manager and Team Manager. The Team Manager was designated as the key contact and gatekeeper. They managed six Senior Reablement Workers, an occupational therapist, 40 Reablement Workers and a referrals coordinator, all of whom were direct employees of the Local Authority. All participants were recruited from staff and service users associated with this geographical area of the service.

I maintained regular face-to face meetings and communication via email and telephone with the Team Manager during the fieldwork alongside occasional updates to the Service Manager. The Director of Adult Social Care and Head of Service for Reablement, Intermediate Care and Regulated Services also received occasional updates predominantly via email. The PPI group which was established during the synthesis stage of the study met again during the fieldwork stage. Their input to this stage is described in section 5.9.2.

5.5 Fieldwork design

The fieldwork took place in Stage 2 of the study in two consecutive phases. The first phase was with reablement staff and the second phase was with service users and their family members. Qualitative data collection methods were selected as being best suited to continuing to refine the theories developed in the realist synthesis and to explore the research questions in a realist way.

Figure 11: Placing of fieldwork within the stages of the study



5.6 Selection, sampling and recruitment of research participants – Phase 1

Staff participants were recruited in two ways according to two data collection methods; face-to-face interviewing and a focus group. The largely purposive approach was determined to provide a sufficient sample to allow for theory development while being practically manageable within the context of the postgraduate study. More detail about the methods themselves are explained in the next section.

For the interviews, I recruited five staff members with potential to offer different insights (Manzano, 2016). Initially the Team Manager invited a representative of each of the team roles within the service to individual meetings with me. Reablement Workers were not included here as their insights were gained by means of a focus group. The purpose of the initial meetings was to introduce potential participants to the study and discuss their questions. I talked through the study with them and left them with an information sheet (Appendix V). This sheet gave them a means of asking further questions and provided a way of giving them time to determine whether or not they would like to participate. The selection of participants encompassed a range of roles (See Table 10). Everyone who was approached subsequently consented to participate.

In advance of recruiting Reablement Workers to a focus group, I attended two team meetings for Reablement Workers. At the first meeting I attended predominantly in the capacity as an observer but also provided the team with a brief introduction to the research in general terms. In the second meeting, I updated the team on progress with the research, introduced the idea of running a focus group with them and discussed initial queries about it. Different Reablement Workers attended the two meetings. The Team Manager agreed to select a sample of Reablement Workers for the focus group. I requested that the sample represent some people who had previously worked in other care environments (e.g. rehabilitation, care homes, traditional home-care) as well as people who had not, as well as people who had been with the service for differing lengths of time. Depth of experience of interacting with family members and the amount and type of experience that they had had were likely to be of interest. I explained that a sample of between six and eight participants would be required for the focus group (Barbour and Kitzinger, 1999). Due to the way that rotas were devised it was recognised that it would not be possible to confirm very far in advance of the focus group who would participate. All the Reablement Workers in the service were women and were white British. The potential focus group participants selected by the Team Manager were given the option to participate or not. Six Reablement Workers took part (See table 10).

These samples were determined according to realist principles. Rather than being driven by notions of data completeness, in realist inquiries choices about sampling are driven by the ideas under investigation, the cases being examined are used to work out the relation between ideas and evidence. It is not the size of the sample that is key but rather how cases are used to interpret and explain the contexts, mechanisms and outcomes under investigation (Emmel, 2013). This means that in practice the sample size is unpredictable. It is suggested that the sample size is continually reviewed during the interview process (Manzano, 2016). This approach to sampling is similar to that of theoretical saturation adopted traditionally in a grounded theory approach (Patton, 2015). Theoretical saturation is considered to have been reached when all potential sources have been sufficiently explored and ongoing collection of data no longer adds novel insights. I recognised, therefore, that it was likely that although it was desirable to collect a large amount of data for the realist inquiry, this did not need to be derived from a large sample of participants. Manzano expresses the rationale for this as follows:

> *"Since the unit of analysis is not the person, but the events and processes around them, every unique programme participant uncovers a collection of micro events and processes, each of which can be explored in multiple ways to test theories."* (ibid p.348)

I kept the option open to request interviews with further participants and/or a second focus group if this was deemed necessary. This judgement was made based on a process of reflection following each interview which fed dynamically into the next interview.

Participants' job roles are listed here. I assigned all research participants pseudonyms and devised a coding system to ensure that any identifying information could not be associated with the pseudonyms. These are used throughout the findings chapters (Chapters 6-9).

Table 10: Study participants' pseudonyms, job roles and years of experience

Pseudonym	**Job role**	**Abbreviated job role (if used)**	**Total years working in care (incl reablement)**	**Number years working in reablement**
Beryl	Service Manager		32	4
Jenny	Team Manager		29	8
Michael	Occupational Therapist	OT	2	2
Susan	Senior Reablement Worker	Senior RW	18	14
Lou	Referrals Coordinator		11	4
Claire	Reablement Worker 1	RW	16	14
Libby	Reablement Worker 2	RW	15	14
Caroline	Reablement Worker 3	RW	3	3
Ellie	Reablement Worker 4	RW	21	14
Jacqueline	Reablement Worker 5	RW	18	9
Denise	Reablement Worker 6	RW	21	3
Jo	Service user	SU	N/A	N/A
Ron	Service user's husband	Family member	N/A	N/A

5.7 Selection, sampling and recruitment of research participants – Phase 2

Initially the aim of Phase 2 of the fieldwork was to investigate whether and how a reabling approach is sustained after service delivery, with former service users and their cohabiting partner or family member (dyads). I wanted to explore whether and how reablement takes on a life of its own after the reablement team has left. The focus was on former service users over the age of 65 and their co-habiting partner or family member who had capacity to consent.

The approach to recruiting these research participants was devised with the Service Manager and Team Manager in order to ensure it was practical. The Team Manager facilitated recruitment by asking Senior Reablement Workers to identify potential study participants, ensuring that all new referrals who met the study criteria were informed about the research study. Nonetheless considerable difficulty was encountered in identifying research participants who matched the recruitment criteria. In spite of making amendments to the criteria, only one dyad agreed to participate in an interview for this phase of the fieldwork (a service user and her husband) before the COVID-19 pandemic meant that no further recruitment was possible. An unknown number of potential participants were invited to take part by the service. Although the interview that was conducted contributed significantly to theory refinement, and will be referred to in the forthcoming chapters, further details about the recruitment aspects of it have been put into Appendix W rather than here.

5.8 Informed consent

All interview and focus group participants had received an information sheet as described above and had had an opportunity to raise queries prior to the interview and focus group. They were provided with a consent form to complete before the interviews and focus group commenced. The information sheet and consent forms were written in plain English. They explained the nature and objectives of the study, clarified all relevant aspects of confidentiality and their right to withdraw. All participants were capable of giving consent for themselves. At the start of all interviews and the focus group, I summarised the points on the consent form again and invited questions. All information leaflets and consent forms can be found in Appendix V.

5.9 Data collection methods

As the focus of the research was on facilitating family engagement, mechanisms that could be triggered at the level of reablement staff were the initial focus of fieldwork. It was my intention to explore and refine the theories about mechanisms with service users and their family members too, in particular those that could be triggered at their level. In order to do this it was necessary to select research methods that seek to understand participants' experiences, interpretations and reflections. Options included interviews, focus groups, surveys and observations (Denzin and

Lincoln, 2011; Silverman, 2011; Creswell, 2013; Barbour, 2014). The first two methods were selected and are discussed below.

5.9.1 Realist qualitative interviews

In a study employing a positivist methodology to ascertain for example, whether an intervention works or not, the function of interviews would typically be to confirm or disprove theories. This would often be achieved by means of structured interview questions with a closed range of ratings relating to pre-determined answers, assessed using quantitative methods. In a study employing a constructivist methodology, to gain a deeper understanding of how individuals involved with the intervention experience it, the function of interviews might typically be to gain an in-depth appreciation of the perspective of individuals and possibly also to observe patterns that emerge from a number of accounts in order to build a theory about the intervention.

A realist approach to qualitative interviewing on the other hand seeks to explore and theorise about the mechanisms underpinning theories that have already been sketched out in an initial way (Manzano, 2016). The approach acknowledges that individuals' ideas and responses sometimes lie beneath the surface and might not necessarily be brought to the surface by the interviewee alone. Instead, through the process of the interviewer sharing ideas about the initial theory, the interviewee helps to refine that theory. "The researcher's theory is the subject matter of the interview, and the subject (stakeholder) is there to confirm, to falsify and, above all, to refine that theory" (Pawson and Tilley, 1997 p155). When this "teacher-learner cycle" (Pawson, 1996) is adopted over a series of interviews, partial knowledge can be combined in different ways to create a greater sense of the larger truth about the intervention.

For this reason, I devised a series of interviews to explore the selected theories with the aim of understanding the partial truth shared by each interview about the same theory, based on their own experience. Building on this understanding of partial truth it was my aim to give the interviewee a perspective on other accounts of the theories in order to move towards a shared understanding of a larger whole; a more in-depth understanding of the theories under development. Realist interviews were used in both phases of the fieldwork. All interviews were audio recorded, encrypted and uploaded onto the University's OneDrive as soon after recording as possible. The recording on the device was then deleted. I transcribed the first and last interview and the focus group verbatim. A University accredited transcriber transcribed the remaining interviews verbatim. Although the value of transcribing everything oneself is acknowledged as a means of familiarising oneself with the data (Robson and McCartan, 2016), I found it better use of time to listen to and proof-read the transcriber's version and to return to the uploaded recordings from time to time. The transcripts were not shared or checked with the participants.

5.9.2 PPI group meeting

The second PPI group meeting took place between the interviews with reablement staff and the focus group with Reablement Workers. I facilitated this meeting at a Carers Support Centre office. The aim of the meeting was to assist with research design, provide context around the theories and engage in discussions about the theories and their relevance to service users and families. Four group members attended this meeting (the fifth was admitted to hospital shortly before the meeting). The group was able to adjudicate priorities among the data from the perspective of families. The insights of two members of the PPI group who had personal experience of being the partner of a reablement service user, provided valuable carer viewpoints.

At the end of the meeting, the group was asked to rank the if-then statements that they had discussed most fully in order of their potential power to explain family engagement in reablement. They were asked to consider the explanatory power of the statements in terms of their ability to potentially explain differences in engagement, the degree to which the statements might be testable in some way and their relevance to reablement in particular as opposed to traditional home-care. These rankings helped me to decide what to discuss in the focus group with Reablement Workers. For example, it added a dimension of exploring the tension between whether Reablement Workers consider that they should be aiming to give families a break or involving them. See Appendix X for a commentary on this meeting.

5.9.3 Realist focus group

In addition to interviews with the staff members identified above, I decided to experiment with using a focus group research method to refine theories with a group of Reablement Workers. The intention here was to use the theories as the subject matter of the focus group. The process of discussion between Reablement Workers, guided by me, would be used as a means of confirming, falsifying and ultimately refining the theories under examination.

Typically in qualitative research, focus groups are used to gain information about participants' views and experiences of a topic. They can be particularly useful for obtaining several perspectives about the same topic and/or gaining insight into people's shared understandings of a topic (Barbour and Kitzinger, 1999; Sim, 1998). Furthermore, they can provide a means of highlighting participants' attitudes, priorities, language and framework of understanding (Kitzinger, 1995). They are, however, also notorious for being difficult to arrange and moderate and run the risk of returning a rather bland consensus. I had significant experience of moderating focus groups and although I had not encountered their use for theory refinement before, I was interested in exploring their potential within a realist approach. Viewed as providing a forum for collaborative discussion in order to refine the ideas produced by the realist synthesis, the method appeared to hold potential to provide data relevant to the exploration of contexts, mechanisms and outcomes.

5.10 Interview and focus group topic guides

Separate topic guides were devised for the Phase 1 interviews and focus group and the Phase 2 interviews. These were informed by the realist synthesis and aimed to explore the if-then statements selected for further refinement. The topic guides (Appendix Y) were discussed with the supervisory team to check the logic, flow and tenor of the questions. They were not devised to be adhered to strictly but rather to provide a framework of prompts and open-ended questions to steer the discussions. Reminders of realist interviewing phraseology were included in the guides (see end of Appendix Y). These were intended to help me provide opportunities for the interviewees to share their experiences in a way that would allow for exploration of their awareness and experiences of the intervention, including their reasoning about the specific theories being refined (Manzano, 2016).

5.11 Interview and focus group settings and duration

All staff interviews and the focus group were held at the reablement service premises and in a way that was intended to minimise disruption to working routines. The interviews were held at a time convenient to the participants and the focus group was held on a day when there would normally have been an onsite team meeting. Each interview lasted around an hour and the focus group an hour and a half. The interview with the service user and her husband took place at their home and lasted just over an hour. Two Reablement Workers were present to introduce me and then they left.

5.12 Data coding and analysis

The key principle guiding data analysis in a realist inquiry is that it should be theory driven (Pawson and Tilley, 1997). The fieldwork was driven by eight theories in the form of if-then statements. Data derived during the course of the interviews and focus group that related to these statements were analysed thematically according to methods set out by Braun and Clarke (Braun and Clarke, 2013) complemented by techniques described by Ellerby (Ellerby, 2009). Braun and Clarke characterise thematic analysis (TA) as being "relatively unique among qualitative analytic methods in that it *only* provides a method for data *analysis*; it does not prescribe methods of data collection, theoretical positions, epistemological or ontological frameworks… One of the main strengths of TA is this flexibility… Themes can be identified in a data-driven, "bottom-up" way,… alternatively, they can be identified in a more "top-down" fashion, where the researcher uses the data to explore particular theoretical ideas, or bring those to bear on the analysis being conducted" (ibid p178). These characteristics fit well with taking a realist approach to being driven by initial theories while remaining open to the generation of new theories during analysis. Braun and Clarke's description of how researchers interact with language in critical qualitative research is particularly pertinent to a realist way of thinking:

> *In critical qualitative research, in contrast [to experiential qualitative research], the focus is not on language as a means to get inside the person's head, but on language as it is used "out there" in the real world. Its interest is in how language gives shape to certain social realities – and the impact of these. While critical qualitative analysis is essentially about language as a mode of communication, interest shifts away from only looking at the semantic content… Rather, language is understood as the main mode by which the reality of our world is created, and so researchers within this tradition use language to explore the ways different versions of reality are created* (ibid p25).

The process of coding and analysing the study's interview and focus group data was an exploration of this creation of different versions of reality. Table 11 provides an overview of each stage of data coding and analysis and indicates who contributed to it. More detail about the contributions can be found in the relevant sections below (5.12.2 and 5.12.5).

Table 11: Summary of coding and analysis methods

Step	Task	Method	Contributors
1	Familiarisation	Braun and Clarke	Researcher
2	First coding	Braun and Clarke	Researcher, supervisor
3	Data mining	Ellerby	Researcher
4	Closed sorting and clustering	Ellerby / Braun and Clarke / Researcher	Researcher
5	Identifying insights	Ellerby	Researcher, Dr Justin Jagosh

5.12.1 Familiarisation

The interview and focus group transcripts were read through while listening to the recordings, largely to check the accuracy of the transcriptions. They were then read again in an active, analytical way to begin to think about the meaning of the data. "Initial noticings" were noted such as the different ways that the participants made sense of the topic (Braun and Clarke, 2013 p204).

5.12.2 First coding

Using Braun and Clarke thematic analysis methods, data that related to the eight theory areas were then coded across the entire dataset. This was achieved using the Comments function of Microsoft Word in a way that ensured that the codes made sense without the data. Codes consisted of a word or a brief phrase that summarised the essence of the data, often followed by a direct quotation. I wanted to ensure that the flavour of the participants' own words came through any subsequent data reduction. Although comments were sometimes labelled as Context, Mechanism Resource, Mechanism Response and Outcome, at this stage these were intended only to be an initial consideration of which category they might be analysed as. A member of the supervisory team reviewed a sample of one out of the six of the printed and coded transcripts with the aim of challenging and confirming the coding. The team agreed that although this means of review had led to interesting discussion, for example about whether data were labelled as contexts or Mechanism Resources, it did not add significant insights at this stage. Rather, it provided transparency for the coding process.

5.12.3 Data mining

At this point, a departure from Braun and Clarke's methods was made. Conscious that the eight theory areas still required significant refinement, I wanted to ensure that as well as contributing to their refinement, the process of data analysis would allow for retroductive thinking and the generation of new theory too. A means of achieving this appeared to be offered by integrating analysis and synthesis as concurrent activities in data processing as described by Ellerby (Ellerby, 2009). I adapted this approach and combined it with elements of Braun and Clarke's methods as described in the following sections. The starting point for this was transferring the comments from the first coding onto Post-it notes, colour-coded by participant.

5.12.4 Closed sorting and clustering

Sorting and clustering techniques were used to organise, reframe and synthesise the data that was on the Post-it notes. Open sorting can be used to group findings into undefined categories. By contrast, closed sorting can be used to group findings into defined categories "to organize data and build upon a determined structure" (Ellerby, 2009). I selected a closed sorting approach, initially grouping the data according to the four conceptual themes as they had been identified at the end of the synthesis.

This involved sorting the Post-its onto large sheets of paper on a wall, each sheet representing one of the four conceptual themes (see photo). Within each theme, Contexts, Mechanism Resources, Mechanism Responses and Outcomes were clustered respectively. Using this technique allowed for considerable reflection, the discovery of patterns in the data and subsequent re-sorting. As a result of experimenting with clustering the data in different ways, one of the conceptual themes was altered. Braun and Clarke's questions relating to developing themes guided this change (Braun and Clarke, 2013 p226). It became apparent that theme three (initially conceived as

"Facilitating family involvement") was too closely aligned with the broad research question which meant that the data within it were too diverse and wide-ranging and could be applied across all of the other themes. Instead, a new theme with its own central organising concept, "Empowering families", was created[3]. This resulted in a redistribution of the if-then statements which were being refined under each theme in a more even way between themes three and four.

The four themes with the associated if-then statements analysed under them follow in Table 12.

Table 12: Themes, associated if-then statements and chapters in which they are reported

Theme 1: Instilling an understanding of reablement (Chapter 6)

1	IF the principles of reablement are understood by service users and their family carers, THEN they will welcome or accept a more observational and encouraging approach, in spite of initial reluctance.

Theme 2: Customising service delivery to family circumstances (Chapter 8)

5	IF professionals respect families and carers and recognise their role as part of the whole care circle, THEN their role will be maximised.
7	IF the content of the intervention is designed with the family carer's needs as a crucial factor, THEN this will encourage their active participation.

Theme 3: Empowering families (Chapter 9)

11	IF family carers are informed about how to support and motivate their relative, THEN this will support them in their role.
14	IF family carers are advised on how to carry out routines after reablement is finished, THEN their confidence in their own ability to provide care and safeguard their own welfare will be increased.

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[3] For the sake of simplicity this theme title has been adopted throughout the thesis

Theme 4: Skilled workforce (Chapter 7)

8	IF there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties, THEN family carers would have an opportunity to provide input on the content of the reablement process.
12	IF family carers are regarded as a resource by the reablement team, THEN they will be able to reinforce the reablement team's work by supporting and motivating the service user.
15	IF the reablement team is able to negotiate and manage different expectations and opinions, THEN this will enhance collaboration.

5.12.5 Identifying insights

In this stage of the analysis, patterns within the groupings of Context, Mechanism Resource, Mechanism Response and Outcome were identified and articulated, and notes made about where ideas spanned the themes. This occurred over a protracted period of time, allowing for insights to incubate (Ellerby, 2009). Findings relating to two of the themes (1 and 4) were discussed with the study's methodology consultant, Dr Justin Jagosh. This helped in particular with the articulation of Mechanism Responses.

Ellerby identifies an additional stage to assist in the identification of insights. She refers to this as "socializing the insights". This involves showing them to people who have not been involved in the research or analysis process. I had planned to do this by means of some workshops that I had been invited to run with reablement managers and staff in another region. Unfortunately these were cancelled due to the COVID-19 pandemic.

5.13 Chapter summary

This chapter has detailed the methods used in the second stage of the study, fieldwork in a reablement service. It shows how I experimented with a novel approach to analysis. Consistent with RAMESES guidelines, this approach occurred iteratively, was retroductive, moved between inductive and deductive processes and included my hunches (The RAMESES II Project, 2017).

The next four chapters describe the findings of the fieldwork, each relating to one of the four conceptual themes identified through the realist synthesis.

Chapter 6: Introduction to Findings and Findings 1 – Instilling an understanding of reablement

6.1 Introduction to findings chapters

The research question for the study is focused on understanding causal explanations for the ways in which reablement teams engage families in older people's home-based reablement. The realist synthesis identified theory-driven insights and a range of questions about possible causal explanations. These were limited by the number of sources available in the literature and required further investigation. This chapter and the following three chapters report on the findings of this investigation according to the four conceptual themes identified in the synthesis. They appear in the following order in the findings chapters:

Chapter 6: Instilling an understanding of reablement

Chapter 7: Skilled workforce

Chapter 8: Customising to family circumstances

Chapter 9: Empowering families

The synthesis had focused predominantly on identifying mechanisms and unpicking them into resources provided through the intervention and, where possible, responses to those resources. The intention of the next stage of the study was to contribute to an enriched understanding of those resources as well as the contexts into which they are introduced. The study's partner service did not have an explicit organisational approach to engaging families in reablement. This did not matter as the purpose of the interviews and focus group was refining theories. It is mentioned here only to highlight the fact that the mechanism resources identified and discussed in the course of the fieldwork had not necessarily been applied with any consistency in the partner organisation. The theorised CMOCs that are included in all four findings chapters are an attempt to incarnate refined theories derived from the fieldwork data (Pawson and Tilley, 1997).

6.2 Structure of findings chapters

Each findings chapter builds on the elements of CMOs that were apparent in the realist synthesis and the questions that they provoked. Naturally, there are links between the four chapters. Where data is given further consideration in a subsequent chapter, this is indicated. The chapters include some discussion of the findings. A fuller discussion and critical analysis of the findings as well as a reflection on the strengths and weaknesses of the approach taken can be found in the Discussion Chapter (Chapter 10).

6.3 Instilling an understanding of reablement

6.3.1 Introduction

The sources reviewed in the realist synthesis revealed a consistently low level of understanding about reablement among anyone who had had no direct experience of it. I encountered the same lack of understanding about the intervention when discussing the study with anyone outside the field of reablement. Although understanding reablement had been selected as a topic to discuss with families and service users, it had not been selected to discuss explicitly in the interviews with reablement staff. However, in the course of analysing the data across all of the interviews and focus group, it became apparent that instilling an understanding of reablement where none existed previously was fundamental and was referred to frequently by all participants.

The chapter examines findings that relate to what appears to be important about the way that reablement is explained, the different responses that might be provoked by this and the outcomes that are likely to result. This means that the activity of instilling an understanding of reablement is regarded as a mechanism resource in this chapter.

The first overarching if-then statement examined in the course of the synthesis referred to the idea of families understanding reablement and is restated below:

1. IF the principles of reablement are understood by service users and their family carers, THEN they will welcome or accept a more observational and encouraging approach, in spite of initial reluctance.

The statement does not suggest how or why having an understanding of reablement might lead to welcoming or accepting it as an approach. It assumes a relationship between the two. The synthesis had demonstrated the importance of understanding reablement and had suggested that grasping the nature of reablement takes time. It suggested that it might be useful to begin to instil an understanding of reablement prior to service delivery as well as at the start of it. There was little exploration of resources that might aid that understanding in the sources that were examined. A better understanding of potential resources, the contexts into which they are introduced, and responses to them, might start to address what it is about having an understanding of reablement that might lead to accepting it as an approach.

The following questions were provoked by gaps in evidence identified in the synthesis. They guided the data analysis.

- What contextual factors are important to consider?
- What is it about reablement that needs to be communicated to families?

6.3.2 Contexts

The synthesis had suggested that prior understanding and/or experience of reablement could be a factor in terms of the way that families engage with it. In the fieldwork, the idea of prior understanding was unpicked and as a result, it is considered here in terms of prior misunderstanding. Ideas about two aspects of context were refined in relation to this. These are described below and are followed by a consideration of mechanism resources introduced into the first context.

Context 1: Family having a prior misunderstanding of reablement

Participants in the staff interviews and focus group remarked that at the start of reablement service users and their families commonly have either no understanding or a misunderstanding of it. They have generally gained an initial idea about what reablement is as a result of being referred into the service from other health or social care professionals or referral services and this is where misunderstanding can originate. Key features of misunderstandings about reablement are that the service user will be cared for in a traditional homecare way, the care they receive will last for a full six weeks, and will be free.

Reablement Workers are frequently referred to as "carers" by the services referring into it, reinforcing the misapprehension that they are going to provide care for service users.

> *The impression I get from family members or the majority of them, is that they feel the information they're given from the social workers is they [Reablement Workers] are carers basically and their job is to assess what someone's long term care needs are and I think there's very little work done with the family member and the reablement team to give them a better picture of what we're all about really…. I would say about 10% of the family members really understand what reablement are about (Michael, OT)* and
>
> *They think we're carers. They think we're there to wait on them for six weeks (Susan, Senior RW).*

This misunderstanding has historical roots. Historically local authority social care services that are home based have focused on providing care for people, rather than focusing on encouraging people to do things for themselves. The interview with the family member affirmed this and also made apparent the misunderstanding that a full six weeks' traditional care was to be anticipated, regardless of how the service user progressed:

> *My initial perception was that I was going to get some help. Yeah? Practically speaking, I got very little, if any. Now that didn't bother me because at the end of six weeks they'd be gone and I'd have to do it anyway, right? (Ron, Family member)*

The idea that this misapprehension can originate from other health and social care professionals or from referral agencies was supported by a discussion that the focus group participants had about having to explain what their job is to their own GP:

> *… reablement's not even recognised in GP surgeries. A GP might say to you "what do you do for work?" (Denise, RW)*
>
> *"What's that?!" [laughs] (Caroline, RW)*
>
> *They don't recognise what reablement is. They don't know what reablement is. (Denise, RW)*
>
> *Even nurses, I've come across nurses, they just say carers. (Claire, RW)*
>
> *I think that if there was more information put into GP surgeries, about our service, people would understand it more. (Denise, RW)*

In data from across the fieldwork, reablement staff observe that many families not only expect reablement to be delivered in the same way as traditional care, and for a full six weeks, but also regard reablement as free. It is notable that the NHS presents reablement as up to six weeks' free care in its online information:

> *Care and Support you can get for free: Help after you come home from hospital – You may be eligible for free care and support at home for up to 6 weeks after a stay in hospital, or to prevent you going into hospital. It's known as intermediate care or reablement. The idea is to get you back on your feet as soon as possible. (NHS, 2018).*

Misunderstanding reablement as a contextual factor, was noted repeatedly during the fieldwork. It provides a backdrop to contextual factors identified in the other chapters of the findings (particularly in the Skilled Workforce and Empowering Families chapters) and could, as such, be considered a macro context.

Context 2: Readiness to understand reablement

Another contextual factor relevant to instilling an understanding of reablement is the family's mental and emotional readiness to absorb new information, including an explanation of what reablement is, particularly when their relative has just been discharged from hospital. This was discussed in the focus group as well as in staff interviews.

> *Literally, they're just out of hospital, so they're out in the morning, we're going in at five o'clock so they're just getting out of that hospital routine and then we go in and go bang! (Ellie, RW)*
>
> And
>
> *Usually it's quite exhausting and I think really when I've been partaking in those original visits, I think sometimes the client is just exhausted and they're just happy to see… they'll just sign anything and say anything just so we would go. But I think there could definitely be some more work around education and better understanding of what reablement services are all about really (Jenny, Team Manager).*

The synthesis had identified initial openness or resistance to reablement as a potential contextual factor for instilling an understanding of it. Readiness to understand reablement is examined with reference to customising reablement to the family's individual circumstances in Chapter 8. For this reason, Context 1 only is taken forward here for analysis.

6.3.3 Mechanism Resource: Providing an explanation of reablement

A single Mechanism Resource will be considered here that could be introduced into the context of family members having a prior misunderstanding of reablement, resulting in different responses and outcomes. The Mechanism Resource considered is providing an explanation of reablement.

Participants identified four elements in connection with providing an explanation of reablement in order to help families to understand it. These are considered in turn:

- Timing of the explanation
- Content of the explanation
- Who reablement is explained as being for
- Having a system to support the explanation of reablement

Timing of the explanation

Although this study is concerned with what is within the capacity of the reablement service itself to deliver, many participants referred to a belief in the value of establishing an accurate understanding of what reablement is before entry into the service. However, the team's contact with the service user is at the first home visit. This first visit often has multiple aims including to explain how the service works, to assess capability and to set initial goals. If family members are present at this meeting, then this is an opportunity for them to gain what might be their first introduction to what reablement is. The Reablement Workers who participated in the focus group discussed the idea that instilling an understanding of reablement is not a one-off activity that could be achieved in an early visit, but rather something that needs to be done on an ongoing basis. It links to the family's mental and emotional readiness to understand reablement.

> *I think that first visit that we do is always the worst though, because you've got completely new people coming in and you sit there, you explain the service and then a week later, they're like "but I don't understand what you're supposed to be doing because you're not…" But even if it's a husband and wife, they don't always take it in… Because the husband or wife is at the end of their tether because they've been looking after the other, then they're bombarded with all this information (Jacqueline, RW).*

In the service that participated in the study, there was no process in place to invite family members routinely to the initial or subsequent visits. If family happen to be present they are given the option to join in. One of the interview participants pointed out that having too many people at the first meeting might prove challenging in terms of focusing on the service user.

Content of the explanation

The synthesis identified a lack of detail about how reablement and its contents might be explained to family members. The importance of distinguishing reablement from traditional homecare had been identified (Glendinning et al., 2010; SCIE, 2012b) and participants endorsed this idea strongly, specifying the need to ensure that families understand that reablement, unlike traditional homecare, is not about "doing for".

SCIE suggests that it is important for families to understand the time-limited nature of the intervention and that they may subsequently have to pay for services that follow it (SCIE, 2012b). The research participants further refined these ideas. As mentioned above, they reported that frequently families understand that reablement will be provided for six weeks in total, rather than for <u>up to</u> six weeks. One participant (Jenny, Team Leader) suggested that this misunderstanding can limit a family's ability and need to plan for the eventuality of reablement ending earlier than six weeks. She suggested the value of communicating that reablement will be offered for up to 42 days and at the same time communicating that, although it is not chargeable during that time, any ongoing care will be subject to charges depending on ongoing needs and financial circumstances. The latter point was discussed in more depth by the focus group participants and will be discussed in Chapter 7 (Skilled Workforce).

The Team Leader also pointed out that families need to understand that the number of visits will vary, with the overall intention of decreasing in frequency. It is common for families to have gained a misunderstanding about this aspect from other care providers:

> *The hospitals always overestimate the visits, so comes out with three/four visits a day, that creates an impression to the family that's what they're going to have forever more and actually our role is to reduce those visits. As long as it's safe in what the person can do, it's the goal of reablement is to reduce the level of service required for the longer term and to make them independently living at home (Jenny, Team Leader).*

Furthermore, the participants suggested that it is useful for Reablement Workers to help families to understand that constant assessment is central to the delivery of the intervention and is connected to a gradual reduction in visits. They also emphasised the importance of explaining how assessment and reduction in visits play a part in determining what happens after reablement:

> *When we start to close visits down, so if we've been going in four times a day and we eventually drastically reduce it to one or two, sometimes throughout the service we will get calls from worried family members who can't understand why we're closing and I think it is just our ability to explain and properly explain what the reablement service is about and how our assessment process is (Michael, OT).*
>
> And
>
> *I think that if a family member understands that this is an assessment service and at the end of it the assessment may not be what you want it to be; but then there's always that discussion that can take place… We're only a short-term assessment service to deem what the ongoing needs are (Jenny, Team Leader).*

The input from research participants added an additional idea concerning what families might understand independence to mean in the context of a maximum of 42 days of reablement. The occupational therapist who was interviewed stressed the importance of families understanding that independence might mean achieving part of an overall task independently rather than being fully independent in all respects:

> *I think because the word reablement is an unhelpful one and really sometimes what I think… I usually describe to a family member that we are almost rehab workers and our job is to rehab someone to be able to wash and dress themselves independently…*
>
> *… So, with someone washing and dressing sometimes, the furthest we may get someone to wash is just that upper body but, even still, the fact that they can still do their upper body is still a good outcome because prior to that they couldn't wash themselves at all (Michael, OT).*

Connected to the idea of independence is the broader health message of staying active. Participants did not refer to this explicitly as an element of instilling an understanding of reablement but did refer to it in discussions about empowering families to engage with reablement. It will therefore be referred to more fully in Chapter 9 (Empowering Families).

Who reablement is explained as being for

The Referrals Coordinator explained that she sometimes sees the need to remind families that the service is primarily for the benefit of the service user:

> *It's just about reminding them obviously, although they're a carer, it's about your husband, your wife, whoever it is, they want to be able to do these tasks for themselves. As much as you want to do it for them, it's much, much better if they can do it for themselves because that makes them more independent and gives them a little bit more self-worth (Lou, Referrals Coordinator).*

A disparity emerged between the literature and participants' practice over focusing the service on supporting a family member. One of the literature sources suggested that if reablement is considered by service users and their family to be an opportunity for respite and support for the family member, then these expectations will not be met (Glendinning et al., 2010). However, in the participating service, reablement is sometimes consciously targeted to assist a family member who is struggling with caring for a relative. In the course of discussion with families who are struggling, Reablement Workers explain that reablement can provide a means of alleviating their stress. This idea is taken up in Chapter 7 (Skilled Workforce).

Having a system to support the explanation of reablement

The importance of having a system in place to support the explanation of reablement was discussed with participants. The participating service aimed for a Senior Reablement Worker to lead the initial assessment visit, accompanied where possible by a Reablement Worker who would be working with the service user afterwards. This was considered by the Service Manager and Team Leader to be an important aspect of instilling an understanding of reablement in families and service users. The participants advocated the potential value of having a set of standard resources that give a consistent message about what reablement is that could be used across health and social care. One of the interview participants connected this to service user and family involvement:

> *The only way you can guarantee family or carer involvement is to have a system, some sort of tick-box exercise where, either in the hospitals or where the person's being referred from, that someone sits down and properly explains what the reablement service is all about to clients… at the moment, it's just not built in. So, I think that is the only way and then you can then educate. And I guess if there was some form of paperwork or leaflet, at the very least, drawn up. Even if there was a leaflet that was drawn up explaining quite clearly how reablement can support the service user and how they can support family carers, I think 'til something like that is drawn up and talked through, or at least issued out, then I don't think you'll ever really get family carers fully involved in the process, not routinely (Michael, OT).*

The same interviewee suggested that gaining an understanding of reablement takes time and equated building that understanding with having opportunities to speak to Reablement Workers regularly throughout the course of reablement. He suggested that the way that reablement is explained might need to be customised to different people and could include an option for families to go into the service for a 30 minute introduction to reablement at the start.

6.3.4 Mechanism Responses: Providing an explanation of reablement

As the study's partner service did not have an explicit approach to instilling an understanding of reablement in families, the mechanism resources identified and discussed in the course of fieldwork had not been applied with any consistency. This called for the application of retroductive thinking to the determination of mechanism responses as well as outcomes. When the mechanism resource "providing an explanation of reablement" includes the elements detailed above and is introduced into the context of families who have a prior misunderstanding of reablement, a range of responses and outcomes are possible. At a basic level, the responses are theorised in two scenarios as: 1) Understanding what reablement is and is not (misunderstanding dispelled); and 2) Failing to understand what reablement is and is not (misunderstanding not dispelled).

In this first of these scenarios where families understand what reablement is and is not, how it differs from traditional homecare and crucially recognise its potential value to both the service user as well as to themselves, then it can be considered that the misunderstanding has been dispelled. This then provides potential for families to accept that the approach might have value for them; an important step in creating the conditions to potentially engage with it. This can be expressed as a theorised CMOC as follows:

Table 13: CMOC1: Misunderstanding dispelled and potential for engagement is established

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing an explanation of reablement re: • Timing • Content • Who for • System to support explanation		Family having a prior misunderstanding of reablement		Misunderstanding dispelled AND family recognise the potential value of the approach for their relative and possibly for themselves too		A basis for potential engagement is established

However, sometimes, even if initial misunderstanding has been dispelled, it is not always the case that a reabling approach is positively welcomed. For example, where families hold the belief that their relative has the right to be cared for in a traditional way, and this is not altered by gaining an understanding of how reablement differs, then they are likely to reject it. This was expressed several times during the fieldwork, particularly regarding service users over the age of 80. One of the reablement staff explained that it is more likely that family members will express this belief than service users, typically in the following way, "They're 87 now, they deserve to be looked after" (Jenny, Team Manager). This can be expressed as a CMOC as follows:

Table 14: CMOC2: Misunderstanding dispelled but reabling approach rejected as not valuable

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing an explanation of reablement re: • Timing • Content • Who for • System to support explanation		Family having a prior misunderstanding of reablement		Misunderstanding dispelled BUT family do not recognise the potential value of the approach for their relative		Family reject reablement as having no value for them

The second scenario was where families fail to understand reablement and this misunderstanding is not dispelled. One of the participants observed that service users and families who continue to interpret reablement as six weeks' "free care" often regard it as a time during which they can disengage from a caring role. This is expressed as a CMOC following her quote.

> *I think we're moving away from the six weeks free because I think that then takes.. because it became an entitlement "Well we've got you for six weeks free, we don't need to do anything" (Susan, Senior RW).*

Table 15: CMOC3: Misunderstanding not dispelled and families disengage

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing an explanation of reablement re: • Timing • Content • Who for • System to support explanation		Family having a prior misunderstanding of reablement		Misunderstanding not dispelled, reablement still regarded as free care		Family reject distinct value of reablement, considering it instead as an opportunity to disengage

The interview conducted with a family member (Ron) and his wife, Jo (the service user) provided a vivid example of where a prior misunderstanding of reablement was not dispelled. In this case the response, rather than being one of disengagement was one of frustration and confusion. Jo had had a brain injury four years previously and had multiple physical support needs as a result. She was not impaired cognitively. Her husband reported that he had been caring capably for her throughout this time. She was referred into reablement following a hospital admission for a broken hip. The hospital service recommended reablement as a service that could take pressure off Ron, and Jo was referred into the service on that basis. Neither of them had any previous experience of reablement and their understanding of it remained low. Ron explained that he experienced the standing back approach that the Reablement Workers took as being watched rather than helped:

> *I didn't know what I expected but I wasn't expecting to be watched like that… I started challenging the older girls [Reablement Workers] that were coming "Are you coming to help or are you just going to watch? Because I'm just trying to find out (Ron, Family member).*

This can be expressed as a CMOC as follows:

Table 16: CMOC4: Misunderstanding not dispelled and reablement experienced negatively

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing an explanation of reablement re: • Timing • Content • Who for • System to support explanation		Family having a prior misunderstanding of reablement		Misunderstanding not dispelled, family still expect traditional care and experience reablement as frustrating and confusing		Basis for engagement not established

Ron's frustration was compounded when he observed that some of the Reablement Workers visiting sometimes combined doing <u>for</u> with a standing back approach, whereas others only adopted a standing back approach:

> *So we had a little bit of a disagreement because some people [Reablement Workers] would come in and offer to help and others at the very start of it were saying "we're just here to observe" (Ron, Family member).*

The mechanism of combining standing back with sometimes doing for is a core subject of scrutiny in Chapter 7 (Skilled Workforce).

Although there was no evidence of this in the fieldwork, it is possible that some families might go along in a passive way with reablement in spite of not understanding it, while still expecting traditional care. It is theorised that this would not provide a basis for active engagement.

6.3.5 Outcomes

The section above shows how different responses might be triggered in the context of family having a prior misunderstanding of reablement. The theorised outcomes relate to readiness to engage with the intervention. One outcome was explicitly reported by the OT who was interviewed. This related to where misunderstanding of reablement is not dispelled and persists to the end of the intervention. He observed that when family members have not understood the aims of reablement sufficiently well, a common outcome at the end of the intervention for them is that they experience feelings of worry:

> *Multiple times I've had a family member on the phone to me at the end of our service saying "I'm really concerned. Why have you closed* [ended reablement for] *mum? We feel she's not washing and dressing adequately. She's wearing the same clothes day after day". And then sometimes you have to explain "Well we've observed that she is able to wash and dress. If she's choosing to wear the same clothes then that is her decision." (Michael, OT).*

6.4 Chapter summary

The synthesis had identified gaps in understanding about what might contribute to or detract from instilling in families an understanding of the principles of reablement. It resulted in the following questions to ask of the data:

- What other contextual factors are significant?
- What is it about reablement that needs to be communicated to families?

The findings in this chapter resulted in the identification of two main contexts one of which was explored further here and the other which will be explored in Chapter 8 (Customising to Family Circumstances). They also resulted in the identification of a number of features of reablement that need to be communicated to families. These features were described as aspects of resources that could be introduced where families having a prior misunderstanding of reablement. They include providing clarity on what reablement is and what it is not. The findings have also resulted in hypothesised responses and consequent outcomes to introducing these resources. Outcomes are expressed in terms of a state of readiness for engagement with reablement.

A significant number of theories refined in the other findings chapters relate back to having established an understanding of what reablement is. For example, ideas relating to the skills required of the workforce in explaining reablement are explored in Chapter 7 and the peculiar circumstances of different families that might impact on their rejection or acceptance of reablement as being something of relevance to them are explored in Chapter 8. The synthesis had also exposed an assumed relationship between gaining an understanding of reablement and accepting it as a relevant approach. This chapter has shown that this relationship cannot be assumed and that there are multiple mechanisms at play. Chapter 9 (Empowering Families) will move on from having instilled an understanding of reablement to empowering families to engage actively with it.

There appears to be a need for further research to establish how best to instil an understanding of reablement in different circumstances. The findings in this chapter, and in particular the articulation of potential mechanism resources and responses, establish a new starting point for such research.

Chapter 7: Findings – Skilled workforce

7.1 Introduction

The findings in this chapter relate to the skills of the workforce in facilitating the engagement of families in reablement. As the frontline workers who are likely to have the most contact with families, the focus is on Reablement Workers here rather than other members of the team. The chapter falls into two sections. The first section (7.2) reflects findings about the additional skillset required by Reablement Workers to work not only with service users but also with their families. The second section (7.4) of the chapter moves on to consider what it is about the way that a Reablement Worker's skillset is applied when working with families, that might cause families to engage with reablement or not. It focuses in particular on the context of facilitating family engagement when differences of opinion arise.

7.2 Additional skillset and organisational skills support required to work with families

It is important to consider the additional skillset required by Reablement Workers to work with families as well as service users. This is because there was a consensus of opinion that working one-to-one with service users who do not have family is more straightforward than working with service users whose families come to the attention of the team during reablement. No references were found in the literature to the additional skillset required of Reablement Workers to interact with families. The first part of this section represents findings from the fieldwork that relate to this personal skillset. The second part relates to organisational support for Reablement Workers working with families. Both are considered as Mechanism Resources.

7.2.1 Mechanism Resource: Reablement Workers' Skillset

The following table (Table 17) sets out skills identified by the research participants that are in addition to the core skillset required of a Reablement Worker which might appear in a job description (Sample in Appendix Z). They differ from techniques used with service users such as activity analysis and energy conservation (Ebrahimi and Chapman, 2018 p143). The Service Manager remarked that levels of confidence in these skills areas vary according to experience. In the interests of brevity, this is an overview. Particular skills will be referred to more fully in other parts of the findings and discussion chapters. An exception to this is the skill of empathising. This is discussed more fully below the table.

Table 17: Reablement Workers' skillset for engaging with families as identified by participants

Skill	**Comments by research participants**
Communication	Communicating with families, whatever the circumstances, is important; talking and listening to them - face-to-face and/or on the phone or by email as well as by means of the care record left in the service user's home. This underpins the other skills.
Relationship-building / building rapport	This needs to be achieved very quickly due to the time-limited nature of reablement and usually in the absence of any history relating to the family situation of the service user.
Explaining what reablement is and its benefits	Participants talked about explaining reablement to families by contrasting it to traditional care and explaining its potential benefit to families as a reduction in stress.
Explaining the family's role in reablement	There was little evidence of explaining to families why they need to step back too during reablement. Michael (OT) explained it as necessary in order for workers to assess the service user's long-term needs. Jenny (Team Manager) explained how families' roles can change during reablement but said that this is not generally explained to families themselves.
Assessing the family's willingness and ability to engage	Finding out what families are willing and able to do in terms of supporting reablement itself and their relative more generally, rather than making assumptions about this.
Advising families on their level of engagement	Helping families to understand what is realistic in terms of their involvement in reablement.
Judging the level of family engagement	Jenny (Team Manager) commented that Reablement Workers can judge the degree to which families have bought into reablement by observing whether they stand back and by the questions they ask in relation to how to encourage their relative.
Persuasion	This can take the form of making suggestions for problem-solving / creative adaptations to everyday life. Susan (Senior RW) referred to regularly "talking people around", giving the example of suggesting to family that they bring the service user's bed downstairs. She also referred to this in terms of opening the family's eyes to what their relative can do.

Skill	**Comments by research participants**
Working with service users who are living with dementia	Working to maintain a focus on reablement rather than traditional care, managing the needs of families that are peculiar to this situation, optimising the service user's sense of familiarity with their family.
Demonstrating equipment and techniques	Showing families how to use new equipment (e.g. medication dispensers, mobility aids and home adaptation devices) and providing basic tips on how to handle service users physically. Participants pointed out that they are not formally trained to train in manual handling or in how to use specialist equipment such as lifting devices.
Safeguarding	Looking out for potential issues including any that might relate to sharing information about the service user with family members.
Navigating family dynamics	Treading a fine line as far as family dynamics are concerned was alluded to.
Negotiation	None of the participants identified this as a necessary skill until it was brought up by me in the discussion refining the related if-then statement. This is the subject of the next section of this chapter.
Empathising	This is discussed more fully below.

7.2.2 Standing back with empathy

The skill of showing empathy is of critical consideration in this thesis. It was brought up by staff participants in the sense of showing empathy towards family members who are struggling with their changed role and circumstances. However, it was only in subsequent analysis of the data from the interview with the family member and service user that ideas about empathy evolved. This was when empathy was considered alongside the core reablement skill of standing back.

As identified in Chapter 1, fundamental to applying a reabling approach is <u>not</u> doing things for the service user. In terms of skillset, this could be considered to be having a mastery of <u>not</u> doing for. Although this might at first sight appear to be the absence of a skill, or an inducement to behave in a passive manner, in fact it refers to actively choosing not to do something for someone, even when one is capable of doing so. This would not be considered a critical skill in traditional homecare work.

The literature had identified that sometimes Reablement Workers who transfer into reablement from a background in traditional homecare services, find it hard to stand back, whereas Reablement Workers who are new to working in people's homes accept a more encouraging approach more readily (Rabiee et al., 2009). It is possible that this variation can impact too on the way that reablement workers interact with families. The family member who was interviewed observed tension between two Reablement Workers who visited his wife together. He noticed that the person who had come from a traditional care background was more inclined to combine a hands off reabling approach with some hands on care; whereas the person who did not have a background in traditional care, frowned on combining the two approaches. This increased the family member's sense of frustration:

> *I don't know with respect to the girls, you know some of them have been with their team a long time, 20 years plus, right? [i.e. pre-dating reablement service provision] Now to all intents and purposes, they're the kind of ones that would probably say "Do you want me to give you a hand with that?" Yeah? Others are solely driven by what they're told and not allowing a degree of flexibility or common sense to come into play. Well you wouldn't see anyone struggling, well me personally, but I'm of a certain age, if I see someone struggling, I would try to help, you know? Forget that part of my job or whatever, you would try to help. But having said that not everybody's the same. I can see that straight away. And some of them are struggling with it because they're not 100% sure what reablement is itself…*
>
> *… But the people who are of a certain age won't stand back and watch you struggle. Now I remember trying to get Jo off the ReTurn onto this wheelchair. The wheelchair's there and I think I may have been struggling a bit just to get her lined up properly. And one person got up and was standing behind, not holding the wheelchair but she was tempted to and it was awkward for her. It was awkward for her because she felt she was being influenced by the person [Reablement Worker] who was still sat down. Do you know what I mean? And like I said [they're] thinking "My instinct is telling me I've got to help them, yeah, but should I?" (Ron, Family member).*

The family member was able to observe that the Reablement Workers had the skills to intervene in this case but were not acting on them. From his perspective, it seemed that they were not showing any empathy in the face of his struggles. He sensed that the more experienced Reablement Worker might show greater flexibility in combining the approaches and might be more inclined to offer to provide some hands on help, whereas the less experienced one was working against her instincts to combine approaches and was remaining hands off. He did not appreciate that allowing him to struggle in order to help him work out how to achieve the task was fundamental to the approach and to the Reablement Worker's skillset. It is possible that if he had felt assured that the Reablement Workers would intervene and do for if they felt it was necessary, or if he had requested, then he would not have experienced this degree of frustration. I have termed this skill "standing back with empathy". It will be discussed further as a mechanism in Chapter 9 (Empowering Families).

It was notable in the interviews and focus group that when discussing ideas about passing skills on to families, participants consistently interpreted this as being associated with demonstrating to family members how to use equipment rather than explaining, suggesting or demonstrating how to apply the principles of reablement more broadly. None of the participants talked in terms of being adept at or educated in training families how to engage in a distinctively reabling way.

7.3 Mechanism Resource: Organisational systems to support Reablement Workers in their interactions with families

In addition to refining ideas about resources at the Reablement Worker level (their skillset), research participants refined ideas about resources at an organisational service level: access to expert backup, equipment, and information about other services and assessments.

7.3.1 Access to expert backup

In the participating service, the role of Senior Reablement Worker is critical to Reablement Workers' support and development. Senior Reablement Workers attend multidisciplinary team meetings and can be called on by Reablement Workers between visits for advice. Reablement Workers in the service can also seek guidance from the team's OT, Team Leader and Manager or social workers from another part of the intermediate care service.

The participating service also uses the expertise of Senior Reablement Workers as a resource for continuing professional development for Reablement Workers. A Senior Reablement Workers generally lead the first reablement visits accompanied by the Reablement Worker who will be continuing to work with that service user. This provides the Reablement Worker with opportunities to learn by observing how the seniors conduct assessments, set goals, explain reablement and deal with situations that arise during these visits with service users and their family members. The Team Manager pointed out that the level of responsibility is very high at the start of reablement due to the number of decisions that need to be made. Observing good practice and sharing decision-making with a senior member of staff who has more experience was thought to increase the confidence of less experienced Reablement Workers. It is possible that this resource might also provide a foundation on which Reablement Workers can continue to explain and justify the reabling approach if misunderstandings or disagreements arise. In the focus group, Reablement Workers discussed contexts in which they would call on a Senior Reablement Worker or in some cases a social worker to communicate directly with family members. It was clear, however, that the need to call on the help of a Senior Reablement Worker as well as the willingness to do so varied between Reablement Workers.

7.3.2 Equipment

Providing Reablement Workers with sufficient, up to date knowledge about what equipment exists, how to use it and access it, enables them to introduce basic equipment and small household adaptations to service users and their family members. The family member who was interviewed experienced frustration, however, when some Reablement Workers knew how to use the specialist lifting equipment that had been introduced and others did not.

7.3.3 Information on other services and assessments

At a service level, sources of knowledge about other services or resources that could be useful for the families of service users can be regarded as a resource. The PPI group suggested that Reablement Workers should be in a position to offer families basic advice on support groups, getting a carers assessment, a care needs assessment and a financial assessment. They suggested that this should form part of the service user's and family's introduction to the service. It was not clear from the data the extent to which Reablement Workers routinely have knowledge about these assessments or access to this knowledge. One of the Reablement Workers suggested in the focus group that she had been discouraged by colleagues from getting involved in financial discussions with families:

> *I did ask that question about do we actually get involved on the first visit. And they said "No, that's really down to the seniors to do that when they go in doing their risk assessment. You know, because if we say something wrong, then they're only going to have an argument. So it's best if we don't get involved in that financial side of it… If they ask me, if they say "Have I got to pay?" I say "It depends on your savings and they'll do a financial assessment and then obviously it'll go from there. And if you have got enough money, you still might have to pay a small charge. (Caroline, RW)*

This part of the chapter has formed a backdrop to the development of the theories relating to the skillset required in dealing with differences of opinion.

7.4 Negotiating and managing differences of opinion

Three of the if-then statements examined in the course of the synthesis (statements 8, 12 and 15) related to the skillset required to work collaboratively with families when differences of opinion arise. Statement 15 is discussed here, 8 and 12 are discussed in section 7.5.

15	IF the reablement team is able to negotiate and manage different expectations and opinions, THEN this will enhance collaboration.

The synthesis had revealed a great many gaps in evidence and thinking in relation to this statement and it was clear that there was scope for refining it. Although the sources acknowledged the potential negative impact of unresolved conflict in general (Pearson et al., 2015; Hjelle, Alvsvåg and Førland, 2016), details around this were minimal. This provoked a great many questions to refine in the fieldwork. Contextual and causal detail was weak which led to questions such as:

- What contextual issues typically give rise to conflict with families?
- What resources do reablement teams introduce to situations of conflict and to what effect?
- What are the outcomes of resolved and unresolved conflict with families?

Unresolved conflict with families during reablement could undermine both the delivery and outcome of the intervention. As understanding more about this area appeared to offer potential to innovate practice and impact on achieving and sustaining reablement outcomes, it became a central area of theory refinement with participants during the fieldwork. Findings are presented here starting with contexts. These contextual elements are followed by an identification and exploration of resources that could be introduced into them.

7.4.1 Contexts: Managing differences of opinion

As with the theory area examined in the previous findings chapter, the synthesis revealed very few specific contextual factors. Through the fieldwork, however, a number of contexts were identified that related to upskilling Reablement Workers to manage differences of opinion with families. These were grouped for practical purposes into five context types:

1. How Reablement Workers regard families in general
2. Issues that pre-date reablement
3. Disagreements within families
4. Disagreements between the family and the reablement team
5. Disagreements that emerge at the end of reablement

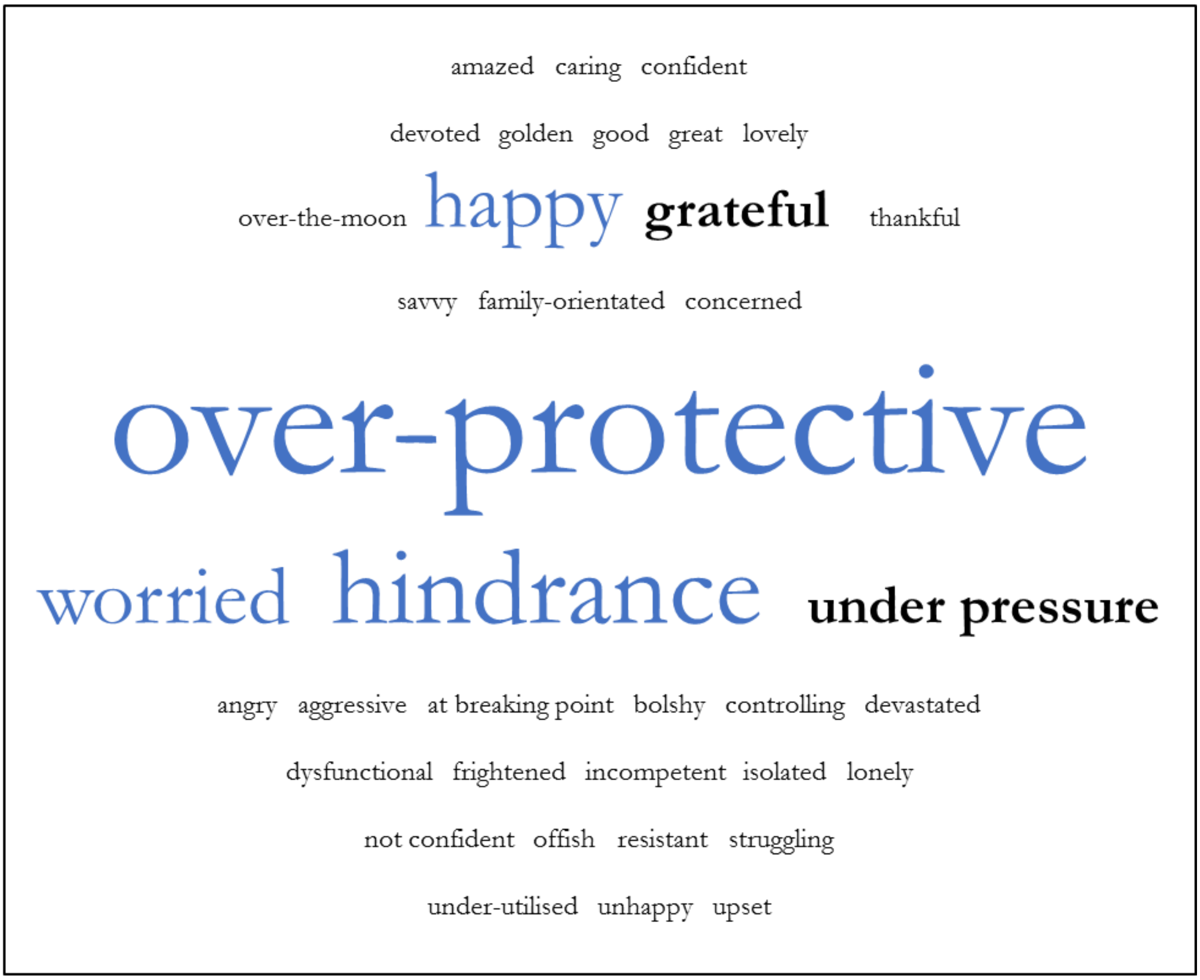
It should be noted that contexts combine in different ways for different people and also they change constantly within an intervention as a result of the introduction of intervention resources as well as factors outside the intervention. These groupings, therefore, are not intended to be rigid. Each context is described below before moving on to an examination of mechanism resources, responses and outcomes.

7.4.1.1 Context 1: How Reablement Workers regard families in general

The Norwegian sources referred to in the synthesis suggested the importance of how reablement teams regard and value families (Hjelle, Alvsvåg and Førland, 2016; Jakobsen and Vik, 2018). This was not referred to in the British sources. In the course of fieldwork, I found that the presiding view of staff participants was that families are experienced as a hindering factor. This resonated with the sentiment expressed by the family members who attended the PPI recruitment session. Speaking from the family's perspective about encounters with care staff in general, they stated that families are often made to feel as though they are in the way. The way that Reablement Workers regard families in general and their belief in the value of engaging them in reablement is considered as a context in this part of the findings.

The word cloud below (Figure 12) represents the words used by staff participants when describing families. The size of font corresponds to the frequency with which they were used (smallest font = 1 occurrence; largest = 6 occurrences). I consider the words in the lower half to be negative; those in the upper half positive; and those in the middle neutral. There are about twice as many negative as positive/neutral words.

Figure 12: Word cloud – words used by staff when describing families



The following comment is one example of how families were often referred to and regarded as a hindrance. Here, the participant linked experiencing family as a hindrance with biting into already limited time with the service user:

> *The problem with reablement in some ways is that to re-able someone you take longer than if you were just to care for them. So, I think having a family member there, they would see as an extra hindrance really and slow the process down maybe. (Michael, OT).*

7.4.1.2 Context 2: Issues that predate reablement

Issues that predate reablement were discussed with participants, including: where the family's desire for traditional care is very strong; where the family has been caring for the service user for a long time before reablement; and financial circumstances. These are described below.

When the service user has been referred into reablement but the family has a strong desire instead for traditional or long-term care for their relative, the context can be one in which the family exerts influence or tries to exert influence on the service user not to follow the instructions of the Reablement Worker or not to demonstrate their capability. This context was referred to by several participants, e.g.

> *She's washed, she's dressed, the Reablement Workers say she's done everything today. So, you go in or you phone her up or you visit her and you say 'Right, you're doing ever so well. We're going to come every other day and see how you're getting on from Monday.' You go in the next day, she's in bed. 'Well why aren't you up?' 'My family said I've got to stay in bed and I'm not to do anything 'til you get here. I'm doing too much for myself.' And that is what we get all the time (Susan, Senior RW).*

In the following situation, this is compounded by the fact that the service user needed to demonstrate a minimum number of homecare visits to qualify for a place in a particular care home. She had been progressing very well with her reablement.

> *Go in the next day, [and the service user was] in her dressing gown, her nightdress. 'Why aren't you washed and dressed?' 'No, I want to go to Sunnyside. My daughter wants me in Sunnyside and I can't do it, you've got to help me.' (Susan, Senior RW)*

Due to prevalence of co-morbidities among older people, families will often have been caring for their relative in some way for a long time before reablement. When Reablement Workers introduce new ways of doing things, this can cause conflict with families who are used to their own ways of doing things. This was particularly apparent in the case of the family member interviewed who had been caring full time for his wife for four years. The same can apply if the family member is used to the service user receiving long term homecare from another agency.

The sources rarely alluded to financial circumstances being an issue, yet this appears to be a contextual factor that could have a significant impact on how families engage with reablement. For family members who receive a Carer's Allowance, this can form part of their motivation to care for their relative in a traditional way. Fear of losing such an allowance or fear on the part of the service user, of losing Attendance Allowance, can lead to resistance to the idea of regaining capability, whether these fears are valid or not – 'That's the family telling them "No, don't get up because they'll stop your benefit."' (Susan, Senior RW). This resistance can present itself part-way through reablement when this fear emerges and can serve to undermine progress that has already been achieved. Another apparently significant financial context is if the service user is a self-funder, i.e. they are not entitled to help with the cost of care from their LA following reablement. Staff reported having observed on numerous occasions that the families of self-funders who are concerned about protecting their own inheritance, tend to over-estimate their relative's capability, for example "They see what they want to see and they're not always realistic about what the person can and can't do" (Jenny, Team Manager).

When families overexert themselves for this reason, it can create a new context over time, as it can lead to carer breakdown which in itself can result in the potentially positive effects of reablement being undone. This is demonstrated in the following focus group exchange:

> *But she's also one of these, because I had him [service user] a couple of years ago as well. And we said to her then, he needed to be put through for ongoing care and she wanted to do everything herself. And then obviously he's come back through [referral agency] and it's the same complaints as two and a half years ago but obviously she's two and a half years older, he isn't any worse than when I had him, but he's all downstairs living now. But her stresses are ten amount of times worse (Ellie, RW).*
>
> *But she don't want to part with the money to make her life easier. I can understand in some ways, do you know what I mean? You see some people and that is a big sort of umm, they see some families getting it and they're not paying for it (Denise, RW)*

Further consideration is given to the context of carers at risk of breakdown in Chapter 8. Finally, in some circumstances families have already decided that they are going to pay for long-term care, prior to receiving reablement. This can reduce their motivation for reablement rather than increase it:

> *"The financial implications impact on reablement because you do have families that the service user is financially above the threshold so they would have to pay so they're not really interested in the reablement side of things" (Jenny, Team Manager).*

7.4.1.3 Context 3: Disagreement within families

Contexts identified during the fieldwork that related to disagreements within families are summarised here. These were: where the disagreement is about the service user; where the disagreement is between the service user and family about the level of family engagement; where the service user asserts their right to not do things that they are capable of doing; and where families notice that the service user provides unreliable reports to the Reablement Workers.

Sometimes Reablement Workers are dealing with situations where a service user is being motivated by one family member to adopt a reabling approach while another is advising against it, for example, "When I went in she was in bed still from the fall and one daughter was telling her she had to get up and the other was telling her to stay put!" (Claire, RW). At other times there is disagreement between the service user and family about the level of family engagement. Different combinations of this context came up during the course of the fieldwork, for example, the service user wanting the family to engage with their reablement but the family not wanting to; or the service user not wanting the family to engage but the family wanting to engage.

Disagreements within families can also arise when the reablement team has to refute what the service user has told the family. This can take the form of the service user telling their family that the team is making them do things or conversely, although they might demonstrate that they are able to do things when a team member is there, they are unwilling to do them when they are alone with a family member:

> *But a lot of people will do it for… it sounds daft to say, not a stranger, maybe somebody in a uniform. They were more willing to participate and be encouraged by somebody like us than their own family and their own family get frustrated with it (Susan, Senior RW).*

The PPI group added that sometimes service users misrepresent the impact of their state of health on their partner or family, for example, by over- or under-estimating the number of times they need to go to the toilet with assistance during the night. In this situation, although a family member can refute the report, care must be taken as sometimes the service user is in denial about how much care their family member is providing. Although this had not been represented in the literature or in the interviews with the reablement team, the PPI group felt that this context was likely to be common across many care situations. They also identified the related context of when the service user gives an unreliable or partial account, citing the example of when a husband had told the Reablement Worker that he had had a stroke "recently", whereas the stroke had been 12 years previously.

7.4.1.4 Context 4: Disagreements between the family and the reablement team

Contexts that relate to this were identified as: the family continues to do things for the service user or stops them trying to do things for themselves during reablement; the family disagrees with the team's assessment of the service user's capability; and the family disagrees with the team's assessment of risk. Participants cited situations where families, although nominally supportive of reablement, consistently work against the approach by doing things for their family member that the family member is supposed to be doing unaided:

> *We do get quite a few where we've got Mr A and his visit's at 9am and by the time you get there Mrs A has already got him up, washed, dressed, given him his breakfast and his meds because she wanted him to be ready for when the 'carers' arrived. So, it's quite a bizarre situation. She needs the help but also she wants him to be presentable for when the carers arrive (Lou, Referrals Coordinator).*

Participants thought that this situation is sometimes driven by the family member's sense of pride, but can also be driven by the service user's preference for having physical contact with family rather than strangers, their own pride or by their desire to get attention from their family.

The reablement manager reported that family often challenge an assessment of capability. This can be that they consider the assessment to be either an overestimate or an underestimate of the service user's capability. For an over-estimate this can be driven by a desire not to take on a care role themselves. Additionally, disagreements between families and staff appear to centre frequently on differing perceptions of acceptable risk. Reablement Workers equated this difference with what they identified as a common family trait; that of being over-protective:

> *"You can't go up the stairs, mum, until the Reablement Worker gets here on the night". She's totally safe on the stairs (Denise, RW)*
>
> *They're making her nervous (Ellie, RW)… Well it's like taking her independence away from her then (Ellie, RW).*
>
> *And they don't realise they're doing it (Caroline, RW).*
>
> *Yeah, they're doing it, they think they're doing a kindness (Ellie, RW).*
>
> *Yeah, I don't think they realise. They're just so frightened something's going to happen to her, they couldn't understand why we couldn't walk down the stairs with her, in front of her. And I said, you know, "If she falls down, she's going to squash me". And that's not happening… But you know, I will have a word with them and I'll just say to stand back a little bit, you know (Denise, RW).*

If over-protectiveness negates risk-taking then the outcome can be unwittingly or wittingly restricting the service user's freedom. One of the participants also connected this over-protectiveness with a level of "devotion".

7.4.1.5 Context 5: Disagreements that emerge at the end of reablement

The final context identified is where disagreements emerge at the end of reablement because the family has concerns about it finishing. Staff participants related that sometimes the first contact that they have with families is right at the end of reablement, when the family expresses worries about it ending. This is often connected to a lacking an understanding of what reablement is. It can, however, also stem from the fact that the family values the social contact that their relative has been enjoying in the course of reablement visits.

This section has focused on identifying a range of contexts relevant to staff managing differences of opinion. The next section examines mechanism resources that are introduced into some of these contexts. These are mechanism resources that came from the synthesis and were discussed with the research participants in order to refine them. For the most part participants did not have experience of consciously implementing these resources themselves, but were nonetheless able to discuss them as hypothetical and to help move the ideas towards CMOCs.

7.5 Mechanism Resources: Managing differences of opinion

If-then statements 8 and 12 were analysed in the synthesis within the conceptual theme of empowering families. They are considered here as particular mechanism resources that could be implemented in contexts of managing differences of opinion. They relate more to an organisational level and are restated here along with the questions that they provoked:

8	IF there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties, THEN family carers would have an opportunity to provide input on the content of the reablement process.

Much of the evidence relating to this if-then statement that was cited in the synthesis was drawn from Norwegian sources. They suggested the value of having in place formal organisational processes that support Reablement Workers to implement information and knowledge exchange. Furthermore they suggested the importance of Reablement Workers valuing families' input and of families feeling knowledgeable about reablement and confident about inputting into it.

Questions provoked by the gaps in synthesis evidence were:

- What is it about routine communication that can trigger Reablement Workers to involve families in the reablement process?
- What is it about routine communication that can trigger families to provide input into the reablement process?

12	IF family carers are regarded as a resource by the reablement team, THEN they will be able to reinforce the reablement team's work by supporting and motivating the service user.

If-then statement 12 appeared to span a number of ideas across the whole study. However, the associated evidence in the synthesis was very patchy. It suggested that although Reablement Workers might feel that time pressures work against using families as a resource, there was potential to draw on the family's knowledge of the service user's preferences. It also suggested that families could be regarded as a resource to help achieve the service user's reablement goals both during and after reablement and that seeing their relative making progress might stimulate them to become more involved.

The questions provoked by the gaps in evidence in the synthesis for this if-then statement were:

- What causes or prevents Reablement Workers from regarding families as a resource and in what contexts?
- If families are regarded as a resource for reablement, what factors contribute to establishing them as such?
- What, if any, link is there between demonstrating to families what is achievable by involving them as a resource, and their motivation to support the service user in a reabling way?

Findings relating to these two mechanism resources are presented here with specific reference to some of the contexts set out above. A third mechanism resource was generated during the data analysis, "demonstrating what is achievable". This is also presented here. Where it was possible to provide an explanation of mechanism responses, theorised CMOCs have been included.

7.5.1 Mechanism Resource 1: Applying a routine for communication with families

This mechanism resource operates at a service level and could be implemented in many of the contexts described. Much of the discussion about this mechanism related to the practicalities of establishing a routine for communication and what might characterise that routine in order for it to be the basis of building rapport. Practical considerations related to issues such as consent, which family member to communicate with, and means of communication.

The PPI group members considered it vital to have as a main contact someone who understands as much about the service user's whole living situation as possible. By contrast, staff participants emphasised the importance of establishing early on whether the service user consents to the involvement of their family at all. The participating service used a standard form for this. The Service Manager remarked, however, that if a service user says that they would rather not involve their family, it is worth exploring why and pointing out the potential benefits of doing so:

> *We would always ask the individual, and sometimes you can have that conversation with the person and get them to understand why it would be of benefit to get the family involved. So it's not just taking it as a blanket "No, I don't want my daughter, or husband, or whoever to be involved". It's maybe looking at the reasons why (Beryl, Service Manager).*

Participants also emphasised the importance of having a system that actively seeks two-way communication with families in their preferred medium, rather than one-way information-giving. If this is established as early in the delivery of reablement as possible, it can serve to signal to service users and families that their input is invited, welcomed and valued. Having a system to follow up queries with dialogue appears to be important to resolve the issues that families raise rather than escalate them. The Service Manager spoke about the value of ongoing dialogue with families during reablement to support rapport-building. Rapport itself can then become a means of understanding the family's concerns, potentially shifting unhelpful dynamics and providing a basis for building trust. The skills identified at the beginning of this chapter included communication and rapport-building. Sometimes, these might be used in a mediating way:

> *It's just constant open dialogue with the families, the service users, because some families might say 'Oh yeah, I'll take on mum's personal care' and mum's going 'No I really don't feel comfortable with them doing it'. So it's making sure that everybody is aware of how everybody feels that's going to be involved in that task so that we can make sure that everybody is getting the support that they need, not just the service users but the families as well (Lou, Referrals Coordinator).*

Reablement Workers in the focus group spoke at length about situations where communication is mostly one-way, from family members to them. In addition to dealing with notes left by family members querying their work, they described how draining it is to provide a listening ear to family members who are feeling under pressure. They stated that the demands of dealing with families in these circumstances was not generally acknowledged by more senior members of the team. The following exchange highlights this:

> *Like you had that before, going back last year, wasn't it? That you was going in there four times a day but you just could not get out once she got chatting to you. (Ellie, RW addressing Denise, RW)*
>
> *Yeah. And it was draining, mentally draining… and you might just say, you know "Can I come out of there four times a day?" And that's not always understood, that person can drain somebody. (Denise, RW)*
>
> *And that could be actually the family member draining you rather than the service user (Jacqueline, RW)*
>
> *… And you go home and you just think "I don't want anyone to talk to me. I don't want to speak to nobody, because I'm just mentally drained (Ellie, RW).*

The next section examines establishing a routine for communications in one of the specific context, where financial circumstances are an issue.

As suggested earlier, it would appear useful to include discussion about finances in routine communications with families, in the early stages of reablement. This discussion could encompass what (if any) allowances the service user and family receive or are eligible to receive, means testing for ongoing care, and how reablement does or does not affect these factors. For self-funders, or those contributing to care costs, the link between achieving the aims of reablement and minimising spend on care could be highlighted, especially if ongoing care needs are likely to be minimal. In the participating service, staff routinely establish early on if a service user is a self-funder or not but their discussions about finance are limited to this. It is theorised here that broader discussions about finance could trigger in Reablement Workers a response of realising an aspect of what might motivate the family to engage with reablement. In self-funding families, the discussions could trigger a response of realising that reablement could contribute to a reduction in future spend on care. These ideas are set out as theorised CMOCs below, the first showing the response for Reablement Workers, the second for families:

Table 18: CMOC5: Reablement Workers understand financial motivations of family

Mechanism resource		Context		Mechanism response		Outcome
Routine for communication includes discussions about particular financial circumstances relevant to the service user and their family	⇒	Self-funding families	⇒	Reablement Workers feel confident that they understand family's financial motivations	⇒	Ability to work with family's motivations

Table 19: CMOC6: Families link reablement with reduction in future care costs

Mechanism resource		Context		Mechanism response		Outcome
Routine for communication includes discussions about particular financial circumstances relevant to the service user and their family	⇒	Self-funding families	⇒	Families realise that reablement could contribute to a reduction in future care costs	⇒	Motivation to support reablement

7.5.2 Mechanism Resource 2: Regarding family as a resource

The second mechanism resource is regarding and using the family members themselves as a resource for reablement. Using families as a resource could be introduced into many contexts within reablement. For the purposes of identifying contexts relating to conflict with families, the data suggested that two contexts in particular apply: where the family has been caring for the service user for a long time before reablement; and where the service user provides unreliable reports.

A reference was made in section 6.3.1 to inviting, welcoming and valuing the input of families in reablement. The nature of their input could be interpreted in a multitude of ways. In the course of fieldwork with members of the reablement team, whenever I introduced the if-then statement regarding family as a resource, it met with confusion. Staff participants did not readily understand what using family members as a resource could mean. By contrast, the PPI group immediately understood the idea and considered it obvious that family should be regarded as a resource by the team. In discussing the idea, focus group participants considered that families could be used more than at present as a resource for providing relevant history and preference information about the service user. The Team Manager supported the potential of using families as a resource for encouraging service users and for endorsing the messages that staff give to service users:

> *I think as a service I think the more we can involve carers and get them on board it's beneficial for us because I do think that we can say lots of things and if you can get carers on board and they're saying the same thing, you've got much more chance of providing a high level of reablement service if we're all saying the same thing (Jenny, Team Manager).*

She also referred to the power of a familiar voice to service users who are living with dementia, compared to the voice of a stranger. The Service Manager was more specific in terms of what sorts of family members might prove to be a valuable resource and whether they would regard themselves as such anyway. This idea is developed more fully in Chapter 8. She also referred to the economic incentive to regard families as a resource:

> *If the family do want to be involved and can be involved and that, then the Reablement Workers would see that as a good resource. But whether the family sees themselves as a resource, I don't know.*
>
> *You would want, we would be encouraging family to be as involved as much as the service user would want them to be involved, because at the end of the day we have got to think of the purse strings. At the end of the day, for ourselves, and ongoing care (Beryl, Service Manager).*

In the context of a family member who has been caring for the service user for a long time before reablement, regarding them as a resource was considered by participants to be helpful on some occasions, including those identified above (e.g. as a source of encouragement and for their familiarity with the service user). However, participants also pointed to instances in which regarding these sorts of family members as a resource could be counter-productive. They cited cases when family members are not open to different ways of doing things or are not on board with the ethos of reablement. In these cases, Reablement Workers sometimes find that it is better to actively discourage the involvement of family members:

> *But we've all, I don't know about the girls, but I've also had it where I've gone into somebody, and they'll be sat there looking at their son or daughter because they know that their son and daughter would do it all and then I say "Can you [family member] leave the room" and then for a couple of days they'll [service user] find it hard because suddenly they have to do this but they can do it… You've got to take them out of the equation… Yeah, even the wife, "Stand back and just, we'll see what he can do and then we'll assess it from there" (Jacqueline, RW)*

These ideas are set out as theorised CMOCs as follows:

Table 20: CMOC7: Families feel assured that their input is valued

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Family regarded as a resource to encourage the reabling approach		Family has been caring for the service user for a long time before reablement		Families feel assured that their input is valued		The work of the team is strengthened by the family's input

Table 21: CMOC8: Families feel excluded

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Family regarded as an impediment to encouraging a the reabling approach		Family has been caring for the service user for a long time before reablement		Families feel excluded		The work of the team is not strengthened by the family's input

Ideas about Reablement Workers' openness to regarding families as a resource and their ability to guide families in how to be a useful resource in reablement have a strong link to ideas about empowering families. These ideas are explored further in Chapter 9.

7.5.3 Mechanism Resource 3: Demonstrating what is achievable

Participants referred to situations in which tension could be dissipated by guiding families to see for themselves how their relative copes with tasks in a new way as a result of reablement. This is captured in the following statement made by the Team Manager:

> *I think daily reablement is a negotiation because negotiation with the service user to try to get them to try and do tasks and move them on to do tasks and with family members as well, just to make them see what reablement is and what their family member can and can't do (Jenny, Team Manager).*

Demonstrating what is achievable and not, and demonstrating it in a persistent way was identified in the data as a useful resource that could be introduced into a number of specific contexts. These include contexts where families continue to do things for the service user or stop the service user trying to do things for themselves and where families disagree with the assessment of capability and over- or under-estimates the capability of their relative.

There is a potential connection between demonstrating what is achievable in reablement and goal setting/monitoring. If families have been involved in the goal setting stages of reablement, or if they are at least aware of the goals that have been set, then a physical demonstration of progress against these might serve to counter disagreement over capability. It could also demonstrate the validity of a certain level of risk-taking that might formerly have been counter-intuitive to families. The PPI group contributed to thinking about family involvement in goal setting. This will be discussed in more detail in the Chapter 9.

By demonstrating to families what is achievable through reablement, Reablement Workers might be able to start to shift mindsets towards standing back. The idiom "seeing is believing" applies to the way the Referrals Coordinator explained this; how witnessing increased capability achieved through reablement regularly dispels families' doubts and initial resistance and might trigger them to become more involved:

> *I think 90% of the time in the first instant everybody is resistant because 'Oh we just want mum to be looked after. We want her to have the best end of life. We just want her to be wrapped in cotton wool and loved and have everything given to her because she's worked so hard her entire life.' But actually we do find the more we work with them and the more they see the improvements in those people and the more independent they become and how that can affect their mental health, their physical health, all of that sort of thing, they do become more convinced (Lou, Referrals Coordinator).*

The following theorised CMOC represents these ideas:

Table 22: CMOC9: Seeing is believing mechanism fires

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Demonstrating to families what is achievable, particularly against reablement goals		Family underestimate their relative's capability		Seeing is believing		Doubts about the effectiveness of reablement are dispelled, increasing the likelihood of engaging with reablement

Demonstrating to families what is achievable is relevant, irrespective of the age of the service user. It was found that families sometimes question the relevance of reablement for people over the age of 90 and in some cases Reablement Workers themselves feel the same. The Senior Reablement Worker who was interviewed described how Reablement Workers need to be able to rationalise why reablement is still relevant, not only to these families, but to themselves as well:

> *I've had a Reablement Worker say to me "Well why should she have to do that? She's 97". I said "But why should she not have the right to do it at 97?" (Jenny, Team Manager)* and
>
> *We've a woman, 100. She's finished. Independent, love her little heart. And I'm thinking "Oh, she needs help, she's 100!" But she doesn't. So, you can't give it to her. It's awful, isn't it? But she'll probably outlive all of us! (Susan, Senior RW)*

However, if the family's motivation for not wanting their relative to cope is very strong, for example, they are determined that a care home is the best option, or they are in denial about their relative's decline and expect a full recovery, even a physical demonstration might not help. In the following situation, an adult son who had moved temporarily in order to be with his mother during reablement had very high expectations and the Reablement Workers identified that he was unable to see for himself the reality of her level of capability:

> *He said "I'm staying for another week and then mum will be fine on her own" (Claire, RW).*
>
> *Yeah, he thought she was going to be exactly as she was before, but that just wasn't going to be the case (Jacqueline, RW).*
>
> *And I was thinking, she's like… there was a lot of verbal prompting just to get her washed (Claire, RW).*
>
> *They don't want to believe it maybe sometimes (Jacqueline, RW).*
>
> *They can't see the changes (Claire, RW).*

This example points to the idea that seeing is believing as a mechanism does not always fire.

Table 23: CMOC10: Seeing is believing mechanism does not fire

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Demonstrating to families what is achievable, particularly against reablement goals		Family over-estimate their relative's capability		Seeing is believing does not fire		Doubts about the effectiveness of reablement persist, feeding resistance to the approach

It was apparent in the staff interviews and in particular in the focus group with Reablement Workers, that sometimes it is Reablement Workers who presume incorrectly that a family's mindset will be fixed immutably against reablement. There appears to be a skill required of Reablement Workers in striking a balance between trusting their own ability to demonstrate the value of reablement to doubting families and having a realistic expectation of how much they can expect families to change in a few weeks. This balance has to be achieved while working within the parameters of an individual family's dynamics:

> *Family dynamics is a big one, because you will not change… not within a short space of time that our service is around for. Because those dynamics could have been around for over 30 years (Beryl, Service Manager).*

Sometimes family dynamics might be at the heart of situations that Reablement Workers find hard to fathom. The focus group participants gave an example of this as being when service users choose not to do tasks that they are newly capable of doing (e.g. washing or dressing) in front of their family. In these situations Reablement Workers can find families turning to them and blaming them for a lack of progress. They remarked that they respond to this situation by explaining that they can encourage but cannot force service users to do something and that there might be days when the service user simply chooses not to do something that they can now do.

7.6 Outcomes

More evidence is required to unpick further the contexts and mechanisms identified here in relation to managing differences of opinion with families. Given the complexities, collecting and interpreting evidence in this area would not be straightforward. It should also be recognised that the data that were collected showed that in certain situations teams determine that it is simply not possible to resolve differences of opinion with families and to build rapport with them. The Team Manager reported that sometimes clashes of character between Reablement Workers and family members result in substituting a different Reablement Worker and that this might ease tension. If however, families persist in obstructing reablement by demotivating the service user, consistently undoing the benefits of reablement during its delivery or failing to do what they have undertaken to do to support reablement, then it can be virtually impossible to turn the situation around, regardless of the Reablement Worker's skill, or intervention from more experienced members of the team. In these circumstances the service user might be kept longer than if the family had not been involved, the service might be withdrawn or the service user might be re-referred into the service at a later stage. In any of these outcomes, the inability to resolve disagreement is likely to result in a reduction in the service user's chance to improve his or her capabilities and a costly use of the team's time and energy.

7.7 Chapter summary

This chapter has addressed gaps identified in the realist synthesis relating to the additional skills required of a reablement service's workforce when interacting with service users' family members. The first part of the chapter presented aspects of the skillset specific to working with families that were identified through the fieldwork. The skill of standing back with empathy was drawn out in particular. This is important to subsequent chapters and is more nuanced than "knowing when to do something for a person… and knowing when to do things alongside and with a person" (SCIE, 2013 p10). Ideas relating to service level support for Reablement Workers in their interactions with families were also refined in this part of the chapter, including access to backup support.

The second part of the chapter adds to thinking on the skillset required in working collaboratively with families when differences of opinion arise. The synthesis had revealed a great many gaps in evidence in this area; an aspect of engaging with families that has the potential to undermine both the process and outcomes of reablement. A number of distinct contextual factors were identified and described and in order to further understanding in this area, particular mechanism resources that could be introduced into some of these specific contexts were examined (applying a routine for communication, regarding the family as a resource and demonstrating what is achievable) and different responses and outcomes hypothesised based on the fieldwork.

The findings set out in this chapter extend understanding about the array of skills required of Reablement Workers in their interactions with families. As pointed out in Chapter 1, it is notable that reablement guidelines do not articulate clearly the desirable outcomes of engaging families in reablement. It is theorised broadly here that building and supporting the skillset identified in this chapter could increase the confidence of Reablement Workers in their interactions with families in the contexts identified, helping to optimise families' engagement with reablement. There is, however, clearly need for further research in this area. A full realist evaluation or another type of study could build on this chapter's findings in order to identify the outcomes of introducing some or all of the mechanism resources identified into the contexts described here.

The next chapter will examine customising service delivery to family circumstances.

Chapter 8: Findings - Customising Service Delivery to Family Circumstances

8.1 Introduction

> *Everybody is so different. We've covered the ones that want to help, we've covered the ones that don't want to help. We've covered the ones that want to sham the … and get the money out of the system. The over protective ones, the ones that don't give a damn …* (Susan, Senior RW)

This chapter explores facilitating engagement by customising service delivery to families' individual circumstances. Customisation embraces the idea of rooting any attempts to engage families in respect for them, as well as designing service delivery with an understanding of their needs, ability and willingness to engage with the intervention. Understanding more about customisation could assist in understanding more about what is "appropriate" in terms of engaging families in reablement (NICE, 2017). The final results chapter follows this one.

In the synthesis, the second group of overarching if-then statements related to this theory area. Two of the three in this group were selected for exploration and refinement with research participants and are restated below:

5 IF professionals respect families and carers and recognise their role as part of the whole care circle, THEN their role will be maximised.

7 IF the content of the intervention is designed with the family carer's needs as a crucial factor, THEN this will encourage their active participation.

The synthesis revealed a lack of evidence specific to England and analysis in relation to these aspects of facilitating family engagement in reablement. With NICE guidelines placing what could be interpreted as a call for discretion in terms of involving families, the need for Reablement Workers to exercise their judgement appears to be key. The synthesis pointed to a need to investigate how this judgement is made and applied, and this was discussed with the reablement team in the interviews and focus group. Gaps in the contextual factors that had been identified in the synthesis were also discussed. One of these, the degree to which Reablement Workers believe in the value of engaging families in reablement, was explored in the previous chapter and it is strongly associated with if-then statement 5 above. This chapter therefore focuses on building explanations related predominantly to if-then statement 7. The synthesis provoked the following questions in relation to this:

- The context of willingness and ability of family is subject to constant change during reablement and might also differ between different family members. What characterises the different contexts of family willingness and ability?
- What sorts of resources can reablement teams introduce into the different contexts identified and to what effect?

As part of the discussions with the reablement team and the PPI group, a set of characteristics that vary from family to family was identified. This helped with thinking and discussion at the time and is attached as Appendix AA.

8.2 Contexts

The Care Act (Department of Health, 2014a) was identified in Chapter 1 as an important aspect of the architecture of reablement as it relates to engaging families. Under its provisions, Local Authorities must not presume that individuals are willing or able to take on a caring role. It would appear to be important, therefore, for reablement teams to establish the degree to which family members are both willing and able to take on a particular role during and potentially after reablement. The sources examined in the synthesis lacked differentiation between these contexts. For these reasons, I created a matrix that provides scope for considering various combinations of the willingness and ability of family members to engage with reablement. The findings here are presented according to this.

Figure 13: Willingness and ability to engage with reablement matrix: four contexts

	Willing	Not willing
Able	1	2
Not able	3	4

In order to help with explanation-building, data relating to each of these four context categories are described below. It is noted here that "not willing" might not be complete refusal but perhaps reluctantly complying.

8.2.1 Context 1: Able and willing to engage with reablement

The combination of families being able and willing to engage with their relative's reablement was not described as common by the research participants. One participant made the point that ability to engage is partly time-dependent for individuals (Jenny, Team Manager). Connected to this, one of the Reablement Workers gave an example of when the combination of able and willing is found in people who temporarily give up work during the delivery of reablement in order to support their relative:

> *It's divided really, isn't it? Some people will go and stay with their mother or father because they might live miles away but they might come up and stay while they're going through reablement because they've been in hospital and they want to make sure they're ok and they want to sort things out and set their home up ready but then they've got to go back to their other life (Libby, RW).*

The research participant's comment suggests that this sort of engagement does not typically extend beyond the delivery of the intervention. A related context is when the reablement team knows that the family member is planning to engage more actively with their relative's ongoing care following reablement. The OT suggested that this situation typically presents itself when the service user is a self-funder and the family has decided to take on a care role rather than pay for care following reablement. The Team Manager pointed out that if the family member is going to be the service user's main carer following reablement, whatever the reason, it is critical to involve them in reablement.

A member of the PPI group remarked that some people who are already used to playing an active, hands-on caring role, might regard reablement as a welcome opportunity to have less responsibility for a fixed period of time. However, they suggested that for many people who are used to considering themselves as an "expert by experience", letting other people in might be hard. Furthermore, the hands off role that they are expected to switch to during reablement could be experienced as a failure in their ability, even though they might be able and willing to engage with it. This is discussed next.

8.2.2 Context 2: Able but not willing to engage with reablement

The family member who was interviewed was an example of someone who could be regarded as an expert by experience in caring for his wife. However, although he was able to engage with reablement, being healthy and having enough time, he did not willingly embrace reablement. He was sure that he wanted physiotherapy instead for his wife and felt the team did not sufficiently customise their approach to his circumstances to persuade him to engage with reablement.

The area of undertaking personal care for a relative was discussed in a variety of ways in terms of ability and willingness to engage. A number of staff participants identified personal care as an area with which families are able but frequently unwilling to engage. They said that they try to be clear to families that this is not a problem, pointing out that it might be better for the relationship if family do not take responsibility for personal care. The Service Manager stated, however, that sometimes service users take it for granted that their family member, particularly their partner, will do their personal care. The Team Manager added that family members might be unwilling to engage with reablement in general as they might fear becoming or being regarded as a carer, and there being no way out of that role once it is taken on.

8.2.3 Context 3: Willing but not able to engage with reablement

Participants gave examples of this combination including where family members want to engage with reablement but cannot because of other commitments (e.g. work or childcare). They also discussed contexts in which families say they are willing to engage in a reabling way but their impulse to care <u>for</u> in a traditional way is stronger, meaning that they struggle with the role. Alternatively, they might have undertaken to help the service user with certain aspects of care related to reablement but fail to do so. The OT commented that this can be because "they've got a problem. They're not competent or confident to do it". This encompasses people whose own health is not strong; co-caring is commonly encountered in the over 65s, where the person receiving reablement is also caring for a family member, frequently their partner.

A context that falls under the combination of willing but not able is when the family member is considered to be at risk of carer breakdown. As the Team Manager pointed out, accepting a change in their family member's health and adapting to the new dynamic that results can be hard for some people. She had observed that partners in particular can struggle to come to terms with the way that their relationship changes as a result of a change in health. Sometimes a service is aware in advance of reablement starting that a family member needs support:

> *Quite a lot of our referrals it'll say on there "At risk of carer breakdown". So, our main role then is to take the stress off the carer, so we're reducing that carer's tasks rather than involving them in more tasks (Lou, Referrals Coordinator).*

This sort of advance information could help to prepare a Reablement Worker for what to expect of family engagement. In other circumstances it is only apparent at the first visit or becomes apparent during reablement that a family member is struggling or at risk of breakdown. The OT who was interviewed observed that sometimes when a family member does not do what they have undertaken to do, this can be indicative of them relying on the service, not wanting it to end, and needing to have pressure taken off them. The Senior Reablement Worker commented that in cases like this, Reablement Workers need to be quite directive, in order to encourage families who are doing a lot of care to take a break and consider other solutions in order to prevent carer breakdown. This will be discussed in section 8.3.

A final situation in which families can appear to be willing to engage with reablement but are not able to do so is when they are motivated by a sense of guilt or duty to keep their relative out of long term care, even though they are not coping with providing the care themselves. Perceptions of duty to care, in particular for parents, vary from culture to culture. There was very little in the sources examined about cultural diversity and the geographical area in which the fieldwork took place was very monocultural. When the potential impact of culture on family engagement was discussed with team members they could only speak anecdotally about hearing from colleagues working in more culturally diverse parts of the city. Their reports only extended to physical traditions such as removing shoes rather than anything related to areas such as cultural duty to care. One of the participants referred to the need for cultural sensitivity in the following way:

> *With certain cultures, obviously, there are certain ways that personal care has to be completed or there are certain tasks that have to be completed in different ways to what we normally would do but, again, it's an ongoing discussion with the family members and the service user on how they like those tasks to be completed because, although it might dictate in their culture this is how it should be done that doesn't necessarily mean that's how they do it because they're of that culture (Lou, Referrals Coordinator).*

Family members who are at risk of breakdown and who are conscious that they are struggling could also be considered to fall within the next context.

8.2.4 Context 4: Not willing and not able to engage with reablement

Only a small number of examples were presented by research participants in relation to this area of the matrix. One was where the family member lives at a distance from the service user. The Team Manager connected this with a higher likelihood of the family being risk averse and not wishing to support or engage with reablement. The participant service regularly communicates with family members who live several hours away from the service user as well as those who live in other countries. Another example cited was when a family member has a substance dependency that prevents any level of engagement. The Service Manager also cited situations in which the team observes that the family is in denial about the decline in their relative's health.

8.2.5 Contexts that span or complicate the matrix

It is important to acknowledge that although the matrix above provided a useful means of identifying and exploring different family contexts that reablement teams encounter, some contexts span the categories and in other cases, contexts shift from one category to another during reablement. Some reasons for shifts can be outside the realm of what is happening in service delivery. However, through direct experience of reablement and gaining an understanding of how it works, a family member's willingness and ability to engage with it might change. This might result in a reinterpretation of both the extent to which they want to care, as well as how they are prepared to engage with reablement itself:

> *It's maybe that it's not until they actually do that, that they realise maybe what they've signed up for, is totally different to what it is in practice. So it's a trial and error situation, isn't it? (Beryl, Service Manager)*

Additional complicating factors for Reablement Workers include: shifts in the dynamics and roles within families as a result of the change in health that has prompted reablement (e.g. child/parent dynamic); families saying things because they think it is what their relative wants to hear; and existing family dynamics which predating reablement. Reablement Workers can only surmise what the latter might be sometimes:

> *Then you get the others that are quite controlling and I think it depends because you get some of these women that are quite controlling over their husbands and makes you wonder if he was a bit of a sod in his time and they're getting their own back. Do you know what I mean? As I say, there's so many different scenarios (Susan, Senior RW).*

Connections between the contexts in this chapter and those identified in other chapters, such as financial position and understanding of reablement will be explored further in the Discussion Chapter (Chapter 10).

8.3 Mechanism Resources

Unpacking aspects of context that relate to family members' ability and willingness to engage with reablement has shown the huge range of family situations that Reablement Workers might encounter. This is an important prerequisite to identifying and customising Mechanism Resources that could be introduced into these contexts. Alongside the ability and willingness of family to engage is the ability and willingness of the reablement team itself to engage with families and the team's belief in the value of doing so. The way that Reablement Workers regard families in general was considered as a contextual factor in the previous chapter. In this chapter, aspects of the team's ability and approach are considered as Mechanism Resources.

Tailoring the delivery of the service to whatever context presents itself, draws on a mastery of many of the skills identified in the previous chapter, such as listening and negotiating. It might also be important to make it clear to families that they are being considered. The synthesis and discussions with the PPI group showed that families want reablement visits to fit in with family life and schedules. However, pressure on Local Authority provision means that this can be hard to achieve. Nonetheless there are other ways in which customisation to family circumstances can take place and been seen to take place. The Mechanism Resources identified during the fieldwork are presented here with theorised CMOCs.

8.3.1 Mechanism Resource 1: Determining family's ability and willingness to engage

This Resource Mechanism describes a conscious determination to take steps to understand and clarify the degree to which individual families are able and willing to engage with reablement, rather than making assumptions, and rather than relying solely on what the service user might say. Sometimes useful information has been gleaned during the referral process in advance of starting reablement; sometimes it is established in the early visits and could feed into determining ability and willingness. With or without this sort of information, determining family members' ability and willingness to engage and taking action is difficult and requires skill:

> *I think, for us, [it's] being able to understand the level of participation that they [family] want. Not going in with an expectation of what they should be doing or they shouldn't be doing or they should want to do. It's about the negotiation of how much they want to be involved. How much the service user wants them involved. So, it's gauging all that and that's why I think with the support of a Reablement Worker and a Senior on the visit it would pull that out more (Jenny, Team Manager).*

This Mechanism Resource relates to all contexts identified above. In all cases the theorised Mechanism Response on the part of Reablement Workers is that they feel able to gauge how able and willing family members are to engage with reablement. The theorised outcome of this is a foundation for collaboration based on the Reablement Worker's understanding of what level of engagement they can realistically seek to encourage in families as the following CMOC shows:

Table 24: CMOC11: Reablement Workers gauging family's ability and willingness to engage

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Determining level of ability/willingness to engage		All combinations of willing and able to engage with reablement		RWs feel able to gauge how able and willing family members are to engage with reablement		Foundation for collaboration established based on RW's understanding of what level of engagement it is realistic to encourage

At the family level, in this same combination of Mechanism Resource and context, the theorised Mechanism Response can be a feeling of being understood by the Reablement Worker, resulting again in a theorised outcome that is a foundation for collaboration.

Table 25: CMOC12: Family members feel their willingness and ability to engage are understood

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Determining level of ability/willingness to engage		All combinations of willing and able to engage with reablement		Family members feel understood by the Reablement Worker		Foundation for collaboration established based on a mutual understanding of the family's willingness and ability to engage

8.3.2 Mechanism Resource 2: Providing families with options for how to engage

Following on from this is the Mechanism Resource of providing families with options for how to engage, without making them feel obliged to do so. As the Team Manager expressed it:

> *I think maybe, as a service, we should be more proactively inviting carers to participate in those … it's quite easy if they live there but … then it's also the negotiation of not making them feel like they've got to be there (Jenny, Team Manager).*

This participant in particular emphasised "striking a happy medium" between providing families with opportunities to engage without being too directive, yet being ready to challenge too if they are either over- or under-estimating their ability to engage. It would appear that this fine judgement needs to be applied to families that fall into the first three categories of the matrix. Alongside proactively inviting families to engage in some way, it also appears to be important to emphasise to them that they should choose how to engage in a way that works for them. The Service Manager endorsed this idea by pointing to a need to identify tasks that the family are comfortable with undertaking:

> *And some family feel that, especially, they can't say no. And I know when you're maybe looking at ongoing care needs, if you identify that they need support with personal care, that they need help shopping, that they need help with laundry, sometimes you'll find that family members would be maybe happy to do the shopping side, so that would be identified, so that would be the resource that would fulfil that need (Beryl, Service Manager).*

The following CMOCs are set in the context of a family member who is willing and able to engage. An example of this context is where the service user is a self-funder and the family wishes to engage during and after reablement but might have some areas they would rather not be involved in, such as personal care. The theorised Mechanism Response and outcome at the family level is depicted in Table 26 and at Reablement Worker level in Table 27:

Table 26: CMOC13: Family level – selecting options for how to engage

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing families with options for how to engage		Family is willing and able and is planning to be involved after reablement		Family feel a sense of relief and control over selecting to engage in the way they want to and are able to		Families are ready to engage in an agreed way in the knowledge that it is possible to exchange for other alternatives if desired

Table 27: CMOC14: Reablement Worker level – offering options for how to engage

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Providing families with options for how to engage		Family is willing and able and is planning to be involved after reablement		RWs feel confident that they are proactively working with families rather than coercing them		Clarity for RWs on what realistically to expect from families

The PPI group suggested that at the beginning of reablement, a list of assistance relevant to the goals should be drawn up. The family member could then decide and agree on what they are both willing and able to do to support the service user achieve his or her goals. They referred in this discussion to the aspect of the Care Act that promotes carers' right to choice and control. The Team Manager also expressed this idea and said that it is important to recognise that the support that families can provide includes social and emotional support. Reaching agreement about support in this way would allow for it to be very clear to the reablement team what level of engagement to expect from the family member based on their choices. This would provide a reference point that could be revisited during the intervention as contexts change. It would appear important to emphasise to families that choices made about the way they engage can be changed and that this is to be expected.

For people who want to do more than they are able to, the Team Manager suggested the value of making it clear that there is a back-up in place and again, that it is possible to change what they undertake to do during reablement. She remarked that it is important to be careful not to give the impression here that the service thinks the family member is unable to help. She provided an example of someone who was initially willing but ultimately not able to engage:

> *Sometimes we've had where a grandson's said 'Yes, I'm going to take over that care' and demonstrated very well in the time we were in but then the lady came back through to us a couple of months later and actually no, he hadn't been going in and doing any of the things that he said he was going to do. She was quite frail by that time. It's also, again, it's the same again 'Yes but I want to do it' and it's being able to politely say 'Yes but we need to put something else in to back up what you're …' you know? (Jenny, Team Manager)*

This implies that there is also a scale of how directive or proactive to be in encouraging families to engage at some level. This idea is taken up in the next chapter, Empowering Families.

8.3.3 Mechanism Resource 3: Helping families to rethink their role

Reablement Workers who notice that a family member is at risk of breakdown or is struggling with their role, are in a position potentially to help them rethink their role. This might involve referral to other services, for example services that can help to determine appropriate benefit entitlements or services that provide carer support. The focus group participants said that sometimes a family member's need to offload seems to be greater than the service user's needs. In these situations reablement staff can provide an ear for families but are also likely to be conscious of how this eats into their time with the service user. However, helping to alleviate pressure on families can also ultimately benefit the service user.

This Resource Mechanism is considered here in two hypothesised CMOCs. The first is in the context of a family member who is not willing but is able to engage. This could be when the family feel obliged to take on a traditional care role as a result of their relative's change in capability, or feel an impulse to take on the role but feel uncomfortable with it. They might in addition fear that the role will become long-term. With the help of the Reablement Worker, they can rethink how they might provide support in light of learning how to stand back as well as receiving information about what other services exist.

Table 28: CMOC15: Helping families rethink their care role

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Helping families to rethink their role		Family is not willing but is able to engage with reablement		Families realise that there are a range of ways that they can support their relative during and after reablement that will not take a heavy toll on them but will still benefit their relative		Families experience an alleviation of pressure and are better able to plan for their involvement with their relative after reablement

The second hypothesised CMOC is in the context of a family member who is willing but unable to engage. This fits the profile of family members who are at risk of breakdown due to taking on more than they can manage, e.g. someone who has been in the role of carer for a long time already, or someone who has stepped into the role recently and is struggling with it. In these circumstances encouraging the family member to let go and rethink their care role is a prevention strategy, as the Service Manager said, 'So you can find it's not just about "Oh what can it take to ease the purse strings of local government finances?" but it's actually thinking, "You're actually at burnout and what will happen? You know, you're going to end up in hospital yourself but what's going to happen then?"' (Beryl, Service Manager). This is set out as follows:

Table 29: CMOC16: Helping families rethink role when at risk of breakdown

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Helping families to rethink their role		Family is willing but is unable to engage with reablement		Families develop an awareness of reablement as a different way of providing support that allows them to step back from the intensity of caring for		A reabling approach is added as an option for families to apply to the way they support their relative; an option that might help relieve pressure or prevent burnout

It is important to refer back to Chapter 7 here and to note that showing empathy towards family members who are struggling can prove draining to Reablement Workers.

In the context where family are unsure about how they will manage when reablement finishes, a resource that can be introduced is helping them to visualise the future and to provide alternatives:

> *Instead of a family member going in and cooking them meals or bringing microwave meals… pre-cooked home… we're saying 'Well why don't you look at Meals on Wheels service?' Sometimes, actually, with the reablement service it's just, as I said earlier, offering people the information regarding other services that could support. I think that's a big part of our role as well. It's about offering alternatives and sometimes trying to reduce the family member's workload. Especially if they are fairly involved (Michael, OT)*

This sort of situation appears to arise typically when the service user is a self-funder and the family is helping to plan how to support them following reablement. Again, this links to the next chapter.

8.3.4 Mechanism Resource 4: Family involvement in goal-setting

The synthesis revealed a disparity in thinking over whether families should be involved in goal-setting during reablement or not, and how this might relate to their willingness and ability to engage with reablement. On one hand, there was endorsement of the idea of inviting families to participate actively in the goal-setting process and the suggestion that if this is not done, then they will not perceive the process as collaborative (Glendinning et al., 2010; Hjelle, Alvsvåg and Førland, 2016). On the other hand was the suggestion that once goals have been set by the reablement team with the service user, they can then be used to show family how to help (SCIE, 2012b). However, neither of these scenarios was apparent in the fieldwork.

The Referrals Coordinator suggested that checking first what families are willing to do is a pre-requisite to helping Reablement Workers identify goals with the service user. The focus group participants, however, said that family are not generally involved in goal-setting. This was found to be the case with the family member interviewed and was also echoed by one of the members of the PPI group whose husband had received reablement from the research partner's reablement team. She gave an example of a time she had been called on to support her husband's reablement. Without her involvement he had agreed a goal with the team which related to gardening. Its achievement depended on his wife pre-preparing pots and soil for him to access. She experienced her involvement with some resentment as an increased burden. Naturally, responses to involving family members in goal setting will vary according to the context of the particular family circumstances.

The same member of the PPI group pointed out that it is important for families to be able to see a viable longer-term impact of reablement goals. They are more likely to subscribe to supporting goals if they consider them to be of benefit in the longer term. She explained that her husband had set a reablement goal of dressing himself without any help. She reported that by the end of reablement he was able to do this again. However, it took him two hours to dress himself unaided. As soon as reablement was over, they returned to her helping him to get dressed in ten minutes in order to be able to get on with what they had planned for the day. This points to the necessity of involving families in goal setting in order for them to identify goals that are going to be useful and have impact in both the immediate and longer term, particularly if those goals have implications for the way the two people interact in their daily lives. Clearly these are nuanced issues and point to how difficult is it for Reablement Workers to judge the psychological and pragmatic factors important to different individuals.

The idea of the sustainability of the approach was brought up in Chapter 1 and is a concern that the study has highlighted. It is possible that this service user never tried to dress himself again after reablement and that his wife always helped him in the interests of expediency. It is also possible that on days that they did not have plans, he did dress himself. Furthermore, it is also possible that although he might not have continued to get himself dressed, he might have applied the approach of doing things for himself to other activities, having learned its benefits during reablement. Understanding more about the longer-term strategic impacts of reablement, particularly on people who cohabit, would appear to be important for the future of the intervention. Although it could not be explored in greater depth in the confines of this study, much of what is covered could help to inform further research among service users and their family members into the area of goal setting and the sustainability of reablement.

8.4 Chapter summary

This chapter has explored customising the delivery of reablement to families' circumstances. This is important not least because of its relationship to fulfilling the provisions of The Care Act (Department of Health, 2014a) but also because of the danger that ignoring the needs of families implies. The realist synthesis had exposed questions about how to determine what might be appropriate in different circumstances. To help unpick these questions a means of considering contexts in terms of willingness and ability to engage with reablement was devised. This was used to examine the data in terms of responses to the introduction of a range of resources into some of these contexts. The findings relate to the ability and willingness of families to engage as well as the ability and willingness of the reablement team itself to engage with families, their belief in the value of doing so and mechanism resources that they could employ. This work provides a basis on which further examination could take place.

The findings revealed explanations for how providing options might allow families to engage with reablement in a way that is appropriate for them and in a way that seeks to minimise any sense of burden. They highlight the importance of helping families to adapt both emotionally and practically to a potential shift in their role towards and relationship with the service user. The next chapter builds on this by looking in more detail at the transition that reablement can represent for families. It is the final results chapter.

Chapter 9: Findings – Empowering families

9.1 Introduction

This final findings chapter draws on accumulated understanding gained in the previous chapters. It examines a range of contexts, and the resources that can be implemented into them, in order to empower families to apply a reabling approach themselves. It ends with a summary of all four findings chapters and is followed by a discussion chapter.

The if-then statements that guided theory-building with participants about empowering families are restated below:

11 IF family carers are informed about how to support and motivate their relative, THEN this will support them in their role.

14 IF family carers are advised on how to carry out routines after reablement is finished, THEN their confidence in their own ability to provide care and safeguard their own welfare will be increased.

Although the synthesis suggested that families could be trained to motivate the service user and to stand back during reablement, there was very little detail about how to do this and what might cause it to work or not. The synthesis also highlighted gaps in ideas about what might cause families to adopt a reabling approach in the longer term, beyond the tasks practised during reablement. It provoked several questions to refine in the fieldwork:

- What contextual factors are important to consider in relation to empowering families to engage with reablement?
- What sorts of resources to empower families are relevant in England?
- Into what contexts can the different resources be applied and to what effect?
- To what degree is a good understanding of a reabling ethos necessary in order to make the most of these resources?
- What is it about the way that learning is passed on to families that is likely to improve the chances of its adoption during and after delivery of the intervention?

- It is notable that outcomes expressed in the sources do not refer to continuing to apply a reabling approach beyond reablement. How are outcomes for empowering families to adopt the approach articulated, if at all?

The final question identified above is considered separately towards the end of the chapter.

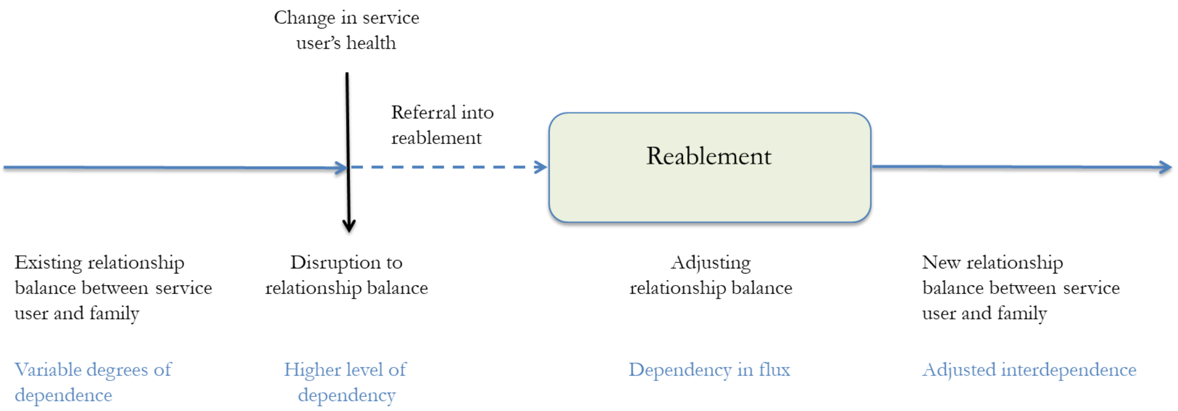
9.2 Contexts

Conceptualising reablement as a time of transition for families is core to this chapter and was inspired by the words of the Team Manager:

> *So they've already had some form of experience before we go in and the change is already there. We have to develop and move both carers and service users into that change to make it manageable (Jenny, Team Manager).*

At the level of family relationships, the change in the service user's health can be seen to represent a disruption to the status quo. It disrupts the former balance between dependence, independence and interdependence in the service user's relationship with family members. During the course of reablement, it is possible to reset that balance. Through the process of restoring skills, the new, higher level of dependency experienced at the start of reablement can be considered to be gradually transformed into a mutually workable ongoing relationship, set within a context of natural decline due to ageing. The following figure illustrates this:

Figure 14: Reablement conceptualised as a transition for families



In terms of the context for empowering families to engage with reablement, it is important to consider this transition in light of the willingness and ability to engage matrix (Chapter 8). The matrix related to the willingness and ability of families to engage with reablement from the start of its delivery. It was used to describe different potential family contexts. The data drawn from the fieldwork that related to empowering families to engage with reablement spanned the matrix. It also captured context that pre-dates service delivery. The existing relationship between the service user and the family could be one in which family is either already providing care of some sort for their relative, or not providing any care. For both of these groups, the change in health that precipitated reablement represents a disruption to the status quo. Aspects of these two groups of context are presented here followed by the Mechanism Resources that could be implemented into them when empowering families.

9.2.1 Context: Family is new to providing care

Sometimes families have little or no prior experience of providing care or support for a relative prior to the change of health that led to reablement. Participants spoke about how this can mean that reablement marks a change to the relationship dynamic. In addition to this, if their relative has never experienced a homecare service before, then reablement marks a transition into having external support in their home. The OT who was interviewed commented on the potential benefits of this in terms of reducing stress for families:

> *I think some of reablement, it's not just about reabling someone but it's getting the client and the family members used to carers going in and maybe actually seeing the benefit of having someone come in to support their father or their mother to alleviate some of the stress (Michael, OT).*

The family member who was interviewed saw reablement in this situation rather as an opportunity for Reablement Workers to demonstrate to families how to do things. As his understanding of reablement was limited, the examples he gave relate to demonstrating how to do for rather than how to reable:

> *Now I would say that for the people that um have just come out of hospital and this is a first event for them, yeah, they would probably benefit from the reablement team saying 'Well, since you've not experienced this, this is how we'd get [your relative] out of her chair, this is how we would do this, this is how we would put [her] to bed. (Ron, Family Member)*

The context of families being new to providing care discussed here implies an adjustment to familial relationships during reablement. It is distinct from a context where families are already providing care or support for a relative.

9.2.2 Context: Family has already been providing care before reablement

Participants identified and discussed two different contexts relating to families in this situation. The first was when families regarded their role as something that they were already managing and that would extend well beyond reablement. The family member who was interviewed had been providing care for his wife for several years before reablement and was sure that he would continue to provide a substantial amount of care once it was over. Thinking about what it was about reablement that might empower him to do things differently, he commented

> *It hasn't made me adapt. I've just got on with the job because I was mindful of the fact that whatever the reablement role is, I've got to do this myself at some stage. I might as well do it now. (Ron, Family Member)*

This suggests that he did not learn anything new from reablement about approaching his care role but regarded it rather as free care. This will be discussed further in this chapter.

The second context for those already providing care is related to the first but is where the family member is struggling to manage their care role and is considered to be at risk of carer breakdown. As described earlier, the participating service sometimes refers people to reablement in order to support a family member to manage their relative's care better. In the first context there was very little change in the balance of dependence achieved during reablement. In the latter case the intention is to achieve a change in the balance of dependence after reablement, so it is anticipated that the balance will be in a state of flux during reablement. This would imply an adjustment to familial relationships during reablement.

In both of the contexts, there can be variation in terms of the extent to which family are planning to continue to provide care after reablement. As described in the previous chapter, they might come from very different places in terms of willingness and ability to care, the extent to which they define themselves by their care role and their expectations of reablement. These varying contexts are all important as the introduction of the same resources into them are likely to provoke different responses and outcomes.

9.3 Mechanism Resources

This section explores mechanism resources that could be implemented in specific contexts with the intention of empowering families. It also looks at potential responses to implementing them and what this might consequently imply for outcomes. As mentioned in Chapter 7 which examined the skills of the workforce, participants mostly interpreted educating or empowering families in very tangible terms, as showing them how to move the service user or how to use equipment. They did not interpret it as passing on the reabling skills that they themselves apply. This meant that much of the discussion with the research participants was in hypothetical terms. This in turn meant that moving the analysis on to CMOCs generally involved a greater degree of retroductive thinking than in other chapters.

9.3.1 Mechanism Resource: Teaching how to stand back with empathy

In Chapter 7, the core skill of standing back with empathy was introduced. The skill had not yet started to be conceptualised in this way when the interviews and focus group were conducted. Nonetheless, ideas relating to teaching families to stand back were explored with the participants. It was clear that the participating Local Authority did not have a structured way of educating or empowering families to adopt reabling approaches themselves. Any information or skills passed on to families was done on an informal, sometimes reactive and often instinctive basis, rather than being consciously initiated by the team.

The following quote from the focus group implied that the Reablement Workers consider the onus is on families to pick up tips, rather than on the team to initiate any sort of skills transfer:

> *If they are staying with their family, lots of times they can often pick up some tips from us, you know, ways to, they're there 24 hours and they can see… how you moved them, and transfer them (Denise, RW)*
>
> *And they're so grateful for it (Libby, RW).*
>
> *And then that sort of helps them then, you know? (Denise, RW)*

The Team Manager talked about moving families to the point of realising that it is beneficial to encourage their relative to do things for themselves and furthermore for families to regard encouragement as an acceptable way to provide support during reablement. The data revealed a range of ways in which standing back with empathy could be conceptualised. These could go from teaching families to do tasks alongside their relatives; to teaching them to stand back but let their relative know that they are on hand to step in if necessary; to teaching them to stand back and encourage with words only. These are illustrated through the data below and are followed by a consideration of what it is that might cause families to accept and adopt these approaches. The following quotes are examples of teaching family members to encourage their relative by sometimes doing things alongside one another:

> *That's like our cases where we go in in the morning and bedtime say, but husband does lunch and we would or might liaise with the husband and say "Could you encourage her to walk into the kitchen to try and participate, even if she just chops a few vegetables or she makes a cup of tea whilst you make the sandwiches? To try and get her to engage as much as possible in those tasks." (Lou, Referrals Co-ordinator)*
>
> And
>
> *It's about acceptance, it's about getting them [the family member] to realise it's ok to say [to the service user] "No, you can do that." When they say "Oh go and make me a cup of tea", "No it's ok, you come and do it with me." And you do get family members that do that and they will say "Oh no, you can go and do that. It's good for you to go and do that." So, you can see an element of encouragement when you're in there (Jenny, Team Manager).*

The family member is combining standing back with offering to achieve a task by working together. This mechanism resource is illustrated by the following CMOC:

Table 30: CMOC17: Teaching family to combine standing back and doing with

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Teaching family to combine standing back and doing with		Family is willing to support reablement		Accepting that sometimes it is useful to mix standing back and doing with in order to encourage the service user		Family knows that sometimes reablement means encouraging the service user by doing things with them instead of for them

"Oh no, you can go and do that. It's good for you to go and do that" represents a second mechanism resource. The family member is encouraging while justifying standing back themselves, by citing the health benefits. This is illustrated by the following CMOC:

Table 31: CMOC18: Teaching family to encourage using the health benefit of standing back

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Teaching family how to encourage their relative to do things for themselves based on an understanding of the health message "use it or lose it"		Family is willing to support reablement		Realising the health benefit of standing back and encouraging their relative to do things for themselves		Family knows how to justify to the service user the value of them doing things for themselves

An example cited by the Senior Reablement Worker illustrates standing back with empathy by family letting their relative know that they are on hand to step in if necessary. In this case, the service user was a man living with dementia and his daughter was guided by the service over the phone in how to prompt him with his reablement tasks:

> *We've spoken to her over the phone because she doesn't know what to do. I said "What you have to do, if the bath board is on just say to your dad – "Right dad, go on then, go in and have your wash. I'm making my bed or I'm doing whatever and call me if you want me." But he can go in and he can wash himself. Just go in and he'll wash because you've prompted him to. Then when he's washed and he's dried – "Right dad go on into your bedroom then. Put your towel round, go into your bedroom, get dressed and I'll just be in here cleaning the bathroom up." Yeah?" (Susan, Senior RW)*

Here, the suggestion is that family members can realise that is sometimes useful to combine prompting with standing back at a small distance, in order to encourage the service user, rather than doing things for them.

There are a number of potential causal factors associated with these illustrations of standing back with empathy, including health literacy, working against instincts and habits, and validation of the family's role in not caring for in a traditional way. These provide further explanation of the CMOCs and are discussed in turn below.

9.3.1.1 Health literacy – the "use it or lose it" message

The mechanism response in CMOC18 was families realising the health benefit of standing back and encouraging their relative to do things for themselves. Families are not always clear about the benefits of reablement in terms of maintaining physical and mental capacity. This health literacy aspect of understanding reablement was referred to in Chapter 6. One of the focus group participants referred to teaching families ways of encouraging their relative to stay active by saying to them "Don't let them sit in a chair all day, make them get up. Just have a walk to the kitchen even if they can't bring their cup of tea back, just walk". *(Denise, RW).* Getting the health message across to families involves pointing out the benefits of staying active as well as the drawbacks of not doing so. This means that part of the response to being taught the message, is families realising that if their relative does not start doing things for themselves then they will become de-skilled. The OT provided an example of the outcome of a family member learning this:

> *A good example is I've been working with a lady recently and … I think the daughter lives very close by, like a couple of streets by, and she goes in daily to see her mother and she really understood the reablement ethos and what she would do – we were only going in twice a day – she would finish work, she works part-time, so she would come in in the afternoon and she actually began taking her mum out to the kitchen, getting her mum to do her own lunch, where prior to us starting she would go out and do it for her. So, that's a rare example, I think, of where a family member has realised that if mum doesn't start doing for herself then she will become very de-skilled (Michael, OT).*

9.3.1.2 Instincts and habits

In the theorised CMOCs above, the contexts were all where the family is willing to support reablement. Here, familial instincts and habits are considered as context. In some cases, the instinct in couples in particular can work in favour of engaging with reablement. This is when the instinct or intrinsic motivation to do everything possible to return to their "normal" life combines with a willingness and ability to adopt the reabling approach:

> *But you know, even like the husband and wife teams, they've been together since they were 14 and they absolutely idolise each other. And you can see they're devastated that one of them is off their feet and they'll try their utmost to get them back to normal so that they can both go back down Tesco's together and have their coffee or something and they sort of work with us, don't they? (Jacqueline, RW)*

In other couples the presiding instinct of the partner is to care <u>for</u>. Participants gave examples of this, such as a husband getting his wife "ready" for the reablement visit by doing everything for her that she was supposed to be doing for herself during the visit. In this sort of context, teaching the family member to override their instincts and habits, and to stand back is necessary for them to engage with reablement and is likely to need to draw on some of the resources mentioned in this chapter.

When the family member is an adult child or grandchild, the instinct to care <u>for</u> can also be very strong. The OT participant demonstrated through personal experience that just because someone understands what reablement is, does not mean that their familial instinct to do <u>for</u> will be over-ridden as a response:

> *I think the issue is when you've got an ill or unwell family member, we're all probably guilty of it to some extent, you will … even as a reablement occupational therapist, if my own grandma is unwell, even when I was at home over Christmas or I was at my auntie and uncle's, I was getting up and making her cups of tea. Your instinct is to sort of wrap someone up in cotton wool. She lives a very independent life anyway, however by me doing that I was stopping her getting up and moving and so I can understand why some family members struggle to use that reablement hat (Michael, OT).*

Understanding this can be considered as an aspect of the reablement team's ability to empathise. It might be useful for teams to help families understand their own journey during reablement and their reactions to it. This leads on to a context identified by the OT where the family member has come to define themselves as a carer. In this context, families could experience the team's attempts to teach them how to stand back, as challenging or undermining their role. The OT went on to say that where the family member's sense of identity is challenged, the resource of reinforcing the health message of reablement might be introduced:

> *with some family members and carers they're supporting their relatives to such an extent that they're actually hindering them and sometimes having that discussion with them and just saying "Actually your family member can do a lot … our client can do a lot more for themselves", sometimes you open their eyes to that as well I guess (Michael, OT).*

This is illustrated in the following CMOC:

Table 32: CMOC19: Increasing family's awareness that standing back can be part of care role

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Helping family to stand back by increasing their understanding of the health message "use it or lose it"		Family is caring for their relative and not adapting to standing back		Increased awareness that doing too much for someone can act as a hindrance and that standing back can be an aspect of their care role		Family can justify to themselves the value of standing back

Having an awareness of how families perceive their role and working with this is considered in another way in the following section.

9.3.1.3 Validating the role of family as a social resource

In helping families to stand back more, there appears to be potential for Reablement Workers to endorse the value of social interaction between the family and the service user, as alluded to in other studies (Glendinning et al., 2010; Beresford et al., 2019). The Senior Reablement Worker referred to encouraging families to step away from doing things for their relative in favour of being with them in a social capacity:

> *The daughter has phoned and I said "Just step back. If your mum phones you then, yeah, talk to her and everything else and when you go and see your mum, instead of going to do things for her, just go and have a cup of tea and a cake and visit. Just visit your mum. Don't do anything else for her."…*
>
> *… that's what I think a lot of these children of elderly parents need to do, is stand back and be the daughter or the son and not the carer and let us try and extend their [the service user's] ability to do things for themselves. (Susan, Senior RW)*

She also suggested that sometimes when family members move away from doing certain tasks for or with the service user (e.g. personal care), then this can help to rebalance the relationship between them. As shown in the CMOC below, it is theorised that Reablement Workers can provide a validation of the family's role as a social resource for their relative and that this can give families reassurance that just being with them makes a difference. One of the participants expressed this from the perspective of benefitting the service user, another from that of the family member cherishing time with their relative while they have the opportunity to do so:

> *They [family members] can be a resource because it is also social interaction for the person, which in a lot of our cases is missing from their lives. (Jenny, Team Manager)* and
>
> *I say [to relatives] "But when that phone doesn't ring you will miss that because that phone might ring seven/eight times a day and one day that phone won't ring and you'll wish to hell it did." (Susan, Senior RW)*

Table 33: CMOC20: Endorsing the value of a social role for families in reablement

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Endorsing the value of the family's role as a source of social interaction		Family needs to step away from the tasks that the service user is working to achieve alone		Family feel assured that interacting on a social level with their relative makes a difference in reablement		Family can justify to themselves the value of standing back

It should be emphasised that the responses here are theorised. It is possible, furthermore that when reablement teams validate a role for families that is more of a social support role rather than a traditional care role, families experience this as having been given permission to step away from hands on care. This might be of relevance to people who consider that providing hands on care for older relatives is a duty, even though it is proving detrimental to their relationship.

9.3.2 Mechanism Resource: Demonstrating or modelling how to stand back

In relation to passing on skills to families, participants also discussed demonstrating to families how to stand back. This was referred to in Chapter 7 and is extended here. The focus group participants were asked if they ever consciously offer to demonstrate or model ways of reabling to families. Their response indicated that they would only do so in response to requests. The Team Manager also suggested that the impetus for families learning by observing would be more likely to come from the families themselves rather than from Reablement Workers:

> *If the [family] carers see them [Reablement Workers] going and doing that, then it's a good way to learn, is observing. "Well, this is how they did it and I'm going to carry it on." (Jenny, Team Manager)*

Participants cited a particular context in which demonstrating how to stand back is of value; when families are concerned about the risk that reablement might present to their relative. The Team Manager commented that when families are risk averse, demonstration of healthy risk-taking can be used as a means of tackling their concerns. The Senior Reablement Worker illustrated this by describing how she explained to an "over-protective" son the necessity of his mother taking risks and demonstrated to him how standing back worked:

> *We went into his mum and he was so offish and he was like '[She] can't do anything!'. But you go through it all and you sit down and you talk and let them see what they can do and bring them round to understanding that they can't be wrapped up in cotton wool. They've got to be able to take some risks. We all take a risk don't we? And they've got to be able to take a risk as well. As long as it's not going to end up in them really hurting themselves…*
>
> *He [subsequently] said "I've never known her like this before. She doesn't usually do anything". He came round to our way of thinking and we ended up keeping the visits in for a week, then bringing the visits down, say to two a day, one a day and then every other day and close and he was fine. But when we first went in he was so bolshy that his mum can't do anything. I think they get over-protective as they get older (Susan, Senior RW).*

There is an element here of the notion that "seeing is believing"; when families get to see a change in their relative's capability over time and equate the reduction in the number of visits with success, that is when they understand the approach and its benefits.

Where a family member feels that they are neither learning anything new, nor are receiving support in traditional care methods, the response and outcome will be very different. The family member who was interviewed, felt that he learned very little from reablement (only a new way of using a slide sheet "That's all I've learned"). Furthermore, he felt that he was not receiving any support and was having to create tasks for the Reablement Workers to do:

> *"I'm not sure how this is going, because ultimately are you helping me or guiding me?" You know? "Because I can't see either as such, you know". And I found myself saying to Jo, "Well let's leave your catheter full for a minute" (Ron, Family member).*

He also worried about the risks implied for himself in adopting the team's approach to standing back:

> *So I'd pose a question like "Look, if you watch me and I fall over, what's the situation?" I said "You're meant to be here helping, and all of a sudden if you decide that you're not going to help and something happens, where do you stand? Because we're all under your care" (Ron, Family member).*

It is clear that his lack of understanding about the purpose of reablement contributed to this situation. These ideas are illustrated by the following theorised CMOC:

Table 34: CMOC21: Not explaining to families the purpose of standing back safely

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Reablement Workers use a reabling approach without explaining to families the purpose of standing back safely		Family is concerned about the risk that reablement might present to their relative		Family's concern is compounded		Family has reduced confidence in reablement

The ideas presented here link back to teaching how to stand back with empathy, as well as demonstrating what is achievable (Chapter 7). Where the service is consciously using reablement to take pressure off a family member, the resource mechanism of demonstrating to them how to stand back, can be an explicit means of supporting them. In this context, the data showed that if the family member has not gained a good understanding of what reablement is, then their response can be one of confusion and irritation. The family member who was interviewed clearly had little understanding of what reablement was. He was used to caring for his wife and was anticipating that the service would take pressure off him, partly by providing care for his wife but also by teaching him new ways of caring for her in a traditional way. He expressed his frustration in the following ways:

> *And for a little while we sort of tolerated it. But I ended up saying "Well there's no point, it seems to be crazy doing this, isn't it? Because ultimately you're just observing me putting her to bed".*
>
> And
>
> *Well like I said you'll never turn down support if it helps. But we got to a stage where I'm making cups of tea; they're [the Reablement Workers are] coming around for cups of tea (Ron, Family Member).*

The final two mechanism resources have a natural link with Reablement Workers' own skillsets and the way they were described in Chapter 7.

9.3.3 Mechanism Resource: Providing tips and guidance

As well as modelling the reablement approach, participants discussed how they provide tips and guidance to families on how to approach daily living tasks and to use associated equipment. Participants referred to introducing families to devices such as one cup kettles and pointing out practical tips such as not over-filling kettles and not buying large milk cartons. They observed that the introduction of small pieces of equipment of this sort can help to bring around families who are initially resistant to reablement:

> *Oh yeah, they can change, can't they? They can see that doing a task that way, or changing a kettle then enables that person to make a hot drink, if we move that kettle, put a lighter one in… (Denise, RW)*

Participants emphasised that as well as explaining how to use equipment, they try to give families time to ask questions about getting around challenges, bearing in mind their own needs. It is sometimes helpful to remind them of tips and guidance by writing them in the care record or explaining again over the phone. As the OT observed, "This is especially useful if the service user has a cognitive deficit, as the family can be used to remind them" (Michael, OT). The participating service did not have any provision for training family members to use specialist equipment.

9.3.4 Mechanism Resource: Offering information about other services

The Team Manager suggested that Reablement Workers can assure families (particularly towards the end of reablement) that they do not need to care in isolation. They can let families know that they have options with regard to their ongoing care role can help them identify local support services for the future. This might help families to feel that they do not need to feel obliged to stick to one role indefinitely. Feeling an obligation or strong instinct to care all of the time can be considered a context and the data suggested that this might particularly, but not exclusively, apply to people who cohabit with the service user. In this context, the mechanism resource of assuring them that they do not need to be in that role all the time and that reablement is a means of making this happen, was identified.

> *"I'm here so I have to be the carer." They've put themselves in that role so, yeah, it is about saying to them "No you don't have to be, not 24/7. You can use the reablement part of the service to encourage to do for themselves and then that would then give you a more free lifestyle in the future." (Jenny, Team Manager)*

This quote suggests that a response to providing this assurance along with a means of achieving it could be that families rethink and re-evaluate their role during reablement, thus using reablement as a transition into a future where the balance between caring for and being with is reset. This is set out in the following CMOC:

Table 35: CMOC22: Advising families that they can change the balance of their care role

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Reablement Workers advise family that they do not need to care 24/7 and how to achieve this		Families feel an obligation or instinct to care 24/7		Families re-evaluate the parameters of their care role, realising they do not need to remain in one role		Reablement provides a means of changing the balance between dependence and interdependence

By contrast to this level of assurance, the focus group participants talked in terms of giving out a leaflet or an instruction to contact the GP if necessary at the end of reablement:

> *Because we have got leaflets to hand to the family (Ellie, RW)*
>
> *Because they're left in the file, aren't they? You just say, any ongoing problems, any issues, contact your GP, you know, if you're struggling, if your circumstances change, contact your GP or Care Direct. (Denise, RW)*
>
> *Yeah, I think we do leave them with enough information, don't we? (Jacqueline, RW)*

This discussion was not pursued in terms of the impact of giving out a leaflet on feelings of connection or translating receipt of a leaflet into actively pursuing what it advertises. There was not enough data in order to understand or theorise the mechanism response regarding families feeling assured that external support exists that might help them in whatever support role they choose to undertake. The PPI Group suggested that it would be useful for information at the end of reablement to include where to get training in areas such as manual handling, first aid and how to deal with a fall if this is of interest to families. Other suggestions included how to access services that supplement family care, such as meal delivery, cleaning services, local social and cultural activities as well as care services.

9.4 Hypothesised Outcomes

To a greater extent than the other findings chapters, this chapter has relied on hypothetical resource mechanisms. This is because the participating service did not have an explicit organisational strategy to pass on reabling skills to family members. For this reason a short section is included here on data relating to how participants hypothesised what the outcomes of taking a more strategic approach to transferring skills to families might be.

Questions remain concerning the potential negative outcomes of educating family members to stand back. Families might misjudge things causing them not to seek help when they need to because they have a misplaced confidence in their own judgement. The Senior Reablement Worker suggested that common sense is likely to prevail, preventing families from pushing the service user too far, while the Team Manager suggested that for certain people a sense of duty will always obscure common sense. More data would be required to explore this further.

In terms of potential positive outcomes, these were partly expressed in a way that refers back to Figure 14 that conceptualised reablement as a transition for families at the start of this chapter. This figure conceptualised the ongoing relationship as rebalanced but still interdependent. One of the focus group participants said:

> *[I] think we do get a good outcome, when we're doing reablement, we get a good outcome. You do make lots of service users independent and their families are happy… And they can go off and have their life and know that they're doing things safely, although they're still, you know, providing input, but not so much (Denise, Reablement Worker).*

The Team Manager expressed a similar idea but with the additional suggestion of reablement helping to maintain quality in the relationship:

> *A good outcome would be that that person was living as independently as possible at home and it could be with just [family] carer support or it could be with external support. But obviously the carer felt included in that outcome and that they were obviously happy with that outcome and that they were still getting their quality time with the person [service user] that we've walked away from (Jenny, Team Manager).*

The Senior Reablement Worker went further still to suggest that passing on learning to families during reablement might increase their capacity to continue applying the approach, not only with the service user but also for themselves in the future:

> *It will help them in their old age as well!... "Well, we used to show our mother how to do it that way, didn't we? Yeah, let's have a go ourselves" (Susan, Senior RW).*

On one hand the Occupational Therapist expressed worry about outcomes:

> *I wonder really sometimes, with some of our clients, when we finish and a family member takes over, how much they use that reablement ethos or if they just resort back to doing onto the person (Michael, OT).*

The same participant, however, envisaged aspirational outcomes for transferring reabling skills to family members who are known to be willing to engage:

> *It would be great, for instance, if a family member is identified that they want to support their parents after we finish we did some joint visits with that family member to show how we are working with this client. However, I don't know… (Michael, OT)*
>
> *So, you're saying if the Reablement Workers are already clear about the willingness of the family to be involved then they would naturally see them as part of ….? (Researcher)*
>
> *Well I think they would have to be instructed, so I think the office would need to say "Look, Margaret is very keen on supporting her mother once our service finished. We must work alongside Margaret so that she has skills." And whether a Reablement Worker would actually feel comfortable doing that, because, in the nicest way I think Reablement Workers could do … everyone could always do with extra training as well but I think … I don't know how confident they would feel to include them to offer that sort of level of support really. It's just an impression I … (Michael, OT)*

He went further to hypothesise that the education of family members in a reabling approach might ultimately lead them to guide subsequent traditional care services in this approach:

> *And maybe if care agencies did take over, family members would be able to instruct them a bit more on what support they want … how they want their carer agencies to support the person. Impart that reablement ethos to the care agency maybe. I don't know (Michael, OT).*

A final comment on the data relates to the extent to which reablement teams consider families to be critical to achieving good outcomes for service users. The Referrals Coordinator and OT both reflected on the fact that the current person-centred emphasis in health and social care could be seen to run counter to the whole notion of active engagement of families in the intervention:

> *It's an ongoing discussion just to keep reminding them [the family] "this isn't necessarily about you and what you want, it's about what they [the service user] want." We have to be person-centred, it's not, you know…? (Lou, Referrals Coordinator)*
>
> And
>
> *I think the problem is in a service like reablement is very much under the ideology of the person who's at the centre of their care and I think sometimes as professionals, and as a reablement service, we sometimes blinker… I don't think family members are necessarily a part of that same circle (Michael, OT).*

The OT did go on, however, to envisage how things might be different:

> *I think we very much focus on the person and, unfortunately, our job is to re-able that person and I think usually family members and partners as carers are under-utilised and I don't know if that's …I guess if we recognised their role more whole-heartedly and we could get them on board, then maybe more family members would be willing to take on the care, not just as carers but more like* Reablement *Workers, I guess (Michael, OT).*

Ideas about person-centred care and balancing service user autonomy with their family situation will be expanded in the next chapter; the discussion of the study findings.

9.5 Chapter summary

This chapter has explored empowering families to engage with reablement. This has importance both in terms of optimising the benefits of the intervention during its delivery, as well as sustaining the positive impacts of the approach more generally beyond delivery. The realist synthesis had revealed gaps in knowledge about how to empower families to motivate their relative, how they might apply a reabling approach themselves and circumstances in which this might work or not. The desired outcomes for empowering families that were identified in the synthesis appeared to be somewhat unambitious in that they focused on supporting the service user's daily routines, rather than focusing on empowering families to feel confident, capable and empowered to utilise the approach themselves. This pointed to a lack of understanding about aspirations for empowering families as well as what might cause families to continue to adopt a reabling approach after delivery of the intervention.

In the course of the chapter, contextual factors were identified within a conceptualisation of reablement as a time of transition for families. This transition represents a time during which the existing relationship between the service user and their family undergoes necessary adjustment and potential rebalancing. The findings explore how the reablement team can play a part in moving the service user and families through this transition, and how mechanism resources, for example coaching families to stand back with empathy, might trigger deeper engagement with the approach. A distinction was made between families who were new to providing care and those who were already providing care in some way before reablement. The findings suggested a causal link between instilling an understanding of reablement and empowering families to engage with it, whereby having an understanding of reablement can be considered a context in itself.

It was notable that the idea of consciously passing reabling skills on to families appeared to be a new consideration for most of the staff participants. Questions remain about who is best placed to transfer reabling skills and messages to families and how they do this in different circumstances. There appears to be potential to explore this further and the ideas presented in this chapter would provide a useful starting point for doing so.

Themes spanning all four findings chapters are brought together in the next and final chapter of this thesis, the discussion chapter.

Chapter 10: Discussion

10.1 Introduction

This chapter draws together the entire study. It starts with a commentary on how the theories resulting from the inquiry developed from the initial Candidate Programme Theories. The central themes that cut across all four findings chapters are then discussed in turn, followed by a discussion of the implications they have for policy, practice and guideline development. A consideration of the study's limitations, including a critical reflection on applying a realist approach to the research question, lead into proposals for future research and reflections on the learning derived from the reflexive approach taken. The chapter concludes with a summary of how the study contributes new knowledge to the field of reablement. An addendum focussing on the learning in light of the COVID-19 pandemic follows this chapter.

10.2 Aim of the research study

The emphasis of the study was predominantly on reablement teams. In terms of reablement teams facilitating family engagement, it investigated what is thought to work, for whom and in what circumstances. The main research question is restated here:

> What are the causal explanations for the ways in which reablement teams engage families in older people's home-based reablement?

Sparked by gaps in knowledge about these causal explanations and in response to specific aspects of the NICE and SCIE guidance on reablement (SCIE, 2013; NICE, 2017), as well as the provisions of the Care Act (Department of Health, 2014a), three subsidiary questions were considered:

1. What contexts are relevant to explanations for the ways in which reablement teams engage families in older people's home-based reablement?
2. What mechanisms can be identified that act at the level of the family, service user and reablement service in these contexts?
3. What outcomes are sought for the engagement of families in home-based reablement and which contexts and mechanisms are thought to affect them?

Although the main emphasis in collecting the data was on reablement teams, the findings of this study will be useful to all stakeholders in the future development of reablement; commissioners, providers, the general public and researchers.

10.3 Presentation of the theories

At the start of the study, eight Candidate Programme Theories (CPTs) were articulated, relating to the following areas:

1. Instilling an understanding of reablement
2. Goal setting and monitoring
3. Risk management
4. Ongoing communication
5. Plan for the end of the service
6. Family respected as part of the whole care circle
7. Family buy-in
8. Customising service delivery to the family's position

Over the course of the realist synthesis, the evidence provided new insights into the Candidate Programme Theories and exposed gaps in thinking. As a result, the theories were developed in an iterative way which resulted in some of them being combined and the identification of a new theory area. They were refined and ultimately presented under four theory areas, each represented by a findings chapter.

Family "buy-in" was understood as a potential outcome of them understanding and knowing what to expect from reablement. This led to CPTs 1 and 7 being combined and refined under the single theory area which focused on the activity of the workforce: "Instilling an understanding of reablement" (Chapter 6).

CPTs 2, 3, 4 and 5 all related to aspects of empowering families to engage with reablement. They were combined and refined, initially under the theory area "Team facilitate active involvement of family" which subsequently became better represented by the theory area "Empowering families" (Chapter 9).

CPT 6 was unpicked into many different elements, for example the team's view of the family's role and the team considering the family's needs. These elements were refined separately within all four theory areas.

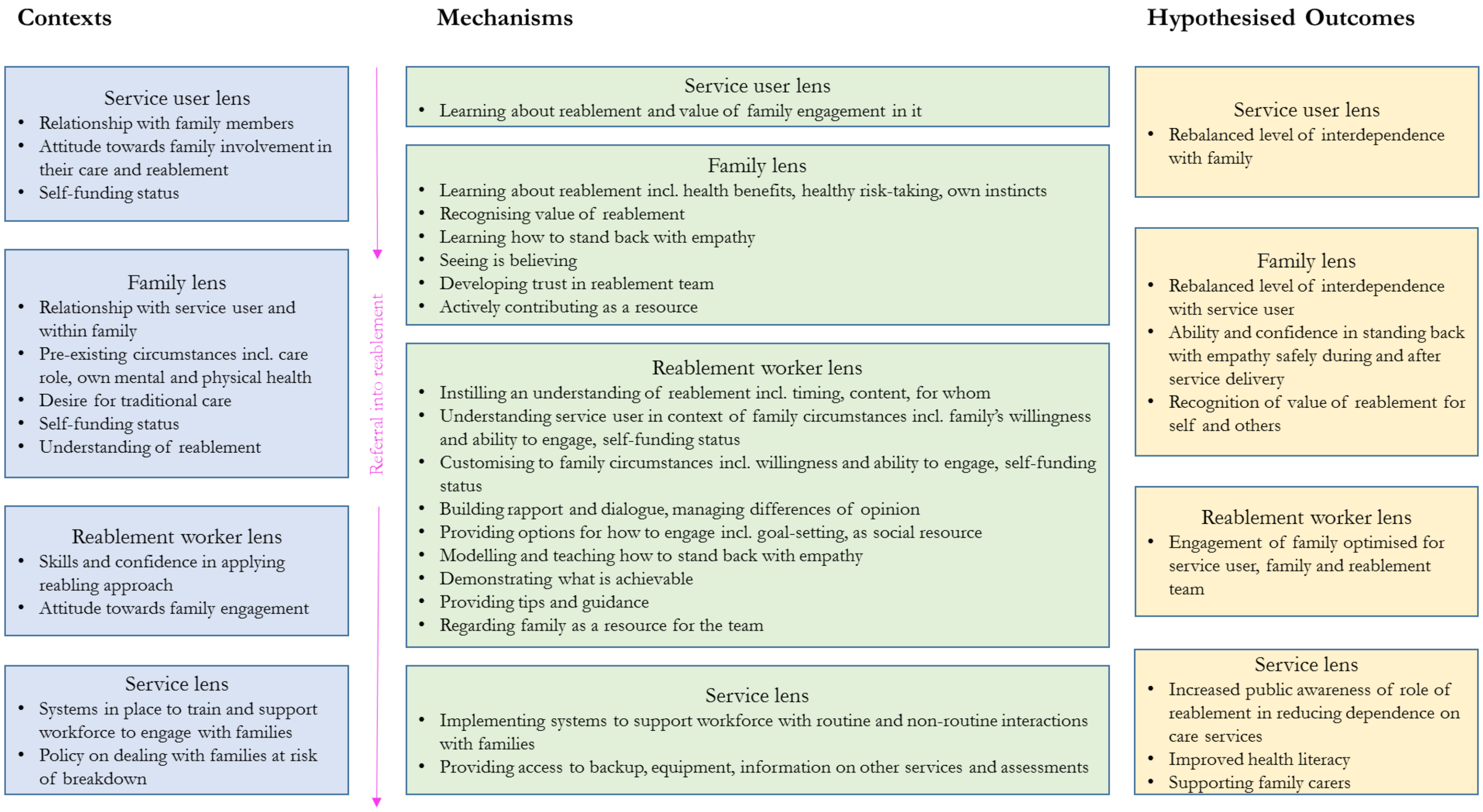
CPT 8 was refined under the theory area "Customising Service Delivery to Family Circumstances" in Chapter 8.

The new theory area to emerge related to the workforce skills required to facilitate family engagement in reablement. Initially this was conceived as "Reablement Workers are skilled negotiators", but as understanding grew it became better represented as "Skilled Workforce" as presented in Chapter 7.

One of the strengths of exploring the research question through a realist lens has been its ability to embrace and examine complexity. This presents a challenge in terms of seeking to provide an overview of all the findings across all four theory areas. The following figure, therefore, should be considered as one of many possible snapshots on the entirety of the findings. It draws on many of the section titles from each of the four findings chapters and depicts the findings from the perspective of service user, family, Reablement Worker and service respectively.

Conditions pre-dating referral into reablement are characterised as context. Mechanisms are represented as a whole rather than being identified as resources or responses. As mechanisms operating at the level of families were a focus of the study rather than those operating at service user level, they are more fully represented here. In both cases these mechanisms are predominantly mechanism responses. Mechanisms operating at the level of Reablement Workers and the service are predominantly mechanism resources, representing what could be offered in order to facilitate family engagement. The outcomes represent hypothesised, best case outcomes.

Figure 15: Overview of Findings Chapters



Contexts

Service user lens

- Relationship with family members
- Attitude towards family involvement in their care and reablement
- Self-funding status

Family lens

- Relationship with service user and within family
- Pre-existing circumstances incl. care role, own mental and physical health
- Desire for traditional care
- Self-funding status
- Understanding of reablement

Reablement worker lens

- Skills and confidence in applying reabling approach
- Attitude towards family engagement

Service lens

- Systems in place to train and support workforce to engage with families
- Policy on dealing with families at risk of breakdown

Mechanisms

Service user lens

- Learning about reablement and value of family engagement in it

Family lens

- Learning about reablement incl. health benefits, healthy risk-taking, own instincts
- Recognising value of reablement
- Learning how to stand back with empathy
- Seeing is believing
- Developing trust in reablement team
- Actively contributing as a resource

Reablement worker lens

- Instilling an understanding of reablement incl. timing, content, for whom
- Understanding service user in context of family circumstances incl. family's willingness and ability to engage, self-funding status
- Customising to family circumstances incl. willingness and ability to engage, self-funding status
- Building rapport and dialogue, managing differences of opinion
- Providing options for how to engage incl. goal-setting, as social resource
- Modelling and teaching how to stand back with empathy
- Demonstrating what is achievable
- Providing tips and guidance
- Regarding family as a resource for the team

Service lens

- Implementing systems to support workforce with routine and non-routine interactions with families
- Providing access to backup, equipment, information on other services and assessments

Hypothesised Outcomes

Service user lens

- Rebalanced level of interdependence with family

Family lens

- Rebalanced level of interdependence with service user
- Ability and confidence in standing back with empathy safely during and after service delivery
- Recognition of value of reablement for self and others

Reablement worker lens

- Engagement of family optimised for service user, family and reablement team

Service lens

- Increased public awareness of role of reablement in reducing dependence on care services
- Improved health literacy
- Supporting family carers

10.4 Cross-cutting themes

Having provided an overview of all the findings chapters, this chapter now moves on to discussing themes that cut across all four theory areas set out in the findings. Rather than providing a summary of the findings, it synthesises them, offering a higher level view and a rationale for why it is important to consider them in this light. This means that some of what is discussed here is an extension of ideas and considerations described in previous chapters. Where relevant, reference is made to how the discussion relates to what is already known; how it reaffirms, diverges from or extends it. The five cross-cutting themes are:

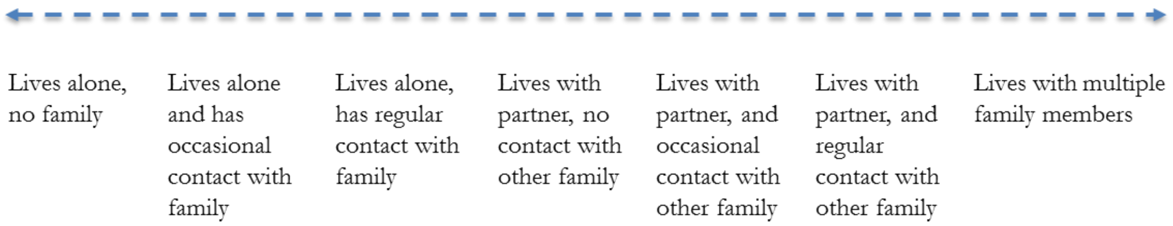
- Shifting to a relationship-centred approach for reablement
- Standing back with empathy: reablement's core mechanism
- Actively engaging families in reablement: the additional skills and support required
- Reframing reablement as a mindset that can be sustained in family life
- Outcomes sought for engaging families in reablement

The following five sections discuss each of the cross-cutting themes in turn.

10.5 Shifting to a relationship-centred approach for reablement

This study suggests the importance of regarding the presence of family members in a service user's life as a distinctive context in the delivery of reablement services. This has been shown to be easily overlooked. There is a difference between a reablement service user who lives alone and who has no contact with any family members, and a service user who does have contact with family. There is a spectrum here that is relevant to the implementation of reablement:

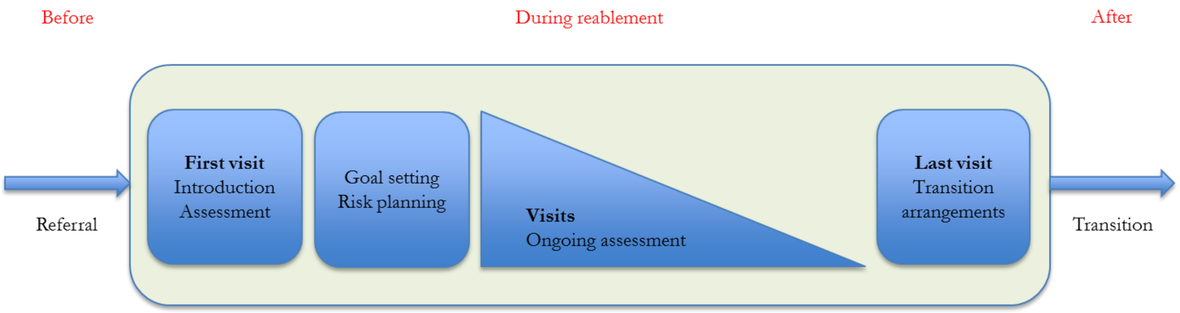
Figure 16: Spectrum of family presence in a service user's life



Clearly a range of other factors could be added to the spectrum such as geographical proximity and varying numbers of family members but it is intended here to be broadly illustrative rather than fully comprehensive of all family situations. It is likely that most people will fall into the central parts of this spectrum.

As described in Chapter 1, reablement is widely considered to be a person-centred intervention, one in which the individual is both a participant and beneficiary. For those people who live alone and do not have contact with family, a person-centred focus is appropriate. In this case, at each juncture in the reablement journey shown below in Figure 17, decisions are made that are person-centred; regarding that person as entirely self-sufficient and autonomous. Goal setting and risk planning is done in the context of being alone. Between visits, the service user can practise newly developing skills without any potential involvement from anyone else and without the possibility that someone else might attempt to do these things for them. Transitioning from reablement into a continuation of living alone with or without any form of ongoing care, there is likely to be strong intrinsic motivation to maintain the skill levels gained during reablement.

Figure 17: The reablement journey



By contrast, where there is potential involvement by a family member or members, another layer of context is added at every juncture in the journey. There are a series of situations in which families could engage, that hold the potential to enhance or to threaten the success of the intervention. The family's circumstances and influence could come into play at the first visit, where assessments are made, including an assessment of what the family is willing and able to do to contribute to the service user's support. At goal planning stage they could contribute to goal setting or not. These goals could vary in their relevance to their lives as a family unit. If they do contribute to goal setting then they could subsequently support the goals or not. During and in between visits, they themselves could adopt a reabling approach towards the service user or not. In planning for what comes after reablement they could play a role in contributing to making decisions about potential future packages of care based on their willingness and ability to play a role in providing care. After reablement they could play a role in either continuing to apply a reabling approach in the specific way that they were during reablement, and/or in applying it to other situations. At all of these junctures complexity is added and multiplied according to how many family members are involved.

This creates a starkly different context to one in which family do not play a part; a context in which the mechanisms of reablement operate differently. There is a danger that if this interconnectedness is overlooked or bypassed, then at each of the junctures in the journey, the potential benefit of the intervention could be undermined.

Existing evidence has identified a potential tension between respecting a reablement service user's autonomy and regarding them as part of a wider care circle (Glendinning et al., 2010; Pearson et al., 2015; Beresford et al., 2019). The study findings reaffirmed evidence relating to this tension. A number of different contexts that might alter the degree to which autonomy could be compromised were identified. These included situations in which there are disagreements between the family and the service user about the level of family engagement; disagreements between family members about the service user's needs; situations where the service user asserts their right not to do things that they are capable of doing; and where the family consistently counters the reabling approach.

However, the nature of autonomy changes in different circumstances. It is different with respect to someone who has family, neighbour or friends present in their life, and someone who does not. This study proposes that tension between respecting a service user's autonomy and regard for their wider care circle should not be ignored. Rather, the service user's relationships with their family and others should be regarded as intrinsic to customising service design and delivery. This requires a shift from a person-centred focus to a relationship-centred focus. Person-centred approaches originate in the work of Dr Carl Rogers in the 1950s in the field of talking therapies. Since then the adoption of person-centred approaches has continued to grow, partly to distinguish them from more bio-medical approaches. Person-centred care is one of the 13 fundamental standards of care that the Care Quality Commission (the independent regulator of health and social care in England) requires health and social care providers to meet (CQC, 2014). This gives a service user the right to expect care or treatment that is tailored to them, meeting their needs and preferences and actively involving them in decision-making about their care.

Relationship-centred care shifts the focus from only being on the person receiving care, to include a recognition that the nature and quality of relationships are central to health and social care and that the needs of staff and families should also be considered. The term relationship-centred care was originally used in 1994 to encompass relationships with and between patients and their medical team (Tresolini and Pew-Fetzer Task Force, 1994). In the field of dementia care, it is more commonly associated with the work of Nolan et al. (Nolan et al., 2004, 2006). Again within this field, Kitwood discusses the importance of considering interdependence between family members when working with people living with dementia (Kitwood and Bredin, 1992). Although the discourse of relationship-centred care and interdependence is common within the field of dementia care, it did not appear in the reablement literature examined. This study's findings, however, suggest that framing reablement from the outset as a relationship-centred service would ensure that the role of families would always be recognised rather than being regarded as an optional addition. The findings suggest that although cognitive ability is frequently not an issue for reablement service users, issues related to physical ability still impact on familial relationships and vice versa. The distinctive context of having family members who could enhance or threaten the success of reablement has been shown to be easily overlooked by this study and indicates the critical importance of its findings. This is discussed with reference to its implications for ongoing development of NICE guidelines in section 10.8.

10.6 Standing back with empathy: reablement's core mechanism

The study has been concerned specifically with the social architecture of reablement; how reablement teams engage families with it. The SCIE definition of reablement was quoted as a starting point for the study. The end of the definition states that reablement

> "is about helping people do as much for themselves as possible rather than doing things for people that they cannot do." (SCIE, 2013)

The core mechanism of standing back with empathy, identified and articulated during the study, extends this idea. Standing back with empathy means having an awareness of the service user's feelings and emotions with regard to undertaking a task themselves, while standing back and letting them do it, perhaps with psychological assistance in the form of encouragement, but with little or no physical assistance. It can be considered to be a mastery of actively choosing not to do for. The effect of not doing for is to provide the service user with increased opportunities to try to do things for themselves. For this to be effective it is suggested that the service user needs to be aware that the Reablement Worker is actively choosing not to do for and could and will step in if required. If the service user is not aware of this, the mechanism will not be triggered, with the result that they might feel frustrated, angry or abandoned.

When family is present during reablement visits, the same applies. If a family member is not conscious of the purpose of standing back with empathy, seeing Reablement Workers failing to step in to help their relative will cause a negative response. A final CMOC illustrates this:

Table 36: CMOC23: Not explaining to families the purpose of standing back with empathy

Mechanism resource	⇒	Context	⇒	Mechanism response	⇒	Outcome
Reablement Workers use a reabling approach without explaining to families the purpose of standing back with empathy		Family perceives caring for as doing for		Family experience confusion, irritation and frustration		Family does not support the reabling approach

There are multiple mechanisms at play here which is why standing back is a core mechanism that spans all of the theory areas. For example, an understanding of the ethos and core mechanism of reablement needs to have been instilled not only in the Reablement Worker but also in the family member and service user. It is not sufficient for the Reablement Workers only to have this understanding, or for Reablement Workers and service users to have this understanding but not families. When more than one family member is involved in some way with reablement, this understanding needs to extend to them all otherwise disagreements are likely to result.

Empathy adds a further layer to this. Having an awareness of the service user's feelings and emotions with regard to undertaking a task themselves means that sometimes Reablement Workers will gauge that it is appropriate to step in and assist. This might simply be because the service user is having a bad day or it might be that they have forgotten the steps that they need to take to accomplish a task. If a service user and their family never witness Reablement Workers stepping in and doing for, they might lose confidence in them. This has implications for practice. Reablement Workers need to know how to judge how far discomfort is beneficial to the service user and their family and when to step in with compassion. It is possible that this is a skill that needs to be taught in different ways to Reablement Workers who are new to the care sector and those who already have experience of more traditional hands-on care.

By the same token, for families to understand how to apply a reabling approach themselves when the team are not present, they need to know that it is sometimes fine to step in and assist. Once the team has withdrawn entirely, this skill is likely to come into play in situations where time is a factor. For example, on some occasions it might be necessary for a family member to help the former service user to get dressed in the interests of getting to an appointment on time, whereas on other occasions where there is no pressure on time, they can be encouraged to dress themselves. This means that standing back with empathy is also knowing at what points adopting a reabling approach without stepping in could be unproductive, disabling or damaging.

The data revealed various ways in which standing back with empathy could be communicated to families. These ranged from teaching families to do tasks along with their relatives; to teaching them to stand back but let their relative know that they are on hand to step in if necessary; to teaching them to stand back and encourage with words only.

Identifying and articulating the mechanism of standing back with empathy in these ways, extends thinking to date about "knowing when to do something for a person… and knowing when to do things alongside and with a person" (SCIE, 2013 p10) and treating service users of all care services with compassion, kindness, dignity and respect (CQC, 2018). The study findings identified a range of contextual factors related to this mechanism. They bring this unseen mechanism to the surface, creating an understanding that could help in the training of reablement staff as well as the education of families to stand back with empathy actively.

10.7 Actively engaging families in reablement: the additional skills and support required

The skill of standing back with empathy is just one of many skills that the findings revealed as necessary for Reablement Workers to master in their interactions with service users and their family members. Existing evidence in the area of Reablement Workers' skillset as it applies to families in England had mostly dealt with passing on advice about equipment, however the study showed that a far more complex set of skills is required to judge when, how and whether to engage families. These skills, many of which relate to building rapport and transferring knowledge and skills associated with the intervention, need to be applied at speed as reablement is time-limited. Just two of the skills related to creating the conditions for family engagement are discussed here: instilling an understanding of reablement and transferring reablement skills.

10.7.1 Instilling an understanding of reablement

The need to establish that families understand how reablement differs from traditional homecare is recognised in the existing literature (Glendinning et al., 2010; Beresford et al., 2019) and is further endorsed by this study. However, the synthesis had exposed that there is no guarantee that gaining an understanding of reablement will lead to an acceptance of it as an approach. Yet, without further overt understanding of the mechanisms that lie beneath this link, it is possible that an implicit assumption remains that there is a direct correlation between families understanding what differentiates reablement and them accepting and/or adopting a reabling ethos themselves. The findings showed that it is not possible to assume a direct relationship here. If families understand what a reabling ethos is, they will not always accept it as the right approach regardless of their circumstances.

The study unpacked multiple contextual factors that had an impact on this causal mechanism. Among these were previous experience of traditional care, pre-existing misunderstanding about what to expect of reablement (including its duration, content and potential impact of future care provision and finance) and strength of desire for traditional care for their relative. Factors relating to a family's willingness and ability to engage in reablement, were also demonstrated to have a significant potential causal impact on translating an understanding of reablement into active adoption of it as an approach during and after service delivery. The study findings examined different contexts related to families' circumstances. Cognisant of the provisions of the Care Act (Department of Health, 2014a), they suggested the importance of customising the approach to engaging families according to their willingness and ability to engage and, importantly, being seen to do this. A range of mechanism resources that could be introduced into these contexts was explored, such as offering families options for how to engage and families selecting those with which they are most comfortable, and helping families to rethink their role in relation to the service user. These all draw on an additional skillset within the reablement team.

The next section discusses this in terms of the skills required of reablement teams to transfer their own reabling skills to families so that families can actively apply the approach themselves.

10.7.2 Transferring reablement skills to families

Although the synthesis suggested that families could be taught to motivate the service user and to stand back during reablement, there were gaps in evidence about how to achieve these things and what might cause them to work or not, particularly in an English context. The Norwegian studies suggested that targeting training for families based on the service user's own training is likely to empower them more than receiving generalised advice and support. This does not map easily onto how reablement is delivered in England. The cycle of goal setting and assessment that characterises reablement in England is not considered to be a training programme. Nor does there appear to be any conscious intention in England to transfer reabling skills to families in a structured way. This sometimes takes place, rather, in an informal, reactive or instinctive way. While recognising that Norwegian reablement services are delivered within a different context to those in England, it seems that English services could derive some learning from them.

The study found that in some instances, "seeing is believing" acted as a mechanism in transferring skills to families and shifting their mindset towards one of reabling rather than doing for. In these instances Reablement Workers combine their efforts to instil a notional understanding of what reablement is, with a demonstration of its impact. Frequently families come from a position of assuming that their relative cannot do something. By explicitly modelling the approach and providing opportunities for the family to witness its effects, Reablement Workers can create a realisation in family members about what their relative is capable of. This open-mindedness about the possibility that their relative can do things for themselves, can in turn serve to inspire an ongoing mindset of reabling. This shift towards a reabling mindset is discussed further below.

The findings also articulated and explored in a new way contexts, mechanisms and outcomes relating to working collaboratively with families when disagreements arise between the family and the reablement team (Chapter 7). This had been identified in the synthesis as an area where there was scope to start to address a great many gaps in evidence and thinking. Although references were made in the literature to the danger of leaving conflict unresolved in general (Pearson et al., 2015; Hjelle, Alvsvåg and Førland, 2016), questions remained about the issues that give rise to conflict with families, ideas about resources that could be introduced into situations of conflict and their potential impact as well as more generally what the outcomes of resolved and unresolved conflict can be. Improving understanding of this area offers potential to innovate practice with respect to both skills training as well as support, contributing to achieving and sustaining positive reablement outcomes.

This improved understanding has been achieved partly through an examination of a range of contexts in which disagreements can arise, including where families undermine reablement by continuing to do things for the service user, or stop them from trying to do things for themselves; where the family disagrees with the team's assessment of the service user's capability or their assessment of risk. Consequently, the identification and exploration of introducing mechanism resources (such as applying a routine for communication, regarding the family as a resource and demonstrating what is achievable) into different contexts extends understanding about upskilling Reablement Workers to deal with these situations.

10.7.3 Additional organisation support required to engage families actively in reablement

It is important to recognise that, in addition to exploring family members' ability and willingness to engage in reablement, the study also exposed the significance of the reablement team's ability and willingness to engage with families and their belief in the value of doing so. Although this had been referred to in the Norwegian literature (Hjelle et al., 2016; Jakobsen and Vik, 2018), it was absent from the English literature. This study's explorations and explanations relating to the potential impacts of families feeling engaged and included, versus not engaged and excluded, go some way to unpicking this aspect of the intervention's delivery. However, more targeted data would be required to investigate this more deeply. Related findings in the study provide a new basis that could be used to guide further investigation.

In the absence of an explicit strategy aimed at actively engaging families in reablement, it is not surprising that ideas about how to support this were lacking in the English literature. However, through the fieldwork, ideas about establishing and supporting the complex additional skillset required to engage families were identified. These included ensuring that there is training and expert backup from more experienced staff to aid Reablement Workers with their interactions with families. They also included the importance of establishing systems that actively encourage Reablement Workers to engage with families and encourage families to engage with the process; systems that support regular communication, decision-making and conflict resolution with families, and that aid rapport and mutual trust to be developed. The findings also explained the importance of Reablement Workers having access to equipment and to information about other services (endorsing recommendations by Beresford et al. (Beresford et al., 2019)) as well as having access to information about assessments relevant to the family's circumstances.

10.8 Reframing reablement as a mindset that can be sustained in family life

It is clear from the findings spanning all four theory areas that reablement is not just a set of physical practices. It is also an ethos that needs to be communicated and demonstrated during the period of reablement by the service provider so that at an individual level, service users and family members can develop a reabling mindset. The study proposes that sustainability of reablement beyond the period of its intensive delivery requires that a deep, comprehensive understanding of the ethos is instilled in the service user and family members. If this understanding is superficial, then there is a risk that the approach will not be sustained beyond the timeframe of service delivery. The study identified that in some cases reablement does not manifest in the longer term because in the face of the pressures of daily life, it is easily pushed aside as impractical.

The findings suggest that a reabling mindset relevant to ongoing family life applies to and considers a person in the context of their entire wellbeing; physical, social, emotional, mental, spiritual and aspirational. This mindset challenges the idea that supporting someone means doing things for them. However, rather than offering a substitution for that idea, it can operate alongside it, through the mechanism of standing back with empathy and stepping in with compassion.

This means that as a result of the study, and in contrast to the initial conception of reablement as it was understood at the start of the study, it is reasonable and potentially beneficial to reframe reablement both as a time-limited intervention as well as a mindset. As a time-limited intervention it offers a period during which the service user is supported to adapt to a change in their health. This adaptation involves learning new ways to approach daily activities that accommodate their current capabilities. The emphasis is on encouraging and supporting the service user to do as much for themselves as they possibly can, and crucially, when they are ready to do it.

As well as being time-limited it is located at a particular point in time in the service user's life as well as the lives of those around them. Seen in this way, reablement could be regarded as a time of transition for service users and their families. During this time, familial relationships adjust and the former balance between dependence, independence and interdependence in the service user's relationship with family members is reset. This means that as well as being a time during which those involved in the service user's life can learn and practise ways of encouraging their relative to do things for themselves, it could also present a useful opportunity for all involved to consider future options relating to care.

As discussed further below, regarding reablement in this way offers potential to contribute to the sustainability of its outcomes.

10.9 Considering outcomes sought for engaging families in reablement

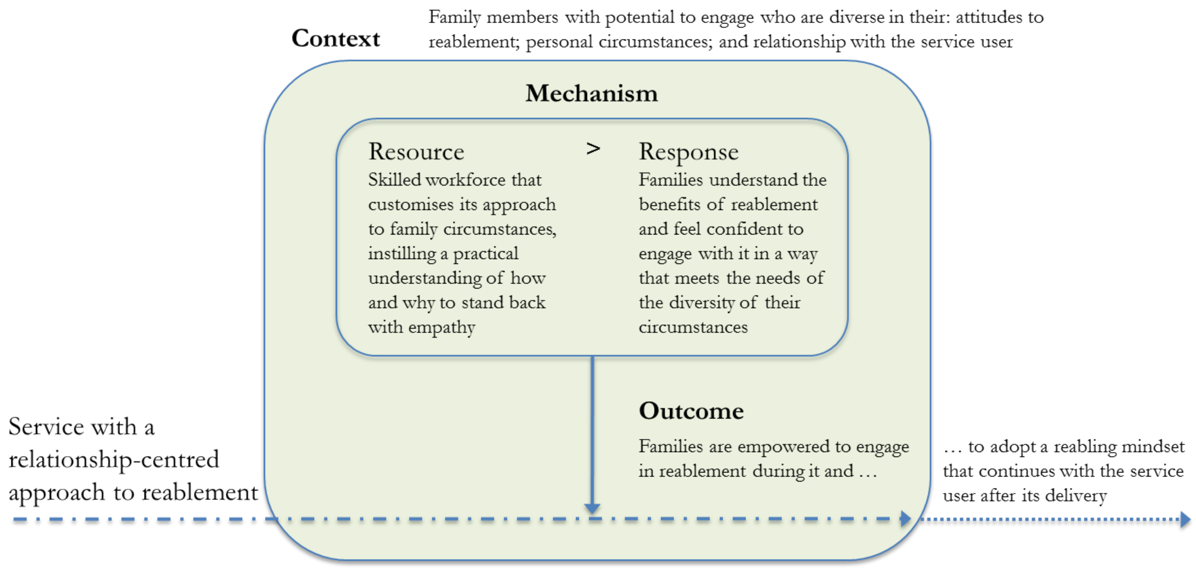
The Architecture of Reablement Chapter identified a lack of clarity over what short- and medium-term outcomes as well as long-term impacts are sought for reablement; in general terms as well as specifically with regard to the engagement of families in it. The third subsidiary research question restated at the start of this chapter relates to this. The realist synthesis and examination of literature published since it was undertaken revealed an acknowledgement of the fact that outcomes for reablement in general are poorly articulated and that there is a lack of evidence to draw on in order to evaluate reablement outcomes, particularly with respect to personal outcomes for service users (Beresford et al., 2019; Doh, Smith and Gevers, 2019). This means that understanding the current and potential impact of the intervention as a whole as well as its constituent parts is difficult to determine.

Through the realist synthesis, a small number of desired outcomes relating to empowering families was identified. These were somewhat limited in scope, particularly in an English context, and focused on supporting daily routines as established during reablement. Although they suggested an outcome for families being attainment of confidence in caring for their relative following reablement, they did not extend to a consideration of the potential benefit of empowering families to feel confident, capable and empowered to utilise the reabling approach themselves either during or after delivery of the intervention. Nor did they examine potentially negative outcomes related to not engaging families or the impact of unresolved conflict with families during reablement. This suggested a gap in understanding both about aspirations for empowering families as well as what might cause them to continue to adopt a reabling approach in life in general beyond delivery of the intervention.

The thesis extends thinking in this area by articulating a wide range of concepts associated with an understanding of a programme theory as it applies to reablement. It proposes that reframing reablement as both a service delivery model as well as a mindset could contribute to optimising its short and medium term outcomes as well as longer term impacts.

The following figure brings together the high level findings. It is followed by considerations of the study findings in terms of reablement policy and practice as well as future research.

Figure 18: High level CMO for facilitating family engagement in reablement



10.10 Implications for reablement policy, practice and guideline development

This research study suggests that there is an inherent risk of undermining the impact of reablement if the particular circumstances and needs of families are ignored. The implications of the findings for policy, practice and guideline development are set out here.

10.10.1 Implications for policy development

The presiding policy framework for reablement continues to be the Care Act (2014) which promotes reablement services and the provision of equipment and adaptations to support people to live independently, reducing the requirement for hospital admissions and ongoing support. Positioned alongside this is the NHS "discharge to assess" policy, where going home to be assessed is the default pathway. Together, these policies mean that LAs are obliged to consider providing reablement before or alongside a needs assessment, and with a view to maximising independence, rather than necessarily aiming to achieve full independence.

This study highlights a number of critical issues for facilitating family engagement in reablement and situates them within a broader paradigm of health and social care policy and delivery. Fundamentally, it emphasises the fact that adoption of a reabling approach by families will not take place in all circumstances; the absence or presence of certain conditions make a difference.

A number of considerations have been highlighted here that have implications for policy development in the field. These relate to:

1. The inherent paradox of aiming to demonstrate capability in a system where future services are allocated according to inability
2. How reablement is defined and promoted
3. Emphasising reablement as a relationship-centred approach as opposed to a person-centred approach
4. Sustaining and measuring reablement outcomes

10.10.1.1 Inherent paradox of aiming to demonstrate capability in a system where future services are allocated according to inability

The first critical policy issue is an acknowledgement of the inherent paradox of embedding a service built on an ethos that promotes building personal capability within a health and social care context that allocates services and resources based on assessment of inability. Promoting personal capability is very much in tune with the requirements that the Care Act (2014) places on LAs to adopt strengths-based approaches, identifying and maximising an individual's strengths and assets to enable them to achieve their desired outcomes. Yet reablement plays a role in assessment for future care services that predominantly retain a focus on traditional home care practices that aim to support people by doing things for them, rather than restoring skills. This means that in some cases, if a service user proves during reablement their inability to undertake tasks associated with daily living skills then they might be eligible for further means-tested care which they would not have been, had they demonstrated their ability to undertake these tasks. This amounts to an extrinsic motivator not to do things for oneself, intentionally working against both the ethos and, more broadly, a strengths-based approach.

For service users who are self-funders, however, the extrinsic motivator to increase ability as a result of the service can work in tandem with the ethos. By extension this applies to their families too. As described in sections 7.4.1 and 7.5.1 of the findings, family members' motivation to subscribe to and support (i.e. engage with) reablement as an approach will be affected by what is likely to happen as a result of or after its delivery and their perception of how that might benefit both their relative as well as themselves. This is a core mechanism of reablement in general that is of critical importance to policy making but is one that was not apparent in the literature examined.

10.10.1.2 How reablement is defined and promoted

There is scope to improve the way that reablement is defined and promoted in order to support its success. Although messaging is likely to be achieved largely at local level, having consistency in what is communicated can be argued to be a strategic, policy level imperative. In spite of the fact that reablement services have been delivered in some form in England since the early 1990s, the term "reablement" continues to have very low recognition among the general public. Moreover, in literature written for public consumption, the study found reablement being referred as "six weeks of free care" by Local Authorities as well as the NHS.

Combining these three elements (six weeks, free and care) as core to reablement works counter to its primary aims. Firstly, the time period of six weeks is not guaranteed and there is a danger that promoting it in this way could discourage people from demonstrating the capability that they attain before six weeks elapse. This adds a complicating layer to motivation to engage with the intervention. Secondly, emphasising that the service is free, although significant, is too closely tied to the other messages. Rather, this aspect should be secondary to an emphasis on the ethos of reablement. Finally, the description "six weeks of free care" implies that the service is focused less on change and the restoration of ability than on free traditional care. Messaging of this type serves as a mechanism that is likely to trigger unhelpful responses.

Another common thread in the way that reablement is currently promoted is the message that it aims to increase or maximise independence. However, independence means different things to different people (Glendinning et al., 2010). Added to this is the fact that "increasing independence" might hold little meaning for older people who are on a trajectory of slowly diminishing faculties. This study suggests that there might be merit, rather, in promoting key mental and physical health messages about the benefits of active ageing. This accords with the NHS Long Term Plan (NHS, 2019) vision to support people to age well.

Furthermore, and from the perspective of family engagement, it is suggested here that most people operate to some extent in interdependent relationships and reablement plays to that. The findings indicate that reablement could be usefully reframed as a time during which the balance between dependence, independence and interdependence can start to be reset. Engaging families in reablement can offer them an opportunity to reflect on and discuss with their relative what support they are willing and able to provide in the short, medium and longer term; what their relative would like; and how these relate to their financial circumstances. These sorts of discussions are extremely difficult to have (Gawande, 2015) and might be easier in the presence of, or initiated by a third party within reablement.

From a policy perspective there might be strategic advantage in terms of families gaining an enhanced understanding of their own willingness and ability to support in different ways and consequently carving out roles for themselves that are achievable, realistic and less likely to lead to carer breakdown situations. Moreover, reframing reablement in this way could present an opportunity to start to teach people skills in adapting to the changes that ageing brings, in the context of their interdependent relationships. The core skill here is standing back with empathy and is one that can continue to be applied after service delivery.

The findings suggest that, essential to communication about this skill, is pragmatism over the way that standing back and doing for are likely to be combined to differing degrees and in differing ways according to the natural rhythm of real life demands. Regarded in this way, reablement also provides an opportunity to validate the range of different care and support activities that families can undertake; regardless of their relationship to the service user. These activities go from simply being with their relative, to encouraging their attempts to do things for themselves, to meeting a more complex range of care needs.

10.10.1.3 Emphasising reablement as a relationship-centred approach

In policy terms there is an inherent contradiction in the idea of engaging families in reablement as well as promoting it as a person-centred intervention. An over-emphasis on it being person-centred might mean that discussions about consent to involve families are foreshortened. The findings in section 7.5.1 suggest that if a service user's first impulse is not to involve families, then rather than take this at face value it might be worth discussing this choice in light of knowledge about what families can bring to care in the longer term. Involving family in the early stages of reablement could provide opportunities to start to establish a dialogue about preferences that work for both or all parties. Ultimately, people function in social contexts and are interdependent on each other. This does not only apply to situations where co-caring is happening. This study, therefore, suggests that it might be more helpful to consider reablement as a relationship-centred intervention.

The term "relationship-centred care" did not emerge from the literature in the course of this study, however it is noted that the Care Act and its related guidance does promote the use of whole family approaches (Department of Health, 2014a, 2015; Department of Health and Social Care, 2020). It has been argued recently, however, that this aspect of the Care Act has received insufficient attention (O'Rourke et al., 2020).

10.10.1.4 Sustaining and measuring reablement outcomes

Existing research and guidance points to a need for further investigation into how to measure the impact of reablement in the longer term (SCIE, 2013; Beresford et al., 2019). In spite of continued investment in reablement in England, it is not yet possible to evidence how and whether its benefits are sustained at the level of the service user or their family. With a "time and task" delivery model remaining the dominant approach in home care generally, there is restricted scope for the measurement of longer-term costs or outcomes that might inform outcomes-based commissioning (Bottery et al, 2018). The findings in Chapters 8 and 9 show that during reablement, the reablement team's activities constitute service level mechanism resources, whereas after reablement these are no longer present, suggesting that it is the service user's and family members' responses and attitudes towards utilising a reabling approach that are the mechanisms that need to be scrutinised. It is apparent that there is a lack of evidence relating to the degree to which these responses are maintained according to context.

On the one hand this means that outcome measurements for reablement are far from comprehensive. It also means that, at the moment, reablement teams have no idea about how and whether reabling approaches themselves are sustained in the lives of the people they work with. Reablement teams report on factors relating to what if any ongoing care former reablement service users are receiving 91 days after going into reablement (e.g. same level, more, moved to care home), however, this does not give them any real sense of the ongoing impact of their reabling work specifically.

10.10.2 Implications for practice and guideline development

While recognising that reablement needs to be delivered within constraints on local budgets, resources and time, this research has highlighted a number of issues that have implications for practice development, particularly with respect to:

1. Workforce skills development and support
2. Adopting a relationship-centred approach
3. Communication about the service to families

10.10.2.1 Workforce skills development and support

In their realist review of integrated working between health and social care professionals and carers, Pearson et al. noted that the active engagement of carers and voluntary services as part of the team are “conspicuous by their absence from many (but not all) practitioner and service manager perceptions of health and social care teams”. They go on to assert that “Providing ways for professionals to address [these] frustrations and subsequently engage with carers and collaboratively develop care plans is therefore vital for the delivery of integrated working” (Pearson et al., 2015). The study findings, particularly those in Chapter 7, have brought into sharp focus the enormous demands made of Reablement Workers in engaging with families. It did not focus on how this job role is typically evaluated or how Reablement Workers are trained. However, it is clear that Reablement Workers need to be able to draw on a wide range of skills, experience and organisational support in order to facilitate the engagement of families.

A Reablement Worker’s skillset is a core resource for the intervention and many aspects of it do not appear to be formally recognised, such as negotiating family dynamics, encouraging family members and empathising with them. The study has found that it is through the application of these skills during ongoing, routine dialogue with families about reablement, coupled with the context of families’ pre-existing attitudes, that families can come to realise the value of reablement or not. Application of this mechanism of dialogue multiple times during the course of reablement is thought to transform a desire for traditional care into a desire for reablement based on families seeing and understanding the value of it.

The study has shown that Reablement Workers need to apply the core skill of standing back with empathy actively in their interactions with the service user. A highly skilled Reablement Worker will judge when to step in with compassion to help. Furthermore, a highly skilled Reablement Worker will be able to teach this skill to families according to their individual contexts and family dynamics, passing on the reabling mindset in such a way that it will permeate the family’s lives once the team has withdrawn. This has implications for Reablement Workers’ training and coaching programmes and the theories presented in this thesis could contribute to such programmes. It is suggested furthermore that service users and families could be enlisted to co-produce and possibly take part in delivering training programmes. These could include vignettes, videos and role-play, for example with respect to modelling the approach and transferring reabling skills to families.

10.10.2.2 Adopting a relationship-centred approach

From an organisational perspective, this means recognising that empathy and relationships are at the heart of the service. Although it is recognised that there are multiple pressures on Local Authority provision, this study provides a starting point for identifying optimum circumstances in which reablement might thrive with respect to existing family support, or encouraging family support in circumstances where it does not already exist. The findings, particularly those set out in Chapter 8, can contribute to a consideration of ways in which customisation to family circumstances can take place and can been seen to take place. It is critical that as well as considering the potentially positive impacts of engaging families in reablement and using them as a resource in themselves, it should be recognised that there are both immediate and longer term impacts on service optimisation when families do not engage. Equally, there are also likely to be practice implications for recognising situations in which families have an over-riding desire for their relative to be cared for in a traditional way to the extent that reablement is not the right fit for them.

10.10.2.3 Communication about the service to families

The findings in Chapter 6 (Instilling an understanding of reablement) explain in greater detail than found elsewhere in the literature some of the aspects peculiar to reablement that it would be helpful to explain to families and how they might be explained. It has highlighted the importance of terminology; the unhelpful use of the word “carer” for staff delivering reablement, and the need for judicious use of the word “independence” in the context of what is feasible to achieve in up to 42 days. The importance of emphasising the fact that families should anticipate a decrease in the number of visits made to their relative in the course of the delivery of reablement based on ongoing assessment of progress was also highlighted. Communication of this needs to run alongside an explanation that families should not expect visits to take place for six weeks regardless of progress. None of the sources examined in the course of the study focused on the importance of explaining to families how reablement might or might not impact on future care options and what it means in the context of a family unit’s financial situation and preferences, yet the findings suggest that this appears to play a potentially significant role in the causal pathway to engaging in the intervention.

10.10.2.4 Implications for guideline development

One of the starting points for this study was the NICE Guidelines for Intermediate Care and Reablement which couch the involvement of family in reablement in discretionary terms (NICE, 2017). These are the first guidelines for reablement and the study has shown that there is scope to improve them in the following ways:

- Acknowledge that for people who have families involved in their life in some way, this affects the delivery of reablement. A relationship-centred approach should be adopted in these circumstances in order to optimise them.
- Replace "as appropriate" with "where they exist" where it refers to family and carers in the guideline. E.g. section 1.3.4 - Actively involve people using services (and their families and carers, as appropriate) in assessments for intermediate care and in decisions such as the setting in which it is provided.
- Consider having separate guidelines for reablement rather than combining it under the umbrella of intermediate care as its purpose and approach are unique. This would facilitate reablement-specific advice and avoid expectations set up by the use of the word "care". For example, in the current iteration of the guideline, under Entering Intermediate Care 1.5.2 it would be useful to add "Give families and carers information about how reablement differs from traditional care".
- In reablement-specific guidelines the section on delivering the intervention could be expanded to take into consideration this study's findings. These include: adopting a relationship-centred approach to ongoing identification and assessment of goals during delivery so that they are attuned to the service user's family circumstances; seeking actively to engage families in reablement as a resource; creating opportunities to model the standing back with empathy approach to families to help develop a reabling mindset; encouraging families and carers to re-examine what they are willing and able to do in the future
- In reablement-specific guidelines the section on transition from reablement could refer to explaining the benefits of sustaining a reabling mindset, regardless of future care arrangements
- Acknowledge the specialist skills required of staff to work in a reabling way

- Consider providing guidance on who is appropriate for referral into reablement. The remit for who can be accepted into reablement varies by LA in England. This means, for example, that sometimes people can be referred into reablement straight from hospital, sometimes not. In relation to families, sometimes reablement is considered a means of supporting a family member or members who might be at risk of breakdown. There are clear policy implications for deciding whether or not to apply the intervention in this way. This aspect did not feature in the literature examined.

The guidelines could be improved by acknowledging more broadly that, although it might be desirable to build an understanding of the particular circumstances and needs of families in a context of mutual trust and rapport over time in any sort of health and social care intervention, in reablement this needs to take place at speed and should, therefore be considered a priority in itself. To focus on reablement as a purely person-centred intervention and consider service users in isolation from their primary social and care networks is likely to impact on the sustainability of the benefits accrued during the intervention. It should be made clear to service users and their families that following reablement, the reabling mindset can continue to be applied in everyday life as well as within or alongside other services.

10.10.3 High level view of the implications of the study

The implications of the study for policy, practice and guidelines as set out here are focused on ensuring that the different circumstances and needs of different families are considered in such a way as to enhance rather than undermine reablement. The aim of the study was explore the causal explanations for the ways in which reablement teams engage families in reablement, rather than to evaluate the degree to which their engagement can be attributed to this or more broadly to other policy, guidance and funding issues. Nonetheless, the implications as set out here indicate that all of these factors are relevant. It is suggested that focusing more attention at a policy level on the promotion of the use of whole family approaches, as set out in the Care Act, and cascading these into reablement guidance and practice, with sufficient resourcing and consideration of the issues set out in this study, could lead to a position in which families engage with reablement in a way that enhances rather than undermines it. Further research would need to be undertaken to establish this in a more robust way.

10.11 Study limitations

The main limitations relating to the study design are set out below. They are followed by a critical reflection on using a realist approach, encompassing its limitations.

10.11.1 Single-site design

As described in Chapter 1, many different models for the delivery of reablement exist, both nationally as well as internationally. The design of the second stage of the study focused on a single site; one geographical wing of one Local Authority's reablement service. It represents a particular combination of delivery model characteristics. Models vary in terms of factors such as their organisational structure within intermediate care, level of integration with the NHS, degree of outsourcing, staffing model, referral pathway, acceptance criteria, approach to goal-setting, assessing and monitoring outcomes, and scope of reablement input, including functional and comprehensive reablement (Beresford et al, 2019). This means that, although the realist synthesis had regard for multiple models of delivery, the theory refinement that took place in the second stage of the study was largely informed by input from one model of delivery only. Consequently, it would not be possible to test every single context, mechanism and outcome configuration presented here within every service. If a multi-site research design had been adopted, a broader range of insights would have contributed to the refinement of the theories. Although this does not undermining this study's findings, it would have added to the understanding of contextual influences and enriched conclusions. Nonetheless, the nature of the realist approach has meant that the core mechanisms of reablement that were identified during the course of the study, such as standing back with empathy, are transferrable to different unidentified contexts associated with different delivery models.

In terms more specifically of population variation, although the participating service represents a city in a part of England that as a whole is diverse, representing many different religions, countries of birth and languages spoken, the wing of the service in which the fieldwork was conducted was situated in a particular cultural context; one with very little cultural diversity. This meant that the participants had not experienced a great range of diversity in terms of factors such as multi-generational cohabitation and cultural notions of familial duty to care, and sense and effects of the burden of caring, as mentioned in Chapter 8. Furthermore, the participants themselves were all white, British and predominantly female. Caution, therefore, needs to be applied when considering the sociocultural transferability of the findings. Modifications would be needed in order to increase the transferability of the findings to reflect the general population and would need to encompass, for example, a wider range of considerations in relation to customising the approach to the particular circumstances of the family and to instilling an understanding of reablement.

10.11.2 Sampling bias

There is a potential sampling bias in the choice of the research participants themselves. The Head of the participating service selected the geographical wing of the service that I could work with, and the Team Manager chose the day for the focus group, meaning only certain Reablement Workers were available to attend. A further series of interviews or a further focus group with different participants might have benefitted the study, adding additional contexts, insights and refinement to theories. Although the range of job roles represented by those interviewed offered exploration and analysis from a variety of perspectives, the themes that were identified through the fieldwork were not disaggregated by job role. The service would have been amenable to setting up further interviews, however, this was not pursued due to my time limitations and my capacity to analyse further data, working primarily alone.

10.11.3 Stakeholder voices

The decision to use a realist approach was taken following the formative stages of the research. Although there was considerable and highly valued stakeholder collaboration in the formative stages, this was not managed in a way that it would have been in a more typical realist inquiry. The result was less input into the initial candidate programme theories by the wider stakeholder group, and a stronger emphasis on deriving them from existing guidance. Although this will have influenced the identification of candidate theories, it also presented an alternative means of arriving at them.

Another impact of not using a realist approach in the formative stages of the study was on the way that discussions were managed with early collaborators. In realist research it is important to frame questions in a way that opens up the black box of causality rather than in a way that seeks to elicit a view on current practice. If a realist approach had been applied right from the beginning of the study, this might have helped to with theory development and led to the selection of a smaller, more focused set of candidate programme theories earlier on in the process. It might have provided earlier insight, for example, into questions around the value that reablement teams place on engaging families in the intervention and their view of families as a potential resource. Another consequence of working with a large number of candidate programme theories was that a great deal of additional data was produced that has not been reported on in this thesis.

Similarly, had the PPI group been recruited earlier in the research process, their contribution could have been drawn on earlier in the study, in order to shape initial theory development. This could have had the effect of increasing the transparency of and collaboration on early decision-making. Subsequent to the formative stages of the study, collaboration with the local Carers Support Centre and the PPI group, as well as with staff operating across all levels of hierarchy within the participating Local Authority, all contributed to theory development in a more recognisably realist way.

In terms of the composition of the PPI group, it is possible that it could have encompassed a greater variation of voices. The people recruited were all already vocal and knowledgeable about carer rights due to their existing association with the Carers Support Centre. The inclusion of a service user's voice and that of a family member currently experiencing reablement would have added potentially valuable perspectives on theory development and the conclusions drawn across the study.

Although this research was undertaken predominantly from the perspective of reablement teams facilitating family engagement, a protocol had been established and ethical approval gained to interview more family and service user participants. This was partly with the intention of understanding more about the ways in which the mindset of reablement is or is not sustained after delivery of the service. Recruitment, however, met a number of obstacles (as described in section 5.7 of Chapter 5). Gaining LA approval for this phase of the work took longer than anticipated, and coincided with a slowing of referrals into the service over the Christmas period. Although the recruitment strategy was altered in response to this, recruitment remained slow and then ground to a halt when COVID-19 intervened (please refer to the Addendum following this chapter). Clearly, had this phase proceeded there would have been greater representation of the voices of both family members and service users in the study. I had to decide whether or not to include the one interview that did take place in this phase of the study. As it generated rich data and insights that helped with theory development, not least in connection with the mechanism of standing back with empathy, I believed that it made a significant contribution and therefore included it. This indicates the potential value of continuing to explore the study findings further with this population.

10.11.4 Lack of country-specific literature

It is noted here that the realist synthesis was limited by the availability of literature specific to the topic of families and reablement in an English context. The Norwegian sources provided many insights that influenced theory development. However, as described in Chapter 4, there are structural and cultural differences between the two countries which imply a limitation to the practical transferability of some of the notions about reablement that apply in a Norwegian context, to models of reablement as delivered in England. These differences (e.g. length of service delivery) would need to be tested in any further work based on the study. It is possible that the breadth of the grey literature examined in the course of the realist synthesis could have been expanded to include, for example, more documents and leaflets produced by English Local Authorities.

10.11.5 Positionality of researcher

The final limitation set out here relates to the positionality of the researcher (Berger, 2015). As described in Chapter 2, my previous experience meant that I could relate both to the service providers as well as to the family members in this study. I did not have former experience of reablement specifically. My experience of dementia and residential care meant I came to the research with certain beliefs, for example, that there is value in regarding families as a resource. It is possible that I was biased in terms of selecting this as one of the factors to explore in the study. Although ideas about regarding families as a resource did not feature strongly in the literature based in reablement practice in England, it did feature more prominently in the Norwegian studies.

10.12 Critical reflections on using a realist approach

A realist approach was adopted for the study primarily in order to explore and explain the causal aspects of family engagement in reablement. This approach has proved to be enormously useful in uncovering and scrutinising ideas about what might work and not with respect to this. It has served to explore underlying assumptions in a way that has proved conducive at a practical level as well as at a conceptual level, in envisaging how the intervention could be reframed. This means that the realist approach has enabled complexity to be embraced in a way that has resulted in insights and implications that are relevant at both practice and policy levels.

Issues relating to using the approach have been reported in the course of the thesis narrative. They are brought together and extended here. Using the approach and adapting it to the peculiar circumstances of this inquiry has proved challenging. The approach itself continues to evolve along with associated guidance and standards related to its use (The RAMESES Project, 2014; The RAMESES II Project, 2017) and its application is not formulaic. Within this context it is increasingly common for PhD candidates to adopt the approach and equally common for them to struggle with the practical aspects its application. The regular and numerous angst-ridden questions posted on the RAMESES international online research email network (rameses@jiscmail.ac.uk) and responses to them attest to this.

10.12.1 Limitations of working as a novice PhD realist researcher

I did not come across Pawson's warning that realist research is "not for novices" (Pawson et al., 2004) until I was already some way into the study. Subsequent to this somewhat bleak warning, Pawson has offered practical advice to PhD candidates using the approach, via the network mentioned above. He suggests focusing on a very small number of programme theories in recognition that this will produce a "partial exploration of a partial set of ideas" about the intervention. This would have been useful to have acknowledged earlier on in the research process. Nonetheless, the approach has proved highly productive, aided by expert methodological support and encouragement from Justin Jagosh as well as the wider realist research community. This helped in the adaptation of the approach to the needs of the research question and the resources available while maintaining adherence to its fundamental principles.

In the realist synthesis, there was a great deal of overlap in the data in terms of mapping onto the theory areas. This meant that managing the synthesis was extremely complex and time intensive. Although the process is notoriously challenging (Dalkin et al., 2015; Emmel et al., 2018), the challenge was intensified as I was encouraged as a PhD student to work more independently than a realist research team would normally do. The data analysis in both the fieldwork as well as the realist synthesis involved a myriad of decision-making. As described in the thesis, it was challenging at times to decide in particular whether an aspect of a theory was a context or a mechanism. This is a difficulty encountered in many realist studies (Rycroft-Malone et al., 2012; Jagosh, 2019). In the context of a PhD, only a small proportion of these decisions could be made in partnership with the supervisory team and other stakeholders. Where this occurred, each person associated with shaping the research brought to it their own personal experiences and epistemological standpoints.

Working in a team would have meant more collaborative formulation of insights, which is more conducive to retroduction. Choices would have been discussed more frequently, reducing the subjectivity of these decisions made. An example of this occurred when the data were coded and analysed at the end of the fieldwork using the Ellerby technique whereby the data are arranged on walls for the researcher(s) to work with (Ellerby, 2009). This was undertaken during one of the COVID-19 pandemic lockdowns, which meant that supervisors could not provide input.

10.12.2 Transparency

Unlike some other forms of systematic literature review, it is not the intention of a realist synthesis to be repeatable by replicating the process undertaken. Rather, it should adhere to realist principles, including transparency (Pawson et al., 2005). In an effort to maintain transparency, I stuck somewhat rigidly the primary sources' wording when creating the if-then statements, with the result that many of them could have been more concise. They also included some colloquial language (such as "buy-in") which continued to be used in the study as a result. Maintaining linguistic links to the sources has ensured that judgements based on them can be traced. As far as practical, I kept records to track decisions and judgements made, however, it is recognised that it was not always possible to capture points at which intuition influenced decision-making. In the course of iterative analysis, a number of re-conceptualisations were partly led by the impulse to communicate the results as coherently as possible to the reader, without losing data richness.

The fieldwork which served to refine the hypotheses produced by the realist synthesis, relied on decisions about which theories to investigate further and with whom. Another research group might have selected different theories. The way that the synthesis and fieldwork have been recorded would enable another group to revisit them in the future as hypotheses can be tracked back to their supporting data. Broadly speaking it was my intention to explore mechanisms that could be triggered at a reablement team level through interviews and a focus group with reablement team members and to explore mechanisms that could be triggered at a family level through interviews with families.

10.12.3 Realist focus groups

Focus groups are not commonly used in realist inquiries. As described in Chapter 5, this format for theory refinement with Reablement Workers was largely chosen for pragmatic reasons in order to limit the disruption to the team's rota. I was conscious that there was a danger that the focus group participants might arrive at consensus about the theories rather than exploring the causal inferences behind them. When a series of interviews is conducted, there is time to consider one interview before undertaking the next. This provides scope to explore refinements to theory cumulatively, building on emergent findings in a realist way, moving back and forth (Westhorp, 2014; Pawson & Tilley, 1997). In a focus group setting, the moderator has less time to reflect between contributions. Undertaking the focus group after the interviews provided time to reflect on the way that the other members of the reablement team had already shaped the theories, however it was necessary to have different expectations for the focus group process.

Although like in interviews, the theory and nuggets of evidence are shared explicitly, in focus groups, encouraging the group to refute and deliberate among themselves is also part of the process (Manzano, 2020). One way in which I facilitated this was to set out cards on the table with the theory statements written on them for all to see. I believe that this visual focus helped the participants to explore around the statements. It also helped me to retain their focus, probing further into what their thinking in relation to the statements was and why they felt their ideas about them were important. It is possible that if the participants had subsequently been provided with a summary of the interpretation of the focus group and how it served to refine theory, this might have enriched the insights further, although it would have demanded much more from the participants. It is not possible to understand how, if at all, the order of the interviews and focus group affected hypothesis refinement. My understanding of the contexts and mechanisms under scrutiny would always have been lower before whichever of these groups I worked with first. Had they been sequenced differently, it is likely that they would have revealed additional insights or a difference in emphasis. Furthermore, although I had significant experience of conducting interviews and focus groups, I was new to the teacher-learner cycle, which is peculiar to the realist approach.

Among the Reablement Workers, two distinct groups had been identified during the study; those who had previous experience of traditional care and those who did not. It is possible that in the focus group format, where both were mixed, the equal flow of ideas from these two groups might have been inhibited and that different interpretations of a reabling approach were not fully expressed. This situation had been expressed by the family member who was interviewed, when he observed tension between Reablement Workers who had different experience of traditional care, as referred to in Chapter 7, section 7.2.2). Although there was potential to set up a further focus group if this situation arose, this was not deemed to be necessary as it was possible to encourage contributions from both groups of Reablement Workers. In fact, they all contributed very vocally and willingly, indicating that they found it stimulating to explore their roles in this way. It is possible that this was facilitated by the fact that the team were used to working with each other in differing combinations. Also, their well-run team meetings took place in the same room used for the focus group, putting them at their ease. Although the focus group provided a useful means of refining theories, limitations presented by theory building at such a fast pace in particular are acknowledged.

In spite of the challenges set out here, I am convinced that the study would not have resulted in the depth of analysis and insight that it has done and would not have opened up as many potential avenues for future research had a realist approach not been adopted.

10.13 Proposals for future research

This study's findings span a wide array of considerations that hold potential to innovate the way that reablement teams facilitate families to engage with the intervention. There is much scope for further research in this and other aspects of reablement in order for its potential to be fully realised. Any such research needs to ensure that the service user and family voice features strongly. A small selection of proposals for future research grounded directly in the findings from this thesis are set out in brief here.

1. Review of existing support and training interventions for reablement teams with respect to engaging families

The study has brought to light the huge demands made of reablement teams and, specifically, Reablement Workers. It was apparent that there are gaps in knowledge about effective ways of supporting and training Reablement Workers to engage family members. It is therefore suggested that there is potential to analyse the most effective ways of achieving this, starting with a review (realist or other) of what is currently in usage. It would be important to embrace a wide range of literature, including materials currently in use across a range of reablement delivery models. An analysis of information and education about reablement aimed at service users and families who are considering or starting reablement could usefully be undertaken alongside this.

2. Refinement of theories formulated in the study with service users and family members

As described in Chapter 5, the researcher has already undertaken a considerable amount of work with a view to refining theories about engaging families in reablement with service users and family members. Due to slow recruitment and the subsequent impact of lockdowns related to the COVID-19 pandemic, only one interview took place in this phase of the inquiry. This phase could be revisited using a realist approach based on the study's findings and addressing its limitations. It would be beneficial to seek input from a range of stakeholders in an advisory capacity in the earliest stages of any such project in order to select a small number of theories on which to focus. Furthermore, the study design should ensure that participating service users and family members are drawn from a diverse range of populations and contexts, including, for example, people affected by dementia, and potentially encompassing a range of reablement delivery models. In devising how to approach the theory refinement it is proposed that relevant middle-range theories on intervention engagement and behaviour change are identified and drawn on.

3. Co-production of resources to support training reablement teams with respect to engaging families

This study's findings suggest that there would be value in creating a research study aimed at producing and piloting resources specific to empowering families to engage in reablement. Such a study could utilise the conceptual platform and findings set out in this thesis. It could also potentially draw on findings resulting from the two proposals for further research described above. Any such production of resources would benefit from being co-produced with service users, their family members and members of reablement teams. Attention should be paid to ensuring that population diversity is reflected in the development of such resources. Subsequently, a realist evaluation based on piloting the resources developed could utilise the contexts, mechanisms and outcomes as identified in this study, drawing on any middle-range theories developed.

10.14 Reflection on learning from the reflexive approach taken

I learned a great deal about myself through adopting a reflexive approach to the study as described in Chapters 3 and 5. Although my enthusiasm for the topic remained consistent throughout, a sense of confidence with regard to applying and adapting the realist approach took a long time to develop. In the hands of a more experienced realist researcher it is doubtless that a more elegant approach to the management of the study would have been applied. Nonetheless the experience has enhanced my ability to embrace complexity. Having to make decisions about what to exclude from the inquiry generally and the thesis write-up in particular relied on a higher level of resilience than I had needed in other roles. I also learned that as a researcher communicating with people outside one's study about it, it is important and valid to express what one is interested in before having final results to share. Finally, the experience of working largely alone, impressed on me the value of the contact and input that I had from my supervisors, PPI group, methodology mentor and the wider research community.

10.15 Contribution to new knowledge

This study has generated new knowledge to inform future development of reablement guidance, policy, service provision and professional development. It has contributed novel hypotheses about what works to facilitate family engagement in reablement and has highlighted the drawbacks of failure to achieve this. It has identified and linked a wide range of complex contextual factors relevant to the field and brought to the surface causal factors relevant to these contexts that could impact on the intervention's outcomes. It augments thinking in this field as these new concepts are explicitly connected with what is already known and a clear direction is given for how they might pave the way for and inform future research.

Improving understanding about the drivers behind family engagement in and adoption of reablement in this way aids practical implementation. By highlighting facilitators and barriers, the study could support Local Authorities to develop sustainable support and practices for their reablement staff. It demonstrates that reablement staff have considerable potential to influence positive behaviours not only among service users but also their families. The findings offer practical ideas that could enable staff to engage families and limit the danger of families reverting to doing things for their relative when the intervention ends. The way that ideas have been explored and set out lends itself to training and development for reablement workers. Reframing reablement as a mindset as well as a service, the study proposes that there is scope to sustain more consciously the benefits of reablement beyond its immediate delivery. This conceptualisation of reablement resonates with the healthy ageing agenda and is transferable to other health, social and community interventions that aim to empower through the restoration of ability.

The findings from this study have contributed to a more deeply informed view of reablement. It was apparent at the start of the study that many aspects of the architecture of reablement are not clearly conceived. As described in Chapter 1, the lack of a standard model for its delivery, the complexity of its composition and its reliance on social contingency create a number of blind spots that obscure a clear vision of how to optimise reablement. Furthermore, there is no universally accepted programme theory for how reablement seeks to achieve its aim. This thesis articulates some of the concepts associated with an understanding of a programme theory as it applies to reablement; both reablement in general as well as more specifically how teams engage families in it. It brings new knowledge to move forward understanding about what reablement is, who the supposed target is and what the supposed outcome is (Shearn et al., 2017). It also conceptualises what reablement could be.

The research adds to academic literature relating to reablement specifically but also to that relating to relationship-centred approaches to health and social care provision. As far as I am aware, realist methodological principles have not been applied to this aspect of reablement before.

The study has contributed to realist methodology. Its principles were applied in an original way to the realist synthesis, for example in the way guidelines were used to inform the development of Candidate Programme Theories, the way the data were coded and analysed and the way the synthesis informed the fieldwork that followed it. Realist methods were applied in a novel way, for example the application of realist interviewing techniques to a focus group format. Lessons learned from working with the approach will assist other researchers in their own interpretations of it, particularly in cases where it is not suitable to undertake a full realist evaluation immediately. The addendum to the thesis comments on how the new knowledge that it offers brings fresh thinking in light of the COVID-19 pandemic.

10.16 Closing reflection

As a result of this research it is clear that there is considerable scope for reablement practitioners to facilitate families to engage actively in reablement both during its delivery and beyond. The study ends by reflecting on the potential of practitioners to impart a reabling mindset to families that remains with them. To recall the words of one of the study participants:

> *"I think we very much focus on the person and, unfortunately, our job is to re-able that person and I think usually family members and partners as carers are under-utilised… I guess if we recognised their role more whole-heartedly and we could get them on board, then maybe more family members would be willing to take on the care, not just as carers but more like Reablement Workers, I guess… And maybe if care agencies did take over [after reablement], family members would be able to instruct them a bit more on what support they want… how they want their carer agencies to support the person. Impart that reablement ethos to the care agency maybe." (Michael, OT).*

Addendum: COVID-19 Pandemic

This addendum was written three weeks into the third national lockdown due to the COVID-19 pandemic, shortly before submission of the thesis. It was important to recognise, if only briefly, what the pandemic means for the study findings and vice versa.

The pandemic has amplified issues relating to health and social care services, including reablement, and the positioning of families within them. In response to COVID-19, the Government has channelled additional funds through the NHS to support health and social care bodies to implement changes to hospital discharges and post-discharge recovery and support services, including reablement[4]. Local Authorities and the NHS need to work closely in order to manage this "home first" approach. The change in remit means that many services have had to expand their capacity and some have had to set up systems very quickly in order to take people directly from hospital. Reablement teams are seeing people with far greater care needs than previously (e.g. more people on oxygen); possibly people with less potential to benefit from a reabling approach and a higher likelihood of needing ongoing care or referral to a residential setting following reablement. LA reablement services have an increased requirement to monitor caseloads and outcomes.

As far as the reablement workforce is concerned, the pandemic has drawn attention to the value of care staff alongside the lack of parity between care sector and NHS staff; their pay, training, development and esteem. The pressures on the mental and physical health of staff, as well as staff shortages have been exacerbated by shortages of personal protective equipment, regular, frequent COVID-19 testing and access to vaccinations. As many reablement workers fit their job around other responsibilities such as childcare, the lockdowns have affected their ability to do their job. Although some services are making greater use of video calling (e.g. to assess equipment needs), this does not always result in efficiencies and can mean that staff need to use their own devices where their service does not provide them.

Since the pandemic started, more families are caring at home and for longer, and are experiencing negative impacts on their own mental and physical health as a result[5]. Older people and their families have become more fearful of admission to care homes and to inviting visitors

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[4] HM Government and NHS Hospital Discharge Service: Policy and Operating Model, (August 2020) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/912199/Hospital_Discharge_Policy_1.pdf (Accessed 27/01/2021)

[5] Carers UK Caring Behind Closed Doors: Six Months On (April 2020) https://www.carersuk.org/images/News_and_campaigns/Caring_Behind_Closed_Doors_Oct20.pdf (Accessed 27/01/2021)

(including reablement workers) into their own homes. Some families either moved in with their older relative or moved them into their own home in order to shield them, others have formed support bubbles. The furlough scheme has, in some cases, given families more time to support older relatives to a greater degree but loss of income and additional inequalities for others has put greater pressure on their ability to support anyone else. The Government has encouraged people to make emergency plans for if they are unable to continue to provide support due to COVID-19.

Alongside leading to a reduction in formal community-based services designed to support older people and their carers, COVID-19 appears to have engendered greater social connectivity. This is evidenced by the emergence of new, positive local and personal community support schemes. These have however accentuated the lack of digital inclusion experienced by many older people and can also be argued to entrench characterisations of older people as vulnerable and who need to be kept separate, at home.

It is hard to determine how much of what has changed will be permanent or semi-permanent. It seems likely that families will continue to take on an increasing burden of support for their older relatives for some time to come. In terms of my research findings, this fortifies the necessity to shift towards a more relationship-centred approach for reablement. This encompasses utilising families as a resource within reablement, for example to spot changes in health, to motivate their relative by standing back with empathy and stepping in with compassion, to help identify appropriate goals and to help to keep their relative physically, socially and intellectually connected while obliged to stay at home due to COVID-19 restrictions. Furthermore it highlights the need to involve families and unpaid carers as much as possible in co-producing solutions aimed at changing or enhancing reablement provision.

However, in order to achieve and sustain family engagement, it is critical that families receive sufficient support for their own longer-term health and wellbeing in their caring role. The study's findings as they relate to the additional skills and support required of reablement workers in actively engaging families in reablement and judging family members' willingness and ability to engage in supporting their relative now and in the future are all the more critical. With reduced opportunities to role-model and demonstrate reabling approaches to families in person, due to shielding and social distancing, there is an increased need for services and reablement workers to find alternative ways to provide clear and timely advice to families on how to support in a non-hands-on way. The research findings can help to identify ways of achieving this and could prove useful in identifying where technology might have a useful part to play, for example in reinforcing routines or with individualised follow-up after reablement.

While reablement services are accepting people with higher levels of care needs in order to maintain the flow of patients from hospital, there is a danger that some of the unique, potential benefits of reablement will be compromised. This study has highlighted the merits of reframing reablement as a mindset that can be sustained in family life. However, this relies on a highly skilled, experienced workforce. The demands of the pandemic has meant that reablement services have needed to increase workforce numbers through recruitment and redeployment. The way that they are trained and developed in applying a reabling ethos will have a significant impact on the degree to which this idea might be realised in practice.

I would argue that beyond reablement provision itself, adopting a reabling approach to supporting older relatives has many potential benefits for families, older people and other service providers, and that much of the learning from this study is extremely pertinent to the circumstances that successive periods of lockdown and the long-term effects of the virus present.

Finally, the pandemic has highlighted our interdependence as humans and communities and this study has demonstrated that many aspects of the reabling ethos are suited to accommodating and supporting fluctuation between dependence and independence. This fortifies the study's findings that relate to the importance of tracking reablement outcomes and longer-term impacts at a personal level for individuals and their families.

References

Age UK (2018) *Intermediate Care and Reablement Factsheet 76*. Available from: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs76_intermediate_care_and_reablement_fcs.pdf. [Accessed 13 December 2017].

Barbour, R. (2014) *Introducing Qualitative Research: A Student's Guide*. 2nd ed. London: Sage Publications Ltd.

Barbour, R. and Kitzinger, J. (1999) *Developing Focus Group Research: Politics, Theory and Practice*. Sage Publications Ltd.

Beresford, B., Mann, R., Parker, G., Kanaan, M., Faria R., Rabiee P., Weatherly, H., Clarke, S., Mayhew E., Duarte A., Laver-Fawcett, A. and Aspinal A. (2019) Reablement services for people at risk of needing social care: the MoRe mixed-methods evaluation. *Health Services and Delivery Research*. 7(16), pp. 1–218.

Berger, R. (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), pp. 219–234.

Bhaskar, R. (1975) *A Realist Theory of Science*. Leeds: London: Verso.

Booth, A. et al. (2019) *Three Rs not two (Rigour/Relevance)?, jiscmail@jiscmail.ac.uk*.

Bottery, S, Jefferson, L, Bennett, L, Hall, P, Cream, J, Dale, V, et al. (2018) *Home care in England. Views from commissioners and providers*. London: The Kings Fund. Available from: https://www.kingsfund.org.uk/sites/default/files/2018-12/Home-care-in-England-report.pdf [Accessed 7 June 2021].

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research*. Sage Publications.

Brennan, N., Bryce, M., Pearson M., Wong, G., Cooper, C. and Archer, J. (2014) Understanding how appraisal of doctors produces its effects: a realist review protocol. pp. 1–5. *BMJ Open* [online]. 4 (6): e005466 [Accessed 20 January 2021].

Carers UK (2010) *Future Care: Care and Technology in the 21st Century*. Available from: http://www.carersuk.org/professionals/resources/research-library/item/2529-future-care-care-and-technology-in-the-21st-century [Accessed 13 December 2017].

Carers UK (2019) *Facts about carers 2019*, *Policy Briefing*. Available from: https://www.carersuk.org/images/Facts_about_Carers_2019.pdf [Accessed 13 December 2017].

Cooke, A., Smith, D. and Booth, A. (2012) Beyond PICO. *Qualitative Health Research*, 22(10), pp. 1435–1443.

CQC (2014) *The fundamental standards*, *Regulations for service providers and managers*. Available from: https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards [Accessed 26 November 2020].

CQC (2018) *The five key questions we ask*. Available from: http://www.cqc.org.uk/content/five-key-questions-we-ask [Accessed 25 October 2020].

CRD (2009) *Systematic Reviews: CRD's guidance for undertaking reviews in health care*, *Centre for Reviews and Dissemination, University of York*. [online]. Available from: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf [Accessed 1 October 2017].

Creswell, J. (2013) *Qualitative Inquiry and Research Design: Choosing among five approaches*. 3rd ed. London: SAGE.

Dalkin, S. (2014) *PhD Thesis: The Realist Evaluation of a Palliative Integrated Care Pathway in Primary Care: What Works, For Whom and in What Circumstances?* Northumbria Univeristy.

Dalkin, S. M., Greenhalgh, J., Jones, D., Cunningham, B. and Lhussier, M. (2015) What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*. 10(1), p. 49.

Denzin, N. and Lincoln, Y. (2011) *Handbook of Qualitative Research*. 4th ed. Sage Publications Inc.

Department of Health (2005) *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*. [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272101/6499.pdf [Accessed 21 January 2021]

Department of Health (2006) *Our health, our care, our say.*, *Our health, our care, our say: a new direction for community services*. [online]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf [Accessed 21 January 2021].

Department of Health (2007) *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*. [online] Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf [Accessed 10 December 2017]

Department of Health (2010) *The Operating Framework for the NHS in England 2011/12*. [online]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216187/dh_122736.pdf [Accessed 21 January 2021].

Department of Health (2014a) *The Care Act 2014* [online]. Available from: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 21 January 2021].

Department of Health (2014b) *The Care Bill – Better Care Fund Fact Sheet 19*. [online]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/270417/Factsheet_19_Better_Care_Fund.pdf [Accessed 25 January 2021]

Department of Health (2015) *The Care Act and whole-family approaches*. [online]. Available from: https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf [Accessed 25 January 2021]

Department of Health and CSED (2007) *Homecare Re-ablement: Efficiency Delivery : supporting sustainable transformation*. [online]. Available from: http://webarchive.nationalarchives.gov.uk/%2B/www.csed.dh.gov.uk/_library/Resources/CSED/DiscussionDoc/HRADiscDoc_Latest_NEW_FORMAT.pdf [Accessed 16 March 2018].

Department of Health and Social Care (2020) *Care and Support Statutory Guidance*. [online]. Available from: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance [Accessed 6 November 2020].

Doh, D., Smith, R. and Gevers, P. (2019) Reviewing the reablement approach to caring for older people. *Ageing and Society*. 40 (6), pp. 1–13.

Dow, B. and McDonald, J. (2007) The invisible contract: shifting care from the hospital to the home. *Australian Health Review* [online] 31(2), pp. 193-202 10p. [Accessed 26 October 2017].

Ebrahimi, V. and Chapman, H. (2018) *Reablement Services in Health and Social Care: a guide to practice for students and support workers*. Edited by V. Ebrahimi and H. Chapman. London: Palgrave.

Ellerby, L. (2009) *Analysis, Plus Synthesis: Turning Data into Insights*, *UX Matters*. [online] Available from: https://www.uxmatters.com/mt/archives/2009/04/analysis-plus-synthesis-turning-data-into-insights.php [Accessed 20 November 2020].

Emmel, N. (2013) *Sampling and Choosing Cases in Qualitative Research: A Realist Approach*. London: Sage Publications.

Emmel, N., Greenhalgh, J., Manzano A., Monaghan M. and Dalkin, S. (eds) (2018) *Doing Realist Research*. London: SAGE Publications Ltd.

Flintshire County Council (2017) *Reablement : A guide for Carers.* Available from: https://www.flintshire.gov.uk/en/PDFFiles/Social-Services/Adult-Social-Services/SSA-A19C-Reablement-Carers.pdf [Accessed 20 January 2021].

Gawande, A. (2015) *Being Mortal*. London: Profile Books Ltd.

Glendinning, C., Jones, K., Baxter, K., Rabiee, P., Curtis, L.A., Wilde, A., Arksey, H. and Forder, J.E. (2010) *Home Care Reablement Services : Investigating the longer-term impacts*. University of York. Social Policy Unit. Available from: https://www.york.ac.uk/inst/spru/research/pdf/Reablement.pdf [Accessed 5 July 2017].

Government Office for Science (2016) *Future of an Ageing Population*. [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535187/gs-16-10-future-of-an-ageing-population.pdf [Accessed 5 July 2017].

Greenhalgh, T., Thorne, S. and Malterud, K. (2018) Time to challenge the spurious hierarchy of systematic over narrative reviews? *European journal of clinical investigation* [online] 48(6)(e12931). [Accessed 10 December 2020].

Hjelle, K. M., Skutle, O., Førland, O and Alvsvåg, H. (2016) The reablement team's voice: a qualitative study of how an integrated multidisciplinary team experiences participation in reablement. *Journal of Multidisciplinary Healthcare*. 9, pp. 575–585.

Hjelle, K. M., Alvsvåg, H. and Førland, O. (2016) The relatives' voice: How do relatives experience participation in reablement? A qualitative study. *Journal of Multidisciplinary Healthcare*. 10, pp. 1–11.

Jagosh, J. (2018) CARES training course materials: Introduction to Realist Evaluation and Synthesis. London.

Jagosh, J. (2019a) *Realist Evaluation and an Architectural Understanding of Social Policy: Illuminating Blind Spots - seminar slides*. Available from: https://www.liverpool.ac.uk/engage/events/2018-2019/realist-evaluation-and-an-architectural-understanding-of-social-policy/ [Accessed 10 February 2019].

Jagosh, J. (2019b) Realist Synthesis for Public Health: Building an Ontologically Deep Understanding of How Programs Work, For Whom, and In Which Contexts. *Annual Review of Public Health*, 40(1), pp. 361–372.

Jagosh, J., Harris, K. and Dorling, H. (2019) *Five Burning Questions Answered about Realist Evaluation*. Available from: https://www.youtube.com/watch?v=DLP5evNW37g [Accessed 8 November 2019].

Jakobsen, F. A. and Vik, K. (2018) Health professionals' perspectives of next of kin in the context of reablement. *Disability and Rehabilitation*. 41 (16), pp. 1–8.

Jesus, T.S., Bright, F. A., Pinho, C. S., Papadimitriou, C., Kayes, N. M. and Cott, C. A. (2019) Scoping review of the person-centered literature in adult physical rehabilitation. *Disability and Rehabilitation* [online]. DOI: 10.1080/09638288.2019.1668483. [Accessed 18 April 2020]

Jones, K. C., Baxter, K., Curtis, L. A., Arksey, H., Forder, J. E., Glendinning, C. and Rabiee, P. (2009) *Investigating the Longer Term Impact of Home Care Re-ablement Services. The Short-term Outcomes and Costs of Home Care Re-ablement Services: Interim Report*. York: University of York.

Kent, J., Payne, C., Stewart, M. and Unell, J. (2000) *External Evaluation of the Home Care Re-ablement Pilot Project (leicestershire County Council)*. Leicester: DeMontfort University.

Kitwood, T. and Bredin, K. (1992) Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*. 12, pp. 269–287.

Kitzinger, J. (1995) Qualitative Research: Introducing Focus Groups. *BMJ Clinical Research*. 311(7000), pp. 299–302.

Langeland, E., Tuntland, H., Folkestad, B., Førland, O., Jacobsen, F. F. and Kjeke, I. (2019) A multicenter investigation of reablement in Norway: A clinical controlled trial. *BMC Geriatrics*. 19(29), pp. 1–12.

Leeds City Council (2011) *Reablement*. Available from: https://www.leeds.gov.uk/docs/reablement booklet.pdf [Accessed 3 March 2018]

Lewin, G., De San Miguel, K., Knuiman, M., Alan, J., Boldy, D., Hendrie, D. and Vandermeulen, S. (2013) A randomised controlled trial of the Home Independence Program, an Australian restorative home-care programme for older adults. *Health and Social Care in the Community*. 21(1), pp. 69–78.

Lewin, G., Allan, J., Patterson, C., Knuiman, M., Boldy, D. and Hendrie, D. (2014) A comparison of the home-care and healthcare service use and costs of older Australians randomised to receive a restorative or a conventional home-care service. *Health & social care in the community*. 22(3), pp. 328–336.

Lewis-Beck, M. S., Bryman, A. and Liao, T. F. (2003) *The Sage Encyclopdia of Social Science Research Methods*. SAGE Publications.

Mann, R., Beresford, B., Parker, G., Rabiee, P. and Wheatherly, H. (2016) Models of reablement evaluation (MoRE): A study protocol of a quasi-experimental mixed methods evaluation of reablement services in England Organization, structure and delivery of healthcare. *BMC Health Services Research*. 16, p 375.

Manzano, A. (2016) The craft of interviewing in realist evaluation. *Evaluation*. 22 (3), pp. 342–360.

Manzano, A. (2020) *Group deliberations (focus groups, etc.) in realist evaluation & realist synthesis webinar* Available from: https://realism.leeds.ac.uk/realismleeds-webinar-series/ [Accessed 2 June 2021].

Martin, G. P., Nancarrow, S., Parker, H., Phelps, K. and Regen, E. L. (2005) Place, policy and practitioners: On rehabilitation, independence and the therapeutic landscape in the changing geography of care provision to older people in the UK. *Social Science and Medicine*. 61(9), pp. 1893–1904.

Merton, R. K. (1968) On Sociological Theories of Middle Range. in *Social Theory and Social Structure*. New York: The Free Press, pp. 39–72.

Meyer, T., Gutenbrunner, C., Bickenbach, J., Cieza, A., Melvin, J., and Stucki, G. (2011) Towards a conceptual description of rehabilitation as a health strategy. *Journal of Rehabilitation Medicine*. 43 (9), pp. 765–769.

Miller, R. and Allen, K. (2013) *Prevention services in adult social care: reablement*. Available from: https://blogs.lse.ac.uk/socialcareevidenceinpractice/files/2013/02/Reablement-Event-January-2013-Final-version1.pdf. [Accessed 18 February 2018].

Moe, C. and Brinchmann, B. S. (2016) Optimising Capacity - A Service User and Caregiver Perspective on Reablement. *Grounded Theory Review*. 15 (2).

Newbronner, E. et al. (2007) *Research into the Longer Term Effects/Impacts of Re-ablement Services*. Available from: http://eprints.whiterose.ac.uk/73250/ [Accessed 8 March 2018].

NHS (2014) *Five Year Forward View*. Available from: https://www.england.nhs.uk/publication/nhs-five-year-forward-view/ [Accessed 20 January 2021]

NHS (2018) *Social Care and Support Guide*. Available from: https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/care-and-support-you-can-get-for-free/ [Accessed 6 April 2020].

NHS England (2016) *Quick Guide: Discharge to Assess*, *NHS England*. Available from: https://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf [Accessed 12 June 2020].

NHS England (2019) *NHS Long Term Plan*. Available from: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ [Accessed 7 June 2021].

NI Health and Social Care Board (2012) *Regional Reablement Service for Northern Ireland Briefing / Position Paper*. Available from: https://westerntrust.hscni.net/download/129/reablement/841/briefing_and_position_paper_regional_reablement_service_in_ni.pdf [Accessed 21 January 2021]

NICE (2014) *Developing NICE guidelines: a guide for stakeholders and the public*. Available from: https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/developing-NICE-guidelines-information-for-stakeholders.pdf. [Accessed 26 January 2021]

NICE (2017) *Intermediate care including reablement NICE guideline NG74*. Available from: https://www.nice.org.uk/guidance/ng74/resources/intermediate-care-including-reablement-pdf-1837634227909 [Accessed 24 October 2017].

NICE (2018a) *Intermediate care including reablement Quality Standard 173*. Available from: https://www.nice.org.uk/guidance/qs173/resources/intermediate-care-including-reablement-pdf-75545659227589. [Accessed 12 September 2018].

NICE (2018b) *Putting NICE guidance into practice Resource impact report: Intermediate care including reablement (NG74)*. Available from: https://www.nice.org.uk/guidance/ng74/resources/resource-impact-report-pdf-4602524941. [Accessed 12 January 2021].

NICE Collaborating Centre for Social Care (2013) *Homecare social care guidance stakeholder scoping workshop notes*. Available from: https://www.nice.org.uk/guidance/ng21/documents/home-care-scoping-workshop-notes2. [Accessed 13 January 2021]

NIHR (2013) *Commissioning Brief 13/01 - Self-care: a focus on the effectiveness of re-ablement interventions*. Available from: www.journalslibrary.nihr.ac.uk/programmes/hsdr/130117/#/ [Accessed 24 January 2020].

NIHR (2018) *National Standards for Public Involvement in Research*. Available from: http://www.invo.org.uk/wp-content/uploads/2018/03/71110_A4_Public_Involvement_Standards_v4_WEB.pdf. [Acessed 24 January 2020].

Nolan, M. R., Davies, S., Brown, J., Keady, J and Nolan, J. (2004) Beyond “person-centred” care: A new vision for gerontological nursing. *Journal of Clinical Nursing*. [online] 13 (3A), pp. 45–53. [Accessed 29 May 2017]

Nolan, M. R., Brown, J., Davies, S., Nolan J. and Keady, J. (2006) *The Senses Framework: Improving care for older people through a relationship-centred approach*. University of Sheffield, Centre for Health and Social Care Research. Available from: http://shura.shu.ac.uk/280/ (Accessed 13 July 2017).

Nuffield Trust (2019) *Nuffield Trust Friday FAQs: Trish Greenhalgh*. Available from: https://www.nuffieldtrust.org.uk/public/news-item/friday-faqs-trish-greenhalgh [Accessed 18

November 2020].

O'Rourke, G., Lloyd, L., Bezzina, A., Cameron, A., Jessiman, T. and Smith, R. (2020) Supporting Older Co-Resident Carers of Older People - The Impact of Care Act Implementation in Four Local Authorities in England. *Social Policy and Society* [online]. 1-14. [Accessed 19 December 2020]

Parsons, J., Rouse, P., Robinson, E., Sheridan, N. and Connoly, M. J. (2012) Goal setting as a feature of homecare services for older people: Does it make a difference? *Age and Ageing*. 41 (1), pp. 24–29.

Parsons, J. G. M., Sheridan, N., Rouse, P., Robinson, E. and Connoly, M. (2013) A randomized controlled trial to determine the effect of a model of restorative home care on physical function and social support among older people. *Archives of Physical Medicine and Rehabilitation*. 94 (6), pp. 1015–1022.

Patton, M. Q. (2015) *Qualitative Research and Evaluation Methods*. 4th ed. Sage Publications Inc.

Pawson, R. (1996) Theorizing the Interview. *The British Journal of Sociology*, 47(2), pp. 295-314.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K.. (2004) *Realist Synthesis: An Introduction*. ESRC Research Methods Programme, University of Manchester. Available from: https://www.betterevaluation.org/en/resources/guide/realist_synthesis_an_introduction [Accessed 30 October 2017]

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K.. (2005) Realist Review - a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research and Policy*. [online]. 10(1), pp. 21–34. Available from: http://www.ncbi.nlm.nih.gov/pubmed/16053581

Pawson, R. (2006) *Evidence-based Policy: A Realist Perspective*. London: SAGE Publications.

Pawson, R. (2014) *The Science of Evaluation: A Realist Manifesto*. SAGE Publications Ltd.

Pawson, R. and Tilley, N. (1997) Realistic Evaluation. in *Encyclopedia of Evaluation*. Thousand Oaks: CA: Sage, p. 235.

Pearson, M., Chilton, R., Woods, H. B., Wyatt, K., Ford, T., Abraham C. and Anderson, R. (2012) Implementing health promotion in schools : protocol for a realist systematic review of research and experience in the United Kingdom (UK). *Systematic Reviews*. [online]. 1 (48) pp. 1–7. [Accessed 18 January 2021].

Pearson, M., Hunt, H., Cooper, C., Shepperd, S., Pawson, R. and Anderson, R. (2013) Intermediate care : a realist review and conceptual framework. Final Report. NIHR Service Delivery and Organisation Programme. Available from: http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_10-1012-07_V01.pdf [Accessed 22 March 2018].

Pearson, M., Hunt, H., Cooper, C., Shepperd, S., Pawson, R. and Anderson, R. (2015) Providing effective and preferred care closer to home: A realist review of intermediate care. *Health and Social Care in the Community*. 23 (6) pp. 577–593.

Pilkington, G. (2012) *Homecare Re-ablement CSSR Scheme Directory Update April 2012*. Gerald Pilkington Associates.

Pitts, J., Sanderson, H., Webster, A. and Skelhorn, L.. (2011) *A new reablement journey*. Available from: https://www.researchgate.net/publication/264999479_A_New_Re-ablement_Journey [Accessed 3 March 2018].

Rabiee, P., Glendinning, C., Arksey, H., Baxter, K., Jones, K. C., Forder, J. E. and Curtis, L. A. (2009) *Investigating the Longer Term Impact of Home Care Re-ablement Services. The Organisation and Content of Home Care Re-ablement Services. Interim Report*. Available from: https://www.york.ac.uk/inst/spru/research/pdf/ReablementOrg.pdf [Accessed 15 January 2021]

Robson, C. (2002) *Real world research: a resource for social scientists and practitioner-researchers*. 2nd ed. John Wiley & Sons.

Robson, C. and McCartan, K. (2016) *Real world research*. 4th ed. John Wiley & Sons.

Royal College of Occupational Therapists (2015) *Reablement Fact Sheet*. London: Royal College of Occupational Therapists.

Rycroft-Malone, J., McCormack, B., Hutchinson, A.M., DeCorby, K., Bucknall, T.K., Kent, B., Schultz, A., Snelgrove-Clarke, E., Stetler, C.B., Titler, M., Wallin, L. and Wilson, V. (2012) Realist synthesis: illustrating the method for implementation research. *Implementation Science.* [online] 7 (1) p33. Available from: http://www.implementationscience.com/content/7/1/33doi:10.1186/1748-5908-7-33.

Sayer, A. (1992) *Method in Social Science*. 2nd ed. Taylor & Francis.

SCIE (2012a) *At a Glance 54: Reablement: a guide for families and carers*, *At a Glance*. Available from: http://www.scie.org.uk/publications/ataglance/ataglance54.asp [Accessed 16 October 2017]

SCIE (2012b) *The role of carers and families in reablement*. Available from: https://www.scie.org.uk/socialcaretv/video-player.asp?v=reablement1 [Accessed 16 October 2017]

SCIE (2013) *Maximising the potential of reablement SCIE Guide 49*. London: Social Care Institute for Excellence.

SCIE (2014) *Role of Carers and Family*. Available from: https://www.scie.org.uk/socialcaretv/video-player.asp?v=reablement1 [Accessed 16 June 2017]

Shearn, K., Allmark, P., Piercy, H. and Hirst, J. (2017) Building Realist Program Theory for Large Complex and Messy Interventions. *International Journal of Qualitative Methods*. 16 (1).

Silverman, D. (2011) *Interpreting qualitative data : a guide to the principles of qualitative research*. 4th ed. London: SAGE Publications.

Sim, J. (1998) Collecting and Analyzing qualitative data: Issues raised by the focus group. *Journal of Advanced Nursing*, 28 (2).

Social Market Foundation (2018) *Caring for Carers*. Available from:

https://www.smf.co.uk/publications/caring-for-carers/ [Accessed 17 November 2020].

Social Services Improvement Agency (2013) *Position statement on reablement services in Wales*. Available from: https://socialcare.wales/cms_assets/file-uploads/2a-reablement-position-statement-web-version-e.pdf. [Accessed 26 May 2017].

Stake, R. E. (1995) *The Art of Case Study Research*. London: Sage.

The RAMESES II Project (2017) *RAMESES Quality Standards for Realist Evaluation: For evaluators and pee-reviewers*. Available from: http://www.ramesesproject.org/media/RE_Quality_Standards_for_evaluators_and_peer_reviewers.pdf. [Accessed 20 November 2020].

The RAMESES Project (2014) *Quality standards for realist synthesis (for researchers and peer-reviewers)*. Available from: https://www.ramesesproject.org/media/RS_qual_standards_researchers.pdf. [Accessed 20 November 2020].

Tinetti, M. E., Baker, D., Gallo, W. T., Nanda, A., Charpentier, P. and O'Leary, J. (2002) Evaluation of restorative care vs usual care for older adults receiving an acute episode of home care. *Journal of the American Medical Association.* 287 (16), pp. 2098–2105.

Tresolini, C. P. and Pew-Fetzer Task Force (1994) *Health professions education and relationship centered care*. San Fransisco: CA: Pew Health Professions Commission.

Tuntland, H., Aaslund MK., Espehaug B., Førland O. and Kjeken I. (2015) Reablement in community-dwelling older adults: A randomised controlled trial. *BMC Geriatrics*, 15 (145).

Wade, D. T. (2020) What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation* [online]. 1-13. Accessed [April 20 2020].

Westhorp, G., Prins, E., Kusters, C., Hultink, M., Guijit, I. and Brouwers, J. (2011) *Realist Evaluation : an overview Report from an Expert Seminar*, *Centre for Development Innovation, Wageningen University & Research centre.* [online] pp1-20 Available from: http://www.managingforimpact.org/sites/default/files/resource/2011_wp_realistevaluationseminar_cecilekusters_2x.pdf. [Accessed 4 December 2017].

Westhorp, G. (2014) Realist Impact Evaluation. *Research and Policy Development*, (September), pp. 1–12.

Wilde, A. and Glendinning, C. (2012) "If they're helping me then how can I be independent?" The perceptions and experience of users of home-care re-ablement services. *Health and Social Care in the Community*. 20 (6), pp. 583–590.

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., and Pawson, R. (2013a) RAMESES publication standards: Realist Synthesis. *BMC Medicine*, 11(21).

Wong, G., Westhorp, G., Pawson, R. and Greenhalgh, T. (2013b) *Realist Synthesis: RAMESES Training Materials*. Available from: http://www.ramesesproject.org/media/Realist_reviews_training_materials.pdf. [Accessed 20 January 2021]

Wong, G. (2018) Making theory from knowledge syntheses useful for public health. *International Journal of Public Health* [online]. 63, 555-556.

Yin, R. K. (2014) *Case Study Research: Design and Methods*. 5th ed. Thousand Oaks, CA: Sage Publications.

Appendix A

High-level definitions of reablement used by agencies in UK - a sample

Source	**Definition of reablement**
Age UK (Age UK, 2018)	Reablement – offers services at home from specially trained social care staff. Rather than undertaking tasks for you, staff work with you to enable you to do things yourself and re-learn skills you may have lost while unwell, and so recover your ability to live safely at home. To meet all your needs, it may mean reablement runs alongside home care.
Department of Health and Social Care (Department of Health and CSED, 2007)	Services for people with poor physical or mental health to help them accommodate their illness by learning or re-learning the skills necessary for daily living.
Health and Social Care Board, Northern Ireland (Health and Social Care Board, 2012)	Reablement is a person-centred approach which is about promoting and maximising independence to allow people to remain in their own home as long as possible. It is designed to enable people to gain or regain their confidence, ability, and necessary skills to live independently, especially after having experienced a health or social care crisis, such as illness, deterioration in health or injury. The aim of Reablement is to help people perform their necessary daily living skills such as personal care, walking, and preparing meals, so that they can remain independent within their own home. Reablement will help you to do things for yourself rather than having to rely on others.
National Institute for Health and Care Excellence (NICE, 2017)	Assessment and interventions provided to people in their home (or care home) aiming to help them recover skills and confidence and maximise their independence. For most people interventions last up to 6 weeks. Reablement is delivered by a multidisciplinary team but most commonly by social care practitioners.
RCOT (Royal College of Occupational Therapists, 2015)	Reablement is a person-centred approach within health and social care that helps individuals to learn or relearn the skills necessary to be able to engage in activities/occupations that are important to them. Services focus on enabling people to do things for themselves, rather than a traditional home care approach of others doing things for them (Royal College of Occupational Therapists, 2015)

Reablement Learning and Improvement Network, Wales (Social Services Improvement Agency, 2013)	Services for people with poor physical or mental health or disability to help them live as independently as possible by learning or relearning the skills necessary for daily living.
Social Care Institute for Excellence (SCIE, 2013)	Reablement is generally designed to help people accommodate illness or disability by learning or re-learning the skills necessary for daily living. These skills may have been lost through deterioration in health and/or increased support needs. Reablement services are generally provided for a period of up to six weeks although people often meet their goals in a far shorter period of time. The focus is on promoting and optimising independent functioning rather than resolving health issues. It is about helping people do as much for themselves as possible rather than doing things for people that they cannot do.

Appendix B

Terminology used in the study

This appendix sets out decisions made about terminology used in the study. Terminology relating to the methodology is discussed in Chapter 1. Decisions made about terminology relating to service users and carers were made in collaboration with the study Patient and Public Involvement group.

Service users

Several decisions needed to be made regarding the terminology to use during this study. The first related to how to refer to the people for whom reablement is designed. The researcher considered referring to them as the recipients of reablement, people undertaking reablement or service users. Recipients of reablement puts the person in a very passive role and is wordy so this was rejected. People undertaking reablement, although representing a move away from this passivity was also considered wordy. The researcher did consider simply using the term person or individual but quickly realised that this would not distinguish them sufficiently easily from the other stakeholders involved in the analysis. Consequently the term service user was adopted. Although this is somewhat utilitarian and impersonal, it is widely understood and presented a useful way of distinguishing this group of individuals. It also lent itself easily to referring to their status once they have been discharged from reablement as "former" service users.

Sometimes it is necessary to refer to the service user in terms of their relationship to a family member. Although the term "loved one" is used by some people, some members of the PPI group found this term had a belittling resonance. We therefore decided in favour of referring to them in this context by the name of their relationship to the family member e.g. wife, son, grandchild.

Older people

Another decision was how to refer to people when referencing age. Many terms exist including older people, older adults, the elderly, seniors and old people. The elderly and old people were considered to be generally and thankfully out of use and seniors is more commonly used outside the UK. It was noted that Age UK, the NHS and various Government bodies including the ONS (Office for National Statistics) all generally (although not consistently) use older people rather than older adults. "Older adults" is useful when distinguishing them specifically from younger adults (from the age of 18 upwards) or children, for example when referring to exercise or diet regimes that are age-appropriate.

There are a multitude of perspectives on what constitutes being "older" and at what age this starts. Statistics on ageing usually categorise older people by being above a specified age. For example, the ONS generally report data on people aged 65 and over, those aged 85 and over, (the latter being referred to as the "oldest old"), or aged 90 and over (the "very old"), although they themselves are in debate about these bands (Office for National Statistics, 2019). For the purposes of this study the researcher is investigating home-based reablement for people who are aged 65 and older. They are referred to as older people. When it is necessary to sub-divide this group, this will be done by reference to their specific age band.

Reablement workers

It is also important to clarify the terminology used in this study to distinguish paid carers from people who play a caring role in a service user's life and who are not paid. In order to minimise potential confusion, where paid carers are employed as reablement workers they will be referred to as reablement workers. Some services use alternative titles such as reablement support worker or support worker but this study will use reablement worker and in the case of the fieldwork undertaken with a particular service, the term senior reablement worker will also be used. Where the carer is paid but is not working in reablement, they will be referred to as a care worker rather than other alternatives such as paid carer, formal carer, care assistant, home carer or care support worker. This was the preferred terminology of the PPI Group.

Families

By contrast, choosing the most appropriate terminology for the study to refer to the relatives of service users was more complex and emotionally charged. In the early stages of the study, the researcher organised a meeting to recruit volunteers to a PPI group. These people, who had been contacted through a local carers support network, expressed strong preferences with regard to terminology.

They indicated a strong rejection of the term "carer". This appeared to stem in part from the different meanings of "care", encompassing to care for (to provide for the needs of) as well as to care about (to feel concern for). It is possible after all to care for someone without caring about them and vice versa. Furthermore, people care sometimes out of a sense of love; sometimes out of a sense of duty or a combination of both. Rejection of the term carer was also explained to the researcher in another way by relatives of service users (who were subsequently recruited to the PPI Group). They articulated the fact that they did not associate with the term "carer" and moreover did not feel the need for a title other than that which denoted their relationship to the service user (wife, husband, daughter, son etc). Nonetheless they acknowledged that at some point it is common for someone who does an increasing amount of care for a relative to recognise a change in their role. This can lead to a shift in their perception of themselves as now fulfilling a carer role. At this stage they might start to associate with the term "carer". Although the group did not associate with the term "family carer" they recognised that this might be terminology that is used by commissioners and policy makers.

These discussions provoked the researcher to think far more deeply than had been anticipated about what terminology to use in the study as a whole and the consequent impact that it would have. As the focus of the research was on the relatives of reablement service users rather than other people who might be involved in a non-professional capacity (e.g. friends or neighbours), the researcher decided to refer to them as either families or family members. Family members are taken to include married and unmarried partners. Relatives could have been an equally acceptable term. These choices meant that any confusion about who the term "carer" referred to was avoided.

From the perspective of organisations by contrast, carers, caregivers, unpaid carers and informal carers are all used. The researcher noticed a shift from unpaid carer in favour of informal carer in documents produced since about 2018. More recently, both have been used together in an article "Unpaid informal care provided by friends and family is essential to our society and the economy", published by the ONS (Storey, Coombs and Leib, 2019 p2). It is noted that "unpaid" often refers to the care itself e.g. the unpaid care that relatives provide. The researcher checked current terminology with Carers UK (which of course has a vested interest in the term carer) and was told:

> "Our preferred term is simply the word carer as that's what reflects legislation although it can occasionally be confused with care workers. Where appropriate we'd often add in the word unpaid if it helps to differentiate from care workers in the context or adds a bit more relevant information.
>
> We've found that the term 'informal carer' isn't very popular with our membership as they feel that there is nothing informal about the support they provide, especially as so many are caring full time and are experts in the care they provide despite being unpaid." (email from Carers UK dated 23/05/2019)

The Department of Health and Social Care states that "A carer is considered to be anyone who spends time looking after or helping a friend, family member or neighbour who, because of their health and care needs, would find it difficult to cope without this help regardless of age or whether they identify as a carer." (Department of Health, 2018)

Traditional homecare

Other decisions that had to be made about terminology to distinguish reablement from other forms of homecare that are focussed on supporting people by doing things for them rather than supporting them to do things for themselves. "Traditional" homecare and "conventional" homecare are both used in documents. Traditional has a sense of being part of long-established ways, whereas conventional has a greater emphasis on what has come to be accepted. Because reablement is being explored in this study as a type of homecare that is relatively new the term traditional homecare will be used as a contrast to reablement.

Engagement

Considerable thought was given to the terminology used to describe the family's connection with reablement and encouraging that connection. This was discussed with the PPI group, supervision team and research participants. The ultimate aim of the study was to produce insights that could help practitioners to optimise a family's connection with reablement. This was achieved by examining what causes families to connect or not with reablement and meant looking both at the practitioners' role in facilitating that connection as well as other aspects of what might cause families to connect. Verbs considered in relation to this connection were involve, participate and engage.

"Involve", due to its transitive nature, was considered to put the emphasis on the practitioner involving the family without encompassing action on the family member's part. For example, reablement teams could involve families in physical parts of the reablement process without necessarily gaining their mental buy-in. This implication of passivity on the part of the family member was considered to be restrictive.

"Participate" by contrast is an intransitive verb and consequently puts emphasis on the family connecting with reablement (again implying a physical connection without necessarily any depth of mental connection) but does not inherently encompass the part played by the practitioner.

"Engage" on the other hand is used both transitively and intransitively. This means that it can encompass the activity of practitioners in engaging families in reablement as well as the action and volition of families engaging in reablement. This was deemed to provide a wider scope for an examination of causal factors.

The distinction between these terms played an important part in the theorising that took place during the study. It is notable that the results of the Beresford et al evaluation of reablement that was published towards the end of this study generated some evidence of the association between engagement and outcomes (Beresford et al, 2019) and in doing so, referred to recent thinking conceptualising engagement in rehabilitation as a multidimensional construct (Bright et al., 2015). The Bright study, a conceptual review of engagement in healthcare and rehabilitation, proposes an understanding of engagement as a "co-constructed process and state [which] challenges some understandings of engagement and makes explicit the clinician's role in engagement." It concludes that "viewing engagement as a co-constructed concept provides a rationale for shifting the responsibility to engage from the patient to the therapeutic dyad. Challenges in engagement may be seen as a prompt to critically reflect on what the clinician is doing and how the two parties are working together and consider new ways of working in order to promote engagement in rehabilitation." (ibid p652). These findings, although concerned with practitioners and service users rather than families, have considerable resonance with this thesis.

The National Institute for Health Research (NIHR) which sets out national standards for public involvement (NIHR, 2018) in research, make the following distinctions between involvement, participation and engagement for the purposes of PPI (NIHR INVOLVE, 2019):

- Involvement – where members of the public are actively involved in research projects and research organisations

- Participation – where people take part in a research study

- Engagement – where information and knowledge about research is provided and disseminated

The distinctions between these terms are noted here as they differ from the way the terms are used in the study. For NIHR, engagement is considered a one-way dissemination of research information from researchers to the public. This explains its subordinate position in relation to involvement and participation in terms of depth of connection.

Stakeholders

The final category of terminology to define relates to the collective term for everyone taking part in the reablement intervention. Choices included stakeholders, parties, actors, players or care circle. The term stakeholders was chosen as the researcher deemed it to capture the meaning of having a vested interest in the intervention. Some of the other terms have particular meanings in research methodologies and were avoided for this reason. The terms "circle of care" or "care circle" are sometimes referred to in the literature cited in this study. These are taken to mean anyone involved in the care of an individual, including anyone who has authorised access to their care information.

Appendix C

NICE Guideline NG74 "Intermediate care including reablement", 2017

Recommendations relating explicitly to the involvement of families and carers are set out below.

Core principles of intermediate care, including reablement

- At all stages of assessment and delivery, ensure good communication between intermediate care practitioners and people using the service and their families and carers. (1.1.2)
- Ensure that the person using intermediate care and their family and carers know who to speak to if they have any questions or concerns about the service, and how to contact them. (1.1.4)

Assessment of need for intermediate care

In relation to assessment of need for intermediate care, the guidance aims "to ensure that the type of intermediate care support is appropriate for the person's needs and circumstances." It recommends:

- Actively involve people using services (and their families and carers, as appropriate) in assessments for intermediate care and in decisions such as the setting in which it is provided (1.3.4)
- When assessing people for intermediate care, explain to them (and their families and carers, as appropriate) about advocacy services and how to contact them if they wish (1.3.5)

Entering intermediate care

- Discuss with the person the aims and objectives of intermediate care and record these discussions. In particular, explain clearly (among other points) that intermediate care works with existing support networks, including friends, family and carers (1.5.1)
- When a person starts using intermediate care, give their family and carers (1.5.2):
    - Information about the service's aims, how it works and the support it will and will not provide
    - Information about resources in the local community that can support them
    - Opportunities to express their wishes and preferences, alongside those of the person using the service
    - Opportunities to ask questions about the service and what it involves
- Complete and document a risk plan with the person (and their family and carers, as appropriate) as part of the intermediate care planning process. Ensure that the risk plan includes:

    - strategies to manage risk; for example, specialist equipment, use of verbal prompts and use of support from others (1.5.9)
- Document the intermediate care goals in an accessible format and give a copy to the person, and to their family and carers if the person agrees to this (1.5.12)

Delivering intermediate care

- Ensure that an intermediate care diary (or record) is completed and kept with the person. This should (among other points) keep the person (and their family and carers, as appropriate) and other staff fully informed about what has been provided and about any incidents or changes (1.6.5)
- Contact the person (or their family or carer) if intermediate care staff are going to be late or unable to visit (1.6.7)

Transition from intermediate care

- Ensure good communication between intermediate care staff and other agencies. There should be a clear plan for when people transfer between services, or when the intermediate care service ends. This should (among other points) be documented and agreed with the person and their family or carers (1.7.2)
- Give people information about other sources of support available at the end of intermediate care, including support for carers (1.7.3)

Appendix D

NICE Quality Standard QS173, 2018

Three of the four quality statements are relevant to home-based reablement and these contain frequent reference to the inclusion of "family and carers as appropriate". They are set out here.

Statement 1: Adults being assessed for intermediate care have a discussion about the support the service will and will not provide.

Rationale: Healthcare professionals in hospitals or the community who are assessing people for intermediate care should have a discussion, provide information and ensure that the person (and their family and carers, as appropriate) understand what intermediate care is and what it can and cannot achieve. This will ensure that people are involved in making decisions about their care and encouraged to engage with the rehabilitation process. It will also enable them to consider any further support they may need in addition to intermediate care.

Quality measures:

a) Evidence that information about the support provided by the local intermediate care service is available.
b) Evidence of local processes to ensure that adults being assessed for intermediate care have a discussion about the support the service will and will not provide.

Outcome: Level of awareness of the support the service provides among adults assessed for intermediate care and their families and carers.

Statement 3: Adults starting intermediate care discuss and agree personalised goals.

Quality measures:

a) Evidence of local arrangements to ensure that staff carrying out assessments for intermediate care are trained to discuss and agree personalised goals with adults starting the service.
b) Evidence of local processes to ensure that personalised goals are documented and shared with the person starting intermediate care, their family and carers (as appropriate), and care staff.

Outcome: a) Satisfaction of adults discharged from intermediate care that the service supported them to achieve their personalised goals. b) Proportion of adults discharged from intermediate care with a level of independence improved from admission

Statement 4: Adults using intermediate care services discuss and agree a transition plan for when their support ends.

Quality measures:

a) Evidence of local referral pathways between intermediate care and statutory, independent and voluntary services.
b) Evidence of local information about where adults leaving intermediate care can get support.
c) Evidence of local processes to ensure that adults using intermediate care services discuss and agree a transition plan for when their support ends.

Outcome: a) Rate of emergency readmissions to hospital within 30 days of discharge from hospital into reablement or rehabilitation services. b) Proportion of people who were still at home 91 days after discharge from hospital into reablement or rehabilitation services. c) Satisfaction of adults with their transition from intermediate care.

Appendix E

Social Care Institute for Excellence (SCIE) Guide 49, 2013

SCIE Guide 49 sets out the following recommendations in relation to the role of families in supporting the reablement process. These recommendations are bulleted in the publication. As they are referred to frequently during the course of this study they were numbered, for ease of reference:

1. Reablement services must recognise the important role played by families, carers and friends. They are part of the whole care circle supporting the individual and this must be genuinely respected.

2. Reablement managers and care workers should ensure that appropriate family and friends receive a clear explanation of the service, particularly in terms of the nature of support provided. There should be a clear description of the aims of reablement.

3. Those referring to and providing reablement must be sensitive to concerns that families may have about the ‘risks’ of this approach. They will need reassurance that their relative is being looked after despite being encouraged to do things independently. At the outset, there should be a frank and sensitive discussion about balancing risk and building independence and this should be reiterated throughout the duration of the service.

4. The reablement team should encourage family members and friends to contribute to the reablement process. As well as motivating the person, family and friends might also benefit from practical tips and techniques for providing support in ways that help achieve goals. If they are completely ‘signed up’ to the concept of reablement, they can help to motivate the person throughout the process. At the end of the service, family and friends can encourage the person to continue using new-found skills so as to maintain their confidence and independence.

5. If family and friends provide regular support to the individual, they should be invited to participate in the assessment process and development of the care plan. This is usually undertaken by a social worker prior to referral to the reablement service. Where conflicts arise, social workers will use their professional judgement and skill to mediate the

individual's and the families' views and needs. (NB this recommendation refers to the period immediately before reablement starts, so is not included in the theory development).

6. Those referring to reablement and reablement workers should be alert to any concerns family members might raise or attempt to voice. These may relate to the support they feel the individual requires or, crucially, to their ability to continue in a caring role. Those referring to reablement should establish exactly what support family members are willing and able to offer. Those providing reablement should also be alert to the fact that this could change over time.

7. If family members and friends provide, or intend to provide, a substantial amount of care, social workers are obliged to offer them a carer's assessment. This will determine whether any help can be given to support them in their caring role and should have been carried out during the assessment phase, before the individual was referred to the reablement service. If it comes to light that this has not happened, the reablement service should inform the social work team.

8. Following a period of reablement, a person may require less or no support, both from formal services and from family and friends. The reablement service should encourage the family to consider continuing to provide social support, catching up on local or family news or going on outings.

9. On the other hand, after reablement, a person may still require ongoing support from formal services and/or family, friends and carers. Even if family and friends express a willingness to provide this support, the reablement service will need to educate them about the sustainability of that support. In other words, families and unpaid carers may need help to accept that the care they can offer now may become too demanding for them to continue in the future.

Appendix F

Expert from diary of researcher reflections

19/3/2018

I've been going through some of the literature for my synthesis today. An article by Larkin, M and Mitchell, W (2016) was particularly interesting as it discussed: the policy of personalisation, the fact that there has been relatively little consideration of family carers' choice within personalisation and the relationship between carers and personalisation also remains under-researched. It referred to the need for more research into constraining variables and "opaque complexities" around carers, choice and personalisation.

This tied in with my worries of the last entry (do relatives care anyway theme) as it encompassed a recognition of the different ways in which families care and how policy impacts on this.

I found some comfort in this and it allowed me to embrace a broader type of carer I think.

Appendix G

Summary of NIHR standards for public involvement and PHWE guidance on public involvement

NIHR standards informed the researcher's approach to working with a PPI group and are set out below (NIHR, 2018):

Standard 1	Inclusive opportunities: We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
Standard 2	Working together: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
Standard 3	Support and learning: We offer and promote support and learning that builds confidence and skills for public involvement in research.
Standard 4	Communications: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.
Standard 5	Impact: To drive improvement, we capture and share the difference that public involvement makes to research.
Standard 6	Governance: We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

People in Health West of England (PHWE), an initiative promoting innovative and effective public involvement in research and evidence-based service improvement, emphasises a number of key points in relation to these standards and to establishing a PPI group (PHWE, 2018). In brief these refer to:

- The benefits of different perspectives on the same issue
- Regarding public involvement as a two-way conversation
- The importance of being explicit about where members of a PPI group sit in relation to the concerns of the research and public concerns
- Keeping a log of involvement activity
- Practicalities in setting up and facilitating a PPI workshop

Appendix H

Recruiting a PPI Group

Having decided that the most expedient way to recruit suitable people to a PPI group would be through an existing network of carers, I approached the local Carers Support Centre. The Carers Engagement and Involvement Lead at the centre thought that the research would resonate with the network's members and agreed to help. Together we designed and distributed a recruitment leaflet via the centre's publicity channels inviting people to an information session about the research (Appendix I). This leaflet was targeted at both existing as well as former carers. It stated clearly that the initial session was for information only and that there would be no obligation to sign up to a group following the initial session. In order to increase its appeal and to provide an opportunity for attendees to learn something new, I offered them a tour of a related facility at the university as part of the session. The recruitment leaflet set out what the commitment would be should attendees wish to become a voluntary research advisory group member. This commitment was described as attendance at two meetings to contribute ideas that would help shape the research, ensuring that carers were at the heart of it.

The Carers Engagement and Involvement Lead emphasised the importance of specifying clearly what the time requirement would be and what might change as a result of group membership. She warned that it is not uncommon for people to have to make last minute cancellations (often due to the demands of their caring role) and also mentioned the likelihood of dominant personalities attending. Following her advice, I included in the leaflet that travel and respite costs would be covered and refreshments provided at the information session.

Information session

A location accessible to people with mobility needs was chosen for the information session. One of my supervisors offered to take notes at the event and a colleague agreed to lead the tour. I designed the session to include refreshments, a presentation about the research and why PPI members were needed, a time for questions and answers, the tour and an explanation of next steps. The target number to recruit from the session was four to six people who would initially meet twice to contribute to the study. The PPI group was referred to as a Research Advisory Group. 13 people attended the information session, seven women and six men, representing a mix of age and ethnicity. All of the people who attended had experience of playing an unpaid caring role in someone else's life, either currently or previously.

During the one and a half hour session, the meaning of reablement and the rationale for the research was explained along with an explanation of why the input of members of the public who had experience of engaging in the care of a family member over the age of 65 was needed. The key reasons for this were expressed as:

- They are the care experts
- Their views are vital to ensure that carers are at the heart of the research
- Research cannot happen without willing participants
- Their input would contribute to practical results that have the potential to inform the development of services and resources that help carers in their support role
- They would widen the perspectives on the research
- "I don't know what I don't know"
- Their involvement might encourage future research participants when they hear that carers themselves had been involved in design

It was explained that the overarching aims of the group would be to:

- Contribute ideas to two meetings after the initial information session
- Help design how to approach family carers
- Ensure that any information provided to research participants is clear and understandable to them

During the question and discussion time, a number of people expressed dislike for the term "carer", saying that they did not associate themselves with it. This caused me to reconsider the term. Subsequently, as a result of further discussions with the PPI group, I decided to avoid the term as far as practical in the study. Other questions related to reablement in different parts of the world, the role of physiotherapists in reablement, whether reablement workers are able to support family carers as well as service users, personalisation in reablement and the typical length of reablement.

Several people shared their experience of feeling "side-lined" or "pushed away" by professionals who were caring for their relative. One of the attendees referred to being made to feel "in the way". It should be noted that attendees had not necessarily had experience of reablement in particular but of a range of care services.

Two other points that were raised at this early stage in the research and which were subsequently pursued in the study, related to how provisions of the Care Act (Department of Health, 2014a) were represented in guidelines for reablement. The first point was that the Care Act stipulates that carers have a legal right to be treated as expert care partners. It was queried whether NICE guidelines for reablement take this into consideration. Related to this was a query over whether the guidelines identify that carers should be able to choose to provide only the care that they are willing to provide.

As a result of the meeting, five people were recruited to the PPI group (three women and two men). All five attended the first meeting and four attended the second (the fifth was admitted to hospital shortly before the meeting). A further three people who had been unable to attend the session were contacted and kept in reserve. I kept in touch with the Carers Engagement and Involvement Lead over the course of the study. She did not take part in the PPI group sessions herself but was interested in updates and invited me to some relevant events.

Appendix I

Recruitment leaflet for PPI Group

If you care, we care.
Carers Support Centre

UWE Bristol
University of the West of England

Opportunity to Take Part in Research on ‘Involving Family Carers in Older People’s Home-based Reablement’

- **Are you caring for a friend, neighbour, parent, spouse or relative aged over 65? Or have you done so previously?**
- **Would you like to find out more about and even possibly be involved in a research study on 'Involving family carers in older people’s home-based reablement'*?**

Come along for a **fascinating tour of the Bristol Robotics Laboratory’s Assisted Living Studio** at **UWE's Frenchay Campus** and find out more about the opportunity to become a voluntary research advisory group member for this UWE Postgraduate Research Study.

The information session takes place on **1.30-3pm on Thursday 2 August.**

The researcher will meet carers who might be interested in shaping the research and in finding out more.

The research findings have the potential to inform the development of services and resources that help carers in their support role. Your involvement would help to ensure that carers are at the heart of the research.

You would be invited to contribute your ideas to two meetings after the initial information session.

You are also welcome to just find out more – you won't have to come to the follow up meetings if you realise at the information session that it's not for you.

Travel and respite costs can be provided. (Receipts for respite costs or bus tickets are needed).

Please contact [name removed], Carers Engagement & Involvement Lead for more information or to book on: [contact details removed].

Hot drinks and light refreshments will be provided.

***Reablement** is a short and intensive service, usually delivered in the home, to help people regain their independence following an illness or injury.

Appendix J

Sample log of PPI group activity

Date	Aim of Activity	Involvement Activity	Who took part	Anticipated outcomes	Unanticipated outcomes	Impacts (anticipated and unanticipated)
27/09/2018	PPI input to realist synthesis - theory development	First Research Advisory Group Meeting	5 carers (3F, 2M)	To establish the group and gain some insights into how they see some of the initial theories that are to be refined in the realist synthesis working. Selected 17 theories related to a holistic view of family involvement. Also to prioritise them if possible	They wanted to express preferred terminology: care workers for people employed to care and carers who are always unpaid and "voluntary"	5 expert carer partners keen to come to the second meeting
					Extremely deep and willing engagement with the topic.	A number of insights and nuances contributed to the research. Did not anticipate just how useful and insightful their comments would be.
					They initially interpreted the if.. then.. statements as items to agree or disagree with rather than commenting on but quickly realised this was not the aim.	
					Meeting was scheduled for 1 hour they unanimously agreed after the 1 hour to extend it for a further hour and to make the next meeting a 2 hour one.	

Appendix K

Full description of eight Candidate Programme Theories

The eight Candidate Programme Theories (CPTs) relate to the following areas:

9. Instilling an understanding of reablement
10. Goal setting and monitoring
11. Risk management
12. Ongoing communication
13. Plan for the end of the service
14. Family respected as part of the whole care circle
15. Family buy-in
16. Customising service delivery to the family's position

They are detailed in the tables, along with an identification of their sources within the NICE and SCIE guidance and questions that they raised at this stage of the synthesis.

CPT1	**Instilling an understanding of reablement**
Sources	NICE Guideline 1.1.4, 1.5.1, 1.5.2, SCIE Guide 2
If-then	IF reablement teams involve families and partners in discussions with the service user explaining what reablement is at the start of the intervention THEN families and carers can understand what reablement can and cannot achieve and how it differs from traditional homecare.

This is a programme theory about the process of kicking off the service effectively and the outcome could be considered an intermediary outcome, as it is limited to having an understanding rather than identifying how that understanding could ultimately benefit reablement. It was noted that there was no contextual aspect to this candidate programme theory in the sources, although stakeholders suggested the importance of well trained staff. The guidelines advise covering particular areas in the initial reablement discussion (e.g. how to communicate with the service, opportunities to express wishes and preferences and to ask questions). These are considered later on in the analysis as a resource aspect of the mechanism.

Initial questions that this candidate programme theory raised were:

- What contributes to managing these discussions effectively?
- How are family members identified in order to invite them to the discussion?
- What contextual factors are important?
- Is it assumed that family members are always open to the discussion?

CPT2	**Goal setting and monitoring**
Sources	NICE Guideline 1.5.11, 1.5.12
If-then	IF the reablement goals are shared with families and partners, in agreement with the service user, THEN families and partners will understand the goals and may be able to help the service user to achieve them.

This is a programme theory about the core process of setting goals both at the beginning of reablement and subsequently monitoring and revisiting them during its course. The guidelines mention the importance of documenting goals in an accessible format. They also suggest recognising social and leisure activities as legitimate goals. Although families are not specifically identified as having a potential role to play in this point in the NICE guidelines, one of the stakeholders (the independent homecare provider) emphasised the potential that families have to contribute to goals of this type. The SCIE guide refers to encouraging families to provide social support following reablement but does not refer to it during reablement. An untested theory also emerged from the literature which suggested that paradoxically, by increasing someone's physical independence within their home through reablement (to the degree that they do not require carers for most tasks) there is a danger that their social contact is reduced which can in turn lead to isolation and loneliness (Aspinal et al., 2016). It was therefore decided to include this particular aspect of goal setting at this early stage so that it could potentially be tested in the study.

Initial questions that this candidate programme theory raised were:

- Is there a difference between when family members are involved in setting the goals and when they simply receive a copy of goals set without their involvement?

- What happens when conflicting or opposing views have not been raised or addressed?

- What happens when the service user does not want to share their goals with family yet the family wishes to play an active role in reablement?

- What causes families to move from understanding the goals to helping the service user achieve them?

CPT3	**Risk management**
Sources	NICE Guideline 1.5.9, SCIE Guide 3
If-then	IF reablement teams involve families and carers in a discussion about balancing risk and building independence at the start and during reablement as well as in risk planning, THEN families will understand the risks implied in aiming to achieve the goals that are set and the strategies for managing and mitigating them.

This programme theory, like the first one, is partly about managing expectations. Again, the outcome could be considered an intermediary outcome, as it is limited to having an understanding rather than identifying how that understanding could ultimately benefit reablement.

Initial questions that this candidate programme theory raised were:

- What sorts of elements contribute to families feeling risk-adverse?

- What is it about the way risks are discussed that can assuage fears?

- What happens when conflicting or opposing views have not been raised or addressed?

CPT4	**Ongoing communication**
Sources	NICE Guideline 1.1.2, 1.6.5, 1.6.7
If-then	IF reablement teams ensure that families and partners have access to a record about what has been provided and any incidents or changes, are able to answer questions and concerns and contact families if they have to change visit arrangements, THEN families and partners will benefit from good communication and will feel fully informed about the provision of the service.

This programme theory is based on the idea of maintaining good channels of communication with families. Its outcome is focussed on the period of reablement alone rather than suggesting how this might influence what happens after reablement is over. It was clear through the initial discussions with stakeholders that different families engage in communication with reablement teams during reablement to very different degrees. They also suggested that changes to or unpredictable visit times were a typical cause of complaint from families.

Initial questions that this candidate programme theory raised were:

- What influences the way and the degree to which families engage in communication with reablement teams?

- How do written records contribute to a sense of families' involvement with reablement?

- Can outcomes still be positive even if communication is considered to be poor by the families?

- To what degree does the vulnerability of the service user and/or family impact on the role and effectiveness of communication?

CPT5	**Plan for the end of the service**
Sources	NICE Guideline 1.7.2, 1.7.3, SCIE Guide 8, 9
If-then	IF reablement teams agree and document a plan for when reablement ends, encourage families and partners to consider continuing to provide social support, encourage them to consider the sustainability of the support they can offer and give them information about other sources of support including support for carers, THEN an effective transition from the service will be made.

Transition from reablement can take a variety of forms. Some service users will require less or no support following reablement, others will require ongoing support at home, provided by an external organisation, the family or a combination. Others will need to transfer to full time care either at home or in another setting. It is also possible that reablement will be offered again at another stage. This context is likely to have a bearing on how transition from the service is managed and experienced.

Initial questions that this candidate programme theory raised were:

- What does effective transition mean from the perspective of the provider, the service user and their family respectively?

- What is it about the way that transition is discussed that might encourage or discourage families from wishing to offer their support following reablement?

- How are families' own support needs taken into consideration?

CPT6	**Family respected as part of the whole care circle**
Sources	NICE Guideline 1.1.2, SCIE Guide 1, 4, 6
If-then	IF reablement teams respect families and partners as an important, active part of the whole care circle, encourage them to contribute to the process as partners, giving them practical tips and techniques for providing support, and maintain good communication with them, THEN families and partners will be empowered to help to contribute towards the service user's independence throughout the process and will be empowered to reinforce the approach with the service user after the end of reablement.

This programme theory is based on the idea of encouraging families to contribute actively to the process of reablement. The SCIE Guide suggests that families can play a role in stimulating, motivating and encouraging service users both during and after reablement in order to encourage them to maintain their confidence and independence. "Care circle" is a term used in the SCIE Guide and is taken to mean the service user's formal and informal network of care.

Initial questions that this candidate programme theory raised were:

- Are there particularly effective ways of achieving this sort of partnership working?

- Does engaging families in this way during reablement have an effect on the ways that families engage after reablement?

- What are the contextual factors that might affect families' willingness to be engaged in this way?

CPT7	**Family buy-in**
Sources	SCIE Guide 4
If-then	IF families and partners are completely "signed up" to the concept of reablement, THEN they can help to motivate the service user throughout and beyond reablement.

This programme theory is closely linked to Candidate Programme Theories 1 (Instilling an understanding of reablement) and 6 (Family respected as part of the whole care circle) but focuses on the degree of buy-in that the family has. At this stage in the synthesis it was decided by the researcher and the supervisory team to keep this as a distinct theory, although it was recognised that it might eventually become an aspect of either context or mechanism as the theories were refined through the synthesis process.

Initial questions that this candidate programme theory raised were:

- What constitutes being "signed up" to different people?
- What happens if there is discord between the wishes of the family and the service user over their degree of involvement?
- Does this need to happen from the start or can it change over time?

CPT8	**Customising service delivery to the family's position**
Sources	SCIE Guide 6, 7
If-then	IF reablement teams have an ongoing understanding of what support family carers are willing and able to offer, their attitudes towards their caring role and their own needs for support, THEN they will be able to devise a reablement plan that works for everyone.

This programme theory is also closely related to Candidate Programme Theory 6 (Family respected as part of the whole care circle) but its emphasis is on the family's own circumstances and volition. It is noted that the Care Act stipulates that a carers assessment should be offered if a substantial amount of care is being provided or is to be provided by the family or partner

(Department of Health, 2014a). The outcome part of the theory was expressed by the stakeholders at the independent homecare provider.

Initial questions that this candidate programme theory raised were:

- What practical implications are implied by this theory within the time constraints of a Local Authority reablement service?

- How well are reablement workers equipped to judge the family's willingness and ability to offer support?

- How accurately are family members able to judge their current and future willingness and ability to offer support?

Appendix L

Search terms used for realist synthesis literature search

Sample:	**Phenomenon of interest:**	**Evaluation:**
Older people AND family carers	Involvement in home-based reablement	Independence
Group 1 Old* Elder* Aged Ageing Aging Senior* "Care recipient*" "Service user*"	***Group 3*** Reablement Re-ablement Enablement Reenablement Re-enablement Restorative Care Restorative Services Rehabilitation	Independen*
Group 2 Carer* Caregiver* "Care giver*" "Family carer*" "Unpaid carer*" "Informal carer*"	***Group 4*** Involve* (d, ment) Network of care Circle of care Community of care Integrated care Participation Shared care Collaborat* (e, ive, ing)	
	Group 5 Home "Home based" Home-based "Home care" Home-care Homecare Community "Ageing in place" "Aging in place"	

Groups 1, 2, 3 and 5 were used for the search. The terms in group 4 were excluded at this stage in order to return a maximum number of hits. It was decided that these could be reintroduced and added to at a later stage depending on which programme theories were to be examined in more detail.

Appendix M

Literature Search Longlist

Lead author	Title	Date	Source document
Allen, K	The (Multi-) Billion Dollar Question: Embedding Prevention and Rehabilitation in English Health and Social Care	2010	Journal of Integrated Care
Almborg, A H	Discharge planning of stroke patients: The relatives' perceptions of participation	2009	Journal of Clinical Nursing
Aspinal, F	New horizons: Reablement - supporting older people towards independence	2016	Age and Ageing
Baker, D	The Design and Implementation of a Restorative Care Model for Home Care	2001	The Gerontologist
Barret, P	Social inclusion through ageing-in-placce with care?	2012	Ageing & Society
Bennett, B	Applying the recovery model to physical rehabilitation	2014	Nursing Standard
Beswisk, A	Maintaining independence in older people	2010	Reviews in Clinical Gerontology
Billings, J	The INTERLINKS framework for long-term care of older people in Europe	2013	Journal of Integrated Care
Bolton, J	Let's get this agenda up and running	2009	Community Care
Bond	Multi-faceted informatics system for digitising and streamlining the reablement care model	2015	Journal of Biomedical Informatics
British Red Cross	Service Redesign: case studies, You're not on your own	2013	Health Service Journal Supplement
Bunn, F	Supporting shared decision-making for older people with multiple health and social care needs: a protocol for a realist synthesis to inform integrated care models	2017	BMJ Open
Callaghan, L	Feeling in control : comparing older people's experiences in different care settings	2013	Ageing & Society

Cameron, A	Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature	2014	Health & social care in the community
Carpentier, N	Successful linkage between formal and informal care systems: The mobilization of outside help by caregivers of persons with Alzheimer's disease	2012	Qualitative Health Research
Chouliara, N	Implementing evidence-based stroke Early Supported Discharge services: A qualitative study of challenges, facilitators and impact	2014	Clinical Rehabilitation
Clark, M	Implementing evidence-based stroke Early Supported Discharge services: A qualitative study of challenges, facilitators and impact	2013	Journal of Integrated Care
Dalemans, R	Measures for rating social participation in people with aphasia: A systematic review	2008	Clinical Rehabilitation
Dalemans, R	Facilitating the participation of people with aphasia in research: A description of strategies	2009	Clinical Rehabilitation
Davies, B	Strategies for achieving best value in commissioned home care	2007	International Journal of Public Sector Management
Dogan, H	Nursing care of elderly people at home and ethical implications: An experience from Istanbul	2004	Nursing Ethics
Doughty, K	New models of assessment and prescription of smart assisted living technologies for personalised support of older and disabled people	2016	Journal of Assistive Technologies
Doughty, K	Digital reablement: a personalised service to reduce admissions and readmissions to hospitals and nursing homes	2013	Journal of Assistive Technologies
Doughty, K	Self-care, plesio-care, telecare and m-care: a new assisted living model	2012	Journal of Assistive Technologies
Durme, T Van	Why Is Case Management Effective? A Realist Evaluation of Case Management for Frail, Community-Dwelling Older People: Lessons Learned from Belgium	2016	Open Journal of Nursing
Ellis-Hill, C	Going home to get on with life: Patients and carers experiences of being discharged from hospital following a stroke	2009	Disability and Rehabilitation

Eyre, V	Rehabilitation Enablement in Chronic Heart Failure-a facilitated self-care rehabilitation intervention in patients with heart failure with preserved ejection fraction (REACH-HFpEF) and their caregivers: rationale and protocol for a single-centre pilot randomised controlled trial	2016	BMJ Open
Fersch, B	Expectations towards home care re-ablement in Danish municipalities	2015	International Journal of Public Sector Management
Francis, J	Reablement: a cost-effective route to better outcomes	2011	SCIE Research Briefing
Ganz, D	Key elements of high-quality primary care for vulnerable elders	2008	Journal of General Internal Medicine
Ghatroae, H	Reablement in Glasgow: Quantitative and qualitative research	2013	Glasgow Council
Giraud, O	Innovations in local domiciliary long-term care: From libertarian criticism to normalisation	2014	Social Policy and Society
Gitlin, L	Conducting Research on Home Environments: Lessons Learned and New Directions	2003	Gerontologist
Gitlin, L	A randomized trial of a multicomponent home intervention to reduce functional difficulties in older adults	2006	Journal of the American Geriatrics Society
Gladden, R	Come together, right now	2013	British Nursing Database
Glendinning, C	Home Care Reablement Services: Investigating the longer-term impacts	2010	Working paper for Dept of Health
Glendinning, C	The effectiveness of home care reablement -- Developing the Evidence Base	2008	Journal of Integrated Care
Goeman, D	Evaluating the Efficacy of the "Support for Life" Program for People with Dementia and Their Families and Carers' to Enable Them to Live Well: A Protocol for a Cluster Stepped Wedge Randomized Controlled Trial	2016	Frontiers in Public Health
Goodman, C	Models of inter professional working for older people living at home: A survey and review of the local strategies of English health and social care statutory organisations	2011	BMC Health Services Research
Goodman, H	Discharging patients from acute care hospitals	2016	Nursing Standard

Harwood, R	Determinants of social engagement in older men	2000	Psychology, Health and Medicine
Hjelle, K	The relatives' voice: How do relatives experience participation in reablement? A qualitative study	2016	Journal of Multidisciplinary Healthcare
Hjelle, K	Driving forces for home-based reablement; a qualitative study of older adults' experiences	2017	Health and Social Care in the Community
Hjelle, K	The reablement team's voice: a qualitative study of how an integrated multidisciplinary team experiences participation in reablement	2016	Journal of Multidisciplinary Healthcare
Hopper. L	Ageing in place: A multi-sensor system for home-based enablement of people with dementia	2015	Alzheimer's and Dementia
Hunt, L	Why Intermediate Care Services Need to be Refreshed	2014	Nursing Times
Jackson, D	EPILOGUE Family and community health nursing: Challenges and moving forward	2012	Contemporary Nurse
Jakobsen, F	Health professionals' perspectives of next of kin in the context of reablement	2018	Disability and Rehabilitation
Janse, B	Formal and informal care for community-dwelling frail elderly people over time: A comparison of integrated and usual care in the Netherlands	2017	Health and Social Care in the Community
Jones, K	Investigating the Longer Term Impact of Home Care Re-ablement Services. The Short-term Outcomes and Costs of Home Care Re-ablement Services: Interim Report	2009	DOH
Jorgensen, D	Why do older people in New Zealand enter residential care rather than choosing to remain at home, and who makes that decision?	2009	Ageing International
Kaehne, A	Bringing Integration Home	2017	Journal of Integrated Care
Kautz, D	Inspiring Hope in Our Rehabilitation Patients, Their Families, and Ourselves	2008	Rehabilitation Nursing British Nursing Database
Kjerstad, E	Reablement in community-dwelling older adults: a cost-effectiveness analysis alongside a randomized controlled trial.	2016	Health Economics review

Kodate, N	Bringing the Family in through the Back Door: the Stealthy Expansion of Family Care in Asian and European Long-Term Care Policy	2017	Journal of Cross-cultural Gerontology
Lanoix, M	The ethics of imperfect cures: models of service delivery and patient vulnerability	2013	J Med Ethics
Larkin, M	Carers, Choice and Personalisation: What Do We Know?	2016	Social Policy and Society
Le Mesurier, N	The Effectiveness of Re-Ablement Provision in South Worcestershire. Enhancing Independence: The Effectiveness of Re-Ablement Provision in South Worcestershire	1999	Journal of Integrated Care
Lees, Liz	Expand HCA role to focus on older people's rehabilitation	2012	Nursing Times
Legg, L	A systematic review of the evidence on home care reablement services	2016	Clinical Rehabilitation
Levack, W	Is goal planning in rehabilitation effective? A systematic review	2006	Clinical Rehabilitation
Lewin, G	A comparison of the home-care and healthcare service use and costs of older Australians randomised to receive a restorative or a conventional home-care service	2014	Health & social care in the community
Lewin, G	A non-randomised controlled trial of the Home Independence Program (HIP): An Australian restorative programme for older home-care clients	2010	Health & social care in the community
Lewin, G	Evidence for the long term cost effectiveness of home care reablement programs	2013	Clinical Interventions in Aging
Lewin, G	A randomised controlled trial of the Home Independence Program, an Australian restorative home-care programme for older adults	2013	Health & social care in the community
Linder, S	Improving Quality of Life and Depression After Stroke Through Telerehabilitation	2015	American Journal of Occupational Therapy
Lohmann, S	The ICF forms a useful framework for clasifying individual patient goals in post-acute rehabilitation	2011	Journal of Rehabilitation Medicine
Lopez-Hartmann, M	The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review	2012	International Journal of Integrated Care

Lorthioir, N	Including relatives in the “Stay Active at Home” program	2018	Clinical Rehabilitation
Lynch, K	Affective equality: Who cares?	2009	Development
MacKenzie, R	Robots, social networking sites and multi-user games: using new and existing assistive technologies to promote human flourishing	2011	Tizard Learning Disability Review
Madison, J	The outcomes oriented approach and older people: Knowledge Zone	2007	Community Care
Mann, R	Models of reablement evaluation (MoRE): A study protocol of a quasi-experimental mixed methods evaluation of reablement services in England Organization, structure and delivery of healthcare	2016	BMC Health Services Research
Manthorpe, J	Long-term impact of home care reablement	2011	Community Care
Manthorpe, J	The Mental Health of Older People: Taking a Long View	2008	Journal of Integrated Care
Manthorpe, J	Volunteers in Intermediate Care: Flexible Friends?	2003	Journal of Integrated Care
McGoldrick, C	Befriending and Re-ablement Service: a better alternative in an age of austerity	2017	International Journal of Sociology and Social Policy
McHugh, J E	A proposed system for the home-based ambient monitoring and enablement of older adults with dementia	2013	Conference poster
McLeod, B	Evaluation of City of Edinburgh Council home care re-ablement service	2009	Scottish Government Social Research Report
Means, R	Communities of place and communities of interest? An exploration of their changing role in later life	2012	Ageing and Society
Meiland, F	Symposia - Technological support in dementia and late life depression	2015	International Psychogeriatrics
Mello, J	The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective	2017	Aging and Mental Health
Metzelthin, S	‘Doing with …’ rather than *‘doing for …’* older adults: rationale and content of the *‘Stay Active at Home’* programme	2017	Clinical Rehabilitation
Mills, K	Enabling occupation at the end of life: A literature review	2015	Palliative & supportive care
Moe, A	Patient influence in home-based reablement for older persons: Qualitative research	2017	BMC Health Services Research

Moe, C	Optimising Capacity - A Service User and Caregiver Perspective on Reablement	2016	Grounded Theory Review
Moe, C	Tailoring reablement: A grounded theory study of establishing reablement in a community setting in Norway	2018	Health and Social Care in the Community
Moore, A	Different Mindset?	2013	HSJ Commissioning Supplement
Newbronner, L	Research into the Longer Term Effects/Impacts of Re-ablement Services	2007	Report for CSED
Newton, C	Personalising reablement: inserting the missing link	2012	Working with Older People
NHS Sandwell and West Birmingham	Remote Controls	2012	Health Service Journal supplement
Palumbo, R	Exploring the meaningfulness of healthcare organizations: a multiple case study	2017	International Journal of Public Sector Management
Parker, G	Intermediate Care, Reablement or Something Else? A Research Note about the Challenges of Defining Services	2014	
Parsons, J	A randomized controlled trial to determine the effect of a model of restorative home care on physical function and social support among older people	2013	Archives of Physical Medicine and Rehabilitation
Parsons, J	Goal setting as a feature of homecare services for older people: Does it make a difference?	2012	Age and Ageing
Parsons, M	Randomised trial of restorative home care for frail older people in New Zealand	2017	Nursing Older People
Patterson, K	Why understanding what matters to the patient matters	2017	Journal of Integrated Care
Peace, S	'Option recognition' in later life: Variations in ageing in place	2011	Ageing and Society
Pearson, M	Providing effective and preferred care closer to home: A realist review of intermediate care	2015	Health and Social Care in the Community
Pearson, M	Intermediate care : a realist review and conceptual framework	2013	National Institute for Health Research Service Delivery and Organisation Programme
Penfold, J	Rapid response team enables patients to remain at home	2014	Primary Health Care

Piškur, B	Participation and social participation: Are they distinct concepts?	2014	Clinical Rehabilitation
Pitts, J	A New Reablement Journey	2011	Ambrey Associates and Helen Sanderson Associates
Poulos, C	A comprehensive approach to reablement in dementia	2017	Alzheimer's and Dementia: Translational Research and Clinical Interventions
Powell Lawton, M	Two transitions in daughters' caregiving careers	2000	Gerontologist
Powell Lawton, M	Motivation in later life: Personal projects and well-being	2002	Psychology and Aging
Rabiee, P	Investigating the Longer Term Impact of Home Care Re-ablement Services. The Organisation and Content of Home Care Re-ablement Services. Interim Report	2009	DOH
Rabiee, P	Exploring the relationships between choice and independence: Experiences of disabled and older people	2013	British Journal of Social Work
Resnick, B	Making a difference: nursing assistants' perspectives of restorative care nursing	2006	Rehabilitation Nursing
Robben, S	Implementation of an innovative web-based conference table for community-dwelling frail older people, their informal caregivers and professionals: A process evaluation	2012	BMC Health Services Research
Roberts, A	Striking a balance between in-person care and the use of eHealth to support the older rural population with chronic pain	2015	International Journal of Qualitative Studies on Health and Well-being
Robinson, L	Assistive technologies in caring for the oldest old: a review of current practice and future directions	2013	Aging Health
Ryburn, B	Enabling independence: Restorative approaches to home care provision for frail older adults	2009	Health and Social Care in the Community
Saez-Pons, J	What has happened today? Memory visualisation of a robot companion to assist user’s memory	2015	Journal of Assistive Technologies
Samuel, M	Re-ablement' shown to reduce demand for care	2007	Community Care
Sanders, T	Homecare Reablement: DOH discussion document	2007	

Santoni de Sio, F	When Should We Use Care Robots? The Nature-of-Activities Approach	2016	Science and Engineering Ethics
Saunders, J	'Teach Me-Show Me'-End-User Personalization of a Smart Home and Companion Robot	2016	IEEE Transactions on Human-Machine Systems
Savitch, N	AT Guide: developing a new way to help people with dementia and their carers find information about assistive technology	2012	Journal of Assistive Technologies
SCIE	The role of carers and families in reablement	2014	SCIE video
SCIE	Maximising the Potential of Reablement	2013	SCIE Guide 49
Smith, R	Wales Strikes Out alone with radical social services plan	2011	Community Care
Steel, E	Currency and Competence of Occupational Therapists and consumers with Rapidly Changing Technology	2017	Occupational Therapy International
Stubbs, J	Sustained health home visiting can improve families' social support and community connectedness	2016	Contemporary Nurse
Suanet, B	Informal and formal home-care use among older adults in Europe: can cross-national differences be explained by societal context and composition?	2012	Ageing and Society
Sugarhood, P	Participation in advanced age: Enacting vlues, an adaptive process	2017	Ageing and Society
Sykes, W	Older people's experiences of home care in England	2011	Equality & Human Rights Commission, Research Report 79
Taylor, J	An integrated practice approach to mobility care	2016	Nursing Standard
Taylor, R	Clinical effectiveness and cost-effectiveness of the Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) facilitated self-care rehabilitation intervention in heart failure patients and caregivers: rationale and protocol for a multicentre randomised controlled trial PROTOCOL	2015	BMJ Open
Tessier, A	Effectiveness of reablement: A systematic review	2016	Healthcare Policy
Tickle, L	Together they cracked it	2009	Community Care
Trappes-Lomax, T	Self-care for people coping with long-term health conditions in the community	2016	Journal of Integrated Care

Trappes-Lomax, T	The User Voice: Older People's Experiences of Reablement and Rehabilitation	2012	Journal of Integrated Care
Tuntland, H	Psychometric properties of the Canadian occupational performance measure in home-dwelling older adults	2016	Journal of Multidisciplinary Healthcare
Tuntland, H	Reablement in community-Dwelling Older Adults: A Randomised Controlled Trial	2015	BMC Geriatrics
Udo, R	Acceptance of Assisted Living Technologies in Europe : Analysis of the major differences in the adoption rates of Assisted Living Technologies across Europe	2014	Book of same title
Whitehead, P	Occupational Therapy in HomEcare Re-ablement Services (OTHERS): Study protocol for a randomized controlled trial	2014	Trials Journal
Wilcox, E	The Silver Line Helpline: a "ChildLine" for older people	2014	Working with Older People
Wilde, A	If they're helping me then how can I be independent? The perceptions and experience of users of home-care re-ablement services	2012	Health and Social Care in the Community
Winkel, A	Reablement in a community setting	2014	Disability and Rehabilitation

Unable to access full documents at the time:

Kent, J	Leicestershire County Council: External Evaluation of the Home Care Reablement Pilot Project	2000	Leicester: Centre for Group Care and Community Care Studies, De Montfort University
Littlechild, R	Littlechild R., Matka E., Bowl R., Guru S. & Le Mesurier N. (2006) Evaluation of the Independence at Home Service for Birmingham Social Care and Health Directorate.	2006	Institute of Applied Social Studies, The University of Birmingham
Pilkington, G	Homecare re-ablement: Why and how providers and commissioners can implement a service	2008	Journal of Care Services Management, vol 2, no 4, pp 354–367

Appendix N

Appraisal assessment form for literature search longlist

High

High relevance to the realist synthesis. This means that:

- the framing of the research and the research questions match the research questions closely
- the empirical findings are clearly described and there is a rich description of the process and context that can greatly advance the theoretical output of the synthesis.
- The paper is a "key informant"

Medium

This category is for studies in which the framing of the primary research is of medium relevance to the synthesis theories. This means that:

- the article reports on a different (but related) intervention to reablement working towards similar outcomes of interest, or
- describes middle range theories that may inform the synthesis (even if there is not relevant empirical data from the paper to populate the CMOs, or
- Has a few areas that are of interest even if it is not entirely clear whether they will be used in the synthesis

Low

This category is for research that has met the selection criteria in terms of relevance to the synthesis questions and the initial programme theories or middle range theories but is relatively thin on the description of context and mechanism.

It is not in the exclusion category because it contains at least one idea or statement about the context, about the mechanism or about conceptualising outcomes that can be used for refining the theory and building a CMO configuration. It might also have useful ideas about the process of conducting a realist synthesis in the field.

Exclude

This category is for a research paper that showed promise on reading the citation, but on reading the full-text paper does not correspond to the research questions, does not have any content that corresponds to the initial programme theories or middle range theory, or does not describe at all the context, mechanisms, or process.

Appendix O

Data extraction: Core descriptors for study 003

Source	
Authors (year) code	Hjelle, KM et al (2016) 003
Title	The relatives' voice: how do relatives experience participation in reablement? A qualitative study
Conceptually-rich / thick / thin	Conceptually rich
Strengths and weaknesses	Sample size is small but dealt with in such a way as to draw out common themes credibly and checked among the research team. Little contextual information on the content of the reablement intervention given here but this is part of a much bigger study. Intention is to focus on family carers and had permission from service users ("family members") to get in touch, would have been interesting to have some context on those service users too – perhaps just basic info like gender, age, health condition
Source type	Qualitative research (phenomenological study)
Aim	To explore and describe how relatives in Norway perceive their experiences with participation in their family member's reablement processes
Topic	
Category	Reablement for older adults – not condition-specific
Location(s)	Norway
Description of reablement type	Home-based. 3 months of reablement

Research methods	
Theoretical approach	Phenomenological (Sandelowski, 2012 and 2000)
Data collection method	Semi-structured face-to-face interviews 1 month after reablement completed to explore experiences in detail. Descriptive questions used
Participants	Family relatives
Sample	Although sample small, representative of M and F, different relationships (child, aunt, spouse) aged 40-70, living with and at varying distances from service user Might have been useful to know approx amount of time participants spent on caring
Analysis	Phenomenological decontextualisation and recontextualisation – qualitative systematic text condensation.
Time of follow-up	Approx 1 month after reablement completed
Findings	
Summary of findings	5 themes emerged: 1) A wish to give and receive information, wish to be involved 2) A wish to be a resource in reablement process 3) Conflicting expectations 4) Having more free time to themselves 5) A lack of follow-up programmes Concludes that there is practical significance for health care services of collaborating with relatives and that municipal health and social care services should consider establishing a system or a routine to foster this collaboration in reablement. Follow-up programmes should be included. Put into the context of existing research as well as directives from WHO and UNECE.

Appendix P

Criteria used for assessing the conceptual richness of sources (Pearson et al., 2013 p29)

Based on criteria proposed by Ritzer (Ritzer, 1991) and Roen et al (Roen et al., 2006)

Conceptually rich	**Thicker description but not conceptually rich**	**Thinner description**
Theoretical concepts are unambiguous and described in sufficient depth to be useful	Description of the programme theory or sufficient information to enable it to be "surfaced"	Insufficient information to enable the programme theory to be "surfaced"
Relationships between and among concepts are clearly articulated	Consideration of the context in which the programme took place	Limited or no consideration of the context in which the programme took place
Concepts sufficiently developed and defined to enable understanding *without* the reader needing to have first-hand experience of an area of practice	Discussion of the differences between programme theory (the design and orientation of a programme – what was intended) and implementation (what "happened in real life")	Limited or no discussion of the differences between programme theory (the design and orientation of a programme – what was intended) and implementation (what "happened in real life")
Concepts grounded strongly in a cited body of literature	Recognition and discussion of the strengths and weaknesses of the programme as implemented	Limited or no discussion of the strengths and weaknesses of the programme as implemented
Concepts are parsimonious (i.e. provide the simplest, but not over-simplified, explanation)	Some attempt to explain anomalous results and findings with reference to context and data	No attempt to explain anomalous results and findings with reference to context and data
-	Description of the factors affecting implementation	Limited or no description of the factors affecting implementation
-	Typified by: Terms – "model", "process" or "function" Verbs – "investigate", "describes", or "explains" Topics – "experiences"	Typified by: Mentioning only an "association" between variables

Appendix Q

Characteristics of core sources and which theories they informed

For the 14 sources identified as having high relevance to the synthesis, a core set of descriptors was collected. These captured information about the source's aims, its strengths and weaknesses for the purposes of the synthesis, the country or countries to which it applies and the type of reablement and service user group it examined. For research studies, information was captured about the research methodology and research methods (theoretical approach, data collection method, participants, sampling and data analysis) along with a summary of the findings. The candidate programme theories (CPT) that the source informed are identified in the last column. Characteristics of the core seven studies are shown here.

First author	Year	Title	Country	Source type	Data collection approach	Reablement category	Participants	CPT
Glendinning	2010	Home Care Re-ablement Services: Investigating the longer-term impacts (prospective longitudinal study)	England	Comparative cost-benefit study (sometimes referred to as an evaluation) of homecare reablement v conventional homecare	Interviews with service users at start, on completion and 9-12 months later using EQ-5D and ASCOT. Interviews with senior and operational managers. Focus groups with front-line staff and observations of reablement visits. In-depth, semi-structured interviews conducted with additional reablement users and carers	Home-based reablement v conventional homecare	Service users, managers, staff, 10 informal carers interviewed	1 2 3 4 5 6 7 8
Hjelle	2016	The relatives' voice: how do relatives experience participation in reablement?	Norway	Qualitative research (phenomenological study)	Semi-structured face-to-face interviews 1 month after reablement completed	Home-based, 3 months	Family relatives	1 2 4 5 6 7 8
Jakobsen	2018	Health professionals' perspectives of next of kin in the context of reablement	Norway	Constructivist Grounded Theory	10 focus groups using semi-structured guides	4-6 weeks. Older adults received reablement up to five times a week	Health professionals	1 2 3 4 5 6 7 8

Pearson	2015	Providing effective and preferred care closer to home: A realist review of intermediate care	UK	Realist review	38 studies included	Intermediate care	N/A	1 2 3 5 6 7 8
Wilde	2012	'If they're helping me then how can I be independent?' The perceptions and experience of users of home-care re-ablement services	England	Part of Glendinning study above	Semi-structured interviews	All models of reablement	34 service users and 10 carers from 5 reablement services	1 2 6 8
SCIE	2013	Maximising the Potential of Reablement	UK and "overseas"	Guide	Based on research and practice evidence about the effectiveness and cost-effectiveness of reablement	Homebased	10 studies, visits to 4 teams (dementia specific), project advisory group	2 5 6 8
SCIE	2014	Role of Carers and Family – online video	UK	14 minute video on reablement with a case study and messages for practice	N/A	Mostly homebased but also features reablement in a reablement unit	Comments from service users and reablement staff from Central Bedfordshire Reablement Team, from E Holzhausen (Director of Policy and Public Affairs, Carers UK) and C Glendinning (York University)	1 2 4 5 6 7 8

Appendix R

Shortlisted sources subsequently deselected for full data analysis

Authors	Title	Date	Reason for deselection
Aspinal, F, Glasby J, Rostgaard, T, Westendorp R	New Horizons: Reablement – supporting older people towards independence	2016	Think-piece, precursor to MoRE project. Overview of where research is at.
Bunn, F, Goodman, C, Manthorpe, J, Durand, M, Hodkinson, I, Rait, G, Millac, P, Davies, SL, Russell, B, Wilson, P	Supporting shared decision-making for older people with multiple health and social care needs: a protocol for a realist synthesis to inform integrated care models	2017	Protocol stage – research itself looks as though it will be relevant when published.
Hjelle, KM, Tuntland, H, Førland, O, Alvsvåg, H	Driving forces for home-based reablement; a qualitative study of older adults' experiences	2017	Insufficient focus on family
Mann, R, Beresford, B, Parker, G, Rabiee, P, Weatherly, H, Faria, R, Kanaan, M, Laver-Fawcett, A, Pilkington, G, Aspinal, F	Models of reablement evaluation (MoRE): a study protocol of a quasi-experimental mixed methods evaluation of reablement services in England	2016	Protocol only
Moe, C, Brinchmann, BS	Optimising Capacity – A Service User and Caregiver Perspective on Reablement	2016	Insufficient focus on family
Pearson, M, Hunt, H, Cooper, C, Shepperd, S, Pawson, R, Anderson, R	Intermediate care: a realist review and conceptual framework	2013	Background paper for the review which has been selected for data analysis
Rabiee, P, Glendinning, C, Arksey, H, Baxter, K, Jones, KC, Forder, J, Curtis, LA	Investigating the Longer Term Impact of Home Care Re-ablement Services	2009	Insufficient focus on family

Appendix S

Summary of total number of if-then statements matched to Candidate Programme Theories (CPTs) – Table S1 and

251 if-then statements matched to 8 candidate theories (derived from 7 core sources) – Table S2

Table S1: Total number of if-then statements matched to CPTs

#	Candidate Programme Theory	Total number of if-then statements matched to it
1	Instilling an understanding of reablement	50
2	Goal setting and monitoring	43
3	Risk management	6
4	Ongoing communication	17
5	Plan for the end of the service	22
6	Family respected as part of the whole care circle	137
7	Family buy-in	24
8	Customising service delivery to family's position	63

Table S2: 251 if-then statements matched to 8 candidate theories

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
1	there is a need for and an expectation of family carers being included in the process	collaborative practices will become embedded, thereby strengthening health care systems and improving health outcomes	003						1			
2	the knowledge and resources of the family carer are regarded as integral components of the rehabilitation process	the knowledge and resources of the family carer are regarded as integral components of the rehabilitation process	003						1			
3	collaborative practice becomes routine	all parties can play a role in changing and advancing collaborative practices in the future	003						1			
4	professionals regard caregivers as coworkers but informal caregivers do not feel like coworkers because they are hardly involved in the decision-making about care	interaction is not truly achieved	003						1			
5	families do not receive information and opportunities to acquire the needed skills	they will not be prepared for their role as caregiver	003						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
6	families are not as fully involved in the rehabilitative process as they could be	they will often be marginalised	003						1			
7	family carers perceive a lack of involvement in care planning	they will not feel engaged	003						1			
8	family carers perceive a lack of recognition and appreciation of the role from health professionals	they will not feel engaged	003						1		1	
9	clinicians are aware of the carer's change in roles and relationship and in their sense of identity	they will be better equipped to support carer's emotional and practical needs	003								1	
10	family carers are trained in such skills as personal care, feeding, swallowing problems, transfers, and mobility activities	this will empower them to a greater degree than offering advice and support, or enhancing their psychological competence	003						1			
11	family carers are involved and supported in reablement	it can enhance their relatives' well-being and can benefit the carer by being able to perform and participate in valued activities	003						1			
12	family carers receive assurance that their older parents would receive care and assistance	this is more important for some than training their parents to live independently	003							1		

Proposition #	**If…**	**Then…**	**Doc ref # * Key below**	**CPT 1**	**CPT 2**	**CPT 3**	**CPT 4**	**CPT 5**	**CPT 6**	**CPT 7**	**CPT 8**	**Other ideas**
13	family carers are invited to provide information about their family member	this will strengthen their involvement in the reablement process	003						1			
14	family carers receive information	this will strengthen their involvement in the reablement process	003	1								
15	goals are set jointly with family carers	this will provide an opportunity for more perspectives and solutions to be considered	003		1							
16	family carers are informed about how to support and motivate their relative to engage in physical exercise and perform everyday activities	they will feel more involved in the reablement process	003		1				1			
17	family carers are given information about the reablement service	they can advise their relative on how to use it	003	1								
18	there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties of the reablement process	family carers would have an opportunity to provide input on the **content** of the reablement process	003				1		1			
19	there is dialogue between the reablement team and family carers	family carers would feel confident that the service user had told them everything of relevance	003				1					

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
20	there is a system that automatically invites families to meetings	they would be able to share and discuss information and knowledge about their relative	003				1		1			
21	family members are given the option to communicate with the reablement team by phone	that would enable family members who live at some distance away to be involved	003				1					
22	there is a process to invite family members to the first reablement meeting	the family member could offer information and views on the situation	003	1								
23	reablement teams routinely contact family carers	reablement teams will know how the family sees their relative's situation	003				1		1			
24	there is a routine process for inviting family carers to be involved in reablement	this will benefit all concerned	003	1					1			
25	family carers are regarded as a resource by the reablement team	family carers will be able to reinforce the reablement team's work by supporting and motivating the service user	003						1			
26	family carers are well-informed about the reablement plan	family carers will be able to support and encourage their relative	003		1							
27	family carers have a role in reablement team that they regard as important	collaboration will be strengthened	003						1	1		
28	family carers are encouraged to share their opinions and knowledge	they will feel part of the reablement team	003						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
29	reablement teams value and respect family carers	family carers will provide a valuable resource for the team	003						1		1	
30	reablement teams initiate the process with a telephone call to family carers	collaboration will be strengthened	003	1								
31	there are conflicting expectations between the three parties	involvement in reablement will be weakened	003	1								
32	there are conflicting expectations between the three parties	the service user may experience disempowerment and a loss of autonomy	003	1								
33	expectations are clarified by all parties	family carers will be able to make conscious choices about how to be involved in the process	003	1								
34	family carers can share feelings of being burdened	family carers could experience reablement as a relief	003								1	
35	family carers feel obliged to be at all meetings	family carers might experience collaboration as a burden	003								1	
36	family carers are given the option to attend meetings	family carers will not feel burdened by their involvement	003								1	
37	family carers want to be invited to collaborate in a way they consider to be important	reablement team may need to be prepared to navigate conflicting expectations	003						1		1	
38	family carers gain free time as a result of reablement team visits	they can experience feelings of relief	003								1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
39	family carers experience reablement team visits as a sharing of responsibility	they can feel relieved, re-energised and that there is a safety-net in place	003						1		1	
40	there is no follow-up programme for service users after their reablement	family members can feel concerned about their relative's health after reablement	003					1				
41	there is no routine or a system of follow-ups after reablement	family members can feel concerned that their relative will not maintain their achieved functions over time	003					1				
42	transition from reablement is experienced as abrupt	family members can feel concerned that their relative will not maintain their achieved functions over time	003					1				
43	transition from reablement is experienced as abrupt	service users and family members can feel this as a sudden loss	003					1				
44	an individualised follow-up programme is in place to check how the service user is progressing	service users will feel motivated to continue to practise their everyday activity skills	003					1				
45	family carer' role is handled well	they will experience sufficient opportunities to obtain information	003						1			
46	family carers know how to manage daily routines	family carers will feel more confident about their caring role	003						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
47	advice given by reablement teams relates to the needs of family carers as well as service users	family carers will feel more confident about their caring role	003								1	
48	family carers are involved in goal-setting	the service user's/older adult's reablement process will be enhanced	003		1							
49	family carers disagree with the goals set	the service user can feel disempowered	003		1							
50	family carers are invited to share their perspectives on their relative's goals	different perspectives can be addressed through dialogue	003		1							
51	there are differences of opinion between any of the parties	a process and structure for decision-making is required that will allow for all voices to be heard	003						1			
52	family carers are given education and skills training in how to support their relative	this will support them in their role as part of the reablement team	003						1			
53	**a system, a routine, a culture and an attitude for sharing information and knowledge with family carers is in place**	collaborative practices could be enhanced	003						1			
54	a framework for cooperation and decision-making between family carers, older adults and health car professionals	the effects of reablement will be strengthened	003						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
55	collaboration is characterised by mutual respect and confidence and trust in one's own and others' knowledge	a fruitful partnership for collaboration can be created	003						1			
56	others' knowledge is appreciated	this will form an essential resource for the reablement process	003						1			
57	family carers contribute to the negotiation of the plan for reablement	family carers will be empowered to take an active role in the process	003	1								
58	family carers contribute actively to reablement	will continue to be extrinsic motivators in maintaining functions after the end of the intervention	003						1			
59	family carers help service users too much	this will undermine the process	005	1						1		
60	family carers make unreasonable demands	this will undermine the process	005	1						1		
61	family carers do not support or have faith in the plan	this will undermine the process	005							1		
62	the reablement team regard family carers as a resource	this will facilitate their involvement	005						1			
63	the reablement team is able to negotiate and manage different expectations and opinions	this will enhance collaboration	005	1	1		1		1			
64	the reablement team understands the perspective/situation of family carers	this will enhance collaboration	005								1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
65	the reablement team understands when it is appropriate to collaborate with family carers	this will smooth collaboration	005				1		1		1	
66	the reablement team regard collaboration with family cares as beneficial to the service user	family carers will feel as though they are truly part of a team	005						1			
67	the reablement team assess the need for assistance differently from the family carers	the reablement team has to spend extra time persuading and negotiating with family carers whether reablement is the right type of assistance for the service user	005	1						1	1	
68	there is disagreement on how reablement is to be delivered between the service user and their family carer	the reablement team needs to know how to manage this (while respecting the autonomy of the service user)	005	1					1	1		
69	family carers are not familiar with the parameters of reablement	they will have unrealistic expectations	005	1								
70	reablement workers feel pressurised by family carers to provide particular support	this can compromise their professional judgement	005							1		
71	the reablement team understand the needs of and pressures on family carers	they could provide specific support for family carers regarding how they could better manage their situation	005								1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
72	the reablement team consider that family carers limit the service user's opportunities to be active	this could undermine the effectiveness of reablement	005			1				1	1	
73	the reablement teams considers that family carers are providing too much practical and physical assistance	this could result in an "assistance trap", conflicting with the aims of reablement	005							1		
74	family carers are concerned that effective reablement will lead to the removal of other services	they could be motivated not to support reablement	005	1						1	1	
75	reablement worker views the service user as entirely autonomous	the reablement worker might consider that it is not always necessary to include family carers	005	1							1	
76	the reablement worker perceives that including the family carer is useful	when they happen to be present	005						1			
77	reablement workers feel ambiguous about when and why to involve family carers	this lack of clarity could be transferred to the family carers and service user	005						1			
78	there is no systematic approach for when and how family carers should be contacted or involved in reablement		005	1			1		1			System or routine for involvement

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
79	the reablement team perceives that there is not always a need to involve family carers in reablement	this could be the result of a conscious choice by the reablement team	005						1			
80	the reablement team perceives that it is the responsibility of the service user to contact family carers	they will not take responsibility for involving the family carer	005						1		1	
81	the reablement team experience a family as dysfunctional	they will not want to interfere between a service user and their relationship to their family carer	005						1		1	
82	family carers provide information and knowledge that the service user cannot communicate clearly		005						1			
83	family carers can provide a more nuanced picture of the actual everyday life of the older person		005						1			
84	the reablement team considers family carers as useful collaboration partners in motivating the older adults to take part in their reablement		005		1				1			

Propositi on #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
85	the reablement team considers family carers as useful collaboration partners in motivating the older adults after the end of the reablement period		005					1				
86	the reablement team guides family carers on how to provide strong support		005						1			
87	the reablement team guides family carers on how to provide strong support including outside the home		005						1			
88	reablement teams inform family carers about what kind of intervention reablement implies (what it is, how it works and what they are taking part in)	expectations can be clarified and written information provided	005	1								
89	family carers disagree with a reabling approach		005							1		
90	family carers are included right from the start of the intervention		005	1					1			
91	(even if) reablement teams regard family carers as important partners and useful to collaborate with in reablement	they do not necessarily feel sure that there is a need to collaborate with or include them.	005						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
92	reablement is emphasised as being person-centred	health professionals might not see older adults as dependent on their family carers	005						1		1	
93	the aim of increased independence is emphasised in reablement	the importance of interaction between service users and their family carers is sometimes not emphasised	005	1					1		1	
94	the perception of what is meant by independence is not tailored to older adults	it is possible to underestimate the need for mutual dependency	005	1	1				1			Interdependence
95	if reablement teams lack routines for combining their work of promoting increased independence for service users with the inclusion of family carers as partners in reablement	even an awareness of the support and assistance given to service users by their next of kin in everyday life will not necessarily translate into active collaboration	005						1			Routines
96	reablement teams acknowledge that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning	they may adopt a family-centred perspective and develop a better understanding of family carers in reablement	005						1			Social dimension
97	all three parties have differing assessments of the need and the desire for assistance		005	1	1							

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98	a family-centred approach is adopted	reablement teams will be able to acknowledge and respect family carers' needs without sacrificing service users' interests or authority	005						1		1	
99	family carers are trained and receive individualised support	this will benefit both them and the service user	005						1			Training for FCs
100	the reablement team considers that the family carers underestimate the service user' capacity	this could undermine the effectiveness of reablement	005	1	1							
101	reablement teams clarify the different perceptions of what service users could and needed to do to continue to participate in desired activities	they could play a role in establishing a dialogue between the service user and their family carer to clear up discrepancies between them.	005		1				1		1	
102	reablement teams experience frustration due to lack of time to carry out and follow up the intervention	they could regard family carers as a resource to help motivate and support service users	005						1			
103	reablement teams view family carers as an extension of the reablement service	family carers might feel forced into a caring role or to take on comprehensive tasks	005						1		1	
104	family carers are involved in decision-making	the autonomy of the service user might be compromised	005		1				1			
105	reablement teams involve family carers fully in reablement	this will reduce the amount of time they are able to devote to the service user	005						1		1	

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106	reablement teams acknowledge that family carers can be a support for the service user	they will be more likely involve them	005						1		1	
107	family carers are given support, information and education linked to their role	they will be better equipped to support reablement	005						1			
108	family carers receive advice on how to maximise service users' independence	they would feel better able to support service users	007						1			
109	family carers welcome the support of, and regular social contact with, home care workers	they may be wary of losing these relationships and not buy into the ethos of maximising long-term independence and quality of life	007							1		
110	if family carers understand that "standing and watching" can be used to identify and assess capability as well as an opportunity to motivate and encourage	they will be more likely to adopt a reabling approach	007	1					1			
111	family carers understand how to use equipment provided		007						1			training equipping
112	family carers prefer a style of intervention that minimises risk	they could be resistant to reablement	007			1				1		

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
113	the aims of the service are explained to service users and their family members prior to the first reablement visit	this could significantly help them manage their perception of risk	007			1						
114	family carers and service users do not understand that the content of the reablement service is open to negotiation	they will not understand how this approach differs from traditional home care services	007	1								
115	family carers adopt a reabling approach themselves	family carers can experience a reduction in stress	007						1	1		
116	family carers are included in discussions about how to apply the approach	family carers can learn about new ways of managing care	007	1					1			
117	family carers apply a standing back approach	family carers could experience an increase in opportunities to spend time on non-caring activities	007						1	1		
118	communication about reablement is given initially in written form	it could easily be overlooked, mislaid or forgotten	007	1						1		
119	family carers learn about reablement from friends who have received it	this is a valued and trusted form of advice	007	1								
120	family carers are relying on the knowledge of service users for their information on reablement	they might not get a full understanding	007	1					1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
121	service users regard reablement primarily as a source of respite and practical and emotional support for informal carers	an understanding of the approach will be compromised and expectations not met	007	1								
122	reablement workers work together well as a team and pass on information between them well	family carers feel well informed e.g. about who would be visiting next	007				1					
123	a small number of people make reablement visits	family carers and service users do not have to keep repeating the same information to different workers.	007				1		1			
124	reablement workers are markedly different in their levels of friendliness and emotional support	negative comparisons will be made	007								1	routine
125	reablement workers are inconsistent about the sort of tasks they undertake	negative comparisons will be made	007						1		1	
126	there are discrepancies in the application of reablement approaches	this will undermine the confidence of service users and their families in the approach and will not allow service users to make consistent progress against their goals	007						1		1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
127	reablement workers do not stick to the schedule they have planned for visits	this can cause frustration and disruption to service users and family carers' plans	007				1		1		1	
128	family carers interpret their involvement in negotiating the content of reablement as involvement in task completion and relationship with reablement workers alone rather than preliminary or ongoing review of needs	they will not perceive the process as collaborative	007						1			
129	family carers are not invited formally to participate in the establishment of reablement goals	they will not perceive the process as collaborative	007		1				1			
130	family carers have the opportunity to chat to reablement workers on a daily basis	they will have valuable opportunities to address areas of unmet need in a relaxed manner, reinforcing the reablement process	007				1		1			
131	the content of the intervention is designed with the carer's needs as a crucial factor	this will encourage their active participation	007		1				1		1	
132	family carers are actively involved in their parents' reablement	this can help reablement workers to communicate with service users	007						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
133	family carers are actively involved in their parents' reablement	help family carers to provide on-going assistance with reablement - continuing routines, liaising with other services and resolving barriers or conflicts	007						1		1	
134	reablement goals are obstructed by a lack of help (e.g. physio) or lack of resources	this can lead to frustrations an demotivation	007		1							
135	re-establishing or increasing social contacts or realising desires to get out of the house are not considered valid reablement goals by anyone in the team	this could exacerbate service users' feeling of loneliness, loss and uncertainty at the end of the reablement period	007		1						1	
136	the principles of reablement are understood by service users and family carers	they will welcome or accept a more observational and encouraging approach, in spite of initial reluctance	007	1						1		
137	equipment recommended to achieve reablement goals is not provided quickly	service users and family carers who can afford it purchase them privately	007		1							equipment
138	larger equipment recommended to achieve reablement goals is not provided quickly	service users and family carers can experience considerable frustration	007		1							equipment
139	equipment is not removed when it is no longer required	this can lead to frustration	007					1				equipment

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
140	family carers engage fully with the reablement process	family carers can learn more structured ways of approaching their relative's needs and new skills in helping with practical tasks	007						1	1		
141	family carers do not live with the service user	the particular time of day that reablement is provided makes a difference to providing a helpful break from their caring responsibilities	007				1				1	
142	information about managing daily routines is passed on from the reablement team or advice relating to family carers' own needs is given	family carers will feel more confident about their caring responsibilities after reablement	007					1	1		1	
143	reablement workers provide clarity on the degree to which they can support family carers	unrealistic expectations will be avoided	007	1					1		1	
144	emotional support is given to family carers	is highly valued and helps to relieve pressure on care-giving relationships	007						1		1	
145	female family carers in particular are encouraged to take a break by reablement workers		007								1	
146	Reablement workers understand that different family carers have different needs	Information and support for family carers can be targeted to their particular needs	007								1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
147	Reablement workers understand that male and female family carers might typically have different needs to each other	Information and support for family carers can be targeted to their particular needs	007								1	
148	family carers are advised on how to carry out routines after reablement is finished	family carers' confidence in their own ability to provide care and safeguard their own welfare will be increased	007					1	1			training
149	reablement interventions are designed to meet the needs of service users and family carers in particular when family carers themselves have significant health problems	this can be regarded as invaluable by both service users and family carers	007								1	
150	Family carers are given advice on safer ways of doing things	their concerns about risks taken during reablement will be allayed	007			1						
151	Family carers are given advice on how to maximise service users' independence	increase their ability to support their relative at the end of reablement	007					1	1			training
152	Family carers feel involved in reablement processes and decision-making	increase their ability to support their relative at the end of reablement	007	1	1			1	1			
153	Service users and family carers are not clear about the likely duration of their reablement	they will feel distressed at the end of the intervention	007	1				1				

Proposition #	**If…**	**Then…**	**Doc ref # * Key below**	**CPT 1**	**CPT 2**	**CPT 3**	**CPT 4**	**CPT 5**	**CPT 6**	**CPT 7**	**CPT 8**	**Other ideas**
154	Service users and family carers are not informed about when reablement is finishing in advance of the last day	they will feel distressed at the end of the intervention	007					1				
155	Service users and family carers are signposted to a range of services beyond information about conventional home care provided by independent agencies	they will understand options for ongoing support after the service has stopped	007					1				
156	service users are not eligible for local authority funding when their reablement has finished	they need to understand the range and cost of other options for support after the service has stopped	007					1				
157	there is a charge for reablement	it should be clear who needs to pay, how much and when	007	1								
158	family carers receive professional support, encouragement and advice	service users will be helped to achieve yet further independence	007						1			
159	reablement teams provide physical help which would otherwise have been beyond the abilities of family carers	will be regarded by them as indispensable	007						1			
160	service users and family carers know that they are being monitored regularly and frequently	they will experience a sense of security	007		1							
161	Reablement visits are made as planned	provide a routine and sense of self-discipline	007				1					

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162	there is continuity in terms of which team members from a small team visit	good relationships can be built	007				1		1			
163	emotional sustenance would be appreciated	reablement workers' company can be experienced as a significant source of emotional sustenance	007								1	
164	good and timely access to physiotherapists, OTs and other specialists is provided	the benefits of reablement will be improved	007	0	0	0	0	0	0	0	0	expertise of reablement team
165	attention is paid to the ways people experience disabling barriers to their independence	further improvements could be experienced	007		1							
166	attention is paid to the social dimensions of service users' and family carers' lives	this would enhance motivations for independence	007								1	social dimension
167	family carers receive direct support or guidance from reablement workers	this can be perceived as very helpful	007						1			training and advice
168	family carers are unsupported	they can experience worries about their own welfare and their diminishing capacities to provide for their relative	007						1		1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
169	reablement workers demonstrate their mix of skills combining medical knowledge with care, support, encouragement and information	this is perceived as highly valuable	007						1			
170	an overall feeling of gratitude is felt by family carers	they may not voice criticisms or requests	007						1		1	
171	service users live alone	continuing improvement can be largely dependent on the maintenance of substantial support and provision of information from informal carers	007					1	1			
172	service users live alone	they might have an increased reliance on sons and daughters	007					1	1			
173	family carers do not live with the service user	they are less likely to receive support from reablement workers or advice on how to maximise their parents' independence	007						1		1	training and advice
174	accessible feedback mechanisms are built into reablement	safeguarding will be supported where service users experience confusion, apprehension or restrictions to providing their opinions	007		1		1		1			
175	service users and family carers feel overwhelmed or unable to complete forms	are unlikely to complete questionnaires	007								1	

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176	there is a low level of communication and negotiation with service users	this can lead to a mismatch between service users' and practitioners' goals	009		1							
177	a close-knit team of rehabilitation professionals develop their re-abling skills and a service-user approach	this fosters a more collaborative decision-making approach around goals that involve service users, relatives and professionals	009		1				1			
178	care staff, including professional carers and support staff are given appropriate professional development opportunities	this will contribute to enabling collaborative decision-making with service users	009						1			staff skilled in collaborative decision-making
179	health and social care professionals work in an integrated fashion with each other and carers	improved service user outcomes are achieved	009						1			
180	good collaborative decision-making is achieved	this may be more important for attaining health and social outcomes that are less to do with physical functioning	009						1			staff skilled in collaborative decision-making
181	good collaborative decision-making is not achieved	desirable functional outcomes may still be attained	009						1			staff skilled in collaborative decision-making

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182	service users are in a vulnerable state	it might not be possible to expect negotiation about the objectives of care to take place on an equal footing	009			1						
183	health and social care professionals are acting in the best interests of vulnerable people	there are limits to how much a genuinely collaborative approach can be implemented	009			1						
184	professional norms and the conventions of service provision in the locality work against negotiation about the objectives of care	willingness and ability of individual practitioners is not enough to engage service users in collaborative decision-making	009		1							
185	service users are experiencing feelings of distress or fear	it may be problematic to try and engage them in a complex decision-making process	009		1				1			
186	service users feel a deference to medical authority	they can feel unable to voice their concerns about their ability to cope	009						1			
187	service users feel unable to negotiate a tapered withdrawal of support services	they could experience a sense of abandonment	009					1				
188	service users are in a vulnerable state at the point of decision-making about early supported discharge	it is necessary for collaborative decision-making to be made together with service users' informal carers	009		1				1			

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189	practitioners recognise a service user's long-term perspective and engages with the aspects of service users' lives that are significant to them	they can reach agreement on objectives of care that link with these goals that extend beyond the period of intermediate care	009		1							
190	service users have previously had negative experiences of community services	this may make collaborative decision-making difficult	009							1		
191	service users feel confident in service standards	collaborative decisions about their care can be made	009		1							
192	the conditions are created for service users to see how their continuing input will actually have some impact on the arrangements for future care	they will feel motivated to engage in collaborative decision-making	009		1							
193	service users and professionals assume that a significant other will take on the role of informal carer	discussions about care can proceed without further examination of the willingness or ability of the significant other to take on this often demanding role	009								1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
194	carers take on the role of carer	it can have a significant impact on their lives, with feelings of obligation and responsibility meaning that activities which take them away from the caring role are experienced as "uneasy".	009								1	
195	service users are consulted in isolation from their primary social and care networks (including family carers)	this is inadequate for organising continuity of care	009					1	1		1	
196	carers do not share the goals of service users or the goals expressed in care plans	this can be a significant issue for integrated working	009		1						1	
197	carers are one of the most significant people in a service user's life	they may play a significant role in setting expectations for re-enablement	009		1				1			
198	a carer's identity leads them to perceive a need to care by "doing for" rather than "enabling", their significant other	the re-enabling ethos may be countered	009	1						1		
199	there are existing relationships within a person's home	a professional cannot simply "over-rule" a carer's input	009						1		1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
200	professionals are provided with ways to address frustrations with carers and subsequently engage with them and collaboratively develop care plans	this is vital for the delivery of integrated working	009						1			staff training
201	patients and their carers are placed at the centre of intermediate care service development and delivery	intermediate care can be thought to "work"	009						1			
202	carers and voluntary services are actively and equally engaged as part of the team	this will contribute to integrated team working	009						1			
203	there is limited existing concordance between care expectations	facilitating professionals to collaboratively develop re-enablement care plans with service users and their carers is particularly important	009		1				1			
204	professionals understand service users' goals as about not just the recovery of functional goals but also the recovery of meaning in their lives (found in activities, relationships and social roles	a holistic approach to wellbeing could be used to foster this and facilitate re-enablement	009		1							
205	users and carers understand the aims and approach of reablement	unrealistic or inappropriate expectations could be avoided	012	1								

Proposition #	**If…**	**Then…**	**Doc ref # * Key below**	**CPT 1**	**CPT 2**	**CPT 3**	**CPT 4**	**CPT 5**	**CPT 6**	**CPT 7**	**CPT 8**	**Other ideas**
206	users have previously experienced standard homecare services, directly or indirectly	they risk having unrealistic or inappropriate expectations of reablement unless they understand its aims and approach	012	1								
207	people received their first explanation of the service by letter or on the first visit from a reablement worker	they are unlikely to have a strong grasp of the reablement approach	012	1								
208	people are pre-occupied by with the trauma and anxieties of a recent fall, pain or life-changin illness	they are likely to have poor recall of or confusion about information they are given in hospital	012	1								
209	service users have contact with large numbers of health and social care staff during their discharge from hospital or following referral to the reablement service	confusion about its aims can be compounded	012	1								
210	relatives are present during visits from reablement workers	uncertainties about the aims of reablement can be resolved	012	1								
211	family carers are used to explain service users' choices	this can contribute towards a richer understanding of cultural preferences and what service users understand by 'independence'	012		1				1			

Propositi on #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
212	family carers need help from reablement workers to use equipment	the timing of their visits is important and can have impacts on users' motivations and confidence to progress as well as reinforcing feelings of dependency	012						1			
213	reablement workers provide guidance on how to provide effective help	this can be beneficial to family carers	012						1			training and advice
214	carers know that their relatives are "checked on"	they can perceive this as a benefit of reablement	012								1	
215	carers learn more structured ways of meeting service users' needs and new ways of carrying out practical care tasks	they can perceive this as a benefit of reablement	012						1			training and advice
216	carers feel that reablement workers have recognised some of their own needs	they can perceive this as a benefit of reablement	012								1	
217	carers feel that reablement workers have increased their confidence in managing daily care routines	they can perceive this as a benefit of reablement	012						1			
218	carers feel that reablement workers have provided emotional support that helped to relieve pressure on caregiving relationships	they can perceive this as a benefit of reablement	012						1		1	

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
219	carers feel that reablement workers recognise their own needs (e.g. through referrals to specific carer support services)	they can perceive this as a benefit of reablement	012								1	
220	carers feel that reablement workers provide advice on how carers could maximise and sustain service users' capabilities and independence	they can contribute to the reablement process	012						1			training and advice
221	reablement workers understand service users' and carers' own priorities for recovery and the aspects of daily life that they consider central to their independence	this appears to be fundamental to successful re-ablement	012		1						1	
222	service users' and carers' own goals are not addressed	this may lead to demotivation, frustration and feelings of failed 'impairment identity' and reablement may be less effective	012		1						1	
223	a more holistic approach that takes account of the needs of family carers and involves them fully in the reablement intervention	this may be beneficial	012						1		1	

Proposition #	**If…**	**Then…**	**Doc ref # * Key below**	**CPT 1**	**CPT 2**	**CPT 3**	**CPT 4**	**CPT 5**	**CPT 6**	**CPT 7**	**CPT 8**	**Other ideas**
224	a person has ongoing support needs at the end of reablement	it is crucial that subsequent services continue to provide support in a way that maintains any progress that person had made	014						1			
225	the individual's family are involved in goal-setting and there are conflicting or opposing views about suitable goals	these must be negotiated sensitively and with professional judgement	014		1							
226	telecare has been used to contribute to monitoring safety and provide reassurance to people and their families	post-reablement procedures should be in place to ensure that telecare systems are not automatically withdrawn at the end of the reablement service	014					1				
227	equipment and systems are being installed for someone who lives alone	it may be helpful for installation to take place when a family member of friend can be available so they also develop an understanding of how to operate them	014						1			
228	reablement staff are trained to work in partnership with people using reablement and their families	they can help them come to terms with loss or impairment of skills	014						1		1	
229	a person's ongoing support needs are going to be met by another (home care) provider	relevant family members should be involved in planning that support	014						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
230	reablement services recognise the important role played by families	they must genuinely respect them as part of the whole care circle	014						1			
231	reablement staff are alert to the fact that the support that family members are willing and able to offer could change over time	they will be better able to manage expectations	014								1	
232	time and effort is taken by family carers to understand how reablement works	family carers can play a key role in assisting with the reablement process	015	1								
233	reablement is described well	family carers will understand what it is and is not	015	1								
234	family carers are worried about how their relative is going to manage	they will want to ensure that they get the best care possible	015							1		
235	family carers wish to help	they will tend to want to be hands on rather than hands off	015	1						1	1	
236	family carers are used to doing things for their relative	reablement teams can train them to learn how to stand back	015						1			training and advice
237	family carers insist that their relative needs care	reablement teams can gather evidence to demonstrate what they can do for themselves	015				1			1		
238	services recognise that families are part of the whole care circle and if they empower them	everybody contributes towards independence for the older person	015						1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
239	people have the right information	they can make the right decisions and help in the right way	015	1					1			
240	reablement teams are very clear about what reablement is and is not (especially re time-limit and possibility of having to pay for services afterwards)	service users and family carers can make the most of the system while it is there	015	1								
241	goals are set and progress is continually assessed	this helps to show family carers how they can help	015		1							
242	family carers can see their relative improving	they will become engaged and will take some responsibility for encouraging their relative to do things	015		1				1			
243	family carers understand that reablement can help	they will come on board	015	1					1			
244	family carers see their relative doing more for themself	they could get some of their own life back	015						1		1	seeing results
245	reablement is to work well	services need to consider the transition of care from professionals to the family	015					1	1			
246	family carers think of reablement as a time when they get more concentrated support	they can feel abandoned at the end	015	1								
247	you involve family carers more in the reablement process	the higher the chance that they will subsequently carry on reinforcing that reablement approach with the service user	015					1	1			

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
248	family carers see successful reablement (service user back to a healthier state)	that will lift their spirits	015		1				1			seeing results
249	family carers move from a position of not knowing what's going on to feeling confident about managing situations and seeing an improvement	they will feel confident that they are doing things right even though they are new to it	015						1			
250	families can encourage the service user in working towards their goals	they can play an important part in the process	015		1							
251	professionals respect families and carers and recognise their role as part of the whole care circle	their role will be maximised	015						1			

* Key to document reference nos.

003	Hjelle
005	Jakobsen
007	Glendinning
009	Pearson
012	Wilde
014	SCIE guide

Proposition #	If…	Then…	Doc ref # * Key below	CPT 1	CPT 2	CPT 3	CPT 4	CPT 5	CPT 6	CPT 7	CPT 8	Other ideas
015	SCIE video											

Appendix T

Full set of 18 overarching if-then statements grouped according to four themes

Statements shown in blue only were taken forward for refinement in Stage 2 of the study.

Theme 1: Instilling an understanding of reablement

#	Overarching if-then statement
1	IF the principles of reablement are understood by service users and their family carers, THEN they will welcome or accept a more observational and encouraging approach, in spite of initial reluctance.
2	IF expectations for reablement are clarified by all parties, THEN family carers will be able to make conscious choices about how to be involved in the process.
3	IF transition from reablement is to work well, THEN services need to consider the transition of care from professionals to the family.
4	IF the is no follow-up programme for service users after their reablement, THEN family members can feel concerned about their relative's health after reablement.

Theme 2: Customising service delivery to family circumstances

#	Overarching if-then statement
5	IF professionals respect families and carers and recognise their role as part of the whole care circle, THEN their role will be maximised.
6	IF reablement workers work together well as a team and pass on information between them well, THEN family carers feel well informed e.g. about who is visiting next.
7	IF the content of the intervention is designed with the family carer's needs as a crucial factor, THEN this will encourage their active participation.

Theme 3: Empowering families

#	**Overarching if-then statement**
8	IF there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties, THEN family carers would have an opportunity to provide input on the content of the reablement process.
9	IF family carers feel involved in reablement processes and decision-making, THEN they will be empowered to take an active role in the process and will increase their ability to support their relative at the end of reablement.
10	IF goals are set jointly with family carers, THEN this will provide an opportunity for more perspectives and solutions to be considered.
11	IF family carers are informed about how to support and motivate their relative, THEN this will support them in their role.
12	IF family carers are regarded as a resource by the reablement team, THEN they will be able to reinforce the reablement team's work by supporting and motivating the service user.
13	IF family carers experience reablement team visits as a sharing of responsibility, THEN they can feel relieved, re-energised and that there is a safety net in place.
14	IF family carers are advised on how to carry out routines after reablement is finished, THEN their confidence in their own ability to provide care and safeguard their own welfare will be increased.

Theme 4: Skilled workforce

#	**Overarching if-then statement**
15	IF the reablement team is able to negotiate and manage different expectations and opinions, THEN this will enhance collaboration.
16	IF the reablement team considers that family carers are providing too much practical and physical assistance, THEN this could result in an "assistance trap", conflicting with the aims of reablement.
17	IF a family-centred approach is adopted, THEN reablement teams will be able to acknowledge and respect family carers' needs without sacrificing service users' interests or authority.
18	IF professionals are provided with ways to address frustrations with family carers and subsequently engage with them and collaboratively develop care plans, THEN this is vital for integrated working.

Appendix U

Ethical approvals

Ethical approval 1 from UWE

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.18.07.206

12th September 2018

Linda Sumpter
[Address removed]

Dear Linda

Application title: Facilitating the support of family carers in older people's homebased reablement

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 6 September 2018 and the study has been given ethical approval to proceed.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
   http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

The Faculty and University Research Ethics Committees (FRECs and UREC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection (including GDPR) compliance. Whilst we will use our best endeavours to identify and notify you of any obvious legal issues that arise in an application, the lead researcher remains responsible for ensuring that the project complies with UWE's policies, and with relevant legislation. If you need help with legal issues please contact safety@uwe.ac.uk (for Health and Safety advice), James2.Button@uwe.ac.uk (for data protection, GDPR and privacy advice).

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: https://teams.uwe.ac.uk/sites/HASgovernance.

We wish you well with your research.

Yours sincerely

[Signature removed]

Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Prof Jane Powell

Ethical approval 2 from UWE

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.19.06.213

18th July 2019

Linda Sumpter
[Address removed]

Dear Linda

Application title: What works when engaging partners and families in the reablement of older people, for whom, how and in what circumstances?

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed.

There is just one comment for you to note. Please note that the information sheet and consent form should contain the privacy notice (not as a separate document) so that the study is GDPR compliant.

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. Amendments should be requested using the form at http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

The Faculty and University Research Ethics Committees (FRECs and UREC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection (including GDPR) compliance Whilst we will use our best endeavours to identify and notify you of any obvious legal issues that arise in an application, the lead researcher remains responsible for ensuring that the project complies with UWE's policies, and with relevant legislation https://intranet.uwe.ac.uk/whats-happening/sites/gdpr/updates/pages/research-and-gdpr-compliance-update-08-may- 2019.aspx. If you need help with legal issues please contact safety@uwe.ac.uk (for Health and Safety advice), James2.Button@uwe.ac.uk (for data protection, GDPR and privacy advice).

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: https://teams.uwe.ac.uk/sites/HASgovernance.
We wish you well with your research.

Yours sincerely

[Signature removed]

Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Prof Jane Powell

Local Authority approvals

The researcher gained approval for undertaking the research with the Local Authority through its research governance process. This was granted on 28 November 2018 for Phase 1 by email from the Adult Principal Social Worker, Head of Service for Mental Health and Area Services

On 28 Nov 2018, at 15:14, [Name removed: Adult Principal Social Worker, Head of Service for Mental Health and Area Services] wrote:

Hi Linda

Your research has now been agreed so you can make contact with [Name removed: Head of Service – Reablement, Intermediate Care and Regulated Service] regarding this matter now directly going forward.

Kind Regards

[Name removed]

Principal Social Worker Adults/ Mental Health Act Manager/ Acting Head of Service Maximising Independence Teams

It was granted on 7 October 2019 for Phase 2:

On 07 Oct2019, at 10:02, [Name removed: Adult Principal Social Worker, Head of Service for Mental Health and Area Services] wrote:

Dear Linda

I can now confirm that you can proceed with your research. The only thing I need to check is that your external hard drive is encrypted.

Kind Regards

[Name removed]

Adult Principal Social Worker / Head of Service for Mental Health and Area Services

Appendix V

Information leaflets and consent forms for study participants

Information sheet for staff interviews Phase 1

Consent form for staff interviews Phase 1

Information sheet for focus group Phase 1

Consent form for focus group Phase 1

Information sheet for family interviews Phase 2

Consent form for family interviews Phase 2

Participant information leaflet for a research study

Facilitating the Support of Family Carers in Reablement

Participant interviews

INVITATION

This is an invitation from a PhD student working at the University of the West of England, Bristol. I would like to invite you to take part in a research study.

This leaflet is to help you decide whether you would like to take part or not. It gives some background into why the research is being done and what would be involved for you if you decide to take part in it.

Please read the following information carefully and discuss it with others if you wish.

My contact details are at the end of the leaflet. Please ask me if anything is unclear or if you would like more information.

- Part 1 of the leaflet tells you the purpose of the study and what will happen if you take part.

- Part 2 gives more detailed information about how the study will be conducted.

PART 1

What is the purpose of the study?

Staff in reablement services support people to learn or re-learn how to carry out everyday activities for themselves. Family members often play a role in supporting their relative before, during and after reablement. Very little research exists on how to facilitate family members to carry out this role.

This research is a small study. The researcher will seek ideas and opinions from staff working in reablement about how to facilitate the support of family members effectively. The study is taking place in Bristol.

The purpose of the study is to explore ways to support the benefits of reablement for service users and their families.

Why have I been invited to take part?

You have been invited because your role in a reablement service gives you unique insights into how the service works. Bristol City Council's Interim Director of Adult Social Care and Head of Service for Reablement, Intermediate Care and Regulated Services have agreed that I can collaborate with the Council's reablement service and have recommended working with you. This part of the research study only involves the South Bristol Intermediate Care Reablement Team.

Do I have to take part?

It is up to you to decide whether or not to join the study. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw from the study up to seven days after your interview by contacting the Research Supervisor. You do not need to give a reason. Taking part, not taking part or withdrawing will not affect your work.

What will I be asked to do if I take part?

Your involvement would be to participate in an interview with me. The main topic of discussion will be how to facilitate the support of family members in reablement. The interview will take place at a convenient time and place for you. It will last for approximately one hour and will be audio recorded so that I can capture your thoughts accurately. You will receive a summary of the findings.

What are the possible disadvantages of taking part?

There are no known disadvantages or significant risks to taking part.

What are the possible benefits of taking part?

I hope you will find taking part in the study interesting and useful. Agreeing to join it will support me to build a greater understanding about how family members can be facilitated to support their relatives through and beyond reablement. The information gained from the study is intended to inform the development of services by sharing what works well, for whom and how.

Research study contacts

Linda Sumpter
Principal PhD Researcher
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: linda.sumpter@uwe.ac.uk

Professor Jane Powell
Research Supervisor
Professor of Public Health Economics and
Director of the Centre for Public Health and Wellbeing
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: jane.powell@uwe.ac.uk

Who is organising and funding the research?

The research is being funded by the University of the West of England, Bristol (UWE) and is in association with Coventry University's Data Driven Research and Innovation Programme. A panel of experts at UWE has reviewed the study for ethical purposes. Linda Sumpter, the principal researcher, is a PhD student at UWE. Linda is an experienced voluntary and community sector project manager and has worked with older people and their carers.

What do I do now?

Thank you for your interest in this research study. If you agree to take part, please let the researcher know.

Thank you for reading this information leaflet

What if there is a problem?

If you experience any difficulties or have any questions or complaints about your part in the research at any stage, please contact me or my Research Supervisor. Contact details for both of us are at the end of this leaflet.

Will my participation in this study be kept confidential?

Yes. I will follow the University's best practice guidelines. All information about you will be handled in confidence. More details about this are in Part 2 of this leaflet.

If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 of this leaflet before deciding.

PART 2

What about confidentiality and data protection?

All information you may give will be treated in the strictest confidence. I will record the discussion and transcribe it afterwards. Any information you give during the interview will be fully anonymised and combined with the views and experiences of other reablement staff who agree to participate. I will use pseudonyms for any quotes from the interview that appear in my reports or presentations about the study.

All electronic information, including the transcript of the audio recording of the interview, will be stored on a secure computer server and access to it will be password protected and available only to me and my supervisors. All information stored electronically will have any personal information such as your name removed so that you cannot be recognised from it.

Any personal information collected on paper such as your name and your signed consent form will be kept in a secure storage facility at the University of the West of England. Information will be stored securely until one year after the PhD is awarded, just in case it needs to be checked. It will then be disposed of professionally.

What will happen to my information if I withdraw from the interview?

Even if you decide to terminate the interview because you do not want to continue with it, then if you agree, the information collected may still be used. If you do not agree to me using the information already collected, I will destroy all data collected from you. However, I need you to let me know within seven days after your interview. After that, the analysis will have started and we will not be able to separate your information.

What will happen to the results at the end of the research study?

At the end of the study I will write a summary of the results which will be available to everyone who takes part. The results will form part of my thesis and may be reported in professional publications or presented at meetings and conferences. You will not be identified by name in any of the reports, publications or presentations.

What if there is a problem?

If you have a concern about any aspect of this study, please speak to me, Linda Sumpter. I will do my best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this through Professor Jane Powell, the Research Supervisor. Please see her contact details at the end of this leaflet.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of the West of England, but you may have to pay the legal costs.

UWE Bristol University of the West of England

Bristol City Council

Consent form for a research study

Facilitating the Support of Family Carers in Reablement

Participant interviews

Please initial all the statements that you agree

I confirm that I have read and understood the information leaflet dated ………….. (version …….) for the above study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw within seven days of the interview without giving any reason.	
I agree to participate in an interview about how to facilitate the support of family carers in reablement effectively and that the interview will be audio-recorded.	
I agree to the resulting study being used for all of the following purposes: Research report and professional journal articles Professional conference presentations Websites about the project Printed and electronic newsletters about the project Teaching and learning	

Signatures

Name of participant ____

Signature ______________________________ Date ____________

Name of person taking consent ______________________________

Signature ______________________________ Date ____________

Research study contacts

Linda Sumpter
Principal PhD Researcher
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: linda.sumpter@uwe.ac.uk

Professor Jane Powell
Research Supervisor
Professor of Public Health Economics and
Director of the Centre for Public Health and Wellbeing
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: jane.powell@uwe.ac.uk

Participant information leaflet for a research study

Facilitating the Support of Family Carers in Reablement

Focus group

INVITATION

This is an invitation from a PhD student working at the University of the West of England, Bristol. I would like to invite you to take part in a research study.

This leaflet is to help you decide whether you would like to take part or not. It gives some background into why the research is being done and what would be involved for you if you decide to take part in it.

Please read the following information carefully and discuss it with others if you wish.

My contact details are at the end of the leaflet. Please ask me if anything is unclear or if you would like more information.

- Part 1 of the leaflet tells you the purpose of the study and what will happen if you take part.

- Part 2 gives more detailed information about how the study will be conducted.

PART 1

What is the purpose of the study?

Staff in reablement services support people to learn or re-learn how to carry out everyday activities for themselves. Family members often play a role in supporting their relative before, during and after reablement. Very little research exists on how to facilitate family members to carry out this role.

This research is a small study. The researcher will seek ideas and opinions from staff working in reablement about how to facilitate the support of family members effectively. The study is taking place in Bristol.

The purpose of the study is to explore ways to support the benefits of reablement for service users and their families.

Why have I been invited to take part?

As the principal researcher, I am looking for staff members who have experience of working with older people (aged 65+) in home-based reablement. Your Team Manager has said that I can invite anyone in your team to take part in a focus group discussion. This part of the research study only involves the South Bristol Intermediate Care Reablement Team.

Do I have to take part?

It is up to you to decide whether or not to join the study. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw from the study up to seven days after you have taken part in the focus group discussion by contacting the Research Supervisor. You do not need to give a reason. Taking part, not taking part or withdrawing will not affect your work.

What will I be asked to do if I take part?

Your involvement would be to participate in a focus group discussion organised by me. The main topic of discussion will be how to facilitate the support of family members in reablement. The focus group will take place at a convenient time and place for you. The discussion will last for one to two hours and will be audio recorded so that I can capture your thoughts accurately. You will receive a summary of my findings.

What are the possible disadvantages of taking part?

There are no known disadvantages or significant risks to taking part.

What are the possible benefits of taking part?

I hope you will find the experience of taking part in the focus group discussion interesting and useful. Agreeing to join the study will support me to build a greater understanding about how family members can be facilitated to support their relatives through and beyond reablement. The information gained from the study is intended to inform the development of services by sharing what works well, for whom and how.

What if there is a problem?

If you experience any difficulties or have any questions or complaints about your part in the research at any stage, please contact me or my Research Supervisor. Contact details for both of us are at the end of this leaflet.

Will my participation in this study be kept confidential?

Yes. I will follow the University's best practice guidelines. All information about you will be handled in confidence. More details about this are in Part 2 of this leaflet.

If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 of this leaflet before deciding.

PART 2

What about confidentiality and data protection?

All information you may give will be treated in the strictest confidence. I will record the discussion and transcribe it afterwards. Any information you give during the focus group will be fully anonymised and combined with the views and experiences of other reablement staff who agree to participate. I will use pseudonyms for any quotes from the discussion that appear in my reports or presentations about the study.

All electronic information, including the transcript of the audio recording of the meeting, will be stored on a secure computer server and access to it will be password protected and available only to me and my supervisors. All information stored electronically will have any personal information such as your name removed so that you cannot be recognised from it.

Any personal information collected on paper such as your name and your signed consent form will be kept in a secure storage facility at the University of the West of England. Information will be stored securely until one year after the PhD is awarded, just in case it needs to be checked. It will then be disposed of professionally.

What will happen to my information if I withdraw from the focus group discussion?

Even if you decide to leave the discussion because you do not want to continue with it, then if you agree, the information collected may still be used. If you do not agree to me using the information already collected, I will destroy all data collected from you. However, I need you to let me know within seven days after you have taken part in the focus group discussion. After that, the analysis will have started and I will not be able to separate your information.

What will happen to the results at the end of the research study?

At the end of the study I will write a summary of the results which will be available to everyone who takes part. The results will form part of my thesis and may be reported in professional publications or presented at meetings and conferences. You will not be identified by name in any of the reports, publications or presentations.

What if there is a problem?

If you have a concern about any aspect of this study, please speak to me, Linda Sumpter. I will do my best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this through Professor Jane Powell, the Research Supervisor. Please see her contact details at the end of this leaflet.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of the West of England, but you may have to pay the legal costs.

Who is organising and funding the research?

The research is being funded by the University of the West of England, Bristol (UWE) and is in association with Coventry University's Data Driven Research and Innovation Programme. A panel of experts at UWE has reviewed the study for ethical purposes. Linda Sumpter, the principal researcher, is a PhD student at UWE. Linda is an experienced voluntary and community sector project manager and has worked with older people and their carers.

What do I do now?

Thank you for your interest in this research study. If you agree to take part, please let the researcher know.

Thank you for reading this information leaflet

Research study contacts

Linda Sumpter
Principal PhD Researcher
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: linda.sumpter@uwe.ac.uk

Professor Jane Powell
Research Supervisor
Professor of Public Health Economics and
Director of the Centre for Public Health and Wellbeing
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: jane.powell@uwe.ac.uk

Consent form for a research study

Facilitating the Support of Family Carers in Reablement

Focus group

Please initial all the statements that you agree

I confirm that I have read and understood the information leaflet dated …………… (version …….) for the above study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw within seven days of the focus group discussion without giving any reason.	
I agree to participate in a focus group about how to facilitate the support of family carers in reablement effectively and that the focus group will be audio-recorded.	
I agree to the resulting study being used for all of the following purposes: Research report and professional journal articles Professional conference presentations Websites about the project Printed and electronic newsletters about the project Teaching and learning	

Signatures

Name of participant ____________________________________

Signature __________________________ Date ___________

Name of person taking consent __________________________

Signature __________________________ Date ___________

Research study contacts

Linda Sumpter
Principal PhD Researcher
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: linda.sumpter@uwe.ac.uk

Professor Jane Powell
Research Supervisor
Professor of Public Health Economics and
Director of the Centre for Public Health and Wellbeing
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: jane.powell@uwe.ac.uk

Engaging in reablement: What works for partners and families

Participant information leaflet for a research study

Invitation

You are invited to take part in a research study conducted by the University of the West of England, Bristol.

This leaflet is to help you decide whether you would like to take part or not. It describes why the study is being done and what would be involved for you if you decide to take part in it.

Please read the following information carefully and discuss it with others if you wish. If you have any queries or would like to know more, please contact the lead researcher, Linda Sumpter, whose contact details at the end of this leaflet.

Who is organising and funding the research?

This research is part of a postgraduate study led by Linda Sumpter, supervised by Professor Jane Powell, Professor of Public Health Economics and Director of the Centre for Public Health and Wellbeing at the University of the West of England, Bristol. The study is funded by this university.

What is the aim of the research?

The research is looking at what works when engaging partners and families in home-based reablement. Although national guidelines advise services to involve partners and families in reablement, very little research exists on what works for different people in different situations.

To help us understand more about this, we are conducting interviews with people who have experience of reablement with Bristol City Council and their families. The aim of the interviews is to collect ideas and information from service users as well as their partner or family member. These will all be anonymised and used to support the development of ideas about what works when engaging partners and families in reablement.

Why have I been invited to take part?

As a postgraduate student, I am interested in finding out what worked for different people and what did not with respect to reablement. The purpose of the interview questions will be to gain information about this. I am approaching people whose reablement service fits with the timing of the research and whose family are engaging in some way with the service.

This is not intended to be feedback for Bristol City Council. The Council will not know who decided to take part in the research and who did not. It will not affect your access to Council services or other services in any way.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form. If you do decide to take part, you are able to withdraw from the research without giving a reason up to seven days after the interview. If you want to withdraw from the study during this time, please contact Professor Jane Powell (contact details at the end of this leaflet). Deciding not to take part or withdrawing from the study does not have any penalty. It will not affect current or future care services that you receive in any way.

What will I be asked to do if I take part?

If you agree to take part, you will be asked to choose a convenient date and time for the researcher to visit you at the home of the service user for an interview. This will be towards the end of the reablement service or shortly after it and will be with the service user and their partner or family member together. The researcher is experienced in this area and is sensitive to issues that it may raise. The interview will take approximately 45 minutes and the researcher will confirm arrangements again closer to the time.

The researcher will discuss with you what has worked and not worked for you about reablement. Your answers will be fully anonymised. Your interview will be recorded on a voice recorder but the recording will not contain your names. You will be given a different name which can be used to re-identify you if you choose to withdraw from the study within the timeframe. The voice recording will be deleted as soon as it has been put into written form. At this point your data will be anonymised and will be analysed with interview data from other anonymised participants.

What data will be collected?

Your name, age, relationship to the other interviewee and contact details will be provided by you before the interview. The Council will provide basic data about your reablement service: How long you have been with the service, the reason for referral, and what your reablement goals are. You will be able to verify this data at the start of the interview. The other data is what is provided through discussion during the interview.

What are the benefits of taking part?

This work has been approved by the Director of Adult Social Care at Bristol City and has been funded by the University of the West of England. If you take part, you will be helping us to gain a better understanding of how reablement works for different people. This could help influence the way that reablement services are designed in the future. We hope that you find the discussion interesting too.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the interview to stop. If you need any support during or after the interview then the researcher will be able to put you in touch with suitable support agencies. The researcher is experienced in conducting interviews and is sensitive to the subject area. The interviews have been designed with these considerations in mind.

What will happen to your information?

All the information that you give will be kept confidential and anonymised when the interview is put into written form. The only circumstance where we may not be able to keep your information confidential is if anyone involved in the interviews appears to be at harm. In this case the researcher would have to ask for help and this may involve giving identifying information to support services.

Hard copy research material will be kept in a locked, secure setting to which only the researcher and supervisors will have access in accordance with the requirements of the University, the Data Protection Act 2018 and General Data Protection Regulations. Personal data will be stored for a year after the award of the PhD.

Voice recordings will be destroyed securely immediately after they have been put into written form and anonymised. Your anonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Where will the results of the research study be published?

The research findings will form part of a postgraduate research paper (thesis) and may be reported in professional publications or presented at meetings and conferences. The researcher will let you know how to see anything that is published. You will not be identified by name in any of the reports, publications or presentations. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The study has been reviewed and approved by the University of the West of England's Health and Applied Sciences Research Ethics Committee and Bristol City Council. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England by email: researchethics@uwe.ac.uk.

What if I have more questions or something goes wrong?

If you have any concern or query about anything to do with this study, please speak to the researcher, Linda Sumpter. She will do her best to answer your questions. If you would prefer to speak to someone else or if you wish to complain formally, you can do this through Professor Jane Powell, the Research Supervisor. Please see her contact details at the end of this leaflet.

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Leaflet and your signed Consent Form to keep.

Research study contacts

Linda Sumpter
Principal PhD Researcher
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY

Tel: [Removed]
Email: linda.sumpter@uwe.ac.uk

Professor Jane Powell
Research Supervisor
Professor of Public Health Economics
and Director of the Centre for Public Health and Wellbeing
University of the West of England
Frenchay Campus
Bristol BS16 1QY

Tel: [Removed]
Email: jane.powell@uwe.ac.uk

Engaging in reablement: What works for partners and families

Consent Form

This consent form will have been given to you with a Participant Information Leaflet. Please ensure that you have read and understood the information contained in the Participant Information Leaflet and asked any questions before you sign this form. If you have any questions please contact the lead researcher or the research supervisor, whose details are set out on the Participant Information Leaflet.

If you are happy to take part in an interview in the service user's home, please sign and date this form below. You will be given a copy to keep for your records.

- We have read and understood the information in the Participant Information Leaflet which we have been given to read before being asked to sign this form;
- We have been given the opportunity to ask questions about the study;
- We have had our questions answered satisfactorily by the research team;
- We agree that anonymised quotes may be used in the final report of this study;
- We understand that our participation is voluntary and that we are free to withdraw at any time until the data has been anonymised, without giving a reason;
- We agree to take part in the research

Name (Printed)…………………………………………………………………….

Signature…………………………………………………. Date…………………….

Name (Printed)…………………………………………………………………….

Signature…………………………………………………. Date…………………….

Appendix W

Phase 2 – Selection, sampling and recruitment of research participants

- **Selection, sampling and recruitment process**
- **Ethics application**
- **Amendment 1 approval**
- **Amendment 2 approval**

Selection, sampling and recruitment process

The focus of Phase 2 was on former service users over the age of 65 and their co-habiting partner or family member who had capacity to consent. This choice was made for pragmatic reasons. People living with dementia or any other condition that meant that they would not have capacity to consent – whether they were the service user or their partner or family member - were not be included in the sample. People with a known mental health condition or known to have a drug or alcohol dependency were not included either. The service was able to screen in order to exclude these groups.

I aimed to interview a small number of dyads in their own home six to eight weeks after discharge from the service. In discussion with the Service Manager and Team Manager a maximum of 10 dyads was agreed. It was recognised, however, that is was possible that fewer than 10 would be needed to meet the aims of the study. The former service users would be a mix of men and women. The geographical area served by the service was not very ethnically diverse so, although it was desirable to include representation from black and minority ethnic communities in the sample, this was not an essential selection criterion.

During the recruitment phase very low numbers of new service users who cohabited with someone were referred to the service. This led to two further non-substantial amendments to the research protocol and ethics approvals. The first amendment extended the recruitment criteria to remove the need for the partner or family member to cohabit with the former service user. As the delay had impacted on the timeframe for the study, a second amendment was made in agreement with the supervisory team and the Local Authority. This moved the timeframe for interviewing participants from a few weeks after discharge from the service to towards the end of reablement or shortly after. See below for the full ethics application and amendments.

University of the
West of England
BRISTOL

APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

This application form should be completed by members of staff and PhD/ Prof Doc students undertaking research which involves human participants. Undergraduate and Masters level students are required to complete this application form where their project has been referred for review by a supervisor to a Faculty Research Ethics Committee (FREC) in accordance with the policy at **http://www1.uwe.ac.uk/research/researchethics.** For research using human tissue, please see separate policy, procedures and guidance linked from **http://www1.uwe.ac.uk/research/researchethics/policyandprocedures.aspx**

Please note that the process takes **up to six weeks** from receipt of a valid application. **The research should not commence until written approval has been received from the University Research Ethics Committee (UREC) or Faculty Research Ethics Committee (FREC).** You should bear this in mind when setting a start date for the project.

APPLICANT DETAILS

Name of Applicant*	Linda Sumpter		
Faculty	HAS	Department	Health and Social Sciences
Status: Staff/PG Student/ MSc Student/ Undergraduate	PG Student	Email address	Linda.Sumpter@uwe.ac.uk
Contact postal address	[Removed]		
Name of co-researchers* (where applicable)	N/A		

*This form must include the name of the UWE Project Manager (normally the budget holder and PI)

FOR STUDENT APPLICANTS ONLY

Name of Supervisor/Director of Studies	Prof Jane Powell
Detail of course/degree for which research is being undertaken	PhD
Supervisor's/Director of Studies' email address	Jane.Powell@uwe.ac.uk
Supervisor's/ Director of Studies' comments	This topic merits further research. Linda has the skills and all the documents and processes are in order. DBS clearance to follow.

For student applications, supervisors should ensure that all of the following are satisfied before the study begins:

- The topic merits further research;
- The student has the skills to carry out the research;
- The participant information sheet is appropriate;
- The procedures for recruitment of research participants and obtained informed consent are appropriate.

PROJECT DETAILS

Project title	What works when engaging partners and families in the reablement of older people, for whom, how and in what circumstances?		
Is this project externally funded?	No		
If externally funded please give PASS reference	N/A		
Proposed start date for the research	August 2019	Anticipated project end date	July 2020

Fieldwork should not begin until ethics approval has been given

DETAILS OF THE PROPOSED WORK

1. Aims, objectives of and background to the research

This should provide the reviewer of the application with sufficient detail to allow them to understand the nature of the project and its rationale, and the ethical context, in terms which are clear to a lay reader. Do not assume that the reader knows you or your area of work. You may provide a copy of your research proposal in addition to completing this section. Please try to keep within 500 words.

This is the second phase of a two–phase study with [name removed]'s Reablement Service. The first phase is complete. The Faculty Research Ethics Committee approved the application for the first phase on 12th September 2018 (UWE REC REF No: HAS.18.07.206).

Aim

The main aim of this postgraduate research study is to investigate what works when engaging the partners and families of older people receiving reablement services.

Background

Reablement is defined by the National Institute for Health and Care Excellence as "Assessment and interventions provided to people in their home (or care home) aiming to help them recover skills and confidence and maximise their independence" (NICE, 2017).

There are a multitude of ways in which reablement is described but the core components can be summarised as follows:

- It is about helping people to do things for themselves, rather than doing things to or for them
- It is time-limited. The maximum time is agreed at the start and is generally between six to eight weeks
- It is goal-focused, with the overall goal being helping people to live in their own home. Goals are agreed between the service user and the reablement team
- It is delivered by a team of professionals from a range of backgrounds
- It is a personalised approach, tailored to the needs and goals of the individual service user
- It assumes that needs and abilities will change during the intervention and that these are assessed and responded to on an ongoing basis. A reassessment is made at the end of reablement
- It may involve providing appropriate equipment and/or assistive technology, and guidance on how to use it

The overall purposes of a reabling approach are understood to maximise the service user's ability to remain living in their own home in order to reduce or minimise their need for ongoing support after reablement. Although NICE guidelines explicitly recommend involving family carers (where they exist) in reablement, there is very little reference in research to date on the extent to which this is happening, under what circumstances it works best and for whom. Furthermore, outcomes for reablement are expressed and measured from the perspective of service providers and cost savings to them. The standard outcome measure relates to the proportion of people aged 65 and over who are still at home 91 days after discharge from hospital into reablement services. Outcomes relating to the success of incorporating a reabling mindset into everyday life following the intervention from the perspective of service users and their families are not reported on in any standardised way, if at all, in the UK.

As partners and families are likely to play an important role in the ongoing support of older people following the intervention, finding appropriate ways to facilitate their involvement in and understanding of the approach as well as understanding how the approach affects the way they live once the intervention is over, could add significantly to its long-term benefits.

Objectives

The objective of this phase of the research is to investigate whether and how a reabling approach is sustained after delivery of the service with service users and their cohabiting partners/family members (dyads). This will contribute to refining theories about the balance between independence and interdependence. Through interviewing dyads, the researcher will explore:

- Whether reablement takes on a life of its own after the reablement team has left
- If so, how the dyad has modified it
- When a reabling approach is used in everyday life
- How the dyad is integrating (if at all) the approach into their life together

2. Research methodology to be used

You should explain how you plan to undertake your research. A copy of the interview schedule/ questionnaire/observation schedule/focus group topic guide should be attached where applicable.

I am using a realist methodology in this research in order to explain how family carers react and respond to their involvement in reablement. This methodology is particularly well suited to the study as it is based on the notion that an intervention like reablement does not create change in itself; change is created by people's responses to the intervention. The approach was specifically designed for the assessment of complex programmes, services, interventions and policy. It focuses on how an intervention works, for whom, under what circumstances and why rather than solely on whether it works or for whom it works.

Central to the approach is the involvement of stakeholders in refining theories about how the intervention works or not. The research has the support of [name removed]'s Director of Adult Social Care ([name removed]) and Head of Service for Reablement, Intermediate Care and Regulated Services ([name removed]) who agreed that I can collaborate with their reablement service during the course of this project.

The first phase of the project was a realist synthesis of existing research and information relating to the involvement of family carers in supporting home-based reablement for older people. This resulted in a set of initial theories about what causes family carers to be involved in reablement and what is thought to impact on their collaboration with service users and reablement practitioners. This phase was predominantly based on evidence derived from literature and documents relevant to the research. This was followed by another phase of research for which ethics approval was gained from the FREC. During this phase fieldwork was conducted with one of the Council's reablement teams. Interviews and a focus group were conducted with staff from this team in order to refine and prioritise the theories coming out of the realist synthesis.

This application relates to the final phase of the research: interviews with service users and their cohabiting partner or family member. I have designed and agreed how to approach this phase with [name removed]'s Service Manager and Team Manager for the reablement service in [name removed]. They have agreed in principle to this phase, pending approval from UWE's Ethics Committee and their own research application reviewers (see section 4 below).

3. SELECTION OF PARTICIPANTS

You must indicate if any of the participants in your sample group are in the categories listed. Research involving adult participants who might not have the capacity to consent or who fall under the Mental Capacity Act must be reviewed either by an NHS Research Ethics Committee or the National Social Care Research Ethics Committee.

If your proposed research involves contact with children or vulnerable adults, or others of the specified categories below, you may need to hold a valid DBS check. Evidence of a DBS check should take the form of an email from the relevant counter signatory confirming the researcher has a valid DBS check for working with children and/or vulnerable adults. It is the responsibility of the applicant to provide this confirmation.

Members of staff requiring DBS checks should contact Human Resources hr@uwe.ac.uk. DBS checks for students are usually organised through the student's faculty, but students in faculties without a DBS counter signatory should contact Leigh Taylor (Leigh.Taylor@uwe.ac.uk).

Will the participants be from any of the following groups? *('x' as appropriate)*

☐ Children under 18*

☐ Adults who are unable to consent for themselves

☐ Adults who are unconscious, very severely ill or have a terminal illness

☐ Adults in emergency situations

☐ Adults with mental illness (particularly if detained under Mental Health Legislation)

☐ Prisoners

☐ Young Offenders

☐ Healthy Volunteers (where procedures may be adverse or invasive)

☐ Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, medical students

☒ Other vulnerable groups – Please see below

☐ None of the above

** If you are researching with children please provide details of completed relevant safeguarding training.*

If any of the above applies, please justify their inclusion in this research.

The focus of this research is people over the age of 65 and their partners/family members. It is likely that some of them will be frail. People living with dementia or any other condition that means that they do not have capacity to consent – whether they are the service user or their partner or family member - will not be included in the sample. People who have a known mental health condition or are known to have a drug or alcohol dependency will not be included either. The Council is able to screen in order to exclude these groups.

4. Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English

In this section, you should explain the rationale for your sample size and describe how you will identify and approach potential participants and recruit them to your study.

In realist studies, choices about sampling are driven by the ideas under investigation, the cases being examined are used to work out the relation between ideas and evidence. It is not the size of the sample that is key but rather how cases are used to interpret and explain the contexts, mechanisms and outcomes under investigation (Sampling and choosing cases in qualitative research: a realist approach, Nick Emmel 2013). In this study I aim to interview to a small number of dyads together – a former reablement service user and the person they live with. This could be their partner or a family member. In discussion with [name removed]'s Service Manager and Team Manager for the reablement service in [name removed], we agreed on a maximum of 10 dyads but it is likely that fewer than this will be needed to meet the aims of the study. The former service users will all be over the age of 65 and a mix of men and women. The area of [name removed] under examination is not very ethnically diverse so, although it is desirable to include an ethnic mix in the sample, this will not be an essential selection criterion.

The Service Manager, Team Manager and I have agreed on the following approach:

1. Introduce the project to potential participants
Senior reablement workers to tell service users who are over 65 years and are cohabiting with someone else (partner or family member) about the project (in brief) when they meet them at the start of reablement. The researcher will provide the Team Manager wording for the senior reablement workers to use (Appendix A).

2. Give potential research participants full information about the project
In their penultimate visit to service users, reablement workers will give service users who are cohabiting with someone and meet the sampling criteria a participant information leaflet (Appendix B) and Privacy Notice (Appendix C) explaining the research in detail. This is to give them enough information to think about whether they would like to take part or not. The reablement worker will ask them if the researcher may attend with the reablement worker at the final visit to tell them about the study.

3. Introduce researcher to service users
In the last visit to service users at the end of their reablement service, the researcher will accompany the reablement worker to introduce herself and establish whether the service user and family would like to take part. If they do then the researcher would ask them to sign a

consent form (Appendix D) and set up a means of communicating with them to organise an interview.

It is acknowledged that a reablement worker's visit is 30 minutes in length and that some visits might not be appropriate (e.g. those focusing on personal care). It might be more appropriate in some cases to arrange a separate visit with a senior reablement worker. The Team Manager is willing to arrange these as necessary.

4. Interviews with former service users and their partner/family member

Having established consent from both service users and their partner or family member, and agreed a date, the researcher will interview former reablement service users and their cohabiting partner/family member in their own home. This would take place around two months after discharge from reablement.

The Team Manager has agreed to provide the following information about those who agree to be interviewed:

- Main reason for receiving reablement
- Their reablement goals
- How long they were with the service
- How long they have waited for a package of care that will follow on from reablement (if relevant)
- If they are receiving a package of care organised through the Council, whether this is funded or self-funded

The researcher has liaised with [name removed]'s Director of Adult Social Care and the Head of Service for Reablement, Intermediate Care and Regulated Services on this study since August 2017 in order to engage their interest in and commitment. They are in support of this second phase of the research and the researcher will continue to liaise with them about progress.

As described above, the researcher will provide participants with a participant information leaflet and consent form in advance of the interviews. The information leaflet will explain that the interview will be recorded and transcribed, and that their identities will be kept strictly confidential. A coding system will be used and the key will be kept confidential, ensuring that any identifying information about them cannot be associated with the pseudonym that is assigned to them. They will have two opportunities to discuss questions; when the researcher first meets them along with a reablement worker, as well as at the beginning of interviews themselves.

The researcher will only engage participants who are capable of understanding verbal explanations and written information in English.

5. What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)

Informed consent is an ethical requirement of most research. Applicants should demonstrate that they are conversant with and have given due consideration to the need for informed consent and that any consent forms prepared for the study ensure that potential research participants are given sufficient information about a study, in a format they understand, to enable them to exercise their right to make an informed decision whether or not to participate in a research study.

You should describe how you will obtain informed consent from the participants and, where this is written consent, include copies of participant information sheets and consent forms. Where other forms of consent are obtained (eg verbal, recorded) you should explain the processes you intend to use. If you do not intend to seek consent or are using covert methods, you need to explain and justify your approach. Please consider carefully whether or not you need to seek consent for archiving or re-use of data.

As detailed above, I will introduce the study to potential participants and provide them with information leaflets, consent forms and an opportunity to ask questions when I first meet them as well as at the beginning of the interviews. This will provide them with the opportunity to clarify any questions they have before deciding whether to participate. Participant information leaflets and consent forms are attached.

I am also submitting an application to the Council's research governance group which will follow the requirements of the Council's Research Governance Framework. I did this successfully for the first phase of the research.

6. What arrangements are in place for participants to withdraw from the study?

Consent must be freely given with sufficient detail to indicate what participating in the study will involve and how they may withdraw. There should be no penalty for withdrawing and the participant is not required to provide any reason.

Please note: allowing participants to withdraw at any time could prejudice your ability to complete your research. It may be appropriate to set a fixed final withdrawal date.

At all stages of the research, participants' involvement is voluntary and the information leaflets make it clear how they can withdraw if they wish to and when they need to do this by (within seven days of their interview).

7. If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality (or the reasons for not doing so)

You should explain what measures you plan to take to ensure that the information provided by research participants is anonymised/pseudonymised (where appropriate) and how it will be kept confidential. In the event that the data are not to be anonymised/pseudonymised, please provide a justification.

Personal data is defined as 'personal information about a living person which is being, or which will be processed as part of a relevant filing system. This personal information includes for example, opinions, photographs and voice recordings' (UWE Data Protection Act 1998, Guidance for Employees).

[name removed] will not be named in the research and the particular service area will not be identified. Participants will be identified by a pseudonym and an indication of their status in the research (former service user, or a co-habiting partner or family member). They are free to withdraw from the study up to seven days after their interview. It they do, all their data will be destroyed immediately. If they do not withdraw, the list that identifies their name alongside the allocated pseudonym will be destroyed by shredding. A list of participants' pseudonym, their contact details, status, age and record of consent will be stored in a password protected spreadsheet. All electronic information will be stored on a secure computer server and access to it will be password protected and available only to me and my supervisors. This means that the data will no longer be attributed to a specific data subject without the additional information.

Participants will be encouraged not to name reablement workers or other staff. If, however, participants refer to staff by name in their contributions, these people will also be given a pseudonym and coded to protect them in the same way. Any other potentially identifying information, such as names of areas of the city will also be given a pseudonym.

8. Please describe how you will store data collected in the course of your research and maintain data Security and protection.

Describe how you will store the data, who will have access to it, and what happens to it at the end of the project, including any arrangements for long-term storage of data and potential re-use. If your research is externally funded, the research sponsors may have specific requirements for retention of records. You should consult the terms and conditions of grant awards for details.

It may be appropriate for the research data to be offered to a data archive for re-use. If this is the case, it is important that consent for this is included in the participant consent form*.*

UWE IT Services provides data protection and encryption facilities - see http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption_facilities_provided_by_uwe_itservices.shtml

I work on UWE’s OneDrive and back up my work regularly onto an external drive which is stored in a locked cabinet at UWE. I also keep any confidential paperwork (such as consent forms) in this cabinet. Hard copies of data, such as any interview notes will typed up or scanned, encrypted, password protected and uploaded onto OneDrive. Where hard copies are no longer needed, they will be shredded at UWE.

Audio recordings will be encrypted and uploaded onto the UWE OneDrive as soon as possible after recording.

I am intending to use NVivo for my work. This is kept on my laptop’s hard drive. I regularly back it up to a UWE shared drive and onto the same external hard drive mentioned above. Both OneDrive and NVivo are password protected.

Please see a Summary Data Management Plan attached (Appendix E).

9. What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you AddRESS these risks?

Describe ethical issues related to the physical, psychological and emotional wellbeing of the participants, and what you will do to protect their wellbeing. If you do not envisage there being any risks to the participants, please make it clear that you have considered the possibility and justify your approach.

Risk: Participants feel obliged to take part

When the senior reablement worker introduces the idea of participating in the research at the beginning of their service, I will ensure that they emphasise the voluntary nature of participation. I will make sure that this is clear in the participant information leaflet and in the conversations I have with potential participants before setting a date for an interview with them.

Risk: Participants sharing personal accounts of their daily lives

Some combinations of participants might find it awkward or embarrassing to talk about what kinds of daily living activities they help each other to achieve. It is also possible that they might disagree with each other on the extent to which one person helps the other. I will contextualise the aims of the research and make it clear that I am aiming to understand their own accounts (separate and together) of what works and does not work for them.

Risk: Misinterpreting the purpose of the visit

Some people might interpret the interview as an opportunity to give feedback on the quality of the service they have received. I will make it clear that this is not the purpose of the interview at the start and will refer them back to the service if they feel they would like to speak to someone from the service again. Others might think that I am interviewing them in a role as an assessor of their current level of ability to complete the tasks they concentrated on during reablement. Equally, they might think that what they say will have a bearing on any application they might make for ongoing care services. I will ensure that I explain the purpose of the interview very clearly and that I emphasise that it is not for any of the purposes suggested here.

Risk: Perception or disclosure of a risk of harm

If I am told something that indicates that someone (staff or service user) was put at risk of harm during the provision of the service or might be at risk within their current home environment then I would discuss this first with the person who has said it before reporting it to the Head of Service.

10. Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this Research that are greater than those encountered in normal day to day life?

Describe any health and safety issues including risks and dangers for both the participants and yourself (if appropriate) and what you will do about them. This might include, for instance, arrangements to ensure that a supervisor or co-researcher has details of your whereabouts and a means of contacting you when you conduct interviews away from your base; or ensuring that a 'chaperone' is available if necessary for one-to-one interviews.

Please check to confirm you have carried out a risk assessment for your research ☒

Myself:

All of these meetings will take place at the homes of former reablement service users. Some of these will have no further link with the reablement service since discharge from it. I will notify my supervisors of my interview timetable and will arrange to report to one of them when I have left each participant's home and for them to contact me if I have not done so within the anticipated timeframe. If for any reason I feel unsafe in a participant's home I will cut short the interview and leave. I will have a mobile phone with me.

11. How will the results of the research be reported and disseminated?

Please indicate in which forms and formats the results of the research will be communicated.

(Select all that apply)

☒ Peer reviewed journal

☒ Conference presentation

☒ Internal report

☒ Dissertation/Thesis

☒ Other publication

☒ Written feedback to research participants

☒ Presentation to participants or relevant community groups

☒ Digital Media

☒ Other (Please specify below)

If there is an opportunity to disseminate findings via a Council publication I will take this up.

12. WILL YOUR RESEARCH BE TAKING PLACE OVERSEAS?

If you intend to undertake research overseas, please provide details of additional issues which this may raise, and describe how you will address these. Eg language, culture, legal framework, insurance, data protection, political climate, health and safety. Please also clarify whether or not ethics approval will be sought locally in another country.

N/A

13. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?

This gives the researcher the opportunity to raise any other ethical issues considered in planning the research or which the researcher feels need raising with the Committee.

Because realist enquiry relies on ongoing collaboration with stakeholders, the research may change as the project progresses. The committee will be updated on any major changes if they arise.

CHECKLIST

Please complete before submitting the form

Please note: supporting documentation should include version numbers and dates

	Yes/No
Is a copy of the research proposal attached?	Yes Appendix F
Have you explained how you will select the participants?	Yes
Is a participant information sheet attached?	Yes Appendix B
Is a participant consent form attached?	Yes Appendix D
Is a copy of your questionnaire/topic guide attached?	Yes Appendix G
Have you described the ethical issues related to the well-being of participants?	Yes
Have you described fully how you will maintain confidentiality?	Yes
Have you included details of data protection including data storage?	Yes Appendix E
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	Yes Appendix H
Is a Risk Assessment form attached? (HAS only)	Yes Appendix I
Have you considered health and safety issues for the participants and researchers?	Yes

Additional Appendices:

A: Wording for Senior Reablement Workers introducing the project

C: Privacy Notice

DECLARATION

The information contained in this application, including any accompanying information, is to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Principal Investigator name	Linda Sumpter
Signature	See signed declaration sheet
Date	18/06/2019
Supervisor or module leader name (where appropriate)	Professor Jane Powell
Signature	[Removed]
Date	18/06/2019

The signed form should be submitted electronically to Committee Services: researchethics@uwe.ac.uk and email copied to the Supervisor/Director of Studies where applicable together with all supporting documentation (research proposal, participant information sheet, consent form etc).

For student applications where an electronic signature is not available from the Supervisor we will require an email from the Supervisor confirming support.

Please provide all the information requested and justify where appropriate.

For further guidance, please see http://www1.uwe.ac.uk/research/researchethics (applicants' information)

Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

UWE research ethics reference number:	HAS.19.06.213 Sumpter
Title of project:	What works when engaging partners and families in the reablement of older people, for whom, how and in what circumstances?
Date of original approval:	18 July 2019
Researcher:	Linda Sumpter
Supervisor (if applicable)	Prof Jane Powell

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

Currently the recruitment strategy outlined in section 4 of the approved ethics application has two essential selection criteria:

1. Reablement service users who are 65 years+ AND
2. Reablement service users who co-habit with someone

I would like to amend criteria 2 only as follows:

1. Reablement service users who are 65 years+ AND
2. Reablement service users who have a family member or partner (co-habiting **or not**) who has engaged with the service in some way while it is being delivered.

Engagement will be determined by [name removed] Reablement Team South. It will include:

1. Contact made directly with the team in the service user's home
2. Contact made by means of the service user's case notes which are kept in their house or
3. Contact made with the team at their office (e.g. by phone, email or visit).

2. Reason for amendment. Please state the reason for the proposed amendment.

The main aim of this postgraduate research study is to investigate what works when engaging the partners and families of older people receiving reablement services. Unfortunately during the recruitment phase very low numbers of new service users who cohabit with someone have been registered to the service.

By including family members who do not cohabit with the service user it is anticipated that more potential participants will be reached, while still informing the aim of the study. This potential amendment has the approval in principle from [name removed]'s Reablement Team Manager, the key contact and gatekeeper for the study.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

This will not give rise to any additional ethical issues. Interviews will remain face-to-face, in the service user's home only and only where both participants have consented to be interviewed. It will not be necessary to collect any additional information such as address details from family members who do not cohabit with service users.

Some minor adjustments to the wording on the consent form and participant information leaflet are required to encompass this amendment. Copies of these which show the proposed amendments are attached.

To be completed by supervisor/ Lead researcher:

Signature:	*Via email*
Date:	

To be completed by Research Ethics Chair:

Send out for review:	☐ *Yes* *X No*
Comments:	*These changes not further ethical issues and the documentation reflects the changes accurately .*
Outcome:	☐ *Approve* ☐ *Approve subject to conditions* ☐ *Refer to Research Ethics Committee*
Date approved:	*21st Jan 2020*
Signature:	*Dr Julie Woodley (via e-mail)*

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

UWE research ethics reference number:	HAS.19.06.213 Sumpter
Title of project:	What works when engaging partners and families in the reablement of older people, for whom, how and in what circumstances?
Date of original approval:	18 July 2019
Researcher:	Linda Sumpter
Supervisor (if applicable)	Prof Jane Powell

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

Subsequent to amendment approved on 21 January 2020, I would like to make a further minor amendment.

In Section 4 of the existing approval (Interviews with former service users and their partner/family member), I planned to interview service users and their family member "around two months after discharge from reablement".

I would like to amend this to shorten this timeframe, to conducting interviews towards the end of their reablement or shortly after discharge from it.

2. Reason for amendment. Please state the reason for the proposed amendment.

Due to delays in recruitment, the timeframe for conducting the interviews is becoming very restrictive. For this reason and in discussion with my supervisory team, I would like to conduct the interviews towards the end of reablement rather than waiting for 6 weeks. This would not change anything other than the way this is described on the consent form and participant information leaflet.

This potential amendment has the approval in principle from [name removed]'s Reablement Team Manager, the key contact and gatekeeper for the study.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

This will not give rise to any additional ethical issues. No additional changes are required to the consent form. Some minor adjustments to the wording on participant information leaflet are required to encompass this amendment. A copy of this proposed amendment is attached.

To be completed by supervisor/ Lead researcher:

Signature:	*By email*
Date:	

To be completed by Research Ethics Chair:

Send out for review:	☐ *Yes* *x No*
Comments:	*This amendment raises no new ethical issues and so can be granted approval.*
Outcome:	*x Approve* ☐ *Approve subject to conditions* ☐ *Refer to Research Ethics Committee*
Date approved:	*23rd Jan 2020*
Signature:	*Dr Julie Woodley (via e-mail)*

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

Appendix X

PPI group meeting 2 - commentary

PPI Research Advisory Group Meeting Note

27 September 2018, PPI Room, Health Tech Hub, UWE

Present: [Names not included]

I asked everyone if they wanted to share something about their own caring responsibilities. Without naming who is who they represented:

A. A wife caring full time for her husband (his health condition not offered)

B. A wife caring for her husband (she said that she has been very clear with herself and service providers about what she is and is not prepared to do herself). She also used to care for her father who was living with dementia and lived quite close to her

C. A mother of an 11 year old autistic boy

D. A husband caring for his wife who is living with vascular dementia. Has been caring for [12+?] years

E. A father caring for his son with a life-threatening illness

4 of them are familiar with each other having contributed through another Carers Centre to various consultations, including [reference removed]. The fifth has had involvement previously with UWE's Right Trousers research project.

1. Initial discussion

About terminology. Their preferred terminology (something 4 of them had recently discussed) is:

Care Worker (someone employed to care)

Carer (always unpaid and "voluntary" – to a greater or lesser degree)

They did not associate with family carer although recognised that it might be necessary to use this in certain write-ups of the research for the purposes of policy makers' terminology.

They discussed the fact that for a long time many of them considered themselves as husband, wife, mother or father to the person they cared for rather than their "carer" but that at some point there has come a time where their perception of themselves has shifted to a recognition that they are fulfilling a carer role and will therefore have some association with the term at this stage.

We discussed "Service User". C said that "loved one" is often used but the others did not feel comfortable with this term.

2. Theories selected to discuss

I selected theories taken from Initial Theory 5 – Holistic View of Family Support as this cuts across the reablement journey timeframe. With where I had got on allocating statements to theories, this had become a bit of a catch-all and I need help in theming it. Looking through the items in that category I had identified potential themes as being:

- Understanding where carers are coming from
- Training carers
- Reassuring carers
- Drawing on carers' knowledge/them as a resource
- Dealing with conflict
- Willingness to involve carers
- Social dimension to reablement

I selected 17 if… then… statements that roughly equated to 4 areas:

- Understanding where carers are coming from (statements 17 45 79 120 135 139 156)
- Person-centred care/autonomy/interdependence (statements 83 85 87 88 104 106 111 113)
- Training carers (18)
- Social dimension to reablement (178)

I explained that the statements had been taken from existing research and that I was wanting to unpick them. In pairs we read through a couple of statements at a time and discussed them between us before discussing them as a group. Initially the group thought that they had to agree or disagree with the statements. They then moved away from this and discussed them in depth.

3. First grouping of theories – understanding where carers are coming from

17	the reablement team is aware of the carer's change in roles and relationship and in their sense of identity	they will be better equipped to support carer's emotional and practical needs	003

This was taken to be obvious so did not provoke much discussion.

45	family carers want to be invited to collaborate in a way they consider to be important	reablement team may need to be prepared to navigate conflicting expectations	003

They represented the voice of carers who **do** very much want to be involved. They pointed out that the perception of the cared for person can be very different to that of the carer and this needs to be understood by reablement workers. The difference in perceptions might relate to what the service user considers they are able to do but also how much they consider that their family carer can do /is willing to do (intimation was that they tend to overestimate this). They pointed out that if family carers are involved in goal-setting then this difference of perceptions would not arise.

79	the reablement team understand the needs of and pressures on family carers	they could provide specific support for family carers regarding how they could better manage their situation	005

In addition to needs and pressures, the group emphasised that willingness and ability needs to be part of this statement. They stressed that it is the right of family carers to decide <u>not</u> to undertake a role or roles.

135	a small number of people make reablement visits	family carers and service users do not have to keep repeating the same information to different workers.	007

This one was considered a key one to flag up. E mentioned how technology should be doing more so that information is easily available. We had a short discussion about access rights to information and the complexity of this both in terms of access to data by professionals as well as carers. We discussed that this might be an issue of whether or not it is feasible for particular reablement teams to be able to guarantee the same reablement worker or not. They emphasised the increased need for information to be easily available where a reablement worker new to a service user visits them. They wondered how reablement workers prepare for visits if paper notes are kept in the service user's house. Discussion about integrated care records – with particular reference to [named removed] and how although this had been a central part of their bid, it is proving extremely challenging to put into practice.

120	family carers welcome the support of, and regular social contact with, home care workers	they may be wary of losing these relationships and not buy into the ethos of maximising long-term independence and quality of life	007

This was difficult to understand because of the way it is written. Once we agreed an understanding, they agreed that expectations need to be addressed at the start of reablement and that they should cover this aspect. At this point, a reablement worker should be able to determine if a family carer is isolated themselves. They wondered whether they do this and if so, do they refer them on for support?

It was discussed that this might be a point at which a family member moves from considering themselves as a relative to considering themselves as a carer – i.e. a change in the way they see their role/self-define.

We had a related discussion about the failings of hospital discharge services and there were several comments and examples given of poor hospital to home transfer. E.g. One person's husband was discharged on a Friday and told that they full support would be available, however because it was then the weekend, this did not materialise until the Monday was caused considerable difficulty and distress. The general consensus was that a wait of 2 days (target for commencement of reablement after discharge) was too long. They also felt it is common for hospital staff to overestimate the ability of the person they are discharging in order to free up beds.

Someone stated that they felt over-prescribing reablement is an issue – ie it was insufficiently well judged to be the right service at the right time.

139	reablement workers do not stick to the schedule they have planned for visits	this can cause frustration and disruption to service users and family carers' plans	007

This was felt strongly to be more than just frustration and disruption but rather as "chaos" and can give rise to confusion for the service user. It gives carers the feeling that reablement teams assume family carers have nothing else to do. This is particularly bad when changes are not communicated. They discussed situations where co-caring is happening (i.e. both parties have health issues that they help each other with) and how changes impact on this.

They also referred to the need to establish who the main contact is going to be and that this person needs to be someone who understands as much about the situation as possible and might not be the service user themselves. They again referred to the situation in which a service user might hold the view that their family carer will do certain things for them. If the family carer is not there and involved in discussions, they will not know that this has been referred to.

Someone pointed out that it is not always possible to establish how "reliable" the view of the service user is. This person gave the example of her relative coming across as very logical, clear and convincing yet only giving partial information (I had a stroke recently – whereas the stroke had been 12 years previously).

They categorically stated that if service users make decisions without the involvement of their carer, then the carer will not buy into the process and is likely to be disruptive.

"Carers are experts on their own experience".

An extension of this idea was expressed as **one cannot rely on service users having a full appreciation of how much is needed of a carer and how much a carer does for them.**

156	emotional support is given to family carers	is highly valued and helps to relieve pressure on care-giving relationships	007

This was not discussed in detail. It was perceived as being obvious.

The above discussion about whether the service user's perception is always to be relied upon led naturally into a discussion about the tensions between person-centred care/autonomy/interdependence (statements 83 85 87 88 104 106 111 113).

4. Person-centred care / autonomy / interdependence

We discussed the inter-linked statements which seemed to reflect a sliding scale of how a reablement worker might regard the need for involving a family carer:

83	reablement worker views the service user as entirely autonomous	the reablement worker might consider that it is **not always** necessary to include family carers	005

87	the reablement team perceives that there is **not always** a need to involve family carers in reablement	this could be the result of a conscious choice by the reablement team	005

85	reablement workers feel **ambiguous** about when and why to involve family carers	this lack of clarity could be transferred to the family carers and service user	005

It was agreed that if as in statement 79 the reablement team understands the needs and pressures on family carers, then the above statements will be contradicted.

111	reablement teams view family carers as an extension of the reablement service	family carers might feel forced into a caring role or to take on comprehensive tasks	005

The team felt strongly that carers should be working in collaboration with the team rather than being considered as an extension of the team.

88	the reablement team perceives that it is the responsibility of the service user to contact family carers	they will not take responsibility for involving the family carer	005

The team disagreed with this, based on their experience.

106	a family-centred approach is adopted	reablement teams will be able to acknowledge and respect family carers' needs without sacrificing service users' interests or authority	005

The above statement appeared to capture thinking on this theme and they felt this approach must be adopted right from the start.

They suggested the idea that at the beginning of reablement a list of assistance relevant to the goals should be drawn up and the carer can decide and agree what they can and cannot do / will and will not do in relation to supporting the service user to achieve their goals. (refer Care Act which states that the carer should be given this choice). This would allow for it to be very clear to the reablement team what level of involvement to expect from the carer.

113	reablement teams involve family carers fully in reablement	this will reduce the amount of time they are able to devote to the service user	005

What does fully mean here? Some carers are always there. It might be useful for carers to have opportunities to speak to reablement workers separately i.e. when they are not with the service user. It was felt that in any case involving the family carers as an extra resource would save money in the long run as it would imply a reduced risk of conflicting goals.

104	reablement teams acknowledge that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning	they may adopt a family-centred perspective and develop a better understanding of family carers in reablement	005

The team had considerable difficulty making sense of the above if… then… statement. I said it could be taken to mean that if reablement teams always regard that the service user as functioning in a social/community context then they will be more likely to involve family carers in the way they want to be and can be involved. This is an extension of the other statements in this section.

We did not discuss 178 and 18, however, 178, is connected to 104.

18	family carers are trained in such skills as personal care, feeding, swallowing problems, transfers, and mobility activities	this will empower them to a greater degree than offering advice and support, or enhancing their psychological competence	003

178	attention is paid to the social dimensions of service users' and family carers' lives	this would enhance motivations for independence	007

Appendix Y

Topic Guides

1. For reablement staff interviews

2. For focus group

3. For family interviews

4. Realist wording prompts

1. Topic guide for reablement staff interviews

Realist Interviews at [Name of Service]

Monday 11th February 2019

For interviews with OT, Team Leader and Senior Reablement Worker (adjusted for Referrals Coordinator and Service Manager)

Aim: To refine through the benefit of their experience some of the ideas coming out of existing research

1. Exploring 7 ideas theories

1. If the reablement team regard partners and families as a resource, then they will be able to reinforce the reablement team's work by supporting and motivating the service user. (25)
    a. Why would this sometimes work?
    b. Why would this sometimes not work?
    c. Rival theory: Discussions about care can proceed without further examination of the willingness or ability of the significant other to take on this often demanding role (193) / might feel forced into a caring role or to take on comprehensive tasks (103)
2. If partners and families are given education and skills training in how to support their relative, then this will support them in their role as part of the reablement team. (16)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?
    c. Rival theory: They might feel concerned that they will lose entitlement to other services following reablement.

3. If reablement teams respect partners and families and recognise their role as part of the whole care circle, their role will be maximised. (251)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?
    c. Rival theory: the reablement worker might consider that it is not always necessary to include family carers (ref service user autonomy) (75) **OR** family might experience collaboration as a burden (35)

4. If the content of the intervention is designed with the partner's and family's needs as a crucial factor, then this will encourage their active participation. (131)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?
    c. Rival theory: Needs and willingness may change over time (231) **OR** they may be wary of losing these relationships and not buy into the ethos of maximising long-term independence and quality of life (109)

5. If the reablement team is able to negotiate and manage different expectations and opinions, then this will enhance collaboration. (63)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?
    c. Rival theory: the reablement team has to spend extra time persuading and negotiating with family carers whether reablement is the right type of assistance for the service user (67) **OR** Experience family as dysfunctional (81)

6. If there is a system, a routine, an automatic process, a culture, and an attitude of giving and receiving information that was valuable to all parties of the reablement process, then partners and families would have an opportunity to provide input on the content of the reablement process. (18)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?

    Rival theory: If families' overall feeling is gratitude they may not want to voice criticisms or requests (170)

7. If partners and families are advised on how to carry out routines after reablement is finished, then their confidence in their own ability to provide care and safeguard their own welfare will be increased. (148)
    a. In what circumstances would this sometimes work?
    b. In what circumstances would this sometimes not work?

    Rival theory: They might subsequently not seek help when they really need it

2. How encompassing are these statements?

3. What things would have the most potential to impact on the service in terms of engaging partners and families?

4. **What things could improve the sustainable impact of the service in terms of engaging partners and families?**
5. **Adjudicate between context groupings – which do you think could help to innovate the intervention? Add any more not considered here**

NB Some service users have nobody else closely involved in their lives. We are not talking about them here. We are talking about people who have a partner and/or family involved in their lives

Characteristics of partner/family member(s)

See Appendix AA

6. **In terms of engaging partners/family carers, what does successful reablement look like? What are the main desirable outcomes?**

e.g. confidence, perception of risk, capacity to motivate, capacity to assess progress, knowing when to intervene and when not, reduced sense of burden, communication, negotiation, partnership, opportunity to develop capacity for judgement, shared decision-making, enhancing independence, returning to balance in interdependence.

7. **Do you have any ideas about striking a balance between autonomy and interdependence in reablement – before, during and after?**

If the reablement team acknowledges that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning, then they may adopt a family-centred perspective and develop a better understanding of family carers in reablement. (96)

2. Topic guide for focus group

Realist Focus Group at [place name removed] Intermediate Care with Reablement Workers

Wednesday 20th February 2019 11.00 - 12.30

Aims:

To seek ideas on the most relevant contexts that impact on the engagement of partners and families in order to understand the spectrum of attitudes and competencies of family.

To explore and adjudicate between selected rival theories drawn from the literature that are triggered at the reablement worker level and to refine them.

Focus Group Guide

1. Emphasise that this not an evaluation of the service or of their skills

2. My background – not reablement but older people living in care/activity coordinators and own experience of caring

3. Check understanding of participant information sheets, answer questions and sign consent forms

4. Ask about length of time with the service and care background

5. Aims of the research (NB partners and families only)

6. ***Aim of the focus group***
    a. ***to share ideas coming out of the existing research and explore them with the benefit of their experience.***
    b. ***Interested in exploring different views not to get agreement.***
    c. ***Interested in why things sometimes work and sometimes don't.***

7. Ground rules and questions

8. What background things are most likely to affect how involved in reablement partners and families get?

    Several ideas are coming out of the existing research. I'm interested in your experience of how important you find these to be.

    Yellow cards. Discuss one by one.

    In your experience has this been true?

Any more key things at this stage that you would add?

9. Would like to tell you about five ideas that are coming out of the research and get your reactions to these in order to refine them. 5 ideas – exploring why things sometimes work and don't.

10. Which of the things we've talked about in terms of involving partners and families have the most potential to keep the positive impact of their work going beyond reablement?

11. If time:

Ideas on outcomes for FCs – what does successful reablement look like for them?

To refine:

Equipping FCs to support their partner or relative appropriately during reablement

Equipping FCs to support their partner or relative appropriately during and after reablement

Giving FCs a break from caring

Introducing carers to a new way of caring that is more reabling, hands off rather than doing for – knowing when to intervene and not

Learning from reablement workers tips and tricks for motivating their partner or relative to do things for themselves

Learning how to judge when it is safe to leave their partner to do something for themselves and when not (new perception of risk)

Learning how to interact with their partner or family to make decisions about things related to independence that affect them both

To feel confident that they can support in the right way

To realise that they do not need to do everything, reducing a sense of burden

To realise that they have choices about what they are willing and able to do as a "carer".

Raising their ability to assess progress.

Improving how they communicate with their relative and share decision-making

Re-establishing a balance between independence and interdependence.

Do you have any ideas about striking a balance between autonomy and interdependence in reablement – before, during and after?

If the reablement team acknowledges that older adults can be considered mutually dependent on their social surroundings regardless of their level of functioning, then they may adopt a family-centred perspective and develop a better understanding of family carers in reablement. (96)

3. Topic guide for family interviews

1. Thanks and introduction

Thanks for agreeing to participate in the research
Introduce myself
Questions and answers about the Participant Information Leaflet.
Check consent forms

2. Purpose

Describe purpose of the research – to understand what works when engaging families in reablement

Describe purpose of the interviews:
- to share some of the ideas coming out of the research so far.
- to find out how accurate you think these are and how you would alter them to be more accurate based on your experience.

3. Procedure

Audio-recording, transcription and outputs
Confidentiality
Description of approach to interview
Timing: We've got 45 mins. I've allocated 5 mins to explain things together and then 15 mins to talk to you individually leaving a bit of time to talk together again at the end. Does that sound ok?

4. Checking information about their reablement

Confirm:

Reason for receiving reablement
First experience of reablement?
Length of time with service so far

Relationship between the two interviewees.

** Start recording here **

5. Discussion of ideas coming out of the research so far

6. What next

Summary of what I will do with findings and their access to them if interested.

7. Thanks

Discussion of each idea coming out of the research

Had you ever heard of reablement before you were referred?

How did you get to understand what it was?

How would you say it differs from other types of homecare?

1. Understanding of reablement (if-then 1)

There's this idea that IF the families of service users undertaking reablement have a good understanding of what it is, THEN even if they might have some reservations about it to start with, they will welcome or accept more of a standing back approach.

Because they understand the benefits of encouraging someone to do things for themselves rather than doing things for them.

Do you think there's any truth in that idea?

2. Family informed about how to support (if-then 11) - upskilling

There's this idea that IF the families of service users undertaking reablement are informed about how to support and motivate their relative, THEN this will support them in their role.

In your experience has this been true?

- Individualised information, advice and training provided to families in line with goals
- Families feel empowered to support
- Families are confident, capable and motivated to support the service user

3. Family advised how to carry out routines after reablement (if-then 14) - upskilling

Another idea coming out of the research is that IF families are advised on how to carry out routines after reablement is finished, THEN this will increase their confidence in their own ability to provide care and will safeguard their own welfare.

Do you think there's any truth in that idea?

4. Family's needs are a crucial factor (if-then 7) – customising

There's another idea that IF the content of reablement is designed with the family's needs as a crucial factor, THEN this will encourage their active participation.

What is crucial about considering the family's needs?

- Family feels valued and empowered
- Willing and able
- Things change

5. Family regarded as a resource (if-then 12) – resource

There's an idea about regarding the family as a resource for reablement. IF reablement teams regard families as a resource, THEN they will be able to reinforce the reablement team's work by supporting and motivating the service user.

In your experience has this been true?

- drawing on the family's knowledge of the service user's preferences
- treat family as a useful resource to help achieve reablement goals both during and after reablement
- families are stimulated by seeing their relative make progress to become more involved themselves

- family becomes motivated to encourage and support the service user in a reabling way (seeing is believing)

- Is concurrence of attitudes towards the family as a resource for reablement necessary to trigger their contribution to and respect for the intervention?

- Interdependence

6. General discussion at end

There is this idea that involving families in reablement, will increase the chance that a reabling approach will be continued afterwards. From your perspective, does that ring true?

How do you think the experience of trying out the reabling approach will affect the way you approach things after reablement?

- Willingness and ability of the partner or family member to engage with reablement before, during and after the intervention
- Confidence and skills in continuing to apply the approach in everyday life after the service

Anything else that you see as important to engaging families in reablement?

4. Realist wording prompts

There’s this idea that… if you do x then y.

Has that been your observation?

In your experience has this been true?

Do you think this will be true?

Do you think there’s any truth in that idea?

What is it about x

that makes a difference?

that makes it difficult for x to do y?

that has an impact on x leading to y?

that motivates you to do xyz?

that you think makes it effective (or not)?

I noticed…

I wondered…

I see, so you’re saying that … is that correct? – reorganise as M-O or CMO in checking question

I see, so you’re saying … What it is about x that doesn’t work for [person type]

I see, so you’re saying … What was it about x that led you to feel that way?

Appendix Z

Sample job description for a reablement worker

Source: https://www.indeed.co.uk/jobs?q=Reablement&l&vjk=d82d2d391a2f0c82 [Accessed 19/01/2021]

Support Worker - Reablement

Peterborough City Council41 reviews - Peterborough

£10.01 - £10.41 an hour - Part-time

Are you looking for a new fulfilling career opportunity?

The reablement team provides a life changing service to people by helping them to regain or attain as much independence as they can in their own homes.

Our support workers do this by motivating and inspiring people to re-learn daily skills and enhance their quality of life.

You will be fully trained to assist our service users to meet their care needs, which can range from motivational support to personal care.

You will work to individualised goal plans, with the aim of encouraging service users to do these things for themselves, wherever possible. We also promote and supply tech equipment to help people.

Preference will be given to candidates with experience in the care sector and we will help support you to reach your full potential by providing you with training, guidance and career development.

We will assist you with gaining your Care Certificate and your Level 2 or 3 Diploma in Health and Social Care, as well as:

- Generous mileage allowance of 30p per mile
- 24 days annual leave entitlement, plus bank holidays (pro rata)
- Membership of the Local Government Pension Scheme
- Up to £3000 retention bonus after 3 years' service (T&C's apply)
- Professional career development
- Excellent management support.

The role involves travel across Peterborough, so you must be a car driver and have access to a vehicle.
The role is a 9 day fortnights on a 2 week rota with set shift patterns. These are:
16 hour position working evenings, 17:30-22:00,
35 hour post (split shift 8:00-14:00 and then 17:30:21:30), and
26 hour post (split shift 8:00-13:00 and then 17:00:19:30)

To be considered for this role please apply directly, or complete the application form, which can be found in the additional documents section and send this to pccrecruitment@peterborough.gov.uk.

This is a rolling campaign, and we will review applications weekly so please don't wait for the closing date to apply. Candidates will be progressed shortly after they apply, and the opportunity will be filled as soon as we identify a suitable candidate, which may be before the closing date. So please don't hesitate, we want to speak to you now! Please bear in mind that a full job history is required and any gaps in employment will need to be clearly explained.

Appendix AA

Characteristics of family members

As part of the discussions with the reablement team and the PPI group, an initial set of characteristics that vary from family to family was identified. These were not intended to be comprehensive but aided thinking at the time.

Characteristics of partner/family member(s)

Relationship to service user	Describe (e.g. partner, adult child, sibling, adult grandchild, niece, nephew)			
Geographical location	Live in	Live <1 mile	Live >1 mile <10 miles	Live > 10 miles
	Live abroad			
Age				
How identify gender				
How identify sexual orientation				
General physical health				
General mental health				
Known dependencies	e.g. substances			
Stress level				
Employment status	Full time	Part time	Unemployed	Retired
Carer status	No other caring responsibilities	Caring for children	Caring for other adults	At risk of carer breakdown
Attitude to caring role				
Financial status				
Education				

How identify ethnic group, religion and national identity				
Previous experience of health and social care services	None	Traditional homecare	Care out of the home	Reablement
Attitude to reablement at the start	Resistant	Open	Convinced	Advocate
Attitude to reablement at the end	Resistant	Open	Convinced	Advocate
Anything else?	Health literacy?			