# THE MEANING OF INDEPENDENCE FOR OLDER PEOPLE: A CONSTRUCTIVIST GROUNDED THEORY STUDY

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October 2015

#### **Abstract**

Independence for older people has emerged as an increasingly important policy priority. This policy imperative has been driven by demographic and economic concerns at the forefront of policy debates in the UK and internationally.

The aim of this thesis was to gain an insight into the meaning of independence for older people through reviews of the English policy context and existing national and international evidence and interviews with older people.

The UK policy context illustrates three, sometimes conflicting, interpretations of independence. These contrasting ideas were also found in the evidence although there is limited empirical research that elucidates the meaning of independence directly from older people. A constructivist grounded theory methodology was used to enable theoretical and empirical exploration. This inherently iterative approach informed the choice of methods and how the primary data was collected and managed.

Analysis of the findings showed that independence is individually constructed and comprises a number of different dimensions. These dimensions can be grouped into two distinct, but interlinked core categories - 'a sense of independence - dynamic and interactive identity'; and 'the practice of independence - dynamic and interactive agency'. The salience of these categories was shaped by older people's life experiences, personal characteristics and wider social/cultural discourses and could change depending on individual circumstances, preferences and context.

These findings have implications for policy and practice. First, the value that older people attribute to independence is compatible with that evident in current policy. However, the points of dissonance between policy interpretations of the *meaning* of independence and older people's constructs of independence could have serious implications for how older people experience policy, service provision, practice. Second, policy and practice interpretations of independence should aim to be consistent with the aspirations of older people accessing services so that they are able to experience the 'independence' they desire.

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## **Acknowledgements**

I would like to acknowledge and thank the following people for their assistance and support. First, I would like to thank the participants who gave their time and opinions, as well as the organisations were assisted with accessing older people willing to take part. Thanks are also due to my supervisor, Professor Caroline Glendinning for her continuing guidance and patience. Furthermore, I also wish to acknowledge my appreciation for the funding received through the Sally Baldwin studentship.

I also want to take this opportunity to thank my family and friends for their continuing support and in particular two people. Thanks are due to Paul for his ongoing support and adding some humour along the way. Special thanks are also due to Fiona for offering critical and constructive advice while completing this thesis.

I am only sad that Clair, my much loved and deeply missed sister is not here to witness the completion of this thesis.

# **Author's Declaration**

The work presented here is my own and has not been submitted for any other degree at the University of York or any other institution. All sources are acknowledged as references.

#### **CHAPTER 1: INTRODUCTION**

#### Introduction

This chapter presents the demographic and associated economic factors that have played a key role in bringing about the current policy emphasis on the promotion of independence for older people. The chapter is split into four sections. The first section presents the demographic and associated economic context within which this research is positioned. The second considers how the term 'older people' has been defined within this research. The third explains why older people's meaning of independence warrants further attention and introduces the research question, aims and objectives for this thesis. The fourth section presents the structure of this thesis and an overview of the content of the subsequent chapters.

#### An ageing and changing population

Population ageing is a global occurrence, the rate at which it is currently occurring is without historical precedent, and the UK is not exempt from this demographic shift (Christensen et al., 2009; Harper, 2006). The older population in the UK is increasing both in absolute terms (i.e. the total number of older people is rising) and in relative terms (i.e. the percentage of older people as part of the total population is increasing) (Office for National Statistics (ONS), 2012). There are three key reasons for this demographic shift. First, medical advances have contributed greatly by continuing to lengthen the average life expectancy of the population and by improving the survival rates for many conditions that would have previously been life-limiting (Featherstone and Whitham, 2010). A second reason for this demographic shift is that many countries experienced a sharp peak in birth rates after the end of the Second World War, with those born in this period often known as the 'baby boomer generation' (Huber and Skidmore, 2003). The UK was not exempt from this trend, and children born as part of this post-war baby boom are now either approaching or are in their seventies (see Sinclair, 2015). Third, fertility rates have been declining, and thus younger generational cohorts are on average having fewer children than previous generations (Huber and Skidmore, 2003). However, more recent statistics suggest that this latter trend is reversing and that the fertility rate is heading

upwards. Indeed, the UK as a whole has experienced a rise in the number of births in the last decade; this increase has been highest in England at 22% (ONS, 2012). Nonetheless, over the next twenty years, this trend of an ageing population is predicted to continue. In 2010, 16% of the UK population was aged 65 or over, and it is anticipated that by 2035 older people in the UK will make up 23% of the total population.

The most significant shift that is occurring as part of the ageing population is the rise in the number of older people aged 85 and over (Dilnot, 2011; Wanless et al., 2006). Often referred to as the 'older old', this generational cohort is currently the fastest growing across all age groupings (Department of Work and Pensions (DWP), 2005). For example, in 2009, there were 1.4 million people in the UK aged 85 and over, but it is anticipated that by 2035 this number will have risen to over 3.5 million, representing 5% of the total UK population (ONS, 2012). Based on existing and anticipated demographic trends, it is this 'older old' age group that is most likely to need support from health and social care services (Bowers et al., 2009). This cohort, however, is likely to have substantively different needs and differing expectations of services than younger older people (DH, 2012a; Bartlett; 2009).

While the ageing population in the UK is a widely acknowledged phenomenon, the future impact of these anticipated demographic shifts is less certain than it may at first appear. This is largely because any forecasts about ageing populations are based on predictions and assumptions about future demographic behaviour and, as such, are not without uncertainty. For example, it remains unknown whether the recent increase in birth rates outlined earlier is set to continue, or whether the impact of health concerns associated with modern lifestyles (for example, obesity, diabetes, the effects of smoking) are going to impact adversely upon average life expectancy (DH, 2009b). Furthermore, it is difficult to predict the actual impact that increased longevity will have upon older people's quality of life and independence. These issues are acknowledged by Spijker and MacInnes (2013, p.2), who state:

More attention will need to be paid to the dynamic relation between morbidity and remaining life expectancy. Age specific disability rates seem

to be falling, yet recently born generations have a worse risk factor profile than older ones. For example, current obesity trends may have a big effect on public health through related diseases such as diabetes. Ageing related diseases like osteoarthritis are predicted to increase and start at a younger age. This may not only result in an increased risk of cardiovascular and other chronic diseases, it also suggests that the ageing process can speed up as well as slow down, with obvious implications for public health policy.

This, in turn, may have significant implications for the provision of support services for older people (Hale et al., 2010). Wanless et al. (2006, p.32) acknowledge this point by stating:

It is clear that the older population will be significantly larger in 20 years' time. What is... more uncertain is the number of older people that remain healthy and independent. Yet knowing the numbers who are in ill health, have disabilities or are dependent is critical information for understanding the expected demand for social care and other services in the future. Old age itself need not generate demand – disability and ill health generate demand – but the chances of a person's health deteriorating are correlated with age.

Given this uncertainty, two opposing theoretical scenarios have been suggested. The first of these is termed the 'compression of morbidity' thesis and is based on the premise that although people are living longer, better health means that any health and social care needs are increasingly compressed into a few final years/months (Huber and Skidmore, 2003). The second is called the 'expansion of morbidity' thesis and is underpinned by the premise that the extra years gained are often for people who are already experiencing poor health and/or disability (Huber and Skidmore, 2003). Obviously, these opposing scenarios would present different and unique challenges to the health and social care services.

An ageing population does present challenges for health and social care services, but the use of inflammatory terms such as a 'time-bomb' in reference to older people's anticipated service use impacts negatively on older people (Lloyd, 2000, p.173). Indeed, some commentators emphasise the positive effects of an

ageing population. For example, Christensen et al. (2009) contend that the ageing of a population is one of the 'most important accomplishments of the 20th century' (2009, p.1196), and the Department of Work and Pensions argues that 'an older Britain is something to celebrate, not to fear' (2005, p.3). Lloyd (2006) has also rejected the notion that an ageing population is necessarily a negative phenomenon. Furthermore, she has suggested that such a discourse has in fact abated, and what has emerged in its place is the need to focus upon managing these demographic changes.

Closely interrelated with most discussions about the ageing population are concerns about the associated economic costs and pressures that it will place upon the state (DWP, 2005; DH, 2006; Lloyd, 2010). This 'burden of care' viewpoint suggests that the continuing growth of the ageing population will place a huge strain on health and social care systems and the taxpayer (Huber and Skidmore, 2003). Historically, older people have been the largest user group of social care, and given the predicted demographic changes outlined above, this will remain the case. Given this, there are economic challenges that need to be addressed (Dilnot, 2011).

However, there remains uncertainty about the actual economic impact and demand for services that have resulted (and will result) from these demographic changes. For example, Spijker and MacInnes (2013, p.2) suggest that some of the claims about service use and economic impact have been overstated:

We should not assume that population ageing itself will strain health and social care systems. Demand for services will rise but continue to be driven by other factors, chiefly progress in medical knowledge and technology, but also the increasing complexity of comorbid age related conditions. However, as others have suggested, the economic costs of old age dependency have typically been exaggerated, especially in the UK.

While the economic impact of the ageing population remains uncertain there is clear evidence showing that the amount of public money spent of older people's social care has been declining over the last ten years and in the 'age of austerity' there is no evidence to suggest that this trend is set to change (Age Concern,

2014; Ismail et al. 2014). Age Concern (2014) found that expenditure on older people's social care stagnated between 2005/06 and 2009/10, and then began to decline sharply from 2010/11 onwards. This has meant that in real terms spending of older people's social care fell by over 15% between 2010/11 and 2013/14 (Health and Social Care Information Centre, 2013), equating to a shortfall of over 1 billion.

Such cuts within social care have had (and will continue to have) a significant impact on older people. Examples include tightening eligibility for publicly funded support focusing more (and often exclusively) on older people assessed as having the greatest needs, increasing the fees payable by the older people for any support, reducing provider's fees, service redesign (including the withdrawal of some schemes) and reducing administrative costs (Ismail et al. 2014).

In addition to the ageing of the population, increasing diversity within the older UK population is also occurring (Sinclair, 2015; Cann, 2009; DWP, 2005). A key example is the increase of older people from different ethnic minority groups (Wanless et al., 2006; Benyon, 2010). Cann (2009, p.40) draws attention to the diversity within the ageing population and highlights the need to remain mindful of a variety of situations and experiences amongst the older people population, by stating:

Generalisations often sound grand. In the case of ageing, they can be breathtaking. The ease with which we opine in one phrase the situation of 20 million people (in the UK alone) in or nearing retirement is extraordinary. 'Older people' are talked about as a unitary group with identical circumstances and personalities. Indeed, part of the endemic ageism of society lies in our readiness to conceptualise a group we call 'older people' and treat them as a homogeneous blob.

# Defining 'older people'

Defining who is classed as 'older' is problematic (Benyon, 2010). This is because two separate and contradictory trends can be identified within policy, the evidence base and wider social/cultural discourses. The first trend regards a

person's chronological age as determining their status as an 'older person'. Historically in the UK, the default meaning of 'older person' has referred to those who have reached the age of entitlement to a statutory state pension. This rigid approach to defining the age at which someone becomes an 'older person' is mirrored in the definition of 'older person' traditionally used within the social care arena: those aged 65 and over are classified as 'older' within the local authority social care environment (Clark, 2009), and this is the age eligibility criterion for many other services aimed at older people in the UK.

The second trend, which stands in contrast to the first, is the move towards widening the population of people who are defined as 'older'. This is particularly evident in policy, where there has been a shift towards lowering the age at which someone is considered an 'older person'. Biggs et al. (2007, p.36) point to this trend by stating 'a striking characteristic of contemporary UK policy is a consistent attempt to drive down the age at which parts of the population are considered "older", in a move to recast the debate in terms of a '50-plus' life-course'. This may mark a deliberate shift towards drawing younger people into debates surrounding ageing and/or be reflective of evolving conceptualisations of ageing as a process (in contrast to conceptions of ageing that regard 'being old' as a fixed state beginning at a clearly defined point).

For the purposes of this thesis, while remaining aware of the potential limitations of defining 'older' people using a chronological approach (for example, information about the number of years an individual has been alive does not say anything about functional ability), it was recognised that there was a need to create an age boundary in order to define the meaning of 'older'.

To reflect the contemporary trend within policy towards lowering the age at which someone is considered an 'older person', it was decided that, for the purposes of the policy and literature review process, an 'older person' was defined as someone aged 50 years or older. However, as this thesis was interested in the meaning of independence for older people *using support services,* including local authority support, it was decided that for the empirical research, age 65 and over was most reflective of the current meaning of 'older' within this context.

## Research question, aims and objectives

In response to the shifting demographic landscape presented earlier there has been an increasing interest amongst academics, professional and policy makers about social care for older people (De Sao Jose et al., 2015). Current social care policy for older people (as well as other user groups) focuses on maximising independence for as long as possible. However, the definition of independence that is used in policy is often not clearly set out, and the discourses evident within policy promoting independence for older people change over time. Thus, there is an 'increasing need for knowledge and evidence-based policy to promote independence in older people' (Rantanen 2013, p.50). In part, this is because there are many different ways of conceptualising independence (see, for example, Arber and Ginn, 1991; Baltes and Silverberg, 1994; Fine and Glendinning, 2005; Hockey and James, 1993; and Porter 1995).

However, while independence is high on the policy agenda (see Chapter 2); there has been a lack of research that has attempted to explore directly older people's perspectives on independence (see Chapter 3). This marks a significant gap in the literature because, as Fenton (2014, p.5) argues, 'just stating that [older] people need independence without a deeper more nuanced understanding of what that means [to them] is fatuous'.

The dearth of evidence about older people's constructs of independence means that we remain unsure about similarities between older people's conceptualisations of the meaning of independence and those of wider stakeholders, especially policy makers and service providers (Bowers et al., 2009). This has implications for how effective the policy and services that draw on these changing, and possibly incompatible, discourses are likely to be for older people. Therefore, understanding older people's conceptualisations of independence is imperative if effective policy implementation and service outcomes are to be achieved. This thesis seeks to gain an understanding of the meaning of independence directly from the perspective of older people using support services in an effort to redress and limit the negative effects of any incompatibilities in understandings.

As part of this thesis, a review of relevant policy (Chapter 2) and a scoping literature review (Chapter 3) were completed. Informed by the findings of these reviews, specifically the lack of emphasis to date on elucidating the meaning of independence directly from older people using a range of support services and the promotion of 'independence' (which has a range of different meanings) in current health and social policy, this thesis has been designed to address and explore the following broad research question:

#### What is the meaning of independence for older people?

This research question will be addressed by fulfilling the following aims:

- To explore the policy related to independence for older people
- To explore the evidence on independence for older people
- To understand older people's conceptualisations of independence
- To understand the factors that influence older people's conceptualisations of independence
- To develop theory grounded in empirical research and contextualised
   within the wider evidence and policy about independence for older people

These aims will be achieved by meeting the following objectives:

- To complete a review of relevant policy
- To complete a scoping literature review of relevant empirical research that directly asks older people about their meaning of independence
- To use primary qualitative research to ask older people using support services about their meaning of independence

#### Structure and content of the thesis

Following the introductory chapter, the thesis is subsequently organised into seven chapters.

#### **Chapter 2: The policy context**

Chapter 2 explores the policy context by reviewing recent English (UK and England specific) social care policy relevant to older people's independence. The aim of this review is to explore critically the impact of key policy trends around the

notion of independence for older people. In order to do so, the chapter describes the parameters of this policy review, presents the wider social and cultural changes shaping policies on independence, discusses the key strategic approaches to promoting independence and the associated mechanisms for delivering independence, and considers the tensions across policy in relation to the promotion of independence.

#### Chapter 3: A scoping literature review

Chapter 3 details the scoping literature review of empirical research studies considering the meaning of independence for older people that was conducted for this research. It presents the methods employed for the scoping literature review and the findings of the review. It then draws together and presents a thematic overview of the relevant empirical research studies, and concludes by highlighting the research gaps identified in the review and how my research aims to redress some of these gaps.

#### Chapter 4: Epistemology, theoretical perspective and methodology

Chapter 4 presents the epistemology, theoretical perspective and methodology used and why particular approaches were chosen. It discusses the epistemological and theoretical perspective adopted for this research, considers the key interpretative methodologies available and explains why a grounded theory approach was adopted and others rejected. To this end, it provides a critical overview of grounded theory by providing a historical overview of the development of the methodology, introducing the three main methodological approaches (traditional, evolved and constructivist (Mills et al., 2006b)), explaining why grounded theory is the most appropriate methodology for this research and presenting the rationale for using a constructivist grounded theory approach. The chapter concludes by presenting the defining principles of grounded theory methodology (theoretical sampling, constant comparative methods and the development of theory), which are employed irrespective of which specific methodological approach is used.

#### Chapter 5: Study design and methods

Chapter 5 presents the study design and methods used to collect, manage and analyse data. It first discusses the rationale for choosing a qualitative study

design and proceeds to describe the practical methods of data collection, including recruitment, the sampling frame for identifying participants and how 'theoretical sampling' was incorporated into the research. It then continues by presenting the data management protocol and, in particular explains the use of computer assisted qualitative data analysis software (CAQDAS). It then outlines the data analysis method integral to grounded theory and discusses the relevant ethical concerns and how these were managed. It concludes by providing a descriptive overview of the characteristics of the participants and considers why recruitment was skewed towards participants with specific characteristics.

#### **Chapter 6: Findings**

Chapter 6 presents the findings from 15 qualitative interviews exploring the meaning of independence for older people using support services. It presents the participants' conceptualisations of independence as different constituent dimensions of identity. These dimensions are considered separately, the purpose of this being to set out the defining characteristics of each dimension, the scope of the participant's meaning and the underpinning analysis. It then presents participants' views of independence through the different constituent dimensions of agency. These dimensions are also considered separately, the purpose again being to set out the defining characteristics of each dimension, the scope of the participant's meaning and the underpinning analysis.

#### **Chapter 7: Discussion and theory building**

Chapter 7 draws together the findings from the primary and secondary data sources and, in line with the constructivist grounded theory methodology, develops a substantive theory of the meaning of independence for older people. It first presents the two distinct but interlinked 'core categories' of participant's constructs of independence: 'a sense of independence - dynamic and interactive identity'; and 'the practice of independence - dynamic and interactive agency'. It demonstrates how 'independence' is a multi-dimensional and dynamic construct. It goes on to discuss the three overarching themes that emerged during the analysis and which help to explain the variation in older people's constructs of independence: 'a valued social construct'; 'continuity and change in constructs of independence'; and 'social relationships and constructs of independence'.

#### **Chapter 8: Evaluation and conclusion**

Chapter 8 provides a reflective and critical evaluation of this thesis. It first presents an overview of the thesis, summarising the existing evidence base, methodology, methods and findings to help to contextualise the conclusions. It then critically reviews the methods and methodology used so that the findings can be considered in light of the strengths and limitations of these approaches. Finally, it evaluates the credibility, originality, resonance and usefulness of this research, and reports the implications of the findings for policy and practice, recommendations for further research and contribution to knowledge.

#### Summary and conclusion of this chapter

This introductory chapter has set out the demographic and associated economic factors that provide the context within which this thesis is positioned. It has shown that the UK population is ageing and becoming more heterogeneous and that these changes have played a key role in the general policy convergence on the promotion of independence for older people. It has also shown that, due to the increasing heterogeneity within the older people population, defining the term 'older people' can be problematic. It has clarified how this population group will be defined in the policy and literature reviews and in the subsequent empirical research.

The research question and the aims and objectives guiding the thesis have been introduced and an overview of the thesis presented. The following chapter presents a review of recent UK and English-specific social care policy relevant to older people's independence.

#### **CHAPTER 2: THE POLICY CONTEXT**

#### Introduction

Promoting and sustaining independence emerged as an increasingly important policy priority during the first decade of the millennium (DH, 2005; DH, 2006). As Powell et al. (2007, p.1056) explain, 'a plethora of [UK] national policy documents relevant to older people has been produced over the past five years, frequently aimed at promoting... individual independence'. Although independence is high on the policy agenda, different policies propose different and sometimes conflicting means for achieving it (Plath, 2009). This chapter presents a review of recent UK and English specific social care policy relevant to older people's independence. The aim of this review is to contextualise the research questions within the relevant policy frameworks, critically explore policy and consider the different notions of independence used within and across them.

This chapter is split into four sections. Section 1 outlines the parameters of this review. Section 2 discusses the wider social and cultural changes shaping policies on independence. Section 3 introduces the three distinct strategic approaches to promoting independence (which reflect three different ways of conceptualising independence) and the associated mechanisms for delivering independence. The fourth section considers these strategic approaches and identifies some of the inherent tensions between them.

## Parameters of this policy review

This chapter explores independence for older people in the English policy context. The primary focus was on policy from 2005 onwards was reviewed because that year saw the publication of three highly relevant policy documents:

- Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit)
- Opportunity Age: Meeting the Challenges of Ageing in the 21<sup>st</sup> Century (Department of Work and Pensions)
- Independence, Well-being and Choice: Our vision for the Future of Social Care for Adults in England (Department of Health)

However, these three policy documents should not be considered in historical isolation; instead, they should be seen as building upon a number of influential policy documents from before 2005 (e.g. DH, 1998; DH, 2001b; Audit Commission, 2004). The Royal Commission on Long Term Care (the Sutherland Report, 1999) advocated that policy should aim to facilitate independence for older people rather than simply focusing on providing care. For example, the Sutherland Report states that 'promoting the continued independence of older people rather than thinking in terms of caring for older people' should be central to thinking on social care provision (1999, p.81). It is clear, therefore, that the promotion of independence has been at the forefront of social care policy for some time, irrespective of political leadership (Challis et al., 2004; Glasby, 2005; Powell et al., 2007). Within the social policy arena, the promotion of independence is not exclusively aimed at older people; it also features prominently in initiatives aimed at a range of user groups. This policy review therefore includes policy aimed at promoting independence among both older people (e.g. Opportunity Age: Meeting the challenges of ageing in the 21st Century (DWP, 2005)) and wider user groups (e.g. Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit, 2005)) and Independence, Wellbeing and Choice (DH, 2005)). In addition to formal policy documents, policy reviews, literature reviews, empirical research studies and discursive/opinion based literature focusing on policy and its impact were used to inform this policy review. While the focus of this review is policy since 2005, it does draw on the wider pre-2005 evidence base because such commentary has implications for policy after 2005.

As the primary empirical research for this thesis was undertaken in England, only UK and England-specific social care policy has been included. Policies that focus *exclusively* on the other UK countries – Northern Ireland, Wales and Scotland – have been excluded owing to the different social care delivery systems that have developed across the UK (Moffatt et al., 2012). For example, The Royal Commission on Long Term Care recommended that personal care should not be means-tested; while Scotland accepted this recommendation, England rejected it. Although important differences in social care delivery exist between the UK countries, the policy emphasis on optimising independence for older people transcends country boundaries. For example, the impact of an ageing population

and the importance ascribed to maintaining older people's independence across the UK is acknowledged in *Opportunity Age: Meeting the challenges of ageing in the 21st Century* (DWP, 2005 p. ix)

The demographic challenge affects all the countries of the UK – some sooner than others... We believe the values of independence, choice and opportunity for older citizens are shared by all countries.

To summarise, the parameters of this review are as follows:

- UK or English-specific social care policy;
- Published from 2005 onwards:
- Policy that includes older people (defined as aged 50 and over) either
  policy that includes older people as part of a universal cross-user group, or
  policy that is aimed specifically at older people;
- Policy that references independence for older people.

Some policy documents were excluded because, although they referenced independence, they did not become legislation (e.g. *Building the National Care Service* (DH, 2010) or because independence was not the primary focus (e.g. *Health and Social Care Act*, (DH, 2012b)). The decision to include policies in this review was therefore a matter of individual judgement based on the particular policy's relevance of the issue of independence and thus its resonance to the research question. Table 1 presents the key policies included within the scope of this chapter.

Table 1: Key policy documents promoting independence among older people, 2005 to 2015

YEAR	POLICY	AUTHOR
2005	Improving the life chances of disabled people	Prime Minister's
		Strategy Unit
	Opportunity Age: Meeting the challenges of	Department of Work
	ageing in the 21st Century	and Pensions
	Opportunity Age: Volume 2 - A social portrait of	Department of Work
	ageing in the UK	and Pensions
	Independence, Well-being and Choice: Our	Department of Health
	vision for the future of social care for adults in	
	England	
2006	Our Health, Our Care, Our Say: A new direction	Department of Health
	for community services	
2007	Putting People First: A shared vision and	Department of Health
	commitment to transformation of adult social	
	care	
2008	The Independent Living Strategy: A cross-	Office of Disability
	government strategy about independent living	Issues
	for disabled people	
2009	Shaping the Future of Care Together	Department of Health
2009	Building a Society for all Ages	Department of Work
		and Pensions
2012	Caring for our Future: Reforming care and	Department of Health
	support	

# Wider social and cultural changes shaping policies on independence

As this section will illustrate, the promotion of independence for older people has been shaped by wider social and cultural factors. Thus, it is important to contextualise policy in light of these social and cultural changes.

#### Social changes

Social changes, in particular within the family structure, and the increasing social diversity of the UK's population are having a considerable impact on the experiences of older people. The increased geographical mobility of families, increased family breakdowns and higher female employment are changing intergenerational relationships and may impact on older people and their service use (DH, 2005; Stenner et al., 2010).

Such changes are recognised in the White Paper *Independence, Well-Being and Choice*, which states that 'changes in population and communities mean that we are living longer, but are less likely to be part of a close-knit family providing support' (DH, 2005, p.10). This suggests that the contemporary changes in the nature of the family structure and the consequent availability/unavailability of informal care may also explain, at least in part, the current prominence of the concept of independence both in policy and in the wider literature.

Other factors are also cited as influencing the policy emphasis on independence for older people. These include suggestions that the current policy drive for independence is, in part, a response to criticisms about services in the past. It has been widely suggested that these services promoted dependence rather than independence and that older people were required to fit into processes and systems rather than services fitting the needs of an individual (Means et al., 2008). Many of these criticisms can be traced back further than 2005. For instance, the 1998 paper *Modernising Social Services* (DH, 1998) states:

We believe that the guiding principle of adult social services should be that they provide the support needed by someone to make most use of their own capacity and potential. All too often, the reverse is true, and they are regarded as services which do things for and to dependent people (para. 2.5).

These criticisms have been particularly strongly directed at services for older people. Critics point to the underlying assumption made in service provision that independence is only a viable aspiration for younger people (DWP, 2005).

#### The social model of disability, older people and independence

A further driver of policy aimed at promoting independence has been the impact of the disabled people's movement, and in particular, disabled people's quest for independent living. Indeed, Improving the *Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005) explicitly rooted itself in the social model of disability and in ideas about independent living that originated from the disabled people's movement. The social model of disability is an explicit rejection of assumptions about the relationship between dependence and disability. The social model maintains disability (and dependence) is created and maintained through the presence of individual and collective social barriers. These barriers prevent disabled people accessing and operating within the social world on the same terms as a non-disabled person (Thomas, 2004).

However, while the social model of disability has been a key driver of policy aimed at promoting independence, the application of the social model of disability to older people remains under-developed. This is despite there being a demographic correlation between disability and ageing, Kennedy and Minkler (1999, p.91) acknowledge this lack of convergence as being a two way process by stating 'there has been an ongoing effort on the part of aging advocates and analysts to distinguish disability from aging... In the area of disability studies, there has likewise been a tendency to distinguish disability from aging'.

The reasons for this current lack of conceptual crossover are unclear, although there are possible explanations. One possible reason lies in the historical roots of the social model of disability and the development of the movement for independent living. Several commentators have argued that the origins were favourable to only a relatively privileged group of disabled people (i.e. male, middle class) and consequently difficulties arise when transferring to other social

groups (Thomas, 1999; Oldman, 2002). A further possible reason is the suggestion the social model of disability by distancing itself from a medical approach to disability alienates older people who may actively want their disability to be medicalised (Means et al. 2008). Oldman (2002) makes a similar point by stating 'paradoxically, it is the original variant of the social model of disability that is problematic in the liberation of older people from the medical model, namely the denial of pain and impairment' (p.804). Thus, while recognising the importance of the social model of disability upon the pursuit of independent living, older people, whether disabled or non-disabled may have different goals than younger disabled people, particularly as regards the relationship between citizenship and independence (Orellana, 2010).

#### Cultural changes

The policy drive for promoting independence for older people also exists within a cultural context. Lloyd (2004, p.251, original emphasis) acknowledges this by stating that 'in contemporary western societies, independence has become the ideal quality of the adult human being and the *sine qua non* of public policies'. From a UK perspective, evidence suggests that the ageing process is often conceived in negative terms. For example, ageing is often seen as a time of dependency and lack of contribution stating 'a societal view of old age [is that it is] a time of dependency, weakness, and a drain on the system' (Bell and Menec 2012, p.2–3).

The emphasis placed on older people's independence and the way this is conceptualised within society can also be attributed to cultural factors. As Arber and Evandrou (1993) suggest, independence is a culturally bound concept and, as such, its meaning varies across different cultural groups. As the diversity of the older population increases, the cultural meaning of independence might change. A key example is the increase of older people in the UK that come from different ethnic minority groups (Wanless et al., 2006; Benyon, 2010). From a Western perspective, independence is commonly conceived within an individualistic normative discourse that assumes that independence primarily equates to non-use of state support and this is the approach that dominates UK public policy. Furthermore, this form of independence is regarded as positive and desirable (Bell and Menec, 2013). Indeed, Lloyd (2012) suggests that this cultural

understanding of independence is so strong that many older people view the prospect of dependency as bleaker than the prospect of death. Arber and Evandrou (1993) are, however, critical of the Western cultural interpretation of independence, suggesting that it has been adopted as part of the 'burden of care' viewpoint and is used to promote policies purported to be cost-saving, such as a shift from institutional to community based care. While this approach assumes that promoting independence will reduce or control public spending on services, the evidence for this is less clear (Munton, 2011).

Changes to policy and practice are also being driven by arguments about the changing expectations of older people themselves (DH, 2012a; Bartlett, 2009). For example, *Independence, Well-Being and Choice* (2005) argues that changes proposed are in part being driven by older peoples' aspirations for independence, it states:

We must continue adapting this support to ensure it meets people's expectations of a high-quality service and **their aspirations for independence** (p.3, emphasis added).

It has been suggested that this generation of older people will be more critical and demanding of social care services than previous generations because they have grown up within a society that, on the one hand, has government provided health and social care and, on the other, has become increasingly individualistic and consumerist. Bowling (2011, para. 2) suggests for example that an 'increasing number of older people... [have] higher expectations for "a good life". As a consequence, it could be argued that this generation may have higher expectations about optimising and maintaining their independence.

However, while there has been much discussion about these supposed cultural changes among the current older generation, there has been a lack of empirical research into whether the purported changes among this generational cohort are actually taking place, and some commentators have suggested that they are largely based on unfounded assumptions (Biggs et al., 2007). Given the lack of specific research on this issue, it may be the case that the grounds for the policy

suggestions and directives on independence for older people have been based largely upon speculation.

# Key strategic approaches to promoting independence and associated mechanisms for delivering independence

The emphasis placed on independence is clearly evident in English (both UK and English specific) policy documents since 2005. Three distinct approaches to promoting independence, which reflect three distinct ways of conceptualising independence, have emerged within current policy aimed at optimising independence for older people. The first approach aims to provide older people with opportunities to exercise choice and control, often through self-directed support. This constructs independence as being about one's ability to make decisions for oneself. The second approach seeks to restore and/or maintain older people's abilities to carry out activities of daily living without assistance, thus it is constructed on the notion that independence is about physical functional ability. This conception of independence is primarily instituted through intermediate care and re-ablement services. The third approach aims to provide long-term financial savings and help people to maintain social independence for as long as possible. This constructs independence as being about social inclusion and social engagement (Curry, 2006) and is associated with preventative and universal input, for example, voluntary befriending services.

The current emphasis on promoting older people's independence has emerged largely in response to changing economic and demographic factors in the UK. To meet these changes, key policy developments since 2005 have placed the promotion of independence centre stage and have set out a long-term vision of social care policy, particularly in the context of an ageing population. For example, *Independence, Well-being and Choice* (DH, 2005) sets out a vision of how social services should strive to address the changing needs of the population. Key to this vision is:

- Challenging the relationship between care and dependency
- Establishing universal services
- Shifting the focus towards preventative care
- Recognising that carers, who are also often older people themselves, have the right support for themselves

Addressing the needs of the social care workforce

Providing older people opportunities to experience choice and control From 2005 onwards, there was a distinct policy shift that aligned choice with control and with the assumption that by enabling older people to have more choice and control they would feel more independent (DWP, 2005; DH, 2005; Prime Minister's Strategy Unit, 2005). For example, the Department of Health stated that 'social care should be about helping people maintain their independence, leaving them with control over their lives, and giving them real choice over those lives, including the services they use' (DH, 2005, p.6). This change was evident across all three key policy papers published in 2005, which emphasised the shift that services needed to make to enable. For example:

Our task now is to continue this transformation right across the field of social care for adults so people are given more choice, higher quality support and greater control over their lives (DH, 2005, p.3).

This strategic shift in policy challenged the idea that independence is solely about functionality (that is, being able perform the functions of daily living unaided). Instead, it reflected the view that choice and control equates to independence and that independence can therefore be maintained/improved by enabling older people to exercise control over the services and assistance they receive. Following this interpretation of independence, an older person may maintain their sense of independence even when they need support from someone else (Fine and Glendinning, 2005).

While choice and control is often presented as key to older people's independence, a critical debate has emerged about the established approaches to promoting choice and control. Some critiques focus on the availability and achievability of choice and control for some older people, while others, more conceptually, raise concerns about the appropriateness of imposing a consumerist understanding to choice and control on a publicly funded social care system and the appropriateness of 'choice and control' for some older people, particularly those with cognitive impairments such as dementia (Glasby et al., 2011; Hafford-Letchfield, 2010).

Several commentators have reported pragmatic concerns about exercising choice and control within the context of social care and that for some older people achieving this might be problematic (Baldock, 2003; Ware et al., 2003; Hafford-Letchfield, 2010). Problems may arise because of factors inherent within the delivery of social care or because of the individual circumstances of the older person needing social care. The availability of options around social care provision and accessibility of information influence whether people are able to exercise choice and control. Baldock (2003) argues that in relation to choice being meaningful older people need to able to make choices between different services, as well as, having the opportunity to exit another and enter another.

Research highlights that access to information and sufficient awareness of options are crucial to the exercising of choice and control, but for older people, these are often lacking. For example, Rabiee (2013, p.12) notes 'being forced into choices because of a lack of knowledge about available alternatives can compromise independence'. Hafford-Letchfield (2010, p.503) makes a similar point by stating that 'choice... [is] dependent on older people being aware of the options available, being able to keep up with what is going on in the world, and not least to be in a position to take advantage of these'.

A further concern that has emerged as part of promoting choice and control (as the mechanisms towards independence) has been the management of personal risk (Glasby and Littlechild, 2009). If older people are genuinely expected to experience choice and control, questions arise about whether this should also include the choice and control to engage in what might be considered 'risky' behaviour (for example, older people making the decision to continue using stairs without assistance when advised not to). Such concerns have been addressed within relevant policies. For example, the Department of Health (2006) promotes co-ownership of risk between services and the individual by stating that 'the risks of independence for individuals are shared with [the service user] and balanced openly against benefits' (p.205). However, it should be noted that any interpretation of risk is subjective, and what one older person may regard as risky behaviour may not be seen as risky by another (Reed et al., 2004). Much of this tension centres on where responsibility ultimately lies should things 'go wrong'.

Furthermore, the exercising of choice and control can be anxiety provoking and overwhelming for older people. Choice necessarily increases the need for older people to make additional decisions, which may prove challenging for some people. This may be especially so during periods of transition such as at the onset of impairment, following bereavement, or when provision is changed from adult services to older peoples' services. Anxiety may be heightened because many older people have unpredictable social care needs, and this may make choice particularly difficult due to the need to make multiple choices while facing changing and unclear outcomes (Rabiee and Glendinning, 2010).

As noted earlier, significant critical attention has been devoted to the role that consumerism plays as a driver of choice and control in social care (Glendinning, 2009; Schwartz, 2004). In providing older people opportunities to exercise choice and control, older people are repositioned as active consumers of care, thereby reinforcing the commodification of health and social care (Glasby et al., 2011). However, being in need and receipt of social care is a fundamentally different experience to having choice and control within a consumerist environment because the relationships that exist between provider and consumer are different (Needham, 2003; Schwarz, 2004; Clarke et al., 2005).

Within a consumerist environment, the recipient of a good or service is assumed to hold power and can therefore adopt an uncompromising 'take it or leave it' stance, safe in the knowledge that there are a variety of different sources for the product. Within a statutory environment, however, while it is possible to exit a service, there might be significant negative consequences of making this choice. In practice, older people are often unable to exercise the choice to exit social care services because the initial need to access social care input is usually beyond the strict control of the service user – often it is first accessed when they are feeling particularly vulnerable – and as such, care access may therefore be viewed as crisis led (Arksey and Glendinning, 2007). In such circumstances, the consumerist approach to the provision of choice and control in a given care setting may actually result in a problematic and overwhelming experience for the service user (Schwarz, 2004; Moffatt et al., 2012).

Consequently, some critics suggest that the consumerist choice and control discourse is inappropriate to a care setting as the end user experience is fundamentally different from that in a conventional consumer-provider market environment (Needham, 2003; Schwarz, 2004; Clarke et al., 2005). For example, a straightforward consumerist approach to social care ultimately neglects some of the wider experiences of service users, experiences that can be highly significant for older people and their independence. More specifically, issues such as the quality of the caring relationship – where aspects such as 'human contact' are frequently the most valued aspects of social care for older people (rather than issues such as how the funding of care is being administered) – are ignored in a consumerist approach (Lloyd, 2010).

Thus, while there has been a strategic shift towards providing older people with an increased sense of choice and control as a means of promoting independence (DH, 2005; DH, 2006), questions remain about the relationship between independence, choice and control. For example, does independence lead to choice and control, or does choice and control lead to independence? Rabiee (2013, p.884) highlights such questions, stating that 'the relationship between choice and independence for disabled and older people is not always as simple and linear as choice policies assume'.

#### Self-directed support

In policy, mechanisms around self-directed support have been promoted in attempts to help older people to experience choice and control, and, therefore, to promote independence. Self-directed support refers to a range of policy initiatives aimed at providing social care users, including older people, with an increased sense of choice and control about how their needs can be best met (Leece and Peace, 2010). Self-directed support allows older people (if they are willing and able) to direct their own support arrangements. Direct payments and personal budgets are two mechanisms for facilitating self-directed support.

#### Direct payments

Direct payments were established under the Community Care (Direct Payments)

Act (DH, 1996), which came into force in April 1997. This gave local authorities in

England the right to provide money directly (or indirectly, for example via a third

sector organisation) to a disabled person in lieu of directly provided services. This allows the recipient to purchase their own community-based social care services, including employing their own personal assistant/s to support and/or assist them in carrying out daily activities. Initially, direct payments were only available to disabled people under the age of 65. However, a subsequent change in legislation now means older people are eligible for direct payments (*Health and Social Care Act* (DH, 2001a)).

#### Personal budgets

Personal budgets were first proposed in *Putting People First* (DH, 2007), which recommended that local authorities roll out personal budgets for all adult user groups (including older people), and were implemented between 2008 and 2011. Local authorities are required in most circumstances to offer a personal budget from which social care (excluding emergency care) is funded. The amount allocated is determined after a social care needs assessment. To this end, the Resource Allocation System (RAS) means that a recipient can know exactly what their personal budget comprises.

A personal budget can be offered as a direct payment or can be managed by the local authority, a proxy or a combination of these approaches. Recipients can either choose to have their personal budget disbursed in the form of a direct payment to buy services from the local authority privately, ask their local authority/care manager to broker services on their behalf or opt for a combination of these. As such, choice (and control) is central to the provision of personal budgets.

While research has shown that direct payments and personal budgets can facilitate choice and control for older people (Glendinning et al., 2008; Hatton and Waters, 2011), there is also evidence to show that this may not be the case for *all* older people (Slay, 2011). This is because in addition to the tensions outlined earlier around providing older people opportunities to experience choice and control, there is evidence to show that self-directed support can be particularly difficult for older people, for example evidence shows that managing a personal budget can be more anxiety provoking for older people than younger people (Slay, 2011).

# Restoring and/or maintaining older people's abilities to carry out activities of daily living without assistance

The second new development in recent policy aimed at optimising independence for older people is the restoration and/or maintenance of their ability to carry out activities of daily living, for example, being able to wash, dress and cook without assistance. To date, this aim has primarily been delivered through services such as intermediate care and, more recently, re-ablement. Indeed, in *Caring for our Future* both intermediate care and re-ablement were cited as being important in helping older people to optimise their independence:

Good re-ablement, intermediate care and post-discharge support means that older people returning home after a stay in hospital should have a temporary support plan that helps them to regain their independence (DH, 2012a, p.60).

While these are often considered, and indeed provided, as distinct services, there is considerable overlap in scope between them, and it can be difficult to distinguish between intermediate care services and re-ablement services. Parker (2014) acknowledges such difficulties and identifies two key characteristics of both intermediate care and re-ablement: their objectives and their time-limited nature. The main objectives of intermediate care and re-ablement are facilitating timely hospital discharge and preventing unnecessary admission to hospital or long-term home care for older people (Jones et al., 2009; Jacobs et al., 2009; Martin et al., 2007). The second shared characteristic of intermediate care and re-ablement, their time-limited nature, usually restricts service delivery up to a maximum of six weeks. The range of services that fall under the scope of intermediate care and re-ablement is diverse and may be provided by acute trusts, partnerships between the NHS and local authorities, or local authorities alone.

Both intermediate care and re-ablement are positioned in policy and practice as playing a key role in optimising independence for older people, and this is supported by Regen et al.'s qualitative study of five UK sites, which found that intermediate care played an important role in promoting independence:

Be it home or a residential environment, the intermediate care setting was generally regarded as being beneficial, particularly in achieving outcomes such as independence and increased confidence (2008, p.634).

Other studies have shown the importance of re-ablement in promoting independence for older people (Petch, 2008; Wilde and Glendinning, 2012; Jones et al., 2009; Rabiee et al., 2009). However, the outcomes that can result from intermediate care are not as far reaching as they might be. The short-term nature of intermediate care, and the importance of achieving outcomes in the short term, means that those who might take longer to achieve independence goals may fail to derive optimum benefit from intermediate care or re-ablement services (Glendinning et al., 2010).

Furthermore, some evidence suggests that the meaning of independence that is promoted by intermediate care and re-ablement might not be fully compatible with older people's aspirations. For example, their focus on reducing the need for long-term support might not always be in line with the aspirations of older people themselves, who may feel they benefit from ongoing support such as daily contact with formal carers (Petch, 2008; Wilde and Glendinning, 2012).

The emphasis on functionality, and, specifically, the ability to carry out activities of daily living without assistance, might also conflict with older people's understanding of independence: wider aspects of independence that could be important to older people, such as social and mental well-being, might be overlooked. This, in turn, might affect the effectiveness of re-ablement. Given that the effectiveness of re-ablement is ultimately dependent on the recipient's motivation to commit to the aims of the programme, if older people are not motivated by the goals promoted by re-ablement, they are less likely to engage actively with it (Glendinning et al., 2010). Indeed, Wilde and Glendinning (2012) state that '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 re-ablement' (p.589).

The specific focus of these services on change (goal) based outcomes, rather than on maintenance outcomes, has also been questioned. Wilde and Glendinning (2012) found that a goal-focused re-ablement was not always compatible with older people's views, cultural norms and aspirations relating to independence. Furthermore, maintenance outcomes may be particularly important in enabling older people to maintain their independence in the face of functional deterioration associated with age and/or long-term conditions (Hudson and Henwood, 2002; Hudson, 2006).

Evidence about the outcomes of intermediate care is limited (Jacobs et al., 2009; Barton et al., 2005). Barton et al. (2005) suggest that the multifaceted nature of intermediate care and the lack of a clear definition of its scope and setting make any systematic review of associated outcomes difficult. Indeed, as can be noted from the above definition, 'intermediate care' does not refer to a specific type of care, but rather to an area of care meant to cover the boundaries between hospital and the community (Challis et al., 2004). Jacobs et al. (2009), who carried out a scoping review of peer-reviewed research studies published between 1990 and 2004 focusing upon social care services for older people in the UK, found that 'in the case of intermediate care services, the dearth of peerreviewed publications is surprising' (p.526). Furthermore, Godfrey et al. (2005) cautions against assuming that there exists a causal connection between an intermediate care intervention and the intended outcome of independence. arguing that the situation is often more complex. Godfrey (2005) suggests that 'independence' is dependent on a wide range of factors that play a role in both why intermediate care is needed in the first instance, as well as a role in the recovery process.

There is also a limited evidence base surrounding re-ablement (Glendinning et al., 2010). Research has tended to focus upon the shorter-term outcomes of reablement and has been small-scale and qualitative in scope (Jones et al., 2009). Jones et al. (2009) comment upon the lack of quantitative evidence about reablement, suggesting that difficulties arise in establishing clear connections between data on re-ablement service use and any later social care and/or use of other support services. In recent years, however, some research has begun to

consider the longer terms outcomes of re-ablement (Glendinning et al., 2010; Wilde and Glendinning, 2012).

#### Preventative low-level input

The third strategic shift in policy aimed at optimising older people's independence has been the move from a crisis-led to a preventative approach (DH, 2005; DH, 2006; DH, 2012a). The following extracts from Department of Health policy documents highlight this policy shift:

We must set out a new direction for health and social care services to meet the future demographic challenges we face. We must reorientate our health and social care services to focus together on prevention and health promotion. This means a shift in the centre of gravity of spending (DH, 2006, p.9).

Intervening early may help to ensure that the needs they have do not worsen, and that the support they are offered can help to give them back their independence, rather than merely meeting their care and support needs (DH, 2009b, p.42).

The new system will promote wellbeing and independence at all stages to reduce the risk of people reaching a crisis point, and so improve their lives (DH, 2012a, p.8).

Policies are increasingly advocating lower level input for older people, primarily in order to prevent and/or delay social care (and health care) needs further downstream. Current policy thus advocates a commitment to proactive input before the need for higher-level social care interventions arise. This preventative approach has three main aims: to provide long-term financial savings, to help people to maintain independence for as long as possible, and to move away from expensive crisis response provision.

This approach is not without precedent. Indeed, until the mid-1990s, social care services provided low-level support to a large number of older people. It is only since 2003 that Fair Access to Care Services (FACS) set out four criteria that

affected whether an older person could access social care services. Eligibility thresholds have tightened, resulting in social care services only providing assistance for older people with very high levels of needs. This shift is evident in the decreased numbers of households receiving home care services (Audit Commission, 2013).

Since preventative low-level input is both diverse and broad, and as its meaning and scope can differ dependent upon the context, it is difficult to define conceptually. Nevertheless, Wistow et al. (2003) suggests a preventative approach incorporates three key aims:

- To prevent or delay the onset of disability and/or ill-health;
- To promote the independence of older people;
- To create inclusive and supportive environments.

Low-level preventative input is not always provided by a health or social care professional (Curry, 2006). Universal information services and low-level support services are often cited as examples of low-level preventative input. In regards to universal services information, advice and signposting services/websites aimed at the general older people population have been increasingly highlighted in the policy as a means of promoting and, more specifically, maintaining independence for as long as possible, as well as promoting social inclusion (DH, 2005; DH, 2009b; DH, 2012a). For example, *Independence, Well-Being and Choice* (2005) states that 'more use of universal services could help people remain better integrated in their communities, prevent social isolation and maintain independence' (p.45).

In relation to 'low-level support services', the term is again wide-ranging and appears to have no standardised definition (Caiels et al., 2010). Examples of such services include gardening, laundry, cleaning and shopping (Clark et al., 1998). In addition, aids, equipment and minor adaptations to the home may also be seen as low-level support services. While it is acknowledged that low-level services are not able to prevent the exacerbation of disability and/or ill health, it is argued that they may delay progression of disability or illness and thus delay the need for higher-level support. Research has showed that these types of services are valued by older people as being instrumental in them maintaining

independence (Clark et al., 2004). However, while in the policy arena there is an increasing interest in the role that low-level preventative care can play in securing older people's independence, the evidence base in support of low-level preventative care remains patchy (Caiels et al., 2010; Allen and Glasby, 2010).

As with intermediate care and re-ablement, this is due in part to conceptual and/or methodological difficulties in establishing the effectiveness of low-level preventive input (Caiels et al., 2010). Indeed, the very essence of some preventative input means that identifying clear outcomes can be problematic. This is because preventative care might not provide immediate outcomes, and it is often difficult to know what the outcome might have been if these services were not offered. In other words, it is difficult to demonstrate that an intervention has directly prevented something from happening or has led it to occurring later or to a lesser extent than it otherwise would have done.

This lack of evidence extends to low-level support services. Caiels et al. (2010) found that 'there is something of a dearth of evidence regarding the cost-effectiveness of low-level interventions, particularly studies that quantify the impact of low-level interventions in terms of the functioning states they hope to achieve'. Curry (2006) suggests that methodological issues can explain some of this lack of evidence. For example, where low-level support has been studied, each study has in fact explored different outcomes and has employed different units of measurement. This methodological inconsistency means that it can be difficult to draw comparisons and to build a coherent, robust overview of the impact of low-level support services.

However, this apparent lack of evidence about the efficacy of low-level support has begun to be addressed by a growing evidence base (especially, qualitative research evidence) that demonstrates the value older people place upon this type of support (Joseph Rowntree Foundation, 2005; Clark et al., 1998; Wanless, 2006). Clark et al. (1998) highlighted the role that befriending can play in supporting independence for older people, while the Wanless Review (2006) pointed to the role that assistance (via aids and equipment) and support can make to delaying an older person's deterioration and thus to deferring the need to move into an institutional care setting. Two national pilot initiatives,

LinkAgePlus and Partnerships for Older People Projects (Windle et al., 2009) have also added to the evidence base by illustrating both the possible benefits that such an approach can offer older people and its potential cost-effectiveness (a chief concern for government).

#### Tensions across policy

This chapter has shown that no single definition of independence prevails in UK policy; rather, its meaning and the means of attaining it vary across the policy agenda. Three different mechanisms aimed at promoting independence have been identified – self-directed support, intermediate care and re-ablement, and universal low-level input – and these are associated with different interpretations of independence, that is, choice and control, self-sufficiency and prevention, respectively. In particular, this chapter has highlighted the distinction between providing older people with the opportunities to experience choice and control, restoring and/or maintaining older people's abilities to carry out activities of daily living without assistance and the more universal shift towards low-level preventative input.

However, a move towards integrating these three strategic elements is necessary because questions remain about the value of policy and subsequent service delivery if they are not working together in a coherent manner. Indeed, while there is a clear and consistent drive towards and emphasis on independence in the policy arena, the overarching connections and relationships between the specific policies on independence are less clearly drawn: for example, while the principles of choice and control may have an important role to play in preventative input for older people, the connection between these is blurred in the policy.

Furthermore, there is a real tension and an ongoing policy debate about whether services should be aimed at those older people assessed as 'most in need' or whether the focus should expand to include lower level preventative and universal input. While there are variations in how national eligibility criteria (FACS) for adult social care services are implemented by individual local authorities, the trend overall is towards eligibility criteria becoming increasingly tightened, with many local authorities funding only those people whose needs are

assessed as being at the 'substantial' or 'critical' level (Fernandez and Snell, 2012). Indeed, the proportion of local authorities that are funding social care only for those older people with needs assessed as substantial or above has increased from 65% in 2006/07 to 87% in 2013/14 (Ismail et al., 2014). While this may not necessarily reduce the numbers of older people accessing services given the wider demographic shift towards an ageing population, it will likely impact upon what 'type' of older person accesses local authority social care, with those assessed as 'critical' – that is, those with high and complex needs – most likely to be eligible to access services. Such an approach is distinctly at odds with the renewed policy focus on low-level preventative and universal support aimed at keeping older people as independent as possible for as long as possible. As noted earlier in this chapter, despite the convergence of policy and practice aimed at optimising independence for older people, there exist gaps in the evidence on the efficacy of certain service implementations, which in turn must cast doubt on the potential effectiveness of these policies. Wanless (2006, xxi) draws attention to this lack of evidence by stating:

More than one million older people (aged 65 and over) currently use publicly funded social care services in England... Yet, despite these considerable sums, there is little information about whether this spending achieves the government's desired aims for older people of promoting choice, independence and prevention.

Challis et al. (2005, p.41) also found that the evidence base surrounding the promotion of independence for older people within policy was limited, stating that:

Within older people's services, the proportion of publications addressing this theme [independence] is perhaps surprisingly low considering the emphasis placed upon issues such as hospital discharge and care at home in current policy.

Thus, there remains a need to more fully develop 'evidence-based policy' in relation to knowledge about what works in optimising independence for older people.

There has also been critical debate about whether the aspirational drive for independence is a positive (and achievable) policy development for all older people regardless of their individual circumstances and the underlying cause of any loss of independence. Hale et al. (2010, p.80) suggest that the drive for independence for all older people may present an 'unrealistic picture' in that it fails to incorporate the cognitive and health difficulties often associated with ageing, particularly for those in need of additional help and support. Scourfield (2007) makes a similar point by suggesting that by continually attaching high status to independence, policy can marginalise older people who need support: 'policies that keep proclaiming the value of independence run the risk of reinforcing negative constructions of people who use public services' (p.117).

Lloyd (2010) also highlights such issues by stating that 'while restoring or maintaining independence is crucially important for some older people, the needs of others for whom this is no longer a possibility should also be acknowledged in social care policies' (p.193). Lymbery (2010) makes a similar point:

There are numerous other issues over which policy appears to skate, rather than engaging fully with their implications. These include the complexity of managing the balance between the enhancement of individuals' independence against the reality that – for many – dependence, vulnerability and the consequent need for protection are dominant features of their lives (p.6).

It is clear from the above, therefore, that although the promotion of independence is a key driver of social care policy aimed at older people, questions remain about what happens to older people when independence is no longer a viable option or is not a desirable outcome for the individual.

Furthermore, none of the policy papers included in this chapter present a clear timetable and/or fully address how sufficient financial commitment by successive governments is going to be achieved. As noted, this lack of clarity is particularly evident with regard to low level preventative input because, as this chapter has shown policy acknowledges the role it can play in older people's independence

lack of funding has historically limited its' implementation and there is no clear vision and/or evidence to suggest this time will be different

#### Summary and conclusion of this chapter

This chapter has set out the relevant social care policy context since 2005. As has been shown, the policy drive towards optimising independence for older people has emerged largely as a reflection of and a response to changing economic and demographic factors and to the changing expectations of older people themselves. While independence is constructed as a positive and unambiguous driver of policy, a more critical debate is developing which, in part, challenges the meaning that current policy ascribes to independence and questions whether the goal of independence is appropriate for all older people.

Thus, given the anticipated increasing demographic and economic pressures and the likelihood that resources will not increase relative to demand, optimising independence for older people is likely to remain high on the policy agenda. However, due to lack of evidence on outcomes, it remains uncertain whether and how independence will be realised. Furthermore, the three different interpretations of independence evident in policy have a clear impact on the mechanisms of delivery of independence. However, there is a lack of evidence on whether these interpretations and delivery mechanisms are actually consistent with the aspirations and experiences of older people, and there is a need, therefore, to develop an understanding of whether the current policy on independence fits in with how older people interpret independence and whether it meets their expectations and needs. This thesis is therefore timely as it aims to start to bridge some of the gaps identified in this policy review. In the following chapter, the scoping literature review is discussed.

#### **CHAPTER 3: SCOPING LITERATURE REVIEW**

#### Introduction

The policy review (chapter 2) indicates that across the policy landscape there are three key interpretations of independence that manifest through different policy mechanisms. However, it is unclear whether these understandings of independence are informed by older people themselves. This scoping review aims to identify and collate the range of existing empirical research that explores independence from the perspective of older people. In this chapter, the methods and findings of this scoping literature review are presented.

The chapter is split into four sections. The first section provides a general overview of the purpose of literature reviews, the aims and characteristics of scoping literature reviews, and justification for the choice of scoping literature review as the method employed for this thesis. The subsequent two sections present the findings of the review. Section 2 presents a descriptive overview of the scope and characteristics of the research studies included in the scoping review. Section 3 presents a thematic overview of the findings from the research studies. Section 4 concludes this chapter by highlighting the gaps in the research base identified through the literature review and how the empirical research conducted for this study aims to bridge some of these gaps.

#### Literature reviews

Literature reviews are an integral and well-established part of the research process (Badger et al., 2000). In general, literature reviews are considered important as they allow new research to build upon existing research findings and, as such, avoid the likelihood of a researcher 're-inventing the wheel' (Badger et al., 2000, p.220). Although there are different approaches to literature reviews, they have two common objectives. The first is to act as a precursor to undertaking new research. The second is to draw together the existing evidence base in order to make an assessment about the range of evidence surrounding a particular topic area (Badger et al., 2000). Both of these objectives are consistent with the rationale for conducting this literature review.

A range of different approaches can be used to review existing evidence (Badger et al., 2000; Grant and Booth, 2009). Within these varying approaches to reviewing the literature, there are both differences and overlaps in the methods used. There are no rigid rules about when to adopt a specific approach; instead, choosing the most appropriate is dependent upon making a judgement about which approach resonates best with the overall aims and purpose of the specific review (Grant and Booth, 2009). The approach chosen for this thesis was a scoping literature review, drawing heavily upon the framework suggested by Arksey and O'Malley (2005).

Scoping reviews are a relatively new approach to reviewing literature and remain as yet only loosely defined (Arksey and O'Malley, 2005). Nevertheless, several commentators have suggested definitions (for example, Anderson et al., 2008; Davis et al., 2009; Grant and Booth, 2009; Mays, Roberts and Popay, 2001). Of these, Grant and Booth's definition most closely matched the aims of this current review because it highlights the role scoping reviews play in the evaluation of existing evidence. Grant and Booth suggest scoping reviews are a 'preliminary assessment of [the] potential size and scope of available research literature [and aim] to identify [the] nature and extent of research evidence' (2009, p.45).

### The scoping review

There were four main reasons why a scoping literature review was favoured over other review methods for this thesis. First, the review needed to be broad in scope in order to map out existing empirical studies that explore the meaning of independence for older people. This was a necessary step because one of the aims of this scoping review was to establish gaps in the existing literature.

Second, the review needed to focus on the substantive research findings in the identified studies rather than the methods used because, as noted, the aim of this review was to identify gaps in the literature as well as gain a sound understanding of the current empirical evidence about the meaning of independence for older people. Third, the precise empirical research questions that were to be addressed through primary research had not yet been established in the early stages of this project. Indeed, one of the key aims of the scoping review was to establish research questions that could then be addressed through empirical research. Fourth, a scoping review not only provided the most

thorough approach to covering the available literature, but also was the most pragmatic choice in the context of limited time and resources.

#### Aims of scoping reviews

The scoping review used for this thesis drew heavily on the framework proposed by Arksey and O'Malley (2005). They suggest that the aims of conducting a scoping review may include:

- Examining the extent, range, and nature of research activity.
- Determining the value for undertaking a full systematic review.
- Summarising and disseminating research findings.
- Identifying research gaps in the existing literature.

Given the intended aim and scope of this thesis, two of these aims – namely, examining the extent, range and nature of research activity, and identifying research gaps in the existing literature – were particularly relevant.

#### Characteristics of a scoping review

Arksey and O'Malley (2005) propose that scoping reviews adopt an iterative, conceptual and reflexive approach. Since scoping reviews are usually broad in coverage, an inclusive approach to evidence is taken. Thus, rather than placing an emphasis on methods and quality control considerations, scoping reviews aim to produce an interpretive and thematic summary of all relevant evidence. While broad in scope, the process of reviewing the literature nevertheless needs to be carried out in an accountable, clear and replicable manner. Arksey and O'Malley (2005) argue that scoping reviews can provide a more flexible approach and offer the opportunity to include different types of evidence produced using a variety of research methods. As a result, scoping reviews can generate a more complete understanding of the subject under review than might be the case when one particular research method is privileged above others. However, this lack of strict methodological criteria for inclusion may have implications for the identification of gaps in the literature. For instance, although gaps may exist, a scoping review might not identify them due to a failure to apply strict criteria on the quality of the methodologies used for the studies included in the review (Levac et al., 2010; Booth and Grant, 2009). This should not imply, however, that scoping reviews are an inferior method of reviewing the literature (Stalker et al., 2006). Rather,

scoping reviews offer a transparent and accountable means of reviewing the literature and do not exclude the idea of quality control per se; rather, they do not ascribe to ideas about a hierarchy of evidence.

#### Methods for scoping review

The scoping review that was undertaken here followed the five-stage framework proposed by Arksey and O'Malley (2005):

- Stage 1: Identifying the research question(s)
- Stage 2: Identifying relevant studies
- Stage 3: Study selection
- Stage 4: Charting the data
- Stage 5: Collating, summarising and reporting the results

Each stage is described in more detail below. Although presented as a series of stages for ease of description, it should be stressed that the process was not necessarily consecutive, but rather iterative. Reflecting this, the search procedure and the modification of keyword terms was a continually evolving process.

#### Stage 1: Identifying the research question

As noted above, scoping reviews tend to address a broad research question, and this approach was consistent with the research question underpinning the parameters of this review. The question that guided this scoping review was:

# What empirical research studies explore the meaning of independence for older people?

This question was arrived at because it was consistent with both the overall research question of this thesis and the aims of this review outlined above. Furthermore, it should be noted that, in keeping with the wider research aims of this thesis, the focus of this question falls on the substantive meaning of independence for older people, rather than on any specific epistemological or methodological perspective. This particular focus in turn serves to justify the decision to conduct a scoping review rather than a systematic review in order to meet the aims of this thesis.

#### Stage 2: The scoping and identification of relevant studies

Once the guiding question had been identified so as to establish the focus of the review, the next stage was to establish the parameters of the search (Arksey and O'Malley, 2005). An initial list of keywords and search terms was established, and these were used to search for relevant studies. While some of these keywords and search terms were used from the outset of the review, some were updated and revised as the review process evolved. Badger et al. (2000) highlight that this process of updating and revising keywords and search terms is a well-established and important part of the literature review process.

#### Searches

The following keywords and search terms were used across a range of data sources and were divided into two categories (see Table 2). The first category comprises keywords and search terms relating to ageing and older people, and the second consists of words relating to independence.

Establishing a definitive list of keyword searches proved problematic as the meaning of independence for older people is a broad topic that has the potential to cut across different disciplinary divides; for example, research relating to independence was identified in the areas of health sciences, psychology, economics and housing studies. There was therefore a need to remain focused and not become over-immersed in research which, while interesting, was not pertinent to the scope of this thesis. For example, research largely originating from health sciences, particularly research associated with medical professions such as physiotherapy, focused upon functional measurements and/or objective assessments of older people's independence by others and did not address the meaning of independence from the perspective of older people themselves.

Table 2: Initial keywords used

Population of study	Area of Interest
Aged	Independence
Ageing/Aging	Independent living
Elderly	Interdependency/
	Interdependence
Old age	Dependency
Older people	Autonomy
Older adult	Choice
	Control
	Self-sufficiency/self sufficiency
	Self-reliance/ selfreliance/ self
	reliance
	Ageing-in-place
	Quality of life
	Well-being/wellbeing

As such, establishing a keyword to be used in searches was not a one-off process. Instead, the keywords used were refined and adjusted as the literature review progressed. It became apparent, for example, that older people's constructs of independence were closely related to wider concepts such as 'well-being' and 'quality of life'. For example, work by Bowling has shown that 'independence' is a major factor in older people's perceptions of quality of life and 'that wellbeing is driven by psychological and social factors such as independence and social interaction, rather than income, education or home ownership' (2011, para 1). During the search process, therefore, keywords were added to or removed from the search queries when they were seen/shown to be relevant/irrelevant.

In an effort to be as comprehensive as possible, four separate and different types of search were carried out. These were electronic database searches, hand

searches of key journals, key website searches and searches of previously accessed bibliographies.

#### Electronic databases

The main method used to identify relevant literature was the use of electronic database searches. This method also enabled repeated searches to be conducted. The electronic databases that were accessed are listed below. These databases were chosen because they are the key databases for the social sciences.

- Applied Social Sciences Index and Abstracts (ASSIA)
- Sociological and Social Services Abstracts
- Social Care Online
- Social Policy and Practice
- International Bibliography of the Social Sciences (IBSS)

These databases were searched using the search terms listed earlier. Where possible, Boolean operators (AND, OR and NOT) and conventions were utilised, and truncation was used to ensure that spelling differences appeared in the searches. Some examples of these other spellings are presented Table 2.

The complexity of the searches varied depending on the search capabilities of each database; for example, Social Care Online does not have the same complex search tools as ASSIA. Searching these electronic databases was a dynamic process. As Arksey and O'Malley highlight, 'the process [a scoping review] is not linear but iterative, requiring researchers to engage with each stage in a reflexive way and, where necessary, repeat steps to ensure that the literature is covered in a comprehensive way' (2005, p.22). Although the main searches that informed the research questions were carried out during the early stages of this research (particularly during the first eighteen months), electronic database searches were also conducted at later stages to update the review with any new evidence. This was the search method that was most fruitful in terms of numbers of studies identified.

#### Hand searches of key journals

In addition to the electronic database searches, a hand search of the journal *Ageing and Society* was performed as the electronic database searches showed this journal was most likely to hold relevant articles. The hand search was conducted because of the possibility that the electronic databases were not upto-date and/or incomplete and that the key word searches therefore might not have identified all relevant studies.

#### Searching key websites

Arksey and O'Malley (2005) suggest that in order to supplement electronic database and hand searches, it can be useful to draw upon research from relevant organisations. This was carried out through a highly focused and limited search of relevant websites. Similar to the searches carried out through electronic databases and hand searches of key journals, searching the websites below was not a one-off process. Rather, these websites were revisited at various points throughout the research period in order to access the most up-to-date material. Although I endeavoured to adopt a methodical approach, there was also a need to remain flexible in order to adapt to the different website structures. Each of the organisational websites was searched to identify their publications and/or research pages, and all relevant links were followed.

In addition to accessing research through the available links, searches were also conducted using the website's search engine and drew upon the keyword and search terms set out in Table 2. The key websites accessed were as follows:

- Age Concern\* www.ageconcern.org.uk
- Care Services Improvement Partnership www.csip.org.uk
- Department of Health www.dh.gov.uk
- ESRC\*\* www.esrc.ac.uk
- Help the Aged\* www.helptheaged.org.uk
- New Dynamics of Ageing www.newdynamics.group.shef.ac.uk
- Kings Fund www.kingsfund.org.uk

<sup>\*</sup>Prior to both organisations merging and becoming www.AgeUK.co.uk

<sup>\*\*</sup>ESRC Growing Older Programme (accessed online)

All the websites accessed were UK-based organisations. UK organisations were chosen because it was reasoned that UK-based research would be of greatest relevance to this thesis. In part, this decision was underpinned by an appreciation that the meaning of independence is culturally determined and that, therefore, the way that independence is understood across different nations is likely to be different (Arber and Evandrou, 1993). A wider Internet search was not deemed appropriate because of the possibility of search engines identifying sites that were either irrelevant or composed of poorly evidenced/referenced material.

#### Searching research registers

Electronic searches of research registers were undertaken to supplement the above searches. To access what was likely to be the most relevant UK-based research about independence and older people, the following research registers were chosen:

- Research in Progress Joseph Rowntree Foundation
- National Research Register for Social Care
- National Research Register

In addition, a search of PhD theses published by students from UK universities and available from the British Library was carried out using the Electronic Theses Online Service (EthOS).

#### Searching references of included studies

The references of included studies were searched to assess if there were additional references relevant to this study. In effect, this process constituted a snowball approach to searching and reviewing the literature. This method was repeated until no further studies were identified, suggesting that data saturation had been reached.

#### Stage 3: Selection criteria

To establish which of the studies identified from these different searches best addressed the research question under consideration, a set of selection criteria was established (see Table 3).

Table 3: Selection criteria (inclusion and exclusion) applied in selecting research studies included in the scoping review

Criteria	Included if	Excluded if		
Language	Written in English	Not written in English		
Time of	Published between January	Published before January		
study	1990 and 2014	1990		
Country	Advanced welfare states i.e.	Non-advanced welfare states		
where	Western and Northern Europe,			
research	Australia, New Zealand,			
was	Canada and USA			
conducted				
Research	Older people and living in	Research that excluded older		
participants	community settings. This could	people.		
	be either part of a mixed			
	participant group study, or a	Older people living in a		
	study that recruited older	residential, nursing home or		
	people only	an acute hospital setting		
Area of	Older people and their	Functional measurements of		
interest	understandings of the meaning	independence only		
	of independence			
Study	Empirical research	Studies that solely comprised		
design		policy, practice guidance,		
		general discussions, book		
		reviews and/or literature		
		reviews		

The application of the selection criteria was a two-stage process. The first stage involved making an individual assessment about whether the title and, when available, the research abstract fulfilled the selection criteria. If this was believed to be the case, then the full article was retrieved and the selection criteria applied fully. However, as Badger et al. (2000) highlight, this process is not infallible because sometimes abstracts do not capture the research in its entirety.

In keeping with the approach suggested by Arksey and O'Malley (2005), the selection criteria were established during the process of identifying relevant research and were based upon gaining a greater awareness of the literature; the setting of the selection criteria was therefore an evolving process. For example, in the UK policy context, individuals aged 65 and older are usually considered to be 'older' people. Initially, only studies including people in this age group were included. However, as the scoping review progressed, this age criterion was redefined to allow for a lower cut off of 50 years because several relevant studies (particularly outside a UK context) had recruited participants from among this younger population. This may mark a deliberate shift towards drawing younger people into debates surrounding ageing and/or be reflective of evolving conceptualisations of ageing as a process (in contrast to conceptions of ageing that regard 'being old' as a fixed state beginning at a clearly defined point). This flexible approach was also applied to the geographical origin of included studies. Initially, the intention was to include only UK studies, but after initial scoping, this restriction was found to be too narrow and was broadened to include other advanced welfare states.

The policy review included documents dated from 2005 because, as outlined in the previous chapter, this was appropriate within the policy context. As it can take several years for evidence to enter policy debates and development (Spicker, 2014), and to understand whether there was an evidence base for the 2005 policy shift, evidence dating from 1990 about older people and independence was included.

Once established, the selection criteria were applied to all potentially relevant research studies in order to determine their relevance. These selection criteria were established in order to access the most relevant empirical research, but also to reflect pragmatic considerations.

For the scoping review, it was decided that the unit of analysis would be the study itself rather than individual research papers generated.

#### Stage 4: Charting the data

The key purpose of this stage was to map out key methodological and demographic characteristics of the identified studies. The software package 'Endnote' was used for bibliographic management, and therefore brief details of each study were incorporated into the Endnote database. These are listed below:

- Country of origin
- Research methods used (qualitative, quantitative or mixed methods)
- Characteristics of research participants

Recording these key descriptive characteristics from the selected study provided a useful starting point for developing the descriptive summary of the included evidence as presented in Section 2.

#### Stage 5: Collating, summarizing and reporting the findings

Arksey and O'Malley (2005) indicate that the purpose of this final stage of the process is to provide structure to the identified evidence base. Two possible methods of achieving this aim are suggested: a basic descriptive summary and an interpretative thematic analysis. Both of these methods are used to present the findings of this review.

#### Limitations of the scoping review

As this review progressed, and although clear selection criteria were established, it was increasingly clear that individual judgement was also part of the process. It also became clear that breadth of coverage needed to be balanced with practical considerations such as time, finances and availability of resources (Levac et al., 2010).

Questions remain about the impact of subjectivity in the process of carrying out a scoping review. For example, while the aim of the keyword searches was to scope for relevant research in a comprehensive manner, the choice of keywords was subjective. Indeed, as part of a literature review of independent living for older people, Leeson et al. (2004, p.11) comment that 'the nebulous nature of the concept of independent living means it is impossible to develop a set of keywords, which would be encompassing enough to exhaust the literature on independent living'. Although Leeson et al. (2004) are commenting upon

independent living rather than independence *per se*, their statement accurately reflects some of the difficulties I encountered when attempting to identify the most useful keywords.

Furthermore, the principal databases covering the topic area obviously guided which studies were included in this scoping review. It should be noted, however, that individual choice on my part also influenced which electronic databases and websites were/were not accessed. There remains the possibility, therefore, that studies accessible only from particular electronic databases or websites were not included due to my lack of awareness of their existence. Overall, such decisions illustrate the key tensions inherent within any scoping review, that is, between the need to be transparent about how decisions are made, and, simultaneously, to recognise that subjectivity and individual judgement play a key role in the selection of the literature for inclusion.

## Descriptive overview of the scope and characteristics of the research studies

This section outlines the descriptive characteristics of the 24 studies included within this scoping review. Table 4 presents a summary of the characteristics of these studies.

#### Country of origin

The UK was the country most represented in this scoping review. This weighting towards UK studies may be a result of the scoping review's selection criteria, for example, studies written in English, published on the websites of English and UK organisations.

#### Characteristics of research participants

The studies detailed a range of demographic characteristics of participants, such as age, gender and living situation. These are discussed next. Although the broad focus of all these studies was independence for older people, the participants' characteristics were diverse within and across the studies. This diversity was evident in several different ways, including whether the research recruited across the user-group divide or solely recruited older people. The majority of studies focused exclusively on older people, but one study also

included the perspectives of other stakeholders (IAHSP, 2004). While, as noted above, several other studies were excluded for this reason, this particular study was included as findings relating to older people were presented separately from those relating to other stakeholders (IAHSP, 2004).

#### Age

There was great diversity in the age of older people recruited to the various studies included in the scoping review, with participants' ages ranging from 50 to 105. While some studies reported on studies that sought responses from participants across a broad age range, others focused on specific age groups within the older people population. For example, Haak et al. (2007) recruited solely from what they defined as the 'older old' population; they reported findings only from people aged between 80 and 89. Studies reporting studies that recruited a younger sub-group of the older population (for example, Denton et al., 2010) tended to focus on ideas and expectations about the future and whether individuals would turn to community services to support their independence, if needed.

#### Gender

With the exception of two studies, all the included research recruited both men and women. Only one of the studies clearly demonstrated an equal gender balance mix. In the remainder, the gender make-up of the samples was unequal. For example, only 4 of the 29 participants were men in Plath's (2008) study, and Tilse et al. (2007) reported that only 5 of their 34 participants were men. Although neither of these studies suggested possible explanations for this lower male recruitment, this might be because of the female-heavy demographic composition of the older population due to women's longer life expectancy (ONS, 2012). One study was gender specific. This was the research by Schank and Lough (1990), which was interested in older women and their understandings of independence.

#### Living situation

While the scoping review's selection criteria focused on studies reporting studies that recruited older people living in the community, the included studies exhibited some diversity as regards the living situations of the participants. For example, most of the studies opted for a broad recruitment strategy, including those

cohabitating as well as those living on their own. There were two exceptions (Haak et al., 2007; Wilken et al., 2002), and both of these focused upon the experiences of older people living on their own.

#### Time focus

There were also differences in the time focus of the studies. Several focused upon older people's expectations of independence and possible future support needs and were interested in ascertaining whether they would turn to community services to support their independence, if needed. For example, some of the studies focused upon future expectations of independence (Quine and Morrell, 2007). Other studies focused upon the present, and explicitly upon current strategies older people were adopting to maintain their independent status (Mack et al., 1997; Yuen et al., 2010).

#### Research methods used

The studies included in this scoping review drew upon a range of research methods spanning the qualitative-quantitative spectrum, including some studies that used a mixed methods approach. As the focus of this scoping review was to identify research that tapped into older people's perspectives of independence, and given that qualitative methods are considered the most appropriate for exploring individual understandings of the phenomenon being researched (Mason, 2004), the majority of studies included are, unsurprisingly, qualitative. These qualitative studies contained a diverse range of sample sizes; for example, seven participants were involved in Breitholtz et al.'s 2013 study, whereas at the other side of spectrum, Yuen et al. (2010) interviewed 163 older people.

The studies using a quantitative approach recruited much larger participant numbers; for example, Quine and Morrell's (2007) study recruited 8881 participants. However, in some of the quantitative studies, the focus upon independence was only a small part of the research. Indeed, Quine and Morrell (2007) report part of the findings from a large-scale quantitative study about the hopes and fears older people have about their future, loss of independence and nursing home admission.

Data collection methods varied. Face-to-face semi-structured interviews were the most-used qualitative method for data collection (Parry et al., 2004; Breheny and Stephens, 2009). Other qualitative methods included participant observation (Portacolone, 2011). The quantitative methods of data collection also varied, but the most frequently used quantitative method was the telephone based survey.

The methods of data analysis also varied. However, as presented in Table 4, many of the studies were vague about the precise methods of data analysis used, instead citing the use of broad qualitative techniques, such as coding and mapping (Breheny and Stephens, 2009). Of the studies that clearly presented the data analysis method that they employed, there was evidence of different qualitative approaches to analysis, including content analysis (Yuen et al., 2010) and grounded theory (Haak et al., 2007). A similar diversity in terms of data analysis was also evident in the quantitative studies.

Several studies initially appeared to meet the selection criteria, but upon more indepth reading were excluded. One notable example was a study by Smith et al. (2007) exploring independence, masculinity and ageing. The abstract states 'this paper draws on semi-structured interviews conducted with 36 older men to examine how older men's understandings of independence relate to their help seeking behaviour and health service use' (p.325). However, when the full article was read, although the substantive scope was highly relevant, its title and abstract were misleading as the age range of the participants did not fulfil the selection criteria (6 participants were aged 35-44 and only 12 of the 36 participants were 65 and over). Data from participants over 65 were not reported separately, and so it was not possible to differentiate these from the younger participants (examples of such articles are Wilde and Glendinning, 2012; Rabiee, 2012). However, Denton et al.'s (2010) study, which covered a range of ages, was included. Although this study tapped into the attitudes of middle-aged adults as well as older adults about using support services, these different age groups were presented separately. This meant it was possible to differentiate the findings for the older population from those for the middle-aged sample, and these data were included in the thematic analysis for this scoping review.

Table 4: Summary of descriptive characteristics of studies included in scoping review

Study	Country of origin	Age range	Sample size	Data collection	Data analysis
Abbott and Fisk (1997)	UK	74-105	146	Face-to-face semi- structured interviews	Not clearly defined
Bell and Menac (2013)	Canada	54-81+	30		Provisional coding, categorization and thematic coding
Breheny and Stephens (2009)	New Zealand	55-70	36	Face-to-face semi- structured interviews	Discourse analysis
Breheny and Stephens (2012)	New Zealand	55-70	48	Face-to-face semi- structured interviews	Discourse analysis
Breitholtz et al. (2013)	Sweden	80-91	7	•	Phenomenological hermeneutic analysis
Denton et al. (2010)	Canada	50+	768		Quantitative analysis Binary logistic regression
Gabriel and Bowling (2004)	UK	65+	999	Mixed methods	Thematic coding

Gunnarsson (2009)	Sweden	77-79	16	3 separate face-to-face interviews	Coding to identify empirical and theoretical concepts
Haak et al. (2007)	Sweden	80-89	40	Face-to-face in-depth interviews	Grounded theory
Hammarström and Torres (2010)	Sweden	77-93	29	Face-to-face semi- structured interviews	Qualitative thematic coding
Institute for Applied Health and Social Policy (2004)	UK	60+	13	Group discussions and individual interviews	Not clearly defined
Langan et al. (1997)	UK	60-98	39	Qualitative interviews	Not clearly defined
Mack et al. (1997)	USA	65+	103	Face-to face interviews - open ended questions	Qualitative coding
Parry et al. (2004)	UK	60+	118	Qualitative interviews	Qualitative coding
Plath (2008)	Australia	65-97	29	Face-to-face in-depth qualitative interviews	Qualitative coding
Portacolone (2011)	USA	75+	41	Participant observation and in-depth interviews	Qualitative coding
Quine and Morrell (2007)	Australia	65+	8881	Telephone survey using open ended questions	Quantitative analysis

Schank and Lough (1990)	USA	85-91	10	Face-to-face in-depth interviews and structured questionnaire	Not clearly defined
Stephenson et al. (1999)	Canada	67-100+	39	Qualitative interviews	Line by line content analysis
Tanner (2001)	UK	70-92	12	Face-to-face in-depth interviews	Grounded theory
Tilse et al. (2007)	Australia	75+	34	Face-to-face semi- structured interviews	Not clearly defined
White and Groves (1997)	Australia	60-93	78	Non-structured interviews	Constant comparative analysis
Wilken et al. (2002)	USA	85+	75	Open-ended qualitative interviews	Content analysis
Yuen et al. (2010)	USA	60+	163	Face-to-face semi- structured interviews	Content analysis

#### Thematic overview of the findings from the research studies

The aim of this third section is to present a thematic analysis of the findings of the scoping review. In accordance with the selection criteria, the findings draw solely upon empirical research involving older people rather than theoretical studies that seek to define independence. As this review aims to provide a broad overview of the identified themes, none of the direct quotes from individual participants that were reported in the studies have been included in this section.

Most of the research studies state that independence for older people is a personally constructed concept that is complex and, at times, even contradictory (Parry et al., 2004; Plath, 2008; Mack et al., 1997). Parry et al. (2004), as part of a large-scale qualitative study, highlighted that their participants possessed diverse interpretations of independence, noting that 'older people did not necessarily draw upon a single constant definition of independence' (Parry et al., 2004, p.28). Portacolone (2011) also found the meaning of independence to be subjective, complex and variable and independence to be central to the lives of many older people. She argues that 'being independent is often intrinsic to the core of one's being and is highly subjective. Each person has a different idea of what it means to be independent. Independence often feels innate, instinctual and unquestionable' (2011, p.815).

A further theme common to many of the research studies was how independence was a changeable concept for many older people. For example, Parry et al. (2004, p.2) referred to the meaning of independence for older people as a 'shifting' concept, one that 'was malleable, adjusting itself to reflect transformed circumstance' (p.28). Plath (2008, p.1357) made a similar point, stating that 'the meaning of independence changed with the context about which they [participants] spoke'. This conceptualisation of independence as being a changeable construct also meant that it could encompass a range of experiences; for example, Breitholtz et al. note that 'independence for older people has both positive aspects, for example to be able to make one's own decisions, and negative aspects in terms of isolation and underestimating one's needs' (2013, p.2).

As a result, this scoping review does not put forward a singular definition of independence for older people. As the scoping review progressed, different aspects of independence emerged as being significant to older people's understanding of independence: the individual dimensions of independence and the wider circumstantial factors affecting independence. The individual dimensions of independence refer to an experience/experiences primarily connected to an individual's sense of self. The circumstantial factors of independence are concerned with wider social and demographic variables. Although these individual dimensions and circumstantial factors are discussed separately, they may be interactive.

#### Individual dimensions of independence for older people

Five dimensions of independence for older people emerged from this scoping literature review.

#### Self-reliance

Older people's independence was often strongly associated with self-reliance and, specifically, an ability to carry out functional tasks – primarily activities of daily living – without the need for assistance (Plath, 2008; Parry et al., 2004; Haak et al., 2007; Institute for Applied Health and Social Policy (IAHSP) 2004). For example, Plath (2008), as part of a qualitative study examining older people's discourse about their experiences of independence, found that 21 out of a total of 29 participants felt that independence meant the ability to 'do things alone'. IAHSP (2004) confirmed the importance that older people placed on self-reliance and found that the emphasis upon self-reliance as a defining feature of independence was stronger for older people than for other stakeholders (other service-user groups, carers, staff members and senior management) involved in their research.

The emphasis on self-reliance is often not wholly individualistically driven. Some studies found that the importance that older people place on self-reliance is, in part, driven by their desire not to affect the lives and independence of other people (IAHSP, 2004). Thus, self-reliance is not solely valued by older people as an end-product, but is also seen as being important in the context of not feeling a 'burden' or 'having to depend on others'. Langan et al. (1996), in a study focused

specifically on the meaning of independence in relation to older people's housing and support needs, also found self-reliance to be a strong defining characteristic of independence for older people. Similarly to IAHSP (2004), the importance of self-reliance was partly driven by the desire not to have an impact upon others. In particular, this study found that to some older people, 'giving in' to offers of help undermined their own independence, and many older people were particularly concerned about placing any 'excessive' demands upon their children. In these cases, participants experienced anxiety associated with being unable to be independent in a self-reliant manner.

Parry et al. (2004), who carried out 118 in-depth interviews with older people from a range of backgrounds, found that the prominence that older people gave to the idea of self-reliance meant that seeking assistance from family and/or friends could be difficult and might lead to feelings of guilt and/or failure. Parry et al. noted:

There were also perceptions that asking for help was an admission of failure, in conflict with a strong personal ethos of self-sufficiency... Often older people commented that they would feel happier accepting help that was offered to them proactively (2004, p.3).

This emphasis on self-reliance and the ensuing desire not to request any additional support from others was evident in research carried out by Plath (2008). She suggests that in addition to older people not wishing to feel a 'burden', there was also a fear of being let down by other people: '[a] reluctance to ask for help or to impose on people and a fear of being let down by others fuelled the desire to do things alone' (p.1359).

As evidenced above, older people often assert that self-reliance is an essential and positive component of their independence. However, several research studies have challenged this view, suggesting that seeing independence in this way may have negative consequences for older people (Plath, 2008; Portacolone, 2011; Breheny and Stephens, 2009). For example, Portacolone (2011) found that for some older people, the emphasis that is placed on independence meant self-reliance was viewed and experienced as a 'moral

imperative of independence'. Under such a discourse, some participants felt there were no viable alternatives to this individualistic understanding of independence rooted in self-reliance. Consequently, they felt duty-bound to maintain independence whatever the personal cost and would go without the assistance needed rather than seek support. Breheny and Stephens (2009) agree, suggesting that older people who place too much focus on self-reliance may avoid asking for assistance even if needed.

Plath (2008, p.1362) also concurs, highlighting the management of risk and loneliness as possible negative outcomes of placing too much emphasis upon self-reliance:

Isolation and the neglect of needs were experienced as a result of doing things alone. In preference to asking for assistance, some older people endure inadequate situations and go without their needs being met. This can lead to feelings of frustration and inadequacy. At times, there are safety concerns because of the physical risks associated with doing certain tasks alone. For some older people, much physical pain accompanied doing things on their own. The satisfaction in achieving independence by doing things alone is at times balanced against isolation, deprivation, frustration and risks to physical well-being.

This finding highlights the paradox of older people conceptualising and 'performing' independence by trying to maintain their independence irrespective of safety concerns. In doing so, they may in fact be compromising their capacity for independence in the future. This is because the dominant discourse of self-reliant independence promotes the 'idealisation' of independence and thus complicates the relationship between self-reliance and independence for some older people. The relationship between self-reliance and independence primarily involves maintaining an individual sense of independence. However, it is often partly driven by not wishing to impact upon others' independence, and thus self-reliance can be experienced by older people in both positive and negative ways.

#### Choice and control

Many of the studies indicated that older people's sense of independence was closely associated with the amount of choice they were afforded and the level of control they were able to experience (Parry et al., 2004; Haak et al., 2007). The significance attached to choice and control is evidenced by Parry et al. (2004), who found that while other aspects of independence were cited as being important, many older people felt that independence would only be lost if they were unable to experience sufficient levels of choice and control. The importance of choice and control to the older person's sense of independence was also highlighted by Plath (2008). In this study, 'making one's own decisions' and prioritising this aspect of independence were highlighted as being important for older people. The decisions discussed by the participants in Plath's (2008) study highlighted the desire to maintain control over a wide range of circumstances. These varied from everyday decisions (for example, shopping) through to major life changes, especially in relation to the choices about moving into residential care.

Haak et al. (2007) also found older people emphasised choice and control. Their participants differentiated between being able to carry out a particular task without assistance and being able to experience choice and control in terms of decisional autonomy. They suggested that they were able to maintain their independence when experiencing declining health if they maintained a sense of control over decision making. Haak et al. noted that:

During the process of functional decline, the participants' view of what was meant by independence changed into a perspective where they considered themselves independent as long as they were able to make choices that were meaningful to them as individuals. Thus, it was no longer the actual performance of activities but the actual decision-making that was important for maintaining independence. (2007, p.22)

While not diminishing the importance of choice and control, a more critical discussion also emerged from the evidence base. Several of the studies highlighted that choices made to promote independence in one area of an older person's life may have implications (not necessarily positive) in another (Parry et

al., 2004). Wilken et al. sound a note of caution about the tendency to overemphasise choice and control by pointing out that control doesn't guarantee independence:

Although internal control is culturally expected and encouraged in Western society, one cannot assume that it is the sole key to successful aging and, ultimately, independent living (2002, p.83).

#### Reciprocity

Several of the studies identified reciprocity as an important dimension of older people's independence (White and Groves, 1997; Tanner, 2001; Parry et al., 2004; Breheny and Stephens, 2009). For example, White and Groves (1997), whose qualitative research involved 78 older participants living in the community, found that reciprocity was an important part of independence, with most participants associating it strongly with feelings of being in control. They found that participants were more likely to feel in control if they were able to reciprocate any assistance received, noting that 'the individual's perceived level of control in the mediation and reciprocation of an interdependent lifestyle is an important cognitive component of independence' (1997, p.87).

Similar findings were also presented by Tanner (2001), who noted that the giveand-take nature of relationships was valued highly by many of the older people
interviewed for her research, and they aimed to maximise their chances to
engage in reciprocal relationships. Consequently, a wide understanding of
reciprocity was presented by many of the older people interviewed, for example,
exchange of money for services provided, looking after family members,
providing emotional support and offering 'indirect support' to the wider
community, such as participating in coffee mornings. Parry et al. (2004) found
that a similar understanding of independence was held by the older people who
participated in their study.

For many older people in these studies, this aspect of independence was defined both in terms of providing and accepting support and was seen as a flexible concept and experience. This suggests that their understanding of reciprocity, as a dimension of independence, represents a recognition of the notion of

'interdependence' and a move away from seeing independence purely in terms of being the polar opposite of dependence. Breheny and Stephens (2009) found that reciprocity is an important aspect of both short and longer-term relationships for older people. Their study highlighted that help and support would tend to be reciprocated within a short period of time, or even immediately in response to an act. Simultaneously, inter-generational reciprocity – for example, between grandparents and their children or grandchildren – was also highlighted. The prominence given to this intergenerational reciprocity and its function as a dimension of independence by those interviewed suggests that older people may feel that assistance is more readily acceptable if it is part of the reciprocity that often exists in family relationships. Furthermore, the older people in the study talked about how important it was that exchanges of assistance were of equal value, and some participants talked about such reciprocity in terms of a 'debit and credit account'. This sense of equivalence of exchange promoted a sense of independence for the respondents, and as Breheny and Stephens (2009, p.1301) note, 'reciprocity may be drawn upon by older people to position themselves as independent, even when they need physical help'. Langan et al. (1996) concur, noting that some older people view reciprocity as a means of diminishing any sense that their independence is being challenged when receiving assistance. There was also evidence to suggest that some older people 'banked' the help that they gave to others, feeling that this could be drawn upon in times when they themselves needed assistance.

When viewed through this lens, independence cannot be seen as a single, distinct and consistent concept. Rather, in some of the studies included in this review, independence took on a more relational meaning in which the different understandings of independence do not exist in isolation from each other, but instead are interdependent and interact with one another (Breheny and Stephens, 2009; White and Groves, 1997; Tanner, 2001). For example, as part of Breheny and Stephens' (2009) study, it was found that reciprocity often acts as a bridge connecting potentially conflicting dimensions of independence such as an individualistic need for self-reliance and the simultaneous need for others. This emphasis upon the role of reciprocity in independence resonates with the wider argument that older people value interdependence as much as, or possibly more than, independence. Indeed, White and Groves (1997) suggest that any

conceptualisation of independence for older people needs to be reframed within the context of interdependence.

#### Social inclusion

A sense of social inclusion or connectivity with others was identified as being a significant dimension of independence for older people (Plath, 2008; IAHSP, 2004). Plath (2008) in particular highlights that the social inclusion of older people is not only dependent on the older people themselves, but also dependent on society supporting older people:

Socially inclusive independence does not require that older people act alone to achieve these goals. The older person is respected, valued and supported by others in their decision making. Socially inclusive independence supports the right of older people to reliable services that involve them in decision making so that services appropriately meet individual needs (Plath, 2008, p.1366).

In a study specifically addressing the relationship between independence and social exclusion, Bell and Menec (2013) found that the moral and cultural need for some of their participants to present themselves as being independent led to 'self-exclusion'. Some participants articulated so strong a fear of being perceived as being old, lonely and/or in need of assistance that they felt compelled to present themselves as 'independent' to others, and this led them to actively exclude themselves from activities and/or involvement with others. Their perceptions of loneliness and perceptions of independence clashed, and it was evident that the participants were constantly balancing these different priorities. This study suggests that addressing the issues around self-exclusion by older people and its relationship to cultural constructions of independence is essential if society is to become more age friendly.

#### Continuity of Identity

Both a positive sense of identity and, in particular, a continued sense of a connection with one's past self were identified as being important aspects of older people's meaning of independence. Indeed, the scoping review revealed that there exists an interdependent relationship between notions of independence

and identity for many older people (Parry et al., 2004; IAHSP, 2004). Older people valued being identified as 'independent', and, simultaneously, an affirmative sense of identity promoted a feeling of independence (Parry et al., 2004; IAHSP, 2004).

Several of the studies (Plath, 2008; IAHSP, 2004; Tanner, 2001) suggest that a variety of changeable factors frequently contribute to an individual's sense of their identity. This in turn suggests that both a continuation of previous roles and identities established at a younger age as well as newer identities that may develop as part of the process of becoming older are important to independence. Tanner (2001) found that the continuation of everyday tasks by older people – for example, shopping and visiting friends and family – not only were valued in terms of the completion of the tasks and their practical functions, but also were crucial aspects of older people's sense of identity and independence. Tanner (2001) found that while many older people faced difficulties in continuing to perform such tasks, they valued these as a means of maintaining a sense of independence. As Tanner observed, 'struggling to maintain routines encompasses "social" as well as "personal" components of identity, acting as a mechanism for preserving reputations of independence and continuing ability' (2001, p.262).

While continuity of identity was highlighted as playing an important role in independence, other research suggested that ageing also provides an opportunity for older people to distance or disassociate themselves from previous roles/identities and ideas surrounding independence and can thus act as a breeding ground for the establishment of new social roles. However, although Plath does not challenge the importance of individual identity and social roles in older people's experience of independence, she suggests that it can be difficult to achieve independence in the wider context of social and cultural prejudices: 'the struggle to maintain independence in terms of a valued social role, in the face of social stigma, ageism, fear and financial disadvantage, can be a difficult one' (2008, p.1364).

Circumstantial factors affecting older people's constructs of independence

This scoping review also identified individual circumstantial factors that impact on constructs of independence. These three factors are health and physical mobility, financial management and security, and housing.

#### Health and physical mobility

In several of the research studies, health was seen by older people as being an extremely important, if not the most important, factor affecting their independence (Mack, 1997; Plath, 2008; Parry et al., 2004). Good health was seen as central to maintaining independence, while poor health was seen as having the potential to prevent independence. Indeed, Mack et al. (1997) found that when participants were prompted to think about the factors that might impact on their independence, individual ill health was the most commonly stated risk.

Research by Parry et al. (2004) also highlighted the importance of health and found that unlike finances, which were rarely voluntarily mentioned by the participants (although this omission could be related to the social taboo around talking about money rather than a genuine feeling that financial concerns were unimportant), good health was frequently cited as being crucial to independence. Parry et al. found that:

Pensioners representing a cross-section of socio-demographic characteristics spontaneously mentioned the importance of maintaining their health in order to preserve their independence... Loss of 'good health' was often equated with 'losing independence' or taking away an accustomed and valued lifestyle (2004, p.32).

While health was seen as a significant determinant of independence for many older people, differences were found to exist between those who were currently experiencing good health and those who were experiencing poor health:

Interestingly definitions of health and ill-health, and the impact of these upon independence, were highly relative. Pensioners with fewer health problems viewed the onset of ill-health as a threat to their independence, subscribing to the attitude, 'you can't be in poor health and be independent'... However, those experiencing a limiting health condition did

not necessarily view themselves as being 'not independent'. While relatively healthy pensioners tended to regard deteriorating health as a threat to their independence, some less healthy pensioners, perhaps with the knowledge of experience and adaptation, still viewed themselves as independent (Parry et al., 2004, p.32).

Conversely, there was also evidence to suggest that older people also viewed independence as a gauge of good health, For example, Haak et al. (2007) found that 'independence in daily activities is considered an important health indicator' (p.17).

Several of the studies found that physical mobility, both inside and outside of the home, was an important aspect of independence for older people (Parry et al., 2004; Gabriel and Bowling, 2004). In particular, the ability to get outside their own homes was regarded by many older people as crucial to their sense of independence. For example, in their research on quality of life, Gabriel and Bowling (2004, p.687) found that over two-thirds of the participants stressed the relationship between mobility and independence as important because:

They wanted to avoid the boredom and monotony of a life confined indoors through immobility, and wanted to continue to be able to do things for themselves, such as shopping and household tasks. Avoidance of dependency on others was a commonly-held value. Retaining their mobility and independence was also said to be important because it enabled the respondents to get outdoors, to enjoy life, to meet other people and to avoid being dependent on other people.

The importance of physical mobility was also acknowledged by Parry et al. (2004). Their research found that the services valued for promoting a sense of independence were those that focused on enabling mobility. Plath (2008) argued that being physically mobile provided both a sense of opportunity and a sense of not being restricted, which in turn promoted feelings of independence for older people. By contrast, where physical mobility was reduced, older people felt that the opportunity to achieve independence was affected. While mobility was shown to be important, wider circumstantial factors also played a role in the interaction

between mobility and having a sense of independence. Indeed, Parry et al. suggest that:

Those who were still fairly fit and mobile mentioned ill-health and loss of mobility as events that could compromise their independence, while those with limiting health conditions had often come to terms with these constraints, and defined independence in different terms (2004, p.37).

While the majority of older people in these studies tended to regard the relationship between mobility and independence in terms of their ability to be mobile outside the home, for some of the older people whose mobility was restricted to the home setting, mobility inside the home was regarded as being crucially important because it facilitated their ability to take care of themselves and thus maintain a degree of independence.

#### Financial management and security

The impact of financial resources on constructs of independence and in particular the way older people's management of and sense of security about their resources, was explored in several studies (Parry et al., 2004; IAHSP, 2004; Tilse et al., 2007). While finances were cited as important, Parry et al. (2004) found older people rarely mentioned them spontaneously. Furthermore, when financial resources were mentioned, they were seen not as the means to independence or as an end product, but as a means of either restricting or providing choices and/or security in order for older people to experience (or not experience) independence.

While the research showed that older people did not regularly draw a direct connection between their income and their independence, when income was mentioned, it tended to be by those with the lowest incomes. Parry et al. (2004, p.35) noted that:

Only a few interviewees spontaneously associated having sufficient finances with being independent. However, they did tend to be those on the lowest incomes, who experienced most restrictions on the range of options available to them.

Parry et al. (2004) found differences between the impact of financial resources on the independence of those older people with savings and/or higher incomes and those with a limited or low income. For some older people with a low income, claiming benefits was sometimes felt to be at odds with their sense of independence. For those with higher incomes and/or savings, financial resources were seen as enabling them to maintain their sense of independence.

Nevertheless, older people who had experienced an increase in income did not regard this increase as important in and of itself. Rather, this increased income enabled them to access greater resources, and this was of importance symbolically as well as practically. As Parry et al. (2004, p.37) comment:

While interviewees did not spontaneously associate increases in their income with an increase in independence, this was implicit in their descriptions of the activities and services which they were able to access as a result.

The relationship between independence and financial resources for older people has also been researched in the context of younger relatives managing the financial affairs of older relatives. Tilse et al. (2007) reported on a case analysis of 34 older people who described their experiences of managing their finances. Analysis showed that three broad situations, linked to a sense of independence, were common for older people. First, for some participants, managing their own financial circumstances was central to their independence. Second, some participants who played a limited role in managing their own financial affairs were content with not having to consider financial matters. Third, some participants were dissatisfied with the level of control that they could exercise over their financial circumstances and felt that this was not compatible with their goal of independence.

#### Accommodation

Housing and the home was identified in many of the studies as playing an important role in older people's independence. Indeed, a study by Haak et al. (2007) showed that some older people regard the ability to remain in one's own home as an important accomplishment and as inseparable from independence

itself. The relationship between housing and independence was evident in broader research about independence (Parry et al., 2004) as well as those studies that focused specifically on housing issues (Langan et al., 1996; Haak et al., 2007).

Two main themes emerged in relation to housing and independence: (a) remaining at home is seen to promote independence, and (b) remaining at home is a signifier to others and themselves of being independent (Mack et al., 1997). Haak et al. (2007) extends this point by highlighting the important role vis-à-vis independence that one's home plays in the context of 'governing daily life'. This suggests that the home plays a broader role for older people than merely offering functional independence. Rather, it acts as an important bridge between control and independence. Haak et al. note that:

Being able to govern meant being in charge of daily life at home in terms of deciding when, how, where, and what kinds of activities should be performed. The issue here is not the actual performance of activities but the making of the decisions (2007, p.19).

The home was also identified by older people as being symbolically important in relation to independence. For some older people, living at home was representative of an independent self. This is primarily because the home was seen as a place to maintain and express individuality and identity (Langan et al., 1996).

While remaining at home may be seen as a positive driver of independence, it is important to note that, at least in part, remaining at home for many older people was influenced by the desire not to enter residential care, and in particular the perceived negative impact that this might have upon their sense of independence (Parry et al., 2004). Quine and Morrell (2007, p.217) also acknowledged the relationship between independence and negative perceptions of residential care by noting that 'fear of nursing home admission could be considered a more specific and extreme form of loss of independence'.

While remaining in their own home is a central aspect of many older people's sense of independence, this does not mean that this is a wholly positive experience. Indeed, for some older people, the desire to maintain independence when experiencing increasingly poor health may result in the home becoming a site of resistance or struggle (Haak et al., 2007). It should be borne in mind, however, that Haak et al.'s study, while drawing attention to important implications for the relation between independence and home, recruited from the 'very old' population (aged 80–89), and its findings might most accurately reflect the experiences of particularly aged and/or infirm people.

Overall, the relationship and role of the home in terms of independence is more complex than a simple dichotomy in which independence is only achieved when living at home, and dependence ensues when living in a residential or institutional setting. The home can be both a signifier of independence as well as a physical space within which independence can be felt and experienced. However, at times it can also become a place where independence is challenged, fraught, and difficult to achieve.

# The gaps identified in the evidence base

As detailed earlier in this chapter, one of the key aims of this scoping review was to identify gaps in the research on independence for older people.

Overall the review identified relatively few empirical research studies which focused upon independence from the perspective of older people living in the community (n=25). Yeun et al. (2007, p.37) draw attention to this dearth of evidence by stating 'few studies have explored... community-dwelling older adults... independence'. From the included studies, it was established that independence is a complex phenomenon for older people, and further research is needed to deconstruct older people's conceptualisation and experience of it. Haak et al. sum up this gap by noting that 'even though the concept of independence is a well-known and central term as a goal [for health and social care policy]... research elucidating what independence really means to older people from their own perspective is limited' (2007, p.16).

Many of the studies included in the scoping review found that independence was a dynamic and changeable concept for older people. Only one study was longitudinal in scope, but this (Gunnarsson, 2009) covered a relatively short period of time (i.e. one year). While this scoping review found that independence is seen as a high priority for older people, less is known about how older people can sustain these feelings of independence in the context of changing circumstances. Such circumstances may include declining mobility, poor health, an increased reliance on others and changed living arrangements. Again, a longitudinal approach may be useful in gaining an insight into these circumstances.

In several of the studies, specific mention was made of the need to deconstruct the *values* that underpin independence. For example, Plath (2008) suggests there is a need to challenge the dichotomy that promotes independence as a social 'good' and dependence as a social 'bad' (Plath, 2008). This scoping review found that although older people highly value independence, the high value placed on independence by society and policy may cause negative outcomes for some older people (Plath, 2008; Portacolone, 2011; Haak et al., 2007). For example, Portacolone states that 'researchers should examine how many people struggle to keep up with the moral imperative of independence' (2011, p.824). While studies included in the review acknowledged the potentially negative consequences of the emphasis that is placed on independence, less is known about how these consequences might impact upon older people's sense of independence.

Gunnarsson remarks that 'research has focused mainly on frail and care demanding older people, and has paid little attention to older people who have a lesser need for care or who receive no home help at all' (2009, p.253). Few of the studies included in the review, recruited older people who did not use services or those that only used lower level services. Indeed, with the exception of Tanner (2001), there was a dearth of UK studies focusing explicitly upon older people with lower level care needs. This suggests that this particular area is in need of further research.

This scoping review found that the literature was limited in terms of theory testing and theory generation about independence for older people. The majority of the empirical research studies did not report drawing on any theoretical framework as part of the research process. The only study that proclaimed a theoretical basis to the research was that by Portacolone (2011) and even in this example there was a lack of clarity about the theory used. Furthermore, the majority of the studies did not generate any theory as part of their findings. The notable exception was the study by Haak et al. (2007), which reported that it generated theory by drawing upon a grounded theory methodology.

It was found that there were notable gaps in the literature regarding specific groups of older people. For example, two studies focused exclusively on older people living on their own, and neither was UK-based research (Portacolone, 2011; Wilken et al., 2002). This is potentially a significant research gap given the demographic trend of increasing numbers of older people living on their own (ONS, 2012). Another notable gap identified was the relative paucity of older men's viewpoints in the research. While the majority of the studies recruited both men and women, few had an equal gender make-up. Instead, most were heavily biased towards women, and the one which used gender as a selection criterion recruited only women. This is potentially an important gap, especially given that the difference between women's and men's life expectancy is reducing (ONS, 2012). In addition, comparative studies were lacking, for example, no studies reported comparing two different age cohorts (for example, younger old people (under 85) and older old people (aged 85 and over)).

Some of these gaps identified in the scoping review are addressed by the empirical research conducted for this thesis. The scoping review helped to focus the research question being explored and the methods and methodology adopted.

- As outlined above, this scoping review revealed that a gap existed for exploring the meaning of independence for older people who may access support across different settings, including low-level services.
- The evidence included in the review suggested that older people's conceptualisation of independence might be dynamic and responsive to changing circumstances. However, this was not explored in any detail

- within the included studies. Thus, qualitative approaches to data collection were chosen as these enable deep and thorough exploration and explanation of phenomena including individual views and meanings.
- The lack of theory rooted in empirical research about independence for older people led to the adoption of constructivist grounded theory as the methodology.

# Summary and conclusion of this chapter

This chapter has presented both the methods and findings of the scoping literature review and has also set out the gaps that were identified in the literature. In summary, independence was cited in many of the research studies as an individually constructed experience for older people. Evidently, independence means different things to different people, and thus no single definition emerged, but instead was shown to comprise individual dimensions, such as self-reliance and circumstantial factors affecting older people's constructs of independence, such as physical health and mobility. In the following chapter, the epistemology, theoretical perspective and methodology underpinning the empirical research is presented.

# CHAPTER 4: EPISTEMOLOGY, THEORETICAL PERSPECTIVE AND METHODOLOGY

#### Introduction

This chapter presents the epistemology, theoretical perspective and methodology used for this research and provides the justification for choosing particular approaches. As outlined earlier (see Chapter 1), the research question is the 'what is the meaning of independence for older people?' This research question guided the choice of the epistemology, theoretical perspective and methodology.

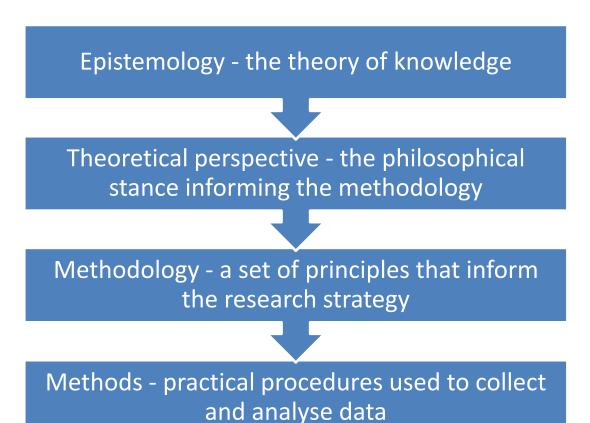
This chapter is split into four sections. The first section focuses on the epistemological and theoretical perspective taken. The second section considers the key interpretative methodologies available and why grounded theory approach was adopted and others rejected. The third section presents a critical overview of grounded theory by providing a historical overview of the development of the methodology, introducing the three main methodological approaches (traditional, evolved and constructivist (Mills et al., 2006b)), explaining why grounded theory is the most appropriate methodology for this research and presenting the rationale for specifically using a constructivist grounded theory approach. The fourth section presents the defining principles of grounded theory methodology irrespective of which specific methodological approach is used. These are theoretical sampling, constant comparative methods and the development of theory.

# **Epistemology and theoretical perspective**

The scope and terminology surrounding epistemologies, theoretical perspectives, methodologies and methods are often presented in an inconsistent and conflicting manner, leading to the appearance of a sometimes confused relationship between these different aspects of the research process (Carter and Little, 2007; Crotty, 2010). To limit such confusion, and to elucidate the links between different parts of the research process, a framework drawing on Crotty's (2010) proposal is used here. Although other frameworks were considered (see, for example, those proposed by Blaikie, 2004; Silverman 2001), the decision to employ Crotty's framework was taken because this framework is accessible and

informative, suits the requirements of PhD research and clearly illustrates the iterative approach adopted in this thesis. This framework is illustrated in Figure 1.

Figure 1: Diagrammatic summary of the research framework proposed by Crotty (2010)



As set out in Figure 1, Crotty's (2010) research framework comprises four key considerations: epistemology, theoretical perspective, methodology and methods. The framework contrasts with other research frameworks such as those of Blaikie (2004) and Guba and Lincoln (1994) in that it does not incorporate an ontological aspect. Crotty argues that the close relationship between ontology and epistemology can lead to the distinctions between the two becoming indecipherable as the knower cannot be separated from what can be known. Crotty contends, therefore, that 'ontological and epistemological issues tend to merge together... to talk about the construction of meaning [epistemology] is to talk of the construction of a meaningful reality [ontology]' (2010, p.10). The epistemology, theoretical perspective and methodology guiding this research are

considered in this chapter. The methods used as part of this research are set out separately in Chapter 5.

#### **Epistemology**

Crotty (2010) outlines three possible epistemological viewpoints that are most likely to be assumed in social research: objectivism, constructionism and subjectivism. Objectivism is rooted in the idea that objective meaning and an external truth exists independently of consciousness and experience (Crotty, 2010). Subjectivism refers to the view that everything is subjective from the person's own experience; that knowledge is subjective and personal and comes from the person's own inner mental state and view of the world. Constructivism, while taking a similar stance to subjectivism, also acknowledges the significance of social relationships to how we learn and thus contends that knowledge is constructed within and between human experiences and the wider contexts. As such, multiple meanings can co-exist, and knowledge is mutually created between the researcher and the researched (Charmaz, 2000).

Of these approaches, a constructivist approach was considered the most appropriate choice given the study's aim and its emphasis on tapping into a multi-dimensional and interpretive understanding of the constructs and meanings of independence for older people.

#### Theoretical perspective

Crotty (2010) suggests that there is a range of theoretical perspectives that support different epistemological viewpoints. The key distinction that is made between theoretical perspectives is between positivism and interpretivism. A positivist perspective is underpinned by an objectivist epistemology in which 'there is a reality out there to be studied, captured and understood' (Denzin and Lincoln, 2003, p.14). Thus, the aim of positivism is to establish the consistencies and uniformity of the social world through the use of 'scientific methods' (Denscombe, 2003). For this research, drawing upon a positivist perspective was not deemed appropriate because the focus would have been upon the quantification of independence rather than an in-depth exploration of the meaning of independence.

Given that a positivist approach was adjudged ill-suited to the aims of this research, the decision was made to adopt an interpretivist theoretical perspective. Interpretivism is strongly associated with the sociologist Max Weber and, in particular, his idea of 'verstehen', which refers to 'understanding something in its context' (Holloway, 1997, p.2). Such a perspective privileges individual understanding of phenomena and thus places the focus on understanding meaning from the perspective of those being researched and recognises that the construction of meaning exists within a wider social context. This perspective is summed up by Orlikowski and Baroudi (1991, p.5):

People create and associate their own subjective and intersubjective meanings as they interact with the world around them. [Interpretative research] attempt[s] to understand phenomena through accessing meaning participants assign to them.

There are two main reasons why interpretivism is compatible with the aims of this research. First, interpretivism places an emphasis on meaning, and as this research is concerned with understanding the meaning that older people ascribe to independence, it is particularly useful for this research. Second, an interpretive approach acknowledges the existence of multiple realities and recognises that understanding is subjective and socially constructed. As such, this theoretical perspective sits within the parameters of constructivism (Schwandt, 2003; Hallberg, 2006), and as illustrated in the choice of epistemology, this emphasis on subjective understanding resonates strongly with the aims of this research, including tapping into individual understandings and constructs of independence directly from the perspective of older people.

# Consideration of possible interpretative methodologies

While there are different methodological approaches to data collection and analysis, the methodology chosen needs to be congruent with the study's epistemology, theoretical perspective and the scope of the research aims and question (Starks and Trinidad, 2007). Several methodologies that tap into the individual ways in which different older people construct their understanding of independence from their experiences and that therefore resonate with the

research epistemology, theoretical perspective, question and aims of this research were considered.

Creswell (2010) suggests five relevant methodological approaches: narrative research, phenomenology, ethnography, case study approaches and grounded theory.

Narrative research is underpinned by two key assumptions. First, individuals construct their own experiences as narratives. Second, the narratives told are dependent on a variety of different contextual circumstances, for example, an individual's past and current experiences, their values and beliefs, and when, why and by whom this narrative is being told (Creswell, 2010). Although considered, narrative research was not used for this research because it places strong emphasis on gathering very detailed data about individual lives, which makes it difficult to move beyond individual cases, and because it recommends focusing on detailed description rather than analysis. Since the aim of the research was to tap into a range of older people's viewpoints and to generate inductive theory, these factors prohibited its use.

Phenomenology is a methodological approach within which 'human experiences are examined through the detailed descriptions of the people being studied' (Creswell, 1994, p.12). A phenomenological approach was considered, but rejected. This was primarily because the scope of phenomenology, while providing rich descriptive detail, is not intended to be explanatory. Furthermore, phenomenology does not aim to construct inductive theory. Given that this was an expressed aim of this research in view of the lack of theory about independence for older people, phenomenology was not considered to be the most appropriate approach for this research.

Ethnography aims to develop an understanding of a particular phenomenon specifically within the context of participant's culture, or 'shared values' (Hammersley and Atkinson, 2004). Therefore, similarly to phenomenology, the focus is upon providing rich descriptive detail. However, ethnography fails to focus upon actions and processes that construct meaning (Charmaz, 2006). As

this research aims to understand how and what older people construct as independence, ethnography was not an appropriate methodology.

Yin (2009, p.18) describes a case study approach as 'an empirical inquiry about a contemporary phenomenon (e.g., a "case"), set within its real-world context - especially when the boundaries between phenomenon and context are not clearly evident'. The case study approach, while appropriate in some ways (for example, its emphasis on the 'real-world' context), arguably favours the collection and analysis of descriptive data for individual cases, making it more difficult to undertake comparative analysis and to generate theory (Yin, 2009).

Having discounted these methodological approaches as being unsuited to meeting the aims of the study, a grounded theory approach seemed to provide the closest methodological fit to meet the aims of the research. In the next section, I discuss the grounded theory approach and set out my rationale for adopting it for this research.

# **Grounded Theory**

As presented in chapter 3, the scoping literature review revealed that the overall evidence base, particularly from a UK context, was small and that there is a distinct lack of theory derived from the empirical research. A notable feature of the review was that there very little theory that focuses specifically on the meaning of independence for older people that is rooted in empirical research.

Reflecting the findings of the policy review and studies included in the scoping review empirical research did not define or deconstruct the term independence, and further it was used uncritically even though its meaning appeared to vary between different policies and/or research studies. To date, little attention has been given to exploring and understanding the underlying values and assumptions surrounding the term 'independence', particularly in relation to older people using support services. Identifying the research approach best suited to addressing this gap and meeting the purposes of this study was therefore necessary. Since no hypothesis was formulated prior to data collection for this research, an approach rooted in inductive reasoning was required. In light of this,

it was felt that a grounded theory approach might offer the best solution. Goulding (1999, p.8) suggests that grounded theory is typically considered apt 'when the topic of interest has been relatively ignored in the literature, or has been given only superficial attention'. Punch (2005, p.159) makes a similar point when he says 'the rationale for doing a grounded theory study is that we have no satisfactory theory on the topic, and that we do not understand enough about it to begin theorizing'. Finally, a grounded theory approach would enable the potentially dynamic process of independence to emerge, as the emphasis would be upon exploration of the meaning of independence for older people rather than the measurement and/or quantification of this experience.

Grounded theory, a methodology that acknowledges individual and social construction of meanings and in which theory generation is inherent, was therefore deemed the most appropriate methodology for this thesis. Although relatively recently developed, grounded theory has quickly become a widely used methodological approach in the social sciences (Bryant and Charmaz, 2010; Gibson and Hartman, 2014). In part, its popularity can be explained thanks to the availability of clear guidelines about 'doing' grounded theory and its aim of establishing theory (Thomas and James, 2006).

However, the existence of such clear guidance on the methods to be employed has also led to debate about whether some research has been inappropriately labelled as grounded theory (Dixon-Woods et al., 2004; Suddaby, 2006). Dixon-Woods et al. (2004) explain that while such research may be inductive and theory-generating, this does not automatically equate to 'grounded theory'. Furthermore, they argue that such assumptions may be disadvantageous to the advancement of grounded theory as a methodology:

Some elements of grounded theory (particularly the constant comparative method of analysis) are especially useful, but the tendency to select some of these techniques to create ad hoc and 'à la carte' approaches to qualitative analysis and still retain the label 'grounded theory' is very unhelpful (p.224).

While acknowledging such criticisms, this thesis has aimed to adopt a more robust approach to the use of a grounded theory methodology, and as will be evidenced throughout this thesis, clear consideration has been given to its epistemological and theoretical perspective underpinnings and to the application of grounded theory methods in both data collection and data analysis.

Since its inception, grounded theory has undergone many methodological and philosophical revisions, and different approaches to using grounded theory have developed. For this reason, Locke (2001) argues that researchers need to be clear about the methodological foundations of the chosen approach to grounded theory and how this informs their methods. Bryant and Charmaz concur:

Researchers need to be familiar with [grounded theory methodology], in all its major forms, in order to be able to understand how they might adapt it in use or revise it into new forms and variations (2010, p.17).

Mills et al. (2006b) propose three distinct methodological approaches to grounded theory that are linked to particular epistemological positions:

- Traditional Grounded Theory (Glaser and Strauss, 1967; Glaser, 1978;
   Strauss, 1987).
- Evolved Grounded Theory (Strauss and Corbin, 1990; Glaser, 1992;
   Strauss and Corbin, 1998).
- Constructivist Grounded Theory (Charmaz, 2000; Charmaz, 2006).

According to Mills et al. (2006b, p.26), irrespective of the approach to grounded theory adopted, it is 'a methodology that seeks to construct theory about issues of importance in people's lives'. The policy and literature reviews both indicated the importance of independence, but what was less certain was whether the meaning and understanding of independence as portrayed in policy (chapter 2) and evidence (chapter 3) are fully compatible with older people's understandings.

When deciding which form of grounded theory to use, Mills et al. (2006b) emphasise the importance of being clear about the iterative links between epistemology, theoretical perspective and methodology. The different methodological approaches to grounded theory are outlined below.

#### Traditional grounded theory

Grounded theory as a methodological approach was first described in *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser and Strauss, 1967), a text which made explicit the research approach developed and applied in *Awareness of Dying* (Glaser and Strauss, 1965). As such, it was Glaser and Strauss (1967, p.2) who coined the term 'grounded theory' and used it to describe 'the discovery of theory from data systematically obtained from social research'. These texts are regarded as seminal primarily because they challenged ideas that quantitative and qualitative research were rooted in similar logic and thus should be evaluated using similar methods (Charmaz, 2008). In particular, Dey (1999) suggests that Glaser and Strauss (1967) questioned two key assumptions that had until that point been the dominant approach to social research (Dey, 1999):

- Should theory testing and confirmation always be the aim of research?
- Should there be a rigid division between theory and the collection of data?

In questioning these assumptions, Glaser and Strauss (1967) shifted the focus in two key ways: from data collection methods to approaches for data analysis and from verifying theory to the formulation of theory.

Traditional grounded theory is thus a methodological approach rooted in objectivism and the seeking of external truth. Both data collection and analysis are regarded as objective processes within which the researcher is neutral and passive (Dey, 1999).

#### **Evolved grounded theory**

Evolved grounded theory emerged primarily from the work of Strauss and Corbin (1990) and can be viewed as a departure from traditional grounded theory both philosophically and in its underlying assumptions and techniques. Unlike traditional grounded theory, this approach acknowledges the existence of multiple realities. Strauss and Corbin explicitly state that they do not ascribe to the idea of a 'pre-existing reality "out there." To think otherwise is to take a

positivistic position that... we reject... Our position is that truth is enacted' (1990, p. 279).

Thus, there is evidence that evolved grounded theory is epistemologically rooted in postpositivism and/or constructivism. Although the philosophical framework underpinning the methodology, and thus the methods used, is not made explicit in the key methodological texts on evolved ground theory, commentators argue that this does not undermine the value of evolved grounded theory, but instead reflects its contemporaneous development (Mills et al., 2006b; Hallberg, 2010) alongside 'the changing moments of qualitative research' (Mills et al., 2006a, p.28).

#### **Constructivist grounded theory**

The most recent methodological advance in grounded theory is 'constructivist grounded theory' (Charmaz, 2006) and is the approach towards grounded theory selected for this research. This approach is underpinned by the epistemology of constructivism and an interpretivist theoretical perspective. This contrasts with traditional grounded theory, which is predicated on the idea that the researcher has a fully objective and thus a positivist approach to research. In a key paper, Charmaz (2000) clearly sets out the differences between an objectivist and constructivist approach to grounded theory and claims that her approach realigns grounded theory away from objectivism and positivism towards a more relativistic, situational and partial approach by 'reclaim[ing] these tools from their positivist underpinnings to form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements' (p.510). Charmaz proceeds to challenge the underlying assumptions of traditional and evolved grounded theory by stating:

Both [traditional and evolved grounded theory]... assume an external reality that researchers can discover and record. Glaser through discovering data, coding it and using comparative methods step by step; Strauss and Corbin through their analytic questions, hypotheses and methodological applications (2000, p.513).

Constructivist grounded theory was specifically chosen for several reasons.

Compared to the other approaches to grounded theory, constructivist grounded theory aligns most closely with the epistemology of constructivism and the theoretical perspective of interpretivism identified and set out earlier in this chapter.

Constructivist grounded theory is both an exploratory and an explanatory methodology and is thus particularly well suited to the development of insights into older people's constructs of independence, especially when little empirical evidence exists in the literature. It is a flexible approach that allows follow-up on key issues that emerge in the data (Charmaz, 2000; Charmaz, 2006). The exploratory and flexible nature of constructivist grounded theory makes it particularly suitable for this research because of the recognition of both theoretical and pragmatic considerations.

Two further reasons underpinned the choice of a constructivist approach to grounded theory: the role of timing of the literature review and reflexivity.

#### The role and timing of the literature review

All approaches to grounded theory aim to minimise any preconceived ideas that exist prior to the collection of data. Depending on which approach is adopted, however, the manner in which existing literature is incorporated (or not) into the research process differs significantly. This means that the role and timing of any literature review conducted could be problematic, and this has been a concern raised by methodologists since the inception of grounded theory (Bryant and Charmaz 2010; Dunne 2011).

Traditional grounded theory advocates that a researcher should have 'no preconceived ideas' prior to the process of data collection and analysis (Glaser and Strauss, 1967). This view was later reaffirmed by Glaser (1992, p.31) when he suggested that 'there is a need not to review any of the literature in the substantive area under study for fear of contaminating, constraining, inhibiting, or impeding the researcher's analysis of codes emergent from the data'. In addition to this methodological reason, there is also a pragmatic argument, which asserts that the relevance of literature can only be known after empirical research has

been carried out. Thus, conducting a literature review prior to data collection may mean that the literature most relevant to the research is not reviewed (Glaser, 1998; Urquhart, 2013).

This lack of a literature review prior to conducting empirical research is a major criticism levelled at traditional and evolved approaches to grounded theory. Both methodological and pragmatic arguments have been made against this stance. Methodologically, the failure to conduct a literature review can result in a failure to acknowledge the implicit theories that may guide the initial stages of data collection and analysis, an approach that has been termed 'naive inductionism' (Dey, 1999; Bryant, 2002). Morse (2001, p.9) argues that this can be particularly problematic to a novice researcher:

Such a naive perspective as working without consulting the literature may be possible for a senior investigator with a vast knowledge of social science theory with many concepts at his or her fingertips and real theoretical wisdom. However, ignoring the literature is a strategy that is fraught with danger for a new investigator. Literature should not be ignored but rather 'bracketed' and used for comparison with emerging categories. Without a theoretical context to draw on, new investigators find themselves rapidly mired in data – the very state that Glaser himself warns against.

While I concur with Morse's view on the need to conduct a literature review prior to data collection, I feel that her notion of 'bracketing' is not compatible with Charmaz's approach to constructivist grounded theory. This is because 'bracketing' assumes that the researcher can 'turn off the tap of ideas' when analysing data. A more constructivist approach is to be open and reflective about one's influence on the scope of the research and/or data collection.

There are also pragmatic reasons why a literature review is necessary. Schreiber (2001) suggests that conducting a literature review prior to undertaking empirical research is necessary in order to fulfil the current expectations of funding and research councils. Furthermore, as part of obtaining ethical approval, researchers are required to be familiar with the relevant literature and to be able to locate their research within the wider field, as well as demonstrate its originality (Hutchinson,

1993). Originality and relevance can be seen as having an ethical dimension as, arguably, it is potentially unethical to waste resources on the study of previously well-researched areas and to subject individuals to unnecessary research (Badger et al., 2000).

The role and need for a literature review prior to the commencement of data collection has also been noted to be of particular importance for PhD students. For example, Urguhart and Fernandez (2006) state:

It is difficult, if not utterly impossible, for the PhD candidate to avoid reviewing the literature for many good reasons, including passing the research committee review (p.461).

#### Dunne (2011) concurs:

The idea of postponing a literature review until data collection and analysis is well underway is simply unworkable for many researchers. This is particularly true for PhD students, whose research funding, ethical approval and progression through the doctoral process may all be heavily dependent upon producing a detailed literature review prior to commencing primary data collection and analysis (p.115–116).

Constructivist grounded theory addresses such criticisms by recommending that the literature should not be ignored prior to embarking upon data collection and analysis. Nevertheless, the aim is not to be constrained by the existing literature, and it is the subsequent analysis of the primary empirical findings that will decide the significance of the existing base in relation to the findings. The literature review is therefore re-examined and extended as part of the analysis of the primary data (Urquhart and Fernandez, 2006). The constructivist grounded theory position on the value and purpose of a literature review thus marks a major divergence from that taken by traditional and evolved grounded theory.

Constructivist grounded theory suggests that reviewing the existing literature prior to carrying out empirical research can serve several roles: it can identify gaps in existing knowledge, and it lowers the potential risk of replicating previous

studies and so 're-inventing the wheel'. Therefore, the main aim of the literature review in a constructivist grounded theory approach is not to identify and establish pre-assigned codes for data analysis, but to identify gaps in current knowledge. Furthermore, as Charmaz (2006) notes, conducting a scoping literature review and policy review prior to undertaking empirical research resonates with a constructivist approach because it avoids conducting research in isolation that may result in non-cumulative theory development.

Given the initial exploratory aim of the scoping literature review (see chapter 3) was to investigate the existing literature on older people's understandings of independence and to identify gaps in the evidence base – the adoption of a constructivist grounded theory approach was deemed appropriate. As the early stages of the literature review progressed, it became clear that the evidence from the scoping literature review (presented in chapter 3) was not sufficient to formulate an upfront testable hypothesis. See chapter 5 for a more detailed discussion of the study's design and methods.

#### The incorporation of reflexivity

Reflexivity, specifically in relation to the contribution of the researcher to the development of theory, is a key characteristic of grounded theory (Cutcliffe, 2000; Schreiber, 2000). For example Cutcliffe (2000) notes:

There is a need for the grounded theory researcher to acknowledge his/her prior knowledge and tacit knowledge, to bring such knowledge into the open, to discuss how it has affected theory development (p.1479).

Reflexivity recognises the role of the researcher in being aware of the impact they are having, of the obvious and innate biases they carry and of the impact of this on the research from the outset (Hall and Callery, 2001). Constructivist grounded theory thus recognises the role of research participants, as well as the researcher, in the process of creating knowledge and theory about the issue being researched, acknowledging that all knowledge generated by the analysis is co-constructed (Holstein and Gubrium, 2008).

Constructivist grounded theory stresses the importance of reflexivity throughout the research process (Mills et al., 2006a) including prior to primary data collection. In the initial stages of research, Charmaz (2006) suggests that there are many different sources of a-priori knowledge and that these in conjunction with the personal assumptions need to be reflected upon. The aim is not is to identify bias, but rather to increase self-awareness about personal assumptions and knowledge and the potential role they may play in the research process. However, what constitutes an assumption can be difficult to define (Birks and Mills, 2011). Birks and Mills (2011) suggest that assumptions can be broken down into four considerations:

- Philosophical position
- Previous knowledge and experiences, both academic and personal
- Expectations about possible outcomes of the research
- Apprehension about the research process and the impact of individual strengths and weaknesses

Given the reflexive approach inherent to constructivist grounded theory, I considered four types of assumptions prior to data collection.

#### Philosophical position

The philosophical position pertinent to this research has already been set out in some detail in this chapter and, therefore, this section focuses on the other three considerations.

Previous knowledge and experiences, both academic and personal

My academic background is relevant to the substantive focus of this thesis. In relation to my previous knowledge, my post-graduate education includes the completion of an MA in Disability Studies, which emphasised the social model of disability and the disabled people's movement for independent living. This may influence my interpretations of participants' understanding of independence.

In relation to the substantive scope of this research, conducting a literature review prior to embarking upon the empirical research was useful as it enabled me to acknowledge and understand some of the underlying assumptions I had in relation to ageing and older people.

Expectations about possible outcomes of the research

My expectations about the possible outcomes of this research are that it will contribute to the body of knowledge about independence and older people. In particular, it will generate substantive theory about the meaning of independence for older people.

Apprehension about the research process and the impact of individual strengths and weaknesses

My apprehensions prior to starting the data collection were mainly rooted in the fact that while I had carried out post-graduate level research prior to starting this thesis, this had been literature-based and did not comprise primary empirical research. From the outset, I also had concerns about the potential difficulties that I might encounter in recruiting older people in receipt of support services and, specifically, not being able to gain sufficient access to this population group.

#### Critical debate around constructivist grounded theory

While maintaining that a constructivist approach to grounded theory was the most apt methodological approach for this research, it is important to acknowledge the critical debate that exists around constructivist grounded theory. Criticism directed specifically at constructivist grounded theory includes suggestions that this approach does not even fall under the remit of grounded theory (Thomas and James, 2006). Glaser (2002, para. 33), in a highly critical paper, argues that '[Charmaz's] constructivist position is totally irrelevant to [grounded theory] methodology'. Glaser's criticism is rooted in his assertion that constructivist grounded theory fails to remove researcher bias and that the potential to privilege the researcher's view above the participant's view remains. Glaser (2002, para. 20) is particularly critical of incorporating reflexivity into constructivist grounded theory, stating that 'the researcher's interactive impact on the data [is] more important than the participants. Constructionism is used to legitimate forcing'. By doing so, Glaser argues that the inductive qualities of traditional and evolved grounded theory are weakened. To this end, Glaser suggests that as the methodology of grounded theory is already firmly established, researchers should only refer to the works of Glaser and Strauss (1967), Glaser (1978) and Glaser (1992).

However, there are clear counter arguments to Glaser (2002), and Bryant (2003) offers a particularly strong response. Bryant argues that Charmaz is not suggesting that a constructivist approach is the only approach, but rather that constructivism should be fully deliberated upon in the context of grounded theory. Bryant (2003) further criticises traditional grounded theory's failure to address the key philosophical assumptions that underpin the approach and contrasts this with constructivist grounded theory. He states:

Glaser... continues to indicate a position uninformed by what are now acknowledged to be key arguments about science, claims to knowledge, and representation that must be taken into account even if only to be challenged and undermined or entirely refuted. If there is a persistent refusal to engage with such issues, then perhaps it indicates a fundamental conceptual weakness in GTM [Grounded theory Method] itself; something which the constructivist reinterpretations seek to remedy (para. 6).

Bryant (2003, para. 14) argues that 'ultimately [grounded theory] is far too valuable a method to leave to the objectivists', claiming that traditional grounded theory is nonsensical insofar as it suggests that theory is just waiting to be 'discovered' in the data. He offers a counter argument about reflexivity, suggesting that it is an important aspect of the research process as it brings to light underlying assumptions and allows them to be identified and recognised.

# Defining the principles of grounded theory methodology

While recognising that grounded theory can be broadly categorised into three distinct methodological approaches (traditional, evolved and constructivist grounded theory), these approaches nevertheless share certain methodological characteristics. In this thesis, therefore, it is accepted that there is a distinct set of procedures (methods) that can be considered intrinsic to the methodology of grounded theory. These ultimately promote theory development. Hood (2007, p.163) suggests that irrespective of whether Glaserian, Straussian and Charmazian approaches are used, there are three inherent principles in grounded theory:

- Theoretical sampling.
- Constant comparative methods.
- Development of theory.

Before discussing the particular methodological approach that was used for this research and the reasons for its adoption (see Chapter 5), it is important to show how the key methodological characteristics of the grounded theory approach distinguish it from other qualitative approaches.

#### Theoretical sampling

Theoretical sampling is one of the characteristics distinguishing grounded theory from other qualitative approaches. Glaser and Strauss (1967, p.45) define theoretical sampling as 'the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and what data to collect next and where to find them, in order to develop his theory as it emerges'. As such, the role of theoretical sampling is to inform the data collection process and, in particular, to develop the core categories (Charmaz, 2006).

Theoretical sampling refers to the process of actively seeking data to confirm and/or refute earlier findings, with the ultimate aim of reaching theoretical sufficiency:

Part of the confusion about theoretical sampling concerns the term, "sampling". Many researchers view this term from the perspective of traditional research design of identifying populations to sample. In contrast, theoretical sampling is predicated on your fresh analytic categories and thus occurs later. Identifying initial research participants, documents, or field sites to study is not theoretical sampling. **Gathering data to fill out** the properties of a tentative category is theoretical sampling [emphasis added] (Charmaz, 2012, pp. 10–11).

Thus, theoretical sampling can refer to the data, as well as, the participants. In other words, theoretical sampling requires researchers to actively source data that develops their theoretical categories and thus plays a crucial role in the development of theory. Therefore, in grounded theory, unlike other qualitative

approaches to data collection, not all the parameters (e.g. sample size, scope of topic guide, and selection criteria for participants) are determined prior to data collection. Instead, theoretical sampling advocates that data collected during the later stages of the research is guided by earlier findings. Theoretical sampling is one of the key strengths of grounded theory as it allows insights that emerge early in the research process from data collection and analysis to guide the scope of later research. The role of theoretical sampling and how it was achieved in this research is discussed in detail in the following chapter.

#### **Constant comparative methods**

Payne (2007, p.68) suggests that 'one of the unique features of grounded theory analysis is the dynamic interplay of data collection and analysis', and this is realised through the use of the constant comparative method. The adoption of an iterative approach to data collection and data analysis through the use of the constant comparative method is central to grounded theory (Hood, 2007). The aim of this is to remain open to explanations, themes and, ultimately, theory emerging directly from the co-constructed data. In grounded theory, rather than waiting until all data has been generated, data analysis begins soon after the first interviews have been carried out. The researcher moves back and forth between data collection and data analysis, with each process influencing the other, resulting in an iterative and cyclical process of data collection and analysis.

Consequently, grounded theory methodology draws upon abductive reasoning where both inductive and deductive processes are used to drive theory-development. Coffey and Atkinson (1996) conceptualise abduction as moving back and forth between the data gathered, the researcher's reflexivity and wider concepts (e.g. those derived from the literature and policy reviews). Instead of being an inductive 'theory comes last' or a deductive 'theory comes first' approach, an abductive approach incorporates both by maintaining that data collection and data analysis happen dialectically (Mason, 2004). The researcher begins by examining the data, reflecting upon all the possibilities and then forming hypotheses to test these theoretical insights (Charmaz, 2006). It has been suggested that the cyclical nature of grounded theory is a key strength because it encourages a close connection between data collection and analysis

(Flick, 2002). How constant comparative method was incorporated into this research is discussed in detail in the following chapter.

#### **Development of theory**

Ultimately, theory development is the key aim of any grounded theory approach. Through the key processes of grounded theory noted above, two specific types of theory can be developed. These are known as substantive theory and formal theory. Substantive theory refers to theoretical suggestions that are unique to the context within which the data is collected. Formal theory describes theory that is able to predict and explain similar phenomena in different contexts. Despite the differences between these two types of theory, they share a key similarity: whatever type of theory is generated, it is empirically grounded. Denscombe (2003, p.123) provides clarification of these two types of theory when he writes:

Two kinds of theory can be generated using the grounded theory approach. The first is linked closely to the empirical situation that has been the subject of study. It is a fairly localized kind of theory and is known as substantive theory. This is by far the most common kind of theory associated with the approach. The other kind of theory is more conceptual, with more general coverage and application to circumstances beyond particular settings. This is known as formal theory.

Charmaz (2006) argues that most grounded theory research leads only to the development of substantive theory because researchers tend to focus on one specific and substantive topic/area of interest. Goulding (2002) concurs with Charmaz and highlights practical considerations that limit the scope of a research project (such as the time and money available), arguing that such constraints mean that it is unlikely that most grounded theory will go beyond the generation of substantive theory. Such considerations resonate with the scope of this study, which is small scale and, as such, is unlikely to have the capacity to elevate specific substantive theory to formal theory. The aim of this study is, therefore, to generate substantive theory about the meaning of independence for older people using support services.

Central to the development of theory are the processes of theoretical saturation and theoretical sufficiency. Theoretical saturation refers to the point at which any new data gathered does not lead to the emergence of any additional theoretical insights or advanced codes (Charmaz, 2006). Therefore, the meaning of 'saturation' in grounded theory differs from how it is used in other qualitative methods, where it is commonly used to describe the point at which additional interviews are not generating any new insights.

However, several commentators have argued that theoretical saturation is a problematic concept, and there is considerable debate about its meaning and the extent to which it can be achieved (Corbin and Strauss, 2008 and Birks and Mills 2011). Because the precise determination of theoretical saturation is difficult to verify, the point at which theoretical saturation is deemed to have been achieved is therefore dependent upon the researcher's subjective judgement. Criticism of the notion of theoretical saturation tends to centre on this subjective determination of when theoretical saturation has occurred. For example, it is argued that this subjectivity means that researchers could claim theoretical saturation in an uncritical manner (Dey, 1999). A further criticism is that theoretical saturation is not a representative term for the purposive and 'narrowing down' approach necessary in theoretical sampling. Rather, the term 'theoretical saturation' suggests a wider and more comprehensive approach to data collection and analysis has been used (Dey, 1999). In response to these criticisms, it has been suggested that grounded theory should strive for 'theoretical sufficiency' rather than theoretical saturation. Dey (1999, p.117) notes that:

It may be more appropriate to refer to category 'sufficiency' rather than 'saturation'... Theoretical 'sufficiency' would then refer to the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications. 'Saturation', on the other hand seems to imply that the process of generating categories (and their properties and relations) has been exhaustive rather than 'good enough'.

In addition to the potential ambiguities around the use of 'theoretical saturation', there is a tension between the amount of data collection and analysis that can

practicably be achieved as part of a PhD study and the amount of data that may be needed to claim theoretical saturation. Furthermore, aiming for theoretical sufficiency resonates more strongly with a constructivist approach to grounded theory as this methodology argues that data can always be subject to reinterpretation (Charmaz, 2006). Consequently, 'theoretical sufficiency' was seen from the early stages of this research as being a more manageable and realistic goal as well as a goal most compatible with the aims of this thesis. For the purposes of this study, therefore, the concept of 'sufficiency' was employed as a guide for the data collection and analysis.

# Summary and conclusion of this chapter

Drawing upon Crottys' (2010) research framework, this chapter has presented the epistemological, theoretical perspective and methodology underpinning this thesis. The rationale for the selection of constructivism and interpretivism as was the choice of a constructivist grounded theory methodology was guided by the aims of this research study: it was felt that the in-depth exploration of constructs of independence by older people would be best served by the adoption of namely a bottom-up approach that enables exploration of constructs of independence by older people and that this inductivist approach would in turn have the potential to generate theory grounded in empirical research. Furthermore, such a methodology is compatible with an epistemological and theoretical perspective that acknowledges the existence of multiple 'truths' and seeks to understand and explore these in their full richness, rather than to ascertain a single, privileged 'truth''

After considering the key interpretative methodologies and the different approaches available in grounded theory, constructivist grounded theory was chosen. This was not only because of its compatibility with the epistemology and theoretical perspectives adopted for this research, but also because it is an exploratory and flexible approach that can be used to explore conceptually challenging issues such as developing an understanding of independence for older people. At an overarching level, grounded theory is appropriate because it generates theory in areas where there is little already known. This resonates with the findings of the scoping review, which suggested that limited empirical

research has been carried out in this area and that there is a lack of theory around the topic. Constructivist grounded theory also recognises the coconstruction of knowledge between the researcher and researched and, as such, incorporates reflexivity into the research process (Charmaz, 2006). Second, in maintaining that there is the need for a literature review prior to data collection, this approach is particularly useful for a new researcher and someone new to the topic area.

In summary, this chapter has explained the rationale for the choice of epistemology, theoretical perspective and methodology used in this thesis. In line with Crotty's framework, the methods that were used and the rationale for choosing them are explained in the next chapter.

## **CHAPTER 5: STUDY DESIGN AND METHODS**

#### Introduction

This chapter focuses on the fourth element of Crotty's (2010) research framework, that is, methods (See Figure 2 in Chapter 4). The methods used for collecting data were informed by the research question and the aims of the research (presented in Chapter 1) and the methodological approach (presented in Chapter 4); namely constructivist grounded theory.

This chapter presents the methods used to collect, manage and analyse data. It is split into five sections. The first discusses the rationale for choosing a qualitative study design and proceeds to describe the practical methods of data collection, including recruitment, the sampling frame for identifying participants and how 'theoretical sampling' was incorporated into the research. The second section presents the data management protocol and, in particular, explains the use of computer assisted qualitative data analysis software (CAQDAS). The third section outlines the data analysis method integral to grounded theory. The fourth section presents the relevant ethical concerns and how these were managed. The fifth section provides a descriptive overview of the characteristics of the participants and considers why the sample was skewed towards participants with specific characteristics.

## Study design and methods of data collection

Based on both the research question/aims and the methodological approach a qualitative approach to data collection was considered the most appropriate method for this research.

Numerous definitions of qualitative research have been proposed (Bryman 2004; Mason, 2004; May, 2003). This research draws upon a widely cited definition of qualitative research proposed by Denzin and Lincoln (2011, p.3):

Qualitative research means different things... Nonetheless, an initial, generic definition can be offered. Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive,

material practices that make the world visible. These practices transform the world. They turn the world into a set of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.

Three key characteristics of qualitative research can be identified from this definition. First, qualitative research focuses upon the collection of non-numerical data, most frequently words, but also other modes of communication such as observations. Second, qualitative research occurs within 'natural settings', meaning that there is no intentional manipulation of the environment and/or context as would be evident in a controlled laboratory environment. Third, and perhaps most importantly for the scope of this study, qualitative research privileges meaning and understanding.

#### Rationale for choosing qualitative methods

As the emphasis was on eliciting an understanding of the meaning of independence directly from the perspective of older people, it was decided during the early stages of the research process that a qualitative approach was the most appropriate. There are several reasons why a qualitative approach was considered the most appropriate for addressing the research question posed in this thesis. First, a qualitative approach fits most closely with the epistemology and theoretical perspective presented in Chapter 4. This is because qualitative research is interpretative in scope and corresponds most closely with the epistemological reasoning of constructivism and the theoretical perspective of interpretivism. Second, the logic of reasoning in qualitative research is largely inductive. Induction subscribes to 'bottom up' logic in which 'theory comes last' (Bryman, 2004), meaning there is movement from the particular to the general. This is compatible with the methodological choice of constructivist grounded theory methodology, because although both a policy review (Chapter 2) and a literature review (Chapter 3) were completed prior to data collection; neither of these generated any predetermined theory and/or hypothesis that could be tested.

Qualitative approaches to data collection also resonated with the research question/aims: to understand independence through older people's lived experiences. These approaches are built on the assumption that individuals interpret events and experiences differently and, as such, demands that a holistic and contextual understanding of the phenomenon being researched is needed.

Moreover, a qualitative approach fulfils the goal that policy and practice should be informed and guided by older people themselves (DH, 2001b; DH, 2005). Furthermore, research has also emphasised the importance of policy and practice of incorporating older people's perspectives (Older People's Steering Group, 2004; Barrett et al., 2012). Thus, a qualitative approach can be seen as providing an appropriate opportunity to shift the focus of research about older people to research which directly asks older people about their experiences and specifically to develop an understanding about their meaning of independence. This is because the aim is not to measure independence in a functional manner, but instead to develop an insight into the meaning of independence for older people. Given that independence is a key driver and is often an aspirational outcome of policy and practice aimed at older people (as described in Chapter 2), research that contributes to a qualitative evidence base by establishing how older people construct independence can be seen as highly relevant.

There are several different methods for collecting data qualitatively, for example, focus groups, observation, documentary analysis (e.g. diaries) and interviews (Long and Godfrey, 2004). Given the potentially sensitive nature of independence and 'loss of independence', it was felt that these issues might be difficult to explore in-depth in a group situation. In addition, to understand individual's personal understandings of independence, it was important to hear each person's views without them being tainted by other people's views, group dynamics and culturally accepted norms that might permeate group meetings. Taking these concerns into account, focus groups were not considered appropriate for this research. Undertaking non-participant observations, although having the potential to enable observation of the functional aspects of independence, such as ability to achieve instrumental activities of daily living, would not facilitate understanding individual's meanings of independence. Thus,

this method was not appropriate for this study. The use and analysis of personal diaries (i.e. documentary analysis) was considered as a possible method to gather the relevant data. However, the scoping review indicated that independence is a complex, 'taken for granted' concept that older people cannot often articulate. Collecting information via diaries would not have allowed for the likelihood of needing to prompt and probe older people about their personal views and meanings of independence. After considering these key qualitative methods interviews were chosen.

#### **Qualitative interviews**

Kvale (1983, p.174) defines the qualitative research interview as 'an interview, whose purpose is to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena'. Thus, qualitative interviews are complex social interactions founded on the belief that participants' lives can be best understood through asking questions and that participants can convey this understanding through describing their experiences (Kings and Horrocks, 2010).

Flick (2002) suggests that different types of interviews can be situated along a continuum of openness and structure. These different types of interviews require varying levels of preparation, conceptualisation and instrumentation. At the highly structured end of the spectrum are structured interviews. In general, this style tends to be more appropriate for conducting quantitative research, given that predetermined boxes or categories are used, and there is very little opportunity for participants to express their unique experiences in any depth (May, 2003).

At the other end of the spectrum are unstructured interviews. These are firmly rooted in the qualitative approach and, as the name suggests, aim to promote complete openness by being non-directive and ensuring a preconceived structure is not imposed on the participant by the researcher. Positioned in between these approaches are semi-structured interviews. Bryman (2008, p.438) describes these as having:

A list of questions or fairly specific topics to be covered, often referred to as an interview guide, but the interviewee has a great deal of leeway in how to reply. Questions may not follow on exactly in the way outlined in the schedule. Questions that are not included in the guide may be asked as the interviewer picks up on things said by the interviewees.

Individual semi-structured interviews were chosen as the principal method of data collection primarily because, as described by Bryman (2008), they follow an overarching structure, and at the same time, enable a degree of flexibility. This flexibility allows the interviewer to seek clarification and request elaboration in order to gain as full a view as possible of the participants' experience or interpretation. It also allows participants to raise issues that the researcher may have overlooked. Semi-structured interviews are well matched with the principles of constructivist grounded theory methodology because they allow for both variety and difference while providing an overall sense of focus (Charmaz, 2006).

#### Approaches to sampling in grounded theory

Congruent with a constructivist grounded theory methodology, two types of sampling were drawn upon in this research, namely, initial sampling and theoretical sampling (Charmaz, 2006). Charmaz (2006, p.100) notes that the relationship and difference between initial and theoretical sampling is as follows:

Initial sampling provides a point of departure, not of theoretical elaboration and refinement... criteria for initial sampling differ from those you invoke while theoretical sampling. Initial sampling in grounded theory is where you start whereas theoretical sampling directs where you go.

As the term suggests, initial sampling is the first type of sampling used in grounded theory. The main aims of initial sampling are to begin the data collection process and to provide a sufficient amount of data to guide the theoretical sampling. This research drew on initial sampling for the first five interviews. The initial sampling frame is outlined below. Theoretical sampling is discussed later in the chapter.

#### Sampling frame: characteristics of research participants

As described in the introductory chapter of this thesis, the UK's population of older people is becoming larger and increasingly heterogeneous (Arber and

Evandrou 1993; Cann, 2009; DWP, 2005). Therefore, key decisions needed to be made about the particular characteristics of 'older people' recruited to this study. First, there was a need to create an age boundary in order to define the meaning of 'older'. This was established at age 65 and over primarily because this is the point at which individuals become classified as 'older' within the local authority social care environment (Clark, 2009) and also reflects the age eligibility criteria for many other services aimed at older people in the UK.

This research employed a broad definition of the kinds of support services an older person may receive so that services provided both by the local authority and by agencies outside the local authority were included. By using this wide definition of 'support services', it was that hoped that participants with varying needs would be included. This wide definition of 'support services' was chosen in an effort to address the gap in the evidence base around understandings of independence for older people using a *range of services*. As the scoping review revealed, much of the research on the meaning of independence for older people has focused on older people in receipt of either one specific service or no support services whatsoever. Owing to this gap in the evidence base, the experiences of older people using a range of services to meet their different and changing needs have effectively been excluded from the research on understandings of independence. This research aims to address this gap.

The policy review illustrated that a 'mixed economy of care' was being promoted across policy documents, with the voluntary sector playing an increasing role in care provision, especially in relation to lower level support (Glasby, 2012). At the same time, the tightening of eligibility criteria means that while an increasing number of older people are living with long-term conditions and needing some assistance to maintain their independence, they do not have high enough care needs to access local authority social care (Wanless et al., 2006). Gunnarsson (2009, p.253) draws attention to this population and their lack of inclusion in the research, by stating:

Many older people, however, are in a grey zone between 'alert senior citizens' and older people needing extensive care. These older people are often invisible in the research.

Thus, to redress these gaps in evidence and policy, it was important to ask a wide range of older people about the meaning of independence.

Older people who may not have been in receipt of support services at the point of interview but who had received help from support services within the previous six months were also eligible to take part in this study. This was to ensure that those individuals who access services ad hoc due to fluctuating needs were included, as well as those who had received support via a service with a fixed duration of support (for example, intermediate care or home care re-ablement as discussed in Chapter 2).

Older people who received only informal support from family, friends or neighbours were excluded from this study. While acknowledging the importance of this support, this decision was made because the term is problematic and no universally accepted definition is available (Weicht, 2015).

The meaning of independence for older people living in residential or nursing home accommodation has been addressed elsewhere (Bland, 1999; Davies et al., 1997; Hillcoat-Nallétamby, 2014). The type and level of support services needed by older people living in this type of accommodation may be significantly different from those provided for older people living in the community. Therefore, it is important to explore independence for older people living in the community. Thus, this research is concerned with the meaning of independence for older people using support services in the community.

This research excludes older people with a known diagnosis of dementia and/or cognitive impairment. A diagnosis of dementia can be seen as a 'crude tool' for the identification of individuals actually living with dementia because there will be some individuals who may have received an early diagnosis and will be relatively asymptomatic, while others who are symptomatic may have not received a diagnosis. Indeed, low levels of diagnosis among those experiencing dementia-related symptoms were highlighted in the National Dementia Strategy (DH, 2009a), which noted that only one-third of people with dementia actually obtain a formal diagnosis. Nevertheless, for the purposes of this research, a known

diagnosis was considered the most efficient method for identifying individuals with impaired mental capacity, including the inability or fluctuating ability to give informed consent.

Older people were also excluded if they did not understand written or spoken English well enough (e.g. have English as a first or native language) to give informed consent or to participate in the interview. As this was a small-scale study (n=15 participants), there were no resources available for translation or for using interpreters. Limited resources also meant that only older people who resided in a limited geographical area could be recruited. Finally, the older people recruited for this study resided in an urban setting, and there is therefore no rural dimension to this research.

Older people were recruited from within the confines of the City of York Council area, and as such, this research did not set out to recruit older people living in rural localities. The rationale for the decision to recruit only an urban sample was that the scope of the research project was not large enough to address the potential differences between independence in rural and urban settings, for example, other research (Manthorpe and Stevens, 2010) has highlighted that the older people's understandings of the meaning of independence can be affected by the geographical accessibility of community resources such as post-offices and shops.

Table 5 summarises the parameters of the sampling frame that was used to guide recruitment for the pilot interviews and in the initial (phase 1) and the theoretical sampling stages (phase 2) of the main study.

**Table 5: Sampling frame for recruiting participants** 

Criteria	Included if	Excluded if	
Accommodation	Living in the community	Living in nursing or	
	(including supported	residential care	
	housing/extra care housing)		
		In hospital	
Age range	e Aged 65 and over Aged und		
Informed consent	Able to give informed consent	Unable to give informed	
		consent	
	Not diagnosed with any form of		
	dementia and/or cognitive	Diagnosed with any form	
	impairments	of dementia and/or	
		cognitive impairments	
Location	Living in York (as defined by	Not living within the	
	City of York council	boundaries of City of York	
	boundaries)	council	
Language	Good understanding of written	No/limited understanding	
	and spoken English	of written and spoken	
		English	
Support services	In receipt of support services	Not receiving any support	
	currently or during the previous	services now or in the last	
	six months	six months	
		Receiving informal support	
		only	

## **Pilot interviews**

Recruitment for the pilot interviews began after approval from the Humanities and Social Sciences Ethics Committee (HSSEC) at the University of York had been received. Members of the adults, older people and carers' team consultation group, a standing group of adults and older people who advise on research undertaken by Social Policy Research Unit (SPRU, University of York), were invited to participate in the pilot. This group was chosen for pragmatic reasons: it was an easily accessible group, included individuals who fulfilled the sampling frame and members were familiar with research. Two members of the

consultation group who met the sampling frame agreed to take part. A suitable time and location for the interview was agreed. The pilot interviews took place at the participant's home and lasted approximately one hour.

The aims of the pilot interviews were to trial the topic guide and to give me experience in qualitative interviewing. Thus, the pilot interviews were transcribed and the transcript discussed and reflected upon with my supervisor, but were not formally analysed and were not included as part of the findings and subsequent theory development. This process helped me to reflect upon how I presented myself during the interview and to identify the changes needed to improve my interviewing technique. For example, I became aware that I was verbally reinforcing particular conceptions of independence; in particular, I was tending to view independence in terms of the ability to carry out functional activities of daily living without assistance. For example, when a participant described being able to cook their own meals on a daily basis, I responded with the phrases 'Well done!' and 'That's good!' This I feel stemmed from a mixture of nervousness and my approach to facilitating the conversation. However, such responses may have increased participants' desire to present a functionally independent self. In subsequent interviews, I concentrated on using more neutral language and also ensured I was mindful of this during the analytic process. This was important to ensure that the definitional and conceptual development of independence reflected the views held by the participants.

I also noticed that I rarely probed or asked for specific examples to illustrate a participant's views when they used phrases such as 'you know' in their response to a question. Charmaz (2001) suggests that when participants use these types of phrases, researchers should not assume that there is a shared understanding and should seek further clarification. To ensure that the meaning of independence that emerged from this research was built upon the actual views of participants, I invited subsequent participants to provide examples wherever possible to reinforce or illustrate their statements about independence.

In the pilot interviews, I started by using 'warm-up' questions, such as asking participants to describe their typical day. This took up more time than anticipated and did not provide the expected information about independence. Thus,

although participants were advised before the interview that independence was central to the study, the sequence in which the topics for discussion were presented on the initial topic guide meant that the key focus of this study, 'independence', was frequently passed by. The reasoning behind my decision to use warm-up questions had been to encourage a conversational environment, but it became clear that I would need to introduce 'independence' at an earlier stage in subsequent interviews. Such issues illustrate the complexity of conducting qualitative interviews and the skills required to be an effective qualitative researcher, skills that I felt improved as the interviews progressed.

## Recruitment to main study

Recruitment was facilitated by services and organisations directly concerned with the welfare and provision of support services to older people in York. These agencies were each approached separately via a letter to their manager in which I introduced myself and outlined the scope of the study. I asked to meet with an appropriate member of staff to discuss the research further and the possibility of the organisation facilitating recruitment of older people. In most cases, this was the manager herself/himself, although in a couple of instances, the manager directed me to contact another member of staff, such as the warden of a supported housing scheme).

Recruitment to this research highlighted the key role gatekeepers can play in this process. Some acted as 'barriers' to recruitment, some were 'facilitators' and others were 'protectors' (e.g. of staff time). As this section will highlight, these roles were not mutually exclusive.

Many gatekeepers were facilitators of recruitment to this study and indeed were willing to assist me with recruitment by providing me with the opportunity to attend social events, talk to possible participants and ask whether they would be willing to participate.

Managers of a couple of organisations that might have been able to facilitate the process of recruitment blocked my initial request for assistance. However, the reasoning behind their refusal was that they were small organisations with limited funding and did not feel they had the time to assist me. Thus, while these

individuals can be seen as 'barriers', they can also be viewed as 'protectors' of limited resources. Second, while gatekeepers are often seen as being someone who holds a senior position, this research found gatekeepers also existed at lower levels of an organisational structure too. There were several occasions when management-level staff had agreed that I could contact potential participants through their organisation, but staff at lower levels in the organisation acted as barriers to this occurring. For example, several managers provided contact details for different services within their organisation – for example, names of wardens of supported housing schemes – but some wardens did not respond and/or responded saying they were unable to assist. As a result, I was blocked from recruiting individuals directly through their service. Upon reflection, I should have been more assertive when this happened, possibly by discussing their reluctance to assist with senior managers and seeking further clarification and assistance.

Thus, while acknowledging the difficulties that could arise when asking for assistance from gatekeepers, accessing participants through organisations that offer support to older people was the most feasible way of gaining access to older people in receipt of support services.

#### Initial recruitment of participants

The initial method of recruitment involved asking the managers if they would be able to send out invitation letters to eligible participants. As a key provider of support services to older people, Age UK York was approached in the first instance. They were keen to assist in recruitment, and given that they are a relatively large organisation, I initially decided not to approach other organisations. This decision was based on my assumption that I would be able to recruit a sufficient number of participants solely via this channel.

Deciding how many invitation letters to send out initially was challenging. However, with agreement from Age UK York, I decided to send out an initial 30 invitation letters and to review the situation after a few weeks had elapsed. The invitation letters sent by Age UK York generated a very low response rate. Only two people in receipt of support services from Age UK York were recruited as participants. York Housing Association was then approached to assist with

recruitment. This organisation was chosen as it manages several supported housing schemes and, as such, has access to a number of older people with support needs. York Housing Association agreed to send out 25 invitation letters. However, this also generated an extremely low response rate, with only one older person recruited through this organisation. The precise reasons for the low recruitment rates via this route remain uncertain, although there are several possibilities as to why recruitment of participants was so low. Of these, the 'cold contact' that was used to recruit interviewees was perhaps most significant. It appears that my decision to send invitation letters to potential participants rather than attempting to meet them face to face may have contributed to the low participation rate. While the invitation letter stated that Age UK York or York Housing Association supported this contact, the recipient may have remained unsure about my credentials as a researcher or the relationship between the research and the organisation through which they were being contacted.

As a result of these very low response rates, I recognised that I needed to reassess my methods of recruitment. After discussion with Age UK York and my supervisor, it was decided that such a low recruitment rate was probably due to potential participants being unwilling to invite someone they had never met into their home. I had been aware of this possibility at the planning stage of this research and had tried to minimise this by stating in the invitatory letter that this research was being supported by an organisation with which they had contact. However, these initial recruitment drives indicated that this was not enough to reassure older people.

Responding to the challenges arising during initial recruitment

Due to these early challenges, and in order to widen recruitment, two revisions to the recruitment method were considered. The first provided the possibility of broadening the sampling frame, and the second allowed me to look at the approach being used to recruit. Given that ethical approval had been granted for the sampling frame set out in Table 5, it was not considered feasible to alter this. Even if this had been possible, I anticipated that, given the low rates of recruitment achieved in my early attempts to enlist participants, retaining the same recruitment method would not necessarily lead to improved recruitment rates. Instead, I decided to adopt a more visible and direct route to recruitment.

Other organisations that provide support services to older people were contacted and asked whether there were any social events for older people that I could attend in order to present the research and attempt to recruit participants. These events provided an opportunity to meet older people, introduce myself, describe the research and explain what taking part would involve. This also enabled me to respond quickly and appropriately to any concerns an individual might have about participating, but within a group setting that was familiar to the older person. If an older person then indicated an interest in participating, I gave them an information letter and a reply slip to take away with them and to return later if they wished to participate. Consequently, opt-in recruitment was maintained.

At these social events, I invited the group as a whole to participate in the research. In a few instances, however, managers/staff at these events suggested that I should approach specific individuals who they thought would be willing and able to take part and advised against approaching certain attendees due to concerns around their mental capacity. The managers' recommendations were based on their awareness of who had the capacity to understand the information given. As I was recruiting in group settings, this information was essential to ensure that only those who fulfilled the eligibility criteria (i.e. those with mental capacity) took part.

The decision to allow a space between the social events and the return of the reply slip was taken because this seemed the most ethical approach. It minimised the chance of an older person feeling any sense of pressure or obligation within a group setting or in my presence to agree to participate there and then. Additionally, having the reply slips (using a pre-paid envelope) returned directly to me at SPRU prevented the organisation through which I accessed the social events from knowing who had decided to take part in the study, thus protecting participants' confidentiality.

When a reply slip was returned, I made direct contact via telephone with the older person at their preferred time. As part of this contact, the study was discussed with the potential participant and they were invited to ask any questions they had about it. In addition, it afforded an opportunity to confirm that participants met the

sampling criteria. I used a simple checklist to provide prompts during this conversation (see Appendix 1). If, after this discussion, the person still wished to take part and they met the sampling criteria, a suitable time and location was arranged for the interview. Table 6 summarises the organisations involved, methods of initial contact and total number of participants recruited. As this Table shows, recruitment rates improved when recruiting 'in-person' via organised social events, although recruitment did remain an on-going challenge. This is discussed further in chapter 8.

Table 6: Organisations involved, methods of initial contact and number of participants recruited

Organisation	Description of organisation	Initial	Participants
		contact	recruited
Age UK, York	Age UK is a registered charity and	Invitation	2
	provides a wide range of personal	letters (30)	
	and practical support, including		
	information, advice and arranging		
	for respite care.		
York Housing	York Housing Association is an	Invitation	1
Association	independent social business	letters (25)	
	working with local people and		
	partner organisations. They provide		
	housing and support services.		
Anchor Housing	England's largest charitable	Allowed me	5
(Guardian	provider of housing and care for the	to join them	
Court)	over-55s. They provide retirement	for their	
	properties and specialist care	communal	
	homes	coffee	
		mornings	
		(8)	
Riverside (De	Registered providers of social	Allowed me	4
La Salle House)	housing in the UK, providing	to join their	
	support and affordable housing to	communal	
	people of all ages and	coffee	
	circumstances throughout England.	mornings	
		(10)	
The Abbeyfield	The Abbeyfield Society is a	Allowed me	3
Society	registered charity that provides	to join their	
(Abbeyfield	housing, support and care for older	'knit and	
House)	people with a range of needs.	natter'	
		group (6)	

#### Theoretical sampling via modification of the topic guide

As presented in chapter 4 theoretical sampling refers to the process of actively seeking data to confirm and/or refute earlier findings, with the ultimate aim of reaching theoretical sufficiency. Thus, theoretical sampling can refer to the data, as well as, the participants.

The modification of the topic guide is widely recognised as a form of theoretical sampling in grounded theory (Charmaz, 2006; Birks and Mills, 2011; Urquhart, 2013). For example, Urquhart (2013, p.179) states:

Even with a short amount of time in the field it should be possible to do some form of theoretical sampling by, for instance, adding useful questions to the interview schedule based on what emerges from the interviews.

This approach to theoretical sampling was adopted for this study. Topic guides are widely used to facilitate semi-structured interviews (Smith, 1995). They allow the researcher to plan the focus of the interviews in advance, but are adaptable enough to allow for some flexibility, including enabling the researcher to vary the sequencing of topics and to react to the answers and cues given by each participant.

The topic guide (see Appendix 6) used for the first five interviews was informed by the findings of the literature and policy reviews, and specifically, the identified gaps in the existing evidence base (see Chapter 3). This topic guide had two key purposes: first, to assist the interview process, and second, to facilitate theoretical sampling. To achieve the latter, the content of the topic guide was revised and refined as the simultaneous data collection and analysis, or 'constant comparative method' (the adoption of an iterative approach to data collection and analysis) progressed.

This approach to theoretical sampling meant that it was not possible to directly select participants in light of the ideas and evidence on independence that emerged during the research process. In other grounded theory research, for example, the significance that the concept of 'loss of independence' might have for a participant if faced with the possibility of moving into a nursing home might

be investigated further by interviewing older people in residential care settings. In this research, however, the emphasis was on the understanding of independence of older people living in their own homes, and it would therefore not have been possible to answer the research question had I followed this route. Furthermore, using a methodologically commonly accepted approach to theoretical sampling might have meant recruiting people with, for example, cognitive difficulties, which I do not have the expertise to deal with in a research context. As such, it was important that I had predefined the sampling frame and theoretical sampling via the modification of the topic guide to ensure that the research would meet ethical approval throughout the process and no participant would be put at risk by my lack of expertise in particular areas. As a result of these constraints, I adapted the topic guide to reflect emerging ideas.

As outlined above, the modified topic guide was developed for this research following data collection and analysis of the first five interviews. By this point, I had been able to identify some key concepts/issues that needed to be explored further. Thus, I adopted a two-phased approach to data collection. An initial round of interviews (n=5) helped to gain insights into older people's meaning of independence and the topic guide was developed and refined in the light of analysis of these initial interviews. Using this modified topic guide, a further round of interviews (n=10) were carried out. Four additional topics were included on the modified topic guide.

#### Geographical mobility

An additional question was included about the impact of distance from family and geographical mobility (both their own and/or other members of the family) upon the participants' independence. This was included because several of the participants in the first phase of interviews (n=5) drew attention to the fact that the support they received to facilitate their independence from relatives was, to some extent, determined by how nearby their relatives lived. This prompted me to incorporate questions about the impact of geographical mobility and, in particular, the role 'distance caring' can play for older people and their independence. Thus, where appropriate, participants were asked about family location and how this influenced their understanding of the meaning of independence (positively and negatively).

### Biographical background

The impact of past experiences and biographical background upon the participants' constructs of independence also emerged as important. The initial topic guide did not include any questions about past experiences and the possible role they play in an older person's constructs of independence and, in particular, their identity as 'independent'. However, analysis of the first phase interviews indicated that past experiences such as divorce and previous job roles were highly significant to some participants' current conceptualisation of independence. As a result, the topic guide was modified to ensure that these issues were covered. The modified topic guide enabled exploration of how meanings attached to independence may have been shaped by participants' previous experiences. Examples of questions incorporated into the topic guide were: 'How has your own past shaped the meaning of independence to you?' and 'Can you think of any important/significant events in your life which affect the meaning of your independence now?'

#### Continuity and change

Analysis of initial interviews also highlighted the centrality of continuity and consistency to the meaning of independence for older people. For example, the initial *in-vivo* code (i.e. a verbatim quote from the participant) of 'being normal' was cited frequently. Simultaneously, however, participants also talked about changes that had happened, were happening or indeed were anticipated – for example, the onset of ill health or moving home – and how these influenced their constructs of independence. This led me to think about the relationships between change and continuity in relation to the meaning of independence. After considering this, I decided to incorporate a question into the topic guide about how participants felt/experienced the apparent tension between valuing continuity while at the same time experiencing change and how this influenced their meaning of independence.

#### Dependency

The modified topic guide also explored more fully participants' wishes to avoid becoming dependent/a burden. This is because in the initial interviews there was

frequent reference to independence being about maintaining balance and reciprocity in family/friendship relationships. Such strong attitudes made me reflect upon whether older people perceived any differences between seeking assistance from informal services and formal services. In the initial interviews, participants appeared especially reluctant to ask for help from their families. Therefore, the modified topic guide was designed to incorporate questions about why they sought assistance and from whom. It also specifically asked whether they found it easier to ask for help from formal services.

# Possible ethical implications of theoretical sampling via modification of the topic guide

As part of gaining ethical approval, I made it clear that I would seek guidance from my supervisors prior to making any changes to the topic guide and, where necessary, re-submit appropriate documentation to the HSSEC. As part of the application for ethical approval I stated 'Any changes to the topic guide, for example, the incorporation of an emerging theme from the early stages of the data analysis into subsequent interviews then advice will be sought from my supervisor regarding the need to inform the HSSEC committee about these changes'. The sampling frame for this research will not be altered during this process. Any major changes will be submitted to this committee for scrutiny". However, I did not need to re-apply to the HSSEC because the changes made to the topic guide were within the parameters of the scope of the phenomenon under study, my supervisor was fully aware of the changes, and the sampling frame (as approved by HSSEC) remained the same throughout the data collection process.

#### Interviews in practice

With only one exception (where the interview took place in the communal lounge of the supported housing scheme where the participant lived), all the interviews took place at the participant's home. All participants greeted me warmly, and we engaged in casual conversation prior to the interview. Although not part of the interview process *per se*, this was nevertheless an important part of the overall interview process as this helped to build rapport. The majority of interviews lasted around one hour although, as will be discussed in detail later, one lasted only 20 minutes and others stretched to an hour and a half.

Throughout the interviews I strove to ensure that my questions were clear and unambiguous. I also asked participants to clarify points if I was unsure of their meaning and constantly tried to ensure that I understood and captured the participants' perspectives accurately. To do this, at the end of each interview, I summarised key messages from that interview and checked these with the participant. I encouraged participants to tell me if this was not an accurate reflection of what they had said and/or meant. In this way, I was able to ensure my understanding of the data was congruent with theirs and thus, validated my interpretations. In addition, I offered participants the opportunity to review the transcripts of their interview (prior to analysis); however this offer was not accepted by any of the participants.

## **Data management**

This section presents how data was managed and processed throughout the research.

# Recording and transcription of interviews

With informed consent from the participants, interviews were audio-recorded and transcribed. The major advantage of audio recording is that it also allows the researcher to focus on the conversation/data rather than on having to write extensive field-notes during the interview. At a practical level, audio recording of interviews allows for participants' responses to be checked and authenticated. However, the presence of a recording device may influence the interaction between researcher and participant and may also affect the fullness of responses (May, 2003). While May (2003) suggests that researchers should be aware of this, he notes that, more often than not, once a recording device is turned on, participants simply forget it is there. Additionally, while each interview was fully transcribed, this does not suggest a complete and unbiased record (Mason, 2004; Arksey and Knight, 2007). Rather, Mason (2004, p.77) notes that 'a transcription is always partial partly because it is an inadequate record of nonverbal aspects of the interaction... and also because judgements are made (usually by the person doing the transcription) about which verbal utterances to turn into text, and how to do it'. Arksey and Knight (2007, p.141) make a similar

point by suggesting that 'a transcript is one interpretation of the interview, and no more than one interpretation'.

The process of transcription for this research was carried out by a professional transcriber who is regularly used by SPRU and thus had proved their reliability, accuracy and consistency and was familiar with the ethical and data security requirements of SPRU and the University. Several commentators recommend transcribing the data yourself, suggesting that it is an important part of analysis and can aid the researcher in gaining familiarisation with data (e.g. Grinnell and Unrau 2011; Rubin and Rubin, 2011). However, due to time limitations and my personal situation –, I am dyslexic and have to manage a long-term health condition – I decided that the process would be expedited by employing a transcription service. Before formal analysis began, however, I double-checked the transcription for accuracy and corrected any errors. Data was then uploaded into a computer assisted qualitative data analysis software (CAQDAS) package (ATLAS.ti).

#### The use of CAQDAS

Criticism has been levelled at the use of CAQDAS for qualitative research, generally, and for grounded theory research, specifically (Birks and Mills, 2011, Seale, 2004). The primary concern is that since CAQDAS packages are commonly modelled on statistical approaches, they impose too rigid a framework, and one that is largely deductive, on to qualitative data (Seale, 2004). Despite these criticisms, I used ATLAS.ti because, for the purposes of this research, I believed that the benefits of CAQDAS, such as providing increased transparency about how the data is organised and coded, out-weighed the drawbacks. Silverman (2004, p.168) suggests that it is particularly suitable for grounded theory, stating that ATLAS.ti was 'explicitly developed to enable a grounded theory approach'. The underlying premise of this assertion is that ATLAS.ti is not inherently hierarchical in approach and thus can support an abductive and iterative approach to reasoning. It is important to reiterate, however, that ATLAS.ti was used purely as a data management tool. It simply facilitated the coding process and pragmatically it also helped when working through the connections between codes as the software allows these to be processed through the creation of 'families'.

# **Data Analysis**

The analysis followed a reflective process that combined coding with writing memos in order to progress from initial coding through to theory development. These processes are presented separately here, but it is important to note that, in practice, these processes were conducted simultaneously in line with the constant comparative method.

## Coding of data

The process of coding data is a defining characteristic of qualitative analysis, and of grounded theory, more specifically (Birks and Mills, 2011; Hallberg, 2006). The overall aim of coding in grounded theory is the development of core categories that are rooted in participant accounts and that explain the phenomenon under consideration.

Berg (2007, p.279) advises that throughout coding the researcher needs to 'to keep the original study aim in mind and to remain open to multiple or unanticipated results that emerge from the data'. While coding is central to qualitative data analysis in general, some processes are unique to grounded theory. Walker and Myrick (2006, p.549) make this point by stating that 'coding, in grounded theory, is similar to its use within the qualitative traditions, but it is also much more. In grounded theory, its level of development and specificity clearly distinguish it from other qualitative methods'.

There are two key differences between coding for grounded theory and other qualitative approaches. The first is the lack of *a priori* coding categories from previous research and/or a literature review prior to data collection and analysis (Birks and Mills, 2006b). A second difference relates to the purpose of coding. The purpose of coding in grounded theory is the conceptualisation of actions and processes, whereas in other forms of qualitative data analysis, the purpose is to establish descriptive detail:

Most qualitative researchers code for themes and topics rather than actions and analytic possibilities. From the very beginning, coding for

actions and theoretical potential distinguishes the grounded theory method and, likely, its product from other types of qualitative research... If you can focus your coding on actions, you have ready grist for seeing sequences and making connections (Charmaz 2008, pp.163–164).

In constructivist grounded theory, coding is carried out using a two-phase process: 'initial' and 'focused' coding (Charmaz, 2008). While these different phases of coding are discussed separately in this chapter, it is important to reiterate that coding in grounded theory is not a linear process. Rather, coding (and memo-ing) was iterative in accordance with the constant comparative method.

#### Initial coding

The first stage of coding is concerned with trying to 'fracture' or 'break open' the data. This allows the researcher to 'learn about gaps and holes in [their] data from the earliest stages of the research' (Charmaz, 2006, p.48). Initial coding represents the start of theory construction and provides an opportunity for initial thinking about theoretical sampling.

Initial coding began by reading through each of the interview transcripts. This process was undertaken to get a general sense of the kinds of things that seemed to be important to the participants' constructs of independence. As advocated by Charmaz, I worked quickly through the initial coding; trying to capture in just a few words (in gerunds/gerunds phrases) those that best described the meaning of independence for the participants. Charmaz (2006, p.48) suggests that the use of gerunds enables the focus to remain on the processes integral to the data and is a means of curtailing the researcher's construction of premature 'conceptual leaps'. These were noted in the margin of the coded transcripts. Examples of initial codes in the form of gerunds phrases that emerged from these data are 'relying on others', 'losing independence' and 'feeling safe'.

In conjunction with gerunds, I also used *in-vivo* codes (direct verbatim quotes from the participants). This resonates with a constructivist approach, which advocates paying close attention to language and, when undertaking the initial

coding, keeping the codes as close to 'grounded' in the data as possible. The use of *in-vivo* codes took two forms. There were examples when *in-vivo* codes were used to capture the same frequently used phases by several different participants (for example, 'keep going', 'being normal' and 'do what I want'). The second form of *in-vivo* codes was used when a participant captured in a couple of words/short phrases an important independence construct (for example, 'being the person that you've always been').

I drew on aspects of both line-by-line coding and incident-by-incident coding. I did not code every single line; for example, where the transcript was purely general conversation and not relevant to the research questions and aims, I did not code the participants' responses. At the same time, however, I made sure that I was thorough and did not skip over any ideas or processes that might be important. This meant that some of the transcript was not coded, while other sections were assigned more than one code.

At this initial stage, I did not want to spend an inordinate amount of time on finding the 'perfect' description for each code I had assigned. There were times when I was not completely satisfied with certain codes that I had developed, particularly those codes that described basic actions such as 'using aids and equipment', because they did not reference the social process behind them or their relationship to independence. However, I made a note beside these codes (R) to remind myself that they needed revising and checking during the later coding stages. Once again, this approach was congruent with the process of generating initial codes in grounded theory as the focus of initial coding is to 'remain open' and not make 'conceptual leaps' too early.

Nevertheless, there were times during the initial coding when I started to think about higher-level analysis. At these points, it was vital to keep reminding myself to remain true to the constructs arising directly from the data and to accept that although I had some preliminary ideas, I must avoid drawing too many conclusions.

The scope of the initial codes was wide ranging. Some of the codes emphasised how the participant was grappling with larger organisational forces, such as

changes to the scheduling of in-home carers or privatisation of services. Some were concerned with how the participant was coping with their individual needs, such as utilising mobility aids. Others, however, were about interpreting abstract concepts such as autonomy or control. When all aspects of independence were coded from the data, I proceeded to the next coding stage, namely 'focused coding'.

## Focused coding

Unlike initial coding, focused coding begins to move the analytical process forward from codes directly rooted in raw data (either in the form of gerunds or 'in-vivo' codes) to codes that offer more analytic interpretations and, as such, raise the level of abstraction (Charmaz, 2006). Again, in order to remain true to a constructivist grounded theory approach, I aimed to make these focused codes action/process-oriented. Three processes were undertaken to produce focused codes: conflating initial codes into focused codes, expanding initial codes into focused codes and considering the relationship between initial codes to conflate or expand initial codes or develop new ones. At the same time, I followed Charmaz's guidance that codes should remain in gerund form as far as possible. For example, rather than developing a focused code called 'accommodation/home', I considered 'living at home' and 'staying in one's own home' as the focused codes because these seemed to be more grounded in social processes explanations and were at the same time consistent with my initial codes and gerunds.

#### Conflating initial codes

I started focused coding by re-reading the transcripts and the initial codes. I started keeping a list of some of the codes that seemed most important, including those that appeared most frequently, although it should be noted that the most frequently occurring codes were not necessarily the most important. Some of the focused codes were simply codes that I had used during the initial coding. There were also examples of similar codes representing the same concept/idea. For example, when undertaking initial analysis, I had developed four codes about change: 'change' 'experiencing change', 'adjusting to change' and 'coping with change'. However, when undertaking focused coding, it became clear that these codes were all expressing the same concept and so were re-coded into 'experiencing change'. This was deemed the most appropriate code because it captured both the gerund form and the wider and different expressions of change. Both 'adjusting' and 'coping' can be viewed as having positive associations, and while some participants did cope positively with and effectively manage change, others had a more mixed experience. Thus, the 'experiencing change' focused code reflected the full range of responses to change, both positive and negative.

#### Expanding initial codes

Other codes were composites or broader/more abstract versions of initial codes that better encompassed a process that participants discussed. For example, several of the initial codes were about participants discussing their desire to reduce the amount of assistance they received and how they saw this as important to retaining their independence. These were brought together into the focused code of 'living with a minimum of intervention'.

#### Considering relationships between initial codes

A key part of the focused coding was to think more fully about the scope of the initial codes and the relationships between them. In particular, focused coding involves thinking critically about the links and relationships between different initial codes. An example of this process was my fuller consideration of the relationship between my initial codes 'staying in one's own home' and 'not wishing to move into residential care'. My analysis for the focused coding indicated that these initial codes reflected two sides of the same coin. These

initial codes were then merged into the focused code: 'the importance of own home'.

Once a list of the most meaningful focused codes had been developed in these ways, I returned to the transcripts and coded larger segments of text. This demanded constant reflection and comparison between interview transcripts and the list of codes. This enabled previously un-coded sections of transcripts to be coded and easily situated within the focused coding frame that developed over time.

The next stage of focused coding is the development of core categories. This involves a process of grouping into categories those focused codes that share the same or similar characteristics. These categories become the starting point for the development of explanatory themes and substantive theory.

## The development of core categories

Core categories develop towards the end of the iterative cycle of data collection and analysis once focused codes have been established (Charmaz, 2006). Core category/categories are rooted in participant's accounts and relate to most of the findings.

At a practical level the development of core categories involved revisiting the focused codes, reviewing them and analysing them in relation to each other. This enabled exploration of the positive and negative relational connections between them and how these relationships change over time. This was an iterative and reflective process in line with the constant comparative method. Through these processes the focused codes fell into two groupings (these are presented and explored fully in chapter 7).

The development of core categories is often cited as being a key of grounded theory (Birks and Mills, 2011; Hallberg, 2006). Indeed, several commentators argue that without core category/categories being established, grounded theory can be limited from achieving any theoretical output (Seale 2004; Dey 2007). However, there is some debate about whether there can be more than one core

category. Charmaz (2006) argued that some phenomena might not be amenable to a single 'core'. This is in contrast to traditional and evolved grounded theory which adhere to the viewpoint that there can only one core category. However, constructivist grounded theory is less dogmatic, instead suggesting that it is possible (and often necessary) to incorporate more than one core category (Charmaz, 2006). Such a broader view is accordance with the underlying epistemology of constructivism and the theoretical perspective of interpretivism outlined in Chapter 4 whereby there is an acknowledgement of multiple truths and realities.

At a practical level this was an integrative process of reviewing and comparing all the focused codes and establishing their relationship with the focused codes. Through these processes the focused codes fell into two core categories (these are presented and explored fully in Chapter 7).

## The development of explanatory themes and substantive theory

The final stage of data analysis was the development of explanatory themes and substantive theory. The aim is reach a higher level of abstraction (than earlier analysis). Explanatory themes are a way of conceptualising relations between focused codes and core categories and thus bear particular significance and form part of the substantive theory.

At a practical level the development of explanatory themes and substantive theory this was an integrative process and involved revisiting the initial codes, focused codes and core categories, reviewing them and analysing them in relation to each other. This enabled exploration of the positive and negative relational connections between them and how these relationships change over time. This was an iterative and reflective process in line with the constant comparative method. Through these processes three explanatory themes which formed part of the substantive theory about independence for older people (these are presented and explored fully in Chapter 7).

#### Writing memos

Writing memos is a key aspect of data analysis and was used throughout the data analysis. Charmaz (2006, p.72) acknowledges the role and importance of memos as being the 'pivotal intermediate step between data collection and writing drafts of papers and often provide the foundations for subsequent writing up of findings'. Memos are notes documenting thoughts about the development of codes and categories and, in particular, the relationships between them as the analysis progresses.

I numbered all the memos, which meant I could go back to earlier versions and resurrect an idea that I might have previously excluded/overlooked if later it became clear that it was important. Numbered memos also served another important function in that they documented the construction of theory.

The earliest stage of memo writing took place during the initial coding. As such, it tended to comprise preliminary thoughts and thus largely consisted of direct quotes from the transcripts. It should be noted that some memos were about a topic discussed by only one participant. This was felt to be appropriate as the aim was not to achieve representativeness in the data (that is, focusing only on the interpretations that appear most frequently), but rather to build theory. Indeed, as the analysis progressed and shifted from carrying out initial coding to focus coding, the memos became more abstract in line with the aim of generating substantive theory about the meaning of independence for older people. For example, one advanced memo focused on the relationship between the sociological theory of 'othering' and participant's construction of independence. Once again, this approach to using memos in the refinement of categories reflected the constructivist grounded theory methodological base used in this study.

Table 7 summarises the study design and methods: the stages of data collection, management, analysis and the outcomes of analysis.

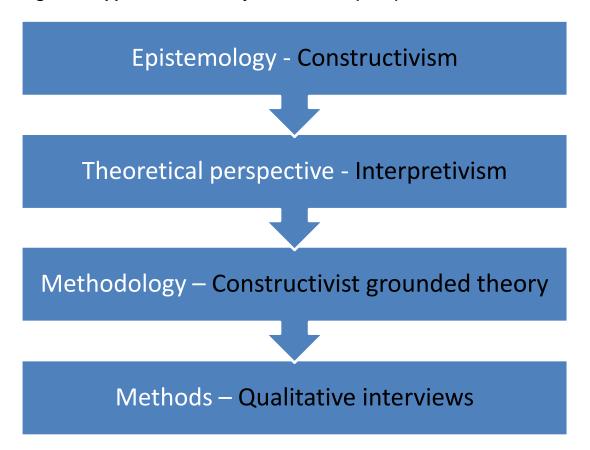
Table 6: Stages of data collection, management, analysis and the outcomes of analysis

Data Collection	Data Management	Data Analysis Methods	Outcomes of Data Analysis
Phase 1 (Qualitative interviews with older people n*=5)	Import transcripts into Atlas.ti	<ul> <li>Initial coding</li> <li>Collating /expanding and considering the relationships between initial codes to form focused codes</li> <li>Memos</li> <li>Reflexivity incorporated</li> </ul>	<ul> <li>Initial and focused codes</li> <li>Modification of topic guide to incorporate findings from phase 1</li> </ul>
Phase 2 (Qualitative interviews with older people n*=10)	Import transcripts into Atlas.ti	<ul> <li>Initial coding of phase 2 interviews</li> <li>Collating /expanding and considering the relationships between initial codes to form focused codes</li> <li>Memos</li> <li>Reflexivity incorporated</li> </ul>	<ul> <li>Initial and focused codes.</li> <li>Affirmation of theoretical sufficiency</li> <li>Identification of core categories</li> <li>Development of explanatory themes and substantive theory about the meaning of independence</li> </ul>

<sup>\*</sup>n = number of participants

Building upon the framework presented in Figure 1 at the beginning of chapter 4, the relevant positions adopted for this research are summarised and illustrated in Figure 2 below:

Figure 2: Application of Crotty's framework (2010) to this research



#### Ethical considerations

Considering the ethical implications of research questions, aims and methods is crucial in social research (Bryman, 2004). The overarching set of ethical principles proposed by the Social Research Association (SRA) was used to guide how this research was conducted and managed. In addition to personal reflection on what constitutes ethical practice, seeking ethical oversight of research protocols and material is central to ensuring research is conducted ethically.

To ensure this study was conducted as ethically as possible, ethical approval was sought and obtained from the University of York (via the HSSE Committee) before research began. As part of this process, consideration was given to several issues: gaining informed consent, informing participants of their right to withdraw, assuring participants of confidentiality and anonymity, and managing possible risk and distress arising from participating in the research.

#### **Gaining informed consent**

A key ethical principle of social research is gaining informed consent from participants. A developed understanding of informed consent entails recognition of the ongoing nature of the process of gaining consent so that it is not simply a one-off or a 'tick box' exercise. Consequently, the need to remain alert to consent issues permeates the entire research process. A crucial part of being able to offer participants the opportunity to give informed consent is the requirement for researchers to be clear and specific about what they are asking the participant to consent to (Mason, 2004). Therefore, if consent is to be meaningful and informed, it is important that participants are provided with sufficient information about what participating in the research entails.

In order to facilitate informed consent, information sheets were provided to potential participants. These information sheets described the aims of the study, what taking part in the research involved and what would happen to the information that was collected (see Appendix 2). Participants were assured that any information they provided would be anonymous and used only for the purpose of the thesis. Before each interview began, the research was explained again and the person was given the opportunity to ask questions. If they were still happy to take part in the interview, they were asked to sign a consent form (see Appendix 5). The consent form emphasised the voluntary nature of participation, their right to withdraw (see next section) and specific consent for issues related to conducting the interview and disseminating findings.

In line with the HSSE Committee guidance, specific consent was sought for audio recording each interview. However, participants were advised that they could still take part if they did not wish to be recorded and that in-depth field-notes would be taken instead to ensure their views and experiences were captured. HSSE Committee guidance also draws attention to the need to distinguish between consent to participate and consent for the findings to be used or published as part of a report. Therefore, the consent form asked explicitly for participants' consent to use direct, though anonymised, quotations in any reports of findings. In one interview, after consent had been given and the interview had started, I became aware that the participant's capacity to give informed consent was questionable. This concern was not based on any outward signs of impaired capacity, and indeed the care manager at her supported housing had previously

indicated that she would be willing (and able) to participate. Rather, my concern stemmed from her comment early in the interview where she stated: 'my memory's beginning to go and it worries me a bit because I forget where everything is'. This statement unsettled me as I was aware that I did not have the skills or the ethical approval to interview participants with cognitive impairments. However, rather than terminating the interview immediately, which would quite likely have been upsetting and confusing to the participant, I decided to continue the interview while remaining mindful of what had been said.

This seemed to be appropriate because the participant made no further statements about memory or cognitive issues and exhibited no outward signs of such difficulties in her responses. Based on these observations and the fact that her care manager had confirmed her as a possible suitable participant, I felt her initial comments had simply reflected her concerns rather than being an indication of significant memory impairment. This example highlights the ethical considerations that must be taken into account when carrying out any research and the need to be aware of the sampling frame throughout the data collection process, not just at the recruitment phase.

#### Right to withdraw

A further guiding ethical principle was the participant's right to withdraw. A wide interpretation of the right to withdraw was taken: participants could choose to decline further participation in the research, decline to answer a particular question, or request the removal of data from the study. Each person was advised that if they agreed to be interviewed, they could stop the interview at any time and/or ask to skip any questions that they did not feel comfortable answering. Participants were advised that they maintained their right to withdraw throughout the research and were under no obligation to provide a reason for this. Additionally, they were informed that withdrawing would not affect any support services they received, now or in the future.

I was also mindful of the potential difficulties that a participant may have in being able to express their desire not to participate further. Graham et al. (2006, p.40) acknowledge these potential difficulties by stating how 'withholding information during a qualitative research interview may be more difficult to operationalise

than participants' anticipate'. Therefore, throughout interviews I was alert and observed for potential cues, such as non-verbal communication, that could indicate participants wanted to stop talking about a particular topic or wanted to end the interview. For example, one of the participants requested that the interview took place in a communal lounge. While obviously agreeing to her preference, the background noise in this location made it difficult to conduct the interview. I also sensed that while it was her choice to be interviewed in a communal setting, it was difficult for her to talk freely, although the possibility must also be considered that her choice of location was indicative of her reluctance to talk too openly. Indeed, this interview was the shortest (lasting only 20 minutes) because, despite having consented to the interview, the participant struggled to answer the questions and appeared uncomfortable when I tried to guide them towards discussing independence. In this instance, I felt the most ethical thing to do was to end the interview and thank her for her contribution. This interaction highlights an important ethical consideration: informed consent is an ongoing process and verbal and non-verbal forms of communication are important cues (Mason, 2004). I decided not to include her contribution as no relevant data had been gathered.

#### Confidentiality and anonymity

The guarantee of participants' confidentiality and anonymity is another central premise of ethical research. To achieve both of these, SPRU's policies on data storage were used. All contact details and raw data were stored in a locked cabinet, and the computer used for analysis was password protected in accordance with SPRU's data protection policy. No personal identifying details, including those of third parties, have been included in this thesis. To this end, each participant was assigned a research participant's number (RP) and any information that might identify any of the participants was removed from the transcripts at the earliest opportunity.

While I was fully committed to maintaining the confidentiality of the research participants, I was aware that there are situations where this might need to be breached; for example, it was accepted that if the participant indicated that they, or someone else, were at risk of harm, then the rules of confidentiality might need to be compromised.

## Managing possible risk and distress

As stated clearly on consent forms and reiterated at the start of interviews, participants were advised that if they said anything that indicated that they were at risk of harm or were harming someone else, I might need to break confidentiality. I made it clear that if I were concerned about a participant's wellbeing, I would discuss this with them and talk about the actions I would need/they would prefer me to take. I made it clear that I would need to discuss any concerns with my supervisors in the first instance. If I felt there was a need to take any action or break confidentiality, this would not occur without prior discussion with my supervisor. If further action was needed, I might need to contact a professional or someone else who could support the participant. If this was required, I advised participants that I would ascertain who their preferred contact would be.

I was aware that the participants might become upset during the interview. Personal issues, such as deteriorating health, recent bereavement, reduced mobility or an increased need for services, are all potentially upsetting topics that might surface when discussing the meaning of independence with older people. Thus, I acknowledged that the meaning of independence can be an emotive topic, especially when a participant feels that their independence has already been affected or will be in the near future.

I decided that in cases where the participant found the interview upsetting or distressing, I would offer, for example, to change the topic being discussed, to pause the interview, or to terminate and/or rearrange the interview. The decision about how to proceed would be guided by each participant's preference. I decided that I would also ask if they wanted to contact anyone, or whether I could contact someone on their behalf who could offer support. I also ensured I had contact details of the relevant local services available, for instance, counselling, bereavement support and social support services (e.g. companionship) that might be of assistance to them. None of the participants felt the need to take a break or terminate the interviews early. In two cases, however, once the interview had ended, we had a brief conversation about seeking further support, and I left

these participants the pre-prepared list of contact details for local relevant support services.

Several participants talked about being lonely and at the end of the interview described how much they had enjoyed the opportunity to talk to someone. I had not anticipated my reaction to leaving a participant's home where such views were expressed. I was acutely aware of what I as a researcher was able and, more importantly, not able to offer the participants. One participant, whose daughters lived abroad, expressed how she felt socially isolated and reiterated many times how she wished we could stay in touch. I felt I was unable to give her what she wanted (i.e. further contact between us), but I spent some time at the end of the interview chatting about the different services available for older people in York and, in particular, the befriending service offered by Age UK York. Although I had anticipated that some participants might express loneliness, I had not anticipated my own personal reaction to hearing it in person; even though I had planned for this scenario, I still felt a sense of regret at being unable to assist her further or offer more than a 'one off' meeting.

By considering and responding to all these considerations ethical approval on the condition that the recruitment information was presented in larger font was granted.

## **Personal safety**

This research involved visiting potentially unfamiliar neighbourhoods and carrying out interviews in participants' homes. These circumstances meant that there was a possible, although minimal, risk to personal safety. In order to minimise this potential risk, I completed relevant documentation (i.e. fieldwork risk assessment form) and followed SPRU policy regarding fieldwork safety, including using the Argyl telephone monitoring and alert system.

# **Demographic characteristics of participants**

As outlined earlier in this chapter the aim was not to recruit a representative sample. However, in order to contextualise the findings the demographic characteristics of the sample are presented

To recap, data collection was split into two phases. Phase 1 comprised five interviews with older people; the analysis of these interviews guided the modification of the topic guide, as presented in chapter 5. Phase 2 comprised a further 10 interviews with older people using the modified topic guide. 15 older people were recruited in total. The following table presents the demographic characteristics of the participants.

**Table 7: Demographic characteristics of participants** 

		Phase 1 (Research Participants n=5)	Phase 2 (Research Participants n=10)
Gender	Male	0	2
	Female	4	9
Age	65–74	0	1
	75–84	3	6
	85+	2	3
Living situation	Alone	5	9
	With spouse/ relatives	0	1
Living arrangements	Supported/sheltered housing	2	10
	Private	3	0
Support	Currently in receipt of a support	4	10
service	service		
accessed	Not currently in receipt of a	1	0
	support service (although has		
	been in the previous six months)		

As Table 8 illustrates, the participants had mixed characteristics, and although it is not possible to ascertain with any certainty why some older people participated

while others did not, there may be several possible reasons as to why this was the case.

Of particular note is the fact that 13 of the 15 participants recruited were women. This may have been because the majority of the recruitment was facilitated through my attending social events, such as coffee mornings and a 'knit and natter' group (see Chapter 5), activities that tend to be gendered and tend to attract women more than men. Furthermore, given that the study was a qualitative research project conducted by a female researcher; this may have influenced the way in which men viewed the research and their interest in participating. In addition, although the gender gap in life expectancy is decreasing, women are, on the whole, still living longer than men, and thus the overall population of older women is larger than the population of older men (ONS, 2012). This sample bias towards women strongly parallels the sample characteristics of other empirical studies identified in the scoping literature review (Plath, 2008; Tilse et al., 2007).

With a single exception, all the participants lived alone. This is consistent with the wider demographic shift of increasing numbers of older people living alone (ONS, 2012), and this, at least in part, might help to explain the recruitment bias towards older people living alone evident in the sample cohort. Furthermore, it might be safe to assume that older people who live on their own are more likely to attend the kind of social events from which I recruited participants because they may feel a greater need to socialise outside the home than those who live with another person. This sample bias towards older people living alone once again parallels the studies identified in the scoping review (Tilse et al., 2007).

The modal age of participants was between 75 and 85 years old, with nine of the participants being in this age grouping. The fewest interviewees were in the 65–75 group, with only one participant belonging to this category. It should be remembered, however, that one of the research criteria was that participants had to be in receipt of a support service. Given that the need for support services tends to increase with age, the disparity between the numbers of participants recruited from the younger age grouping and the older age grouping might be explained as the result of there being fewer people in the younger age group who

met the selection criteria. This younger age grouping may also be less likely to self-classify as 'older' and, as such, may have regarded the scope of this research as having no relevance to them. The third age grouping was for those aged 85 years old and above. Five participants from this age grouping were recruited. Again, there are several potential reasons for the low recruitment rate from among this age grouping. These include poorer health, the higher rate of dementia associated with ageing and the increased likelihood of living in an institutional environment. It should be borne in mind that participants who fell into either of these latter two categories were automatically excluded from the recruitment process because the sampling frame (see Table 5 in Chapter 5) established that participants must be living in the community and able to give informed consent. These selection criteria and the practical issues of recruiting people from an age group that tends to be in poorer health than its younger counterparts might help to explain the low level of recruitment from this age grouping.

# Summary and conclusion of this chapter

This chapter has presented the methods used to collect, manage and analyse data and the challenges that had to be overcome to maintain a constructivist grounded theory approach, recruit individuals and collect data from older people.

To summarise, the aim of the study was to gain an insight into the meaning of independence directly from the perspective of older people, and a qualitative approach incorporating the principles of a constructivist grounded theory was considered the most appropriate to achieve this aim. In line with the principles of grounded theory methodology, a first phase of semi-structured interviews was conducted with a small sample of older people, and analysis of these interviews shaped the focus of the subsequent round of interviews.

While a qualitative approach to data collection resonated with the research aim and methodology, specific challenges arose in the process, particularly around low recruitment. This chapter has highlighted how these 'sticking points' were managed. Finally, the ethical issues relevant to this research and the steps that

were taken to manage them were discussed. The next chapter presents the findings.

# **CHAPTER 6: FINDINGS**

# Introduction

This chapter presents the findings from 15 qualitative interviews exploring the meaning of independence for older people using support services. In accordance with the methodological principles and analytical processes of constructivist grounded theory (Charmaz, 2006), the presentation of the findings aims to reflect the movement from early analysis (coding and memo-ing) towards the development of theory (see Chapter 7).

This chapter is split into three sections. Section 1 discusses the presentation and illustration of the findings. Sections 2 and 3 present the findings from analysis of the interviews through initial and focused coding and the development of core categories as described in chapter 5. Analysis found two sets of focused codes: dimensions related to identity and dimensions related to agency. Section 2 presents the participants' conceptualisations of independence as different constituent dimensions of identity. These dimensions are considered separately, the purpose of this being to set out the defining characteristics of each dimension, the scope of the participant's meaning and the underpinning analysis. Section 3 presents the different constituent dimensions of agency held by participants. These dimensions are also considered separately, the purpose again being to set out the defining characteristics of each dimension, the scope of the participant's meaning and the underpinning analysis.

# Presenting and illustrating the findings

Qualitative research frequently incorporates direct quotes from participants as a key means of evidencing the findings (Silverman, 2004). The use of quotes can provide a direct insight into a participant's experience, and it has been suggested that their inclusion may promote transparency (Dales, 2006).

The quotations used as part of the presentation of findings in this chapter provide illustrative examples of the key issues that emerged during the analysis.

Quotations from the transcripts have all been kept as close to the original text as possible, but short utterances and/or conversational prompts such as 'Yes',

'Hmmm' and 'Okay' (made either by the participant or by me) have been removed because I felt that they detracted from the text itself. From a methodological perspective, the removal of such utterances and conversational prompts was not deemed consequential (unlike in other methodological approaches such as discourse analysis). This is because the emphasis is on understanding content rather than discourse. Each quotation is labelled with the research participant's number (RP) and the identifying line number in the transcript, referred to as text units (tu).

There was also a need to consider the use of numerical/quantitative data when presenting the findings. While some qualitative researchers do present their findings in numeric terms, I considered this not to be in keeping with the constructivist theoretical perspective underpinning the research. For instance, Maxwell (2010, p.475) notes:

Numerical data [is] incompatible with a constructivist stance for research, as such data imply the existence of a single "objective" reality that can be measured and statistically analyzed to reach generalizable conclusions.

Nevertheless, in my use of phases such as 'some', 'usually' and 'most', I am aware that the findings are quantified, albeit in a very basic way.

# Independence and dimensions of identity

Independence was found to be key to a participant's identity, both in terms of their personal identity and their social identity. Personal identity refers to how participants constructed independence as an individual characteristic. Social identity refers to how participants constructed the meaning of independence in relation to others, and this, as will be evidenced, often reflected internalised dominant social/cultural discourses about independence. There was evidence of interplay of both personal and social facets of identity within participants' conceptualisations of independence, and this shaped participants' ideas about who they thought they were and how they wanted to be seen by others. It showed that the meaning of independence is created and sustained both by participants' sense of self and by their social relationships.

The findings indicated that the participants' conceptualisations of independence, and self-evaluations of their own independence, were associated with five different, but interactive dimensions of identity. These were: an established identity; an aspirational identity; an adaptive identity; a forced identity; and a comparative identity. Table 9 summarises the stages of analysis that took place to develop the different constituent dimensions of 'a sense of independence'. Their meaning in relation to participant's independence is explained in this chapter.

Table 8: Participant's constructs of independence: initial codes and focused codes

EXAMPLES OF INITIAL CODES*	FOCUSED CODES
Carrying on as previously	An established identity
Staying the same	(What one is)
Intrinsic part of self/ used to being independent	
Always been independent.	
Being normal	
keeping going	An aspirational identity
Persevering	(What one wants to be)
Valuing independence	
Aspiring/striving to be independent for as long as possible	
Adapting to change	An adaptive identity
Accepting/coming to terms with changing circumstances	(What one changes)
Pacing self	
Recognising declining capabilities	
Anticipating escalating care needs/need for assistance	
Thinking about independence in a different way	
No option other than to be independent	A forced identity
Not wanting to be a burden	(What one has to be)
Not wanting to impact on others' (their children's) lives	

Not wanting to rely on others	
Fearful of needing to depend on others	
Respecting others' roles and responsibilities	
Feeling can't keep asking for assistance	
Keeping myself to myself	
Comparing own situation with others'	A comparative identity
Other peoples' attitudes impacting on one's independence	(Who one is comparing/compared to)
Past experiences and roles	

<sup>\*</sup>Initial codes in italic were 'in-vivo' codes

# An established identity

'Established identity' refers to independence being a stable and embedded aspect of a participant's identity. Participants viewed independence as a key characteristic of who they were and how they thought of themselves. In other words, it was central to who they were. Independence as an established identity manifested itself in two different ways. First, it was established in relation to and as a consequence of life experiences; second, independence was spoken about in terms of being an innate characteristic and thus embedded quality of who they were.

Some participants referred to their independence in terms of seeking to continue being the same person and living the same life that they had previously. In one sense, this established identity as 'independent' might be viewed as being embedded within their sense of self.

I think my independence has stayed the same, in as much as I can do for myself (RP14, tu265).

Independence is having and living the life you've always lived (RP5, tu0726).

Participants often expressed this idea of continuity in practical terms, such as being able to carry on with their functional activities of daily living and/or not yet having had to change their lifestyle too much. For some participants, established feelings of independence continued even after they were unable to perform the roles that they felt had bolstered their independence to begin with; for example, even after having retired from the careers that had provided them with economic independence, they believed that they had retained their independence. Indeed some participants appeared to maintain a sense of their identity as 'independent' through a connection to their past employment and/or activities. For example, the following quote suggests that although the participant had retired some years earlier, the independent identity that she had established while in employment had not ceased:

I was an Area Manager for 25 years, looking after about 200 people, so I've always been independent... But that was there, and you can't have that kind of life for several years and then all at once, it stops and you're not independent anymore (RP4, tu0386).

For others, their established identity as 'independent' was the result of stoicism and endurance.

I'm just carrying on with my own life as I've always done, as long as I'm physically able to, and I intend to go on doing that (RP3, tu293).

People say to me, "How do you do it? How do you manage to be like this at that – at your age?" And the only thing I can say is, you just carry on as you always have done, as far as it's possible. And I mean, as I said, I get up in the morning and I do exactly the same as I did when I was 15 (RP3, tu293).

It doesn't matter how old you are, how young you are, you're just the same, but it's just getting on and carrying on, really (RP4, tu1037).

Participants were often clear that a sense of an 'independent' identity had been established at a young age, often in their formative years:

I've always been independent. Well, I say always. Since I've grown up (RP4, tu0698).

Some participants articulated that their established identity as 'independent' was the result of material hardship experienced earlier in life. These participants retained an embedded sense of independence derived from their earlier hardships:

I started being independent on the day I left home. We all did in those days. Once a girl reached fourteen, you had to leave home; [your parents] couldn't afford to keep you (RP12, tu135).

Others suggested that they had been brought up to be independent in line with the expectations of the time. It appears, therefore, that their sense of independence had been established in part through dominant social/cultural discourses at a younger age:

That's the way we were brought up to be independent, look after yourself and your family and that's what I do, I carry on (RP10, tu048).

Other participants suggested that their sense of independence as an established identity was not rooted in their life experiences, but rather formed an intrinsic part of who they were. In other words, they viewed independence as an inherent characteristic of the individual. For example, one participant suggested that independence was in their 'nature':

I don't know how to express independence, but it is part of my nature. Independence actually means being, as far as possible, the person that you've always been (RP1, tu0399).

Another participant made a similar point when discussing their conceptualisation of independence, albeit with a slightly different emphasis. For them, independence was again about being who they have always been, but the emphasis was placed on continuity of mind, rather than continuity of 'doing':

Even if you can't do everything... your thoughts and independence don't alter with age... unless you get so poorly and ill (RP2, tu0399).

To conclude, it was apparent from the findings that participants had formed strongly embedded identities around the concept of independence. For many, this was in large part formed through their life experiences, and despite the many changes that participants had experienced in their lives – for example, declining mobility and moving between different types of accommodation – most emphasised that they were committed to retaining their independence if possible. Indeed, even when major life roles had ceased, the participants' experiences of their 'former life' were deeply embedded and established as constituent elements of their constructs of independence. However, while independence was seen as

a core part of their sense of self, participants did not necessarily reflect on their independence on a day-to-day basis. Instead, for most, independence was just one part of who they have always been.

## An aspirational identity

'Aspirational identity' refers to participants striving both to experience and to maintain an independent sense of self for as long as possible. This drive to retain an independent identity was often expressed by participants as being a key reason to 'keep going' and/or for 'carrying on'. This was particularly apparent in interviews with some of the participants who had faced or were facing difficulties with regard to deteriorating health and/or mobility. The following participants talked about their aspiration to remain independent, which motivated their physical and mental efforts to persevere:

I feel that if everything was done for you or someone was with you all the time or you had – unless you absolutely need such a lot of extra help – I do think it would be very easy just to give in. I think being independent keeps you going (RP1, tu0844).

I don't know how you describe independence... my physical ability is not as good as it was before the heart attack and it was frustrating and it still is because I stagger about like a drunken woman around the house sometimes and it's the medication and I'm not that steady on my feet. But, as I say, it's my independence and my mind that keeps me going (RP2, tu462).

If you didn't have your independence, you wouldn't have the same sense of occasionally get up and go and try something new (RP15, tu0848).

Other participants also expressed their drive for independence, but with a slightly different emphasis: their aspiration for independence was focused around a strong sense of determination not to "give in":

There were many times I could have given up, but no way do I want to not be independent (RP3, tu620).

I'm too independent for my own good, but I don't want to give in. I don't want to sit in this chair and just deteriorate (RP2, tu0108).

While this strong drive for independence was evident throughout all the accounts given by participants, many acknowledged that remaining independent for the rest of their lives may not be possible:

I'm independent and as far and as long as I can, I will be independent (RP10, tu040).

I definitely want to keep my independence as long as ever I possibly can (RP14, tu272).

My independence means a lot to me, and I've got it, and as long as I can keep it I will, however old I get (RP15, tu517).

As can be seen in these quotes, participants commonly used the phrase 'as long as' when discussing this aspirational identity dimension of independence. This suggests that participants held a degree of uncertainty about their future independence, and while independence is a desired state, there is also acknowledgement that it may not be possible forever. By using this phrase, participants recognised that their independence is an experience that may be transient, finite and time-limited and that changeable circumstances, particularly ill health, can thwart independence.

While independence was important for the majority of participants, there was also acknowledgement that attaching such a high value to the notion of independence may lead to unintended consequences. More specifically, the need to experience and maintain independence can mean that participants at times may feel the need to disguise their declining capabilities. For some participants, 'carrying on' and 'continuity' in their pursuit of independence meant that they chose to under report their declining health, and that by doing so, they may have received inadequate support and assistance:

You try to keep going and try to keep going. You don't get any help because they think you're coping. But it's me, myself, that's coping, forcing myself, whereas if I gave in, I know I would maybe get more help. But that's not me nature (RP2, tu0701).

Another participant spoke at some length about the possibility of 'losing' her independence. Her testimony points to a view in which loss of her independence – that is to say, the aspirational value that she placed on independence – would mean that she would not be happy:

If you can't be independent, you're not happy because you can't do what you want to do; you can't be who you want to be (RP4, tu03190).

To conclude, while participants clearly aspired to be independent and to maintain a sense of independence for as long as possible, this was often coupled with an acknowledgement that it may not last forever and thus could not be taken for granted, particularly at their age. Many spoke of how grateful they were; they felt they were in a privileged position to have continued to feel independent as they had aged and expressed hopes that they would continue to do so in the future. Thus, while their constructs of independence were aspirational, there was evidence that participants also had a reflective attitude towards the potentially transient nature of independence.

## An adaptive identity

'Adaptive identity' refers to the participants' acknowledgement that independence is changeable, and in order to maintain an 'independent' identity, the meaning of independence must be continually redefined so as to maintain its validity. Participants were aware that their circumstances (particularly issues of health and/or mobility) may change, and this may necessitate a re-evaluation of their meaning of independence. Thus, an 'adaptive identity' highlights that participants' understood independence as an evolving rather than a fixed construct.

Different adaptive processes were evident: some participants highlighted the need to adapt in a practical and pragmatic manner to their changing circumstances in order to maintain their independence, while others placed an

emphasis on attitudinal adaptation and changing expectations of how much they could achieve without assistance. Furthermore, there was evidence to suggest that adaptation was not a one-off event and/or process for the participants; instead, they adapted repeatedly (often in different ways) as needed in order to maintain their sense of self as being independent agent/actor.

As noted, many participants adopted a range of practical and pragmatic approaches in order to maintain their sense of independence. One of the processes commonly mentioned by participants was their need to 'pace themselves' to their changing abilities. Many felt their ability to be active and carry out activities of daily living was declining, and they therefore felt they needed to adapt the timing and level of their daily activities in order to maintain their independence. Participants stated that they limited or gave up some household tasks (for example, heavy housework such as hoovering) and/or paid for domestic assistance:

I mean, I get tired, so I've got to pace myself. You see, I was finding, up to Christmas and after, I was doing too much, 'cause after Christmas I more or less collapsed and I had to have three and a half days in bed because the doctor said I'd just done far too much. So I'm really realising I've got to pace myself to keep my independence (RP14, tu033).

Others provided practical examples of pacing themselves in order to adapt to their declining health and/or mobility. In particular, participants allowed more time for completing a given task and/or reduced the number of times (i.e. per week or per day) they completed a task. However, what seemed most important to these participants was not that they had to change their daily routines, but that they were still able to carry out the tasks without involving others and by doing so maintain a feeling of independence:

I don't have a shower every day 'cause I can't, 'cause it takes too much out of me, so I just have to have one every other day (RP14, tu009).

Nowadays that I really can't do more than two things in one day... if I have you and [my carer] this morning I wouldn't go to the Co-op... I would leave it until tomorrow (RP1, tu0099).

Other participants adapted in different practical ways. For example, rather than pacing themselves in terms of how much they did, some adapted by changing the way in which they carried out a task:

I can do my own ironing. Now I have to sit down; I can't stand up and do it. It takes me longer, but at least, I'm doing it (RP9, tu608).

Participants also talked about the need for aids and/or special equipment as a means of pragmatically adapting to declining health and/or mobility. For example, one participant discussed the possibility of using a walker in the future. There was evidence of adaptation and compromise in the way she spoke about using this aid in order to maintain her independence:

I definitely want to keep my independence as long as ever I possibly can. Even if I have to have, one of these walkers to walk about with (RP3, tu272).

As noted, participants adapted by changing their attitudes and re-evaluating their expectations of how much they could achieve as they became older, and many voiced that one form of adaptation was the need to accept changes. For some, acceptance was about adapting to the changes in circumstances that had already happened, while for others it was about considering and anticipating possible changes and/or health deterioration in the future. While the participants were not necessarily happy that their circumstances had changed (or may change), participants overall felt that they had come to terms with these changes and that acceptance was necessary in order to re-conceptualise their sense of independence.

It's a case of, you have got used to being independent. Then you have to get used to the fact that it has changed and you can't do everything

anymore, so you have to be independent but in a different way (RP3, tu495).

Independence is about coming to terms, I think, with the inability to do certain things (RP6, tu282).

You have to get used to the fact that you can't do it anymore. I mean, my legs just won't go (RP3, tu495).

I don't expect people to wipe my bum. Why should I expect them to clean my house? I mean, the fact that I'm considering having a cleaner is indicative, I think, of how I feel about myself, really. I've, sort of, come to accept, to some degree, that I'm no longer able to do what I should do (RP6, tu535).

My health is the most important to me, but I won't get it – keep it forever, I know that. You can't do. You gradually – but – and I don't particularly want – it isn't my – to say, "Oh, I want to live to be 100". But you just don't know and you have to try and accept that, and if it comes along, I've just got to make the most of it as it comes along (RP5, tu289).

I've had to settle down to know I can't walk... It's something you've got to get used to, and you must accept it...Well if you don't accept it, it'll drive you mad. It would drive you mad. Oh no, I've accepted it (RP12, tu286).

As is evident in the above quotes, participants talked most about declining health and/or mobility as being the most likely changes that they would need to accept and adapt to. Others, however, talked about accepting and adapting in relation to other key life circumstances, for example, bereavement. References were made to independence having to be re-established, or in other words, participants recognised the need in some cases to learn a different type of independence. For example, one participant who had been widowed spoke at some length about having to adapt to changing circumstances; this significant change in her circumstances precipitated an individual re-negotiation of what independence meant to her.

The only thing I was aware of was losing my husband, although for about three years after I'd been in here I missed him like the dickens and that was the only thing that worried me that was – but you have to accept these things and get on with life, don't you? As I say, I made two or three friends in here and gradually I got in, took over. It's, kind of, being independent of him I think, more than anything, because he was one of the type of men that you could rely on to do anything (RP12, tu207).

For others, adaptation was about using different strategies to maintain their sense of self as independent. For example, some participants whose physical mobility had been restricted adapted by shifting the focus of the meaning of independence towards their adaptation/adaptability state of mind:

In actual fact, I'm more forward thinking than an able-bodied person, because that's how I have been for so many years, you see... You see, I've always said, "There's a way around this, there's a way around", and that's how I think; it's not impossible, unless, I, couldn't conquer it, but I will try and try until it does work (RP1 tu085).

To conclude, many participants' constructs of independence relied on being adaptive to changes in their own abilities and circumstances. Participants understood independence as being achieved by prioritising what was important and by adapting so as to realise these revised goals in a manner that was meaningful to them personally. Personal experiences influenced how independence was defined and refined when the circumstances of the participants changed.

#### A forced identity

'Forced identity' refers to participants articulating that maintaining an identity as 'independent' was not always an active choice. Rather, at times, being independent was the only option participants felt they had. This sense of 'forced identity' manifested itself in two ways: some participants felt that they had either a limited social network or no social network at all, while others stressed that it was more a matter of not wishing to feel that they were placing a 'burden' on others.

In the first instance, some participants were aware that because of their current personal circumstances, they had a limited/no social network (family, neighbours and/or friends) that could be accessed when needed. Consequently, they felt that there was no choice but to be independent. For these participants, independence was experienced as a 'forced identity' because it involved a lack of choice – doing everything for themselves was their only option:

I've been a widow for nearly 35 years. I've had to fend for myself and I've had to do things that, if I'd had a man about the house he would have done them for me (RP13, tu107).

My marriage wasn't very good, and I learnt not to rely on other people. I had to do what I had to do, and otherwise, I would have had no life at all in my estimation (RP3, tu317).

I had to do everything. I done everything myself. I couldn't ask for help or anything. I done it all myself. I would struggle with it. Struggle with it. Well, I haven't got the sort of family you could ask for help (RP12, tu170).

Another way in which a 'forced identity' manifested itself was the acknowledgment by some participants that, although they had access to a social network, they were unwilling to ask people in their social network for assistance. This was a pervasive discourse across the interviews. Participants did not wish to actively seek assistance because they felt it would impact adversely on their independence. While this decision was clearly based to some extent on the participants' preference for maintaining their sense of an independent self (i.e. doing things for themselves), it was strongly influenced by their equally powerful determination not to be a 'burden' to others. Participants expressed this determination mostly in the context of their relationships with their adult children.

It's the one thing I don't want to be. I don't see why they (his children) – and I don't mean look after me, 'cause they would to a degree, but I wouldn't want – well, no, how to put it? I just wouldn't want it, but I think the

simple answer again, going back to it, is I don't want to be a burden to them (RP10, tu485).

While participants did not wish to be a burden, they were also keen to point out that those who might seem able to provide some support and/or assist them (particularly adult children) may not actually be in the position to do so, and thus it was their (moral) responsibility to remain self-reliant. Often this led to participants offering explanations (for example, not wishing to impose of their children 'busy' lives and/or not overly worrying their children) as to why their family members were unable to assist them:

I have a daughter that lives in the village, but she works long hours and shifts, so you can't rely on your family because, well, a) it's wrong and b) during the night, she might be away at work and things (RP4, tu0110).

The kids are always saying "If you ever want, you know, just ask". But I don't like asking 'em for anything. But I didn't want to be bothering them, you see. They have enough with their own families these days, 'cause they go and look after their grandchildren more than ever (RP9, tu477).

Another participant also talked about not wishing to involve their adult children. They discussed the purchasing of a new bed for themselves, and while they felt concerned about how they would manage the delivery of it to their flat, they self-imposed a boundary between themselves and their son in regards to when and how they sought assistance from him.

It's just that I respect their independence. I respect them and think, well, I mean, sometimes I think, oh, I'll ring Stuart and then, no, I won't. I'll wait a while, and things like that. At the moment I've got pressure on about a mattress, and I thought I'll ring him today, and then I thought, no, I won't. I'll wait 'til he comes around. So that's the kind of attitude that I have (RP11, tu370).

Participants often used negative terms and/or examples of acute circumstances – for example, "wrong", "bothering them" and "desperately ill" – when considering

whether to ask for assistance. While the primary reason that participants did not request assistance appeared to be a desire not to be seen as a burden, it can be argued that by understanding the importance of their own needs these participants were in effect self-regulating and thus minimising their need for assistance, and thereby reinforcing their belief in not asking for help for as long as possible. In drawing on the negative cultural discourses around reliance on others, many participants rejected the option of seeking assistance from others and thus imposed limitations on themselves with regard to the extent of assistance they were happy to request:

Being on my own, I have got to go and get it. I won't get that cup of tea unless I leave my bed and come down and get – and do it. Unless I'm desperately ill, and then I would phone the neighbour. She'd pop in and pop the kettle on or something (RP1, tu826).

I just won't ask for help and somebody might offer and I'll say, "Oh no, no. No, it's alright. I can manage" (RP2, tu0495).

Neighbours are very kind – they get the urgent bits [of shopping] – but you know how it is, there are things you feel you can't keep asking them (RP1, tu508).

Other participants made similar points about their desire not to be perceived as a burden, and this forced them to downplay their symptoms when they experienced pain and were unwell:

I don't show when I'm in pain and everything. I just – I'm very private about that, 'cause I don't want – I mean, sometimes I'm in agony, but I won't let on. I don't want to trouble other people, 'cause everybody has their own troubles (RP2, tu0304).

As things have got worse, of course, there's more responsibility for them. I do try my utmost not to have to call them, if I can help it. They really will do anything for me, but then, you don't want that. If that's where independence comes in, it might mean not nice independence, being

lonely, but you don't want to have to bring other people to help you (RP4, tu0726).

To conclude, many participants experienced independence as a 'forced identity'. This was due to their particular circumstances and a perceived lack of available support and/or strong social/cultural discourses that, in placing a high value on independence, meant that participants felt a need to be self-reliant, whatever the personal cost. This 'forced identity' also highlighted that participants' independence was driven largely by a desire not to be a 'burden' on others. Thus, for many participants, self-reliance was about minimising their impact upon others, even in cases where other people were happy to help them.

## A comparative identity

'Comparative identity' refers to the ways in which participants maintained their independence by drawing contrasts and making judgements. By definition, the drawing of a comparison requires the use of a comparator. The interviews illustrated that participants' sense of independence was in part established by reflecting on themselves and others. They compared their current sense of independence with their past self and/or with their expectations of their future self. In addition, their constructs of independence were framed through comparisons with others and how they perceived other people's levels of independence.

In relation to comparisons made with their younger selves, it is perhaps not surprising that participants often felt less independent now than they had when they were younger:

I was really faster when I was younger, the harder the battle, the harder I've fought with it, knowing – because the children were young and everything, but now my independence is tending to wane a bit (RP1, tu319).

Participants also spoke about their future, and comparisons were made between their current independence and their anticipated future self. Again, unsurprisingly, the focus was on the likelihood of their health deteriorating further. Many of the participants appeared to be anxious and uncertain about their future health status, what this would mean to their independence, and whether they would be able to 'manage'. For example, one participant who experienced significant health concerns stated:

I'm frightened, in a way. I think I'm frightened of everything in the future. I think with all my health problems will I be able to keep independent? Will I be able to manage? (RP2, tu0519).

As previously mentioned, participants also defined their independence by comparing their own perceived level of independence with how independent (or not) they considered others to be. Often, participants' statements took the form of comparisons between their own situation and that of others perceived as being less independent. For example:

My independence I don't rely too much on other people for help. Obviously a lot of people aren't like me. They're housebound and they're in ill health and they do need someone to rely on (RP13, tu87).

Since going into the home, I have found them [her sisters] less capable... and not being able to get out, meet people in shops... that's why I'd like to be as independent and as capable as possible (RP1, tu842).

A lot of them here, like, they're in wheelchairs and if they can't push their selves it annoys 'em because they can't get out unless you have a carer, and I suppose because they've always been independent and once they're in their wheelchairs and can't do anything, then I think it's frustrating for them (RP9, tu208).

I don't want to just be sat in the house all the time, like one or two friends I know have, and I don't want to end up like that (RP2, tu0025).

I say, "Well, there's a lot I can't do, but if I can do it, I'm going to do it", but that's just me. I mean, I couldn't speak for other people on that at all, because some people just sit down and give up (RP4, tu0378).

People who are not healthy couldn't do anything like I do, and I know that... when my mother went into a home — I'm going back a number of years ago and I just watched her wither away. It's just something I don't see the sense of it. I'll maybe look at it different when I get there, but at the moment, I just don't see the sense (RP10, tu406).

It can be suggested that participants were not only comparing themselves to others, but were also externalising or 'othering' dependency. As evidenced above, participants partly constructed their own identity of independence through the way in which they perceived themselves in relation to 'the other'. There was evidence of a process of 'othering' among participants who projected the label of 'dependent' on to others who they perceived not to have as high levels of independence as themselves. In part, this served a role in terms of fostering the participants' self-identity regarding independence.

Comments such as 'felt sorry for' and 'other people worse off than me' all indicate the undesirable (and feared) position that these participants perceived others to be in. However, it is important to highlight that the circumstances presented by the participants reflect their perceptions of others' circumstances rather than actual knowledge of their lived experiences.

I've seen so many I've felt sorry for who physically have not been able to do stuff, and naturally it's more difficult for them to be independent (RP1, tu218).

If you're really desperate, they [Age UK] do your shopping and that for you, but I always think there're other people worse off than me that needs that service (RP2, tu0144).

As such, there is no evidence to suggest that there is a dichotomy between independence and dependence; rather, the evidence suggests that the participants actively constructed their meanings of independence by comparing their judgement of their own independence with their perceived view of the

independence of others. Conceptually, therefore, independence should be understood as a relative concept.

To conclude, many participants made comparisons as a means of evaluating their own sense of independence. Participants compared themselves to their earlier selves (comparison over time) and also with other older people. Upon closer analysis, many participants appeared to be doing this in order to be able to self-identify as independent. Thus, while participants emphasised the high value that they placed on defining themselves as 'independent', their sense of independence was often a comparative identity, and this often meant projecting 'not being independent' on to others. For many participants, therefore, being independent was an identity formed *by and in comparison* to others, as well as, their current selves with their former selves.

# Independence and dimensions of agency

Agency means the ability to act and the meaning, motivation and purpose that participants bring to their activity. The participant's conceptualisation of independence and the way in which they assessed their personal independence was determined by the level of agency (the ability to act and the meaning, motivation and purpose that individuals bring to their activity) they felt they had. Independence was constructed as four distinct, but interactive dimensions: decisional agency, executional agency, relational agency and supported agency. Table 9 summarises the stages of analysis that took place to develop the different constituent dimensions of 'the practice of independence'. Their meaning in relation to participant's independence is explained in this chapter.

Table 9: Participant's constructs of independence: initial codes and focused codes

EXAMPLES OF INITIAL CODES*	FOCUSED CODES
Being able to carry out routine activities of daily living	Executional agency
Liking things done own way	(What one is able to do)
Getting places (to and/or in)	
Mobilising	
Doing everything you can	
Retaining own decision making	Decisional agency
Being on one's own schedule	(What one decides/ chooses to do)
Taking own risks	
Being in control of how money is spent	
Reciprocating assistance	Relational agency
Engaging in social interaction	(How one chooses to interact with
Maintaining family relationships and roles	others)
Maintaining and creating friendship	
Involving carers	Supported agency
System restricting what assistance can be offered	(How one is assisted)

<sup>\*</sup>Initial codes in italic were 'in-vivo' code

## **Decisional agency**

For many participants, independence and its maintenance was understood in terms of their ability to make their own decisions. Decisional agency primarily means being self-determined in accordance with personal preferences and values. Indeed, for many participants, independence was associated with maintaining overall responsibility for their own lives. This included personal responsibility both for big decisions, such as where they lived, and for everyday decisions, such as what food they ate.

Decisional agency was associated with a sense of ownership of any decisions they made, including any consequences, positive or otherwise. Two participants summed up such an attitude by stating

If you make a decision, good or bad, you stick by it. You got to get on with it (RP10, tu210).

But as regards my own decisions, I made them, and if it goes wrong, it's me. I can't blame anybody at all (RP5, tu096).

Many of the participants" accounts illustrated a variety of everyday circumstances that demonstrated how participants viewed independence as being about making their own decisions. Making everyday decisions independently was not something new to the participants, but rather a continuation of roles and behaviour from their past selves, and for some participants, the failure to make decisions about the future was viewed as a failure to take responsibility for one's own future independence.

For example, one participant noted:

I mean, as long as I'm able to make my own decisions, why ask my family to do it, because I know what I need (RP 15, tu0379).

All my life, I've made my own decisions... I've made decisions about the children and about myself, my husband, you know, what clothes we buy; all those kind of things I've always been responsible for (RP4, tu0484).

For other participants, decisional agency was about being able to live according to their own schedule and being free from the constraints and/or demands of others. For example, some participants talked about being able to do things how they like, to get up at whatever time they decide, or to stay up as late as they wish, without having to conform to any prescribed institutional or organisational schedule. In other words, they were able to make choices that suited them.

I waken very early, and I have an early cup of tea, and I watch World News and the currency of the day because I frequently get some exchange.

Then I go back to bed because that's my privilege as a retired person (RP1, tu023).

This is independence, having this, especially a little bungalow of my own, everything flat, on the flat, you see, and I'm completely un-interfered with... I can do my own thing. I can get up when I like. I can go to bed when I like. Sometimes, when I'm reading a book, it has been known to be four in the morning; it's just, oh, I'll read a bit more and I'll read a bit more and you're not watching the time... you see, and – but then I can get up at ten, or whatever I want (RP 15, tu0387).

For other participants, there was a specific emphasis on maintaining decisional agency in the context of their financial affairs. Financial resources were seen not as an end product, but rather as a means of either restricting or providing choices and/or security for participants. As such, decisional agency was not related to how much money they had, but rather how the money was used:

Independence is being able to write your own cheque without somebody having to steer the way (RP8, tu137).

Folks say, 'Well, would you get married again?' No, I wouldn't, because of this part of the independence: I can go where I like. I can go away when I like. I can come in when I like. I can spend my money as I like. I don't have to answer to anybody (RP14, tu323).

Others suggested that remaining in their own homes was important to maintaining their decisional agency.

I think it's having control and, well, choice as well. I mean, I don't know really how to describe it. I can do what I like. If I want to shut that door and stop anybody coming in, I can do it, and I can do what I like (RP12, tu028).

Staying in my own home is important to me. Yeah, with my own people and my own things, my own – you see, they can't – people that come in can't come in and tell me what to do... This is my home and I remind them of that if ever they're overstepping the mark. I say to them, "this is my home and you're a visitor to me" (RP4, tu0769).

Indeed, several participants were very sceptical that maintaining decisional agency would be possible should they move into a care home. They voiced concerns that they would become subject to the rules of others and that their lifestyle would become regulated by others, leaving little room for personal choice and preference. Several participants made references to their experiences of respite care in residential care homes:

I was only there for a week – but I was just thinking in the long term, well, there wasn't much choice. The staff were nice and all that, but you couldn't suddenly decide that you would have a long lie in and have breakfast at teatime or something (RP 15, tu0936).

At times, participants' decisional agency also involved personal risk taking. This meant placing themselves in what could be perceived, either by themselves or by others, as a 'risky' situation. For example, a participant spoke at length about her decision to ignore the advice of professionals and use her motability scooters to attend church. She weighed up the 'risk' of using her motability scooter for a longer journey than was advised against the benefits she personally derived from seeing others and being part of her church community. The following quote illustrates her view:

You've got to put yourself, I suppose, in some sort of danger, really, to do it, but there's no other way. You either go or you don't go. It's as simple as that, and you make the decision. I mean, people might say, "Well, the Vicar would come to you", but then you're missing all the other people that are there (RP4, tu0338).

At the same time there was also evidence to show that participants also made decisions which could be perceived as minimising risk taking. For example, one participant spoke about not leaving her house if it had been snowing and/or was icy in order to avoid the possibility of a fall which she felt would risk her 'independence'.

While decisional agency was clearly associated with self-determination, participants also discussed the wider influences that have an impact on their experiences of decisional agency. These included negative stereotypes about ageing that could compromise their opportunities to exert decisional agency. In the following quotes, participants asserted the value that they place on maintaining decisional agency and made it clear that they had no time for perceptions or actions by others that would negatively affect their sense of independence. Participants were very keen to distance themselves from other people's assumptions about their capacity for decisional agency:

I don't want people making decisions for me, and I want to be able to be compos mentis all the time, and it's difficult at times when people don't understand. Just because you're getting older and have a disability, they seem to think that you lose your marbles (RP8, tu193).

Being able to make your own choice, you don't want people thrusting things upon you as you get older. You should be able to decide what you want to do and when you want to do it. It seems that once you get in the hands of Social Services you'd only do what they want you to do, and they get very annoyed when you do something that you shouldn't do (RP14, tu285).

This is one thing that does annoy me intensely, is the fact that a lot of people, when you're old, they think you're childish. I mean, my memory is perfect and [I] can make my own choices (RP5, tu549).

Another participant, while underlining the value of decisional agency, was sceptical whether decisional agency was actually available and/or realistic. Indeed, this participant noted that there was a tension at times between the actual and desired levels of decisional agency:

I'm always worried about this word 'choice', 'cause I don't think it's – in some senses, it's meaningless, because you want choices, but you can't have them 'cause the things are not available (RP6, tu282).

This highlights that at times participants felt they did not always have the agency to make the decisions that they wanted to make.

To conclude, decisional agency was an important dimension of many participants' conceptualisation of independence, and the way in which they assessed their personal independence was often determined by the level of decisional agency they had. Thus, participants viewed decisional agency in terms of their freedom to act in pursuit of individual preferences. However, participants recognised that decisional agency was not always freely available, and participant narratives suggested that there was at times a dissonance between their actual and their desired levels of decisional agency.

#### Executional agency

Executional agency refers to participants being able to carry out activities necessary for daily living unaided, or to put it differently, being able to act upon decisions without the need for assistance from others. Similar to their discussion of decisional agency, participant accounts of executional agency were wideranging, and executional agency was stated to be an important and valued aspect of their independence.

For many participants, their ability to exercise executional agency was evident in the context of their daily living activities and/or personal care. For example, shopping, cooking, housework and showering were all highlighted as tasks that were important to their independence, and participants stated that, where possible, it was important for them to carry out these tasks unaided:

At the moment, I'm okay and I can be independent. I can go about doing my own shopping. I can do my own housework and look after myself (RP12, tu087).

If you can keep going, doing your own shopping and doing your own housework and that sort of thing... I think they're all pretty important towards being independent (RP13, tu207).

Another participant highlighted the importance of buying and cooking her own food. Even though she lived in supported housing where she could have all her meals provided for her, she stated that cooking was important to her, and she would continue to buy food and cook for herself for as long as possible:

I'm buying my own, not because there's anything wrong with the food.

There isn't. It's very good. I understand everybody else says so, but it's just after the job that I'm used to doing, and being a reasonable cook, I like things done my way and I like to have what I want, and as long as I can do it, I'm going to (RP3, tu041).

For many participants, there was a strong desire to do everything they possibly could without assistance. Although participants talked about the significant length of time and/or amount of energy such activities took, what appeared to be important was not the time and/or energy needed to complete these tasks, but that they had been able to carry out such tasks without assistance. This attitude was expressed by several different participants, for example one said:

I'm a bit a bit bad on my legs sometimes and get this bad foot. Apart from that, I just – you just struggle, don't you? I mean, you've nobody else to look after and it don't matter how long it takes you to do anything, does it really? You can take all day. I've struggled doing the bed, changing the

bedding – 'cause me arms aren't that good, but at least I can be independent (RP9, tu427).

Participants also highlighted the importance of remaining mobile as contributing to their executional agency. Participants had a broad meaning of mobility – for some it was associated with keeping their driving licence, while for others mobility pertained to maintaining the ability to walk and/or getting out of the house. However, no matter what was emphasised, most participants associated mobility with executional agency and thus independence.

I think driving develops into independence. I mean, driving as a young lad is what we called in the service 'cab happy'. I would drive anything anywhere and anytime. No, I mean, I think that comes as you get older. It's more important to me, because it was – in the job I had, I had to have a car. Well, I had a company car, and so if I'd lost my licence, then I would have lost my job. But for independence purposes, it wasn't really important, but now it is (RP10, tu274).

Another participant clearly asserted that her independence had been taken away from her when she unable to drive:

I mean, I've a boxful of medication to take 'cause I still do see double.

That's why they took my licence off me. I can't drive now, you see, so that took my independence away (RP5, tu0798).

For some participants, the loss of mobility was regarded as a significant threat to their executional agency because their diminishing mobility meant that getting out and about now required the involvement of someone else to assist them. In particular, they highlighted that reduced mobility meant their executional agency was weakened because of loss of control over activities and/or actions. For example:

When I could walk, I could go into the village myself. I had crutches, even at that time, but I could go myself into the village and do my own shopping. Instead, now, I've got to wait for somebody coming to get things for me,

they're going to the shops and things... My independence has gone. It's gone a lot; from that point of view, yes, it certainly has... Well, it's just not a nice feeling not to be able to just put your coat on and go to the shop, and things like that (RP4, tu0311).

I've lost it in, like, being free to just get on a bus and go where I want, and I've lost that, which is very frustrating. I feel somehow I'm sat here waiting for somebody to take me somewhere, whereas that's against my nature. I'd like to get my coat on and get up to the bus and even if I don't want anything, just go (RP2, tu0895).

As was the case with decisional agency, participants also talked about the wider influences that affected their executional agency, and these again included the influence of negative stereotypes about ageing:

When I go out with my walker now, people fall over themselves to help me. I mean, I'm demanding attention now without any idea of doing so... It annoys me, but I've got to be nice and pleasant, haven't I, and say, "Thank you very much," 'cause that's... 'cause I don't want to — I want to do what I want to do, but they don't know that. I've got to say, "Thank you very much," and be decent about it, haven't I? (RP3, tu422).

One participant was particularly clear about the relationship and interplay between decisional agency and executional agency. She was aware that they could make decisions, but this alone was not enough for them to feel independent because she was unable to carry out activities without assistance:

I can make decisions for myself but I can't carry them out... I've got to then bring someone else in to see it. Put these things into operation, like the carer and the people coming in... I couldn't be possibly independent with any of the things I've done because I can't do them. I mean, there are lots of things that you would like not to have to be dependent – you'd like to be independent with, but common sense tells you I can't do what I used to do, so I can't be independent.

In the beginning, I didn't find it concerned me at all, because it was only – in my mind it was a way of doing things for myself. I was making the decision that someone would come and sort of, make it so things were there for me, and this is really – that's how it started. And it started so, sort of, calmly and quietly that it got up on you before you realised what stage you'd got to... absolutely no question about it, I've lost all my independence (RP4, tu0284).

To conclude, executional agency was an important dimension of many participants' conceptualisation of independence. Participants viewed executional agency being an important dimension of their independence as it enabled them to carry out activities necessary for daily living unaided, or to put it differently, being able to act upon decisions without the need for assistance from others.

## Relational agency

'Relational agency' refers to participants being able to contribute to, maintain and draw upon social networks as and when needed in order to have and maintain independence. The participants' testimonies indicate that their independence was affected by the existence and the characteristics of these networks. Participants' understanding and experience of social networking varied; some saw their social network exclusively in terms of being family based, while others spoke of their social network encompassing a wider range of people, including friends and/or neighbours. Key to the participants' understanding of relational agency was the idea of reciprocity, defined as providing support for others and/or accepting support. The giving and receiving of support was seen as important not only in terms of practical assistance, but also in terms of supporting others within their social network to feel that they were helping themselves to remain independent.

The participants' accounts of relational agency highlighted the importance of reciprocity within relationships to their independence. They were keen to highlight the importance of both offering and receiving assistance when necessary from their social network:

You go through your life being – giving and taking, don't you? That's important (RP8, tu209)

I like helping people. I mean, if [neighbour] – she's the same with me – if [neighbour] not well, [I'll ask] "Do you want any shopping?" "Well, I could do with a loaf." "I'm going into the village. Right, do you want anything else?" And the same if I'm not well, [neighbour] says "I'm going in the village, what do you want?" (RP14, tu494).

However, while many participants valued a 'give and take' approach to relationships, they stressed the importance of maintaining a sense that the exchange of support within this reciprocal arrangement was 'equal'. For some, this meant being able to pay for any assistance received, as noted by the following participant:

The lady next door said, "[friend] says he would do your garden for you". Well, I won't have – he said he didn't want anything, but I won't have that. I mean, I'm too independent and also it's not the way to go, I don't think so anyway. He's quite happy with what he gets. Every two months he gets something in his hand (RP 15, tu0749).

Others were reflective about the changing and possibly diminishing pool of their peer social network and the impact this had on their relational agency:

When you get older you, kind of, lose all your friends and you're — well, I used to help them a lot and they'd help me, kind of thing. Well, you don't get that now. I do with my neighbour. We help each other out and go shopping for each other and things like that so that it works out, but independent? And it gets narrower every year... insomuch as, I mean, you rely on your friends, don't you? And your old comrades and what have you, and they're no longer there. That's part of life (RP11, tu457).

I had to do everything for him, you know? I had to help him in the shower and dress, dress him. And then, he might get a bit of respite, you know, for a few weeks, but I still had to put his socks on and fasten buttons and that. Now I'm having trouble and I've nobody to help me (RP2, 0487).

Other participants felt that their social networks were such that they were unable to seek support and/or assistance freely if needed. For some, this manifested as a clear need to maintain relationship boundaries and for family not to adopt the role of carer:

I wouldn't want my daughter-in-law to be coming and having to help me get dressed and do all these things. I want them here as my family, not my carers (RP4, tu0742).

The participants' accounts of relational agency also highlighted the relationship between how others treated them and their own sense of independence:

As far as possible, independence is just being treated as normal, because we really are normal, we're just old (RP15, tu0399).

To conclude, relational agency was identified as being important to many participants with regard to their sense of independence. Having a social network, and specifically one through which they could provide and/or accept support, was deemed important by participants. However, participants also recognised that their social network, particularly their peer network, had changed as they had aged, and for some this had led to a diminishing sense of relational agency.

## Supported agency

Some participants explained that despite having assistance from care and support staff, they were still able to maintain their sense of independence. Unlike relational agency, supported agency had no requirement or expectation from either side that this support should be reciprocated. Indeed, in the case of supported agency, reciprocity and/or mutuality was not always achievable or even appropriate. This is because such support did not entail the same obligations and need to balance reciprocities that may be present when requesting help from informal social networks.

For some participants, getting support was vital as it allowed them to maintain their current sense of independence:

It just depends how you look on independence because you can't be independent of everybody, but if you get the help, that makes you feel you've got your independence, you're getting a long way towards it. And that's how I feel it goes, you've got to get on with life, really, and do the best you can (RP4, tu1045).

For other participants, the emphasis was upon knowing there was support available and that this could easily be tapped into if needed. The knowledge that support could be available in certain circumstances enabled participants to remain feeling independent as it provided them with confidence and reassurance, as well as a sense of safety and security. In other words, it provided these participants with a sense of having a safety net. This was expressed by the following participant:

I think independence is being able to really do things on your own and help's there if need be... I think you should be able to contact somebody because, I mean, we all think we can do everything, but as you get older you can't, can you? (RP9, tu185).

This sentiment was particularly noted by those who lived in supported housing. Indeed, knowing that support was available as and when needed was often voiced by participants as a reason for their relocation. While the participants emphasised the importance of the flexibility of support provided in supported housing, there was also a sense that they felt that their future health needs could be met if necessary:

You know that if you are taken ill, you see, at night, I mean, I have done it. Not many times, but I have been, and then to know that you can press the button and somebody will come and see you. Well, you see, when I was in my house, I couldn't (RP14, tu132).

I live in sheltered housing because you feel safe and you've got wardens that you can fall back on. And also the pull cords you see in every room, if you fall or you need any help. I think it all helps you be independent, because if you were at home then you wouldn't have that reassurance (RP13, tu051).

Supported housing allowed these participants to feel that they were in control of when and from whom they sought support, and this sense of agency over the support they received promoted their feelings of independence. Participants, whether they were in receipt of home care packages or time-limited support, saw supported agency as a means of preserving their sense of independence. There was recognition that seeking support in certain circumstances might enable them to feel more independent in others.

For some participants, therefore, there was evidence to suggest that supported agency involved making 'trade-offs' between different aspects of their independence, and that it was possible for these participants to feel independent in certain areas of their life and less so in others. This involved balancing priorities – for instance, balancing doing things on their own versus accepting support (as well as the type and the extent of support they were willing to accept). For example, one participant saw remaining at home as a key determinant of her sense of independence. Because she equated remaining in her own home so closely with maintaining her sense of independence, she suggested that should her health decline, she would seek support in other aspects of her life so as to remain at home. She anticipated that choosing to remain at home might mean having to accept that changes would need to occur elsewhere, but she was willing to accept these changes if it enabled her to remain in her own home:

To stop in my own house, I'd crawl about. But, if it really came to it, I'd really have to cut down on different things and have more help (RP2, tu0128).

Another participant made a similar point in relation to balancing different aspects of their independence. Moving into supported housing meant she no longer had to worry about issues such as house maintenance, but at the same time, having support did not make her feel she had lost their independence:

It's nice to have (Warden) around 'cause, I mean, to be honest, I find it difficult when it comes to doing things in the house. I'm very glad that I don't have to worry about the drains or the roof, or that sort of stuff, but I can keep my independence (RP6, tu040).

While some participants accepted the support and saw it as part of maintaining their independence, they still highlighted the imperative to do as much for themselves as they possibly could. No matter how small the contribution they could make to different tasks, doing so was symbolically significant to their practice of independence. Thus, even when their independence was contingent on the support by others, participants were keen to focus on what they could achieve without assistance, rather than what they could not:

As long as I can do this myself, I will. The carers are quite surprised at me 'cause all they've got to do is make the bed... that's all I want them for, is to make my bed. I just can't walk around the bed and do that. I do my own washing, and I send most to the laundry, and I do that all myself. I don't have anybody help me to do anything else, just make my bed (RP12, tu028).

In fact, I'm one of those people who, if I could do it, I'll do it, I'll do anything I can to save them (carers) having to do it. I mean, for instance, the Horlicks. I have a beaker of Horlicks at night. It's always ready for the mix with the milk in the bottom. I can do that (RP4, tu0880).

However, while supported agency was a key dimension of some participants' independence, there was also awareness of the possible limitations that support services could engender. This awareness of the limitations was evident for participants who were currently accessing home care, as well as those who were not.

For those in receipt of home care, some suggested that while supported agency helped maintain their independence, and in some cases was essential to enabling them to live in their own home, it also meant a loss in terms of other types of agency. For example, the following quote illustrates the lack of

decisional agency that can occur in supported housing – the participant no longer experienced a sense of choice and control over when she got out of bed in the morning:

They're bound to time. They come in and they've got to get my telephone and clock in, it's a nightmare. You've got to get up when they come. They don't come on time each day, so you'll be in bed thinking, it's time I was up. I want to be up, it's eight o'clock or whatever, gone, and so there I'm waiting for them coming to get me out of bed (RP4, tu0149).

Other participants were also aware of inflexibility with regard to the specific roles of support staff and recognised that even while being supported, there was still a need to remain independent:

She's a bit restricted though as what she can do, and she can't shop for you or take – have any dealings with money or things like that. You can't rely on her – your independence through (Warden). You've got to, kind of, be independent yourself (RP11, tu299).

Participants not currently in receipt of state-funded social care were also aware of the limitations, and voiced an awareness of the strict eligibility criteria used for assessment for state-provided support:

I don't seem to come into that bracket (social services support) – I think it's because I don't need people coming in two or three times a day to put me to bed and get me up and all that sort of thing... but you can't have domestic help on its own, and I only need domestic help at the moment (RP 15, tu0218).

While many participants suggested that 'supported agency' was an important means of maintaining their independence, others were sceptical whether it was even possible to receive assistance from others and still remain independent. For example, the following participant suggested that his need to remain independent was so strong that he would question the value of living if he needed "help". For him, there was a real sense of the 'burden of being a burden':

I wouldn't want it to get to that stage. When I get to a certain stage of life you just close my eyes and say, "Au revoir" and that's it. I'm dependent if I've got to have help. Doesn't matter who it is, you've lost your independence (RP10, tu454).

Nonetheless, it is important to acknowledge that the participant who expressed this view had not yet experienced a situation that required home care. Indeed, the narratives of participants who did receive home care suggest that such strong views are likely to be modified and moderated over time.

In conclusion, some participants felt able to maintain independence despite receiving support services and regarded supported agency as a critical dimension of their independence. It was found that some participants were able to maintain their subjective sense of independence while receiving support within a non-reciprocal relationship. Most often, support came from carers paid to support the participants rather than help from friends and family. Participants pointed to two distinct aspects of supported agency that were important to maintaining their independence, namely, the ease of access to and the availability of support.

### Summary and conclusion of this chapter

This chapter has presented the findings of this research. The findings do not proclaim to have identified a single definition of independence; instead its meaning can be complex and, as this chapter has shown, comprised of different but interactive constituent dimensions of identity and agency. As presented in Tables 9 and 10 two groups of focused codes emerged, the first group of codes were all bound together by their emphasis on independence being about identity and a 'feeling' of independence; this led to the core category of 'the sense of independence'. The second group of focused codes were bound together by their emphasis on independence being about agency and 'acting' independent; this led to the core category of 'the practice of independence'.

In the following chapter, the relationships between and across the dimensions of 'a sense of independence' (identity) and 'the practice of independence' (agency) are discussed in detail, both in relation to themselves and through the lens of existing literature.

### **CHAPTER 7: DISCUSSION AND THEORY BUILDING**

### Introduction

In this chapter, the focus moves from detailed reporting and analysis of the findings, to generating some general statements about the construction and meaning of independence for older people by drawing on and integrating insights from the policy and literature review chapters and other literature. Thus, the aim of this chapter is to draw together the findings from the primary (Chapter 6) and secondary data sources (Chapters 2 and 3) and, in line with the constructivist grounded theory methodology and the aims of this thesis, develop a substantive theory of the meaning of independence for older people.

Constructivist grounded theory emphasises that contextualising the findings of research within the wider literature provides a richer and more nuanced understanding of the meaning of independence for older people (Urquhart, 2013; Charmaz, 2006). In this chapter, therefore, the findings are also contextualised within the wider theoretical, policy and empirical literature. This inclusion of broader evidence beyond the parameters of the initial policy and literature reviews was guided by the primary findings and analysis, and further demonstrates the iterative approach that is fundamental to constructivist grounded theory methodology (Charmaz, 2006; Schreiber, 2001).

As presented in the previous chapter, analysis across the interviews reveals that the participants did not have a universal meaning of independence. This chapter will build upon this further by showing that 'independence' is a multi-dimensional and dynamic construct.

This chapter is split into two sections. The first section presents the two distinct but interlinked 'core categories' of participants' constructs of independence: 'a sense of independence – dynamic and interactive identity'; and 'the practice of independence – dynamic and interactive agency'. The second section focus is on the overarching themes that emerged through analysis of the findings and which explain the connections and tensions inherent within meanings of independence and thus highlight the dynamic (i.e. changing and finely balanced) nature of older

people's constructs of independence. The analysis identified three explanatory themes: 'a valued social construct'; 'continuity and change in constructs of independence'; and 'social relationships and constructs of independence'.

### Exploring relationships between the core categories of independence

Independence held a complex meaning for the participants and, as presented in the previous chapter, comprised a number of dimensions. The characteristics and parameters of these dimensions have been fully explored in the previous chapter. Although these are distinctive dimensions, they do not function in isolation, but rather relate and interact in complex and dynamic ways.

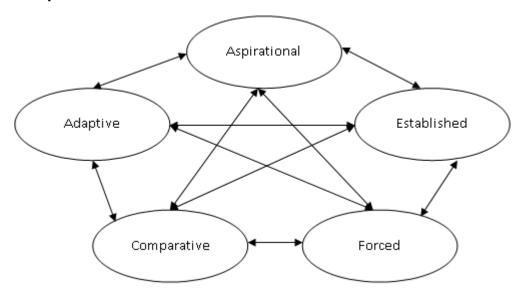
As presented in Chapter 6 (see Tables 9 and 10), two groups of focused codes emerged. The first group of codes were bound together by the emphasis that they placed on identity and a 'feeling' of independence, and this led to the core category of 'the sense of independence'. The second group of focused codes were bound together by their emphasis on agency and 'acting' independent, and this led to the core category of 'the practice of independence'. These core categories and their associated dimensions interacted with each other, and this section provides selected examples to illustrate the different types of interactions.

Three types of interactions were identified. First, positive and negative relationships between the different dimensions were evident. Second, there were bi-directional relationships as well as multidirectional relationships between the different dimensions. Third, the individual dimensions interact across the two core categories.

### Interactions between dimensions within the core category 'a sense of independence'

The analysis showed that there was an interactive relationship between the different dimensions of 'a sense of independence'. Each individual dimension of 'a sense of independence' was related to the others, and as outlined earlier (and as will be discussed in more detail later in this chapter), the interactions between them could manifest themselves in several different ways.

Figure 3: Interactions between dimensions in the core category 'a sense of independence'



For instance, a participant's experience of one dimension could have a positive impact on another, with, for example, participants often stating that 'being independent' was a key reason to 'keep going' and/or for 'carrying on' (an aspirational identity), and this often meant that having a strong sense of perseverance enabled them to maintain (for as long as possible) their 'established' sense of independence.

The analysis also showed that the interactions of the dimensions could be negative, and this can be illustrated by the relationship between a 'forced identity' and 'comparative identity'. While acknowledging that some participants were in reality 'forced' to be self-sufficient owing to the fact that they had no one to turn to for support, others were 'forced' because did not want to transgress and/or compromise their identity as 'independent' (and thus did not seek any support/assistance) and specifically did not want to be seen by themselves or others as 'dependent' (a comparative identity).

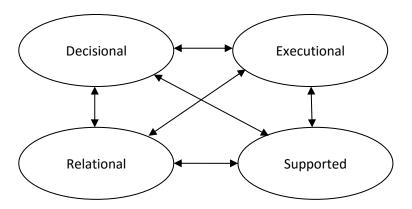
The connections between these individual dimensions are non-hierarchical, fluid, and contextual. The dimensions interrelate in complex ways, and thus the particular salience of each dimension is dependent on the individual and their context. These interactions demonstrate the complexity of how independence is constructed by older people. While acknowledging that the specific interactions

that take place between the different dimensions are fundamentally dependent on the individual and the context, the range of possible interactions that can occur between the different dimensions contained within 'a sense of independence' are presented in Figure 3.

### Interactions between dimensions within the core category 'the practice of independence'

There was also evidence of dynamic interaction between the dimensions within 'the practice of independence' category. As presented in Figure 4, the analysis again revealed that each individual dimension of 'the practice of independence' shared a relationship with the others.

Figure 4: Interactions between dimensions in the core category 'the practice of independence'



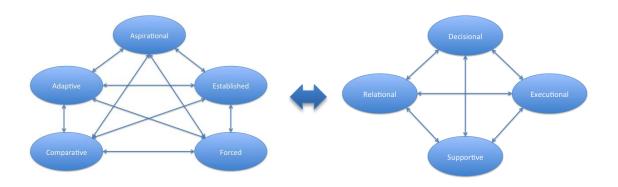
These relationships were not confined to one dimension impacting solely upon another dimension; rather, one dimension could impact on several different dimensions at the same time. For example, while 'supported agency' refers to participants being 'supported' in order to maintain their 'independence', it is evident that through being 'supported', participants were able to continue to experience the other three dimensions of 'the practice of independence', namely, 'decisional agency', 'executional agency' and 'relational agency'.

Thus, the non-hierarchical, fluid, and contextual connections between these individual dimensions of 'the practice of independence' meant that all the dimensions interrelated with each other in complex ways and that the particular salience of each dimension was therefore dependent on the individual and their context. The relationships between the different dimensions are presented in Figure 4.

### Interactions across the two core categories of the sense and practice of independence

Different and dynamic interaction also existed *across* the dimensions of 'a sense of independence' and 'the practice of independence'. This meant that one (or more) dimension of 'a sense of independence' could interact with one (or more) dimension of 'the practice of independence'. The possible interactions are presented in Figure 5.

Figure 5: Interactions across the dimensions of the two core categories



For example, 'relational agency' (a dimension of the 'the practice of independence') describes how participants interacted with others, and in

particular the importance of reciprocity as a dimension of their independence. However, reciprocity, and specifically treating others and being treated by others in the same way as always, also implies that independence comes both from within us and through our interactions with others, and thus it is part of older people's 'established identity'. Another example was participants their sense of independence as manifested through an 'adaptive identity' was often expressed via their decision to accept certain things over others and to act upon this decision (i.e. decisional agency).

Simultaneous interactions could occur between more than two dimensions. For example, participants' adaptation to changing circumstances (an adaptive identity) helped them to maintain control (decisional agency), but at times adapting also made their disability/ageing clearly visible to them and others. For example, the use of aids and equipment could lead to feelings of being 'the other' (a comparative identity) as such adaptations represented a changing identity.

As this section has shown, the core categories and their associated dimensions are interlinked, but they do not exist within a formal hierarchy. Instead, their importance and influence is dependent on the individual and their context. For most participants, their personal constructs of independence incorporated many of these of dimensions. However, although many of the dimensions may be experienced simultaneously, some dimensions can have more influence than others at particular times in older people's lives. For example, the findings showed that participants with high support needs placed a greater emphasis on 'supported agency' at this point in their lives than they had done at an earlier stage of their lives and/or than another participant with lower (or no) support needs. As such, each older person's conceptualisation of independence changed over time in relation to his or her changing circumstances and in response to both their perceptions of and the input from people around them.

The interactions between and across the core categories and their associated dimensions point to the multidimensionality and fluidity of older people's constructions of independence. This multi-dimensionality means that the meaning of independence for older people has what might be considered a paradoxical quality in that it incorporates seemingly conflicting characteristics

and/or experiences. For instance, the findings of this study showed that older people's meaning of independence was responsive to their changing circumstances and shifted relative to the perceived situation of others, with the result that older people were often simultaneously able to feel independent in one area of their life and less so in others.

### **Explanatory themes**

While acknowledging the unique personal and social contexts of the participants involved in this research, further analysis revealed three themes that help to explain the connections and tensions inherent within meanings of independence and highlight the dynamic (i.e. changing and finely balanced) nature of older people's constructs of independence:

- Independence as a valued social construct.
- Continuity and change in constructs of independence.
- Social relationships and constructs of independence.

These key explanatory themes help to explain the variation in an older person's construction of independence at both a single point in time and over time. They are thus highly significant in terms of the aims of this study and form part of the substantive theory presented later in this chapter (see Figure 6). As previously described, substantive theory refers to theoretical suggestions that are unique to the context within which the data is collected.

It is important to note that these explanatory themes are influenced by both social and cultural factors. Participants constructed their conceptions of independence within the context of the prevailing current discourses on ageing and independence within society. 'Cultural factors' such as cultural understandings (that is, ideas, beliefs and practices) of the various factors that comprise the concept of independence (for example, cultural understandings of social and individual space, familial ties, relationships and interrelationships) also played a role. The following sections discuss each of these themes in turn.

#### A valued social construct

Across all elements of this research, including the literature and policy reviews and subsequent empirical work, it was evident that independence – however constructed in the accounts of the participants - was highly valued. This section explores the ways in which participants valued independence, some of which are evident in and compatible with other research. By using an in-depth and iterative approach to the analysis, however, this section also offers new insights into how older people value independence. As this section will show, participants discussed the value of independence in several different ways and often conflated two somewhat different understandings of the meaning of 'value': participants often drew little or no distinction between the notions of 'valuing independence' and 'independence as being valuable/important'. In this section, therefore, the meaning of 'value' is broadly defined.

#### Cultural discourses and policy

Evidence from the research interviews showed that dominant cultural discourses about independence, especially as regards to ideas of self-reliance were reflected in older people's constructs of independence. The findings showed that there was a dynamic relationship between pervasive and changing cultural/social assumptions about independence and the participants' constructs of independence.

From a Western perspective, independence is regarded as a universal ideal and is highly valued (Bell and Menec, 2013; Weicht, 2011). This dominant cultural discourse has been challenged, however. For example, O'Shea (2011, p.14) states that 'opponents... typically claim that seeking to be independent is a misguided or harmful ideal for finite, dependent creatures like ourselves, or that it has at least been overvalued in modern social and political life'. In particular, there are cultural imperative and moral overtones attached to the notion of independence, and these are internalised and often create additional imperatives for older people to continue viewing themselves as independent.

The cultural importance that is attached to independence is reflected in UK social care policy, where independence is often promoted as being the ideal for older people (DWP, 2005; DH, 2005; DH, 2006). This is particularly evident in policies promoting 'successful ageing' (AgeUK, 2013). These emphasise maximizing

independence and thus reflect normative cultural assumptions that a good quality of life can only be achieved if someone is 'independent' (Sin, 2007; Portacolone, 2011). In this context, however, the moral value of independence promoted in policy is shaped by the imperative of reducing costs. This may make the definition of independence that informs current policy somewhat limited/unidimensional as it is conceptualised within narrow parameters – it focuses primarily on functional independence (i.e. doing things for yourself without support from others) – and is seen as an absolute and/or binary construct (i.e. you are either independent or you are not).

Such policy initiatives were (in part) originally intended to challenge both negative stereotypes about older people and the view that ageing is a process of decline and dependency. Policy aimed to change these ideas by promoting a discourse in which older people could be seen as independent and 'successful'. This discourse promoted the view that it is possible to age successfully, or in other words, that it is possible to be independent as you age. However, while the emphasis that current policy places upon independence has been positive for those older people who can achieve an independent lifestyle, those who cannot may feel side-lined (see Scourfield, 2007; Lloyd, 2006).

Other research has also recognised that independence is a highly valued socio-cultural construct (Portacolone, 2011; Plath, 2008; Bell and Menec, 2013). For example, Portacolone (2011) argues that the seemingly intuitive and innate value placed on independence is socially produced both through individual experiences and through cultural discourses that come into play through social and institutional practices. The participants in this study also emphasised the importance that they attached to the construct of independence. For instance, when participants felt that their independence was compromised – for example, due to declining health – the need to avoid/minimise feelings of 'dependence' became the imperative in their daily lives, and the anxiety that participants felt about the possibility of becoming increasingly dependent is illustrative of the value that they placed on their constructs of independence. Again, these narratives are in line with those found in other research. For example, Lloyd (2014) and Parry et al. (2004) found that older people express fear about the possibility of losing their independence.

Given this cultural and policy emphasis, it is perhaps not surprising that older people value independence. At times, the participants in this study placed a high value on one specific dimension of independence, meaning that the other dimensions (which may also be valued, but possibly to a lesser extent at that point in time) were diminished in importance relative to the particular dimension that they considered most important. Irrespective of the individual dimension (or dimensions) of independence that participants deemed to be most central to their construct of independence, one overriding feature was evident across all the participants' testimonies: all of them expressed the high value that they placed on their *own* particular conception of what independence meant to them.

## The value of independence as illustrated through the dimensions of 'a sense of independence'

The value ascribed to independence was shown in all the dimensions of identity described in the previous chapter. Participants reported that independence had been a focus throughout their lives and not just in old age (an established identity). Indeed, while recognising that many aspects of their lives had changed as they aged, the value that they attached to independence was reported to have remained high across the life course.

The interviews with older people confirmed the cultural value that is attributed to independence and highlighted that the value placed on independence reinforces older people's drive for independence (see aspirational identity). Participants' accounts emphasised the importance of aspiring to feel independent (an aspirational identity). The aspirational value attached to independence meant it often motivated participants to 'keep going' and was commonly identified as a key personal goal. An embedded ideology of self-reliance and 'keeping going' has been evidenced as being of value to older people in other research (Secker et al., 2003; Tanner, 2001). Furthermore, participants' willingness to change, reorder their priorities and find new strategies (an adaptive identity) in order to sustain their sense of their independence showed the value they placed on independence.

The high value that participants placed on independence was also evident when their conception of independence was constructed as a 'comparative identity'. 'Comparative identity' refers to the ways in which participants maintained their independence by drawing contrasts and making judgements. Participants regularly assessed their own level of independence by comparing themselves with others (a comparative identity), often constructing a hierarchy of independence that they used to judge themselves and others and decide with whom they would associate. Participants were keen to distance themselves from those they perceived as not being independent and those they perceived as not striving for independence. Such attitudes perhaps in part reflect the dominant cultural and policy discourses about independence and successful ageing outlined earlier. The analysis of the interviews indicated that older people adhered to some of the normative cultural assumptions outlined earlier and distanced themselves mentally (i.e. thinking "I'm not like them") and socially (i.e. avoiding social contact) from those they perceived not to be as 'independent' or ageing as successfully as them. Indeed, there was evidence of participants 'othering' those who they perceived as less 'independent'. 'Othering' refers to when an individual distinguishes themselves as different from others (Twigg, 2000). As part of this process, and as noted earlier, a separation is created between 'us' and 'them' and is often associated with negative judgements about 'the other' person. Negative judgements were made by several of the participants about the perceived situation of others and their independence (or lack of independence). This highlights the value that the participants placed on 'independence' and the undesirability of 'dependence'. As this finding is not something that is evident in other research, it appears that this study has identified another factor that might be important with regard to policy around older people's independence. For example, loneliness and isolation may be heightened by older people distancing themselves from others because they do not wish to be associated with those they perceive as not independent. This has clear implications for the well-being of those concerned.

Due to the high value placed on independence, participants felt duty-bound to maintain an identity of being 'independent', often at a high personal cost (forced identity). Some spoke about a fear of being perceived as 'dependent', and this led to them refraining from doing activities that would require assistance. For

example, some participants shunned using aids such as a walking stick because of its perceived association with not being independent. Because of the high value placed on independence, this often led to them disguising their declining capabilities and/or avoiding seeking support.

As regards independence being constructed as a 'forced identity', participants' narratives showed that the value of independence was often constructed against a subjective fear of dependency and moral assumptions that independence was about not 'burdening' others. Their concerns and values were particularly grounded in not 'burdening' their adult children, and they strove to minimise any impact on them. The meaning of independence holding a *moral* value is also evident in previous research (for example, in Breheny and Stephens (2012)). However, this research found that participants' understanding of 'burden' in the context of independence is more nuanced than has been reported elsewhere. This research indicates that the moral imperative not to burden others could be problematic for older people as they felt burdened by striving to be independent (see Chapter 6). Thus, while the high value attached to independence was often seen as a positive driver in participants' lives, it is important to acknowledge that it may also have a negative impact. Participants felt that they had to maintain a facade of independence, whatever the personal cost, because of the high value they, and society, placed on independence.

# The value of independence as illustrated through the dimensions of 'the practice of independence'

The value ascribed to independence was also evident as part of the dimensions of agency described in the previous chapter, and participants highly valued the ability to 'act' independently. Participants placed great value and importance on being able to make decisions (decisional agency). Participants valued choice and control as key to their construct of independence. More specifically, they valued being able to make decisions and choices that reflected their values on independence.

Participants also placed a high value on being active and engaged with activities of daily living (executional agency). Their ability to continue performing everyday tasks – for example, shopping and visiting friends and family – was valued not only in terms of the simple completion of the tasks and their practical functions,

but also as a way of minimising the need to involve others. Thus, executional agency was valued by older people not solely in terms of self-reliance, but as being important in the context of not feeling a 'burden' or 'having to depend on others'. Given the cultural and policy emphasis on being able to carry out daily tasks without assistance, it is unsurprising that the participants in this study valued executional agency highly. However, as outlined in Chapter 6, functional independence was only one element in their conceptualisation of independence.

Furthermore, partly because of the high value that participants placed on their independence, some were willing to be supported in order to maintain an overall sense of independence (supported agency). Thus, they valued independence and at the same time valued the support received, recognising that this could contribute to their overall practice of independence. However, this was not always the case. Some participants stated that they would rather refuse all help because they saw it as of less value than their executional agency and would in fact refuse it rather than compromise the agency dimensions of independence. There is the possibility, however, that those who stated that they would refuse help did so on account of their experience of not needing to receive assistance as yet. Needing additional assistance was more a hypothetical possibility and as such for those older people independence might not be the central issue for them, but an epiphenomenon of a desire not to accept the ageing process and the vulnerability that it brings. Thus, some participants held the viewpoint that accepting any help would compromise their sense of independence, while others saw it as helping to sustain their independence.

Many participants' narratives reflected this emphasis on functional independence. The ability to continue to carry out activities of daily living was a dominant theme across the interviews, and references to functional independence were made in relation to several of the dimensions. For example, in relation to the 'established identity' dimension of independence, participants often expressed the idea of continuity in practical terms, such as being able to carry on with their functional activities of daily living and/or not yet having had to change their lifestyle too much. An emphasis on functional independence was also evident within the dimension of 'executional agency', with participants stressing the importance of being able to carry out activities necessary for daily living unaided.

While there was evidence across the dimensions of identity and agency that independence was a valued construct, closer analysis showed that while the value of independence was not questioned in itself, participants provided a range of discourses on its value. It is important, therefore, to recognise that different participants valued their independence differently, both in terms of what they valued and why it was valued. For example, for some participants independence held an embedded value, while for others the value of independence was as an enabler of self-determination. At points, therefore, tensions emerged as participants balanced the different dimensions of identity and agency with the multiple and competing values associated with independence. Consequently, participants often had to prioritise what they individually valued most.

### Continuity and change in constructs of independence

The second explanatory theme identified as being key to older people's constructs of independence is 'continuity and change', and specifically maintaining a sense of continuity while responding to – and themselves initiating – change. Many of the dimensions of identity and agency showed participants' constructs of independence were associated with maintaining continuity: continuity of who they are (as evidenced in the dimensions of identity), and continuity of how they acted (as evidenced in the dimensions of agency). At the same time, however, older people acknowledged that in order to maintain independence, they needed to be willing and able to change, either in response to shifting circumstances or/and with respect to the relative weight they ascribed to the different dimensions of independence. Older people's constructs of independence were moulded by the tensions between the competing drives and/or needs for continuity and change (i.e. this tension, conflict between the desire for continuity in the face of change means that the constructs of independence are necessarily dynamic rather than static

A construct of independence that incorporates continuity and change challenges the policy view of independence as being something that one has or does not have. The analysis of interviews showed that older people did not see independence as a static experience; rather, they described how they attempted

to maintain their sense of independence over time in response to changing circumstances.

## Continuity as illustrated through the dimensions of 'a sense of independence'

Continuity was evident in several of the dimensions of identity and was perhaps most strongly apparent as part of an 'established identity'. Participants often spoke about their independence as being a continuation of an identity established at a younger age and that they 'took it for granted', suggesting that it was integral to whom they were and how they defined themselves. However, it is important to acknowledge that this may reflect the nature of the sample and the social construction of the interview (see Chapter 8). Nevertheless similar findings are evident in other research, for example, Portacolone (2011, p.815) also found independence had a largely undisputed status in older people's lives, noting that 'being independent' and/or 'being the same person' were often central to older people's sense of identity.

All participants built their current constructs of independence in part on their earlier experiences. Some participants' constructs of independence also incorporated a sense of continuity with activities and/or roles that had now ceased. For some participants, this type of connection with their past created a mental and moral resource to sustain established constructs of independence even when activities and/or roles had changed and/or stopped. However, the findings also showed that for other participants, this triggered feelings of sadness, loss and reflection about their independence and created a dissonance between what they 'knew and valued' about themselves and what they currently experienced.

The centrality of continuity was also evident in other dimensions of identity. For example, many participants said that a principal aim was to maintain an 'independent' identity in the future. Participants accepted that maintaining their current levels of independence across all dimensions was not likely to be possible in the future. Instead, they aspired to be able to maintain current constructs and experiences of independence in the face of likely physical and cognitive deterioration as they aged (an aspirational identity).

Continuity was also evident when participants' constructs of independence took the form of a comparative identity. Participants were clear that in order to maintain a sense of continuity they compared themselves with others.

Specifically, continuity of feeling 'more' independent than another social group and the way in which they 'stayed on top' was achieved by shifting the boundaries of whom they compared themselves with. For example, participants who lived in supported housing often commented that they were able to make their own meals (despite having the option to eat their meals in the communal dining room) and compared themselves favourably to those who had their meals cooked for them. The comparative identity that they construct helps to retain a sense of continuity of independence (a sense of their established identity as being independent) once again showing the dynamic nature of older people's constructs of independence.

# Continuity as illustrated through the dimensions of 'the practice of independence'

The dimensions of agency also showed that participants constructed independence in terms of continuity of action. Most participants were keen to discuss ways in which they still acted independently. They particularly emphasised being able to maintain their functional ability and their usual social relationships and roles, and to continue making decisions for themselves (that were consistent with their long-term values). This latter point was particularly emphasised in relation to being able to exercise choice and control. For example, many participants were particularly keen to continue to exercise control over their financial affairs.

As regards continuity in relation to executional agency, participants discussed being able to carry out everyday activities in a habitual and routine way, such as cooking and getting dressed without assistance. Some participants detailed functional activities and the importance of carrying out these out. While many felt capable of doing so, they often acknowledged that, at times, they needed to apply great effort to accomplish these aims. Indeed, emphasising their ability to maintain their current functional levels of independence appeared to offer the

participants some comfort and limited their fear about what might happen in the future. For example, one participant stated they were willing to continue to use a walking stick and willing to think about using it for the rest of their life, rather than confront the possibility of physical deterioration and having to use more advanced equipment such as a wheelchair.

The older people interviewed regarded their continuing ability to perform these practical activities as being about more than just performing activities of daily living; it became a way in which they expressed their independence. Tanner (2001) also found that many older people experienced difficulty in maintaining these types of tasks, but valued them as a means of maintaining a sense of continuity of independence. As Tanner observed, 'struggling to maintain routines encompasses "social" as well as "personal" components of identity, acting as a mechanism for preserving reputations of independence and continuing ability' (2001, p.262) .

The importance of continuity was also evident in 'supported agency'. Older people who had daily contact with a carer or carers placed a high regard on continuity of the relationship with their carer. Older people expressed fear about how they would maintain continuity of care if their needs changed. Having a carer who they knew and who knew them was very important. This is not surprising and has been documented extensively in other research (Katz et al., 2011; Bowers et al., 2009).

The fact that the participants' constructs of independence were framed by continuity of identity and agency may in part explain why it is often difficult for older people to deal with points of transition when their sense (identity) of independence is affected. However, the findings also indicated that older people's constructs of independence incorporated change and, in particular, the importance of balancing continuity and change to maintain a construct of independence that was personally meaningful.

### Change as illustrated through the dimensions of identity and agency

While continuity was intrinsic to older people's feelings of independence, participants also demonstrated a significant capability (often in the absence of any other choice) for change. As part of the dimensions of both identity and

agency, participants talked about change in many different ways. The perceived reasons for a change in participants' constructs of independence often reflected changes relating to their personal circumstances (for example, declining health, experiences of bereavement) and external changes (for example, experiencing ageist stereotyping attitudes). Some participants associated change with positive outcomes (e.g. moving into supported housing for some had brought reassurance and companionship), while others associated change with loss and decline. Declining health was mentioned most frequently, but it is important to note that many health changes were set in a wider context of day-to-day life. For example, participants frequently highlighted the interrelationship between health, mobility and independence. At the same time, ageing and the changes associated with it (retirement, new health conditions, loss and bereavement) were also seen by some participants as a potential catalyst to promote a change in self-perception, through which they adapted and redefined their constructs of independence. Thus, the older people interviewed acknowledged that independence was not a static concept, but one whose meaning incorporated change in relation to their shifting circumstances and their understanding, expectations and aspirations about independence. Indeed, while many participants acknowledged that change brought about a degree of movement from feeling a sense of independence towards feelings of dependence, this was not inevitable. Thus, change was not simply 'loss' of independence; there was also evidence to suggest that participants changed (adapted) in order to sustain both a sense and practice of independence. For example, participants' adapted by using aids and equipment, paying for domestic assistance, and trying to optimize what they were able to do. One participant, for instance, made and froze meals for herself on a 'good' day so that when she was not feeling so able, she had them ready.

Participants' responses to their shifting circumstances was clearly evident as part of an 'adaptive identity'. Indeed, there was evidence to indicate that an adaptive identity played a key role in how participants both defined and sustained their constructs of independence. Participants adapted in many different ways, and their readiness to change was largely underpinned by the value that they placed on independence (as shown earlier in this chapter). For example, some participants accepted support as their circumstances changed in order to

maintain their sense of agency and were willing to do this because of the aspirational value that they attached to independence. For the participants, then, adapting to their varying circumstances was viewed as more realistic than striving for something less attainable, or developing a fear of what one might become.

For many participants adapting was not simply about that they had to change, but that they were still able to carry out tasks without involving others by balancing what they would accept and what they would not. For example, they might choose to use a walk-in shower without the need for assistance from others, rather than opting to take a bath, which would require assistance. This finding is compatible with the dominant interpretation of independence in the policy arena, which emphasises self-sufficiency (see Chapter 2). It also shows how participants conceptualised dependence as requiring support from others. This is explored in detail later in this chapter. However, as will be shown, participants also valued reciprocity. While this might initially appear contradictory – one might assume that there would be a conflict between the notions of self-sufficiency and reciprocity – it in fact points to the multi-dimensional and dynamic nature of older people's constructs of independence.

Furthermore, participants adapted to their changing circumstances to avoid becoming more dependent, as they saw this in a negative light. When older people's circumstances changed, they were often prompted to re-evaluate their conceptions of independence and adapt by focusing on areas where they felt their sense of independence has not been lost and/or compromised. Thus, participants focused on other dimensions of independence and how these interact to create and sustain their independence, rather than on the dimensions of independence which had been lost and/or compromised. For example, some participants with declining health shifted the focus of their personal construct of independence from one based on the ability to carry out activities of daily living without assistance, to one based on emotional well-being.

The degree of choice and control that participants experienced when responding to changes in their circumstances affected their constructs of independence. The way participants' experienced this choice and involvement could promote and/or damage their sense of independence. Those who felt such changes had been

imposed on them without discussion or consent felt particularly aggrieved. Conversely, those who had been involved in the decisions more often saw the changes as sensible and necessary steps that allowed them to remain feeling as independent as possible.

#### Balancing continuity and change

While continuity and change have been presented separately, this is not to suggest there are mutually exclusive experiences and/or binary opposites. Rather, participants' constructs of independence were complex and the relationship between continuity and change was dynamic and shifting. Continuity was important because participants drew on a sense of identity and agency developed over the life course to construct their conceptualisations of independence. However, on the other hand, participants acknowledged that ageing brings changes (often permanent) that affect how they conceptualize and construct their sense of independence and that, therefore, necessitate adaptation both in terms of their behaviour and the relative weight they ascribe to the different but interrelated dimensions of independence described in Chapter 6. For example, defining themselves as independent was taken-for-granted as part of their everyday lives (an established identity) until something occurred that interrupted this situation. At such moments, participants often reflected on their independence, and while (as described earlier) the value of independence was fixed, the construct of independence was malleable.

Participants' constructs of independence showed an interaction between continuity and change, and specifically the incorporation of change and continuity simultaneously. As such, the meaning of continuity for participants was not so much about sameness, but about the incorporation of change and new directions. Indeed, when change and continuity are considered as complementary concepts in this way, they present the idea that the meaning of independence can encompass the idea of continuity through change. For example, some participants had moved into supported housing when they realised that, due to progressively declining mobility, they needed single-level accommodation so that they could continue to be able to move around their own home unaided. Thus, while this involved a change, it enabled a sense of

continuity in the sense that they were able to continue to access all areas of their own home, avoid needing to use equipment, and did not have to move into residential/nursing care. There was, therefore, a 'trade-off' between moving and at the same time retaining a personally meaningful sense and practice of independence. This further suggests, therefore, that the meaning that older people ascribe to independence is constructed in a multidirectional way.

A similar point is also made by Gibson (1998 p.198), who states that such tradeoffs can be regarded as a 'positive adaptation strategy, if dependence in some areas is used to protect reduced resources in order to maintain independence in "key" areas for that individual. Certain levels of dependency can thus be seen as positive (and 'normal') at latter stages of the life cycle'.

Maintaining continuity of identity was evidenced in the scoping literature review as being important to older people's independence (Parry et al., 2004; IAHSP, 2004; Tanner, 2001). The findings of this study reinforce this earlier finding that maintaining a sense of continuity of identity is important to older people's conceptualisations of independence. However, the findings of this research expand upon ideas about the relationship between continuity and independence by showing that continuity is not about stasis, but describes an ongoing process of balancing and rebalancing priorities in the face of change.

Older people were willing to receive some help but could nevertheless still feel themselves to be 'independent'. The analysis showed that participants' constructs of independence could also incorporate assistance/support from others without there being a requirement or expectation from either side that this support should be reciprocated (supported agency). Indeed, participants recognised that support from others in certain circumstances was *required* in order to enable them to be independent and thus were willing to accept help in some circumstances in order to protect and maximise their independence. For example, one participant spoke about the need to balance her need for privacy within her own home while at the same time recognising that she needed daily assistance with personal care. She therefore accepted support workers coming into her home as it enabled her to remain at home (and not move into residential care). Here again, we see a trade-off, a sense of someone balancing competing

aspects of their construct of independence: she compromised some of her privacy (one aspect of her independence) in order to remain living at home (another, perhaps more important aspect of her independence). Constructing independence in these terms was most evident in the accounts of participants who were in receipt of high-level support services (i.e. those receiving multiple daily contacts from formal carers). This is perhaps because these older people felt that there was no choice but to accept support, and chose to view the support as reinforcing rather than undermining their independence. They therefore reconstructed their meaning of independence to incorporate this rather than conceptualising themselves as having become 'dependent'. Similar discourses of independence are also evident in other research (Baltes, 1996; Secker, 2003; Sixsmith and Sixsmith, 2008). For example, Sixsmith and Sixsmith (2008, p.226) found that 'where social support was essential... retaining psychological control over such services helped older people feel independent, even in the face of substantial domestic and personal care'. Baltes (1996, p.145) proposes viewing this reconstruction of the meaning of independence by older people needing support and assistance as a 'self-regulated dependency', whereby older people are willing to accept help and see it as a means of sustaining their independence.

#### Social relationships and constructs of independence

The third explanatory theme identified as being key to older people's constructs of independence is their relations with other people, that is to say, their social relationships. This section discusses the conflicts between the narrow individualistic interpretation of independence (i.e. self-sufficiency) evident in policy and the broader constructs of independence presented by the participants in this research. It shows how the interpretation of independence in the policy arena fails to fully capture the importance of social relationships to constructs of independence. As presented in Chapter 6, participants' accounts illustrated that their constructs of independence came from within and through their interactions with others, and specifically within the relational cultural norms of mutuality and reciprocity. Thus, for these older people, independence also incorporated ideas of dependence and interdependence.

The analysis showed that independence also held a relational value for the participants. Participants explicitly stated that they valued social relationships and specifically mentioned that being able to reciprocate was an important aspect of their independence. The give-and-take nature of relationships was something participants highly valued, and as a result, many aimed to maximise their chances to engage in reciprocal relationships.

# Social relationships as illustrated through the dimensions of identity and agency

The complex relationship between dependence, interdependence and independence was evident across several of the dimensions of identity and agency. Interdependence was particularly evident in the dimensions of 'relational agency' and 'adaptive identity'. Both of these dimensions showed that participants' constructs of independence involved other people.

'Relational agency' primarily describes the importance that being part of a social network has to constructs of independence, and especially how social networks serve the role of providing opportunities to engage in acts of reciprocation. The 'relational agency' dimension is therefore particularly relevant to the understanding of older people's social relationships and conceptions of independence given that the analysis showed the importance of *reciprocity* to participants' constructs of independence. Indeed, many of the participants regarded any support given to other people as part of the reciprocal relationships associated with being a member of a social network rather than as 'care' *per se*. Examples of such reciprocal support included offering to go shopping for a neighbour if they were unwell, and vice versa. Older people talked about valuing these acts of friendship and companionship in the context of their notions of independence, and that part of being 'independent' was remaining responsive and supportive towards others.

Interestingly, it was noted that for those participants who emphasised reciprocity, their practice of independence appeared to benefit in three key ways: it allowed them to feel less (and ideally not at all) burdensome on others; it allowed them to accept help from others in a way that did not compromise their independence, instead serving as a means of balancing support and/or assistance; and it

allowed them to enhance their sense of their own (superior) independence. Reciprocity was also a mechanism through which participants who perceived themselves as being more independent distanced themselves from those they perceived as being less 'independent'. Thus, reciprocity on the part of participants was not simply rooted in altruism, but also provided 'evidence' of their independence both to themselves and to others. For example, some participants insisted on providing payment for services rendered by other family members (e.g. gardening). Such payment served as a marker both to themselves and to others of their independence.

Acknowledging reciprocity as being part of older people's constructs of independence is evident within existing literature that argues reciprocity is a key means of rebuffing the notion of being dependent on others (Fine and Glendinning, 2005; White and Groves, 1997; Parry et al., 2004; Breheny and Stephens, 2009). For example, Breheny and Stephens (2009, p.1301) note that 'reciprocity may be drawn upon by older people to position themselves as independent, even when they need physical help'. Other research has found that older people were more likely to be depressed when they felt unable to reciprocate (Davey and Eggebeen, 1998; Wolff and Agree, 2004).

However, other participants felt that accepting help and support without reciprocating it was restrictive, limiting and potentially incompatible with their construct of independence. This viewpoint was most often expressed by participants who were currently receiving lower-level support services, for example, befriending. Indeed, for these participants, the prospect of receiving significant amounts of support – for example, the need to have formal carers coming into their house daily to assist with personal care, or moving into residential care placements – was articulated simply as a state of dependency, and was seen by many as 'giving up' and the 'beginning of the end' of independence. Overall, participants who had yet to experience needing higher levels of formal assistance/help were less able to see it as a supportive intervention to maintain their independence and instead viewed it as something that would undermine their independence. This reticence resonates with previous research (for example, Simpson et al., 2003) and was particularly strong amongst the participants when they were reflecting upon the possibility of having to move

into residential care. In line with this, Quine and Morrell (2007, p.217) suggest that 'fear of nursing home admission could be considered a more specific and extreme form of loss of independence'.

The analysis showed that participants strove to seek to maintain a sense of balance between independence, interdependence and dependence within their social relationships, and that if they felt unable to achieve this, for some, this led to feelings of distress. Indeed, the balancing of these feelings of independence, dependence and interdependence was a key means of older people constructing independence in terms of aspiring for self-sufficiency (an aspirational identity and an executional agency) and the concurrent acknowledgment that their circumstances have and will change (an adaptive identity).

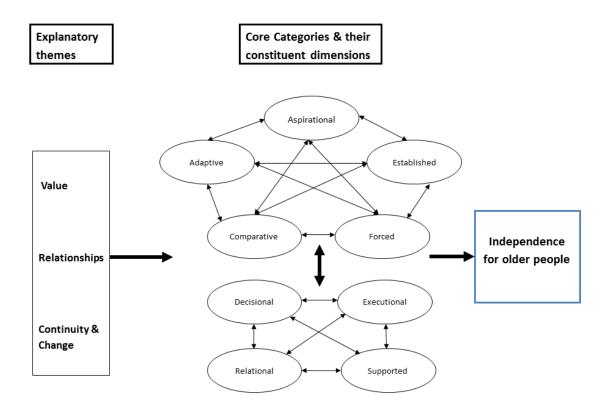
As presented in Chapter 2, current policy conceptualises independence within narrow parameters, focusing primarily on functional independence (i.e. doing things for yourself without support from others) and regarding it as a binary concept (i.e. you are either independent or you are not). The participants' constructs of independence that incorporated ideas of dependence and interdependence challenge the view that a straightforward dichotomy exists between independence and dependence, a view that dominates much of the discourse and policy on ageing. This finding is in line with the ethic of care framework, which refutes the independence/dependence dichotomy and instead emphasises interdependence (Daly and Lewis, 2000; Williams, 2001). The findings of this research showed that participants' constructs of independence were more complex and nuanced than the policy model of independence allows for.

## A substantive theory about the meaning of independence for older people

Older people's independence is determined by the dynamic interactions between aspects of how they view themselves (identity) and how they are able and enabled to act (agency). These dynamic interactions are influenced by sociocultural norms and experiences (i.e. values, relationships, and continuity and change).

A diagrammatic conceptual framework is presented below to illustrate this substantive theory about the meaning of independence for older people.

Figure 6: A substantive theory about the meaning of independence for older people



### Summary and conclusion of this chapter

This chapter has brought together the findings from primary and secondary data sources. It has presented a substantive theory on the meaning of independence for older people grounded in the primary findings of this research, but supported by insights gained from the wider evidence base. This chapter has shown that the meaning of independence for older people is context specific and is influenced by a range of different factors that interact in complex and dynamic ways.

Two distinct but interlinked 'core categories' of participants' constructs of independence – that is, 'a sense of independence – dynamic and interactive identity' and 'the practice of independence – dynamic and interactive agency' –

and their associated dimensions have been presented. The particular salience of each dimension is dependent on the individual and the context. Across the dataset and between the narratives the empirical research showed that different dimensions resonated more strongly with some participants than others, as the emphasis placed on these individual dimensions was shaped by an older person's life experiences (both past and current), personal characteristics and wider social/cultural discourses.

Three explanatory themes that elucidated the variation in the meaning of independence for older people were identified; these were a 'valued social construct', 'continuity and change in constructs of independence' and 'social relationships and constructs of independence'. These themes provided further evidence that older people's independence is not static, but rather constructed through the balancing and rebalancing of different dimensions of independence. In particular, a 'valued social construct' showed that the meaning of independence for older people was affected and shaped by cultural/social influences. 'Continuity and change in constructs of independence' showed that these were not mutually exclusive experiences and/or binary opposites. Rather, participants' constructs of independence were complex and the relationship between continuity and change was dynamic and shifting. 'Social relationships and constructs of independence' showed that older people's constructs of independence were not purely based around autonomy (and isolation), but rather on incorporated social relationships.

Thus, a substantive theory about the meaning of independence for older people has been established. It shows that independence is multi-dimensional and dynamic, representing the complex and ongoing interweaving of lived experiences and social/cultural discourses. Furthermore, at times, and as discussed in this chapter, there were paradoxes and contradictions both within individual participant's narratives as well as across the data set. These contradictions again reflected the dynamic and interactive conceptualisation of independence held by older people. Therefore, these findings do not proclaim to have identified a single definition of independence; instead, its meaning can be complex, context specific and/or subject to change over time. Thus, rather than being a static, collective outcome, the findings of this research show that

independence for older people is individually constructed, multi-dimensional and continually being balanced and rebalanced. When considered together in association with dominant cultural/social discourses, the analysis of the findings has generated a contextually specific multi-dimensional, interactive and dynamic understanding (substantive theory) of the meaning of independence for older people.

In the following concluding chapter, an overview of this thesis is presented, the methods and methodology are evaluated, and the extent to which this research meets the quality criteria proposed by Charmaz (2006) is considered.

### **CHAPTER 8: EVALUATION AND CONCLUSION**

#### Introduction

The aim of this concluding chapter is to review and evaluate this thesis. This chapter is split into three sections. Section 1 presents an overview of this thesis, summarising the existing evidence base, methodology, methods and findings to help to contextualise the conclusions. Section 2 critically reviews the methods and methodology used so that the findings can be considered in light of the strengths and limitations of these approaches. Section 3 evaluates the credibility, originality, resonance and usefulness of this research and reports the implications of the findings for policy and practice, recommendations for further research and contribution to knowledge.

#### Overview of the thesis

This research has elucidated the meaning of independence for older people. The UK population is ageing, and older people's expectations about their independence are also changing. Given the likelihood that resources will not increase relative to demand, optimising independence for older people is likely to remain high on the health and social care policy agenda. In this demographic and policy context, it is essential that the meaning of independence for older people is understood.

Prior to the commencement of primary qualitative research, a policy review and a scoping literature review were carried out. The aim of the policy review was to explore and contextualise the meaning of 'independence' within the English policy and service delivery environment. Optimising independence is a key driver of health and social care policy and reflects changing demographic and fiscal concerns. However, when conducting the thematic analysis for the policy review, three distinct strategic approaches to promoting independence, accompanied by associated mechanisms for delivering independence are evident within current policy. First, providing older people opportunities to experience choice and control, often through self-directed support; second, restoring and/or maintaining older people's abilities to carry out activities of daily living without assistance, primarily through instituting services such as intermediate care and re-ablement;

and third, the shift towards preventative care, including low-level support such as voluntary befriending services, which emphasises the importance of older people being as independent (as possible) for as long as possible. However, the policy review showed that there was a lack of integration between these strategic shifts in policy.

Following on from the policy review, which had revealed the variability in the meaning of independence within policy and practice; it was decided to explore further the available evidence on the meaning of independence by shifting the focus from the consideration of policy towards examination of the existing empirical evidence base. A scoping literature review was completed that explored and collated the existing empirical evidence on 'independence' from the perspective of older people. The aim of the scoping literature review was two-fold; first, to establish the available evidence on the meaning of independence for older people, and second, to identify research gaps. In summary, no single definition of independence emerged, but instead was shown to comprise of individual dimensions, such as self-reliance and circumstantial factors affecting older people's constructs of independence, such as physical health and mobility.

Specific gaps identified in the scoping review were addressed by the empirical research conducted for this thesis. The scoping review helped to focus the research question being explored and the methods and methodology adopted. First, the scoping review revealed existing research focused on older people recruited from single service settings and that a gap existed for exploring the meaning of independence for older people who may access support across different settings, including low-level services. Second, the evidence included in the scoping review suggested that older people's conceptualisation of independence might be dynamic and responsive to changing circumstances. However, this was not explored in any detail within the included studies. Third, the scoping literature review also showed that there was a lack of theory rooted in empirical research about independence for older people, and this gap was a key driver of the decision to adopt a constructivist grounded theory methodology. Thus, qualitative approaches to data collection were chosen as these enable deep and thorough exploration and explanation of phenomena including individual views and meanings.

The constructivist grounded theory methodology was chosen because its' underpinning epistemology and theoretical perspectives are most appropriate when research aims to understand the meaning of a phenomenon directly from an individual's perspective. Furthermore, given the lack of theory about independence for older people outlined above, constructing an inductive theory was a key element of this research.

The distinctive elements of grounded theory, which include theoretical sampling (of participants and/or data), the constant comparative method and the development of theory (Hood, 2007), enable exploration of under-theorised and/or conceptually challenging issues such as the meaning of independence for older people. Constructivist grounded theory adheres to these methodological principles while pointing to the overriding need for the researcher to be both personally and methodologically reflective throughout the research process. This acknowledgement of my position within the research process is important as it is underpinned by a belief that researcher subjectivity and bias cannot be completely removed, nor would it be appropriate to attempt to do so. This reflexivity adds to the transparency and creditability of the research process (Mruck and Mey 2010).

Participants were selected according to the pre-established parameters of the sampling frame. Older people (aged 65 and over) living in York within the community (including supported housing/extra care housing), not diagnosed with any form of dementia and/or cognitive impairments, and who were currently in receipt of support services currently or during the previous six months were eligible to participate.

To adhere to the central tenets of grounded theory, a two-phase approach to data collection was adopted. Informed by the policy and literature reviews, which shaped the topic guide, a first phase of interviews was conducted (n=5). In line with constant comparative methods, the topic guide was further developed and refined in light of the analysis of these initial interviews, and a second phase of interviews was conducted (n=10) using the modified topic guide. In total, 15 interviews were conducted.

Data analysis incorporated the key principles of constant comparative methods, and thus the analysis was iterative. Data analysis consisted of coding and memoing. The coding process had two phases: initial coding and focused coding. The chief characteristic of the initial coding process was to remain 'open' to the data. Focused coding was more selective and conceptual than initial coding; for example, many of the codes identified in this phase were composites or broader/more abstract versions of initial codes that better encompassed a process participant's were discussing. The development of core categories and explanatory categories took place towards the end of the iterative cycle of data collection and analysis. The aim was to reach a higher level of abstraction around which a substantive theory could be constructed. Memoing was used throughout and was a pivotal step between data collection, analysis and writing up.

Analysis across all the interviews showed that participants conceptualised independence as 'the sense of independence – identity' and 'the practice of independence – agency'. Both of these core categories consisted of different dimensions. 'The sense of independence' consisted of five dimensions: 'an aspirational identity', 'an established identity', 'a comparative identity', 'a forced identity' and 'an adaptive identity'. 'The practice of independence' consisted of four dimensions: 'decisional agency', 'executional agency', 'relational agency' and 'supported agency'. Although these dimensions are presented here as separate entities, they were in fact interrelated and existed within a complex system of dynamic interaction. One dimension of identity and/or agency has direct relevance to another, and the connections between the dimensions are non-hierarchical, fluid and contextual.

Further analysis identified three explanatory themes that drew together the ways in which the different dimensions of identity and agency relate and interact. These are 'a valued social construct' which showed that participants placed great importance of their 'sense' and 'practice' of independence and aspired to maintain both for as long as possible. Second, 'continuity and change' showed that across the dimensions of the 'sense' and 'practice' of independence participant's constructs of independence were dynamic and shifting between maintaining a stability and consistency while at the same time acknowledging

ageing brings changes (often permanent). Third, 'social relationships' shows that relationships with others and specifically reciprocity were incorporated into older people's constructs of independence. These findings have built into a substantive theory of independence for older people. Older people's independence is determined by the dynamic interactions between aspects of how they view themselves (identity) and how they are able and enabled to act (agency). These dynamic interactions are influenced by socio-cultural norms and experiences (i.e. values, relationships, and continuity and change) (see Figure 6, chapter 7). Developing this holistic understanding of the meaning of independence from the perspective of older people and developing the findings into a substantive theory would not have been possible without the iterative approach that is fundamental to grounded theory.

Central to the reflective approach proposed by Charmaz (2006) is the need to undertake a critical review of the methods. Therefore, the strengths and limitations of the methods and methodology used and the extent to which this research meets the quality criteria proposed by Charmaz (2006) are outlined below.

#### Critical review of methods

All research has strengths and limitations, and a key part of the research process is to reflect upon these (Blaikie, 2004; Silverman, 2001). Acknowledging possible limitations does not undermine the value of the research; rather, it promotes a transparent reflection on and critique of the research (Oakley, 2000). The aim of this section is to critically review the methods (e.g. the process of identifying and recruiting the sample) and the incorporation of the defining principles associated with constructivist grounded theory (e.g. theoretical sampling) so that the findings can be considered in light of the strengths and limitations of the approaches used.

Limitations associated with the sampling frame and the recruited sample
As described in detail in chapter 5, there were clear pragmatic, ethical and
methodological reasons that determined the sampling frame. However, their

application meant that some specific groups of older people were excluded from participating.

The inclusion criterion of a good understanding of written and spoken English had the potential to hinder the recruitment of older people from a diverse range of ethnic backgrounds. While I was not privy to information about the ethnicity of those older people who were sent invitation letters, it was clear when I attempted to facilitate recruitment by attending community social groups that there was no ethnic diversity amongst potential participants.

It is likely that this is low recruitment of older people from ethic minority groups is in part reflective of the wider demographic profile of York. York has a relatively non-diverse population with only 8% of the total population being from a non-White background (and the majority are younger people) (Craig et al., 2010). Thus, participation of older people from a range of ethnic backgrounds may have increased if the geographical area of recruitment had been different, and/or information letters translated and/or recruitment materials/interviews offered in other languages. However, this would have had significant implications for my research resources and would have involved financial costs that I could not have met. It should be noted, however, that this lack of ethnic diversity among the older people in the sample is not a limitation unique to this research. Some larger-scale studies have also highlighted this gap and have stressed that efforts to address this should be a research priority, especially given the demographic changes occurring in the UK older population (Blood and Bamford 2010; Leeson 2004). In light of the findings of this study, which show that the meaning of independence is, at least in part, culturally constructed, then it is possible that people from different ethnic backgrounds have different interpretations of independence and experience independence differently, and the need to address this gap is all the more evident.

This research occurred within the boundaries of the City of York. Potentially this can be seen as a limitation as it meant this research lacked a rural dimension. This is especially important as the ageing of the population in England is more pronounced in rural than urban areas (ONS, 2013) and further demographic

shifts in the older people population such as counter-urbanisation will intensify this trend (Manthorpe and Stevens, 2010).

While this research aimed to recruit both men and women, only two men chose to participate; the possible reasons for this have been outlined in chapter 5. Other research has indicated that men and women tend to report maintaining independence in relation to different tasks and it has, therefore, been argued that they view independence differently (Mentsen Ness et al., 2014). Due to the small number of men recruited to this study, gender differences were not able to be explored in any depth. However, the dimensions of independence outlined in this thesis were common across the interviews with both men and with women. This possibly reflects the methodology employed here which enabled analysis to move beyond descriptive (e.g. task-based) understandings of independence towards an explanatory understanding of older people's constructions of independence.

As outlined in Chapter 5 one of the selection criteria was participants aged 65 and over. Upon reflection this should have been aged 75 and over as it would have more accurately reflected the demographic 'type' of older person this research was interested in, i.e. those older people who had already felt the need to access some form of additional support in order to maintain their 'independence'.

While the aim of this research was to recruit older people using a range of support services it is important to acknowledge that due to the paths of recruitment used i.e. attending social events at supported housing this meant that the sample recruited was highly skewed towards those who live in supported housing. This may have had an impact on the findings, for example, the explanatory theme of 'continuity and change' may have emerged more strongly within this particular population because many of the participants by default of having already moved from private accommodation into supported housing had already had to made significant changes to their lives.

Despite these limitations, the participants in this research represented a wide age range (i.e. 65 to 93) and accessed a variety of different support services. While

acknowledging that the scope of the sampling frame and methods of recruitment determined who participated in this research, a key strength of this work is that it ensured that older people's views about independence were heard. Bowers et al. (2009) suggest that researchers often assume that older people will be too tired, 'private' or uninterested to participate in research. Indeed, researchers are not immune from everyday social attitudes. As presented in earlier chapters, there is a high cultural importance placed on independence within our society from which researchers are not immune. Additionally, pejorative social attitudes about ageing and older people are pervasive in society. Walker (2005, p.117), drawing upon research from the ESRC Growing Older Programme, shows that researchers are not exempt from such attitudes and highlights the possibility that they might make assumptions and stereotype older people:

Within Western societies negative stereotypes of old age are common.

Prevalent stereotypes are that most older people are: confused, resigned to decline, tired, slow, dependent (Unsworth et al 2001). Stereotypes tend to restrict and guide people's thought processes, and researchers themselves are not free of stereotypical thinking.

From the outset, I set out to challenge these perceptions because I do not subscribe to such condescending views about older people and their ability to participate in research. Furthermore, the research questions demanded that I included older people directly in the research and did not rely on the views of proxies (for example, family members or carers). This is particularly important as recent research has shown that proxies may hold different opinions than older people themselves (Glendinning et al., 2008).

#### Recruitment and sample size

Recruitment was an ongoing concern throughout the data collection process. As presented in Chapter 5, despite having essentially been "vetted" by the organisation responsible for providing support services to potential participants, which sent out invitation letters on my behalf, the uptake that occurred through this recruitment pathway was extremely low. As a result of these very low response rates, I recognised that I needed to reassess my methods of recruitment. I therefore recruited directly (face-to-face) through different

community groups. This pathway increased both the recruitment rate and the range and diversity of support services (i.e. the range of support services that participants were in receipt of) that were represented in the sample. Upon reflection, I recognised that this revised approach to recruitment had yielded relatively good results quite quickly, and had I used a more direct approach from the start of the research, I might have been able to shorten the time taken to recruit participants and perhaps increase the number of participants. It should be remembered that low recruitment is often an issue for researchers studying the experiences of older people, and several commentators have acknowledged the difficulties posed in recruiting from the older population (Harris and Dyson, 2001; Davies et al., 2010). However, as the recruitment process for this study shows, while a less direct and impersonal approach to recruitment – the use of invitation letters – did prove to be unfruitful, recruitment of older people was possible when a more direct and visible approach was employed. While of course this finding should be treated with caution given the small-scale nature of this study, the improved recruitment rates that occurred after I adopted a more direct and personal approach to the recruitment of older people suggest that such an approach can reap dividends.

This research did not aim to recruit a statistically representative sample, but rather to understand the concept of 'independence' from older people's perspectives. The study's small sample size therefore allowed the in-depth enquiry and analysis essential to answering the research questions. It enabled the *in-depth* nature exploration participant's constructs of independence. Given this a small-scale qualitative study offers the greatest likelihood of being able to explore these issues and concepts in the greatest depth given the time and resource limits, Indeed, if the study been larger in scale, it is unlikely to have been possible to explore in the detail the 'actual understandings of independence' of the participants.

#### Incorporating the defining principles of grounded theory

As presented in chapter 4, Hood (2007, p.163) sets out three distinguishing principles of grounded theory methodology:

- Theoretical sampling
- Constant comparative methods

#### Development of theory

The ways in which these principles were incorporated into this research are now critically reviewed. Initially grounded theory seemed to offer clear methodological guidance. This includes, for example, clearly defined stages for coding, as well as a 'bottom up' approach to the process, which is conspicuous in grounded theory's lack of *a-priori* categories for data analysis. However, as I became more immersed within the data collection and analysis, I also found the guidance at times to be too prescriptive and difficult to incorporate into the research process. For example, when faced with low recruitment and the necessity of remaining within the predefined sampling frame, I was concerned about how I would be able to practise theoretical sampling. The reflective nature of constructivist grounded theory meant that I was able to modify the method (as outlined in Chapter 5) while staying within the methodological parameters and quality requirements.

#### Theoretical sampling

As described in chapter 5 theoretical sampling of data was achieved via a process of modification of the topic guide. A two-phased approach to data collection and analysis was undertaken. The first phase incorporated five interviews and was based on a topic guide which had been developed from the evidence and policy reviews. The second phase comprised a further ten interviews and was guided by analysis of the findings from the first phase. Through the modification of the topic guide the aim of the second phase was to build upon the coding and the emerging themes identified in the first phase through further data collection and concurrent analysis, i.e. issues that had not being originally identified as important within the topic guide were added, which then led to clarifying and re-clarifying the coding in light of further evidence. Thus while phased, data collection and analysis was conducted in an iterative manner. Thus, as more interviews were undertaken, the topic guide was iteratively modified in response to reflect the emerging findings. While maintaining that this was the most appropriate and pragmatic approach to theoretical sampling for this study, nevertheless this approach had possible limitations: for example, the significance that the concept of 'loss of independence' might have for a participant if faced with the possibility of moving into a nursing home might be

investigated further by interviewing older people in residential care settings. In this research, however, the emphasis was on the understanding of independence of older people living in their own homes, and it would therefore not have been possible to answer the research question had I followed this route. However, utilising theoretical sampling via the modification of the topic guide enhanced the quality of the data collected in relation to the research question as it enabled the understanding of the complex nature of constructs of independence for older people.

#### Constant comparative methods

To recap constant comparative methods refers to the concurrent collection of data, analysis and theory construction. The process of constant comparison was applied throughout the research process. For example, initial and focused codes were compared and reviewed against each other for similarities and differences. Using the process of constant comparison in this research facilitated an iterative and reflective approach to be taken to data collection, analysis and theory development. This enabled an exploration of under-theorised and/or conceptually challenging issues such as the meaning of independence for older people.

#### Development of theory

The findings of this research are expressed as a substantive theory about the meaning of independence for older people. Substantive theory refers to theoretical suggestions that are unique to the context within which the data is collected. While, as described above, some of the key techniques of grounded theory were adapted, a constructivist grounded theory methodology was adhered to throughout, and the iterative and reflective approach to data collection and analysis that was utilised has offered more than a simple descriptive account of the meaning of independence for older people. Rather, through rigorous analysis (see Chapter 5) this research has entered the terrain of empirically grounded theory building and as such has met aims of this research.

While maintaining that this research has developed 'substantive theory' (i.e. theoretical suggestions that are unique to the context within which the data is collected – see chapter 4) about independence for older people, it is important to

acknowledge the critical debate around grounded theory's ability to develop theory and specifically what 'theory' is and how to define it (Birks and Mills, 2011; Charmaz, 2007). Charmaz (2012, p.3) acknowledges this debate by writing:

What constitutes theory has neither been agreed upon nor codified. I say use the strategies that work for you and your study but be aware of what you do and what you claim.

Although writing specifically in relation to social gerontology on the difficulty of defining 'theory', Hendricks et al. (2010, p. 288) make a similar point:

It ought not be surprising that there is little unanimity about what constitutes theory in social gerontology; disconcerting but hardly surprising given the complex nature of our subject matter.

In light of both 'warnings', and specifically the statement by Charmaz (2012, p.3) to "be aware of what you do and what you claim" throughout this thesis, I have endeavoured to provide a transparent and reflective account of the processes involved and how the data was collected and analysed. The scope of the theory development in this research has been to increase the understanding of the meaning of independence for older people, rather than to generate theory that is explanatory and/or predictive (i.e. formal theory – see chapter 4). There is also full acknowledgment that the findings and subsequent theory development are interpretative, context dependent and open to further research.

In addition, as experienced by many researchers, pragmatic considerations such as finite time, limited financial resources and being a lone researcher all played a role in how far the guiding principles of grounded theory could be achieved. Despite these challenges, due to the flexible nature of constructivist grounded theory, the key principles of grounded theory could be adhered to throughout the research process albeit with some modifications within the parameters of this methodology.

## Applying quality criteria

There is little agreement on what appropriate quality criteria are, or indeed whether the use of criteria is even appropriate in qualitative research (Mays and Pope, 2000; Seale, 2006). While acknowledging that there is critical debate about what constitutes quality criteria in qualitative research, in accordance with its methodological foundations, this research draws on the specific evaluative criteria identified by Charmaz (2006) to assess the value of this constructivist grounded theory study. This approach stands in contrast to a positivist approach in that it proposes qualitative research is distinctive and separate to quantitative research and, as such, cannot be evaluated by the widely used criteria of validity, generalisability, reliability and neutrality (Mason, 2004).

Charmaz (2006) suggests that when evaluating research that uses a constructivist grounded theory methodology, four criteria should be used: credibility, originality, resonance and usefulness. While Charmaz (2006) does not suggest hierarchy within these criteria, she does advise that a combination of "credibility" and "originality" enhances the further two criteria of "resonance" and "usefulness". These quality criteria are presented below in Table 11, after which consideration is given to how this research met (or did not meet) these quality criteria.

Table 10: Quality criteria for evaluating constructivist grounded theory studies\*

Studies						
Credibility	Has the research achieved familiarity with the topic?					
	Are there strong links between gathered data and					
	argument?					
	Is data sufficient to merit claims?					
	Do categories offer a wide range of empirical					
	observations?					
	Has the research provided enough evidence for the					
	researcher's claims to allow the reader to form an					
	independent assessment?					
Originality	Do the categories offer new insights?					
	Does the analysis provide a new conceptual rendering of					
	the data?					
	What is the social and theoretical significance of this					
	work?					
	How does grounded theory challenge, extend, and refine					
	current ideas, concepts and practices?					
Resonance	Do categories portray fullness of the studied experience?					
	Are taken for granted meanings revealed in this thesis?					
	Does the grounded theory make sense to the participants					
	or individuals who may experience similar experiences?					
	Does analysis offer them deeper insights about their lives					
	and worlds?					
Usefulness	Does the analysis offer interpretations that can be used in					
	everyday lives/worlds?					
	Can the analysis inspire further research in other					
	substantive areas?					
	How does the work contribute to knowledge?					

<sup>\*</sup>see Charmaz 2006, pp. 182-183

#### Credibility

Credibility refers to the logic and conceptual grounding associated with the research (Birks and Mills, 2011). As presented in Table 11, when considering the credibility of research that has drawn upon a constructivist grounded theory methodology, several questions need to be considered. First, there is a need to assess if "familiarity" with the studied phenomenon is evident (Charmaz, 2006). This is a key strength of this thesis, as a methodical review of the policy and empirical evidence relevant to independence for older people were completed prior to primary data collection. Both informed the subsequent empirical research by providing background and orientation into independence and ageing and were also used to inform the initial topic guide.

This research also exhibits a strong connection between the data and findings/analysis. In line with constant comparative methods, an iterative and reflective approach was taken to data collection and analysis, and thus there is a close interrelationship between them. Coding, memoing and the use of direct quotes from participants all enhanced the credibility of this research as they strengthened the link between the primary data gathered and the presentation of the findings. A reflexive approach to the connection between the data and subsequent analysis was further promoted by discussions with my supervisor about the emergent codes and categories and the subsequent development of theory.

Charmaz poses the question: "is data sufficient to merit claims?" when considering creditability of the research. As outlined in chapter 5, the goal in this research was to achieve 'theoretical sufficiency'. Sufficiency does not refer to the frequency with which something is stated by several different participants. Indeed, the opposite may be the case, whereby one participant presents something very insightful and this becomes an important aspect of the analysis. Thus, the emphasis was not upon the frequency of data per se, but rather its' potential for theoretical development. Given this theoretical sufficiency, more attention is given to the depth of data and analysis than to the number of participants. Thus, despite there being only 15 participants, the richness of the data allowed theory development.

As regards Charmaz's point about enabling the reader to make an 'independent assessment', I believe that the high levels of transparency in this research readily facilitate the reader's ability to achieve this. Indeed, I believe that one of this study's strengths is its high levels of transparency. To this end, I provided detailed and transparent accounts of the underpinning epistemological, theoretical and methodological positions (see Chapter 4), the methods of data collection and analysis (see chapter 5), and the findings and analysis (see chapters 6 and 7). Furthermore, in line with a constructivist grounded methodology and constant comparative methods, significant attention has been given to maintaining a cohesive and iterative relationship between these different aspects of the research strategy. With regard to this point, Chapter 5 clearly sets out how the data collection and analysis evolved in line with constant comparative methods.

#### Originality

Originality is achieved when research provides an innovative understanding of the studied phenomenon (Charmaz, 2006). This research has presented a 'new conceptual rendering of the data' through the identification of two core categories and their associated dimensions; 'a sense of independence' and 'the practice of independence'. Further analysis revealed three themes that helped to explain the connections and tensions inherent within meanings of independence and the highlight the dynamic (i.e. changing and finely balanced) nature of older people's constructs of independence. The findings and subsequent analysis led to the development of a substantive theory about the meaning of independence for older people. This can be considered 'original' as the scoping review presented in Chapter 2 highlighted the lack of theory building that was evident in the empirical studies about independence for older people.

The social and theoretical relevance of this thesis and whether it challenges current concepts and practice are considered later in this chapter as part of the evaluation of the 'usefulness' of this research.

#### Resonance

Resonance refers to whether the research holds meaning and relevance to those to whom it may be relevant (Birks and Mills, 2011). Through in-depth analysis two

core categories were identified which portrayed the fullness of older people's practice and agency of independence. Indeed, the very nature of this research has enabled an in-depth exploration of the meaning of independence – and the breadth and depth of the core categories and their associated dimensions enabled the development of theory derived from the findings (see chapters 6 and 7). In regards to whether 'taken for granted meanings' are revealed in this thesis, these are discussed (albeit not explicitly in these terms) in Chapters 6 and 7 and specifically the 'taken for granted' aspect of an independent identity (as part of 'an established identity').

Resonance also refers to how theory developed would be/can be understood by participants or others in the same situation. In other words, would they understand and relate to the theory developed and whether they accept that it reflected their experiences and feelings. Participants were offered the chance to review the transcripts of their interviews (prior to analysis) if they wished. However, upon reflecting on the degree to which I have achieved 'resonance' in this study, this is something that perhaps could have been more robust. For example, a more through approach to participant validation of findings may have promoted further resonance. This could have been achieved by presenting the participants with the analysis in its early stages and asking whether they felt it reflected their constructs of independence.

In relation to whether the analysis offers older people 'deeper insights about their lives and worlds' this analysis shows the complex interrelationship between the various dimensions of independence both reflect the older people's constructs of independence and shows that independence is a complex concept that contains elements of both continuity and change and interdependence. Specially, the findings of this thesis could provide insights to older people and professional's working with them about both 'maintenance of independence' and 'loss of independence'.

#### **Usefulness**

Usefulness broadly relates to whether the findings and emergent theory might be of use to others (Charmaz, 2006). Given an ageing population and associated factors such as economic pressures, the cultural importance of independence,

and wider attitudinal and social changes that are emerging within this population, it is argued that the findings within this thesis are particularly timely.

Table 11 identifies three key specific areas of 'usefulness': implications for policy and practice, recommendations for future research and the contribution to knowledge. These areas are now considered. While these areas are considered separately, it is important to acknowledge they are not mutually exclusive.

#### Implications for policy and practice

This section considers the 'everyday' usefulness of this research in the context of recent and current UK social care policy and practice for older people. As presented in Chapter 2, the promotion of independence for older people is high on the policy agenda. The findings of this research have shown that older people highly value independence, and this finding is compatible with the current policy emphasis on independence (DH, 2005; DH, 2012a). However, while the value placed on independence is evident in both the findings and current policy, there is variance and dissonance between the older people's narratives presented in this thesis and policy with regard to the *meaning* of independence and how it is best achieved.

Within policy and practice, there is also a strong emphasis on older people's practical and functional needs in relation to independence, and due to this emphasis, current policy may fail to fully account for the multi-dimensional nature of independence evidenced in this research. The findings showed that older people's constructs of independence have a much broader scope than simply physical functionality and in particular highlighted the importance of mutuality and reciprocity (inter-dependence) in older people's constructs of independence. Thus, there remains a possible gap around how support services can best support a relational, rather than individualistic understanding of independence.

The findings also showed that when older people need additional support and/or assistance to facilitate/maintain their independence, their responses to this need may be complex and delicate. For example, the findings illustrated that there may be reluctance on the part of older people to agree readily to support and/or assistance due to the feeling that it is incompatible with their established identity

of being 'independent' or that it involves becoming a 'burden' to others. Such feelings often meant that seeking assistance and support (particularly when unable to reciprocate) was counterintuitive to older people's constructs of independence. Thus, in order for policy and practice to be most effective, there needs to be recognition on the part of both policy makers and practitioners of the complexity of feelings that older people often experience in terms of how they feel about independence and accepting support and/or assistance.

The findings also showed that older people's independence was not only constructed in relation to their current lived experiences, but was informed by their long and varied past experiences. Personal biography and lived experiences affected both the value ascribed to independence and the meaning of independence. However, older people's first contact with statutory services in relation to their 'independence' is often at a time of crisis (DH, 2010), and the focus is thus primarily on meeting immediate needs. There is the possibility, therefore, that in order to be most effective, policy and practice needs to more fully recognise and value the role of personal biography, generational cohort ideas about independence and how these impact on older people's constructs of independence.

Policy and practice that are congruent and meaningful to the (changing) aspirations of older people are most likely to offer the greatest benefit to them; ultimately of policy should be consistent with the aspirations of those who are accessing it. Thus, understanding what independence means to older people is fundamental to the effective delivery of services, and a failure to appreciate fully the meaning of independence for older people may mean that it is difficult to implement policy in practice.

While these implications for policy and practice are grounded within the findings, it is important to acknowledge (as presented in chapter 1) of the current fiscal climate (austerity) within these recommendations are being made in. Prolonged and continued reduction of financial resources directed towards support services for older people will inevitably mean that some of proposed implications may be difficult to implement. This is because they would potentially require more (not less) resources being directed towards older people who need additional support

in order for them to maintain a 'sense' and 'practice' of independence which is meaningful to them. For example, there would be cost implications if policy and practice were to more fully account for the multi-dimensional nature of independence as evidenced in this research. In particular, a move towards a more relational understanding of independence and the value of taking a life story approach to older people's independence. However, while such suggestions would possibly cost more (particularly in the short-term) maintaining a 'sense' and 'practice' of independence that is meaningful to older people should be highly valued within policy and practice. Thus, this research can be seen as a further reason why it is important to challenge the austerity cuts currently happening to older people's social care.

#### Recommendations for further research

An additional consideration when evaluating the "usefulness" of a study is the need to ask the following question: "can the analysis inspire further research?" The findings, analysis and subsequent theory development that have been carried out in this thesis point to several possibilities for further research:

- A longitudinal research design would allow further exploration of the dynamic way in which older people's constructs of independence are balanced and rebalanced and how this evolves over time in response to changing circumstances.
- This research has shown that older people hold a relational understanding of independence, which stands in sharp contrast to the narrow, individualistic interpretation of independence (i.e. self-sufficiency and/or isolation from others) dominant in social care policy. Further research could focus on how older people's support services can best incorporate and promote the relational dimensions of independence.
- This research has also shown that older people's meaning of independence is
  responsive to their changing circumstances and shifts relative to the perceived
  situation of others, with the result that older people are often simultaneously
  able to feel independent in one area of their life and less so in others. In policy,

however, independence is often conceptualised in more binary terms – as something you are/have or you are not/do not have. Further research could focus on how older people's support services can best incorporate and facilitate understanding of independence as being part of a continuum.

• As presented earlier this research aimed for 'theoretical sufficiency' meaning that the theory developed is open to further development. Further research could continue to apply a constructivist grounded theory methodology to test/develop the theory proposed further by interviewing more older people, applying constant comparative methods to data collection and analysis in order to develop the substantive theory presented in chapter 7 (see Figure 6) further with the aim being of 'theoretical saturation'.

#### Contribution to knowledge

Charmaz (2006) suggests that when evaluating the "usefulness" of research, it is important to ask how the work contributes to knowledge. This research makes both a methodological and substantive contribution to knowledge.

Methodologically, this research contributes to knowledge in two key ways. First, it contributes to the methodological development of constructivist grounded theory by reflecting upon some of the pragmatic difficulties that arose from incorporating the defining principles of grounded theory, and specifically constructivist grounded theory, and how these were overcome. Second, by using a constructivist grounded theory, a methodology that, to my knowledge, has not been utilised when elucidating older people's meaning of independence. It has shown that constructivist grounded theory is a methodology that is highly relevant with researching older people.

Substantively this research has contributed by developing a highly nuanced understanding of independence for older people that is grounded in the primary findings and analysis as well as being contextualised within the wider evidence and policy. In similarity with the findings of the scoping literature review no single definition of 'independence' emerged from the empirical research of this research. However, the primary research showed that older people's constructs

of independence are multi-dimensional and comprised of 'a sense of independence – identity' and 'the practice of independence – agency'. Within these categories different dimensions are identified which interact in dynamic ways. One dimension had relevance to another and the connections between the dimensions were non-hierarchical, fluid and contextual.

Three overarching explanatory themes that bridged the dimensions of independence were identified. These were 'a valued construct', 'continuity and change' and 'dependence and inter-dependence'. All showed that older people's constructs of independence involved a process of balancing and rebalancing understandings of what it means to be independent. The meaning of independence for older people, therefore, is constructed not only in terms of achievement (for example, achieving self-reliance/functional independence), but also in terms of adaptation. This means that older people's constructs of independence have a certain paradoxical quality in that they may incorporate seemingly conflicting characteristics and/or experiences and thus have the potential to be both positive and negative. It also means that older people's constructs of independence are responsive to their changing circumstances and shift relative to the perceived situation of others, with the result that older people are often simultaneously able to feel independent in one area of their life and less so in others. However, when considered the core categories and their associated dimensions and the explanatory themes are considered together this research has generated a contextually specific multi-dimensional and dynamic understanding (substantive theory – see Figure 6, chapter 7) of the meaning of independence for older people.

Through a combination of policy review, exploration of the exiting evidence base, and empirical enquiry, this thesis has comprehensively explored the meaning of independence for older people. It makes a unique contribution to the body of knowledge about what independence means to older people and thus adds to the limited number of empirical studies that provide a direct insight into this subject.

## **APPENDICES**

# **APPENDIX 1: Demographic information**

		Tick as appropriate
Gender	Male	
	Female	
Age	65–74	
	75–84	
	85+	
Living situation	Alone	
	With spouse/ relatives	
Living arrangements	Supported/sheltered housing	
	Private	
Support service accessed	Currently in receipt of a support service	
	Not currently in receipt of a support service (although has been in the previous six months)	

## **APPENDIX 2: Recruitment information**

- a) Information leaflet
- b) Invitation letter





## The Meaning of Independence for Older People

This leaflet explains the purpose of the research study you are being invited to participate in, and, what it will involve if you decide to take part. Please take time to read the following information carefully and discuss it with others if you wish.

#### What is the research about?

The aim of this research is to find out more about older people's views and understandings of the meaning of independence. Therefore, we are interested in your own experiences of independence and what independence means to *you*.

## Who is undertaking this study?

Alison Allam is a post graduate researcher based at Social Policy Research Unit (SPRU) at the University of York. She is being supervised by Professor Caroline Glendinning.

#### What is involved?

Alison would like to talk to you about your experiences and feelings about independence and about the help you receive. Alison would visit you at home, or somewhere else if you prefer.

You can ask someone else to be there during the interview although what Alison is interested in is *your* opinions and experiences of independence. Ethical approval for this study has been given from the University of York.

## Do I have to take part?

No it is completely up to you whether you take part or not. If you do decide to take part, you can change your mind at any time without the need to provide a reason. Whether or not you take part will not impact upon any services or help you may receive.

## What would happen in the interview?

Alison would like to interview you at a time and place that suits you in order to find out more about the meaning of independence for you. The interview will last approximately one hour.

## What will happen to the information?

The interviews will be analysed and a report will be written. This report will form part of Alison's PhD thesis.

#### Is it confidential?

Yes. Your name and any other identifying information will not be used in any reports of the study.

## What happens next?

If you are willing to take part please complete the enclosed reply slip and return in the freepost envelope provided. You do not need to use a stamp. Alison will then contact you to answer any questions you may have and if you decide to go ahead, we can arrange an interview time and place that is convenient for you.

#### Contact details and further information

Using the detail below please contact Alison or Professor Caroline Glendinning if you would like further information:

Social Policy Research Unit
University of York
York
YO10 5DD
Telephone 01904 321950
Alison Allam email address:
ama502@york.ac.uk
Caroline Glendinning email address:
caroline.glendinning@york.ac.uk

Thank you for taking the time to read this.

## THE UNIVERSITY of York

AM/SP



SOCIAL POLICY RESEARCH UNIT University of York Heslington, York, YO10 5DD Telephone: (01904) 321950 Fax: (01904) 321953

Website:

www.york.ac.uk/inst/spru

E-mail:

ama502@york.ac.uk

Dear Sir/Madam

This letter is to invite you to take part in a research study about the meaning of independence for older people using support services. The researcher is Alison Allam who is currently a post-graduate researcher based at the Social Policy Research Unit.

Please find enclosed an information sheet which tells you more about what the study is about and what would be involved should you choose to take part. Please take some time to read the information sheet and discuss with other people if you wish. If after reading the information sheet you are interested in taking part please could you complete and return the enclosed reply slip in the stamped addressed envelope provided.

Thank you for considering taking part in this research study.

Yours sincerely

Alison Allam
Post-graduate Research Student

Enc. Information sheet Reply slip Pre-paid envelope

## **APPENDIX 3: Reply Slip**

## The Meaning of Independence for Older People

If you are interested in taking part in this study please complete and return this form using the stamped addressed envelope provided. Thank you.

,				
I am interested in takin	ng part in this st	udy and	happy to be	contacted:
Yes				
YOUR CONTACT DE	TAII S			
TOUR CONTACT DE	IAILS			
Name				
Addross				
Address				
Telephone number				
E-mail (if applicable)				
Most preferred method	d of contact			
wost preferred metho	d of contact			
Letter				
Telephone				
E-mail				
L-IIIaII				
Preferred time by tele	phone to contac	ct you		
Morning	Afternoon		Evening	

### **APPENDIX 4: Initial Topic Guide**

#### Pre-interview protocol

- Introduce self
- Remind participant that the key aim of the interviews is to explore what independence means to them

#### **Gaining Consent**

- They do not have to answer any questions they feel uncomfortable with and may at any time ask for the interview to be stopped without the need to give a reason.
- Taking part (or not) will not impact upon any services they may receive.
- Explain how quotes will be used this research, i.e. individual quotes may be used in reporting of findings, but no identifying information will be used.
- Highlight the only exception in regard to the need to break confidentiality would be if they said something to indicate that they or someone else is at risk of harm.
- Ask whether there are any elements of the consent form which they are unsure about and wish to clarify. If happy ask for the consent form to be signed.
- Switch on recorder and record verbal consent

#### Possible prompts that can be used throughout interview:

- Could you describe further?
- Tell me about?
- How does that differ from?
- Can you give me an example of?

#### Individual views about the meaning of independence

a) Can you describe what independence means to you?

#### **Prompts:**

- A sense of carrying on being 'who you are' (continuity of identity)
- Being able to carry out tasks without assistance
- Choice and control
- b) What areas of your day to day life are important to and/or do you associate with independence?

#### **Prompts:**

- Accommodation
- Finances management and security
- Heath/Physical mobility
- c) Is being able to carry out everyday tasks without assistance an aspect of independence? Are they important and/or necessary part of independence?

#### **Prompts:**

- Self-sufficiency
- Aids and equipment are they perceived as signifying a loss of independence or do they help support/maintain independence?
- d) Are there any aspects of your independence which you feel are more important to you than others?
- e) Is there anything which you feel promotes your independence on a daily basis?
- f) Is there anything which you feel limits your independence on a daily basis? What would constitute the biggest threat to independence?

#### The role of social support/social roles on the meaning of independence

a) Does independence involve others?

#### **Prompts:**

- Reciprocity
- Is a sense of 'give and take' and/or helping others important to your sense of independence?
- Family/friends/neighbours
- b) What activities/hobbies are important to you and do (and how) these contribute to independence?
- c) Is carrying on with established social contacts and/or social roles an important aspect of independence?

#### The role of support services on the meaning of independence

a) Can you tell me about the help you are currently getting, or have got in the last six months?

#### **Prompts:**

- Aids and Equipment
- Voluntary sector services
- Services provided directly from local authority

- Self-directed support direct payments
- b) Can you tell me about the circumstances which prompted the need to receive this help?

#### **Prompts:**

- Were you worried about getting this help and the impact on independence - and were any of your concerns justified?
- Does the help any help you received impact (positive or negative) on the meaning of independence?
- Are there any ways in which you feel that the help we have talked about could be improved to promote independence?
- c) Are there any ways in which the help you receive limit or interfere with your independence?

#### Prompts:

- Ask for examples
- d) Can you think about whether any extra help that would help you to feel more independent?

#### **Ending question**

a) Is there anything else you would like to add/say about what independence means to you?

#### **Ending of interview**

- Check participant is feeling OK with ending the interview.
- Inform the participant that they have the opportunity to receive a copy of the transcript and are invited to remove or add anything should you wish to do so.
- Thank participant for input and taking the time to participate.

## **APPENDIX 5: Modified Topic Guide**

As described in chapter 4, after analysis of phase 1 of the interviews four additional topics were included on the modified topic guide. These new topics are italicised here to facilitate reading.

#### Pre-interview protocol

- Introduce self
- Remind participant that the key aim of the interviews is to explore what independence means to them

### **Gaining Consent**

- They do not have to answer any questions they feel uncomfortable with and may at any time ask for the interview to be stopped without the need to give a reason.
- Taking part (or not) will not impact upon any services they may receive.
- Explain how quotes will be used this research, i.e. individual quotes may be used in reporting of findings, but no identifying information will be used.
- Highlight the only exception in regard to the need to break confidentiality would be if they said something to indicate that they or someone else is at risk of harm.
- Ask whether there are any elements of the consent form which they are unsure about and wish to clarify. If happy ask for the consent form to be signed.
- Switch on recorder and record verbal consent

#### Possible prompts that can be used throughout interview:

- Could you describe further?
- Tell me about?
- How does that differ from?
- Can you give me an example of?

#### Individual views about the meaning of independence

a) Can you describe what independence means to you?

#### **Prompts:**

A sense of carrying on being 'who you are' (continuity of identity)

- o Being able to carry out tasks without assistance
- Choice and control
- b) The relationship between continuity and change?

#### **Prompts:**

- Do you feel that independence is being able to change and adapt to different circumstances?
- Can you think of any anticipated changes and how these may impact on what independence means?
- c) The impact of personal background and experiences on what independence means?

#### **Prompts:**

- o How has your own past shaped the meaning of independence to you?'
- Can you think of any important/significant events (both positive and negative) in your life which affect your meaning of independence now?
- d) What areas of your day-to-day life are important to and/or you associate with independence?

#### Prompts:

- o Accommodation
- Finances management and security
- Heath/Physical mobility
- e) Is being able to carry out everyday tasks without assistance an aspect of independence? Are they important and/or necessary part of independence?

#### **Prompts:**

- Self-sufficiency
- Aids and equipment are they perceived as signifying a loss of independence or do they help support/maintain independence?
- f) Are there any aspects of your independence which you feel are more important to you than others?
- g) Is there anything which you feel promotes your independence on a daily basis?
- h) Is there anything which you feel limits your independence on a daily basis? What would constitute the biggest threat to independence?

#### The role of social support/social roles on the meaning of independence

a) Does independence involve others?

#### **Prompts:**

Reciprocity

- Is a sense of 'give and take' and/or helping others important to your sense of independence?
- Family/friends/neighbours
- b) What activities/hobbies are important to you and do (and how) these contribute to independence?
- c) Is carrying on with established social contacts and/or social roles an important aspect of independence?
- d) Do you feel how far (or need) supportive family/friends lives from your impacts upon independence?

#### The role of support services on the meaning of independence

a) Can you tell me about the help you are currently getting, or have got in the last six months?

#### **Prompts:**

- Aids and Equipment
- Voluntary sector services
- Services provided directly from local authority
- Self-directed support direct payments
- b) Can you tell me about the circumstances which prompted the need to receive this help?

#### **Prompts:**

- Were you worried about getting this help and the impact on independence - and were any of your concerns justified?
- Does the help any help you received impact (positive or negative) on the meaning of independence?
- Are there any ways in which you feel that the help we have talked about could be improved to promote independence?
- O How do you feel about having if needed to ask for help from different sort of people e.g. professionals, friends/family? Are there are any differences and do they impact on independence?
- c) Are there any ways in which the help you receive limit or interfere with your independence? Ask for examples

d) Can you think about whether any extra help that would help you to feel more independent?

#### **Ending question**

a) Is there anything else you would like to add/say about what independence means to you?

#### **Ending of interview**

- Check participant is feeling OK with ending the interview.
- Inform the participant that they have the opportunity to receive a copy of the transcript and are invited to remove or add anything should you wish to do so.
- Thank participant for input and taking the time to participate.

### **APPENDIX 6: Consent Form**





#### **Consent Form**

## The Meaning of Independence for Older People

The purpose of this form is for you to state whether or not you agree to take part in the study. Please read and answer every question. If there is anything you do not understand, or if you want more information please ask.

	Please tick	
	Yes	No
I have read the information leaflet and understand to purpose of the research and what is involved.	he	
I understand that the study is confidential and I will be named in any reports.	not	
I agree individual quotes may be used as part of the reporting of findings, but no identifying information vibe used.		
I agree for this interview to be recorded. (If no to this question the interview can still take place as I will as to take detailed notes).		
I understand that if I say anything that makes the researcher think that I am at risk of harm, they will have to tell the appropriate authorities.		
I am willing to be interviewed as part of this study.		
Name of participant:		_
Signature:		
Signature of researcher:		
Date:		

## **APPENDIX 7: List of Local support organisations**

## Contact details for local organisations that offer support:

Age UK York offers a range support services. These include practical support for example, equipment hire. They also provide services offering social support for example, befriending:

## Age UK York

Norman Collinson House
70 Walmgate
York
YO1 9TL
Phone 01904 627995
Email ageukyork@ageukyork.org.uk

The Older Citizens Advocacy Project provides a free and independent advocacy service

## **Older Citizens Advocacy York**

52 Townend Street York YO31 7QG **Phone** 01904 676200

Email info@ocay.org.uk

St. Sampsons centre is a social centre for older people offering a range of social opportunities.

#### St Sampsons Centre

Church St York YO1 8BE

Phone 01904 652247

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