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**Supporting people with an intellectual
disability and dementia: a constructivist
grounded theory study exploring care
providers' views and experiences**

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Glossary of Key Terms

Alzheimer's Disease (AD)	A type of dementia which causes atrophy in parts of the brain, such as the cerebral hemisphere. It kills and destroys brain cells and neurons, particularly affecting the temporal region. Over time, damage spreads to grey matter and the hippocampus. Two of the main neuropathological changes associated with AD are abnormal build ups of senile plaques and neurofibrillary tangles within the brain
Constructivist Grounded Theory	A contemporary version of grounded theory which shifts its epistemological foundations from positivist to constructivist. Constructivist grounded theory's constructivist paradigm is underpinned by the belief that realities are multiple and are constructed through social interactions
Dementia	An umbrella term describing a wide range of diseases and disorders of the brain. Although with differing fundamental causes, they all result in progressively deteriorating intellectual functioning, including a decline in cognitive performance and memory
Dementia Care Pathway	A tool for 'designing care processes, implementing clinical governance, streamlining delivered care, improving the quality of clinical care and ensuring the clinical care is based on the latest research' (Vanhaecht, Panella, van Zelm, & Sermeus, 2010, p.118).
Family Carers	A family member (this can include immediate or extended family, blood related or related by marriage) of someone with both an intellectual disability and dementia, who has provided (or has done so in the past) care and support for the individual.
Grounded Theory	A qualitative methodology that focuses on developing theories which are built inductively from the data. It applies unique features, such as comparative methods, with analysis starting as soon as the first data are collected.
Healthcare Professional	A trained professional who has currently or recently been on the care team of an individual with an intellectual disability and dementia, such as a nurse.

Intellectual Disability	People with an intellectual disability have an intellectual impairment, a social or adaptive dysfunction, and an early onset (before the age of 18).
Paid Carer	Someone who has currently or has previously been a caregiver to an individual with an intellectual disability and dementia, and is/ was employed to do so.

Abstract

Background

A growing field of research illustrates that carers often lack the necessary training and knowledge to provide the best care and support for people with an intellectual disability and dementia. Less research has explored carers' support needs, and the role of support structures and strategies to support carers in their role.

One recommended framework for planning and delivering support and services is the Dementia Care Pathway (DCP). Though widely implemented, little empirical evidence has explored the role of DCPs in the care and support of carers and people with an intellectual disability. This thesis aimed to provide an understanding of the experiences of carers, and to critically explore DCPs and other support structures within those experiences.

Methods

This study implemented a Constructivist Grounded Theory (CGT) methodology. Data were obtained through 23 semi-structured interviews with two family carers, eight paid carers, and eight healthcare professionals.

Findings

The CGT produced five interrelated categories (*Impact of Dementia, Challenging the Diagnosis Process, Continuum of Support, Continuity, and Continuum of Understanding*), which explained the multiple forms of burden experienced by carers, and the factors that alleviated or compounded this burden. Social support alleviated the impact of the dementia on the carer; however, the difference in the level and type of support between paid and family carers influenced the level of burden they

experienced, their ability to apply person-centred dementia care and ability to provide a dementia-friendly environment. The DCP acted as a framework that influenced the timing of dementia care planning and delivery of support, and alleviated the impact of the dementia on paid carers by supporting the development of dementia capable carers.

Conclusion

Overall, this study demonstrates the importance of planning for and supporting carers' holistic needs alongside the people they are supporting. DCPs offer a framework that can alleviate the impact of the dementia through timely post-diagnostic planning and support. Implications for supporting carers and DCP development are discussed.

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Chapter One: Introduction

1.1. Introduction

In recent times, there has been a growing awareness that people with an intellectual disability are living longer, and with this, developing age-related mental health problems, such as dementia. As there is an increase in the number of people with an intellectual disability who develop dementia, new and significant challenges will be experienced by their families, support staff and services (Watchman, 2014). Though there is an increasing amount of research exploring these experiences, there is a limited understanding of the structures and strategies drawn upon by paid and family carers, and how these inform the support they deliver to meet the person's changing needs. Furthermore, little is known about the role of a recommended support structure, the Dementia Care Pathway (DCP), in the support of carers and of people with an intellectual disability and dementia. Utilising a Constructivist Grounded Theory (CGT) methodology, this thesis is an exploration of the experiences of paid and family carers, and the role of a DCP in these experiences.

This Chapter starts with an explanation of the use and location of literature within this thesis. This is followed by background information and definitions of key concepts including the umbrella term, dementia, and the different types of dementia, intellectual disability, and information on these conditions when they co-exist. The development of different models of mental health services for people with an intellectual disability and dementia are described, before critically discussing person-centred care and care planning, two key components within dementia support. The underpinnings of a recommended framework for delivering person-centred dementia

services and supports, namely the care pathway, are discussed, with the limited empirical literature discussing their use being critically explored within dementia, intellectual disability, and the two conditions combined.

The empirical literature has illustrated both the impact and challenges of supporting people with an intellectual disability when dementia presents and worsens; this research has been explored to develop a rationale for this thesis. This Chapter continues with an introduction to reflexivity; exploring the researcher's experience and knowledge within the intellectual disability and dementia field, before providing an overview of the rationale for this research study, on which the research aims and questions are based, and brief details of this research study. The Chapter ends with a brief outline of the subsequent Chapters of the thesis.

1.2 Note on the Applied Methodology

In accordance with the methodology used, CGT, a thorough substantive literature review was not carried out until post data analysis. This is an important tenet of CGT, which helps to avoid 'importing preconceived ideas and imposing them on your work' (Charmaz, 2006, p.165), whilst encouraging the researcher to articulate their own ideas. Nevertheless, CGT recognises that a researcher may have familiarity with the research topic and literature (Charmaz, 2014), combined with 'guiding interests, sensitising concepts, and disciplinary perspectives' which act as departure points to develop the researcher's ideas but not limit them (Charmaz, 2006, p.17). This is pertinent in a PhD context, where the researcher is required to critically engage with the theoretical and empirical literature when developing the research study. Therefore, as advocated by prominent grounded theorists (Charmaz, 2014; Dunne, 2011; Urquhart, 2007), Chapter One contains a preliminary exploration of the literature that

has been used to contextualise this study, to critically discuss key terms and existing knowledge within this topic, and to provide a rationale for the research aims and questions. It has also acted to sensitise the researcher to current thinking within the intellectual disability and dementia field. This has meant critically engaging with key literature. This literature has focused on the experiences of paid and family carers supporting people with an intellectual disability and dementia, and the role of DCPs in these experiences. However, as Charmaz (2014) writes, grounded theories, with their strong focus on inductivity, may be unpredictable, making the extensive exploration of every theoretical route fruitless, as they may not be raised through the data. Therefore, within Chapter Five, there is a re-engagement with the literature, using the CGT and its key concepts to extensively and critically explore relevant literature and to compare it with the CGT and its findings.

The rationale for the use and positioning of literature within this thesis is further explored and explicated in Chapter Two. Having already engaged with the intellectual disability and dementia literature, it was essential to be reflective and to acknowledge the researcher's pre-existing knowledge acquired through previous roles and education (Bryant & Chamraz, 2007; Chamberlain, 2004; Charmaz, 2006, 2014). The use of reflexivity is also further discussed in Chapter Two.

1.3. Terminology

Internationally, there are various terms used to describe and categorise people with an intellectual disability. For instance, in the UK, the term learning disability has predominantly been used (Priest & Gibbs, 2004), and more recently with the social model of disability movement, the term learning difficulty has been introduced (Nunkoosing, 2011). In the USA, the terms mental retardation or mental deficiency are

used, whilst across Australasia the term intellectual impairment is in use (Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006). Other terms used are mental handicap (Tuffrey-Wijne et al., 2006) and developmental disability (Priest & Gibbs, 2004). Throughout this thesis, the term 'intellectual disability' is used. Intellectual disability is a widely-used term, both internationally and within academia. However, through some of the material within this thesis, such as the participant information sheets, the terminology has been adapted to the language more familiar to the participants; this meant using the term 'learning disability'.

Throughout this research study, the focus was not on any one type of dementia; therefore, the generic term dementia has been used, unless the literature specifically states a type of dementia. Furthermore, when the term carer/s has been used, this refers to both paid and family carers.

1.4. Background

Life expectancy in the United Kingdom (UK) is increasing, currently standing at 78.1 years for males and 82.1 years for females, with future projections for males born in 2011 being 90.3 years, and for females 93.8 years (BBC News, 2006; UK National Statistics, 2013a). Consequently, between 1985 and 2010 there has been a 20% increase in the number of people aged 65 or older, to the figure of 10.3 million (UK National Statistics, 2013b). This increase had been attributed to various factors, such as improvements in (and greater access to) health services, nutrition and medicine (Royal Geographical Society, 2013).

With such age rises there have been corresponding increases in the prevalence of dementia. In the UK, it is estimated that 820,000 people have some form of dementia

(Alzheimer's Research UK, 2012a), which is projected to increase to one million by 2021, and 1.7 million in 2051 (Alzheimer's Society, 2012a).

1.4.1. Defining dementia.

Dementia is an umbrella term used to describe a group of symptoms, and includes a wide range of diseases and disorders of the brain. Although with differing fundamental causes, they all result in progressively deteriorating intellectual functioning, including a decline in cognitive performance and memory (Kerr, 2007; Prasher, 2005). This decline is so severe that eventually cognitive impairment is compounded by alterations in mood and motivation, and deterioration in behaviour and social skills (Janicki & Dalton, 1999; Kerr, 2007; Prasher, 2005). The World Health Organisation (WHO, 2010) defines dementia as:

'a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation' (WHO, ICD-10, Chapter 5).

Cells within specific parts of the brain fail to work properly, and in some forms, cells eventually die (Alzheimer's Research UK, 2012b; Alzheimer's Society, 2012b). In many aspects, dementia is individualistic; its speed and severity vary from person to person, depending on the form of dementia (Alzheimer's Research UK, 2012b;

Alzheimer's Society, 2012b), but the course is always deteriorative. There is currently no cure, but the disease's progression may be slowed or better coped with through appropriate support, psychological treatments and medication. Some of the main types of dementia will now be briefly described.

Accounting for 62% of all cases of dementia in the UK, Alzheimer's disease (AD) is the most common form of dementia, yet its exact cause is elusive (Alzheimer's Society, 2013). It causes atrophy in parts of the brain, such as the cerebral hemisphere. It kills and destroys brain cells and neurons, particularly affecting the temporal region. Over time, damage spreads to grey matter and the hippocampus (Prasher, 2005).

Two of the main neuropathological changes associated with AD are abnormal build ups of senile plaques and neurofibrillary tangles within the brain (Prasher, 2005). Senile plaques, seen outside the brain cells, are areas of degeneration and are linked to beta-amyloid protein. This central core protein is created from amyloid precursor protein (APP), a considerably larger protein. Primarily, plaques are absent of any central amyloid. Senile plaques which are observed within AD then begin to appear; these have a central amyloid core with a shell of inflammation surrounding it. This precedes the development of burn-out plaques which consist of just the core with an outer shell of debris (Prasher, 2005).

The formation of neurofibrillary tangles is seen within the actual cell body. They form through altered tau proteins which make paired helical filaments; these then bundle together. AD fundamentally alters the structure of the brain cells which prevents them from functioning correctly. Death of brain cells consequently results in clinical features of dementia.

Vascular dementia is the second most common type of dementia, affecting approximately 150,000 people within the UK, (Alzheimer's Society, 2018). This form of

dementia, sometimes called 'stroke related dementia' is caused by a reduction in the blood supply to the brain through damaged blood vessels, for instance, due to cerebral vascular accident (CVA; Watchman, 2017). As the blood vessels in the brain are damaged by a CVA, the oxygenated blood's access to brain cells is restricted; consequently, the brain cells eventually die (Alzheimer's Society, 2018). As the brain cells die, the symptoms of vascular dementia, such as difficulties with memory, thinking, and/or reasoning present.

Around 10-15 people out of every 100 with dementia develop dementia with Lewy bodies. Dementia with Lewy bodies is caused by a build-up of small round clumps of protein inside nerve cells in the brain (Alzheimer's Research UK, 2018). Lewy bodies are formed as the protein alpha-synuclein clumps together; these clumps subsequently damage how the nerve cells work and communicate (Alzheimer's Research UK, 2018). How dementia with Lewy bodies affects the person will partly depend on within which part of the brain the Lewy bodies are present. Dementia with Lewy bodies may affect areas of the brain that control thinking, memory and movement, causing symptoms such as periods of confusion, movement problems, visual hallucinations, and sleep disturbances (Alzheimer's Research UK, 2018).

Frontotemporal dementia is a rarer form of dementia comprising a range of different conditions which damage the frontotemporal lobes of the brain. In frontotemporal dementia, it is thought that abnormal proteins build up in the nerve cells in the frontal and/or temporal lobes of the brain, causing clumps and the death of nerve cells; consequently, changing the pathways which connect both lobes. Additionally, some of the 'chemical messengers that transmit signals between nerve cells are also lost' (Alzheimer's Society, 2018). Over time, the tissue in the brain's frontal and temporal lobes shrink, as more and more nerve cells die (Watchman, 2017);

consequently, this causes symptoms such as personality and behaviour changes, and difficulties with language (Alzheimer's Society, 2018).

1.4.2. Understanding dementia.

The previous section has detailed biological changes associated with different forms of dementia which present as clinical features; however, different models and/or frameworks have been offered to understand how people experience dementia. How dementia is understood by carers and healthcare professionals is important in the kind of support they provide (Dodd, 2014). Buijssen (2005) offers further understanding of dementia and the psychological consequences for the individual. He suggests two laws of dementia: law of disturbed encoding; and law of roll-back memory. In the law of disturbed encoding, the person is no longer able to 'transport information from their short-term memory to their long-term memory' (p. 25). As the individual is unable to form new memories for the things they experience, they may become disorientated when in an unfamiliar environment; disorientated with time; less able to learn new things; inclined to misplace things, and prone to experiencing anxiety and stress.

The law of roll-back memory involves the long-term memory. After the dementia presents and worsens, the individual is less able to form new memories. Though long-term memories will initially remain intact, as the dementia worsens, these too begin to deteriorate. This deterioration starts with the most recent memories and progresses until the individual's remaining memories are of their early childhood. The consequences of the law of roll-back memory are the individual experiences loss in the ability to perform daily skills; memory loss; deterioration in self-care skills; personality changes; deterioration in ability to find words and a decrease in vocabulary; and a decline in social skills and increased inappropriate behaviour (Buijssen, 2005).

Another framework used to understand dementia is the social model theory (SMT). In the UK, the SMT was developed in the late 1970s and is rooted in the work of a group of physically disabled people who formed the Union of the Physically Impaired Against Segregation (UPIAS; Gilliard, Means, Beattie, & Daker-White, 2005). Through their publication, the Principles of Disability (Union of the Physically Impaired Against Segregation, 1976), the authors argued that the individual may have an impairment (loss of function due to their condition); however, they are physically disabled (how society views their impairment) through a broad range of social, economic, attitudinal, physical, and environmental factors (Gilliard et al., 2005; Oliver, 1996; Mental Health Foundation, 2015a).

Within dementia, the SMT shifts the focus away from the medical model view of dementia, where the person's experiences and actions are explained by the disease process and behaviours present according to the stage of the dementia (Taft, Fazio, Seman, & Stansell, 1997). Instead, it illustrates that whilst people with dementia have a cognitive impairment, their disability develops from how they are excluded and/or treated by others and the social and environmental barriers in place (British Psychological Society [BPS] & Royal College of Psychiatry [RCP], 2015; Gillard et al., 2005). Within the context of this research study, the SMT illustrates the possible role of carers and healthcare professionals in how people with an intellectual disability experience dementia (Brooker & Latham, 2016). Emphasis is on people without dementia reaching out to people with dementia; removing barriers and ensuring their inclusion (Gilliard et al., 2005).

The British Psychological Society (BPS) and Royal College of Psychiatry (RCP) (2015) state that the SMT provides a framework to better enable carers and healthcare professionals to understand 'that dementia is not the fault of the individual; that the

focus is on the person's remaining skills rather than losses; that the individual can be fully understood; the influence of an enabling or supportive environment; the key value of appropriate communication; and opportunities for stress-free and failure-free activities' (p. 49). However, Gillard et al. (2005), advocates of the SMT for dementia, state that though it provides a useful framework to understand experiences of dementia and care, it may not fully address the impact which the individual's impairment (changing cognitive ability) has on their lives.

1.4.3. Defining intellectual disability.

The World Health Organisation (2016) defines intellectual disability as 'a state of arrested or incomplete development of the mind' (ICD-10 'Mental and behavioural disorders F70-79'). It is essential that three internationally established criteria are met before an intellectual disability is identified or diagnosed. The individual needs to have an intellectual impairment, a social or adaptive dysfunction, and an early onset (before the age of 18) (Holland, 2011; Kerr, 1997). Within the UK's classification of severity of intellectual disability, there are four different levels which correspond with/ are classified by different levels of intelligence quotient (IQ) measurement; these are mild intellectual disability (IQ between 50-69), moderate intellectual disability (IQ between 35-49), severe intellectual disability (IQ between 20-334), and profound intellectual disability (IQ below 20) (ICD-10, 2016)

As illustrated in Table 1.1. (see page 11) there are four time periods in which an intellectual disability may occur: the preconceptual, prenatal, perinatal, and the postnatal and beyond periods (before 18 years old.); the causes for each period may generally be categorised as either heredity or environmental factors, with each period having differing causations (Carnaby, 2007; Watson, 2007).

Table 1.1. Aetiology of Intellectual Disabilities (Carnaby, 2007; Watson, 2007)

Period	Hereditary Factors	Environmental Factors	Biomedical Factors
Preconceptual	Parental genotype	Maternal health	
Prenatal	Chromosomal and genetic disorders, such as Down syndrome or fragile X syndrome	Infections, maternal health, nutrition and toxic agents	
Perinatal	Premature labour, asphyxia or other difficulties during giving birth, as well as injury		Various infections in the womb e.g. toxoplasmosis
Postnatal and beyond (before 18 years old)	Untreated genetic disorders such as Phenylketonuria (PKU)	Infections, trauma, toxic agents, nutrition, social and sensory deprivation	

One of the most common hereditary causes of an intellectual disability is Down syndrome (DS). This is a genetic condition which is accompanied by delayed development and by some degree of intellectual disability; the severity varies significantly between individuals. It is estimated that there are 60,000 people in the UK with Down syndrome. The most common cause, accounting for 94% of the Down syndrome population, is the presence of an extra copy of chromosome 21 in the cells of the body. A further cause of Down syndrome is translocation; this occurs when part of one of the three copies of chromosome 21 attaches to another chromosome, and accounts for 3% of the Down syndrome population. The final 3% comes from Mosaic Down syndrome; this occurs when cells with the extra chromosome 21 become mixed with normal cells (Down Syndrome Extra 21, 2012).

1.4.4. Ageing and intellectual disability: Dementia

Historically, people with an intellectual disability have had a low life expectancy, yet increases have been gained over the past 80 years (Strydom et al., 2010). As shown in Table 1.2., people with a mild intellectual disability now have a life expectancy of 74, so are living to a similar age as the general population. Additionally, there are more people across the intellectual disability spectrum of severity living until middle and older age. With more people living into old age, there have been population increases of 53% from 1960-1995 (Cooper & Holland, 2007).

Increases in the number of people with dementia have also occurred in people with an intellectual disability. In almost all aspects, dementia presents in a similar fashion for people with an intellectual disability as for those without (Alzheimer's Society, 2011), yet there are several differences. For unknown reasons, people with an intellectual disability are at greater risk of developing dementia than the general population (Alzheimer's Society, 2011; Cooper & Holland, 2007; Prasher, 2005).

Table 1.2. Life Expectancy of People with an Intellectual Disability (Bittles et al., 2002; Cooper & Holland, 2007; Holland, 2000; Puri, Lekh, Langa, Zamas, & Singh, 1995)

	Year of Birth	Mean Life Expectancy (years)	Year	Life Expectancy
Down Syndrome	1929	9	Today	50+ years
Intellectual Disabilities (other causes)	1930s	Men: 15 Women: 22	Today	Mild intellectual disability: 74 Moderate: 67 Severe: 58

Symptoms at the early stages may appear to be different from the general population; people with Down syndrome or severe forms of intellectual disability, for example, may present with mood and personality changes rather than the declines in memory as first seen in the general population (Alzheimer's Society, 2011; Cooper & Holland, 2007). Dementia may progress more rapidly; it is less likely to be correctly diagnosed, and more likely to be diagnosed at a later stage (Alzheimer's Society, 2011; Prasher, 2005).

People with Down syndrome present a special case in relation to dementia; they are significantly more likely to present with AD than either the general population or people with other forms of intellectual disability (Alzheimer's Society, 2011; Cooper & Holland, 2007; Prasher, 2005). The most prominent explanation revolves around chromosome 21. Unlike people with other forms of intellectual disability and the general population who have two copies of chromosome 21, most people with Down syndrome have three copies in every cell in the body (Kerr, 2007). Chromosome 21 contains the gene for beta-amyloid precursor protein; this creates the beta-amyloid protein which is linked to AD (Kerr, 2007). Neuropathological studies have found increased deposits of this protein in the early childhood of people with Down syndrome which precedes the later development of the neuropathological features of Alzheimer's disease, namely plaques and tangles (Cooper & Holland, 2007; Mann, 1988; Prasher, 2005). Most people with Down syndrome develop these prior to the age of 40, though few present with the clinical features of dementia until their 50s (Cooper & Holland, 2007; Kerr, 2007; Mann, 1988). A minority never present with symptoms of AD even with the presence of neuropathological features. An important feature of this thesis is the support delivered to people with an intellectual disability and dementia; the next section highlights the challenges that people with an intellectual disability may have in accessing the same services and supports as people without an intellectual disability.

1.5. Intellectual Disability and Health Care

As dementia is more prevalent in people with an intellectual disability than in the general population, it is reasonable to assume that more families, carers, healthcare professionals and services will experience dementia, and provide support and care to individuals with both an intellectual disability and dementia. Some people with an intellectual disability may be vulnerable and also marginalised from mainstream society (The Department of Health (DH), 2009a). The DH (2000, pp. 8-9) defines a vulnerable adult as someone:

‘Who is or may need community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation’

Marginalisation, on the other hand, means that some people are restricted from positions and resources within society; they are on the margins of society and are thought unable to contribute to society (Schiffer & Schatz, 2008).

People with an intellectual disability may be vulnerable to discrimination and abuse, breaches of their human rights, inequalities in care, and may be marginalised and thus denied the same life chances as the general population (Black, 2013; DH, 2009a; Emerson, Baines, Allerton, & Welch, 2011; Turning Point, 2004). For instance, the *Treat Me Right* (Mencap, 2004) and *Death by Indifference* (Mencap, 2007) reports have exposed inequalities in, and barriers to receiving good care, in addition to institutional discrimination experienced within the NHS. These inequalities have been supported by the Disability Rights Commission (DRC) who reported the health

inequalities that people with an intellectual disability and mental health problems experience, which included fewer screening tests and health investigations (DRC, 2006). Despite such reports, abuse, discrimination and poor care are still experienced by people with an intellectual disability, as documented in the Winterbourne View Hospital report (DH, 2012a) and the Confidential Enquiry into Premature Deaths of People with Learning Disabilities report (Heslop et al., 2013). These reports paint a picture of poor, unequal healthcare combined with institutional discrimination leading to neglect and sometimes death. Considering such evidence, one can confidently predict that dementia care for people with an intellectual disability has followed a similar path.

Attempts have been made to improve healthcare for people with an intellectual disability, more recently through the Building the Right Support report (Local Government Association, Association of Directors of Adult Social Services, & NHS England, 2015) and the Transforming Care programme national plan, the Time for Change: The Challenge Ahead report (Bubb, Brittan, & Dixon, 2016). Both reports highlight several recommendations to reduce the reliance on inpatient services, and reduce the number of people with an intellectual disability who are still in institutional care, through the development of community-based services. These reports also make recommendations around the improvement of care, support and access to services. However, such reports have also criticised the lack of progress which has been made since the Winterbourne View Hospital abuse scandal in 2011.

As illustrated throughout the reports discussed in this section, care and support services have been central in the healthcare of people with an intellectual disability; understanding the role of these services is an important element of this research. Section 1.6. provides the context to the development of services within intellectual

disability, before outlining and evaluating different models of delivering dementia services, which aim to ensure access to quality care and support.

1.6. Service Delivery Context

Intellectual disability has a long history within the UK. To understand the current service context for people with an intellectual disability and dementia, it is important to explore some of the key historical aspects which have influenced it. As society's attitudes towards people with an intellectual disability have changed, so have intellectual disability services. Historically, it was believed that people with an intellectual disability lacked the cognitive capacity to have a mental health problem (Smiley, 2005); consequently, little attention was paid to providing mental health services. Most people with an intellectual disability received all their support within institutions. The popularisation of institutions emerged as the UK transformed from an agricultural to an industrial society. This transformation contributed to the challenges that people with an intellectual disability faced when trying to contribute to the workforce (Brigham, 2000), resulting in their exclusion from production processes. Families often became unable to support non-productive family members (Brigham, 2000). Simultaneously, there were calls to segregate people with an intellectual disability, which was mirrored by a growing number of institutions built to care for them.

The Victorian and Georgian eras oversaw increasing institutionalisation of people with an intellectual disability, with institutions becoming their main care provider (Digby, 1996). This resulted in the building of 'large mental deficiency 'colonies'' (Priest & Gibbs, 2004, p.4), which were believed to provide the security, care, and the treatment many families could not, whilst preventing the genes of people with intellectual disabilities being passed on to future generations (Jackson, 1996).

By the early 1900s public opinion had begun to change, with the suitability of institutions being questioned. In 1954, the institutionalised population reached its peak at approximately 150,000. By this time growing evidence highlighted institutions' harmful effects. For instance, Barton (1959, as cited in Norman & Redfern, 1997) found that aspects of institutional life increased the probability of patients contracting a further 'disease' which was independent of their original illness or condition; Barton called this institutional neurosis. These aspects consisted of deprivation of contact with the outside world, lack of activities and the implementation of enforced idleness (Norman & Redfern, 1997). Those institutionalised had a loss of interest, increased submissiveness, a loss of individuality and a lack of initiative and apathy. This finding was identified by Goffman (1968), who found that institutionalised patients had lost their control, individuality and personality, due to those institutionalised carrying out all activities, such as, sleep, work, and play, in the same establishment, according to the same routines.

These concerns were reflected in policy change. The Percy Report (1954-57) *recommended moving from the use of hospital-based to community-based care*; consequently, the Mental Health Act (1959) abolished the 1913 Mental Deficiency Act procedures of compulsory certification and detention for mental defectives (this included people with an intellectual disability; Webb, 2013), and stated that people should only be admitted to institutions on a voluntary basis or if they were a danger to themselves or others. The Better Services for the Mentally Handicapped (Department of Health and Social Security, 1971) White Paper set out the programme for deinstitutionalisation in the UK. This paper stipulated that by 1991 there would be a 50% reduction in hospital places and an increase in the 'provision of local-authority based residential and day care' (Atherton, 2007, p.58). These changes coincided with,

and were advocated by, the principle of normalisation within services (Hamlin & Oakes, 2008). Wolfensberger (1972) argued that institutions were poorly designed and run, resulting in residents being dehumanised. Wolfensberger defined normalisation as the 'utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible' (p.28). Wolfensberger promoted the view that people with disability should live a 'normal life'; consequently, advocating moving people with an intellectual disability out of institutions and into community-based care.

In the UK, O'Brien and Tyne (1981) adapted the principles of normalisation and operationalised them into five service accomplishments: community presence; choice; competence; respect; and community presence. These provided a framework for services within the UK for people with an intellectual disability. Successive legislation, which has directed service provision for people with an intellectual disability, advocated the 'principles of an ordinary life' (Atherton, 2007, p.59). For example, the NHS and Community Care Act (1990) enabled implementation of support structures, such as an increase in the range of domiciliary, day and respite services, enabling people with an intellectual disability to remain in their own homes. It endorsed independent care options and placed greater importance on providing support for informal carers (Atherton, 2007). Such legislation and changes in attitudes helped to oversee deinstitutionalisation, with the number of institutionalised people with an intellectual disability in England and Wales being reduced from 65,000 in the 1960s to 1,500 in 2003 (Hamlin & Oakes, 2008).

Since the 1980s, efforts have been made to gain a greater understanding of mental health problems in people with an intellectual disability (Smiley, 2005), and to consider how best to care and provide support for these individuals. This is reflected

in more recent policy, such as the Valuing People (DH, 2001) White Paper, which aimed to further improve the lives of people with an intellectual disability, by promoting new national objectives to improve their rights, independence, choice and inclusion including greater access to mainstream healthcare and improvement in health equality. The White Paper places emphasis on the use of mainstream mental health services, and states that people with an intellectual disability and mental health problems should 'be able to access services and be treated in the same way as anyone else' (DH, 2001, p. 66).

This emphasis was further supported by the Valuing People Now (DH, 2009a) three-year strategy, which again advocated the use of mainstream mental health services and the person's right to use these. The strategy recognises that some people with an intellectual disability require both mainstream and specialist services. However, it highlights areas for improvement, such as lack of access to mainstream services, lack of communication and cooperation between mainstream mental health and specialist intellectual disability services, and a lack of appropriate assessment and treatment (DH, 2009a).

1.6.1. Dementia services.

The dementia services used by people with an intellectual disability vary between: specialised services provided by an intellectual disability team (Benbow et al., 2010); mainstream services available to the general population (Chaplin, Paschos, & O'Hara, 2010); or integrated services, which make use of the expertise and resources of both specialised and mainstream services (Hall, Higgins, Hassiotis, & Samuels, 2006). Both the Valuing People: A New Strategy for Learning Disabilities for the 21st century (DH, 2001) and the Valuing People Now strategy (DH, 2009a) have

advocated that people with an intellectual disability should first and foremost have access to mainstream mental health services, while specialist intellectual disability services should provide support and facilitation. The Royal College of Psychiatrists Working Group (2004) states that the responsibility of care for individuals with an intellectual disability and dementia should be taken by the service which has the 'greatest expertise in relation to the care needs of an individual' (p. 4).

In reality, the decision about which service model people with an intellectual disability and dementia use may depend on factors including geographical location, and individual NHS Trusts and other resources (Benbow et al., 2010). Healthcare professionals' beliefs and assumptions about different services may also play a role in referral decisions (Graham et al., 2003). Several challenges have been highlighted for both mainstream and specialised services. As indicated through the Healthcare for All (2008) report, people with an intellectual disability may already experience many barriers in accessing adequate healthcare and services within mainstream services, such as finding it more difficult to access appropriate services for conditions not associated with their intellectual disability. This is compounded by a lack of reasonable adjustments made across services and a lack of knowledge around intellectual disability by healthcare professionals (Michael & Richardson, 2008). Several further barriers to accessing health services, such as challenges with communication, insufficient facilities, and mainstream health professionals lacking interpersonal skills when caring for people with an intellectual disability, have been highlighted (Alborz, McNally, & Glendinning, 2005). Such evidence highlights the inequalities and barriers of access to mainstream services for people with an intellectual disability; this may only be heightened by the presence of dementia, as staff may feel ill-equipped to deal with complex mental health problems (Bouras & Holt, 2004).

As the suitability of mainstream services for people with an intellectual disability and dementia has been questioned, specialised services, which may already have knowledge of the individual, and have expertise around intellectual disability, have been recommended (Benbow, Grizell, & Griffiths, 2014). However, the changing demographics across this population is presenting intellectual disability services with new challenges. As an increasing number of people with an intellectual disability present with dementia, services and staff are experiencing symptoms and issues which are challenging 'traditional intellectual disability service approaches and philosophies' (McCarron, McCallion, Reilly, & Mulryan, 2014, p. 241). Intellectual disability services, which have traditionally supported a younger population, may not have the expertise, facilities or resources to cope with an influx of people with dementia (Benbow et al., 2010); whilst mainstream old age psychiatry services may be ill-equipped and lack the expertise to support someone with an intellectual disability, intellectual disability psychiatric services may not have an in-depth knowledge of dementia to care for these individuals.

Benbow et al. (2010) indicated that across both specialised intellectual disability psychiatry services and generic old age psychiatry services, dementia services are patchy and depend on individual interest and development in local services. There are concerns about how adequately equipped these services are to support and care for people with an intellectual disability and dementia. Benbow et al. surveyed members of the Executive committees of the Faculties of Old Age Psychiatry (OAP) and Intellectual Disability. From the 444 returned surveys, 399 comments were analysed. In response to a question asking about existing services for people with an intellectual disability and dementia, 27% of the 399 respondents indicated that there were no specific or specialised services. Further analysis specifically highlighted gaps in

services relating to issues with staff training/ resources, a need for specialist accommodation, absence of a service, and an ignorance of this service user group by professionals.

Gaps in resources and expertise across both service models have resulted in the bringing together of mainstream and specialised services in inter-disciplinary and multi-disciplinary teams to provide integrated services (Hall, Higgins, Hassiotis, & Samuels, 2006). For example, Hall et al. (2006) developed an integrated mental health service in London where all patients are cared for by the same nursing team, who received specialised intellectual disability training. Additionally, inpatient facilities consisted of specialist beds within mainstream acute psychiatric wards for people with a mild intellectual disability (Hall et al., 2006). The clinical outcomes of this integrated mental health service are encouraging. Hall et al. found improvements across a broad range of outcome measures at discharge and 6 months after admission for patients. Patients significantly improved in functioning and had a significant reduction in the severity of their mental health problems. Improvements were also found for psychiatric symptoms and overall functioning, whilst patients had fewer unmet needs.

The source of services, and their access to knowledge, expertise, and resources will undoubtedly influence their role in the quality of lives of people with an intellectual disability and dementia. As illustrated in section 1.4.2., with the description of the social model theory to understanding dementia, and further highlighted in section 1.7., the care and support delivered by healthcare professionals within healthcare services, and by others, such as family and paid carers, who are likely to provide direct support to the individual, can have a positive and/or negative impact on people with an intellectual disability and dementia. An important element of how dementia care, support, and services are planned and delivered is the philosophical underpinning

adopted and applied. Section 1.7. provides context to the role of services, healthcare professionals, and carers in the quality of life of people with an intellectual disability and dementia. It details the current guidelines for the delivery and planning of dementia care, and critically discusses the philosophical underpinnings of dementia care; whilst illustrating the central role of carers, healthcare professionals, and services in ensuring the quality of life of the people they support with dementia, and highlighting the equally important, but often neglected need to ensure family and paid carers are appropriately supported in their role.

1.7. Dementia Care

To better understand the role of others, such as family and paid carers, in the support of people with an intellectual disability and dementia, it is important to understand the philosophy underpinning the planning and delivery of care, support, and services. The Edinburgh Principles (2002), an important document and source of guidance for the development of support and services within intellectual disability and dementia, states that support should be underpinned by an appropriate philosophy that fosters quality of life, whilst advocating a person-centred approach. Putting the person at the centre of support is not new within intellectual disability services (Dodd, 2014). Both Valuing People (2001) and Valuing People Now (2009) advocate support being underpinned by the individual's wishes, preferences, and aspirations; whilst ensuring the active control and inclusion of people within decisions about their lives.

The BPS Dementia Advisory Group (2016) further advocates an approach to care and support which focuses on the person rather than the disease; individually tailoring support to the person's needs across their journey with dementia, and helping the person to live well with the dementia. Additionally, the BPS and RCP (2015) state

that support should be underpinned by a holistic, individual, person-centred approach that reflects the person's happiness, comfort, security. Support should be informed by the individuals:

'expressed views and a wide range of personal factors, including profile of abilities and communication needs, cultural background, life experiences, significant relationships with family, carers and peers, and preferred activities, as well as working to minimise known risks' (BPS & RCP, 2015, p. 40).

Guidance illustrates that support needs to adapt to the changing needs of the person with an intellectual disability and dementia, ensuring that the person has 'stress-free, failure-free but individualised care that is consistent but without time pressures' (BPS & RCP, 2015, p.53); care that considers both the social and physical aspects of the person's life, and ensure their social needs are met (BPS & RCP, 2015; Dodd et al. 2017). Additionally, support should focus on skill maintenance rather than development of new skills (The Edinburgh Principles, 2002); this may be in contrast to the philosophy of care of intellectual disability services, where traditionally the focus has been on skill and competency development. Support also needs to be planned rather than reactive; considering and planning for possible 'stressors' (BPS & RCP, 2015; The Edinburgh Principles, 2002) and ensuring the future needs of the individual and their carer are met. Recent National Institute for Health and Clinical Excellence's (NICE, 2018) and Public Health England (2018) guidelines emphasise the need for advance care planning (see section 1.7.3.) to ensure the individual has as much control and choice as possible in planning their own lives.

Importantly, support needs to be informed by the participation of people with an intellectual disability and dementia, and those closest to them; ensuring, where possible, the active, meaningful involvement of people with an intellectual disability and dementia within the decision-making process in aspects of their care and own lives (BPS, 2016; BPS & RCP, 2015; Dodd, 2017; NICE, 2018). Similar points are reflected in recent guidance, which advocate a rights-based approach to supporting people with an intellectual disability to live well both with and without dementia (Alzheimer's Society, 2015; Valuing People Now, 2009; Voluntary Organisations Disability Group, 2017). In a rights-based approach, emphasis is placed on Participation, Accountability, Non-discrimination, Empowerment, and Legality (PANEL). The rights-based approach puts the rights of people living with dementia and their carers to actively participate in 'all decisions which affect their lives and wellbeing' (World Health Organisation [WHO], 2015, p.1) at the forefront of support; whilst placing accountability on those providing care and support to uphold the rights of care recipients.

1.7.1. Person-centred care.

As demonstrated throughout the guidance described in 1.7, a person-centred approach is an important underpinning of the delivery and planning of support for people with an intellectual disability and dementia. Person-Centred Care (PCC) within dementia can be attributed to the theoretical work of Tom Kitwood (1997). Kitwood challenged the medical model of dementia, instead, believing that how the dementia is experienced is informed by an Enriched Model of Dementia. This model takes into account interconnected biopsychosocial factors, including neurological impairment, psychological factors such as health and individual psychology, and the social environment in which they live. Kitwood (1997) believed that all people with dementia

have psychosocial needs that centre around love, including attachment, comfort, identity, occupation, and inclusion.

Kitwood's (1997) work around personhood, the Enriched Model of Dementia, the impact of Malignant Social Psychology, and taking the individual's standpoint shifted how people with dementia are viewed and cared for. These concepts and standpoint are the theoretical underpinnings of PCC (Brooker & Latham, 2015). Personhood, someone's individuality, is defined as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997, p.8). It is not exclusively linked to the individual's cognitive functioning, which deteriorates as the dementia worsens, but is also 'socially constructed in an interactional environment' (Smebye & Kirkevold, 2013, p.2). Kitwood emphasised the need for relationships, interaction and inclusion to ensure personhood. This has implications for caregivers; those not supporting someone's personhood may encourage higher levels of challenging behaviour, distress, apathy, and even depersonalisation; in contrast, those providing an environment which maintains and nurtures personhood, encouraging greater inclusion, better ensure well-being and social confidence.

Malignant Social Psychology encompasses a variety of behaviours that undermine the personhood and well-being of the individual, for example, where people are ignored, not listened to, outpaced, disempowered, stigmatised, and/or labelled (Mitchell & Agnelli, 2015). Generally, these behaviours occur where caregivers have a lack of knowledge and training, before becoming intertwined within caring culture. Repeated Malignant Social Psychology behaviours become normalised within the organisational culture (Brooker & Latham, 2015). New staff then learn these behaviours, through role modelling, from established staff.

Person centred care illustrates the need to understand the unique experiences of the individual, taking a holistic approach to their needs, whilst understanding and using the individual's unique perspectives, life history, interests, preferences and needs to inform care (Brooker & Latham, 2015; Mitchell & Agnelli, 2015); even when their subjective experience differs from what others deem as 'reality' (Kitwood, 1997). Through 'positive person work', such as recognition, collaboration, validation, facilitation, giving, and celebration (Mitchell & Agnelli, 2015), the caregiver can promote and nurture personhood, individuality, autonomy and well-being (Brooker & Latham, 2015).

Nevertheless, PCC and its theoretical underpinnings have been criticised in several ways. For instance, Dewing (2004) questioned the academic rigour of Kitwood's work, which appeared to be developed from little empirical evidence, whilst Adams (1996) questioned the reliability and validity of Kitwood's methods, as they lacked transparency and robustness.

Furthermore, critics have targeted Kitwood's lack of clarity of how PCC translates into practice (Dewy, 2008) and lack of guidance of how it can be implemented by carers and healthcare professionals across contrasting settings (Moore et al., 2017); making it difficult to apply PCC into practice (Edvardsson, Fethersonhaugh, Gibson, & Nay, 2010). This abstractness could make delivering PCC challenging for carers, especially for family carers who are less likely to receive the necessary support and training. This is compounded by the lack of a clear definition of PCC, which has taken on different meanings for different people in different environments (Brooker & Latham, 2015; Fazio, Pace, Flinner, & Kallmyer, 2018; Manthorpe & Samsi, 2016). Brooker (2007, p.12) and later Brooker and Latham (2015) have tried to clarify PCC through the widely applied VIPS model: 'valuing people with

dementia and those who care for them (V); treating people as individuals (I); looking at the world from the perspective of the person with dementia (P); and a positive social environment (S)'.

Nolan et al. (2004) suggest that PCC neglects to consider others, such as caregivers, who are considered in terms of the impact of their relationship on the person with dementia. Consequently, PCC may neglect the issues of family and paid carers (Wilson, Swarbrick, Pilling & Keady, 2012). Instead of PCC, Ryan, Nolan, Reid, and Enderby (2008) recommend the application of a relationship-centred approach. This is a complementary philosophy of care where all those involved 'appreciate the importance of their relationships with each other' (Wilson et al. 2012, p.78). Personhood is simultaneously recognised for both the person receiving care, and the person providing care (Suchman, 2006). Consequently, supportive interventions are implemented to meet the needs of both the individual with dementia and their carers.

Nevertheless, the use of PCC has been advocated and widely-used throughout dementia care (DH, 2009b). Brooker's (2007) VIPS framework for PCC has been used within NICE (2006; updated 2016) clinical guidance for dementia care. The use of a PCC approach has been further reinforced within the 'Living well with dementia: A national dementia strategy' (DH, 2009b), which emphasises putting the person with dementia and their carers at the heart of their care through an inclusive process.

1.7.2. Care planning.

To ensure the person's personhood and rights are maintained, and that care is informed by the individual and their preferences, NICE (2018) advocates the principles of person-centred planning (PCP). Care plans are electronic or paper-based documents, that are personalised to suit the individual, and set out how the individual's

care and support needs are to be met (NHS, 2018). Care plans are likely to be developed through input of many people, including healthcare professionals and carers (Matousova-Done & Gates, 2006), again highlighting the importance of both in ensuring the person with an intellectual disability and dementia is supported and cared for. They can be used to ensure that an individual receives the same care no matter which member of staff is providing support; and to record the care delivered to and received by the individual (NHS, 2018; Royal College of Nursing, 2016). PCP is a cluster of concepts which may be used as a tool to ensure a person-centred approach and guide good practice (McNally, 2006). PCP has become increasingly important as a mechanism for implementing the four objectives (rights, independence, choice, and inclusion) of the Valuing People (2001) White paper. Mansell and Beadle-Brown (2004, p. 69) state that PCP aims to consider the 'aspirations and capacities expressed by the service user or those speaking on their behalf, rather than needs and deficiencies'. Like the principles of PCC, PCP provides a method which focuses on the individual's preferences and what is important to them. It aims to make changes in the person's life; focusing on what is important to the individual now and in the future, and ensuring, in collaboration with those closest to the person, that actions are taken, and support put in place to facilitate this (Dowling, Manthorpe, & Cowley, 2006; McNally, 2006). This approach goes beyond just including the person, but actively aims to help them 'take control and own their plan' (Lay & Kirk, 2012, p. 147). PCP is composed of a variety of approaches, including essential lifestyle planning, making action plans, and personal futures planning (Dowling, Manthorpe, & Cowley, 2006; McNally, 2006; Ryan & Carey, 2009); at the heart of these approaches is PCC. PCPs are responsive to the changing needs and aspirations of those they focus on. However, perhaps the most damning criticism of PCP is the lack of quality evidence to support its effectiveness

and use (McNally, 2005; Millard, 2015). PCP is a method of planning and implementing care that has been widely used within intellectual disability, and shares the underpinning principles of PCC. Importantly, both PCP and PCC place the individual's preferences and what is important to them at the forefront of care. To better achieve this, it is especially important, when dementia is present, that PCP is started as early as possible to better ensure the individual is involved in the care planning process.

Dementia is a degenerative disease, which results in progressively deteriorating intellectual functioning. Therefore, to ensure the preferences and wishes of the person with an intellectual disability are met and upheld, it is important that care planning considers the individual's future needs and wants as early as is feasibly possible.

1.7.3. Advance Care Planning (ACP).

A core concept within care planning for people with dementia, which is recommended to ensure the delivery of person-centred care, is advance care planning (ACP) (Beck, McIlpatrick, Hasson, & Leavey, 2017; NHS England, 2017; Social Care Institute for Excellence [SCIE], 2018). ACP is widely recommended through UK guidance (e.g. NHS End of Life Care Programme) to be offered to all patients with palliative, life-limiting illnesses, such as cancer and dementia (DH, 2008).

ACP is a multi-stage process whereby the patient and key stakeholders, achieve a shared understanding of the individual's preferences and wishes of the sort of care and treatment they want to receive as their dementia worsens, including where they wish to live and their preferred place of death (NHS England, 2017; Robinson et., 2012). It is about planning for a time when the person with dementia cannot make some decisions themselves (Social Care and Institute for Excellence, 2015). Dempsey (2013) emphasises the importance of this process taking place prior to the individual

losing their mental capacity. Importantly, ACP has been described as a process, rather than a one-off event (Beck et al., 2017; SCIE, 2018). ACP aims to empower the individual with dementia and support their autonomy (Dixon, Karagiannidou, & Knapp, 2018). It is underpinned by a person-centred philosophy, as the person with dementia is supported to make decisions about their own future support, care, and living arrangements (Dempsey, 2013).

Previous research has illustrated the potential benefits of ACP within non-dementia populations, such as increased feelings of autonomy (Bisson, Hampton, Rosser, & Holm, 2009), patient satisfaction (Singer et al., 1998; Tierney et al., 2001), and improved quality of care (Detering, Hancock, Reade, & Silvester, 2010). Within the dementia population, the extant literature has shown that ACP can help patients and family and paid carers to think about and plan for the future, supporting people with dementia to make their wishes and preferences known, and resulting in patients' feelings of relief and reducing levels of worry about the future (Poppe, Burleigh, & Banerjee, 2013). Furthermore, ACP has been associated with some improved end-of-life outcomes (including the person dying in their preferred place of death, a decrease in hospital admissions, a decrease in burdensome transitions), and increased carer satisfaction (Dixon et al., 2018).

Although, in principle, ACP has been recognised as an important element of person-centred care planning within dementia (Beck et al., 2017; Robinson et al., 2012), the literature has highlighted barriers to implementing ACP in practice, including: a lack of appropriate knowledge and skills in healthcare professionals (Dempsey, 2013; Livingston et al., 2013; Robinson et al., 2012); discomfort with speaking about aspects of ACP, such as end-of-life care (Dempsey, 2013); healthcare professionals' concerns about being able to deliver patient choice (Robinson et al.,

2012); and families and healthcare professionals' initiative or lack of it, and/ or their willingness or reluctance to initiate ACP (Steen et al., 2014). Without sufficient training and/or support, it is likely that ACP is not engaged in by paid or family carers; meaning missed opportunities to ensure the active involvement of people with an intellectual disability and dementia in decisions relating to their future quality of life.

1.8. Care Pathways: A Framework for Guiding Care Planning and Delivery

As explicated within the previous section (1.7.), underpinning support and care with a PCC approach is important for ensuring the quality of life, personhood and rights of the individual with dementia. Dementia Care Pathways (DCPs) are a recommended framework (BPS & RCP, 2015) for the planning and delivery of services and support, which can ensure the principles of PCC are implemented, through a multi-disciplinary approach. Equally important is the role DCPs may have in the support of carers. Paid carers and family carers may need support to apply the principles and concepts of PCC (Dodd, 2014) and better ensure the quality of life of people they are supporting, but also require their own needs to be met; DCPs are able to provide such support, alongside meeting the physical, psychological, and social needs of carers. This section 1.8. critically discusses the use of DCPs, and the limited empirical evidence, but increasing use, in intellectual disability and dementia services.

Various terms (including clinical pathway, integrated care pathway, critical care pathway and care maps) are used interchangeably to describe a care pathway-approach, with some having slightly differing meanings (Samsi & Manthorpe, 2014). Within this thesis, care pathway, the more general term which encompasses the above alternative terms, has been used.

Within the UK, care pathways were introduced during the early 1990s to improve standards and outcomes in healthcare, whilst reducing costs (Powell & Kwiatek, 2006). Care pathways aim to establish measurable outcomes, exhibit a greater level of efficiency in both care and cost, and to be flexible to meet changing healthcare needs (Allen, 1997). Campbell, Hotchkiss, Bradshaw, and Porteous (1998, p.317) state that care pathways are 'structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem' and can be used to implement national guidelines into local protocols and clinical practice. Vanhaecht, Panella, van Zelm, and Sermeus (2010, p.118) define care pathways as tools for 'designing care processes, implementing clinical governance, streamlining delivered care, improving the quality of clinical care and ensuring the clinical care is based on the latest research'. Vanhaecht et al. (2010) state that care pathways are used to implement a philosophy of care, such as PCC; they ensure that this is standardised and followed up. Care pathways may be used flexibly; forming all or part of a patient's care and have been widely applied across healthcare settings, medical conditions (e.g. depression, asthma, epilepsy), and surgical conditions and procedures (e.g. joint replacement, colectomy, mastectomy; Campbell et al., 1998; RCP, 2017). In their simplest form, care pathways are documents which state the patient's pre-determined journey through services. Key elements of any care pathway are the healthcare professionals, usually drawn from multi-disciplinary teams, who deliver the services and support, and ensure the pathway is followed.

Increasingly, the qualities of care pathways have been evidenced within the literature, with benefits noted for healthcare professionals, patients and carers. They are said to improve the quality of care delivered to patients whilst reducing costs and providing a coordinated approach to evidence-based assessment, interventions, and

service provision (Atwal & Caldwell, 2002). They have also been shown to improve multi-disciplinary communication, teamwork and relationships between healthcare professionals, as well as an understanding of each other's role (Ahmad et al. 2007; Kulakkottu, 2016; Powell & Kwiatek, 2006; Vanhaecht et al., 2010), and knowledge (Kulakkottu, 2016). Finally, they have demonstrated improved consistency in care, whilst reducing a patient's length of stay in hospitals (Rotter et al., 2010).

The rhetoric around the implementation of care pathways has been persuasive, as healthcare services are increasingly using pathways in an attempt to ensure multi-disciplinary working to improve care outcomes whilst reducing costs and variations in services. However, there remains a dearth of quality evidence supporting their implementation, use and effectiveness (Allen, Gillen, & Rixson, 2009; Jenkins et al., 2008; De Luc et al., 2001; Kwan & Sandercock, 2004; Powell & Kwiatek, 2006; Sulch & Kalra, 2000). The evidence which exists is sometimes inconsistent (De Luc et al., 2001; Vanhaecht et al., 2010). Allen et al. (2009), through a systematic review, have shown that care pathways' effectiveness may be limited to specific contexts. Allen et al. reviewed seven studies and reported that care pathways were most effective under predictable patient care trajectories, such as surgical areas with stable, set routines, and less effective for conditions where care trajectories are not predictable; such as dementia, which may vary in its course and between individuals. The effectiveness of care pathways was reported to be less clear where recovery pathways varied; and more effective in ensuring behaviour changes (within staff) where services have pre-established deficits. One shortcoming of this review was the limited number of reviewed trials, which covered a wide range of patient groups and settings; consequently, there may be uncertainty about the reliability and the generalisability of their conclusions. Worryingly, Sleeman et al. (2015) write that care pathways, whilst

providing some benefits, mainly for healthcare professionals, may have negative outcomes for patient care as they promote a 'tick box' approach and inhibit individualised care. Such an approach is inconsistent with the PCC advocated within intellectual disability and dementia services.

For people with an intellectual disability, well-developed and implemented care pathways have been advocated as a tool to reduce variations in the quality of care and ensure people with an intellectual disability (and their carers where appropriate) receive timely and necessary support (RCP, 2014). Like the broader field of literature, there is a paucity of research which has evaluated the effectiveness of care pathways for people with intellectual disabilities, who may have co-morbid conditions and require the use of multiple pathways (Powell & Kwiatek, 2006; RCP, 2014; Wood et al., 2014). However, the available evidence for the use of care pathways, which have focused on single conditions alongside the individual's intellectual disability, have exhibited some positive outcomes (Ahmad et al., 2007; Devapriam, Alexander, Gumber, Pitcher, & Gangadharan, 2014), such as reduced lengths of stay in hospital.

Within dementia, care pathways have been described as an effective tool to assist 'in streamlining a system of care to ensure patients with dementia receive equal, effective, evidence-based treatment and support which is timely and responsive to the needs' of the individual and their carers (Sullivan, Mannix, & Timmons, 2017, p. 189). Dementia care pathways (DCPs) have been implemented to provide timely, person-centred services and support from the diagnosis of dementia to end-of-life care, or for specific elements of the dementia journey, such as the diagnosis process, and to ensure the individual's carers are also supported. Furthermore, DCPs may be influential in post-diagnosis care and service planning and delivery; ensuring that the needs of people with an intellectual disability and carers are met, and the principles of

PCC and the latest guidance are implemented. The literature illustrates the wide variety of DCPs in development and use for both people with and without an intellectual disability (Derbyshire County Council & Derbyshire Healthcare NHS Foundation Trust, 2014).

The popularity and perceived ability of DCPs to ensure consistency, quality and timely services and support is reflected in their increasing use. In 2010, only 6% of hospitals in the UK reported having a DCP; in 2013, this had increased to 36% while a further 51% of hospitals were developing one (RCP, 2013); how many of these relate to people with an intellectual disability and dementia is currently unknown. The limited available research has shown the possible benefits of DCPs, such as reducing waiting times and increasing diagnosis rates (Wells & Smith, 2017). However, challenges have been reported with the provision of post-diagnostic support through DCPs (Wells & Smith, 2016), and the insufficient evidence for the use of DCPs (Sullivan et al., 2017). DCPs and other care pathways are increasingly being developed and implemented, without a clear empirical evidence-base for their effectiveness (Samsi & Manthorpe, 2014; Sullivan, Mannix, & Timmons, 2017).

Rahman (2017) writes that the use of supporting evidence from the wider literature for the implementation of DCPs may not be appropriate for people with an intellectual disability and/ or dementia. Much of the available evidence is based on single medical condition care pathways, which has excluded people with co-morbidities. People with an intellectual disability and/ or dementia may have an increased risk of co-morbidity compared to those without (Bunn et al., 2014; Cooper et al., 2015).

Within the intellectual disability and dementia field, there is a dearth of literature which has explored the role of DCPs for carers and people with an intellectual disability

and dementia. Much of the literature has provided descriptions of developing or newly implemented DCPs (Cairns, Lamb, & Smith, 2010; Jervis & Prinsloo, 2008; Kalsy et al. 2005), with few providing empirical insight into how DCPs are viewed or experienced. Jenkins et al. (2008) offers some understanding of the usefulness and views of a (at the time) relatively new DCP, and its role in the support of carers and people with an intellectual disability and dementia. Through a grounded theory service evaluation, three family carers, two paid carers, one team leader, and two supported housing managers were interviewed, to explore their experience of the Gwent NHS Healthcare Trust and Local Social Care DCP. The DCP focused on the diagnosis stage of dementia but provided ongoing support post-diagnosis, and provided multi-agency review meetings to adjust care plans. It made use of intellectual disability and mainstream services to try to provide early assessment, timely interventions, and training for carers. Jenkins et al. provided a descriptive account of participants' knowledge, engagement, and views of the DCP. They reported that participants were generally positive about their experiences of the DCP and the services it provided. However, few reported receiving pathway review meetings, making it difficult to assess any long-term benefits. There was also a lack of clarity and knowledge of the DCP and its role. Interestingly, whilst training had been offered to paid carers, none had been offered to carers in a 'family' situation; though both family participants reported being provided either advice, literature, and/ or had contact with professionals.

As the service evaluation took place soon after the pathway had been implemented, it is difficult to truly understand the role and impact of the DCP for people with an intellectual disability and their carers. Crucially, whilst Jenkins et al.'s (2008) Grounded Theory provided insight into carers' awareness of a DCP and its different components (i.e. training, access to case coordinator, and services), it does

not fully explore and/ or provide details of the role of the DCP and the type of support (including the philosophical underpinning) it provided. Furthermore, it does not offer an extensive understanding of how the journey of people with an intellectual disability and their carers are influenced by the DCP. This is compounded by Jenkins et al. (2008) not including healthcare professionals' views as data within the grounded theory; meaning less of a holistic picture was explored.

Overall, DCPs may offer a practical option for multi-disciplinary, person-centred services, care planning and support. The limited evidence has shown that DCPs can play a positive supportive role for carers (though this may only relate to training) and people with an intellectual disability and dementia. However, given that care pathways may be less effective within comorbidity and unpredictable health conditions, and the paucity of research supporting their use, there is a need for more empirical research to explore the role of DCPs; how they influence the journey of paid and family carers and the people with an intellectual disability and dementia they are supporting; and to inform best practice. Building on the work of Jenkins et al. (2008), this research study aimed to explore the role of a well-established DCP in the support of paid and family carers and the people with an intellectual disability and dementia they are supporting through multiple perspectives, including DCP healthcare professionals, paid carers and family carers. Importantly, through the study's CGT, it aimed to better understand the role of the DCP.

The Intellectual Disability Dementia Care Pathway (IDDCP) within this research study focuses on providing a diagnosis of dementia and post-diagnostic support. The IDDCP consists of a multi-disciplinary team of healthcare professionals, including psychiatrists, community nurses, and occupational therapists. Once an individual with an intellectual disability who is suspected of dementia is referred to the IDDCP, they

are screened for dementia, and assessed for other possible physical and mental health causes of the changes. These data are collated and then discussed by the IDDCP team, who provide one of three outcomes: a diagnosis of dementia, dementia is excluded, or a suspected case of dementia. Where there is a suspected case of dementia, the initial dementia screening is used as a baseline and the initial assessments are repeated up to a year later. This later assessment is then compared to the baseline to see if there are any changes. If/ when a diagnosis is given, the IDDCP's team plan and provide post-diagnosis medication and support; for paid and family carers, this may involve training, information, and advice (see Appendix A for a diagram of the IDDCP).

A central part of this thesis is to understand the experiences of paid and family carers. An important undercurrent of dementia care is the central role of paid and family carers; both in the delivery of care which promotes the wellbeing and personhood of the individual with dementia, and the support they need in their role to ensure this, and their own wellbeing. Section 1.9. discusses paid and family carers' experiences of supporting the changing needs of people with an intellectual disability and dementia.

1.9. Paid and Family Carers

As previously outlined, this research study focuses on the experiences of both family and paid carers. Paid carers are defined as formal caregivers who are paid to support people with an intellectual disability and dementia; whilst family carers are informal caregivers who support a member of their family, unpaid. Both family and paid carers have an essential role in the quality of life and personhood of people with an intellectual disability and dementia (Brooker, 2004, 2007; Brooker & Latham, 2015; Kitwood, 1997; Wills et al., 1997; Bhathik & Standen, 2014; Cleary & Doody, 2017; Iacono, Bigby,

Carling-Jenkins, & Torr, 2014; Wilkinson, Kerr, & Cunningham, 2005), making it important to understand and meet carers' holistic needs. This is supported by the UK government's 'National Dementia Strategy' (DH, 2009b), 'The Prime Minister's Challenge 2012' (DH, 2012b), 'The Prime Minister's Challenge on Dementia 2020' (DH, 2015), and NICE's (2018) clinical guidance; which all emphasise the importance of meeting the holistic needs of carers alongside the person with an intellectual disability and dementia, within the dementia care planning process.

The knowledge, experiences, skills, and the availability of support and resources to carers underpin how they experience their role, the approach they take, and their ability to ensure the changing support needs and the wants of the individual are appropriately met (Cleary & Doody, 2017). Within the intellectual disability and dementia literature, a small but growing body of empirical research has shed light on carers' experiences. In the remainder of section 1.9., key themes, drawn from the literature in relation to how paid and family carers experience supporting someone with an intellectual disability and dementia, are discussed.

1.9.1. Carer knowledge.

A lack of knowledge of dementia may significantly influence carers' experiences of delivering and planning support, and may result in inappropriate responses to dementia-related changes. For instance, without the appropriate knowledge, carers may mistakenly attribute dementia-related symptoms to the person's intellectual disability or other co-morbid conditions; this is called diagnostic overshadowing (Reiss, Levitan & Szyszko, 1982; Manson & Scior, 2004). Without understanding that the person is experiencing symptoms of dementia, carers may not discuss the changes with anyone else; potentially delaying diagnosis and decision-making processes, which

are the basis for long-term care planning (Clearly & Doody, 2017; Janicki, 2011). Such negative experiences will distress both carers and the person with dementia.

Even with the increased awareness and focus on dementia and the increasing contact between services and people with an intellectual disability and dementia, research has highlighted that carers lack sufficient knowledge of dementia and are not provided with sufficient training (Herron & Priest, 2013; Iacono et al., 2014; Whitehouse, Chamberlain, & Tunna; 2000). For instance, carers find it challenging to identify less intrusive and disruptive dementia-related changes, only identifying such changes and raising alarms once more advanced, intrusive symptoms of dementia such as loss of ability to perform daily tasks, appear (Herron & Priest, 2013; Whitehouse et al., 2000).

Carers may also experience difficulties in understanding the progression and course of dementia and associated behaviours (Iacono et al., 2014), and their impact on the individual as the dementia worsens (Furniss, LoveSeed, Lippold, & Dodd, 2012). However, paid carers, who may have greater access to resources, may have a greater level of knowledge and awareness of dementia compared to family carers (Furniss et al., 2012).

1.9.2. Carer burden.

The impact of supporting the changing needs and the increasing dependency of someone with an intellectual disability and dementia is prominently discussed across the literature (Courtenay, Jokinen, & Strydom, 2010; Doody & Clearly, 2017; Furniss et al., 2012; Iacono et al., 2014; Janicki et al., 2005; McLaughlin & Jones, 2010). These increased needs can put pressure on carers if they are not appropriately equipped to cope, manage, and support them (Clearly & Doody, 2017). The burden of

care is considered a major healthcare issue (Truzzi et al., 2012), with literature illustrating the possible impact on carers' physical (such as injury) and mental health (such as anxiety and depression) (Bromley, 2014). Bialon and Coke (2012, p.210) further explicate the demands placed on carers, stating that caregiver burden is the 'psychosocial and physical reaction to the imbalance of demands placed on the caregiver by various factors, including personal time, multiple roles, physical and emotional states, financial resources, and formal care resources'. This illustrates the concept of multidimensional burden (Lin, 2008), where carers can be impacted upon physically, psychologically, socially, and financially; and how factors such as available resources influence this burden. Though caregiver burden has been predominately applied to family carers, factors such as physical and emotional states and care resources are also applicable to paid carers. Experiences of burden through the carer role has been linked to a negative impact upon the quality of care delivery (BPS, 2016; O'Hara et al., 2010; Wang, Xiao, He, Ullah, & Bellis, 2014).

Supporting someone with dementia may also impact upon carers through burnout and compassion fatigue (Duffy, Oyebode, & Allen, 2009; Keidel, 2002; Lindgren, Pass, & Sime, 1990; Mutkins, Brown, Thorsteinsson, 2011; Porter et al., 2010). Burnout is an ongoing emotional state which occurs in response to persistent, uncontrollable work stress (Duffy et al., 2009; Maslach, Schaufeli, & Leiter, 2001). It is defined as having three dimensions: emotional exhaustion, depersonalisation and a lack of perceived personal accomplishment (Duffy et al., 2009; Maslach, Jackson, & Leiter, 1996). Paid carers providing support to people with an intellectual disability or dementia experience stressful work environments which may increase their risk of burnout (Ballard, Lowery, & Powell, 2000; Mutkins et al., 2011). Like caregiver burden, paid carers may be negatively impacted upon by burnout, as they experience periods

of low mood, fatigue and loss of motivation (Schaufeli & Enzmann, 1998). Consequently, this may impact on the support and care delivered, as the paid carer may not apply a person-centred approach when supporting the person with an intellectual disability and dementia; for instance, by not engaging with the person in an impersonal way (Buunk & Schaufeli, 1993).

Coetzee and Klopper (2010, p. 237) define compassion fatigue as 'the final result of a progressive and cumulative process that is caused by prolonged, continuous and intense contact with patients, the use of self and exposure to stress'. Bush (2009) further elaborates, stating that compassion fatigue is induced through prolonged caring for people with trauma, suffering, or/ and illness. Both family and paid carers of people with dementia may experience the preconditions of compassion fatigue, as they provide continuous, prolonged care and support, which may impact upon them emotionally (e.g. feelings of hopelessness or helplessness; Day, Anderson, & Davis, 2014; Blair & Perry, 2017). A consequence of compassion fatigue is that carers may experience symptoms of apathy, anger, and depression (Adams, Boscarino, & Figley, 2006; Day & Anderson, 2011). The impact of supporting and caring for someone with an intellectual disability and dementia illustrates the importance of understanding the holistic needs of carers alongside those they care for.

The intellectual disability literature provides both quantitative and qualitative empirical evidence demonstrating the impact of dementia on carers, and how this changes as dementia worsens and the needs of the individual with an intellectual disability change. For instance, carers spend an increased amount of time on support as dementia presents and worsens (Janicki, Dalton, McCallion, Baxley, & Zendell, 2005; McCarron, Gill, McCallion, & Begley, 2005); and the type and intensity of care varies across the different stages of dementia (Janicki et al., 2005; McCarron et al.,

2005). McCarron et al. (2005) found that at mid-stage dementia, supporting behaviour and supervising eating and drinking were more time-consuming, compared to end stage where assisting with toilet use and health-related care were more time consuming.

In contrast, Lloyd, Kalsy, and Gatherer (2008) compared the scores of carers of people with Down syndrome and dementia with those caring for people with Down syndrome without any additional cognitive decline, using the Caregiver Activities Scale-Intellectual disabilities (CAS-ID), the Caregiver Difficulties Scale-Intellectual Disabilities (CDS-ID), and the Maslach Burnout Inventory (MBI). There was no significant difference between the time spent on caregiving between both groups. Carers of people with Down syndrome and dementia experienced significantly greater levels of emotional exhaustion, compared to carers of people with Down syndrome without dementia. However, no data were collected or analysed on comorbid conditions, which makes it difficult to judge if emotional impact was due to supporting someone with Down syndrome and dementia alone, or whether carers were additionally impacted upon by comorbid conditions.

The qualitative literature adds to the findings provided by the quantitative research, and has further demonstrated the physical (McLaughlin & Jones, 2010; Iacono et al., 2014), emotional (Furniss et al., 2012; McLaughlin & Jones, 2010; Iacono et al., 2014; Wilkinson, Kerr, & Cunningham, 2005) social (McLaughlin & Jones, 2010), and for family carers, financial (Janicki, Zendall, & DeHaven, 2010) impact of supporting the changing needs of someone with an intellectual disability and dementia. For instance, carers found it physically and emotionally challenging as the ability of the person with an intellectual disability deteriorated and their personality changed; making them more dependent on their carers (Iacono et al., 2014; McLaughlin & Jones, 2010).

This may be compounded by the difficulty carers' experience with the unpredictability of care created by the dementia, with carer tasks varying from day-to-day (Iacono et al., 2014). The dementia may also take away an important figure to speak to for carers. For family carers, the increased medical appointments during full dementia assessments may have also compounded their ability to maintain employment and/ or to uphold existing social commitments (McLaughlin & Jones, 2010).

Furniss et al. (2012) carried out semi-structured interviews with two family carers, three family members, and eight paid carers. The authors further clarify the impact on carers' experiences, highlighting that frequent emotional impact was influenced by the person they cared for being uncooperative, verbally aggressive and waking through the night. Carers reported 'anticipatory grief', as they had to come to terms with the loss of the individual's skills and abilities, as well as planning for their death and funeral arrangements, thus increasing the emotional impact. However, Furniss et al. provided few details of the role of carers in this planning process, and whether they involved people with an intellectual disability and dementia in the planning of their own care.

1.9.3. Coping and support.

Given the prevalence of carer burden identified in the literature, it is of the utmost importance that carers' own physical, psychological, and social needs are planned for and met (BPS, 2016; BPS & RCP, 2015; DH, 2009b, 2012b, 2015; NICE, 2006, 2018). This is important, as a lack of assistance and ability to access appropriate services can impact carer burden (Janicki, Zendall, & DeHaven, 2010); whilst well supported carers are 'better able to provide support over a longer period' (BPS, 2016, p.20).

Available guidance has emphasised the need for carers to be able to access adequate support and services, whilst recommending that interventions and care plans should be personalised to carers. NICE (2006) suggest several interventions for carers, including: individual or group psychoeducation; peer-support groups; and training courses about dementia, services and benefits, and communication and problem solving in the care of people with dementia. Additionally, the BPS Dementia Advisory Group (BPS, 2016) recommend that carers of people with an intellectual disability receive emotional and psychological support, information, skills training, and increased social support.

A small but growing amount of empirical research offers some understanding of how carers cope with supporting the changing and increased needs of someone with an intellectual disability and dementia. Perera and Standen (2014), through two focus groups with community intellectual disability nurses and nine semi-structure interviews with family and paid carers, explored coping strategies. It is not clear from the paper how intellectual disability nurse data were included in the analysis and informed the findings. Nevertheless, Perera and Standen highlighted that carers used strategies to help cope with the increased demands and impact of support, including having a high tolerance, being flexible, and being optimistic about managing unpredictability. Carers developed practical strategies for commonly occurring problems; these were used to reduce stress or to support the carer's wellbeing. For instance, to reduce stress, carers would physically or emotionally distance themselves from stress; this meant accepting extra support from other carers or family members which allowed for engagement in other activities. However, these findings were drawn from a small sample, and few specific details of the participants were provided (i.e. the precise number of paid and

family carers), making it difficult to judge the transferability of the findings to the different participant groups.

The literature has also demonstrated that social support, such as that of fellow carers, family members, and healthcare professionals is important in helping to ensure the wellbeing of carers (Chambers, Ryan, & Connor, 2001; Parkinson, Carr, Rushmer, & Abley, 2017). Mattson and Hall (2011, p.184) define social support 'as a transactional communicative process, including verbal and/or nonverbal communication, that aims to improve an individual's feelings of coping, competence, belonging, and/or esteem'. This definition emphasises how social support can provide positive outcomes for recipients. Greenberg et al. (1997) illustrate the importance of social support within carers' experiences, including receiving information and advice, remaining socially active, and helping with the carer role and emotional support. Even though social support is not an explicit focus throughout the intellectual disability and dementia literature when exploring the experiences of carers, previous research has shown that carers draw on a range of social supports (including other carers, family members, friends, and healthcare professionals; Carling-Jenkins et al., 2012; McLaughlin & Jones, 2010; Perera & Standen, 2014), to help alleviate the burden of support and ensure the needs of the individual with dementia are met.

However, support from others, in particular services, was not always planned or accessible (Janicki et al., 2010). For instance, Iacono et al. (2014) illustrated that services may have a limited supportive role in carers' experiences. They reported that carers were uncertain about the type of specialist support they may access, although they sought support from a multitude of services and a wide range of healthcare professionals. Conversely, when the participants did not agree with the advice of professionals, they opted not to follow it. As Iacono et al. state, a potential outcome of

this is ill-informed care that may place people with an intellectual disability at risk. However, as Iacono et al.'s study was conducted in Australia, the participants' experiences of services may be different to those of carers within the UK. Within Australia, carers in group homes draw support from mainstream healthcare systems; whereas in the UK, this support may come from intellectual disability services (Iacono et al., 2014). The inconsistent role of services may be compounded by carers' uncertainty about what support services are available (Furniss et al. 2010; Iacono et al., 2014), especially for family carers and relatives who have a lack of information about the services available to them, and when to ask for support (Furniss et al., 2010). A lack of appropriate planned and/or available support to meet the changing holistic needs of carers may impact upon carers' abilities to deliver appropriate person-centred support.

1.9.4. Delivering support.

Paid and family carers may experience many challenges when supporting the dementia needs of people with an intellectual disability. Limited research has explored the support strategies delivered by carers and how these change as the dementia worsens. The research that is available generally illustrates challenges with delivering support and meeting the changing needs of people with an intellectual disability and dementia, and the lack of proactive planning (Clearly & Doody, 2017). The literature further highlights that care may be reactive rather than planned (Iacono et al., 2014), as carers learn as they go along and commonly feel uncertainty and lacking in expertise to provide the best care and support (Wilkinson et al., 2005); this is unsurprising given that carers do not always receive the necessary training in dementia. Iacono et al. highlight that where carers were uncertain of the cause of the

changes in the person they supported, they utilised their pre-established knowledge in intellectual disability and challenging behaviour to explain changes and to inform support strategies. However, this changed as carers became more aware of the dementia and implemented more appropriate strategies which provided comfort and reassurance for the people they supported. Iacono et al. demonstrate that planning care, to meet their client's future needs, becomes more challenging as dementia presented and worsened; as carers were uncertain about the course of these changes and how they would materialise; again, emphasising the importance of sufficient knowledge and awareness (Dodd, 2014). The authors found that the support delivered by carers, in response to client dementia-related changes, was underpinned by a trial and error approach; however, efforts were made to maintain successful support strategies, with carers trying to ensure a consistent approach.

Encouragingly, research has provided insight into the usefulness of training to help carers deliver appropriate support. Furniss et al. (2012) showed that paid carers, who described themselves as having formal training and/ or experience of dementia care, changed or adapted the supported they delivered to ensure their clients' changing needs were met; though few details were provide to understand these adaptations. Similarly, Wilkinson et al. (2005) demonstrated that carers who received relevant, practice-based and person-centred training, had greater confidence, provided higher quality support, and reduced levels of stress.

In summary, the available empirical research has provided valuable insight into carers' experiences, including carer burden, the strategies and supports carers use to ensure their own wellbeing, as well as the supports they deliver. However, there is still a dearth of knowledge of carers' changing needs, their role in ensuring the wellbeing of people with an intellectual disability and dementia, and the support strategies they

use (Cleary & Doody, 2017; Courtenay, Jokinen, & Strydom, 2010; Furniss et al., 2012; Iacono et al., 2014). Courtenay et al. call for more research to address the gaps in 'knowledge about the experience and effective strategies used within intellectual disability settings' and in knowledge about 'the needs of carers in different care settings' (p.32). In particular, there is limited research in relation to family carers. Furthermore, Wilkinson and Janicki (2002) write that research is needed to understand how the different philosophies of care within intellectual disability and dementia care are used and the possible conflict between these. Understanding carers' experiences, support strategies, and support needs will help to address these gaps; and is essential, as this understanding will contribute towards helping services and organisations to provide necessary support to ensure carer wellbeing, and that carers provide appropriate support (Lloyd et al., 2008). An aim of this research is to explore and better understand family and paid carers' experiences, the role they play in delivering support, the supports they draw upon and how this contributes to their experiences.

1.10. Pathway to my PhD Research

Conscious that I was applying a qualitative methodology which prioritised inductiveness over prior data and knowledge, it was important to be reflexive throughout this thesis. The path to this PhD research study has developed through a combination of experience, volunteering, and education. My interest in intellectual disability and dementia emerged through my role as a support worker for people with an intellectual disability. During this time, I travelled around Stoke-on-Trent, UK, working in supported housing; providing what I believed to be person-centred care to a range of adults with an intellectual disability. I gradually became part of a team of support workers, supporting older people with an intellectual disability and mental

health conditions. During this time, I supported more individuals with either a suspected or confirmed diagnosis of dementia, despite minimal training. These experiences spurred me back into education and formed the foundations of my MSc Clinical Psychological Research dissertation, entitled 'Support workers' knowledge about dementia: a vignette study', which with Dr Helena Priest, in 2013, was published in the journal 'Advances in Mental Health and Intellectual Disabilities'. It was at this point I began to specialise in intellectual disability and dementia research.

My MSc helped me to focus on support worker knowledge within dementia and intellectual disability, but it was not until volunteering for the Alzheimer's Society as a group facilitator that I truly became interested in the personal experiences of paid and family carers. This role brought me into their world, and the group became a form of support for those attending. Seeing first-hand how dementia was affecting families and paid carers, and helping these people by listening to their journeys, inspired me to want to do more. The role of group facilitator motivated me and helped me to understand, from different perspectives, just how damaging dementia can be; however, I had a feeling of being unfulfilled, as my support was constrained to a few hours a month, and I was unable to achieve the impact I wanted to make in the people's lives. At the same time, I started to question how dementia was experienced by family and paid carers. These experiences paved the path to my PhD, which has evolved to focus on experiences from different perspectives in relation to intellectual disability and dementia, care, and services.

I recognise that across this time and experiences, I have gained an insight into a carer's knowledge and key literature within the intellectual disability and dementia field, which have undoubtedly influenced and informed my thoughts. Constructive Grounded Theory (CGT), the methodology I draw upon throughout this research study,

acknowledges that the researcher does not come to the research process with an empty mind (Charmaz, 2014), but instead uses this experience and knowledge as a starting point, whilst being reflective of its influence. Throughout this thesis, I have been reflective of these influences in an attempt to critically understand their role within my thinking.

1.11. Overview of Research Study

Dementia is seldom experienced in isolation; it affects the family, family carers and paid carers. A growing field of research on carers' knowledge of dementia in people with intellectual disabilities demonstrates paid carers often lack the necessary training and knowledge to provide the best care and support (Herron & Priest, 2013). Less research has explored the support needs of both family and paid carers, the role of support strategies to help ensure the carer's wellbeing, and the support carers' deliver to better ensure the wellbeing of people with an intellectual disability and dementia.

The use of a multi-disciplinary approach is advocated to providing services to support people with an intellectual disability and dementia, and their carers, across the journey of dementia. One recommended framework for care and service delivery is the Dementia Care Pathway (DCP). However, although widely implemented, little empirical evidence has explored the role of the DCP for people with an intellectual disability and dementia, and their carers.

The initial aim of this research study was to explore, from multiple perspectives, how people experienced living with intellectual disability and dementia, and also supporting people with an intellectual disability and dementia. This meant, ideally, collecting data from people with an intellectual disability and dementia, their carers, and healthcare professionals. However, although extensive attempts were made to

enable the participation of people with an intellectual disability and dementia, the challenges experienced throughout recruitment meant that only one person with an intellectual disability and dementia agreed to participate. At a later point of the study it transpired that this individual's diagnosis of dementia was retracted and therefore they did not meet the participant criteria. Thus, the decision was taken not to include this participant and their data in the research, as it would not have enabled the initial research aim to be addressed.

The focus of this research study, as reflected through the altered research aims and questions, was adjusted. Therefore, through a CGT methodology, semi-structured interviews were carried out with 18 participants drawn from paid carers, family carers, and healthcare professionals to address the research aims and answer the research questions.

Research Aims

This research aimed to:

1. Explore family and paid carers' views and experiences of supporting someone with an intellectual disability and dementia.
2. Explore the role of healthcare professionals and support systems, with a focus on one Intellectual Disability Dementia Care Pathway, in the support of family and paid carers and people with an intellectual disability and dementia.

Research Questions

Three primary research questions were identified:

- 1) How do family and/or paid carers view and experience supporting someone with an intellectual disability and dementia?

- 2) What support systems and strategies are in place for carers, and how do these strategies contribute to support for carers?
- 3) What is the role of an Intellectual Disability Dementia Care Pathway, and its healthcare professionals, in the support of carers and people with an intellectual disability and dementia?

1.12. Structure of Thesis

In Chapter Two, the epistemological and ontological underpinnings applied within this research study, and the influence these have had on this study, are presented. A brief historical overview of the development of grounded theory, and its various offshoots are explicated; this provides context and rationale for the selection of CGT. The key tenets and strategies of CGT are explored, and where appropriate, critically discussed. The second part of Chapter Two focuses on providing details of the study's methods. The inherent ethical considerations, and the steps taken in achieving NHS ethical approval, are described in depth, before providing details of the inclusion criteria for the three participant groups: paid carers, family carers, and healthcare professionals. How participants were accessed and the relevant recruitment procedures are then illustrated. This is followed by an explanation and justification of the research study's data collection method; multiple semi-structured interviews. Chapter Two ends with a description of the interview procedure, before being reflective about the recruitment and data collection journey.

Chapter Three contains the step-by-step procedure of how the analytic stages of CGT have been applied, with the use of examples from the data set; this includes initial coding, focused coding, categorising, and memo writing.

Chapter Four presents the categories developed through analysing the data from healthcare professionals, family and paid carers. From this, the core category, *Impact of Dementia*, and four underpinning categories, *Challenging the Diagnosis Process*, *Continuum of Support*, *Continuum of Understanding*, and *Continuity* are discussed.

Chapter Five presents the substantial literature review, which was conducted once the concepts and the analytic relationships between them were developed. The literature review procedure is detailed, before presenting the findings of the extensive literature review and the introduction of extant theory. This literature review is guided by the data, staying close to it, and being shaped by it. Findings are interwoven with the previously stated CGT.

Chapter Six provides an overview of the findings and the extent to which they answer the research questions. The novel contributions of the findings to the literature on intellectual disability and dementia, practice and research are discussed. This thesis is critically evaluated, highlighting strengths and weaknesses, before discussing areas for future research, implications and possible applications.

Each Chapter will start with an overview, and end with a personal reflection and a summary. The personal reflection will be written in the first person as it represents the researcher's personal thoughts and reflections of the research process.

Chapter Two: Methodology and Methods

2.1. Introduction

This Chapter explicates key components of this research study, the theoretical and methodological underpinnings, and the methods used. This Chapter starts by discussing the subjectivist epistemological and relativist ontological underpinnings brought to this research study through the adopted methodology, Constructivist Grounded Theory (CGT). A brief historical overview of the development of Grounded Theory (GT) is detailed, before describing and where relevant, critically discussing CGT's key tenets and strategies. Through this, the rationale for adopting CGT over other forms of GT and other methodologies is developed and explicated.

Following the course of the research process, the process of gaining NHS ethical approval, and the ethical considerations and procedures put in place to ensure ethical research are described. To give context to the exhaustive efforts made by the researcher and challenges experienced across recruitment, the journey of accessing participants and the recruitment process are detailed. This is followed by details of the three participant groups recruited within this research study (family carers, paid carers, and healthcare professionals). To illustrate the selection and appropriateness of semi-structured interviews within this study, other forms of interviews are critiqued, before discussing the usefulness of multiple semi-structured interviews to better apply the CGT methodological tenets and strategies. To ensure transparency, and allow readers of this thesis to clearly understand the interview process, the procedure used throughout the interviews is described. Lincoln and Guba's (1985) concept of

trustworthiness is then used to illustrate how the quality of this research study has been ensured. This Chapter ends reflectively, before summarising the Chapter.

2.2. Theoretical Underpinnings

A researcher's beliefs around ontology, epistemology and methodology (Denzin & Lincoln, 2003) determine what can be achieved in research (Chamberlain, 2004). Within this research, research methods are the techniques used to gather and analyse data; and methodology is the strategy that informs the decisions behind the selection of methods which appropriately address the research aims and answer the research questions (Crotty, 2015). Research methods and methodology are informed and underpinned by ontological and epistemological assumptions (Crotty, 2015; Denzin & Lincoln, 2000). Ontology refers to how the nature of being is understood; whilst epistemology refers to the theory of knowledge and how this is constructed (Crotty, 2015). Appropriately aligned methods, methodology, ontological and epistemological position ensures good research practice and allow the research aims to be addressed and research questions to be answered (Chamberlain, 2004). It was therefore important to be reflexive and explicate the ontological and epistemological underpinnings of this study: informing the reader of their implications to the methodology and research (Denzin & Lincoln, 2000; Chamberlain, 2004).

Reflexivity involves being aware of the implications of these theoretical underpinnings for the methodology and methods, and the rigour in which all are applied and implemented (Chamberlain, 2004): being reflexive about how these influence, shape, and focus the research. For instance, the researcher's own relativist ontological and subjectivist epistemological beliefs influenced the decision to select CGT as the methodology, as the two were aligned; consequently, a combination of these beliefs

and CGT informed the decision to select semi-structured interviews: a method of data collection which enabled exploration of experiences of dementia. Being transparent and reflexive of theoretical decisions is an important aspect of this research, as every component of the study, including the final CGT, has been influenced by these assumptions and the decisions the researcher imposed on the research. Prior to discussing the methodology used in this research study, it is important to outline the ontological and epistemological position which have influenced the decision on which methodology to apply. See Figure 2.1. for a visual overview of this research study.

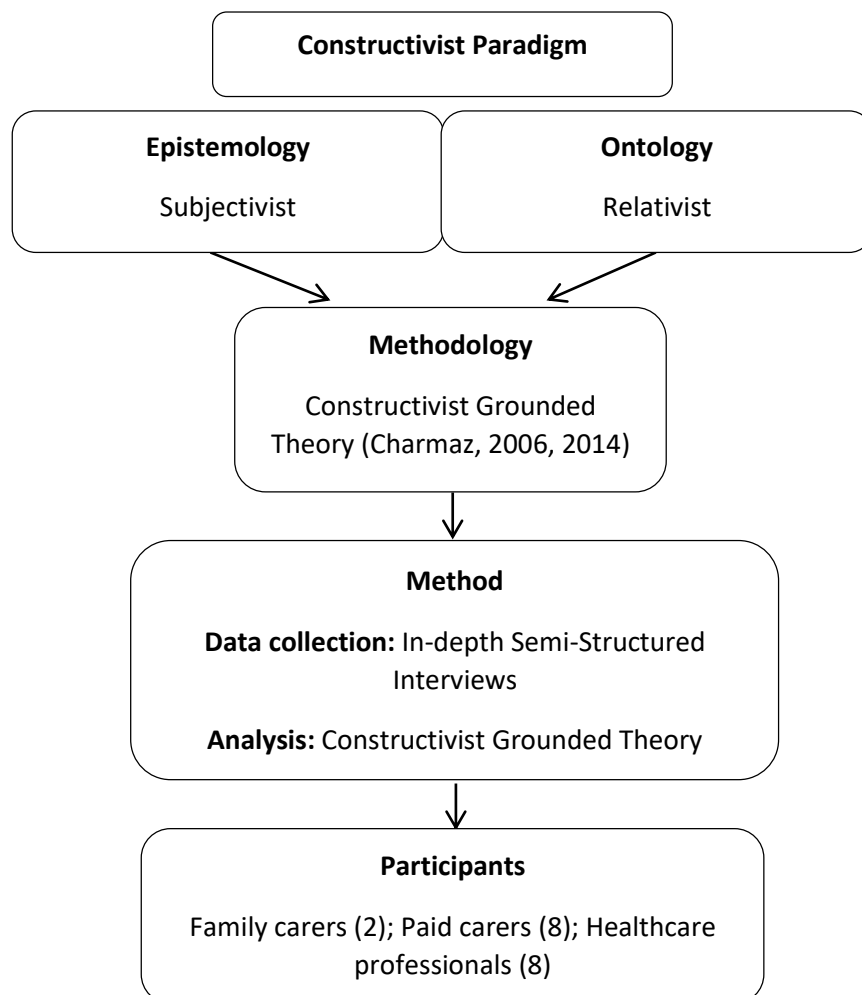


Figure 2.1. A Visual Representation of this Research Study

2.3. Ontological and Epistemological Position

Aligned with Charmaz's (2006, 2014) position within Constructivist Grounded Theory (CGT), this research has been informed by a constructivist paradigm; this is ontologically relativist, asserting that realities are multiple and are socially constructed (Guba & Lincoln, 2005). This contrasts to a realist ontological position, which underpins a positivist paradigm, where there is deemed to be an objective external reality; one which is separate from people's description and interpretation of it (Flick, 2014). In a realist position, research can be used to understand and reflect a single reality (Crotty, 2015).

Within a relativist ontological position, realities are the constructions of people; their constructions are an attempt to make sense of their experiences, and are developed through social interactions (Guba & Lincoln, 2005). As people are unique individuals, they bring their own unique perspective and background to making sense of their experiences (Lee, 2012). Their constructions are informed by the type, and the amount and level of prior knowledge brought to the task by people (Guba & Lincoln, 2005). Therefore, realities are multiple, specific, and changing, with each person's subjective experience being equally valid (Charmaz, 2000). For instance, the researcher's perception of asthma (having had it all their life) may be very different to that of their friend (who has recently been told they have asthma). Both realities are equally valid; however, they are likely to be informed by different contexts and personal responses. Similarly, it is recognised that participants have their own unique, subjective experiences of dementia.

Within a relativist ontological position, the purpose of empirical research is to 'understand the subjective experience of reality and multiple truths' (Levers, 2013, p. 2). Therefore, through this research study, a relativist ontological position meant

recognising, being sensitive to and focusing on the participants' perspective of their experiences of dementia, the context to these experiences, and acknowledging that there are multiple realities of dementia. This position was well aligned with the research aims and questions which focused on the participants' subjective experiences of dementia (Crotty, 2015; Flick, 2014).

In line with the ontological position, and remaining true to the constructivist paradigm (Charmaz, 2014), a subjectivist epistemology has been adopted. In doing so, it is acknowledged 'that an inquirer and the inquired-into are interlocked in such a way that the findings of an investigation are the literal creation of the inquiry process' (Guba & Lincoln, 1989, p. 84). Therefore, understanding is co-created through the 'knower' and the 'respondent' (Lee, 2013). Complementing the relativist ontological position, subjectivism holds that a person's reality is co-created through their interaction with others.

This position contrasts with objectivism, where truth and meaning are independent of human subjectivity (Levers, 2013). Crotty (2015) writes that within objectivism, as reality is independent of a person's subjectivity, contextual factors are removed to observe and understand the phenomena. Therefore, the researcher believes they conduct their inquiry value-free, without bias. What is being observed is not influenced by the researcher, their previous knowledge and experiences, and the researcher is uninfluenced by what is being observed (Lee, 2012). This conflicted with the researcher's own epistemological beliefs.

Within a subjectivist approach, data and analysis, rather than being uninfluenced by the interaction between researcher and participants, is the co-creation of their shared experiences and relationships throughout the research process (e.g. semi-structured interviews; Charmaz, 2000; Lee, 2012; Levers, 2013). For instance,

the reciprocal processes of each interview, which were mutually guided by the researcher's questions and the participant's responses, influenced the co-creation of the data which informed the findings of this research study. Consequently, a transparent process was applied throughout this thesis, to better understand and illustrate the influence of the researcher's beliefs and interests across the research process. This meant being alert to the researcher's starting assumptions and presumptions, such as those brought to the analysis from their previous knowledge of the literature, from their MSc research and PhD research proposal, and the influence this had on the research (Charmaz, 2006). Willig's (2001) notion of personal reflexivity, how the researcher's experiences, beliefs, and interests have influenced this research and been influenced by the research process, was adopted to illuminate the researcher's values and the influence they had on the construction of the data and theory. A reflexive approach is applied throughout this thesis, specifically within Chapter One, with the researcher's impetus to engage in this research and knowledge of the literature, at the end of each chapter, and a transparent analytical process (see Chapter Three).

2.4. Qualitative Methodology

Within this thesis, a qualitative methodology has been used to explore the research aims and to answer the research questions stated in Chapter One (section 1.11). Denzin and Lincoln (1994, p. 2) state that qualitative research is:

'multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. 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...Accordingly, qualitative research deploys a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand'.

This quote illustrates the appropriateness of a qualitative methodology for this study which is underpinned by a constructivist paradigm. The in-depth focus of the participant's subjective experiences through qualitative research (Flick, 2014) is well aligned with the constructivist paradigm's relativist and subjectivist underpinning and their concern with the participant's unique perspectives and constructions of their experiences (Guba & Lincoln, 1989; Lincoln & Guba, 1985).

Furthermore, qualitative research's focus on exploring and understanding the experiences of participants is well aligned with this study's research aims and questions (see Chapter 1.11.), which were to explore the subjective experiences of carers and healthcare professionals. The use of a qualitative methodology is further supported through the extant research (Furniss, LoveSeed, Lippold, & Dodd, 2012; Iacono, Bigby, Carling-Jenkins, & Torr, 2014; McLaughlin & Jones, 2010), which has illustrated its appropriateness and effectiveness for this research topic.

Within this research study a variation of original grounded theory (GT; Glaser & Strauss, 1967) was used: Constructivist Grounded Theory (CGT; Charmaz, 2014). CGT, its methodological strategies, and the rationale for its application, will be explicated. However, to provide context for the use and rationale of this variation of GT, its historical development will first be critically explored.

2.5. The Development of Grounded Theory

GT was constructed during the 1960s, where quantitative methods had gained dominance within many disciplines, arising out of a positivistic stance. This dominance assumed a passive, unbiased researcher who played no role in creating data, and the existence of an external world separate from the researcher and their methods (Charmaz, 2014). During this period, original GT was developed with the publication of 'The Discovery of Grounded Theory' (Glaser & Strauss, 1967). Through this publication, Glaser and Strauss questioned the established positivistic orthodoxy, the priority placed on verification of existing theories, and the development of theory by making deductions from priori assumptions and hypotheses (Glaser & Strauss, 1967).

Glaser and Strauss brought together two of sociology's contrasting traditions: positivism and pragmatism. Glaser, through his Columbia University training in quantitative research, brought codifying to GT and the creation of middle-range theories; helping to demystifying the research process (Glaser & Strauss, 1967; Charmaz, 2014). Middle-range theories explain a specific set of social phenomena and are grounded in the data; they contrast with grand theories, which explain phenomena at a societal level (Charmaz, 2006). Strauss, with his training in pragmatism and symbolic interactionism, brought 'notions of human agency, emergent processes, social and subjective meanings, problem-solving practices, and the open-ended study of action' (Charmaz, 2014, p. 9). Glaser and Strauss offered a systematic approach to qualitative research (Bryant & Charmaz, 2007); this is an enduring strength of GT: a clear step-by-step procedure, rendering it replicable. For the researcher, this systematic, inductive approach proved to be an appealing aspect and initial draw to GT as a methodology in this study. However, the theoretical underpinnings of the original GT produced a qualitative methodology with distinct positivist and objectivist

features (Bryant & Charmaz, 2007). These features resulted in 'dispassionate empiricism, rigorous codified methods, emphasis on emergent discoveries, and its somewhat ambiguous specialised language that echoes quantitative methods' (Charmaz, 2006, p.7). Specifically, its positioning of an objective researcher, uninfluenced by the research process, and being value-free throughout the research process, so not influencing the data collection and analysis, is not compatible with the constructivist underpinnings of this research study and the researcher's own belief.

Through the 1960s, there was a growing body of critique for quantification within sociology (Blumer, 1954; Mills, 1959; Kuhn, 1962) and major epistemological shifts; a social constructionist challenge to the positivist orthodox (Berger & Luckmann, 1966; Garfinkel, 1967). Social constructionism claims that people construct their realities and that these are multiple; this contrasts with positivism which believed there was one reality to be discovered. Through social constructionism, knowledge and experiences are a construction of interactions, which are sustained through everyday social processes, and are historically and culturally specific (Burr, 2015). However, up until the early 1980s, the GT method was scarcely influenced by these developments (Bryant & Charmaz, 2007). This resulted in GT being criticised for epistemological naivety; it failed to adapt to the changing epistemological stance within social research.

2.5.1. Post-positivist grounded theory.

Since its development, and in more recent times, GT has been advanced through differing variations. All variations share several basic strategies, including: analysing the data at an early stage; conducting analysis and data collection simultaneously; the use of comparative methods; developing tentative inductive categories that attempt to explain the data; and engaging in sampling to further refine

categories (Charmaz & Belgrave, 2012). However, there are key differences across variations which have influenced the choice of methodology in this research study.

GT's first alteration was established within the 'Basics of qualitative research: grounded theory procedures and techniques' (Strauss & Corbin, 1990, 1998), where the authors developed GT to a post-positivist method of verification (Bryant & Charmaz, 2007). Post-positivism is underpinned by an objectivist epistemology and critical realist ontological position (Levers, 2013). This approach applied the language of positivism, but recognises that whilst there are objective truths, these are near impossible to discover (Crotty, 2015). Under this paradigm, 'knowledge is fallible because it is shaped by contextual influences'; yet, objectivist procedures are relied upon to bring the researcher closer to the truth (Levers. 2013, p. 3).

Strauss and Corbin, digressing from the key tenets of original GT, introduced further objectivist assumptions through technical procedures which are applied to the data, rather than letting the data direct the methodological decisions (Atkinson, Coffey, & Delamont, 2003; Charmaz, 2014). For instance, axial coding has been used as 'a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by using a coding paradigm involving conditions, context, action/interactional strategies, and consequences' (p. 96). The coding paradigm is used to organise and connect subcategories of data to a central idea, or phenomenon. Strauss and Corbin propose six predetermined subcategories that guide data collection and analysis: 'conditions, phenomena, context, intervening conditions, actions/strategies, and consequences' (Kendall, 1999, p. 747). However, such procedures have been criticised for reducing the inductivity of the GT, as data and analysis are forced into preconceived categories. (Charmaz, 2014; Glaser, 1992; Kendall, 1999). Therefore, Strauss and Corbin's approach to GT, with

its post-positivistic stance and some of their procedures (e.g. axial coding), would not complement this study's constructivist paradigm which emphasises subjective experiences, and would lessen the influence and positioning of the participants' data within the GT.

Overall, both Glaser and Strauss's (1967), and Strauss and Corbin's (1990, 1998) version of GT have been criticised for an outdated epistemology (Charmaz, 2014), with their positivist and post-positivist assumptions of an external reality, and a passive, unbiased, objective observer or the application of methodological strategies which are not conducive to inductivity. Consequently, both approaches to GT, due to their theoretical underpinnings, and how these have been applied through strategies, are not appropriate to the constructivist paradigm of this research study.

These criticisms have resulted in the development of the methodological approach adopted in this research study, Charmaz's (2006, 2014) CGT, which utilises GT strategies, but embraces Guba and Lincoln's (1989) constructivist paradigm (Charmaz, 2006; Clarke, 2005). CGT will now be described.

2.6. Constructivist Grounded Theory

This section provides an overview of CGT and its methodological strategies. Due to their central but debated application within CGT, two elements of this methodology, the delayed literature review and theoretical saturation, are further critically discussed and how these have been applied within this study explicated. A detailed description of how data are progressively processed through CGT's different levels of analysis within this research study is described in detail throughout Chapter Three.

CGT is a contemporary variation of original GT which addresses some of the fundamental criticisms of previous versions of GT by Glaser and Strauss (1967) and

Strauss and Corbin (1990, 1998): their objectivist and post-positivistic positioning. In contrast, CGT firmly shifts GT's epistemological foundations from positivist to constructivist (Birks & Mills, 2015). The main difference between CGT and original GT lies within its ontological and epistemological underpinnings, and what this means for the methodology. CGT's constructivist paradigm, like the theoretical underpinnings of this study, is underpinned by the belief that realities are subjective, unique, and multiple, and are a construction of the interactive process. Within research, this constructivist stance means data are a construction of the interactive process between the researcher and participant through the data collection and analysis process (Miller, Bonner, & Francis, 2006). Therefore, it is recognised that the research process and CGT are influenced by the researcher and their knowledge and beliefs, the participants, and the interactive process between the two.

CGT is an approach for conducting inquiry in a systematic, inductive, iterative and comparative manner, whilst emphasising theory development. The researcher starts with the area of research, collecting pertinent data, and follows the analytical leads drawn from this to develop the final interpretive theory (Charmaz, 2014); this contrasts with other, more positivist, quantitative approaches which start with theory or a theoretical framework to guide the research and analysis. Data collection and analysis are simultaneous, iterative processes; encouraging the researcher to stay intricately close to the data (Birks & Mills, 2015). Analysis starts as soon as data are collected and are revisited as more data are collected and the researcher's understanding becomes more sophisticated. It is underpinned by constant comparative methods; data, codes and tentative categories are constantly compared with one another across the analysis process to develop more abstract concepts, and to illuminate the relationships between properties of categories within the constructed

theory (Charmaz, 2014; Birks & Mills, 2015). The final CGT is inductively constructed with emphasis placed on the participants' data; therefore, it is grounded in the data and relevant to the research topic. Memo-writing is engaged with across the process, where the researcher interacts with the data to form and develop ideas.

A pertinent methodological strategy and component of CGT is theoretical sampling. Hood (2007) writes that theoretical sampling is used to narrow the focus on emerging categories, developing and refining them. Further clarifying theoretical sampling, Charmaz (2014) states that it is used to seek new 'people, events, or information to illuminate and define the properties, boundaries and relevance' (Charmaz, 2014, p. 345) of categories. Here, Charmaz illustrates how theoretical sampling is used across different elements of the research process; for example, recruiting more participants from existing participant groups to clarify developing categories and their properties; and/or recruiting participants from additional, different participant groups to further expand categories and their properties. Through this research study, theoretical sampling, as advocated (Charmaz, 2014; Glaser & Strauss, 1967), was engaged in once tentative categories were developed. Theoretical sampling was implemented through different methods, including: seeking out new information by recruiting more participants from existing participant groups (paid carers, family carers, and healthcare professionals); and seeking out new information by introducing new questions into interview schedules. Further details of how theoretical sampling has been applied is discussed in more detail in sections 2.12.1. and 2.15.

Within CGT the idea that theory is something which exists in the data, that the researcher discovers, is rejected (Charmaz, 2014); instead, theory is viewed as being constructed through the researcher's interactions with participants, perspectives and

research practices (Bryan, 2003; Miller, Bonner, & Francis, 2006; Charmaz, 2006, 2014). Therefore, within CGT and this research study, the final CGT is an 'interpretive portrayal of the study's world, not an exact picture' (Charmaz & Belgrave, 2012, p. 349), and is one of many possible constructions of reality (Walker, 2014). It incorporates the subjectivity of the researcher and participants (Birks & Mills, 2015; Saldana, 2015). A CGT, through its inductive approach, builds from specifics (participant experiences) with the aim to move towards more general statements of the data, which are contextually situated (Charmaz, 2014). The final CGT theory is one that highlights 'relationships between abstract concepts and may aim for either explanation or understanding' (Thornberg & Charmaz, 2012, p. 41).

Two unique and central elements of a CGT methodology, which need to be further critically discussed, are how the extant literature is used and the meaning of theoretical saturation.

2.6.1. Engagement with the literature.

Within most methodologies for research, reviewing pertinent literature is performed at an early stage and prior to when the research study is carried out. Webster and Watson (2002) argue that a 'review of prior, relevant literature is an essential feature of any academic project' (p. 13). Careful and effective literature reviews help to: provide the underpinnings for advancing knowledge; identify topics in need of research (Roberts & Priest, 2010; Webster & Watson, 2002); prevent duplicating the work of others; contextualise the study (McCann & Clark, 2003); and reveal how the topic has been explored to date (Denzin, 2002).

CGT advocates an approach that attempts to limit the researcher's engagement with extant literature, to prevent the development of preconceived assumptions of the

research topic and these being forced on the data; instead, emphasising the importance of developing theory out of the data through an inductive approach (Charmaz, 2014). This equates to prioritising data in the construction of theory rather than forcing data into preconceived categories developed through the engagement with the extant literature (Dunne, 2011). A unique and debated methodological decision through CGT, to better ensure inductivity, is the timing and extent of engagement with the extant literature (Bryant & Charmaz, 2007; Dunne, 2011; McGhee et al., 2007). Importantly, this debate lies around the 'when' and 'to what extent' the researcher engages with the extant literature prior to data analysis, not whether a literature review needs to be carried out at all.

In original GT, Glaser and Strauss (1967) strongly advocated their purist stance, stating that reviewing the extant substantive literature should be delayed until after 'the analytic core of categories has emerged' (p. 37). Glaser (1998) has continued to advocate this position, which is supported by other prominent grounded theorists (Holton, 2007; Stern, 1994). It is believed that this stance helps to limit preconceived ideas, developed from the extant literature, from being imported and imposed onto the data (Charmaz, 2014). Consequently, it is argued that such an approach would ensure the GT is developed from the empirical data, directed by it, rather than being 'contaminated' by existing frameworks and literature (Charmaz, 2014; Dunne, 2011).

However, the purist stance is criticised for failing to acknowledge that researchers may come to the research process already influenced by their pre-held knowledge and experiences of a topic, and already familiar with the substantive literature (Bulmer, 1979; Charmaz, 2014; Cutcliffe, 2000; Dey, 1999; Dunne, 2011). Strauss, in his later work with Corbin (Strauss & Corbin, 1998), acknowledged that the researcher may bring their accumulated knowledge in professional and disciplinary

literature to the research process. Nevertheless, remaining cautious about the depth of any initial engagement with the literature, Strauss and Corbin (1998, p.49) state that 'the researcher does not want to be steeped in the literature that he or she is constrained or even stifled by it'. This emphasises a constrained approach to the initial literature review.

Recognising that researchers do not come to the study with a 'blank slate', and that reviewing extant literature may be required in formal proposals, such as for study funding or for PhD processes, grounded theorists have advocated a preliminary, limited review of the literature. Smith and Biley (1997) acknowledge that a thorough, comprehensive literature review should be delayed until at least data collection; yet, believe engaging with the literature prior to data collection may be beneficial (Smith & Biley, 1997). Similarly, Birks and Mills (2011) see a preliminary review of the literature as being an important method for developing early theoretical sensitivity: 'the ability to "see relevant data" and to reflect upon empirical data material with the help of theoretical terms' (Kelle, 2007, p. 611).

Dunne (2011) argues for a 'middle ground': a stance which maintains the original GT's ethos towards the literature and concern about extant literature and theory unduly influencing the development of the GT; whilst simultaneously acknowledging the potential advantages, at an early stage of the research process, of engaging with the extant literature in the substantive area. Within a 'middle ground' stance, Urquhart (2007) argues for a limited preliminary literature review, which should be used as an orientating process, to ensure the researcher is aware of the current thinking within their related field; whilst the literature review is further developed once the GT has been constructed. This is supported by Dunne (2011), who sees a limited preliminary literature review as a method to contextualise the study, before engaging

with extant theoretical concepts after data analysis. The 'middle ground' stance may help to address concerns around the inclusion of irrelevant literature at an early stage, and the exclusion of relevant material during research development.

Furthermore, it is recognised that the unpredictability of GT studies may mean extant literature, which appears relevant at the early stages of a study, may become irrelevant as the GT is constructed and developed (Charmaz, 2014). GT may take the research into new substantive areas. Therefore, within a 'middle ground' stance, a review of the substantive literature is performed after the construction of the GT's categories, to ensure the literature is relevant to the categories of the CGT.

To better ensure that data shaped the analysis, Charmaz (2014), whilst recognising the need to engage with the key extant literature through early research development, advises to let the material lie dormant until categories and the relationships between them are developed. Furthermore, Henwood and Pidgeon (2003) advocate theoretical agnosticism: 'a critical stance towards earlier theories that neither denies nor accepts their potential relevance for the researcher's study without rigorous scrutiny' (Charmaz, 2014, p.345).

Upon careful and critical consideration and recognising the pre-held knowledge and experiences of the researcher, this research study's stance towards the literature is positioned within the 'middle ground' (Dunne, 2011). This approach ensured an inductive approach was maintained and the key tenet of GT upheld. A preliminary review of the literature was undertaken during the development phase of this research, with a substantial literature review being undertaken after the CGT's categories and the relationship between them were developed. Therefore, the initial review of the literature is situated in Chapter One. As stated in Chapter 1.2., the initial review of the literature was used to contextualise this study, to critically define and discuss key

terms, concepts and existing knowledge relevant to carers' experiences of supporting someone with an intellectual disability and dementia, and of the role of Dementia Care Pathways (DCPs); simultaneously providing a rationale for the research aims and questions. It has acted to sensitise the researcher to the current thinking within the intellectual disability and dementia field. The preliminary review of the literature has also been used to satisfy the University's requirements of the research proposal process, as well as to gain NHS ethical approval (see section 2.8. for more detail).

The substantial literature review, which was performed after the categories of CGT were developed, has been guided by the theoretical concepts drawn from the CGT. It has been used to systematically and critically engage, in depth, with the substantive literature, and position the findings of the CGT within the field of intellectual disability and dementia. The substantial literature review is presented and discussed in Chapter Five.

2.6.2. Theoretical saturation.

Theoretical saturation is a key tenet of grounded theory (GT), which has been widely used as a criterion for stopping data collection and/ or analysis (Charmaz, 2014; Glazer & Strauss, 1967; Saunders et al., 2017). Charmaz (2014) states that theoretical saturation is something grounded theorists should aim to achieve, but also something they should critically consider before applying it within research. Salient is the variation in what grounded theorists define as saturation in their research. In this section 2.6.2., the different components of saturation, within GT, are firstly discussed, before explicating how theoretical saturation has been applied within this research study. A detailed description of the researcher's attempts to ensure a rich level of saturation,

the implemented quality checks to ensure this, and the challenges experienced across the process of saturation are discussed across the remainder of this Chapter.

Glaser and Strauss (1967, p.61), within original GT, state that theoretical saturation is a:

‘criterion of judging when to stop sampling the different groups pertinent to a category...Saturation means that no additional data are being found whereby the sociologist can develop properties of the category. As he [or she] sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated. He [or she] goes out of his [or her] way to look for groups that stretch diversity of data as far as possible, just to make certain that saturation is based on the widest possible range of data on the category.’

This passage of text emphasises that a richer level of theoretically saturated categories does not occur through repetition of the same events, codes or themes, but rather when categories are robustly defined; when there are no new properties and the already developed properties adequately account for patterns in the data. Additional data are collected to saturate categories and develop theory. Within this stance, theoretical saturation is driven by theoretical sampling: the searching of new ‘people, events, or information’ to fully define the properties and boundaries of tentative categories (Charmaz, 2014, p. 345). Glaser and Strauss’s (1967) position on saturation has been advocated by Charmaz (2014) through CGT.

A second model of saturation, from a GT standpoint, is what Saunders et al. (2017) term ‘inductive thematic saturation’. Like theoretical saturation, the focus of

inductive thematic saturation remains at the level of analysis; however, rather than the completeness of developed theoretical categories, here, saturation focuses on the identification of 'new codes or themes, and is based on the number of such codes or themes' (Saunders et al., p. 4). This approach has been applied by prominent grounded theorists (Birks & Mills, 2015; Urquhart, 2013). For instance, Urquhart (2013, p.194) indicates that saturation is achieved when no new codes occur in the data, but rather 'mounting instances of the same codes'. Given (2016) defines saturation as the point where no new emergent themes can be drawn from the data.

A further pertinent point raised by Saunders et al. (2017) is whether the researcher views saturation as an event or a process. Here, an event or point equates to a dichotomous stance, where saturation is either achieved or not achieved. The researcher asks, 'has theoretical saturation been achieved?'. In contrast, taking a process approach, the dichotomous stance is problematic (Dey, 1999; Saunders et al, 2017; Nelson, 2016), as it does not acknowledge that saturation is an 'ongoing, cumulative judgement' (Saunders et al., p.8) made by the researcher. When viewing saturation as a process, the researcher focuses on 'how much theoretical saturation is sufficient' (Saunders et al.). Consequently, as more data are collected and categories developed to be more robust, the analysis becomes richer and more insightful. This stance has been advocated by Strauss and Corbin (1998), who view saturation as a 'matter of degree', with the acknowledgment there is the possibility that new interpretations can materialise (Dey, 2006; Strauss & Corbin, 1998); therefore, writing that data should be collected to the point where 'new' did not further develop categories and the theory.

Charmaz (2014) writes that the grounded theorist should be reflexive and open about how they have applied saturation and what can be achieved through their

grounded theory. Within this research study, with its focus on developing an inductive, robust theory to better achieve the research aims and answer the research questions (see Chapter 1.11), the application of inductive thematic saturation would not have been appropriate as its focus is not on robustly defining the theory. Instead, Glaser and Strauss's (1967) model of theoretical saturation, as advocated by Charmaz (2014), has been utilised. Consequently, 'sampling, data collection and data analysis' (Bryant, 2012, p.18) were combined in an attempt to fully develop categories of the final theory; this meant seeking out new participants, events and information, in an attempt to fully define properties of the final grounded theory's categories. Theoretical saturation was applied as a process, recognising that new interpretations and events can possibly emerge (Dey, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Consequently, attempts were made to collect data to the point where 'new' data did not further develop categories and the theory.

This section has given a detailed overview of CGT and evaluated some of its debated key components. Now the rationale for the use of CGT over other forms of GT and methodologies is explicated.

2.7. Alternative Methodologies

When considering the current research, initially through the research aims, questions, rationale, and the previous literature's methodologies, it was apparent that the methodology must explore experiences, through an inductive approach, and one which was suited to under-researched areas. The methodology had to be one which provided a systematic approach to data collection and processing, and one which emphasised an interpretative understanding of experiences. CGT is well-fitted and strongly suited to addressing the research aims and answering the research questions, and is aligned

with the researcher's ontological and epistemological stance. Its constructivist underpinnings and inductive approach intensified the focus on the subjective experiences of participants, whilst recognising the interactive role between the researcher and participant within the final CGT. This was complemented by the systematic methodological tenets and strategies, such as the iterative, constant comparative approach of CGT, which better ensured a theory informed and supported by participant experiences; making the CGT relevant and useful to better understanding the experiences of carers and the role of a DCP. One recognised benefit of CGT is its suitability to under-researched areas; areas where the literature and theory do not yet exist or are limited so do not override the direction of the analysis as laid out by participant experiences (Charmaz, 2006; Glaser and Strauss, 1967; Schreiber & Stern, 2001). As demonstrated within this thesis (see Chapters One and Five) there is only a small amount of literature and theory exploring carers' experiences of supporting people with an intellectual disability and dementia, and the role of a Dementia Care Pathway (DCP).

CGT is an advanced, complex qualitative methodology; however, it is recognised by the researcher and within the literature (Nagel, Burns, Tilley, & Aubin, 2015, p. 374) that there is a lack of 'road maps' for the implementation of CGT. Indeed, Charmaz (2014) writes that CGT is a flexible methodology and does not provide a concrete analytical procedure for novice grounded theorists to follow. This lack of concrete guidance could result in a novice grounded theorist making methodological errors (Hussein, Hirst, Salyers, & Osuji, 2014). To ensure the tenets and methodological strategies of CGT were appropriately implemented, a wide variety of key texts (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Charmaz, 2006, 2014), and articles (Mills, Bonner & Francis, 2006; Hunter, Murphy, Grealish, Casey, & Keady,

2011) were studied, and national CGT workshops led by leading grounded theorists (Professor Tony Bryant; Professor Karen Locke) were attended. Alongside CGT, other methodologies were considered.

Ethnography was considered but ruled out at an early stage. This methodology aims to provide an 'insider' perspective of everyday life and explores participants' experiences and their social interactions, and the meaning participants apply to their experiences (Sharkey & Larsen, 2005). This is achieved through the researcher's in-depth engagement with participants over time. Through multiple methods, such as observations, interviews and documentary data, data source are triangulated with each other; this provides a 'detailed and comprehensive account of different social phenomena (actions, behaviour, interactions, beliefs)' (Reeves, Peller, Goldman, & Kitto, 2013, p. 1365). Reeves, Kuper, and Hodges (2008) state that ethnography, as a methodology, is useful for addressing a variety of research questions within the health professions; including generating 'rich and detailed' accounts of healthcare professionals, how they interact and approach delivering care to the people they support, as well as detailed accounts of patients' experiences of care. This made it very relevant to the aims of this research study.

An ethnographic approach would have provided rich insight into participants' experiences of support in their setting. However, Reeves et al. (2008) state that the ethnographic approach can be problematic when trying to secure repeated access over long periods of time, and where there is a lack of flexibility. Undertaking a part-time PhD, the researcher was working varying part-time roles with inconsistent work patterns, making it challenging to use such an approach when gaining access to and remaining in the participants' settings. Additionally, it was anticipated that some participants may not be currently supporting people with an intellectual disability and

dementia, but had done so previously. This was the case for both family carers. This made it an impractical methodology to achieve the research aims and to answer the research questions.

Alongside CGT, interpretative phenomenological analysis (IPA) was a methodology considered early in the research development process. IPA is a practical, systematic qualitative methodology which focuses, in detail, on the individual's experiences; how they make sense of their experiences and attach meaning to events. Its philosophical underpinning of phenomenology (study of experience in detail and depth) and hermeneutics (interpretation), combined with an idiographic perspective mean that IPA is suited to research which explores how 'individuals are perceiving the particular situations they are facing, how they are making sense of their personal and social world' (Smith & Osborn, 2007, p. 55), and has been widely used to explore experiences of health. This focus and IPA's systematic approach, meant an IPA methodology was well suited to this study, which aimed to explore and understand the participants' experiences and views. Its recognition of an active researcher, who brings their own conceptions to the research process, and its concern for 'how meanings are constructed by individuals within both a social and personal world' (Smith & Osborn, 2007, p.54) were well aligned with the researcher's own theoretical stance (see section 2.3.). Furthermore, IPA had previously been reportedly used within similar research (Furniss, Loveseed, Dodd, & Lippold, 2012) exploring the experiences of care providers, illustrating its applicability to this research study.

However, it was important that any findings from this research study were closely informed and shaped by the participants' views and experiences; whilst IPA advocates an inductive approach, CGT's unique methodological tools, in the researcher's opinion, were better able to achieve this. For instance, its delayed

substantive literature review ensured the analysis was more directed by the participants' experiences; analysing data as soon as it was collected, utilising constant comparative methods, and theoretical sampling, better ensured that the participants' experiences and views helped to direct and shape the analysis and CGT (Bryant & Charmaz, 2007).

This section has explicated the philosophical and theoretical underpinnings and methodology of this research study. Details of the ethical approval process, recruitment process, participants, methods, and interview procedure are now described and discussed. This is presented in the order in which these research elements were performed, starting with gaining ethical approval to undertake the research study.

2.8. Ethical Approval

This study was submitted to the University independent peer review process and then the NHS Research Ethics Committee (REC). The independent review was conducted by a senior representative of Keele University's Joint Independent Peer Review Committee, who assessed the quality of the then proposed research, before giving feedback (see Appendix B). The committee required clarification about certain elements of the research study, such as the recruitment process. Following approval (see Appendix C) from the University, NHS ethical approval was sought. The application was reviewed by the Black Country REC, who invited the researcher to a formal interview to discuss the research study. These committees can consist of up to 18 members, where one third are lay members. Their role includes safeguarding the 'rights, safety, dignity and well-being of research participants, independently of research sponsors' (NHS, 2013, para. 1). Issues raised focused on practical aspects of the study, such as adjusting the information sheets to include required statements

and what processes were in place if any of the participants became stressed. The committee initially provided a provisional opinion letter (see Appendix D), which detailed their requirements before they could give a favourable ethical opinion. A favourable opinion was provided in response to changes.

After REC approval was given, NHS Trust Research and Development (R&D) reviewed the application and provided permission to conduct the research in the local Trust. A contact within the NHS R&D was contacted in relation to minor amendments, and where necessary they sent updated documents to the researcher. A detailed description of the extensive work and steps taken to gain NHS ethical approval are presented in Appendix E.

2.9. Ethical Principles

Throughout the process of designing the research study, and whilst the REC application was being developed, multiple ethical principles had to be considered, and were at the forefront of every decision. Within any research, the 'dignity, rights, safety and well-being of participants must be the primary consideration' (DH, 2005, p. 7). This research study adhered to the 2011 British Psychological Society's (BPS) Code of Research Ethics and Conduct. At the heart of this are a set of ethical principles which inform our choices throughout research; these consist of: informed consent; risk; confidentiality; and anonymity (BPS, 2011; DH, 2005). These ethical principles and the steps taken to ensure they were adhered to are now described.

To gain informed consent from carers and healthcare professionals, Keele University and NHS guidelines were followed for creating invitation letters, information sheets, and consent forms (see Appendix F1, 2, 3; G1, 2, 3; and H1, 2, 3). For all participants, every step was taken to facilitate informed consent: all documents were

presented in non-technical language; the researcher's contact details were provided, so the participant could ask them any further questions; adaptations were made when needed, for instance, if a participant had difficulty with reading the text, it was presented orally; information was given at every possible point, this included through the invitation letter, information sheet, and when meeting in person at the first interview prior to gaining consent, and where relevant, reiterated at the second interview.

The British Psychological Society (BPS; 2011) defines risk, in relation to research, as 'the potential physical or psychological harm, discomfort or stress to human participants that a research project may generate' (p.13). These risks may be wide ranging and include risks to participants' personal social status, values and beliefs, privacy, and relationships. Thus, researchers must consider not only the immediate consequences for participants, but also the wider consequences, which may be directly attributable to the research, or may occur outside of it or upon its completion. With this in mind, risk assessments, when conducting research, not only consider the risk to participants whilst taking part in the research but the wider implications for them. If any risks are present to participants, these must be in 'proportion to the potential benefit' (DH, 2005, p. 8).

Judging all possible risk factors at the outset of this research was difficult, yet it was of the utmost importance to identify as many as possible, and to develop and implement appropriate procedures to reduce these risks as far as possible. The protection of participants was a fundamental factor across all aspects of this research. Procedures were put in place to prevent or minimise any risk, to any participant. Risk was evaluated as being minimal, as supported through the ethical application process. However, there was the possibility that participants drawn from family and paid carers would speak about experiences which they may have found emotionally challenging.

A number of measures were applied to counteract this: all participants were made aware of their ability to stop interviews; participants had the opportunity to have a supportive person of their choice present; participants also selected the location of the interview, in order to help alleviate any additional emotional strain or stress, and practical issues, such as being able to leave home, and transport; and information of support services were provided on all participants' information sheets.

The BPS (2011) highlights the importance of the research's risk being evaluated by the appropriate levels of ethical review; this has been applied through the NHS REC, where ethical approval was granted. Further, the risk and procedures put in place to reduce them were stringently checked by the research team, and through the Independent Peer Review process.

Anonymity is essential to ethical research practice; this especially applies to the current research where one component is to explore the support provided by carers and local services. It is the responsibility of the researcher to reassure all participants, and ensure that the data they provide 'cannot be traced back to them in reports, presentations and other forms of dissemination' (Crow & Willis, 2008, p. 1). The utmost care and consideration was taken to provide and uphold the anonymity of participants. This was achieved through standard good practice measures (Willis, Crow, Health, & Charles, 2006): all participants' names were replaced with pseudonyms and identifiable information was avoided in the write up. A digital recorder was used during each interview. Additionally, informed consent was requested for the publication of direct quotations from all participants, with all data remaining anonymised.

In the context of research, confidentiality is taken to mean that 'identifiable information about individuals collected during the process of research will not be disclosed and that the identity of research participants will be protected through various

processes' (Wiles, 2012, p. 42). This entails confidentiality of the participants' personal data and data provided through interviews (DH, 2005). Measures were put in place to achieve this: consent was requested for personal information, including the participant's address, for correspondence between the participant and researcher. Interview recordings were downloaded onto a password protected computer, which was in a secure office, only accessible by a designated key fob; only the researcher had access to this fob. Similarly, the transcripts of each participant's interview/s were kept on the same password protected computer, and located in the same secure office space at Keele University. Paper copies were also located in this office, under lock and key in a filing cabinet. This office was always locked. Keele University Code of Good Research Practice was followed throughout this process (Keele University, 2013).

2.10. Research Sites

Participants were recruited from two research sites: the first was an Intellectual Disability Dementia Care Pathway (IDDCP) situated in the Midlands in the UK; the second was a housing and care organisation also situated in the Midlands in the UK. The IDDCP provides dementia services and support for people with an intellectual disability from their referral until the end of life, with most of their involvement centring on the assessment and diagnosis process. It also provides supportive services, such as information, advice, and training, to family and paid carers. The IDDCP is a part of local intellectual disability services, and consisted of a small team of psychiatrists, nurses and occupational therapists.

The housing and care organisation is a not-for-profit organisation which provides a range of care and support services. The organisation specialises in dementia care and intellectual disability care homes. It is a large local organisation

which has many homes and sites across the local region. They provide a choice of housing options ranging from supported small group homes to care homes.

2.11. The Recruitment Process

As detailed in Chapter 1.11, this research study originally aimed to recruit participants with an intellectual disability and dementia. Access to family carers and paid carers was, at least initially, dependent on access to people with an intellectual disability and dementia as detailed. Therefore, though this thesis has been framed around carers and healthcare professionals, this section has needed to contain brief information about access and recruitment to people with an intellectual disability and dementia, in order to provide context to the access and recruitment of family carers and paid carers.

Participant groups were recruited in two stages. Healthcare professionals from the IDDCP were recruited first, followed by the remaining participant groups: family carers, paid carers, and healthcare professionals not affiliated with the IDDCP. Recruiting in this order had a number of benefits: IDDCP healthcare professionals were gatekeepers for the other participants (not including healthcare professionals not affiliated with the IDDCP); rapport was developed over their interviews, which helped to attain their support and cooperation when accessing other participant groups; it also provided an opportunity to learn the structure of support and services provided by the IDDCP and experienced by the other three participant groups; allowing for familiarisation with roles, terminology and abbreviations, and ensuring later interviews were informed.

The common aspect across recruitment for all participant groups was the need to use gatekeepers within the organisation to access participants and initiate the recruitment process.

2.11.1. Healthcare professional recruitment procedure.

Participants were identified and initially contacted by an employee of the organisation (gatekeepers) who agreed to support access and recruitment; this was the IDDCP clinical lead for the six participants recruited from the IDDCP; and a senior manager within the housing and care organisation for the remaining two healthcare professionals. Inclusion criteria were applied when identifying participants (see Table 2.1.).

Table 2.1. Healthcare Professional Inclusion Criteria.

Participant Group	Inclusion criteria
Healthcare professionals	Needed to be 18 years old or over, currently or have recently been on the care team of an individual with an intellectual disability and dementia.

The researcher provided an information sheet to gatekeepers and discussed the research with them in face-to-face meetings. This provided gatekeepers sufficient information to discuss the research with participants, and then to gauge their interest in taking part. Participants who wished to further discuss the research and their participation, had to agree to be contacted by the researcher through email.

Initial contact with participants by the researcher consisted of an informal conversation about the research by email. This contained a standardised statement (see Appendix F¹) detailing the purpose of the study, and what was required of the participant. They were then asked if they would like to take part in the research; if they agreed, a date, time and location for an interview was arranged. In total eight

healthcare professionals participated. All healthcare professionals worked or had worked within the NHS (see Table 2.3., page 94, for participant demographics).

2.11.2. Family carers and paid carers recruitment procedure.

Across the IDDCP and Housing and Support organisation, one route of access to paid and family carers was reliant on access and attempted recruitment of people with an intellectual disability and dementia. All participants were initially identified through gatekeepers, who were either IDDCP healthcare professionals, or senior management staff working within the housing and care organisation, using a set of inclusion criteria (see Table 2.2.). Recruitment was similar across organisations.

Table 2.2. Inclusion Criteria.

Participant Group	Inclusion criteria
Family carers	Needed to be 18 or over, be a family member (this can include immediate or extended family, blood related or related by marriage) of someone with both an intellectual disability and dementia, and provided (or have done so in the past) care and support for the individual.
Paid carers	Needed to be 18 years old or over, currently or have previously been a caregiver to an individual with an intellectual disability and dementia, and are/ were employed to do so.

Gatekeepers either phoned people with an intellectual disability and dementia or directly approached them as they contacted services. Where people with an intellectual disability and dementia were contacted by telephone they were briefly told the details of the study, asked for permission to use their address, and whether an invitation pack (see Appendix G^{1, 2, 3}; and H^{1, 2, 3}) could be sent to them and/ or their carer/s; this method allowed for easier identification of and access to family carers and paid carers. If people from any of the carer participant groups were interested in talking further about the research, and they met the inclusion criteria, they needed to return their 'opt in' slip in a pre-stamped envelope. Through this, participants also provided permission to use their personal contact details for further correspondence with the researcher. Once the completed 'opt in' slip was received by the researcher, a detailed information sheet was sent to participants. After seven days, participants were contacted by the researcher, and asked if they wished to take part in the research. If they agreed to participate, a date, time and location for an interview were organised by the researcher.

Alternatively, family carers and paid carers were approached by a gatekeeper as they encountered services across the two supporting organisations. This usually occurred as people with an intellectual disability and dementia, who were accompanied by their carer, attended appointments or were visited at home. The gatekeeper then briefly discussed the research with use of the research study information sheet (see Appendix G^{1, 2, 3}; and H^{1, 2, 3}). Both family carers and paid carers were given the option to read the information sheet themselves, or if they needed assistance from the researcher. The gatekeeper encouraged participants to consider the information carefully before filling out the invitation pack's 'opt in' slip. Participants who wanted to discuss the research further filled in a reply slip with their contact details. When 'opt in'

slips were immediately filled out, they were collected and saved by gatekeepers. Alternatively, the individual took home the invitation pack before sending the 'opt in' slip in a pre-addressed and stamped envelope. Once the completed 'opt in' slip was received by the researcher, participants were contacted, and their participation was discussed. If they agreed to participate, the date, time and location for an interview were organised by the researcher.

2.11.3. Deviations from the recruitment procedure.

There were a number of examples where recruitment deviated from agreed procedures, though these were still within ethically approved guidelines. An additional family carer was identified and recruited through snowball sampling, as participants provided links to other participants. For instance, when interviewing a family carer they provided contact details of their sister, who had also cared for their family member and had agreed to discuss their participation. In this case, the participant was contacted by the researcher and the research was discussed. They were then asked if they would like to know more about the research, and if yes, have an information pack (see Appendix G^{1, 2, 3}; and H^{1, 2, 3}) sent out providing full details of the study. This participant was then contacted seven days later, and asked if they would be willing to take part in the research, and if so, a date, time, and location for the interview was organised by the researcher.

There were also cases when recruiting paid carers deviated from the agreed procedure. Having forgotten 'opt-in' slips, gatekeepers briefly discussed the research with the participant, before taking their contact details if they were interested in discussing the research further. When the researcher contacted these individuals, they were asked to confirm whether they still wished to discuss the research, if so, an

information pack was sent out. Participants were called seven days later by the researcher to discuss whether they wished to take part in the research, and if so, a date, time, and location of the interview were organised.

2.12. Participants

In line with Constructivist Grounded Theory (CGT), the sample for this research study was selected to provide a rich context to the experiences of supporting someone with dementia and to answer the research questions. The sample was also selected to provide diversity and range within the CGT (Glaser & Strauss, 1967); drawing on multiple participant groups to construct a well-informed CGT. Participants were initially recruited through a purposive sampling strategy (Charmaz, 2014) and comprised of three different groups: family carers; paid carers; and healthcare professionals. However, under the tenets of CGT, where necessary theoretical sampling (see section 2.6. for a description of theoretical sampling) was applied. The challenges of engaging in theoretical sampling have been discussed through the literature, which has illustrated the difficulties of negotiating ethical panels who require details of participant groups and expected numbers (Birks & Mills, 2015; Bryant & Charmaz, 2007; Charmaz, 2014). Within this research study, the researcher was required to identify pertinent participant groups from an early stage to satisfy peer-review, research ethics, and university requirements. However, through these processes evidence was provided to justify a flexible approach to the recruitment, and if necessary, of new participant groups and additional participant numbers. In total, 18 participants (all females) were recruited across three different participant groups (see Table 2.3., page 94, for the full sample).

2.12.1. Participant numbers.

The number of participants recruited for each group was dependent on three factors: the applied methodology; access to participants; and the number of identified potential participants who met the inclusion criteria. Ultimately, the aim was to reach a rich level of theoretical saturation (this is discussed in detail in section 2.6.2.) (Charmaz, 2014). This meant sufficiently defining the properties of the developing categories and theory. To try and achieve this, theoretical sampling was applied: the seeking of 'people, events, or information to illuminate and define the properties, boundaries and relevance' (Charmaz, 2014, p. 345) of categories.

The 'events' and 'information' elements of theoretical sampling are discussed in section 2.16. Relevant here are 'People' as this meant participants. Participants were sought after as a tentative category was developed and when its properties needed to be defined; however, theoretical sampling and therefore saturation were dependent on the number of potential participants available and access.

The extant literature illustrates how accessing new participants and/ or participant groups through theoretical sampling can be challenging and sometimes not possible (Birks & Mills, 2015). Where this is the case, Birks and Mills (2015) write that the researcher needs to acknowledge the challenges and limitations faced, and the impact this has on the final grounded theory. Within this research study, theoretical sampling was sometimes not possible as access to the participants was restricted. A combination of restricted access, and only a small number of identified potential participants meeting the inclusion criteria (see Table 2.2., page 87) meant that only two family carers were recruited. The consequence of this for the level of saturation and the impact on the CGT is discussed in Chapter Six. Gatekeepers indicated that other potential participants were sought, but found they did not meet the inclusion

criteria: family members of people with an intellectual disability and dementia had no experience of caring for or supporting the individual.

2.12.2. Participant demographics: Family carers.

In total, two family carers participated. They were both female, aged between 50-69 years old. They were sisters, part of the same family and had previously provided care and support to their family member with an intellectual disability and dementia over a period where their family member had moved from supported living, due to losing mobility and the accommodation being unable to facilitate his needs, to the family home. Eventually, their family member moved into a dementia nursing unit, with both sisters taking turns to visit their family member.

2.12.3. Paid carers.

In total, eight paid carers participated. All were female and aged between 30-59 years old. All participants cared, or had done so previously, for people with an intellectual disability and dementia in small supported accommodation, and were paid employees of an organisation which provided support and care for people with an intellectual disability. Three of these participants were in a senior carer position. Experience varied with all participants supporting people with an intellectual disability and many other comorbid conditions, with years of experience varying from less than one year to 20+ years. Two paid carers worked in the same supported housing.

2.12.4. Healthcare professionals.

In total, eight healthcare professionals participated. All were female and aged between 40-59 years old. These participants consisted of one occupational therapist,

one psychiatrist, and six community intellectual disability nurses. Six of the eight participants worked on the IDDCP. All healthcare professionals on the IDDCP were involved in the assessment process, with community nurses administering a battery of dementia and/ or physical assessments. The occupational therapist carried out more functional observations of tasks; whilst the consultant psychiatrist led and oversaw the running of the IDDCP, and was involved in the assessment and diagnosis process. The remaining two participants worked for a local housing and support organisation. Both were practicing nurses working within a residential setting for people with an intellectual disability, many of whom had comorbid conditions, such as dementia, and people with dementia.

Table 2.3. Demographics for all Participants.

Participant Pseudonym	Age range	Sex	Participant group	Number of interviews
Alex	40-49	F	Healthcare professional	1
Ash	40-49	F	Healthcare professional	1
Brook	50-59	F	Healthcare professional	1
Carroll	50-59	F	Healthcare professional	1
Dale	50-59	F	Healthcare professional	1
Frankie	50-59	F	Healthcare professional	1
Jesse	40-49	F	Healthcare professional	1
Morgan	50-59	F	Healthcare professional	1
Pat	30-39	F	Paid carer	2
Sam	50-59	F	Paid carer	1
Shawn	50-59	F	Paid carer	2
Stevie	50-59	F	Paid carer	1
Taylor	50-59	F	Paid carer	2
Glen	40-49	F	Paid carer	1
Kelly	50-59	F	Paid carer	1
Kennedy	30-39	F	Paid carer	1
Lee	60-69	F	Family carer	2
Robin	50-59	F	Family carer	2
Total amount of interviews				23

*Age ranges, rather than the participants' actual ages, are reported to ensure individual participants are not easily identified through the demographic data. All participant names have been replaced with pseudonyms.

2.13. Method of Data Collection: Semi-Structured Interviews

The appropriate alignment of ontological and epistemological assumptions, methodology and methods ensures good research practice (Chamberlain, 2004). A qualitative approach was adopted as its concern with meaning and how people make sense of and experience the world around them (Willig, 2010), is well aligned with the focus of this research (see Chapter 1.11) exploration of the participants' experiences of dementia. It is also well aligned with the constructivist paradigm underpinning of this research (as discussed in section 2.3. and 2.4.). However, it was important to select a qualitative research method which fitted and complemented the underpinnings of this research. The stand out method to use was a type of interview, as this allows participants to discuss their experiences.

Qualitative research interviews have been defined as 'conversations with a purpose' (Burgess, 1984, p.102), where there is a 'two-way process where researcher and participant engage in a dialogue to explore the topic' (Taylor, 2005, p.39). The aim is to explore the 'insider perspective' (Taylor, 2005, p.39), whilst focusing on the experiences, life histories, thoughts, and feelings of participants, in their own words (Howitt, 2010). This is complemented by the focus that interviews facilitate on 'participants' statements about their experiences, how they portray this experience, and what it means to them' (Charmaz, 2014, p.58). The flexibility of interviews also encourages a natural flow of conversation, giving respondents the freedom to explore

unforeseen avenues of thought, and allowing the exploration of sensitive topics (Coolican, 2009). Through this research, it is recognised that interviews are 'performed retrospective accounts' (Charmaz & Belgrave, 2012, p. 350) in response to questions; and that interviewees' construct their 'performance', explaining and justifying their views, experiences, actions and past events from the present. Consequently, interviews provide the researcher with a representation of the participants' experiences; how they have perceived it and constructed it (Flick, 2015; Murray, 2015).

2.13.1. Selecting an interview type.

After discussions with both PhD supervisors, and much consideration, the decision was taken to use semi-structured interviews. The compatibility of semi-structured interviews with CGT was a further drawing point to the method (see sections 2.13.2 and 2.15. for further discussion). Semi-structured interviews were used to collect data; however, when deciding to use this type of qualitative interview, it was important to critically explore the different types of interviews available, and select the one which best facilitated answering the research questions. There are various types of qualitative interviews; three were considered carefully: structured, unstructured, and semi-structured interviews.

Structured interviews are rigid, as interviewers ask predetermined questions in a specific order. Once the participant responds to a question, the next question is asked without deviating from the prescribed question order and without asking probing questions (Berg & Lune, 2012). They are used when the researcher has a good idea about what they want to find through the interview (Berg & Lune, 2012; Flick, 2006). This made it unsuitable for this research study, which places emphasis on understanding the participant's experience, following their journey and what they find

important; this would require deviating from the interview schedule questions and order, as well as asking probing questions. It is also poorly aligned with the methodology, where a researcher acknowledges they enter an interview with their own ideas, but which advocates an open mind to all possible avenues (Charmaz, 2014); and the constant comparison method, which may entail introducing new questions into successive interviews as more abstract categories and concepts are generated (Charmaz, 2014).

In contrast, unstructured interviews are flexible as the interviewer has a set of topics to explore in place of an interview schedule; however, questions are not necessarily predetermined (DiCicco-Bloom & Crabtree, 2006). The interview is led by the participant. This makes interviews unpredictable. Consequently, interviewers have to adapt to the participant's responses, generating appropriate questions and follow-up questions within the interview (Berg & Lune, 2012). This requires a skilled and experienced interviewer, who can cover their research topics by developing questions during the interview and reacting to the participant's responses (DiCicco-Bloom & Crabtree, 2006). The flexibility of unstructured interviews, and the central role of the participant and their journey, made it appropriate to use; however, Taylor (2005) states that a researcher needs to consider whether they have the necessary skills for qualitative interviewing. One concern was a lack of experience and necessary skills to carry out unstructured interviews on a possibly sensitive topic, such as experiences of dementia; and whether this inexperience would harm participants, due to insensitively developed questions during the interview, and prevent the research aims and questions being fully explored.

Semi-structured interviews provided a balance between structured and unstructured. They entail asking participants a 'number of predetermined questions

and special topics' (Berg & Lune, 2012, p.112), in a consistent and progressive order. However, semi-structured interviews are flexible; the interviewer goes beyond predetermined questions and probes the participant (DiCicco-Bloom & Crabtree, 2006). This meant following the participants' experience and trying to fully explore it before moving to a different question. Consequently, the ordering of the questions changed and new questions were introduced. The combination of having some predetermined questions, which would help to ensure that the research questions were answered, and the flexibility to change and introduce questions to better understand participants' views and experiences, made semi-structured more suitable than either structured or unstructured interviews. Additionally, it was well aligned with the CGT methodology, as it enabled the introduction of new interview questions to the interview guide, which supported elements of theoretical sampling, specifically, seeking of events and information to illuminate properties of categories (Charmaz, 2014).

2.13.2. Suitability of semi-structured interviews.

When considering whether semi-structured interviews were the most appropriate method of data collection, it was important to remain open to all options, and to critically explore the rationale for their use. To achieve this, three questions were considered:

- Does interviewing fit my philosophy of research and epistemological stance?
- Does interviewing fit my research aims and question?
- Will interviews gather the best data to address these aims and questions?

(Taylor, 2005, p.40)

Philosophically and epistemologically, semi-structured interviews are appropriate for research studies that seek to 'access the participants' understanding of the world and

their experiences' (Taylor, 2005, p. 40). These underpinnings made it ideal for this research study, where the aim was to explore participants' views, understanding and experiences of dementia. Turner (1981) suggests that grounded theory is well suited to processing qualitative data such as that gathered through semi-structured interviews. This method's underpinnings complemented the research study's methodology. Both focused on the subjective experiences of the individual, as interviews enabled an 'abstract understanding of studied life' (Charmaz, 2014, p.342) by providing access to peoples' experiences of dementia.

Similarly, semi-structured interviews are suited to research aims and questions which focus on 'how participants understand and construct meanings about the experiences of their daily lives' (Taylor, 2005, p. 41). This makes it an appropriate method to address this research study's aims and answer its research questions, which focus on the experience of supporting someone with an intellectual disability and dementia.

2.14. Multiple Interviews

Initially, it was planned that family and paid carer participant groups would take part in two semi-structured interviews each. The underlying reasons for inclusion of second interviews was to gain as much depth and richness about experiences as possible; to collect a more complete picture of carers' experiences.

Knox and Burkard (2009) write that single interviews may miss important information, and may fail to elicit the 'vital contextual information that would more likely emerge across multiple interviews' (p.7). In contrast, multiple interviews allow for experiences to be explored in greater depth. This is supported by Charmaz (1990) who demonstrated, through her exploratory work with people with a chronic illness, that

multiple interviews may be appropriate when such a significant illness is present to 'get through the basic information about the course of his or her illness, much less tap all the areas the researcher needs to cover' (p. 1167). Though the carers did not have dementia, the close and intimate relationship paid and family carer participants had in this research study with the people they supported meant they too had a lot of 'basic information' about their observations of the course and worsening of dementia. Second interviews were important to further explore carers' experiences, as it was not always possible to probe these in as much depth as needed in the first interview.

Flowers (2008) illuminates the possible advantages of using multiple interviews with the same participant, including better enabling the researcher to become aware of lost opportunities from the first interview; whilst allowing the researcher to gain greater clarity and richness from the interviewee during the second interview. Furthermore, multiple interviews with each participant may induce stronger relationships between the researcher and participants; facilitating a more comfortable environment, and encouraging the participant to discuss difficult or emotionally laden experiences (Adler & Adler, 2002; Ely, Anzul, Friedman, Garner, & Steinmetz, 1991).

Second interviews also allowed for better application of principles and strategies of CGT, such as theoretical sampling (Birks & Mills, 2015; Charmaz, 2014; Walker, 2015*). Here, the researcher was able to analyse the participant's data, further developing the CGT, and then to go back to the participant to collect additional pertinent data to refine categories and their properties. This aided the development of a rich level of saturation (Birks & Mills, 2015; Glaser & Strauss, 1967; Urquhart, 2007).

However, after three second interviews with paid carers, the decision was taken to reduce the number of such interviews to one interview each. These second interviews were not producing new theoretical leads, with many of the participants

being unable to provide new information for the developing categories. Both family carers still took part in two interviews. Healthcare professional participants took part in one interview each.

2.15. Constructivist Grounded Theory and Focused Semi-Structured Interviews

Once applied, a CGT methodology had implications across semi-structured interviews. Specifically, key tenets of CGT, including constant comparative methods and theoretical sampling, meant that semi-structured interviews gradually became more focused to obtain a rich level of theoretical saturation.

Here, more focus refers to developing and introducing new interview questions into later interviews which teased out further information about a category's properties. This process started after initial interviews for each participant were transcribed, and constant comparative methods were applied (Charmaz & Bryant, 2007). This entailed comparing initial codes and focused codes within and across interviews; subsequently, categories and theory were developed (Birks & Mills, 2015). At this stage, emphasis was placed on sufficiently developing the properties of the constructed categories and theory. To do this, theoretical sampling was applied.

'Events' and 'information' were sought once a tentative category was developed and when its properties needed to be defined; this involved introducing new questions into subsequent interviews (Mills, Bonner, & Francis, 2006). However, this did not result in full interview guides being substantially altered from those used in initial interviews; instead, most questions from the original interview guide remained intact, but either a new question was introduced or questions which were eliciting no new information for properties were replaced. For instance, during Robin's first interview, she regularly touched upon feeling responsible for her family member with an

intellectual disability and dementia. After analysing the interview and applying comparative methods, further questions were asked in the second interview to develop a greater understanding of this potential property of a category, including what it was like to have this responsibility, whether it had influenced them or their family, and in what way. This provided greater insight into the burden which Robin experienced, and how she needed support from her family to better manage the needs of their family member with dementia.

2.16. Interview Procedure

The interview procedure was similar across all three participant groups; though there were variations in the interview guide and the use of tools of communication. There were three stages to all interviews: pre, during, and post-interviews. Before the interview, procedures were in place to ensure that all of the necessary material and equipment was taken to each interview, and the safety of the researcher. A pre-interview check list was developed (see Appendix I) and was ticked off for each interview; this entailed: checking that the correct participant group interview guide, information sheet, and consent form were taken; checking and, if needed, replacing batteries in the digital recorder, and ensuring it was in working condition; contacting the participant on the day, prior the interview, to ensure that they were still aware that the interview was taking place, and to check they were still available and the address of where they wished to be interviewed; and ensuring researcher safety, by leaving details of the location of the interview with a trusted colleague.

At the start of each interview, an interview check list was used, and key points discussed with participants to ensure that the interview followed the procedure put in place to ensure NHS ethical compliance. This was split into two sections, the first

provided instructions on starting the interview, such as 'briefly give an overview of the research' and 'Provide the participant with a study information sheet and ensure that they have adequate time to read the information thoroughly'. The participant information sheet (see Appendix F^{1, 2, 3}; G^{1, 2, 3}; and H^{1, 2, 3}) had already been given to participants prior to arranging the interview; however, it was again verbally explained, and participants were given as much time as needed to re-read through it.

Once participants had re-read the information sheet, the second part of the interview check list was used. This contained specific pieces of information which stressed key points of the information sheet to participants, such as, emphasising to the participant that 'to accurately capture what is being said, the interview is audiotaped' or 'any quotations that are used will be completely anonymous'. Two consent forms (see Appendix F^{1, 2, 3}; G^{1, 2, 3}; and H^{1, 2, 3}) were then provided to the participants (one for them to keep, and one for the researcher's records) and written consent was obtained. Process consent was applied, where informed consent was obtained at every interview (for those who participated in multiple interviews) (Usher & Auther, 1998). This ensured continuing consent throughout the research study.

The participant was told that they could take a break, or if they felt it necessary, stop the interview at any point, and that their data would be kept confidential and anonymous. After obtaining permission to digitally record the interview, the interview guide was used. There was a different interview guide for each participant group (see Appendix J^{1, 2, 3, 4}). These were designed to be sensitive to discussions around dementia. The initial question used across the different participant groups asked participants to say a bit about themselves: their name, employer and role (if relevant). As rapport developed, participants were gradually eased into more sensitive questions about their experiences of dementia. Interviews were ended once all the interview

guide was covered and/ or when the participant had nothing else they wanted to add or discuss. Participants were directed to key sections of the information sheet which provided details of the researcher, in case they had any further questions, as well as details of support they could access if they felt that they required it. For participant groups taking part in a second interview, a date, time and location was arranged with the researcher. The same procedure was used in all second interviews.

Immediately after the interview, and prior to any other participant interview, interviews were transcribed. The playscript method was applied. This required focusing 'on the words which are said, not how they are said' (Howitt, 2015, p. 140). This method was aligned with the research focus: the experiences of participants. This meant focusing on the words participants said about their experiences. Each interview was transcribed on a word document with the use of 'Express Scribe transcription software'. The free version of this software is a specialised transcribing programme which allows users to slow down, speed up, and pause digital recordings (NCH software, 2015). After being transcribed, interviews were immediately analysed under the conventions of CGT (see Chapter Three for more details). Time was also taken to reflect on each interview as it was transcribed. Questions were critiqued and, where necessary, reworded, and the lessons learnt applied to the next interview. For instance, it was evident that paid carers may have experienced services and support from the IDDCP, but did not know that it was called this. Consequently, these questions produced confused looks from the participants or defensiveness as they may have believed it was something they should be aware of. After initial interviews with carers, questions which included the IDDCP were reworded to focus on external services. This produced a greater depth of experiences. Where participants discussed services and support provided from the IDDCP, the IDDCP was discussed and original questions asked.

2.17. Ensuring the Quality of this Research Study

Ensuring the quality of this research study was important. The positivist concepts of validity, reliability, and generalisability cannot be used to evaluate qualitative research (Flick, 2015; Shenton, 2004; Willig, 2013). Lincoln and Guba (1985) proposed alternative criteria to evaluate the quality of qualitative research: trustworthiness and authenticity. Trustworthiness, the more influential of the two (Flick, 2015; Taylor, 2016), has been applied when accessing the quality of this research study. Trustworthiness consists of four criteria:

- Credibility
- Transferability
- Dependability
- Confirmability

Credibility refers to the degree to which the research study findings match with reality. It was important to illustrate the processes in place which ensured the researcher had accurately recorded the phenomena (Shenton, 2004). Investigator triangulation was implemented to ensure credibility (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). As described in Chapter Three, the researcher's study supervisors reviewed the analysis with the researcher.

Transferability refers to the degree to which the findings of this research study can be transferred to other settings or contexts (Shenton, 2004). To achieve this, Lincoln and Guba (1985) recommended providing thick description of the phenomenon. Details of the two study sites have been described. Illustrative quotes have also been used to support the researcher's interpretations, and allow others to form their own interpretations of the data.

Dependability refers to consistency and repeatability within research findings (Lincoln & Guba, 1985; Shenton, 2004). To address dependability, the research processes needs to be clearly explicated; enabling other researchers to at least replicate the research study (Shenton, 2004). An extensive description of the methodology, methods and analysis process have been provided across Chapter Two.

Confirmability refers to the degree to which the research study's findings are underpinned by the experiences of the participants, and not the preferences of the researcher (Lincoln & Guba, 1985). Through the methodology, it was recognised that findings were informed by both the participants and the researcher (Guba & Lincoln, 1989); however, as described across this Chapter, steps were taken to ensure preference was given to the participants' voices, and transparency for analytical decisions. To ensure confirmability it was important to implement two strategies: reflexivity and an audit trail. A reflexive approach was taken throughout, with reflexive commentary across Chapters within this thesis. Additionally, a clear audit trail from data collection to data analysis, and the interpretation of data are detailed across Chapter Three and Appendix K.

2.18. Personal Reflections

2.18.1. Recruitment.

The recruitment process was perhaps one of the most potent lessons I learned throughout my PhD journey. Having initially been optimistic about the likelihood of recruiting a good number of participants across all participant groups, with time, my optimism was replaced with concern; this included for people with an intellectual disability and dementia. As previously discussed in Chapter One and Two, attempts

were made to recruit this participant group but due to the challenges experienced through recruitment, their voice was not included within this research study.

Having worked closely with gatekeepers to ensure clear procedures for recruitment, it was disappointing to experience challenges across both carer groups and people with an intellectual disability and dementia, once these were implemented. Across all sites of recruitment, challenges with recruitment were exacerbated by overestimation of numbers of potential participants and gatekeepers lacking the resources to support recruitment, and challenges in communication between gatekeepers and myself. Gatekeepers, especially those from the IDDCP, already worked in demanding roles, and found it challenging to spare time in seeking out participants and then to go through the research process. Consequently, fewer than expected participants were recruited from the family carer and people with an intellectual disability and dementia participant groups.

A great amount of time, effort and resources were applied throughout the recruitment process with, in many cases, little in return. Several unsuccessful attempts were made to access participants through various organisations, this included care organisations, intellectual disability and dementia special interest groups, charities, support groups, and healthcare professionals from different NHS trusts. Many of these, such as the special interest groups, were composed of members from across the UK who worked for various organisations, including universities, the NHS, charities, and care providers. This allowed for the research study to be advertised across a range of organisations, and reached professionals specifically working with the carers of people with an intellectual disability and dementia.

Other organisations, though not specialising in intellectual disabilities, were national organisations that specialised in dementia, so may have provided access to

participants. However, accessing large organisations required the completion of time-consuming applications. For instance, access to the Alzheimer's society required completing an application form, whilst collating and appending the IRAS application. This input of time and resources proved to be fruitless, as after acknowledging the application through an automated reply there was no further contact, and no response to further emails sent about the progression of the application. Similar experiences occurred across organisations. Other organisations, whilst allowing access, were unable to locate participants who met the participant criteria.

There were many positive examples where gatekeepers went above and beyond to ensure recruitment; one such example was a gatekeeper who helped to recruit six of the eight paid carers. Reflecting on this experience, I deliberated on possible underpinning causes. I questioned whether the implemented procedure for recruiting gatekeepers could have been refined. Not including all gatekeepers within early discussions meant the lead contact (someone in a senior position) agreed the participant recruitment procedure without consulting other gatekeepers; however, this may have meant time challenges and resources were not fully considered. This was a stark reminder of the importance of a collaborative process when designing research.

2.18.2. Data collection.

The semi-structured interviews provided an opportunity to apply and develop pertinent research skills. Salient here was communication. Having felt apprehensive prior to initial interviews, with every interview, my awareness of my own ability and confidence grew. I took time to analyse good areas of the interviews and areas which I could improve on. Missed opportunities, where I overlooked chances to ask pertinent probing questions, were not uncommon in earlier interviews; for instance, when Alex

spoke about providing a diagnosis to people with an intellectual disability, I did not probe further to better understand how this was achieved. However, I noticed, with experience, my ability to insert timely, well-constructed probing questions developed. For instance, when Frankie spoke about providing a diagnosis to people with an intellectual disability and dementia, how this was achieved was further probed with questions such as 'how did you give people with an intellectual disability and dementia a diagnosis of dementia?' and 'could you tell me more about this?'. These kinds of questions elicited further, richer data from the participant which helped to develop a richer CGT.

The interview guide provided an important tool, prompt and safety net during interviews. This was strictly adhered to during initial interviews, when I needed more support with what questions to ask and felt less able to go 'off-road'. As I experienced more interviews, this approach was superseded by following the participants' lead. In doing so, the interviews evolved; instead of simply getting answers to researcher constructed questions, this elicited experiences which revealed unexpected avenues. This meant allowing participants to fully discuss experiences, whether they were relevant or largely off topic.

2.19. Summary

In this Chapter, the theoretical underpinnings, methodology, and methods have been explicated. It has detailed the constructivist stance taken within this research study, which is underpinned by a relativist belief of multiple realities, and a subjectivist view illustrating that the final CGT is one co-constructed between the interactive process between the researcher and the participants. This constructivist paradigm flows through the CGT methodology adopted and applied within this study. This Chapter has

provided a rationale for the use of CGT, including its alignment with the researcher's theoretical beliefs, and its systematic, inductive approach, ensuring a theory developed through the data. The key tenets, methodological strategies, and analytical processes pertaining to CGT, have been described and critically discussed where necessary.

An in-depth account of the ethical review process, and the extensive efforts across access and recruitment have been detailed and where relevant reflected upon. It has highlighted the challenges, at times, of working with gatekeepers to recruit participants. This study has used semi-structured interviews to elicit in-depth conversations and rich data from paid carers, family carers, and healthcare professionals. The alignment between the theoretical underpinnings, methodology, and methods, and their suitability to effectively address the research aims and answer the research questions has been demonstrated. Furthermore, this Chapter has provided an extensive explanation of the interview process. In Chapter Three, how CGT has been applied to analyse the interview data across carers and healthcare professionals has been comprehensively detailed.

Chapter Three: Analytical Procedure

3.1. Introduction

Within this Chapter, the specific procedures used to manage and analyse the data drawn from family carers, paid carers, and health care professionals, are described. The key analytical stages and methods of Constructivist Grounded Theory (CGT) (Charmaz, 2014), including initial coding, focused coding, categorising, and memo-writing, are explained; how these have been applied within this research is demonstrated through a worked example of a participant, Pat (Paid Carer; PC). As the analysis reaches the categorising stage, which discusses data comparisons across participants, the dataset (all participants combined) is used. The quality checks in place, specifically investigator triangulation, are explicated, before detailing how data were managed and the practical procedure used by the researcher to code and process the data through the stages of CGT.

3.2. Applying Constructivist Grounded Theory

Through CGT, raw data were actively processed by applying different analytical stages, each stage raising the data to a more abstract level until the CGT was developed: providing an interpretive explanation of the participants' experiences (Charmaz, 2014). Data processing was initiated through initial coding and focused coding. Figure 3.1. (see page 112) provides a visual representation of the analysis process.

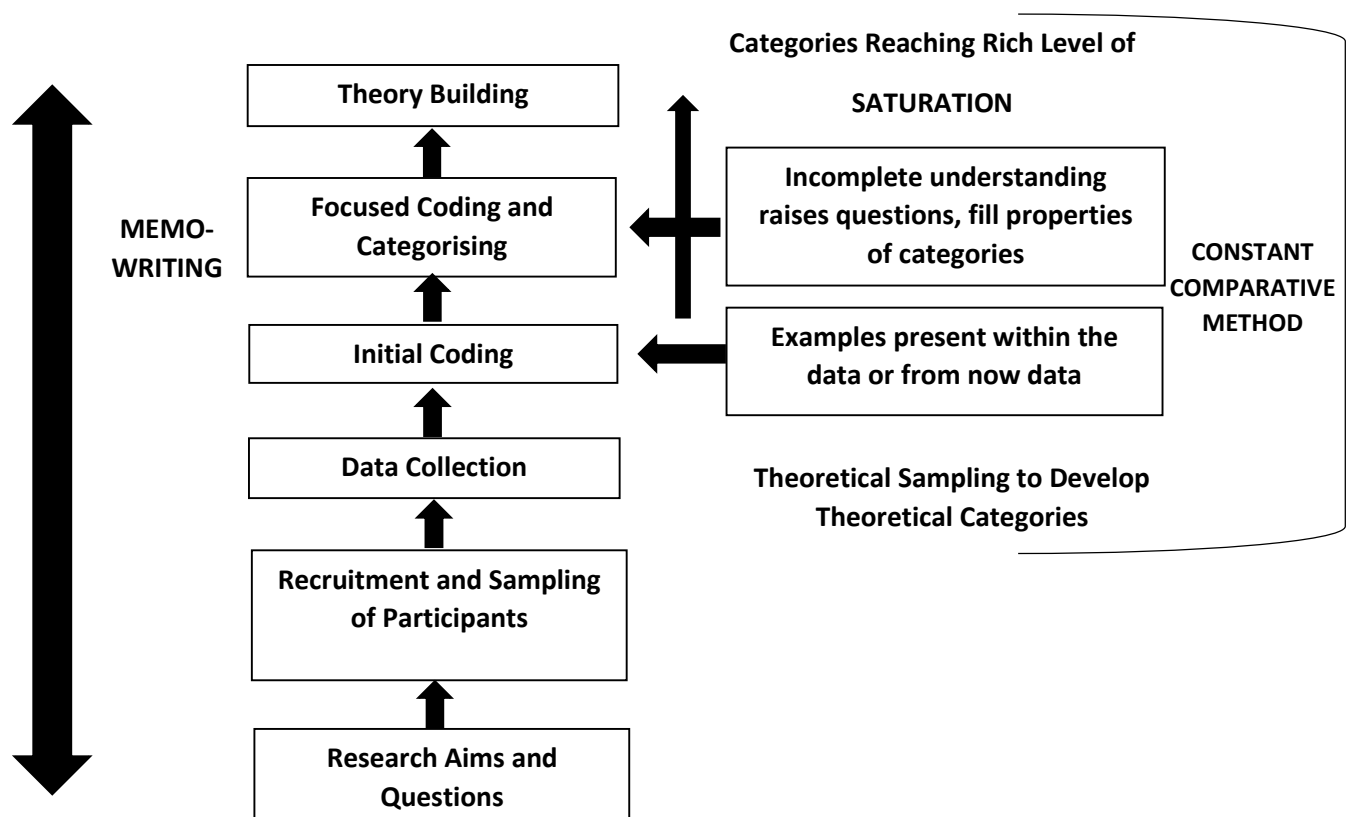


Figure 3.1. A visual representation of Constructivist Grounded Theory (Charmaz, 2014, p. 18).

3.2.1. Initial coding.

Analysis of each interview started with initial coding, which was applied as soon as the first interview was transcribed. The aim was to label segments of data; staying inductive by describing what was happening in each segment, avoiding being too interpretive, and preventing the researcher's voice taking precedence over participants' voices (Breckenridge, Jones, Elliott, & Nicol, 2012; Mills, Bonner, & Francis, 2006). Inductive initial codes acted as the foundation of the final theory being firmly grounded in the participants' experiences (Charmaz, 2014). To be thorough and consistent when analysing the data, segments were restricted to a line or short

sentence of the transcript (see Figure 3.2., page 115, for an example of the thorough process applied).

Throughout initial coding, gerunds and in vivo codes were applied. Gerunds, which are formed with verbs but function as nouns and end in 'ing', such as *Trying to help the service user* (Pat, line 58) provided a sense of action and helped to identify processes: single events which were linked and remained close to the data (Glaser, 1978). In vivo initial codes are codes labelled with terms or phrases which participants said during interviews (Charmaz, 2014); for example, *Not seeing them as a 'statistic like GPs'* (Pat, line 63). Such codes maintained the participants' 'meanings of their views and actions in the coding itself' (Charmaz, 2014, p. 134). In vivo codes were utilised throughout to maintain the essence of the participant's voice and the meaning they constructed through the segment of data.

The inductiveness, or how close the code remained to the data, was checked by the researcher after completing initial coding for each transcript, by carefully re-reading the transcript and initial codes. This quality check ensured initial codes better represented the participant's voice. Inevitably, some initial codes were reworded to be more representative of the data extract. For example, in Figure 3.2. (see page 115), line 64-65 was initially coded as *Use of medication*. Re-reading this initial code, it did not fully summarise the data extract, so was replaced with *Overcoming challenges with help*, as this better represented the participant's voice. Once the researcher was satisfied with initial coding, and their description of data, focused coding was implemented: focusing the analysis and raising its abstractness. However, initial codes remained provisional until the categories were fully developed; they were changeable throughout the analytical process. This allowed for further analytic possibilities to be explored, as codes which best fit the data were developed.

3.2.2. Focused coding.

Focused coding entailed organising and managing the developing analysis; focusing the analysis, as initial codes were explored and decisions about which to focus upon were made (Charmaz, 2014). Focused coding drew the researcher further into engaging with the participant's transcript, as data extracts were re-read and compared with initial codes to direct and develop focused codes. When focused coding, initial codes were raised based on their prevalence, importance to the research questions, and which initial codes make the most analytic sense. Practically, this equated to raising and synthesising initial codes which were underpinned by the same or similar meaning; or where initial codes were pulled together to build a picture; or single codes which added a unique perspective or were central to the research questions. Consequently, focused codes were composed of one or many initial codes. Table 3.1. (see page 116) highlights how the initial codes shown in Figure 3.2. (see page 115) directed the analysis, and were raised and synthesised to form focused codes. For example, the initial codes *Trying to help the client in a person-centred way* and *Not seeing them as a "statistic like GPs"* were synthesised together to form a focused code which explicated the individuality they illuminated; this was labelled *Treated client as an individual*.

Focused codes were usually given a new label, which detailed and illustrated the underlying meaning of the raised initial codes (as demonstrated in the previous example); again, to illustrate action and processes, gerunds were applied where possible to label focused codes, for example, *Addressing shortcomings* (from Table 3.1., page 116). However, In vivo focused coding was also utilised, where labels of initial codes were maintained for focused codes when either a level of abstractness was achieved, or when the researcher believed an important element of the



Figure 3.2. Sample of Initial Coding.

participant's voice was represented in the initial code label. For example, the initial code *Being able to "just pick up the phone" for support* incorporated a piece of Pat's voice and illustrated an important method of accessing support. To maintain its meaning, this initial code was raised to a focused code, with its label intact. This ensured the data and participant's voice directed and were rooted in the progressing analysis.

Table 3.1. Examples of Focused Coding (Pat, Interview 1, Page 2).

Focused Code	Initial Code
Addressing shortcomings	Taking steps to overcome shortcomings; Following advice and guidance from consultant
Losing support	Losing support
Feeling the loss of support	Affected 'terribly' with the loss of the health facilitation team; Appreciating support; A sadly missed form of support
Treated client as an individual	Trying to help the client in a person-centred way; Not seeing them as a 'statistic like GPs'
GP not adapted	Not adapted for the client
Services lacking understanding of intellectual disability	Not all services are understanding of LD let alone LD and dementia
Responsive to us	Responsive to requests; Supported by a team

Focused coding was performed on each page of the transcript: ensuring thoroughness in the developing theory. Again, after completing focused coding, the researcher re-read the focused codes, checking their fit to initial codes; where necessary focused code labels were changed to ensure better representation and explanation of initial codes. For example, for Pat, the focused code, *Communicating changes to staff* became *Supporting staff awareness*. The latter better illustrated the process which underpinned the initial codes: the support offered to staff to ensure awareness of changes in the person with an intellectual disability and dementia.

Once satisfied that focused codes had focused the data whilst maintaining and being rooted in the participant's voice, and to ensure the data for each participant was manageable, focused codes were clustered together to form overarching focused codes. Focused codes from across each participant transcript/s, were brought together based on shared meaning (see Table 3.2., page 118 for an example of this process). Focused codes were compared to one another by reading the initial codes and data extracts which underpinned them. Where there were similarities, focused codes were clustered together to form an overarching focused code; this could include focused codes at the opposite ends of the same continuum. For instance, for Pat, the overarching focused code *Continuum of support* encompassed focused codes which illuminated being supported as well as losing support (see Table 3.2., page 118). Both came under continuum of support but highlighted different properties of the overarching focused code.

Table 3.2. Sample of Overarching Focused Codes and the Clustering of Focused Codes from which they were Developed (Pat).

Sample of Overarching Focused Code	Sample of Clustered Focused Codes
Continuum of support	Being supported by external services Responsive to us Supported by company Being able to 'just pick up the phone' for support Missing a stepping stone Having to manage without facilitation team Consequence of loss of support
Understanding	Treated the client as an individual Services accommodating client Lack of understanding results in lack of adaptations Need for professionals to have understanding
Impact of dementia	Burden of dementia Negative emotions after diagnosis Added demands of dementia for carer Taking more time
Continuity	Ensuring client can stay at home Upskilling ourselves so they can stay at home Ensuring the client is kept at home Making it work

The number of focused codes which formed overarching focused codes depended on their prevalence throughout the participant transcript/s. Constant

comparison of focused codes across the transcript/s, enabled the properties of overarching focused codes to be defined. To maintain their relationship with the data and the participant's voice, focused and initial codes were placed in each participant's analysis document (see Appendix K for an example of each participant's analysis document), alongside the relevant overarching focused code. This provided physical evidence, an audit trail, of the overarching focused code's meaning. This also allowed the researcher to compare overarching focused codes with one another: their meaning and properties. This highlighted overarching focused codes which needed to be subsumed into other overarching focused codes due to shared meaning. For example, by comparing Pat's overarching focused codes, her focused codes, initial codes, and data extracts, the overarching focused code, *Loss of support*, was subsumed into *Being supported*, and re-labelled *Continuum of support*. The researcher believed both to be properties of experiences of support.

Bringing focused codes together, to form overarching focused codes, progressed the analysis; it increased its abstractness, and developed understanding of the processes in each participant's experiences. Like previous stages of the analysis, overarching focused codes were checked by the researcher for their representation of focused codes and the data, and the understanding they provided for the participant's experience. This was supported through constant comparison. As focused codes were clustered, and overarching focused codes compared, a constant checking process was applied to ensure that it made analytical sense for focused codes to be clustered under an overarching focused code.

3.2.3. Categorising.

Once satisfied that overarching focused codes provided an understanding of each participant's experience, data were categorised. This is the process of selecting overarching focused codes which hold overriding significance or clustering overarching focused codes together based on a common underlying theme. Categorising raised the analysis from descriptive to more abstract ideas about what was happening across participants' experiences (Birks & Mills, 2015; Charmaz, 2014). As more data were analysed and categories developed, the properties (the defining characteristics) of a category were explicated, as were the conditions under which these properties operated and changed, and their relationship to other categories (Charmaz, 2014).

This meant applying constant comparison methods, comparing overarching focused codes across participants, immediately after each participant's overarching focused codes were completed. The researcher used each participant's analysis document to categorise overarching focused codes; their meaning was checked and developed through the document as they were compared across participants, and properties of the developing category teased out. Simultaneously, overarching focused codes were examined visually on a laminated A0 piece of paper. Both methods allowed for overarching focused codes to be compared, which were categorised, and brought together, based on shared meaning. For example, the category *Continuity* brought together overarching focused codes which had shared meaning, such as *Staying in place*, *Stability*, *Accommodation*, *Continuity in home*, *Needing Intellectual Disability Services*, and *Keeping people in intellectual disability services*. These overarching focused codes illuminated the need to maintain continuity in both the home of the person with an intellectual disability and dementia, and their access to support from

intellectual disability services; as well as the consequences when continuity in either was disrupted.

As more data were collected to develop categories, their properties were explicated and defined. As categorising was performed, the researcher considered what underpinned the developing categories and what was tying them to one another. This thinking started to draw the categories together and provide an understanding of the experiences of dementia.

3.2.4. Memo writing.

Memos were written throughout the analytical process, from initial coding to categories. Memo-writing provided a space to engage and interact with the data to form and develop ideas (Charmaz 2014; Lempert, 2007), as demonstrated in Figure 3.3. (see page 122). Dementia training was an early memo which was developed whilst analysing paid carer data. It provided a space for the researcher to lay out their thought process throughout initial and focused coding, and when raising focused codes to overarching focused codes. Raw data were used to illustrate and support analytical ideas.

Dementia Training

Dementia training was prominent across paid carers and held a role in different areas of their experiences, as well as having consequences for the people they cared for with an intellectual disability and dementia. Dementia training was an underpinning of understanding as it provided an awareness of dementia. It allowed paid carers to act appropriately when faced with dementia related changes, as well as providing reassurance for their actions; however, training was responsive, and in many cases paid carers had to initially push for their own training.

To me, dementia training links into *Understanding*. Dementia training is one which helped paid carers understand the changes which were occurring in their clients with an intellectual disability and dementia. It was through training that paid carers became more aware of the symptoms and changes of dementia. Dementia training helped carers to spot dementia related changes in clients. It was an enabling tool as it provided carers with the skills to respond to dementia related changes: to ensure they received they appropriate support. This linked into actions, as training helped paid carers to carry out appropriate actions. To me, this combination of increased awareness and having the skills to act, was an important factor in the client's life. For instance, Shawn (PC), received training from their employers which helped them to understand the dementia and adapt their support to meet the person's dementia needs. For instance:

'Oo lots, we've had training, we've had dementia training, erm|we done quite a bit actually...Erm, with the dementia training though it was really good, you were made to understand more. It's like we say. It's helped me understand the little things, like you know before when we used to say no duck its Monday the 15th and she'd say no its Thursday the 3rd so, we learnt that we go with her and where she is at the time' (Shawn (PC), lines 180-187).

Understanding the dementia allowed carers to implement appropriate actions to symptoms of the dementia. Shawn (PC) captured this as they illustrated the level of dementia training they carried out, and how this enabled them to understand how to approach and support dementia-related changes, which was better adapted to meet their needs.

1

Figure 3.3. Sample of an Early Memo.

Memos were used to help conceptualise data in narrative form; they were a place to write thought processes, explicating the comparisons and connections made between codes, whilst highlighting directions to follow, and being reflexive (Charmaz, 2014). Memo writing was used to raise overarching focused codes to categories (Charmaz, 2014). They explicated the researcher's thinking and analytical decisions, and were used to develop a theoretical explanation of the data (Lempert, 2007). Memos progressed the analysis by illuminating the underpinning processes of the participants' experiences. Each memo took a similar format, and was guided by Charmaz (2014, p. 171) who stated that a memo should:

- Define its analytic properties
- Make comparisons between data and data, data and codes, codes and codes, codes and categories, categories and categories
- Be composed of raw data
- Provide sufficient empirical evidence to support definitions of the memo and analytical claims about it

Memos were progressive and constantly developed throughout the stages of analysis. Initially, they detailed the researcher's thoughts of the overarching focused codes for participants, but as these were categorised, memos evolved. As categories were developed, new memos were written: older memos were incorporated into new memos, and/ or new memos were written to explain the data. For instance, *Loss* was an early memo, written about the loss of the skills, personality and behaviour in the person with an intellectual disability as dementia presented, and the emotional impact this had on paid and family carers. As more participants' data were analysed, further properties of *Loss* emerged, such as *increased and varied support demands*; this illustrated how the loss of skills, personality and behaviours impacted upon paid and

family carers' time by introducing increased demands and more varied support needs than previously experienced. This was incorporated into the *Loss* memo.

As more overarching focused codes were categorised, *Loss* became a property of the category *Impact of Dementia*. The *Loss* memo was subsumed into a new memo. This new memo, which represented a category, was then elaborated by exploring the variance within categories through its properties, and by supporting interpretation through pertinent participant quotes. Containing the participants' voice also emphasised the memos' grounding in the data; consequently, this made it easier to transfer memos into the analysis (Lempert, 2007). Concurrently, other memos were written, merged together, and advanced through the same process, as emerging categories were developed. As categories and their properties were fully developed, they became concepts of the CGT. Concepts are defined as abstract ideas that account for data and have specifiable properties and boundaries' (Charmaz, 2014, p. 342).

3.3. Quality Checking

An important element of CGT is checking that one's preconceptions have not overridden the participant's voice, or taken the analysis astray from the direction lay out by the data. To ensure this did not occur, and that the analytical process and interpretations drawn from the data were informed and logical, researcher triangulation was used; this was the process of the research supervisors examining the analytical process with the researcher to check for accuracy and consistency. This checking process occurred across all stages of the analytic process, starting with initial and focused codes. A sample of coded transcripts across the participant groups was discussed within the research team, at supervisory meetings, where initial and focused

codes were explained to both supervisors and assessed; for initial codes this was their inductiveness, and for focused codes this was how closely they represented the cluster of initial codes. Any feedback was used when analysing data. For instance, in the first analysed transcript, both supervisors believed that a small number of initial codes went beyond the data, and represented the researcher's interpretation; these initial codes were altered, to be more inductive, and the advice used for future participant transcripts.

The same process was used when developing overarching focused codes. The participant's analysis document was discussed between the researcher and two supervisors, where, through the analysis document for each participant, everyone was able to see pertinent quotes, the focused codes which informed the overarching focused code, the initial codes which informed the focused code, and a brief description. Overarching focused codes were individually discussed, and where necessary, advice was provided by both supervisors. For instance, for Pat, both supervisors suggested that the initial overarching focused codes *Loss of support* and *Being supported* could represent different ends of the spectrum for the same focused code; consequently, these were merged and became *Continuum of support*.

As the analysis progressed, memos and categories were discussed between the researcher and supervisory team. The same process was used across memos and categories. Memos, many of which were developed into a category in the results section, and developed categories were sent to supervisors. Feedback on content and writing style was provided. For instance, for the developing memo *Impact of dementia*, there were a few examples where the participant quote did not clearly support the corresponding commentary. This feedback was used to produce a clearer link between quotes and commentary. This memo was then placed in the results section.

Implementing triangulation by having both supervisors assess the researcher's ideas and interpretations brought a level of quality checking between the team. As the analysis progressed and became more theoretical, a core category (*Impact of Dementia*) and four underpinning categories (*Challenging the Diagnosis Process*; *Continuum of Support*; *Continuum of Understanding*; and *Continuity*) were developed. Categories and the relationship between them were then discussed with both supervisors.

3.4. Management of the Data

From the outset, it was anticipated that there would be a large amount of qualitative data to manage. Data were manually processed, as opposed to using software, such as Nvivo (QSR International, 2017), due to the researcher's preference, and guidance from Saldana (2016), who recommends that new qualitative researchers should experience the ownership of the work through manual analysis. Additionally, it was evident that manual coding allowed the researcher to better engage 'hands on' with the data. Therefore, coding was carried out manually through Microsoft Word, using features including 'New Comment' and 'textbox'.

3.4.1. Coding transcripts.

Each transcript was coded on a Microsoft Word document. In the right-hand margin of the document, lines and sentences were initially coded using the 'New Comment' feature (see Figure 3.2., page 115). This feature allowed for coded segments of data to be highlighted and matched to the code. After initial coding, focused codes were developed. Focused codes were listed in a textbox on the left-hand margin of the Word document (see Appendix L).

After each document was fully initial and focused coded, a list of the focused codes from each page of each participant's transcript was copied and pasted onto a Microsoft Word document (see Appendix M). After comparing these codes, focused codes were clustered together into an overarching focused code to condense the data, making it manageable, before documenting it into an analysis document for each participant (see Appendix K). This document contained a table with five columns for each overarching focused code: 1) Quotes 2) Overarching Focused Code title 3) Focused codes 4) Initial Codes 5) Memo. At the end of the document was a space to provide a memo on the researcher's interpretations of the interview (see Appendix K).

Column one was a space to insert pertinent quotes which best illustrated the overarching focused code and its properties. Column two was a space to insert the label of the overarching focused code; these labels represented the focused codes they contained. Column three contained a list of the focused codes from the transcript which underpinned the overarching focused code. Column four contained the initial codes which underpinned the focused codes. Column five contained a memo which detailed the researcher's thought process for each overarching focused code.

After this process was completed for each participant's transcript, the developed overarching focused codes were copied and pasted onto a Microsoft Word document, and each overarching focused code was cut out. The participant number was on each overarching focused code to ensure it was identifiable. These overarching focused codes were then put onto A0 laminated white paper, and visually compared (see Appendix N). As overarching focused codes were raised and developed into categories, memos were generated on a Microsoft Word document (see Figure 3.3., page 122). Data extracts were used within memos to firmly ground them in the data; as advocated in CGT (Charmaz, 2014).

Using this process of managing the data, there was a strong audit trail documented for each participant, and from the raw data to the developed categories and properties of the CGT. This process not only allowed a visual representation of the development of theory, it also grounded the theory in the participants' experiences.

3.5. Personal Reflections of Managing and Analysing Data

As a novice grounded theorist, I anticipated possible challenges of managing and analysing large amounts of raw data. As an inquisitive researcher, I tried to ensure I was prepared by undertaking various GT training courses and reading widely, which consisted of key texts. These better enabled me to tackle my analysis, but the lack of standardised practical guidance hindered my confidence. Exploring the literature, and seeing CGT applied differently across research and methodology textbooks and theses only compounded my confusion. Two areas were particularly concerning to me: how do I manage the massive, and in many cases, overwhelming amount of data? and how do I ensure I am not losing important parts of the participant's voice when raising codes? My supervisory sessions were essential to overcoming these early hurdles. Talking through my interpretation of CGT, and how I envisioned applying CGT in a manner which suited my analysis, I started to feel evermore confident.

I was conscious that I entered the analysis with knowledge of key literature pertinent to my research, as reflected on in the introduction. Mindful of this, I tried to ensure a clear, strong analytical trail of my decisions. I found using memos and applying a structured format of data management helped me to explicate my thought process and to justify my analytical decisions: ensuring concepts within the GT were informed from the data. A combination of memo-writing and using a visual method to cluster overarching focused codes helped me to manage the data. I started to feel a

sense of satisfaction and excitement as categories were developed; yet, it was not until I had analysed all the data that it occurred to me that I had successfully applied CGT. I felt confident in my understanding of the principles of CGT, and how I applied these to thoroughly analyse the data. As I finished my analysis, I did not feel like a novice grounded theorist, but instead one with a developing expertise.

3.6. Summary

This chapter has provided a detailed description of the meticulous analytical process implemented. How the data has been actively processed through the different analytical stages has been illustrated. It has shown how the analysis, starting with empirical data, became increasingly more abstract in the construction of the CGTs underpinning categories. Importantly, across this process, the participant's voice was at the heart of decisions and the direction of the inductive analysis. This Chapter provided a clear audit trail from initial coding to categorising data, and the final write up of the findings; this ensures Lincoln and Guba's (1985) notion of trustworthiness. The final product of this systematic analytic process, a core category and four underpinning categories, is presented in Chapter Four.

Chapter Four: The Constructivist Grounded Theory

4.1. Introduction

Within this Chapter, the Constructivist Grounded Theory (CGT) is detailed and the findings discussed. Where relevant, literature has been used to clarify key terms, and discuss findings. The CGT's core category, *Impact of Dementia*, which is shared across all family and paid carer experiences, is explained. The four categories that underpin and inform the *Impact of Dementia* are explored and their relationship to the core category clarified (see Figure 4.1., page 132, which provides details of the core category, four underpinning categories, and their properties). All four underpinning categories (*Challenging the Diagnosis Process*, *Continuum of Support*, *Continuum of Understanding*, and *Continuation*) highlight the needs and wants of carers across the stages of dementia; when these were not met, this increased carer burden and negatively impacted on the carer's role to maintain the personhood and quality of care for people with an intellectual disability and dementia. Furthermore, the role of an Intellectual Disability Dementia Care Pathway (IDDCP) in the support of carers and people with an intellectual disability is illustrated across the CGT. For the core category and each underpinning category, the range of properties under which each category operated are explicated. Where necessary properties have been further clarified with headings, for example, in the core category, *Impact of Dementia*, the property *Loss* is composed of *emotional impact*, *helplessness*, and *increased and varied demands*.

The CGT has been developed exclusively from the data of paid and family carers, and healthcare professionals. Additionally, it was recognised that whilst there were elements of dementia which both family and paid carers experienced, how they experienced these varied due to their different circumstances. For instance, seeing a

family member with dementia deteriorate may have brought more intense experiences of sadness, compared to being a paid carer, supporting a service user with an intellectual disability and dementia. Nonetheless, there were enough similarities to allow the data to be represented within one theory. Throughout Chapter Four, pseudonyms have been used in place of participants' names. To identify which participant group they are from, the abbreviation FC (family carer), PC (paid carer), and HCP (healthcare professional) have been placed next to pseudonyms.

4.2. The Constructivist Grounded Theory

As illustrated in Figure 4.1., the CGT was composed of a core category and four underpinning categories. This section briefly explicates the CGT; the interrelated relationship of the underpinning categories and how they influenced the carers' experiences of supporting people with an intellectual disability and dementia. The categories and relationships between them are further explored and detailed in-depth within the remaining sections of this Chapter. Within the **Continuum of support**, the support, or lack of support, received by carers could alleviate or compound the **Impact of Dementia**. Support, such as training, provided carers with greater knowledge of the symptoms of dementia (**Continuum of Understanding**), which informed a timelier start of the diagnosis process (**Challenging the Diagnosis Process**).

Appropriate support improved carer understanding of how to ensure the needs of the individual with an intellectual disability and dementia were met. When carer understanding was supported, carers implemented strategies and environmental changes to better ensure **Continuity** in the home for the individual with an intellectual disability and dementia. Where there was a lack of support, for instance due to barriers,

carers struggled to understand the dementia, how to support an individual with an intellectual disability and dementia, and how to ensure 'Ageing in place'.

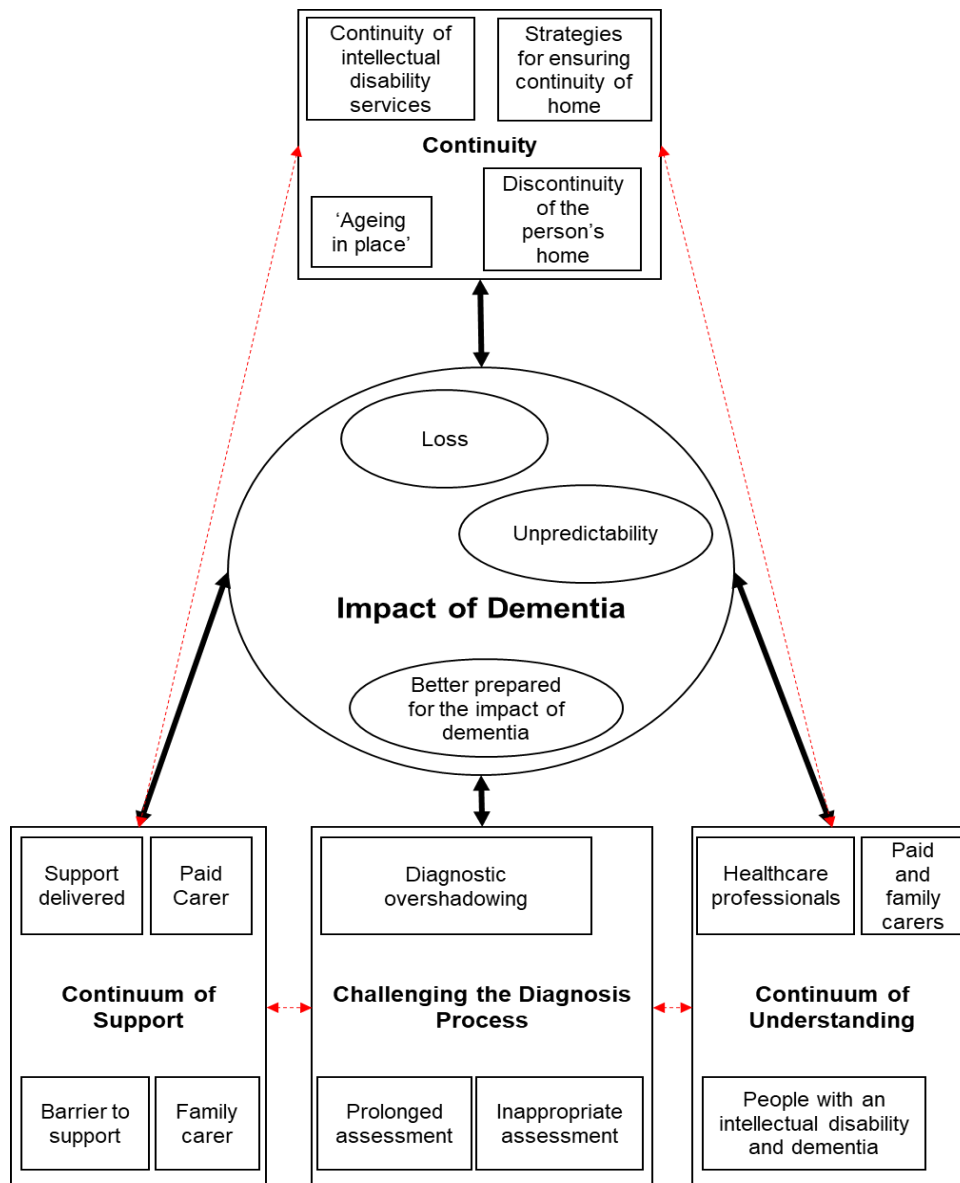


Figure 4.1. Visual Representation of the Constructivist Grounded Theory's Core Category and Categories, and Properties.

Challenging the Diagnosis Process was experienced when, without sufficient appropriate support (**Continuum of support**), and knowledge and understanding (**Continuum of understanding**) of dementia and its symptoms, carers initiated the diagnosis process at a later stage of dementia.

The challenges of obtaining a diagnosis influenced the **Continuum of Support**, as it could delay the timing of post-diagnostic support for carers and people with an intellectual disability and dementia, and sometimes meant the strategies to ensuring **Continuity** in care were not implemented at an early stage of the dementia. Not being sufficiently supported and being unable to maintain the home for life for the person with dementia could compound the **Impact of Dementia** for carers.

Continuum of Understanding related to the level of understanding of carers and healthcare professionals, and the impact this had on how they interacted and supported people with an intellectual disability and dementia. Where carers and healthcare professionals had a good understanding of intellectual disability and dementia, it alleviated the **Impact of Dementia** on carers, as it reduced the amount of burden they experienced. However, without the appropriate support to understand dementia, carers were unsure how to support the person when dementia presented and how to maintain an '*Ageing n Place*' model.

Ensuring **Continuity** in the home and intellectual disability services for people with an intellectual disability and dementia was important to participants. **Continuity** was influenced by the **Continuum of Support** (e.g. level of support received by carers), **Continuum of Understanding** (knowledge of how to adapt care practices and the physical environment), and **Challenging the Diagnosis Process** (training and changes to the physical environment were usually reactive and in response to a diagnosis). **Continuity** could compound or alleviate the **Impact of Dementia**, as it increased burden for carers, but also increased a sense of satisfaction when carers could maintain a home for the person with dementia. The CGT's categories, how they underpin the core category, and the relationship between them are now further elaborated.

4.3. Core Category: Impact of Dementia

Dementia was seen as a cruel disease which caused loss and suffering. *Impact of Dementia* reflected the dementia's impact upon the person with an intellectual disability and dementia, family carers and paid carers. *Impact of Dementia* was composed of many shared experiences, such as feelings of sadness; yet how these were experienced varied between participants.

Impact of Dementia was underpinned by loss and unpredictability. The reported loss of skills of the person with an intellectual disability, and the perceived loss of the person's unique personality and subsequent changes in behaviour, resulted in emotional impact upon paid and family carers, such as helplessness, concern, and grief. This was compounded by increased and varied demands, such as the time spent providing support. The unpredictability in the person's ability, personality and behaviour, which participants reported as manifesting as dementia worsened, compounded the *Impact of Dementia*, as it led to experiences of increased and varied support demands for carers.

4.3.1. Loss.

Impact of Dementia started with the loss of skills in people with an intellectual disability and dementia. As the dementia worsened, their personality, behaviours and skills, all of which made them unique to their carer, started to change and disappear. Family and paid carers' experiences were defined by loss, as the person they cared for lost skills they once had, such as the ability to swallow, communication skills, and the ability to recognise those they once knew. As they lost these skills, and as the dementia worsened, elements which made them unique to carers, such as their

behaviours and personality, changed, which carers perceived as loss of who the person used to be. This loss was illustrated by Robin (FC) and Kelly (PC):

‘His dementia’s quite bad now. It’s nothing, you know, like before it was just he was getting confused. Now he’s got the blankness in his eyes and nothing really. I don’t know, nothing excites him anymore’ (Robin (FC), lines 62-64).

‘Physically mobility wise she, she lost all ability like that...she was a massive personality, she was Downs...she was like a little magpie, and she got such a strong personality, and she used to tell you these fantastic stories how she used to drove cattle all the way from Spain, you know on foot, and she’ll tell you she was a lorry drive and she’d drive, and deep sea dive. She was larger than life, but then when we saw the decline in her, and the spark had gone from her eyes’ (Kelly (PC), lines 297-305).

Both participants experienced loss within the person when they saw ‘blankness’ in their eyes, the loss of a ‘spark’. These represented changes in the person’s personality and behaviours, and consequently, loss of the unique elements of the person the carer once knew. This was supported when Robin (FC) stated, ‘nothing excites him anymore’; this illuminated the changes which underpinned loss from the carer’s perspective. They struggled to understand what the person, who they once knew so well, enjoyed: what made them happy. Similarly, when Kelly (PC) said ‘She was larger than life, but then when we saw the decline in her, and the spark had gone from her eyes’, she further demonstrated the loss that dementia created. It took away a larger than life personality; a piece of that person. Loss impacted upon paid and family carers

through emotional impact, feelings of helplessness, and by introducing increased and varied demands.

Emotional impact.

As dementia took away characteristics of the person, such as their personality, skills, and behaviour, carers were impacted upon psychologically through their emotions, as seeing this loss, seeing less of the pieces of that person, was a 'heart-breaking' experience which invoked sadness. Carers felt more concerned, worried, anxious, heart-broken, helpless and felt grief when the worsening dementia impacted upon the person with an intellectual disability. Pat (PC) and Shawn (PC) discussed their experiences of the emotional impact of loss:

'So, I think staff have found it a little bit hard emotionally because each week we see a little bit less of that person because the dementia's changing him' (Pat (PC), lines 217-219).

'Cus sometimes, I don't know if it happens with everybody but with me being here for so long now and knowing them, knowing what they are capable of and you know what they can't do now, it's heart breaking (Shawn (PC), lines 197-200).

These data extracts encapsulated how carers found it challenging to see deterioration in the person with dementia, and in particular, as Shawn (PC) illustrated, the loss of what they were once capable of. This may have been compounded by carers' knowledge that people with an intellectual disability, already having a cognitive

impairment, may find it more challenging to develop skills than someone without a cognitive impairment. Paid and family carers played an integral part in supporting them to develop and maintain new skills; enabling them to be as independent as possible. Seeing skills, which both the person with an intellectual disability and dementia and their carers have worked so hard to develop, to then slowly disappear, would cause feelings of, for example, sadness and anxiety.

The relationship the carer had with the individual also underpinned the intensity of the emotional impact. When a carer and the individual had a long-standing relationship, where a family member had grown up with the individual, or where the paid carer had supported the individual for many years, and they had grown to understand each other, people may experience emotional impact. Bearing this in mind, the intensity of the emotional impact of seeing this loss may have differed between paid and family carers. Both family carer participants were siblings of their family member who had dementia; they had grown up with their family member, eventually becoming carers for him. They had experienced and been a part of their family member's journey; for instance, helping their family member to learn new skills and celebrating their achievements. Seeing the loss of their family member's skills and changed personality and behaviour, may have been experienced differently, producing more intense feelings of loss, compared to a paid carer who did not share these experiences.

Helplessness.

Helplessness was what family carers felt, having seen the deterioration of their family member's skills, personality and behaviour, and believed they could do nothing to help. Helplessness frustrated family carers, as they could do little to prevent the

decline in their family member. They struggled with the concept of loss; they struggled with the inevitable deterioration and loss their family member experienced, and their feelings of inability: helplessness. This was demonstrated by Robin (FC):

‘There’s nothing you can do, so that’s, you feel helpless really, but there’s not really a lot we can do about it’ (Robin (FC), interview 1, lines 76-77).

Helplessness was a feeling exclusive to family carers. Paid carers did not show helplessness. This may have been underpinned by the differences in their roles. Though both provided support to an individual with dementia, a family carer, unlike a paid carer, did not go home at the end of a shift. A family carer’s time and focus was on their family member, who they had a strong relationship and long history with. Additionally, family carers were less likely to be given the same level and form of support as paid carers. For instance, their understanding of how to support someone with dementia was usually based on their own research. Their knowledge needs were not supported by employees or healthcare professionals, unlike many paid carers, who had a developing understanding of the dementia and how to respond to dementia-related changes. This contrasted with previous research, such as Herron and Priest (2013), which found most paid carers received no dementia training and lacked an understanding of the dementia. Without knowledge of how to support their family member’s dementia needs, family carers felt helpless when dementia related changes presented, and they were uncertain of the correct actions.

Increased and varied demands.

Loss also induced increased and varied demands on carers. This was captured by Pat (PC) and Shawn (PC) who discussed the implications of changes in the skills, personality, and behaviour of the person with an intellectual disability and dementia, for increased demands:

‘Things take a lot longer with them, personal care, obviously, there’s more incidents with them, they don’t slot in to the group living as much’ (Pat (PC), lines 116-118).

‘Some days she can’t tell you what she’s eating so we’re prompting her, we’ll load a fork up for her, but in the meantime we’re saying right [client’s name], half a sprout on here with a bit of potato, put it to your mouth, so we’ll have to put it to her hand and then sort of guide it to up to her mouth’ (Shawn (PC), lines 17-21).

Dementia compounded existing support needs, such as with personal care, which now took significantly longer with the loss of skills, but also introduced new demands, such as supporting meal times. As dementia worsened, carers also had to manage behaviour changes, which resulted in increased incidents, such as wandering. This combination of increased time spent on pre-existing support needs, increased management of behaviour changes, and new demands, meant providing more time and focus to the individual with an intellectual disability and dementia, and less with others’ sharing the accommodation. Similar experiences were described by family carers, for instance, new, varied demands arose as dementia worsened and their

family member started to wander off, get lost and become forgetful. This increased time and new support demands placed on family carers; consequently, this caused strain on the family as they tried to juggle this with other elements of their lives, such as their family and business.

4.3.2. Unpredictability.

As dementia worsened, and the person with an intellectual disability lost their skills, and experienced personality and behavioural changes, they became more unpredictable. Unpredictability was the daily uncertainty experienced by family and paid carers when supporting the person with an intellectual disability and dementia. It compounded the impact that dementia had on carers, as there were daily uncertainties in the person's ability, personality and behaviour. Stevie (PC) and Sam (PC) discussed how dementia introduced greater unpredictability in support:

'Makes it harder, it does make it harder. Unpredictable more than anything else, but it's just something you have to deal with, really' (Stevie (PC), lines 28-29).

'Day to day, you're best asking me hour by hour because you just don't know' (Sam (PC), lines 201-202).

Unpredictability may have made supporting the person's emotional and physical needs more challenging as carers were not able to apply the usual routine, and needed to change it to the individual's needs on that day. Compounding this was the rate of unpredictability. It was not only that support became unpredictable, it was the scale of

this, as carers reported unpredictability on an hourly basis; again, preventing routine and consistency in support and planning, and making their actions more reactive.

Unpredictability prevented certainty, planning and routine; consequently, the carer's role became more challenging and reactive. The carer's routine became reactive to the version of the individual they experienced on one particular day, knowing their personality and behaviour could change but not being certain how; therefore, carers felt on 'edge' as the support required was unpredictable and varied. Shawn (PC) and Robin (FC) highlighted how support became more unpredictable and the possible consequences for people with an intellectual disability and dementia, and their carers:

'Well, everything changes with her now, cus obviously care plans, risk assessments, all that's been changed with her now. Support levels been changed with her, everything's just changed, you know it's a whole new routine with her, and there again depending on what day she's having. You know, you could have two good days with her, where she's more or less doing a lot of the normal stuff, but then you could have two days where she hasn't got a clue. And then there's also through the night, we've got waking staff through the night, because some nights, she'll lie awake all night talking, so they'll go into her and obviously take her to the toilet and take her a warm drink into her if she wants one' (Shawn (PC), lines 154-165).

'But when he was living with mum it did because it was a strain on all the family really because, you know, if he sort of wanted to wander off down the village,

then my son would pick him up and take him back and it was just sort of very difficult' (Robin (FC), lines 57-61).

All the procedures put in place, such as care plans and risk assessments, had to be changed as dementia presented and progressed; however, as the person's support needs were not always predictable and varied from day to day, this became more challenging and reactive. New support structures had to be put in place to ensure the safety of the person with an intellectual disability and dementia, such as night-time support, and having family carers and members checking in more often. For family carers, there was also a concern about the strain caused by their family member's unpredictable behaviour, which made them feel more worried, anxious, and apprehensive.

Though the unpredictability in personality and behaviour changes had challenging implications for carers, one paid carer tried to put a positive spin on unpredictability. Shawn (PC) had little choice but to accept the unpredictability of the personality and behaviour changes of the person with an intellectual disability and dementia:

'You know, because it's just different, you can never have two days the same, which is really good cause it keeps you on your toes, you know' (Shawn (PC), lines 215-217).

4.3.3. Better prepared for the impact of dementia.

Dementia had life altering implications for the person with an intellectual disability and dementia, and their paid and family carers. However, some participants

felt that carers' previous experiences may have resulted in the dementia, at least initially, having less of an impact on the quality of their lives compared to carers who had not experienced supporting someone with a cognitive impairment. This was illustrated by an experienced healthcare professional who stated:

'The paid carers have actually just taken it as just another day, it's just part of the job that we do, we don't, this sounds awful, we don't see a diagnosis of dementia as that big a deal, it's not going to suddenly end somebody's quality of life because everything that we do in learning disability services is about promoting people's quality of life for people who are already at a disadvantage. So to us I suppose it's just another little thing that we're going to do today' (Jesse (HCP), lines 166-172).

As carers have experienced supporting people 'already at a disadvantage', the support needs which arose when the dementia presented were just another part of their caring role. This also applied to family carers, who like paid carers are experienced in meeting the supportive needs of someone with a cognitive impairment. For instance, many of the supportive needs which arose in the advanced stages of the dementia, such as supporting loss of mobility, are the same impairments which carers supported in people with more severe intellectual disabilities. As carers of people with an intellectual disability and dementia had prior experience of supporting the needs of someone with a cognitive impairment, they may be better able to cope with, and manage, the increased and varied demands placed on them, so the dementia may have less of an impact upon them. Additionally, it was common for paid carers to have access to support structures, such as intellectual disability services.

People with an intellectual disability and dementia, family and paid carers were all directly affected by the dementia. There were common underpinnings for family and paid carers, but how these were experienced differed due to their different situations. Additionally, whilst family and paid carers may be better prepared to cope with the *Impact of Dementia*, they still experienced loss and suffering. What follows are four categories that encapsulated factors which underpin and inform the *Impact of Dementia*.

4.4. Underpinning Category: Challenging the Diagnosis Process

A diagnosis was a tool which enabled understanding, planning, appropriate actions, and timely post-diagnostic interventions. For healthcare professionals and carers, it facilitated understanding of the changes in the people they supported, and enabled implementation of appropriate support strategies to meet their needs and better ensure wellbeing. For people with an intellectual disability and dementia, it may aid understanding of the changes they experienced in the present and what they may experience in the future. The role a diagnosis can have means it is important that it is timely. Healthcare professionals and carers raised the importance of a diagnosis:

‘The sooner that you can get a clinical intervention and a diagnosis, there’s a better chance of slowing down the progression of the disease because we can start people on medication or do things that just help that person to slow down the progression of that dementia. If there’s a delay in that diagnosis, or we even just miss those clues because we assume it’s part of the learning disability, or something similar, then obviously that’s going to have a long term impact on the person with dementia isn’t it’ (Jesse (HCP), lines 323-330).

‘I think it affected him because staff, because the staffing, so the type of support they were in receipt of, I think if the staff had got that diagnosis earlier we could have tailored our support a bit better’ (Glen (PC), lines 325-327).

‘So it helped us to understand more and helped...us to manage her better. For her to live a better life. You know, just the best way possible (Sam (PC), lines 141-145).

A timely diagnosis enabled the implementation of appropriate medication, and support strategies and structures to ensure the wellbeing of the person with an intellectual disability. It provided greater understanding of the changes observed in the person with an intellectual disability and dementia. An untimely diagnosis acted as an obstacle to implementing individually tailored support for meeting the person’s needs, and compounded the *Impact of Dementia*. Nevertheless, a diagnosis was not a linear process. *Challenging the Diagnosis Process* illustrated how the *Impact of Dementia* challenged the diagnosis process. A combination of intellectual disability, dementia, and the role of healthcare professionals and carers, introduced complexity into the diagnosis process, which contributed to a lengthy, challenging process underpinned by uncertainty for people with an intellectual disability and their carers.

4.4.1. Diagnostic overshadowing.

One challenge of obtaining a diagnosis was initiating the diagnosis process. Healthcare professionals and carers were essential in instigating a referral; they worked closely with people with an intellectual disability, which better positioned them

to identify dementia-related changes. At the forefront were carers, who provided intimate, regular support with the person with an intellectual disability. However, carers and healthcare professionals experienced difficulties with separating the person's intellectual disability from the dementia. The referral process was impaired by challenges around diagnostic overshadowing; this is where behaviours and actions which may be indicative of the dementia are instead attributed or misinterpreted as the person's intellectual disability or comorbid condition/s (Reiss, Levitan & Szyszko, 1982; Manson & Scior, 2004). For instance, more aggressive behaviour or social withdrawal, which may be symptoms of the dementia, were instead believed to be an element of the intellectual disability. Diagnostic overshadowing was reflected in Jesse's (HCP) and Robin's (PC) experiences:

'The first thing we noticed was the change in behaviour, but at the time you couldn't pin point it to being part of the dementia, and what's difficult there is that it can be masked into the learning disability. It is just part of the learning disability' (Jesse (HCP), lines 49-52).

'With learning disabilities I think it's hard to know whether it's just a problem with their disability, that their having a problem with something, or it's the start of dementia. So I think we had a few years where we were very unsure' (Robin (FC), lines 31-34).

Where dementia compounded elements of the person's intellectual disability or premorbid health problems, healthcare professionals and carers may have attributed

this to the intellectual disability rather than the dementia. This illuminated the difficulty of identifying the dementia and making a referral. Glen (PC) supported this:

‘You know like this gentleman not seeing, that was the first thing him seeing things in his drinks, and you do put that down to the learning disability, like I say he got problems with his eye sight, you put it down to that, so if we’d maybe, it could have been something as simple as changing the cup, or doing something different that could have made all the difference in that gentleman taking his drinks instead of it being a stressful time every time he went through a phase where he wouldn’t drink or take drinks’ (Glen (PC), lines 330-337).

This difficulty may be partly explained by impaired communication. 50% of people with an intellectual disability have some form of impaired communication (Kerr, Fraser, & Felce, 1996), which is compounded by the dementia. People with an intellectual disability may find it difficult to describe symptoms, which subsequently made it challenging for healthcare professionals and carers to identify particular dementia-related changes which overlapped with the person’s intellectual disability. Glen (PC) encapsulated this when discussing her challenges with noticing the symptoms of the dementia:

‘You don’t see the same kind of symptoms because she doesn’t verbalise...see that something wasn’t quite as it should be, it was way down the line, and like I say the seizure was the first, and I was on duty when that happened, and even at that point you don’t link it to dementia do you, you don’t, it’s not something you think about yet, so the lack of communication was definitely a big point

which meant that diagnosis didn't happen till down the line' (Glen (PC), lines 61-70).

Where the individual's impaired communication prevented them from articulating the changes they experienced, carers found it challenging not to explain subtle changes as being part of the person's intellectual disability. In the presence of impaired communication, it was not until more noticeable changes presented, in this case seizures, that the carer started to suspect something was wrong. The onset of seizures is a common indicator of dementia for people with an intellectual disability, especially people with Down syndrome, and it is generally thought to occur earlier in the presentation of dementia than in the general population (British Psychological Society [BPS] & Royal College and Psychiatrists [RCP], 2015). Where diagnostic overshadowing occurred, there was an increased likelihood of a delayed diagnosis. Consequently, this compounded the impact on wellbeing of the person with an intellectual disability and dementia, who could experience frustration as they lacked an understanding of the changes (assuming a diagnosis was shared) and may not receive the appropriate support to meet their needs. Furthermore, a delayed diagnosis could impact upon carers, who may struggle to understand specific support needs without a clear idea that dementia was present, and not receive the appropriate support for their own wellbeing.

4.4.2. Prolonged assessment.

Once a referral was made, usually at a progressed stage of the dementia, acquiring a diagnosis was a lengthy process which entailed ruling out other possible causes of the symptoms, multiple members of the Intellectual Disability Dementia Care

Pathway (IDDCP) team implementing intricate parts of the diagnosis process, and where necessary, repeated assessments over a period of time. An implication of this was a prolonged period of uncertainty from the person being referred to the IDDCP, to getting a diagnosis.

Ruling out all possibilities.

A diagnosis of dementia was not a simple process within people with an intellectual disability. There are many conditions which may mimic some of the symptoms of the dementia, making it a challenge to provide certainty of the underlying cause. This required healthcare professionals spending time ruling out such conditions. For instance, sensory impairments, such as hearing and visual problems may result in changed and confused behaviour, which are mistaken for symptoms of dementia. This was encapsulated by Alex (HCP) as she described the diagnosis process:

‘A community nurse will be allocated first because we want to rule out any physical causes such as a UTI or an audiology problem so we try to rule out any physical health before then they come on to the pathway’ (Alex (HCP), lines 54-57).

Importance was placed on understanding the causes of the symptoms. Dementia was not considered until other causes, such as physical and environmental changes, were assessed and ruled out. This was a necessary step but one which prolonged the diagnosis process. This was compounded by the challenges people with an intellectual disability may have in describing their symptoms. A person without an intellectual

disability may be better able to describe the source of their symptoms, for instance, if they had a visual impairment such as cataracts; as compared to someone with an intellectual disability who may find it difficult to do the same. This meant a broad range of conditions needed to be considered, for example, a visual impairment may cause symptoms associated with physical and mental health problems, such as social withdrawal and confusion. Only when other conditions were ruled out, were people with an intellectual disability registered on the IDDCP; though this did not necessarily mean they would receive a diagnosis of dementia.

This process was exacerbated by the number of inappropriate referrals for assessment to the IDDCP:

'I think we have a lot of inappropriate referrals for dementia, because dementia seems to be one of these words which is in at the minute, and people think oh, he's showing these funny signs, he's doing this. So, people don't look at the physical health. We get quite a lot of referrals where their carers think they're dementing, but they've got a UTI or they are physically unwell' (Ash (HCP), lines 64-70).

Again, the emphasis was on physical conditions which produced possible similar symptoms to the dementia, resulting in people being referred to the IDDCP team. The IDDCP was a small team, already overextended by a growing patient register and the pluralistic nature of their role; healthcare professionals had a broad knowledge and worked across intellectual disability, not just the IDDCP and dementia. Inappropriate referrals took resources and healthcare professionals away from those who needed the support they offered. It highlighted a growing awareness of dementia by carers.

The combination of carers' challenges to understand the symptoms of the dementia, combined with the increased publicity and awareness of 'dementia' may have meant that carers and others neglected to consider alternative possibilities; instead, they may have incorrectly assumed 'funny signs', which they struggled to explain, were the dementia. Nevertheless, though the symptoms may have been caused by something other than the dementia, a referral did allow healthcare professionals to gain a baseline for the individual, which could be used in future referrals.

Reactive baseline.

Having a baseline of the person's capability, whilst healthy, was an important tool in the diagnosis of dementia. A baseline provided information of the person's capability which could then be compared with repeated assessments to check for dementia-related declines. However, baselining in this service had to be reactive, as initial assessments were only carried out once a referral came into the IDDCP team:

'The referral will come through to a meeting and a community nurse will be allocated first because we want to rule out any physical causes, such as a UTI or an audiology problem, so we try to rule out any physical health [problem] before then they come on to the pathway. So, if there is evidence of loss of skill then the client will come to community nursing and occupational therapy, where we would do a baseline' (Alex (HCP), lines 53-59).

Within the IDDCP, when dementia could not be confirmed or excluded through the initial dementia assessments, these assessments became the baseline score against

which longitudinal repeated tests were compared. However, a reactive baseline brought challenges when assessing the person for dementia-related decline:

‘It’s very difficult because the dementia, or the potential of the dementia could, is often not seen until quite late with some people and then you can’t get those baselines when they’re at their best really. It’s important to get those baselines when they’re at their best, especially people with Down Syndrome’ (Carroll (HCP), lines 34-38).

As referrals often came in once the dementia had worsened, due to diagnostic overshadowing, and the symptoms became more recognisable, a reactive baseline meant carrying out assessments once deterioration in functioning had already occurred. This made it challenging to gauge premorbid functioning and therefore to judge dementia-related deterioration through a one-off set of assessments. Consequently, where a reactive baselining was applied, it was necessary to implement repeated testing at a later date to gather longitudinal data to compare with the baseline data. This allowed healthcare professionals to judge any deterioration in functioning over this time due to the dementia. Compounding the need for repeated assessments was how progressed the dementia was, and the individual’s abilities, such as communication. An issue with this reactive approach, where a repeated assessment was needed for a confirmed diagnosis, was the time lapse between the baseline and the repeated assessments:

‘At the moment we do a baseline and then we say probably repeat in a year’ (Alex (HCP), lines 78-79).

A year without a confirmed diagnosis meant a long period of uncertainty. Though the IDDCP had input during this time, for instance, acting as a support structure for paid carers and the people they were assessing, a lack of certainty meant actions were uninformed, dementia medication was not being provided and/ or inappropriate support strategies were implemented. Additionally, having long periods of time between baseline and reassessment could cause uncertainty for the person with an intellectual disability and dementia, who may experience further changes and decline over this period, but have no certainty as to why.

A prompt, timely diagnosis ensured that focus could be given to appropriate changes in support strategies and structures, medication, and preparing carers for dementia-related changes; helping to ensure the wellbeing of people with an intellectual disability and dementia, and that carers were more confident in meeting the holistic needs of the individual. Furthermore, such an approach provided the foundations for Advance Care Planning (ACP). Diagnosing dementia at an earlier stage would better allow carers to actively involve people with an intellectual disability in decisions for their future support. However, applying reactive baselining, when the person had already experienced dementia-related deterioration in their cognitive functioning, prolonged the diagnosis process, and in many cases, prevented a timely diagnosis.

4.4.3. Inappropriate assessment.

A few participants across healthcare professionals and paid carers raised concerns about the appropriateness of the assessments used throughout the diagnosis process:

'The biggest challenge I found is in diagnosis, because when they do that kind of early dementia test, well how do you do that on someone who already can't count backwards from ten, or already couldn't remember a name or address of somebody that you told them, or already didn't know who the queen of England was. So, how do you base that assessment on well if they've declined over the past twelve months, based on what, they didn't know it to start with, or they might not know it now but that might just be because they wouldn't have known it 'cause of the learning disability' (Jesse (HCP), lines 301-309).

There was a concern that the dementia assessments used with people with an intellectual disability were not adapted to their ability; they were not sensitive to the individual, who was already unable to answer some of the assessment questions. Consequently, they may have scored low on answers, indicating dementia, though dementia was not present. This concern was further raised by Brook (HCP):

'I think probably some of it is, getting a diagnosis, because it is more difficult to diagnose...if I've gone out and done my screen and the person has sort of scored 100% on everything, then we've felt, I've spoke to [Doctor's name], who said that perhaps the assessments aren't sensitive enough, and that we'd refer somebody to the generic [mental health service], but like a lot of the genic screening is just insensitive to our client group, I mean, you know for example counting, erm, from 100 backwards in 7, most of the people I support there's just no way they'd be able to do that, so it is, I suppose our client group it is more difficult to assess really' (Brook (HCP), lines 377-387).

Differences were experienced between the IDDCP and generic mental health services. Though the IDDCP used assessments adapted for people with an intellectual disability, such as the Dementia Questionnaire for People with Learning Disabilities (DLD; Eurlings, Evenhuis, & Kengen, 2006), Brook highlighted how these tools may not have been sensitive enough for some people, so the dementia may have been missed. On the rare occasions where generic mental health services were utilised, the assessment was often too challenging, requiring people to perform tasks they could not do without the dementia, resulting in an increased likelihood of changes being incorrectly attributed to dementia. This illuminated the possible challenges and a need for the assessment to be sensitive to the individual. It would be difficult to provide a certain diagnosis through the examples described above. This made it important to the IDDCP to use and draw upon a set of assessments which allowed for a holistic picture to be pulled together. Assessments through the IDDCP drew on multiple sources from the individual's home and from services, including interviewing long-term carers. Combining this information with dementia assessments, and comparing the baseline to the repeat assessments allowed for a more informed diagnosis to be made. However, this process highlighted the time consuming and challenging nature of acquiring a diagnosis for some people with an intellectual disability.

The challenges experienced across the diagnosis process were epitomised by Taylor, a paid carer participant, who supported an individual with schizophrenia, and was also given a confirmed diagnosis of dementia; however, eventually, the diagnosis was retracted. Taylor (PC) described being told the IDDCP team were unable to put the person's changes and decline down to dementia; they were instead attributed to other comorbid conditions:

‘She said to me, erm that what happened was, because it’s only certain, it isn’t all the time, and it’s only now and again, they can’t put it down to dementia. Like I say, with him having schizophrenia and slight forgetfulness anyway it is a hard thing to suss out really’ (Taylor (PC), lines 37-40).

This highlighted the challenges that may arise when trying to assess whether a person with an intellectual disability has dementia. A combination of the person’s intellectual disability, with impaired communication skills, and comorbid conditions may have underpinned the initial incorrect diagnosis. A consequence of this incorrect diagnosis was a period where paid carers approached changes as being due to the dementia; subsequently, responses and support were adapted to the dementia. For instance, Taylor reported the individual seeing people in their room, and responded by removing their mirrors, as may be appropriate for someone with dementia; however, for someone without dementia, other responses may have needed to be implemented. More concerning, the individual received unnecessary dementia medication.

Overall, the diagnosis process was challenging within intellectual disability. It illustrated the impact that others may have on the wellbeing of people with an intellectual disability. The decisions service providers made, such as to implement a reactive approach to baselining, the challenges in utilising an appropriate dementia assessment tool, diagnostic overshadowing, and the impaired communication process between the carer and individual with an intellectual disability, all contributed to possible lengthy periods from referral to a diagnosis. An untimely diagnosis may have meant uninformed actions, with the appropriate medication, and support strategies and structures not being implemented to meet the needs of carers and people with an

intellectual disability and dementia. It may also mean a time of uncertainty, and a period where the person's quality of life is impacted upon, as well as their carers. However, it must be recognised that any decisions around the process of the diagnosis are informed by a multitude of factors, such as limited funding.

4.5. Underpinning Category: Continuum of Support

Continuum of Support referred to the support delivered by family and paid carers, and how this was underpinned by support structures and strategies which paid and family carers drew upon, when available, to ensure that the people they supported lived a fulfilling life with dementia. The support structures and strategies in place were diverse and were provided by varying sources, for instance, training and information from healthcare professionals from an IDDCP. To ensure people with an intellectual disability had their psychological, physical and social needs met, paid and family carers were supported, where appropriate, by: the IDDCP; and/ or their employer; and/ or management; and/ or family; and/ or colleagues. Through this process, support also alleviated the psychological and physical impact of the dementia upon carers, for instance, as carers supported each other and spread out the burden of support. The social underpinnings of support were important within the *Continuum of Support*. For instance, the colleagues of paid carers, and family members of family carers, provided relief for stress and worrying.

How support was experienced differed between paid and family carers; yet for both it was intricately linked with the support delivered to people with an intellectual disability and dementia. Carers are positioned to provide both helpful and unhelpful responses. For instance, people with dementia may start to re-live their past, wanting to go back to their family home, and to see their parents (who may not be alive). When

it is safe to do so, a helpful response may be to follow people into their world, understanding their perspective and ensuring their safety. An unhelpful response may be to repeatedly shut down the person's reality and to reorient them to the present, which could confuse them and produce unwanted changes in behaviour. Ensuring carers could provide the right support was vital, as inappropriate responses to the dementia may compound the *Impact of Dementia*.

Continuum of Support was also defined by a lack/loss of support for paid and family carers, which compounded the impact of the dementia upon carers, but also meant people with an intellectual disability and dementia not receiving appropriate dementia support. For instance, family carers were not provided with dementia training or information; consequently, they were uncertain about their actions and how to support their family member's dementia needs. This may have resulted in their family member not receiving the appropriate dementia support.

4.5.1. Support delivered to people with an intellectual disability and dementia.

People with an intellectual disability and dementia received support from various sources, with all having a shared underpinning: ensuring the person's wellbeing and that they lived a fulfilling life with the dementia. All participants described their commitment to ensuring this outcome. It was this commitment which drove participants to always strive for what was best for the person with an intellectual disability and dementia. For carers, this desire and commitment was demonstrated through their actions. To ensure their psychological, physical and social needs were met, carers attempted to underpin support with a person-centred approach.

Person-centred support.

Family carers, paid carers, and healthcare professionals highlighted the importance of maintaining a person-centred approach to ensure that the person they were supporting lived a fulfilling life with the dementia. The support they provided was underpinned by compassion, taking the person's perspective, spending time with the person, treating them as an individual, showing them respect, and adapting and providing support to meet their individual needs. This was demonstrated by Ash (HCP), Taylor (PC), Kelly (PC), and Lee (FC):

'It's really, erm, planning your care, or planning your goals or planning your actions around that person, and it's getting to know that person, because everyone with a learning disability presents differently' (Ash (HCP), lines 186-189).

'With caring with dementia, well making sure that they have their life to the full, that's the main thing, and what they need, cause obviously they've all got different needs, you know you do respect and all that for them you know' (Taylor (PC), lines 75-78).

'With dementia, we find that we just live in their life, in their world' (Kelly (PC), lines 119-120).

'We always find something that makes him smile, but that's all that matters isn't it' (Lee (FC), interview 2, lines 65-66)

All participants looked beyond the person's intellectual disability and dementia, and saw an individual and adapted to and supported their individual needs. They tried to view the world from the person's perspective, and tried to understand their support needs. This generally resulted in support which was personalised and addressed the current needs of the person. Carers applied a person-centred approach which incorporated both individualised intellectual disability and dementia support. An example of this was highlighted by Kelly (PC) in the above quote, who tried to understand the person's journey, validating their feelings rather than 'the 'truth' of the situation' (BPS & Royal College and Psychiatrists, 2015, p. 64). For example, as the person relived their past and believed friends from their past were present or deceased family members were alive, some carers acknowledged these people and spoke to the person about them. When safe to do so, validating the individual's feelings may prevent further 'immediate confusion or distress' (BPS & Royal College and Psychiatrists, 2015, p. 64).

These experiences reflected the importance of the person's social environment. Paid and family carers tried to provide a warm caring atmosphere, where the person was respected, and where their individual preferences and perspectives informed support. In doing so, carers tried to address the individual's social environment, a key tenet of Brooker's (2007) person-centred dementia care model, and helped to maintain their personhood when experiencing decline (Kitwood, 1997). Personhood is 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997, p.8). Carers described implementing supports which they felt showed the individual with an intellectual disability and dementia that they are valued, as explicated by Kennedy (PC):

'making sure he's getting enough nutrition, hydration and that sort of thing...making sure he's comfortable. Erm, making sure his needs are met really, and then obviously as well as that social interaction. Making sure that we, although he's in his room, you know we're in there with him at some point, not just when he's having diet or fluids, or when we do change him, you know we make sure we have a bit of time with him, so he just doesn't feel like he's in there on his own (Kennedy (PC), lines 78-87).

Here, Kennedy emphasised the importance of a holistic approach which ensured the physical wellbeing and personhood of the individual. They tried to make the person feel comfortable and valued. They illustrated the importance of meeting the individual's social needs by spending time with the person, to ensure they did not feel alone.

Carers attempted to instil personhood as they treated the person as an individual, with warmth and respect, and took their perspective, whilst trying to maintain the individual through ensuring they could still do the things they enjoyed. Carers provided examples of drawing on their knowledge of the individual to ensure they still engaged in the things they enjoyed. This is shown by Sam (PC):

'You know they enjoy going out, she's always gone out, here at ***** their perhaps in two or three days a week if that, doing different activities, why shouldn't she [go out] she's always doing things like that' (Sam (PC), lines 187-190).

Sam thought it was important that the person she was supporting with an intellectual disability continued to engage in the things they enjoyed even when the dementia presented. Shawn (PC) further illustrated drawing on their knowledge of the individual, to create a sensory pillow which had on it things that the participant enjoyed doing, such as using a zip:

'We've just made her a cushion and its got all kind of things on like a zip for her to undo, bells for noise, scratchy, erm buttons all kind, then on the back we've made this big flower for her, but it's like a bit of bling bling in the middle so she can lift the petals and everything up or play with the bling bling...it brings her back sometimes because she has worked in a few little places, she like zipping her trousers or a cardigan, cause she'll say this is my cardigan, and then she'll zip her zip from the pillow then she'll do it as if she doing, if she got a jumper she'll perhaps do it as she's zipping it up' (Shawn (PC), lines 24-41)

However, as explicated in Chapter 1.7., a person-centred approach is underpinned by the inclusion of people with an intellectual disability and dementia in decisions; as is illustrated across *Continuum of Understanding and Continuity*, this was generally not the case as participants did not always involve people with an intellectual disability and dementia in the decision making process.

The importance of amalgamating the person-centred approaches used in both intellectual disability support and dementia support was encapsulated by Jesse (HCP):

'I suppose it's about how you adapt your support. It's about saying you know in learning disability services we've always really been led by person-centred

approach and I think it's important to maintain that person-centred approach and one of the things that we've always strived to do with a diagnosis is to say "well how do we continue your support in a manner that suits what's important to you for you now and in the future and still enable you to stay at your, you know where you live now in your own home with your family support around you", and try not to I suppose lose that person into dementia services, but try and wrap the dementia care around the learning disability services' (Jesse (HCP), lines 104-113).

It was important to maintain a person-centred approach at the forefront of support, ensuring the person's preferences were preserved, such as living at home. Jesse emphasises the need for continuity through intellectual disability services, and the need to maintain this when she states that dementia care should be wrapped around intellectual disability services. It was equally important to recognise that dementia introduced new challenges, which meant applying adapted support that incorporated dementia support. This was necessary to maintain the person in intellectual disability services.

Applying some of the principles and approaches advocated within dementia support was not always a straight forward process, with some participants finding it challenging as they felt it sometimes conflicted with their perceptions of intellectual disability support. Both intellectual disability and dementia support advocate a person-centred approach and share many underpinning principles, such as valuing people (their rights and entitlements) and treating people as individuals (Brooker, 2007); however, how these are applied sometimes differ.

For instance, Glen (PC) highlighted the conflict felt between her perception of intellectual disability support and dementia support:

'It's really difficult and it's something that I found hard, when coming from a learning disability background when somebody believes or thinks something that's not true, in a learning disability service you try to explain to somebody that it's not true...it kind of goes against the grain to go along with that kind of reality with somebody with learning disabilities and that then supporting somebody with dementia, that's a totally different way of supporting somebody. That that's quite tough and it's something I found quite hard, and you know we talk about doll therapy seems to be the big thing in dementia services...and it just makes the hairs on the back of my neck to think that you're giving somebody a doll which is totally age inappropriate because in learning disability services that's not the kind of thing we encourage or certainly kind of advocate for somebody, yet in a dementia service user, it's the opposite, so those two somewhere will make staff feel in conflict about how they will support somebody so we've got to raise awareness, so we've got to kind of make people understand why we're doing things in the way we're doing it' (Glen (PC), lines 198-216).

It is important to acknowledge that dementia support does not just advocate following the person's reality as a response, but acknowledges that reorienting the person is sometimes necessary for their safety. Similarly, reorienting is not the only approach applied within intellectual disability, when people are confused and disorientated; however, Glen (PC) illuminated this as a key distinction between the two approaches,

which they struggled to apply due to their experience and training in intellectual disability support.

Additionally, they felt a sense of uneasiness with some of the approaches used within dementia support, which they deemed as age-inappropriate. Age-appropriateness is one principle which may be applied when supporting people with an intellectual disability, however, it is not the only correct way of working with someone with an intellectual disability. From the researcher's own perspective, having worked in services where people with an intellectual disability engage in activities, such as playing with dolls and action figures, which may be deemed as age-inappropriate, doing so helped to ensure the person's individual preferences were met.

This challenge arose out of the perceived conflict between the intellectual disability model of care informed by a social model, which advocates individual rights and choice, and the development of personal abilities across the lifespan (Watchman, 2005); and the dementia care model, which recognises that the individual's deteriorating abilities results in an 'increasing dependency on structure and directive services, as well as nursing and medical care' (Watchman, 2005, p. 160). The carer, being trained and/or experienced in applying certain principles, found it difficult to then incorporate additional principles which they felt went 'against the grain'. This illuminated the need for caution when expecting carers to implement new models of support. However, as the participant stated, this conflict can be resolved through awareness. This meant applying appropriate training, which highlighted the differences and similarities between intellectual disability and dementia support, the justification for support, and how they can be incorporated to provide a person-centred approach.

Being their voice.

Carers had to be the voice of people with an intellectual disability and dementia, who found it challenging to use their own voice; this was to ensure they received the necessary information, support and services. Lee (FC) and Shawn (PC) illustrated this when they discussed an interaction with hospital healthcare professionals:

'Basically, because we are attentive, nobody's been able to do anything wrong I suppose, but I suppose if you've got somebody who's not got a mum or dad left or a sister, I couldn't imagine what it'd be like really, you know what I'm saying, its, we fight every corner at the hospital when somebody went off to go to another patient, we just didn't let it happen like you know, we said "oh, cause he doesn't talk to you, o he wants attention, we talk, we're his sisters" and they did come back and they were good, but everybody isn't going to have that' (Lee (FC), interview 2, lines 156-163).

'It's like when you go to the hospital, they just haven't got a clue, and when I used to say to them well you know we've got care plans and this is how it works this way and they just totally ignore you and then they just say well, and sometimes you've got to be really fiery, stand your ground cause you've got to be their voice because they can't do it themselves, then they looking down and saying well I'll just do this and I'll get somebody else' (Shawn (PC), Interview 2, lines 142-148).

Carers may already be experienced in supporting the person's voice, as people with an intellectual disability may have already found it challenging to communicate or fight

their own corner, prior to dementia. However, the impact that dementia had on the person with an intellectual disability, such as the deterioration of their communication, may have made the need to be their voice more necessary. The importance of them having a supportive figure, whether that be a family member or paid carer, who can 'be their voice' and 'fight every corner' when they were unable to, was illuminated through these data extracts. Carers were aware of this responsibility, when they stated, 'sometimes you've got to be really fiery' and 'I suppose if you've got somebody who's not got a mum or dad left or a sister, I couldn't imagine what it'd be like really'; they understood that they needed to use their own position to push for the necessary support. The power that carers had in ensuring the person received appropriate support was illustrated by the outcome: the change in the support provided by healthcare professionals. However, Shawn (PC) illustrated the possible challenges carers may face when trying to be the person's voice, as they felt ignored. This required carers to 'stand their ground'; something which not all carers may be confident with doing, and may mean people with an intellectual disability not having the necessary support.

Carers were the focal point of support for people with an intellectual disability and dementia. This made it necessary and important for both family and paid carers to be fully supported themselves. Giving carers the tools and alleviating the impact that the dementia had upon them, enabled carers to help ensure people with an intellectual disability and dementia lived a fulfilling life with dementia, informed by their own preferences.

4.5.2. Cycle of support: Paid carers.

Paid carers were the most direct form of support for people with an intellectual disability and dementia living away from their family, and were essential in helping them to live a fulfilling life with dementia. To facilitate this, paid carers were supported throughout their role to alleviate the burden they experienced and to provide the necessary dementia support; for instance, they were provided with emotional support, training, information and advice. They highlighted a range of support structures and strategies, and the context under which they were utilised. For instance, to alleviate the psychological impact of the dementia, they received emotional support from the wider care team, including managers and fellow carers. Paid carers described how they would support each other, as colleagues, through difficult emotional situations, such as seeing the person they support decline. This was reflected in Shawn's (PC) experiences:

'It's absolutely brilliant yeah. Cus sometimes, I don't know if it happens with everybody but with me being here for so long now and knowing them, knowing what they are capable of and you know what they can't do now, it's heart breaking and it's good to know that you've got somebody there that you can come off and let some steam off, and you know I'm not having a good'un today. But yeah, they're brill, we've got a cracking team here' (Shawn (PC), interview 1, lines 197-203).

This data extract illustrated the social underpinnings of support. Carers needed others in their own support; having someone to talk to during difficult times, to discuss their sadness, and concerns, to meet their own psychological needs. It allowed them to 'let

some steam off'. This social element of support acted as an important support mechanism, allowing paid carers to alleviate their feelings of sadness, concerns, and stress, and preventing it from progressing, for instance, into burn-out. Being supported emotionally helped to alleviate the impact that the dementia had upon paid carers, allowing them to better cope and manage when seeing deterioration in people with an intellectual disability and dementia; consequently, they would have been better able to support the needs of people with an intellectual disability and dementia.

Emotional support was generally reactive, informal and reliant on the initiative of the paid carer. For instance, they sought out fellow carers to discuss their feelings. However, for some paid carers, support structures were proactively implemented, encouraging them to reflect and discuss the emotional impact the dementia had upon them. Pat (PC) described the implementation of an open-door policy, staff meetings, and monthly reflection sheets, where emotional support was provided.

Paid carers were also supported to better manage the extra and varied workload demands placed on them as dementia worsened. This support came from various sources, including healthcare professionals from the IDDCP and intellectual disability services, their employer, management, and fellow carers. One prominent feature of paid carers' experiences was being given the tools, through training and education, to provide dementia support, and consequently, better support the person with an intellectual disability. These tools were underpinned by skills and knowledge developed through training and information, such as knowledge of following the person's journey when safe to do so, and supporting the individual during meal times.

Healthcare professionals from the IDDCP, organisations and management all played a central role in ensuring paid carers were dementia trained and sufficiently prepared to carry out their role. For instance, as Alex (HCP) and Jesse (HCP) stated:

'We give them the skills to be able say that they can make the clients' lives meaningful by doing it this way' (Alex (HCP), lines 361-363).

'I suppose we're kind of guiding staff, we're kind of moulding staff into, you know, what does a good carer look like' (Jesse (HCP), lines 243-245).

Both data extracts encapsulated this notion of 'giving carers the tools', as healthcare professionals moulded paid carers, and gave them the skills and knowledge to help support the dementia needs of people with an intellectual disability. This was underpinned by both healthcare professionals' and paid carers' desire to ensure the person's wellbeing. Ensuring paid carers were dementia trained, so that they understood how to better support the person, was a support strategy; one which had become more commonly implemented as compulsory training, to mould the workforce into dementia trained carers.

The benefits of this support were evident across most paid carers, who described how training enabled them to apply their new understanding to provide dementia support. This is demonstrated by Kelly (PC):

'You know, yeah, and with dementia, we find that we just live in their life, in their world, and not correct them, we've learnt over the years, you know with training, to try and do that and like take mirrors down out of the rooms, because they don't recognise themselves' (Kelly (PC), lines 119-123).

Training enabled paid carers to better understand dementia and the changes which were necessary to ensure the people they supported lived a meaningful life with the dementia. For instance, by understanding that the person with dementia may not recognise themselves, they understood possible causes of changes in behaviour and confusion in the person they supported. In this case, taking away mirrors stopped the person from imagining seeing an intruder in their room, and they slept more peacefully.

Training made paid carers more aware of the changes they could make to meet the psychological and physical needs of the people they supported. As paid carers were better able to support and manage the needs of people with an intellectual disability and dementia, implementing the necessary changes and adaptations, and training helped to alleviate the impact dementia had upon them. For instance, as they removed the mirror and the person had a more peaceful sleep, less night time support was required. Training helped to take support from being reactive to being proactively implemented. For instance, mirrors were taken out of rooms, busy periods in the town centre were avoided which helped prevent confusion, alarms were put in place to prevent people from potentially wandering into dangerous situations, extra support was provided during busy times of the day, meal times were adapted by using dementia friendly cutlery and plates; for example, plates are a different colour to the table so it is easier for the individual to see. Again, this alleviated the impact of dementia upon paid carers as these strategies lessened the burden of support, and may have helped people with an intellectual disability and dementia, as it reduced their confusion and stress.

Support went beyond training. Paid carers utilised support structures whenever they felt it necessary, to ensure that the person's needs were met. When paid carers were unable to provide the necessary support, or needed guidance, they drew on

support from healthcare professionals from the IDDCP and intellectual disability services, management, and fellow paid carers. Paid carers supported the person with an intellectual disability and dementia to the best of their ability, but relied on support from others when they lacked the skill and knowledge. This was illustrated by Shawn (PC):

‘We just do as much as we can for them and get as much support and help ourselves really’ (Shawn (PC), interview 2, lines 159-160).

Support for paid carers was also about accessibility during uncertainty of actions. Healthcare professionals, especially those from the IDDCP, played a pivotal role in supporting paid carers. Six out of eight paid carers discussed how IDDCP healthcare professionals’ support enabled them to support people with an intellectual disability and dementia. As demonstrated by Pat (PC) and Shawn (PC):

‘Yeah, but we would just generally, again I would like to think we’ve got a good relationship with the nurses up **** street and you know we could always just ring up and say, “do you have any support that you could offer for this”’ (Pat (PC), interview 1, lines 302-305).

‘There’s much more support and everything. I mean our Dr **** they’re amazing, they’re a cracking Doctor [from the IDDCP] with them, we look to them a lot for you know if we’re ever stuck they will direct us to the right way like’ (Shawn (PC), interview 2, lines 153-156).

Both data extracts encapsulated ease of access to IDDCP healthcare professionals' support. By having direct access, paid carers sought out support, from those with the necessary skills and knowledge, when they needed guidance. IDDCP healthcare professionals clarified and directed actions for paid carers, which enabled paid carers to provide the necessary support; this not only helped to ensure the needs of people with an intellectual disability and dementia were appropriately met, it helped to alleviate the impact the dementia had upon paid carers, as they had professionals to seek out when they were struggling, thus relieving pressure.

Paid carers also relied heavily upon involved care teams, which included their managers and fellow paid carers. They supported each other through a variety of strategies, including, changeovers (where carers communicate the events of the day in relation to the people they supported), sharing the burden, and sharing ideas. Five out of eight paid carers discussed how their care team communicated regular updates about the person with an intellectual disability and dementia. Changeovers provided a platform for paid carers, who had finished or started their shift, to discuss any changes and support strategies in place. Changeovers helped paid carers to better understand the needs of the person they were supporting on that day. For instance, if a paid carer had not been on shift for a period, the person's behaviour and personality may have changed, so changeovers made them more aware of this. Additionally, care teams shared ideas on how to support the person with an intellectual disability and dementia, as demonstrated by Sam (PC):

'Our employers are excellent, our managers are excellent, erm, if you struggle, that door's always open and if I shouted *** or **** they'll be out like a shot, and you know they'll say have you tried this and have you tired that because

sometimes if you're in that situation you think, your minds blank ain't it, our managers are excellent' (Sam (PC), lines 229-234).

Being able to access such support allowed paid carers to implement the necessary support strategies, and removed some of the burden. Being able to draw upon ideas when unsure of the appropriate course of action removed some of the pressure carers felt. Simultaneously, by collaborating with others with differing knowledge, skills and expertise, it ensured that the right support was being implemented.

However, support was not always available, with paid carers indicating experiences where there was a lack of support or where they lost support. This had adverse consequences both for the carer and the person with an intellectual disability and dementia. For instance, Pat (PC) described the loss of support provided by the health facilitation team due to funding cuts, and the impact this had on the care team and individual with an intellectual disability and dementia:

'Terribly, erm we relied heavily on the support from the health facilitation team. It was *** and *** mainly, and they were absolutely fantastic, they would come out to the home, erm and they would support us with any queries that we've got' (Pat (PC), interview 1, lines 54-56).

'I know in my last interview I mentioned about the health facilitation team, obviously, that's no more. When we had them on board they were absolutely fantastic, they were literally at the end of the phone for lots and lots of support. We're not so lucky now...so we are kind of missing that stepping stone and that

led to oh contact such and such they can help you with that' (Pat (PC), interview 2, lines 280-288).

Losing a 'stepping stone', between the supported living home and services, compounded difficulties. It took away a support structure for paid carers, which had implications for more timely access to services for people with an intellectual disability. Losing the expertise of the healthcare facilitation team meant the *Impact of Dementia* upon carers was greater, as there was slower access to needed services and less guidance; this meant the supportive needs which presented as dementia worsens may not have been as effectively met.

4.5.3. Cycle of Support: Family carers.

Like paid carers, support enabled family carers to better support their family member with an intellectual disability to live a meaningful life with dementia, but also alleviated the impact of dementia upon family carers. However, family carers experienced many challenges in accessing support and had few support structures to draw upon. Most support for family carers came from other family members. Both family carers relied on the support of each other and family members, to support their family member with dementia. This was encapsulated by family carers Lee (FC) and Robin (FC) when they stated:

'We just stick together as a family, we help each other, have a moan, have a tear, or just, you know, it's what you do, yeah' (Lee (FC), interview 2, lines 70-71).

‘Well just each other, talking as sisters, talking with husbands you know, sons, just family really. You know, you just have to talk through and hope that you’re doing the right thing, and that’s all you can do really. I don’t know how anybody does it when they’re on their own; it must be very difficult’ (Robin (FC), interview 2, lines 105-109).

These data extracts illuminated the importance of the social underpinnings of support. Support was both emotional and physical, and helped to reduce the burden of the family carers’ supportive role. Families became a team that ensured constant support for their family member. This became essential as the dementia worsened and their family member deteriorated. Supporting each other helped to alleviate the impact of dementia upon family carers, as they shared emotional experiences and the burden of support, but also ensured that their family member was safe and being supported.

A lack of sources of support to draw upon was a prominent feature of family carer experiences. Both family carers experienced less support from services, which made them more reliant on other family members; consequently, the burden of support increased across the whole family as dementia worsened and support from services was unavailable. There was a need for support from those with the appropriate expertise, as demonstrated by family carers’ discussions around wanting involvement of services from an early stage; however, as was characteristic of both family carers’ experiences, the same expertise provided to paid carers, was not accessed by family carers. Both family carers did not have access to the specialised skills and knowledge of the IDDCP or intellectual disability service healthcare professionals to utilise in times of uncertainty, to ask any queries, to alleviate any of their concerns or the burden of support caused by the worsening dementia. Instead, they had to learn on the journey,

as a family, through experience and carrying out their own research. For instance, in place of dementia training, both family carers found their own resources, usually through their own research on the internet; this was supported by Lee (FC), when discussing informational support after her family member's diagnosis, who stated:

'No, we just had to keep looking on the computer' (Lee (FC), interview 1, line 267).

Support was not easily accessible for family carers. This had consequences for both family carers and their family member with dementia:

'It was frustrating because we knew there was things wrong. We knew that he was vulnerable at home but we couldn't get any of the social workers until things got really bad, didn't seem to want to help, and I think that was the frustrating part because you don't know what help, else you can do really...it was just a constant strain and worry. That's all you can really, we were always on pins, waiting for the phone call really' (Robin (FC), interview 2, lines 85-91).

This data extract illustrated a lack of timely support and the impact this had on the family. Support was received once the situation had worsened and had got 'really bad' for the carer and family member with dementia. This compounded the impact that the dementia had upon the family, as they felt frustrated, were strained and constantly concerned without the needed support. Additionally, when the participant stated that their family member was 'vulnerable at home' they were raising concerns of safety; without the necessary support, they were concerned for their family member's safety.

They felt unsupported in their role; they did not know how to support some of the skill, behaviour and personality changes caused by the worsening dementia; this may be explained by the lack of access to support structures which could have provided the expertise to support them. This compounded the impact that dementia had upon them, but also meant their family member may not have received the necessary support.

The lack of support structures in place and support received by family carers, as compared to paid carers, may be explained by the role of awareness. Both family carers had supported their family member with an intellectual disability all their lives, with little engagement with intellectual disability services. Intellectual disability services, such as the IDDCP relied on awareness for access to the service; their awareness of the person with an intellectual disability having dementia, and carers' awareness of the service: both enabled access. The importance of this was illustrated by Alex (HCP) and Frankie (HCP) when discussing the route to getting a dementia diagnosis and support:

'If people are aware of our team, so within a group home or day services, I would imagine, well usually they would make a referral' (Alex (HCP), lines 49-51).

'So yeah there's support. It's there, as long as it's acknowledged' (Frankie (HCP), lines 277-278).

These data extracts demonstrated the need of awareness to start the process of support. Getting a diagnosis from intellectual disability services was the first step in receiving specialised support, but this may have relied upon being aware of the IDDCP team. This was a challenge for family carers, with neither being aware or having

experience of the IDDCP or its team. Their family member was referred through their GP, which is one possible route of accessing the IDDCP, but instead received a diagnosis through generic mental health services. However, the support received from generic services was limited in comparison to that provided by intellectual disability services. This was evident when looking across paid and family carer experiences, with paid carers having intellectual disability services as a support structure, receiving timely and extensive support; whereas, family carers who were referred through generic services to get a diagnosis, experienced little support. This emphasises the importance of having access to intellectual disability services, specifically, the IDDCP, to ensure access to specialised support; this may partly be achieved by ensuring all dementia referrals for people with an intellectual disability go to the IDDCP. This may have helped to alleviate the impact of the dementia upon carers, and aided them to provide the necessary dementia support.

Without the support of intellectual disability services, family carers had fewer support structures to access, and relied on their family. To compensate for this, to ensure their family member's needs were being met, both family carers hired paid carers to support them in their role:

'We did when at home, we had home helpers coming in, erm which we paid for because, I know this sounds, this is going sound awful but, with [family member] having dementia we knew, cause we both got, me sister was working then, and I got my little grandchildren and that coming and everything. We got busy lives, so we had a home help person in the morning and a home help last thing at night' (Robin (FC), interview 1, lines 106-111).

This quote showed how Robin implemented her own support structures. Hiring paid carers helped her to ensure the safety of their family member, but also allowed her to undertake other responsibilities knowing they were safe. This extra support helped to alleviate the stress and concern experienced by both family carers; however, Robin (FC) experienced guilt for utilising paid carers. Having supported the family member, as a close-knit family, all their lives, she may have experienced feelings of guilt when being unable to meet her family member's needs, and having to spend less time carrying out what she saw as her duty, to spend more time on their own 'busy lives'.

4.5.4. Barriers to support.

Across all participant groups, barriers to providing support were highlighted. Barriers, such as a lack of funding and time, prevented professionals providing carers with the support they felt necessary, and in many cases prevented carers from providing the support they deemed necessary for people with an intellectual disability and dementia.

Funding.

Funding was a prominent barrier to support, both cuts in funding and a lack of funding. This was highlighted by Pat (PC) when she described the loss of healthcare facilitators due to funding cuts, and Morgan (HCP) who discussed the impact that funding cuts had upon support:

'I think it would be invaluable if they got a member of their team who did specialise in some way. There used to be, I think her name was *****, a consultant learning disability nurse who went in to work with the clinical teams

to support people with learning disability, it's like everything else the funding gets cut and that post goes away' (Morgan (HCP), lines 321-325).

Funding took away necessary specialist skills and knowledge, such as the dual trained healthcare professional, which were not replaced. This support structure helped to enable healthcare professionals and carers to appropriately support the needs of someone with an intellectual disability and dementia; but funding cuts took away this important support structure from other healthcare professionals, carers, and people with an intellectual disability and dementia.

Funding constraints may have also resulted in delayed support. As areas of the NHS and Social Services have seen tighter funding budgets, and have experienced ever greater numbers of referrals, delays in providing services have increased. Robin (FC) described the difficulties of accessing a social worker, and how support was only provided once the family had 'hit rock bottom':

'That is something that I do think perhaps if you got more help with things like that, but I suppose it's money. They don't say "well this is the best way" until it's dire really. I think you have to, as a family you have to become, come hit rock bottom before they will help you to go into some sort of residential field really, and I think that probably comes down to money and it's only going to get worse that (Robin (FC), interview 1, lines 153-158).

This delay in support may have been a consequence of funding. Access to funding and subsequently support, was delayed until no alternative was available and the family member's safety could not be secured through family carers alone. As funding was cut

and/or access to it restricted, so was the availability of resources which both carers and people with an intellectual and disability drew support from. This may have negative consequences for carers and their ability to support the needs and ensure the quality of life of someone with an intellectual disability living with dementia.

Excessive paperwork.

Factors which drew paid carers away from their primary role of caring, impacted upon the support they provided to people with an intellectual disability and dementia in a supported living setting. One prominent feature of this was what carers deemed as, in many cases, excessive paperwork. Though this issue was applicable to supporting people without dementia, the dementia as it worsened increased the need to provide more prolonged support; paperwork may have been a barrier to this. Keeping detailed records of the daily routine and behaviour of the people they were supporting was a feature of supporting someone with an intellectual disability, and was vital for designing and implementing person-centred care plans and support; however, paid carers and healthcare professionals felt it took them away from the reason they became carers: to support the individual. Quotes from Kelly (PC) and Morgan (HCP) encapsulated this thinking:

‘There’s too much paper work at the moment. I know you’ve got to have it but it’s ridiculous and at times the paper work takes over your perception of what the job should be like and it does get me down...and I think sometimes with all the paperwork that people have, even the you know the support staff, they aren’t, they don’t want that, they just want to come and care (Kelly (PC), lines 39-50).

'A lot of paper work to be honest, it's all about justifications now, and sometimes I do worry that more of the paper work is taking over the time that should be spent with the individuals, not so much here but in a smaller unit living, where the hands-on carers are also responsible for filling in the paper work, so that's been a big change to be honest' (Morgan (HCP), lines 17-22).

Unable to specialise.

A further challenge which may have acted as a barrier to services and support for carers and people with an intellectual disability and dementia was the focus healthcare professionals from the IDDCP had on dementia. Healthcare professionals who worked on the IDDCP were required to work across and have knowledge of a broad range of areas (e.g. across different health conditions not just dementia), across intellectual disability services. A consequence of working across intellectual disability services meant that healthcare professionals were unable to specialise in intellectual disability and dementia. This was encapsulated by Brook (HCP) and Carroll (HCP):

'It's now been asked to be more generic across everybody. Which is good because everybody needs to be aware of it, but sometimes that dilutes that interest...everybody's expected to do it now, and I don't know if that's been positive or a negative thing really, we're not sure yet, but we're all expected to be generic workers rather than specialists...I think it could dilute what you know, erm but that's the way that service has been directed at the moment' (Carroll (HCP), lines 150-160).

'Another issue is time factors, because you know I don't just see people, you know in relation to sort of dementia, I see people with, you know in relation to lots of other issues as well...if you're just working in one area you'd become more of an expert in it, than if you're trying to work in lots of different other issues' (Brook (HCP), lines 313-321).

A consequence of having a generic focus over a specialised focus was that healthcare professionals felt that it 'diluted' their knowledge; meaning it prevented them from having expertise in dementia. Additionally, having generic knowledge meant that healthcare professionals were expected to work across intellectual disability, which resulted in large, varied caseloads; this again prevented the development of specialised knowledge. Compounding this was the lack of dementia training healthcare professionals received. Most of their training was specific to their role on the IDDCP, for instance, those involved in the diagnosis process were only trained to carry out dementia assessments. Their inability to specialise may have acted as a barrier to providing specialised support for carers and people with an intellectual disability and dementia.

Overall, being supported better facilitated carers' wellbeing and better enabled carers to ensure people with an intellectual disability and dementia lived a fulfilling life with dementia. Supporting carers both alleviated the impact that the dementia had upon them, but allowed them to better support, with the appropriate tools, the needs of people with an intellectual disability and dementia. The social underpinnings of support ensured the psychological needs of carers were met. Strong support structures and strategies were in place for paid carers, which better enabled them to meet dementia needs. However, and worryingly, the family carer participants were not as

fortunate and relied more on their family for support; this would have negative consequences on the carers wellbeing and the support they deliver.

4.6. Underpinning Category: Continuum of Understanding

Understanding was a concept frequently used by participants. Within the *Continuum of Understanding*, understanding referred to an underlying knowledge which allowed healthcare professionals, paid and family carers to appropriately act towards, adjust to and support the needs of people with an intellectual disability and dementia. Understanding informed action: how the healthcare professional or carer acted when engaging with people with an intellectual disability and dementia, and the decisions they made. There was no uniformity across participant groups in *Continuum of Understanding*. It was defined by variations between family and paid carers', and healthcare professionals' understanding across both intellectual disability and dementia. Informed understanding underpinned more positive interactions between people with an intellectual disability and dementia, and others, such as healthcare professionals. It helped to ensure some of the tenets of a person-centred approach informed support. A lack of understanding underpinned more negative interactions, which compounded experiences of the dementia for family and paid carers, and may negatively impact upon people with an intellectual disability and dementia.

Continuum of Understanding also referred to the understanding held by people with an intellectual disability and dementia. It focused on their ability to understand the dementia, the role of others in this understanding, and the implications of others' decisions on whether a diagnosis was disclosed.

4.6.1. Healthcare professionals: Understanding an intellectual disability and the dementia.

The understanding which healthcare professionals held of intellectual disability and dementia impacted upon the interactions and support they delivered to people with an intellectual disability and dementia. Though an understanding of both intellectual disability and dementia was necessary and important, participants illustrated understanding of intellectual disability as significant for informing actions: delivering appropriate support, and the impact of this upon people with an intellectual disability and their carers. Generally, generic healthcare professionals, such as doctors and nurses in GP practices and hospitals, were viewed as lacking the appropriate understanding of intellectual disability. Consequently, their actions were not always appropriate. This was supported across carers, such as Pat (PC), who repeatedly discussed their concerns about the inappropriate support provided by generic healthcare professionals in relation to the person's intellectual disability:

'No, they don't adapt their ways, erm as much as they could to get the best of a situation...they don't take into consideration the learning disability, and they could make things a lot easier, erm for example, double appointments, erm understanding that certain medications you know need to be in a certain way. Erm just to help make all those small things easier, you know, make it a bit smoother' (Pat (PC), lines 366-372).

Though generic healthcare professionals' lack of understanding of intellectual disability is present with or without dementia, dementia created further challenges to understanding the individual's needs. However, experiences were diverse, with

participants describing generic healthcare professionals with and without an understanding of intellectual disability, and the contrasting impact of their actions. This diversity of understanding was reflected through Shawn's (PC) experiences:

'You know if you say to them you've got to give them that little bit longer and you might have to explain it again, simple terminology or even if we've asked for pictorial, so then it ends up that we're saying listen we start talking to them then, well this is what the doctor said, and then you've got like them nagging at you, and it's a knock on effect to them cause if they see the doctors, then they don't cooperate not one little bit do they, they shut down then that's it you get nothing off them. But then it's like Dr ****, they can get anything out of them, they're brilliant with them. It's like the chiropodists you know the opticians they don't take no nonsense off them but they respect them and the same time our lot respect them as well. So they're brilliant and they help them a lot cause they explain a lot to them' (Shawn (PC), lines 191-203).

Some healthcare professionals within generic services lacked an understanding of intellectual disability which meant that some of the person's basic needs were not met, such as reasonable adjustments in communication to facilitate their understanding. A person-centred approach was not applied. As Shawn (PC) illuminated, the healthcare professional made little attempt to simplify their terminology, to provide extra time for the person to adequately digest information, or use tools to support communication. The presence of the dementia would have made such adjustments even more pertinent. This lack of understanding had consequences, as the person 'shut down';

carers had to manage this behaviour and try to interpret and adapt the healthcare professional's original message into an accessible format.

In contrast, when generic healthcare professionals better understood the person's intellectual disability needs, their actions were underpinned by a person-centred approach; they adjusted their support to meet the individual's needs. For instance, the chiropodist and optician took the time to fully explain the process, and showed them respect; consequently, they cooperated with and mutually respected the chiropodist and optician.

Through Pat and Shawn, the importance of understanding the person's intellectual disability was highlighted. Having this understanding enabled appropriate actions, and would help to prevent compounding factors, such as 'shutting down' from impacting upon the person's engagement with healthcare professionals and service providers: helping to ensure their needs and wants were met. The level of understanding healthcare professionals within generic services may be informed by a combination of training and experience. Though government policy advocates the use of generic services to meet the needs and wants of people with an intellectual disability (Department of Health (DH), 2001), evidence has highlighted that healthcare professionals in, for instance, generic mental health services, lacked the knowledge and skills to support the needs of people with an intellectual disability (Hassiotis, Guinn, Tanzarella, McCarthy, & Roy, 2015). The absence of reasonable adjustments by healthcare professionals may be underpinned by insufficient training in supporting the needs of people with an intellectual disability, and/ or experience of supporting someone with an intellectual disability with or without dementia.

Interestingly, understanding of dementia was rarely discussed when exploring interactions between generic healthcare professionals and people with an intellectual

disability and dementia. The focus was exclusively on their understanding of the person's intellectual disability needs. One possible explanation may be the overlapping elements of the person's intellectual disability and the dementia. Dementia can compound impairments which already exist, such as in communication skills. It was vital that healthcare professionals understood intellectual disability, as these needs did not go away with the presence of dementia; instead, some of the needs were amplified. A good understanding guided appropriate action which ensured that the person's intellectual disability and dementia needs were met. For instance, an understanding of the adaptations needed to facilitate accessible communication would help to overcome communication challenges experienced due to the intellectual disability and dementia; improving the likelihood of people with an intellectual disability understanding any information. It was important not to forget or neglect the person's intellectual disability needs.

In contrast, as one would expect, healthcare professionals within intellectual disability services, specifically the IDDCP, had a greater understanding of how to meet the needs of people with an intellectual disability and dementia; again, the person's intellectual disability needs were at the forefront of support. Many examples reflected this, as exhibited through healthcare professionals' actions, and the positive experiences described by paid carers. For instance, Kennedy (PC) described the person-centred support provided by intellectual disability healthcare professionals from the IDDCP:

'Nurses [from the IDDCP] come in and do bloods in here, which is less distressing for him. They've been quite amenable again, so that's really good, they are really good with us. The staff at ***** are great as well. They treat

them like an individual. They've always adapted to their need, individual needs, even before dementia. They explain things to them. That really helps our lot' (Kennedy (PC), lines 134-140).

Intellectual disability healthcare professionals did not forget the person's intellectual disability needs and applied a person-centred approach, the same approach utilised prior to the dementia; demonstrating how their understanding of intellectual disability informed their support. This understanding enabled them to adapt their support to the person. When dementia was present, the same person-centred principles were maintained. Again, this may be due to possible overlaps between both cognitive impairments, such as the need to support understanding through accessible communication and supporting 'bizarre behaviours' (Glen (PC), line 64), which meant an intellectual disability approach to support was effective when dementia presented.

Applying their understanding through a person-centred approach helped IDDCP healthcare professionals to better meet both the person's intellectual disability and dementia needs; however, the actions of healthcare professionals from the IDDCP were also informed by an understanding of the dementia, which enabled them to amalgamate an intellectual disability model and a dementia model of support to ensure the individual's intellectual disability and dementia needs were met.

4.6.2. Carers: Understanding an intellectual disability and the dementia.

Understanding was viewed somewhat differently when it came to carers. The focus shifted from understanding the intellectual disability, to understanding how to

support the dementia. Again, this may be unsurprising as it would be expected that carers supporting people with an intellectual disability would have the appropriate knowledge to enable such support. Both family and paid carers' high level of understanding of intellectual disability enabled them to better apply a person-centred approach to meet the person's individual needs as the dementia presented and worsened; such actions helped to ensure their wellbeing. However, paid carer understanding of the person's dementia was poor, at least prior to training. This initial understanding had possible implications for the support delivered, and quality of life. For example, Glen (PC) explicated difficulties with understanding the dementia, and how this translated into supporting the person's dementia needs:

'I certainly at that point didn't understand much about dementia, cause as I say in our heads it was just something that happened to old people, not younger people that were younger with learning disability and Down syndrome. I don't know really, it's hard to say, I think we just managed it' (Glen (PC), lines 121-125).

Importantly, this illuminated the possible challenges of understanding dementia. Dementia being exclusive to older people is a common misconception which may be particularly damaging for people with an intellectual disability, specifically, people with Down syndrome, who are more likely to present with dementia at a younger age. Not being aware of this may mean carers missing symptoms of dementia, as they believe the person to be too young to present with it. A lack of understanding of the dementia also influenced the support provided. Without this understanding, carers were more likely to 'just manage': applying a reactive approach. However, in many cases a

proactive approach, which could only be applied by understanding the dementia, was necessary to ensure the individual's wellbeing.

Nevertheless, most paid carers showed a developing understanding of the person's dementia needs. This was somewhat in contrast to previous research (Herron & Priest, 2013) which highlighted poor understanding of dementia in paid carers; this subsequently informed inappropriate responses to dementia-related changes. A combination of the carer's experience of dementia and training facilitated their understanding. When carers had little interaction with someone with dementia, and an absence of training, there was a low level of understanding. However, when carers had prior experience of interacting with someone with dementia and/ or training, they had a better understanding. These underpinnings were encapsulated through informed actions, such as adapting support. For instance, Shawn (PC), received training from her employers which helped her to understand and adapt support to meet the person's dementia needs:

'Oo lots, we've had training, we've had dementia training, we done quite a bit actually...With the dementia training though it was really good, you were made to understand more. It's helped me understand the little things, like you know before when we used to say no duck its Monday the 15th and she'd say no its Thursday the 3rd so, we learnt that we go with her and where she is at the time' (Shawn (PC), lines 180-187).

Stevie (PC) was new to the care industry, and had no dementia training, but did have personal experience of supporting a family member with dementia, which she believed helped her to understand and support the person's dementia needs:

'What helped me has been caring for my dad. My dad had the early stages of dementia, so before he passed away I had dealt with a little bit of it, so I knew what to do' (Stevie (PC) lines 65-68).

Such experiences were shared by other paid carers, who used their personal and work related experience of dementia, to inform their actions. Across both Shawn and Stevie, a combination of understanding of how to engage and support the person's dementia needs resulted in better, appropriate support for the person with an intellectual disability and dementia. It is important to acknowledge that whilst training for paid carers translated into developing confidence and knowledge in how to support someone's needs, it did not prevent diagnostic overshadowing. This highlights the need to address the delivery and outcomes of training.

In contrast to paid carers, both family carers, who received little support from services, such as the IDDCP, had a poorer understanding of the dementia, which was reflected in their experiences of helplessness, as they struggled to understand how to support their family member's dementia needs:

'I think that was the frustrating part because you don't know what help, else you can do really, and I mean we used to go every day, and it was just a constant strain and worry' (Robin (FC), interview 2, lines 88-91).

Family carers did not always know the appropriate action when supporting their family member's dementia needs; this was exacerbated as the dementia worsened, behaviours changed and skills were lost. A lack of understanding of the dementia

compounded the impact it had upon both family carers, who felt uneasy, stressed, and concerned as they were uncertain of their actions. Like generic healthcare professionals, underpinning this may have been the absence of training, information and experience of supporting someone with dementia. As discussed in the *Continuum of Support*, family carers were provided with no training and little information in relation to their knowledge needs of dementia.

4.6.3. Understanding in people with an intellectual disability and dementia.

Understanding was an important element of how people with an intellectual disability, as discussed by healthcare professionals and carers, negotiated life with dementia. Integral to this is how the person understands their diagnosis, as this will allow them to better understand the changes which they experience. However, people with an intellectual disability may find it difficult to comprehend new or complex information: the more severe the intellectual disability, the more this is exacerbated. This difficulty would be further compounded as the dementia presented and worsened. Consequently, people with an intellectual disability may find it difficult to understand information given about their diagnosis of the dementia without support and reasonable adjustments making it accessible. It was essential to apply a person-centred approach when disclosing a diagnosis: facilitating understanding. An accessible diagnosis is where a disclosed diagnosis is tailored to the individual's level of understanding, delivering it through a format they are familiar with and understand.

Central to a disclosed diagnosis was the prominent role of healthcare professionals and carers. Their actions informed whether a diagnosis was disclosed, and therefore influenced understanding of the dementia. However, actions were not

always informed by evidence, but instead by others' perceptions of the person's capacity to understand the dementia, whether it was in the person's best interest, and their ability to make the diagnosis meaningful. Generally, a diagnosis was shared with those judged to be more capable, and with an ability to comprehend the concept of 'dementia'. This was captured by Pat (PC) when discussing sharing a diagnosis to the person with dementia:

'I think the level of understanding prior to the diagnosis, I don't think they could understand what dementia is. I think the service users, close relatives, ourselves as a staff team that's supported them for many years and professionals haven't gone out of the way to try and explain to them because we wouldn't want to distress them anymore, or make any more changes to their life you know. We've kind of fought so hard to try and keep them here in their home, so we don't see that telling them would make any difference. Obviously, you know, we have to, we're thoroughly explain different processes and why they've been done' (Pat (PC), lines 147-156).

Sharing a diagnosis was determined by the individual's level of understanding. However, as demonstrated through *Challenging the Diagnosis Process*, it was likely that a diagnosis was made only at a progressed stage of the dementia; consequently, people with an intellectual disability and dementia had reduced capacity to understand a diagnosis at the time disclosure was an option. This made it less likely for the diagnosis to be disclosed. Additionally, there were concerns that disclosing a diagnosis would needlessly burden individuals, adding to the distress already experienced through the dementia. The carer's priority was to ensure the individual's needs were

met. To them, this made sharing a diagnosis redundant. Instead, they explained and justified the different support structures and strategies, to help the person with an intellectual disability and dementia understand the support process they were experiencing.

Compounding the likelihood of a diagnosis being shared was the difficulty of ensuring the diagnosis was meaningful to the person:

‘It’s an area we struggle with actually, it’s tricky. I mean we’ve had people who it’s been quite appropriate to tell them they had dementia, and it’s usually in the form of memory problems, with remembering things or the things they struggle with now. For most of the people, we do try and tell people what is wrong with them, but for most people it isn’t particularly meaningful...For other people I don’t think we do particularly communicate what is wrong, not because we don’t want to, but it doesn’t seem to be meaningful what we do try and tell them’ (Dale (HCP), lines 46-59).

Again, the individual’s capacity to understand was central to whether an attempt was made to facilitate their understanding of the dementia. When the healthcare professional deemed them to have the capacity to understand, a diagnosis was shared in an accessible format, for instance, by explaining the dementia through the changes already experienced, such as forgetfulness. However, for those less capable of understanding the dementia, healthcare professionals and carers found it challenging to make sharing the diagnosis meaningful, which sometimes prevented the disclosure of a diagnosis. Their understanding of the disclosure process informed their actions.

Sharing a meaningful, individualised diagnosis of the dementia would have facilitated the person's understanding of dementia and the changes they were experiencing; however, when a diagnosis was not shared, or it was not meaningful, both people with an intellectual disability and dementia, and carers were impacted upon. This was encapsulated by Stevie (PC) and Glen (PC). Stevie (PC) supported an individual who did not have their diagnosis shared with them and discussed the implications of this:

'No, no definitely not, they're scared. It scares them big time' (Stevie (PC), line 44).

'He's scared he's very frightened, in everything he does, he doesn't know what you're doing to him. He's scared you can tell by his face' (Stevie (PC), lines 57-59).

In the absence of a meaningful diagnosis, the person lacked an understanding of the changes and the new support strategies they experienced. Consequently, they were scared, frightened and confused. This may compound the challenges of support, as detailed by Glen (PC):

'How on earth can people help people with that [dementia] if they don't understand themselves, so that was the problem with the staff team that we had...I would say no, no understanding. Now whether that's partly us, maybe we should have sat down and explained things a bit more, certainly to the gentleman who perhaps could have understood' (Glen (PC), lines 312-323).

When people did not understand their diagnosis, when they did not understand the dementia, carers experienced difficulties implementing new support strategies to meet the person's additional and varying needs. Implementing new supports may have compounded their distress and confusion; for instance, they may have been confused as to why they were being supported by IDDCP healthcare professionals, and why they had to attend consultations at a dementia clinic. Glen (PC) also supported the idea of the central role of others in facilitating the person's understanding of their diagnosis and dementia-related changes, through their belief that they could have provided a more sufficient explanation of the dementia. This illustrated a lack of emphasis placed on finding out if the person wished to know their diagnosis and if so, sharing a meaningful, accessible diagnosis. This may be underpinned by a belief that they may not truly understand the concept of dementia, and/or a lack of confidence and knowledge to disclose a diagnosis. Ultimately, people with an intellectual disability had little or no involvement in the decision on disclosing their diagnosis. Pertinent here are Kitwood's (1997) ideas of personhood and Malignant Social Psychology (MSP). Someone's personhood can be undermined 'when individual needs and rights are not considered, when powerful negative emotions are ignored or invalidated, and when increasing isolation from human relationships occurs' (Brooker, 2007, p.16). Not actively involving people with an intellectual disability in their diagnosis would disempower them; preventing them from owning their diagnosis, and making informed decisions about their support and future.

Individual approach to sharing a diagnosis.

An important underpinning of understanding the dementia for people with an intellectual disability, was an individual, person-centred approach to sharing their diagnosis. Three out of eight healthcare professionals mentioned applying a person-centred approach when sharing a diagnosis. Carroll (HCP) discussed the individual approach taken through the initial considerations prior to sharing a diagnosis:

‘There’ll be some attempt to understand the capacity of the individual and how we would actually share that in a way that they would understand as much as they can’ (Carroll, lines 81-84).

Attempts were made to provide a diagnosis which was adapted to meet the person’s capacity; this meant understanding their ability to comprehend the dementia, and developing strategies to support this comprehension. Ash (HCP) shed further light on the individual approach applied when she discussed the strategies implemented to ensure a meaningful, accessible diagnosis:

‘Every time I see them I’ll talk about it, we’ve got some easy read leaflets on dementia with some, with some pictures, you know which people can respond quite well to. So, I’m preparing right from the beginning so you know there is no surprises’ (Ash (HCP), lines 154-160).

Sharing a diagnosis was not seen as a one-off event, but rather a process. Understanding of the dementia was developed over multiple encounters, where the healthcare professional would impart information about dementia to the person with an

intellectual disability and dementia. They utilised accessible communication resources to facilitate their understanding.

Other healthcare professionals discussed spending time with the individual, letting them ask questions about their diagnosis and creating an understanding together. These strategies helped to better ensure people with an intellectual disability and dementia understood their diagnosis, and the changes which they experienced. Interestingly, none of the carers discussed attempts to individualise the person's diagnosis: to make it meaningful and accessible to the person. As actions are underpinned by understanding, one explanation may be carers lacked the knowledge to deliver a meaningful, accessible diagnosis; however, their belief that disclosing a diagnosis held no benefits for people likely not to understand the concept of dementia, also informed their actions. A meaningful diagnosis had the potential to help people understand the dementia, and for them to be actively involved in decisions about their future support and care.

Overall, understanding was diverse and varied across participant groups. Understanding informed how healthcare professionals acted towards the decisions they made, and how they approached and engaged with people with an intellectual disability and dementia. For healthcare professionals, in particular, those from generic services, the focus was on their understanding of intellectual disability, and how this transpired in their actions towards people with an intellectual disability and dementia. For carers, understanding focused on dementia. Again, this understanding varied, but as dementia has become more high profile, it appeared that paid carers' understanding of dementia has improved. In contrast, family carers had less understanding of dementia, underpinned by little support.

Understanding was reported to be important in how people with an intellectual disability negotiated the dementia. With an individualised, meaningful diagnosis, they may be better able to understand the dementia-related changes they experienced. Healthcare professionals and carers influenced this understanding through the decisions they made on disclosing a diagnosis, and whether it was made accessible. Across all participant groups, understanding underpinned actions and ensured the wellbeing of people with an intellectual disability and dementia. Additionally, having knowledge and understanding appeared to alleviate the emotional burden carers' experienced.

4.7. Underpinning Category: Continuity

Continuity referred to maintaining consistency in the lives of people with an intellectual disability and dementia. There was a sense that the wellbeing of people with an intellectual disability and dementia was better achieved by maintaining continuity through their support. Continuity in both their home and service provision maintained the person's support structures and systems. Where there was a lack of continuity, as the person with an intellectual disability and dementia was moved out of their home into a generic dementia nursing home and/or out of intellectual disability services, the impact of dementia could be compounded.

There were factors which either helped to maintain continuity, such as adaptations and adjustments in support and the person's home environment; or which broke continuity, such as when the dementia worsened and appropriate adaptations were not implemented to meet the person's support needs and ensure their safety.

4.7.1. 'Ageing in place'.

Continuity in the person's home was prominent across participant experiences. Most participants illustrated how they tried to implement the principles of an 'ageing in place' model of care. 'Ageing in place' is where care and support is adapted to the individual's changing needs within their home (Watchman, 2008). This was more evident through paid carers, who provided examples of supporting people with an intellectual disability and dementia in their home under the systems and supports of 'ageing in place'.

Underpinning this were the participants' beliefs that it was essential people with an intellectual disability and dementia stayed in their home for as long as possible, to help ensure their wellbeing. Moving the person from their home could compound the dementia, as it took people with an intellectual disability and dementia out of their familiar setting, where they encountered the challenges of navigating a new environment. This was captured by Pat (PC) and Ash (HCP):

'It's nice to see and think that they've not had to go to a dementia home and I'm not saying that every dementia home is bad, it's just, it's not home for them. It wouldn't be home. To move them would, they've all said it would have such a dramatic negative effect on their wellbeing, it's likely to increase the deterioration quicker erm' (Pat (PC), interview 2, lines 363-368).

'If you move people, there's a big impact if you move people, because they can't orientate themselves, they can't remember, and sort of I know I went into a care home in *** the other week and it was massive; I couldn't find my way out [both

laugh] yeah, that sort of thing, so how does someone go on who's put here. It's overwhelming' (Ash (HCP), lines 282-288).

The possible compounding impact upon the person when moved out of their home, and into a care home, was emphasised. It speeded up their deterioration and overwhelmed them. Both participants demonstrated their concerns about the suitability of care homes for people with an intellectual disability and dementia, and the challenges they would face if moved into one. Though disorientation and forgetfulness are symptoms of the dementia, moving the person to a new environment exacerbate both. Keeping the person in the familiar setting of their home would not prevent these symptoms from arising, but may help them to be better managed under familiar support structures.

Maintaining this continuity was underpinned by consistency. To safeguard wellbeing, people with an intellectual disability and dementia were better positioned in an environment which held familiarity, with carers who had experienced their journey, and understood their individual needs and preferences. This was encapsulated by Jesse (HCP):

'Yeah, cause that, that's the familiarity for the people that we support, and we become that circle of support and I think that for somebody who's already got a learning disability, we then have a diagnosis of dementia, and suddenly we take that person out of that circle of support and put them somewhere completely new and different, that's going to be even more confusing than just the dementia diagnosis itself' (Jesse (HCP), lines 197-202).

Jesse illuminated the essence of continuity in the person's home: the maintenance of the individual's circle of support. The relationship between the person with an intellectual disability and their carer was essential. Moving the person from their home, in many cases, meant removing these relationships: taking away established support structures and strategies. This compounded the impact of the dementia as people with an intellectual disability and dementia faced the challenges of navigating a new environment, support structures and strategies. New carers may never truly understand the person, their individuality, like the paid or family carers who supported them for long periods of time prior to being moved.

Both paid carers and healthcare professionals had a particularly strong commitment to maintaining this continuity in the person's home. This was reinforced by their desire to support the individual until the end of life or for as long as possible with the dementia:

'I think the one thing that I always find in all the services I've worked is straight away, the first response that (paid) carers, when we say "you know, so and so, we think there's a possibility of a diagnosis of dementia", "well they're not going to move him are they, he's going be able to stay here, we're going still be able to care for him until the end of his dementia", yeah, why not, why shouldn't we, you know' (Jesse (HCP), lines 188-193).

Many of the healthcare professionals and paid carers had long-established, strong relationships with the people they supported. This attachment strengthened their commitment to ensure the person with an intellectual disability and dementia was supported in their home until the end-of-life. Underpinning this commitment was a

concern that moving the individual out of their home would negatively impact them; thoughts of being unable to maintain continuity induced negative emotions for carers, as illustrated by Glen (PC):

‘It’s hard because everyone was very fond of her because she lived there for a long time, and it’s difficult to think you can’t manage or support her’ (Glen (PC), lines 129-131).

Continuity in the person’s home was viewed somewhat differently by family carers. Like paid carers and healthcare professionals, both family carers wanted to keep their family member in their home; they wanted the best possible support for their family member, and they felt uneasy in moving their family member into a nursing home, at least initially. However, both family carers eventually saw nursing homes as a suitable option to meet their family members increasing support needs and ensure their safety. After initial reservations, they spoke positively about having to move their family member into a nursing home. This was illustrated by Lee (FC) and Robin (FC):

‘It has got the beds which go up and down, it has got the hoists if needed. I know it took every penny that he’s allowed in his allowance...the doctors are so convenient, and they weren’t ringing doctors thinking hey its 4 hours from now, they’re only round the corner, and then they had an excellent reputation as far as we knew, you know, cause it’s not about how clinical or how clean everywhere is, it’s just about caring. Knowing he’s safe, he was on one level he wasn’t going to fall down a flight of stairs... ***** seems to have a good level [of staff]’ (Lee (FC), Interview 1, lines 211-231).

'It was the best thing for them, you know. [Family member] was much better off' (Robin (FC), interview 1, lines 150-151).

The nursing home provided for many of the person's needs which family carers eventually could not, as indicated when Robin (HCP) stated '**** was much better off'. As family members experienced challenges in implementing the principles of 'ageing in place', a 'referral out' model became a viable option. This is where the person receives care and support from an alternative service; this means moving the individual into a generic social care facility or a nursing led facility (Watchman, 2008). The nursing home had the resources, equipment, environment and staff to ensure support and safety as the person's dementia worsened. There was a sense that the family support circle was being replaced by more able structures and strategies. Knowing their family member was safe helped to alleviate stress and anxiety for both family carers, as they felt their family member was receiving the best support.

This greater acceptance of moving their family member into a nursing home may have been underpinned by family carers' awareness that they did not possess the necessary resources to ensure 'ageing in place' and support their family members worsening dementia. As discussed in the *Continuum of Support*, family carers and their family member with dementia had access to fewer support structures and strategies; consequently, they may have been less able to support their family member's wellbeing and safety, resulting in a greater need to move their family member out of their home and into a nursing home.

4.7.2. Discontinuity of the person's home.

As highlighted, continuity in the individual's home could help to ensure wellbeing, given the right support structures, strategies, and philosophy of care are available and in place. However, there was an awareness that continuity was not always possible or desirable. Usually, the person's best interests underpinned decisions to move them from their home; however, the impact of the dementia upon their peers also informed decisions. Decisions on moving the person out of their home revolved around three overlapping factors: the wellbeing of peers, the suitability of their current environment, and the abilities of the care team. The latter two factors related to the ability to apply the principles of 'ageing in place'. For instance, Pat (PC) discussed moving the person if their dementia had too much of an impact upon the person's peers:

'If ever we felt the incidents were becoming too frequent or they're having too much of an effect then obviously we'd look at suitable alternative replacement, but we're not there yet, nowhere near that, and you know we want it be a home for life and we've been told that if we were to move either of the service users it would have a negative detrimental effect on their wellbeing, and obviously that's paramount so until we come to a point where the incidents are having too much of a negative impact or too risky for all involved' (Pat (PC) interview 2, lines 150-157).

This reasoning behind moving the person highlighted paid carers' considerations when supporting both people with an intellectual disability and dementia, and people with an intellectual disability without dementia. Pat (PC) had to consider the impact on

housemates, against the impact of moving the person with dementia out of their home. Though they wanted it to be a home for life, when the impact on others became too great, when there was too much of a risk, alternative accommodation was considered.

The suitability of the environment was also an important factor when deciding to move an individual out of their home. It was not always possible for the principles of 'ageing in place' to be applied. Where homes were deemed to be unsuitable for the person's worsening dementia needs and were not/ could not be adapted, a new home setting had to be located for the person. For instance, as Lee (FC) stated:

'Knowing he's safe, he was on one level he wasn't going to fall down a flight of stairs. It was a beautiful home but it was Victorian and there was no stair lift coming down and things like that, and the young girls, on nights was always when we got rung up because basically there was only one on nights with four people, cause she could neither lift them or do anything. She had to ring for an ambulance, she couldn't ring us first so we could go help lift him cause that's not within their category, she had to ring for an ambulance, and I can understand that, so it's a case of they need more people to look after them really, you know' (Lee (FC), interview 1, lines 219-228).

Lee's family member with dementia moved from supported living, back to the family home, before having to move to a nursing home for older people. The original decision to move their family member back to the family home was based on the unsuitability of the environment to their family member's needs. It did not have the necessary adaptations, such as a stair lift or bedrooms on the ground floor, to provide an adequate, safe home for their family member. Consequently, this meant removing the

person away from their friends, established support circle, support structures and strategies. However, moving them back into the family home ensured an appropriate physical environment, which was better adapted to meet the family member's needs at that time.

This data extract illuminated the importance of future planning to ensure the person with an intellectual disability and dementia could have a home for life. In this example, the additional needs which may present in someone with dementia, such as loss of mobility, were not considered, so extra staff and facilities were not provided. One possible reason for this was funding. As discussed in the *Continuum of Support*, many participants highlighted a lack of funding as a barrier to receiving the necessary support. It may have been deemed more cost effective to have moved the individual, than to have adapted an ageing setting.

Overlapping with the suitability of the home environment, was carers' ability to support the person with an intellectual disability and dementia in their home. Though participants wanted to provide a home for life, many lacked training in end-of-life support, which meant it was not always possible. Where the necessary end-of-life support could not be accessed, the person with an intellectual disability and dementia had to be moved to where this expertise was available. Again, this highlighted the importance of considering future training needs to ensure the person could remain in their home for life, whilst maintaining their wellbeing.

Unsurprisingly, like other elements of this CGT, people with an intellectual disability and dementia were discussed as receivers of support. Salient was their lack of involvement within the decision-making process: actively directing their present and future support. Decisions were made for them by carers and healthcare professionals. Again, this could undermine the individual's personhood, as it would disempower them:

prevented from having active input about their future. This contrasts with guidance, such as that of advance care planning (ACP), which advocates early discussions with people with dementia around their future care, including their future living arrangements leading to the end of life. However, it is recognised that ACP with the individual may be influenced by the individual's level of intellectual disability and stage of dementia.

4.7.3. Strategies ensuring continuity of home: Support and the environment.

Keeping people in their home was important to participants. To help ensure this, strategies were implemented, such as seeking support to facilitate adaptations of the environment and support strategies. For instance, as part of the cycle of support, discussed in the *Continuum of Support*, healthcare professionals from the IDDCP and care organisations provided paid carers with the tools to facilitate continuity in the person's home. This was predominately achieved through training. Training brought knowledge and understanding about dementia and ensured appropriate actions. This understanding allowed paid carers to support the person with dementia and ensure they remained in their home. For instance, as Sam (PC) stated:

'The college course, it just made me question everything I was doing with the person with dementia...and we've got an old lady now with dementia, and we just go into her world, which we do now, we make the needed changes to meet her additional needs' (Sam (PC), lines 18-22).

This reflected the important role of support in maintaining the 'ageing in place' model. The training allowed necessary support strategies to be implemented; this helped Sam (PC) to manage the person's behaviour, by preventing confusion and disorientation, and averted incidents which impacted upon carers and peers.

Further adaptations, within supported living, included extra support which ensured the person's needs were met and they were safe, for instance, night staff were introduced to ensure the person's needs were met through the night and to prevent wandering. Other examples included adaptations to their living environment, for instance: paid carers utilised adapted cutlery and plates to enable eating; took down mirrors so the person did not think someone was in their room; put in hoists when there was a loss of mobility; and adapted access around the building so it was alarmed to prevent people with dementia, coming to harm from wandering. Such adaptations not only safeguarded quality of life for people with an intellectual disability, it ensured better support and safety for the person with dementia in their home.

Family carers had fewer tools at their disposal to ensure their family member stayed in their home. As both family carers had little access to support structures, they utilised their own financial resources and shared the burden of support across the family. Both family carers hired paid carers, which enabled them to keep their family member with dementia in their home setting for as long as possible:

'When they were at home you'd have perhaps the social worker once every 6 months come, you know. We did when at home, we had home helps coming in, erm which we paid for because, I know this sounds, this is going sound awful but, with them both having dementia we knew, cause we both got, me sister was working then, and I got my little grandchildren and that coming and

everything. We got busy lives, so we had a home help person in the morning and a home help last thing at night' (Robin (FC), interview 1, lines 105-111).

This demonstrated the family carer's awareness that extra support was needed to ensure their family members stayed in their home, and willingness to use their own resources to achieve this. However, it also illuminated the guilt they felt for needing support from others when they said, 'this is going to sound awful'. Having been brought up as a family, to support each other as a family, it was challenging for family carers to initially accept that they needed support from others, outside of the family, to ensure continuity. Again, this also highlighted the challenges family carers face when supporting their family member, and trying to maintain continuity in their family member's home. The lack of resources available to family carers meant that they were not always able to apply the principles of 'ageing in place' which were commonly replaced by that of 'staying at home': where the accommodation remained the same, but carers did not apply the principles of 'ageing in place' (Watchman, 2008).

4.7.4. Continuity of intellectual disability services.

Continuity extended to maintaining intellectual disability services as the primary source of service provision. There was a sense that people with an intellectual disability and dementia were better able to have their support needs tended to in intellectual disability services, as compared to generic services, where understanding of intellectual disability varied, and support did not meet the individual's needs. This was encapsulated by Jesse (HCP):

‘And I think that’s really important, and I think it’s a vital part, and what I’d hate to do, and again not to disrespect the role of mental health nurses, but when you get a diagnosis of dementia, and you move in to that mental health sector, we run that risk of forgetting the very important needs of someone with learning disability, and again we don’t want just to isolate somebody in learning disability services if we think they would benefit from that intervention from the mental health team’ (Jesse (HCP), lines 360-366).

Here, the centrality of the person’s intellectual disability support needs was highlighted. There was concern that generic mental health services would neglect their intellectual disability needs. Like many healthcare professional participants, there was a belief that intellectual disability services were better positioned to support their intellectual disability needs, alongside their dementia; whilst generic services were best utilised when it provided benefits to the person’s wellbeing. Still, there was a concern of isolating people in either intellectual disability or generic mental health services, when there was a need to utilise both services; highlighting the need for interdisciplinary collaboration between services to ensure the person’s needs were met. This was further supported by Morgan (HCP):

‘Yeah, and that’s why I think, erm no worries about ****, but I don’t think that he gets all that he should get because with him being under the dementia umbrella rather than the learning disability one it covers the funding for his bed has come from the dementia pot, not the learning disability pot, so he hasn’t got the learning disability cover, so and there should be able to have at least have somebody with the dual training or somebody who covers both, and, and for

some strange reason every person I meet that's not under the learning disability umbrella, the physios the health and safety, the OT, they all think learning disability people are violent, so they know, they think it's all about challenging behaviour and it isn't, there's people, I mean not the people with challenging behaviour are wonderful people but there's very few of them with those sort of concerns, so you know that, it's that side that there's a slight ignorance which goes with it to be honest' (Morgan (HCP), lines).

Morgan (HCP) supported an individual with an intellectual disability and dementia who had been moved out of intellectual disability services and into generic services. However, this brought challenges in that generic healthcare professionals did not have the necessary understanding of an intellectual disability. Consequently, some had misconceptions of people with an intellectual disability, which may have influenced their actions. When the participant discussed the need for dual trained healthcare professionals, there was recognition that collaboration between services was necessary to ensure the person received the appropriate support. This, combined with their belief that 'the intellectual disability transfers really well to dementia person centred care and stuff' (Morgan (HCP), lines 11-12), explicated a need to have a healthcare professional from intellectual disability services, who understood how to provide person-centred support to someone with an intellectual disability, whilst also meeting their dementia needs. This was further captured by Jesse (HCP):

'I think dementia should sit in learning disability nursing anyway. I don't think it should sit in mental health nursing and that's not to disregard or disrespect the skills of mental health nurses, I think that's to identify and accept the skill of

people working in cognitive impairment, for a learning disability nurse to then be able to reshape her support around someone with learning disability and dementia, is a far more natural process than trying to shape a mental health supporter to bring in a learning disability nursing, if that makes sense, and I think if we look at the people that we support with learning disabilities who've got that cognitive impairment already, the dementia's just another aspect of that, it's not just everything about that person and I think that's what we see differently is that you know, we see the person as a person, just they got additional support needs...I still believe that learning disability nurses are the right people to look after somebody with dementia, because that cognitive impairment, it's just natural part of that nursing (Jesse (HCP), lines 132-148).

Jesse illuminated how intellectual disability healthcare professionals, already supporting the complex needs of people with cognitive impairments, had the skills and experience to provide the necessary support for someone with dementia. The support philosophy was central to this, as indicated when the participant stated, 'I think that's what we see differently'. Person-centred support was a key tenet underpinning the support Intellectual disability healthcare professionals provided, they saw the individual; consequently, their support was individualistic. Though a person-centred approach is advocated and applied throughout dementia support (Brooker, 2007), the participant believed generic mental health services focused more on the cognitive impairment and less of the individual.

Maintaining continuity in intellectual disability services also brought stability, as the same care team and environment were in place. This benefited people with an intellectual disability, who received support from a familiar care team and support

structures. It also benefited paid carers, who had developed strong support networks with intellectual disability services, such as the IDDCP. Taking them away from these services may have caused confusion and untimely support, as relationships and structures had to be established in a new setting.

Overall, continuity meant consistency in support. It entailed utilising, where possible and beneficial, an 'ageing in place' model, to maintain established support circles, structures and systems. This better ensured the delivery of person-centred support, which helped them to live a meaningful life with dementia. The carer's ability to ensure continuity was reliant on support; consequently, paid carers, who had greater access to support, were better able to ensure the principles of 'ageing in place' were implemented. In contrast, family carers had little support from services, instead being reliant on other family members, which meant their family member had to move to a nursing home setting.

Continuity meant maintaining the person's access to intellectual disability services, who were better positioned to meet their support needs. Dementia was approached as another cognitive impairment alongside their intellectual disability; something intellectual disability staff already had experience of supporting. However, there was a need to work interdisciplinary with generic mental health services when in the best interest of the person with an intellectual disability and dementia. There was also a need for more dual trained healthcare professionals within intellectual disability services.

4.8. Personal Reflections on the Constructivist Grounded Theory

Conceptualising data within this Constructivist Grounded Theory (CGT) has helped me to better understand factors which underpinned the experiences of carers (family and

paid), such as the supportive role of others, including fellow paid carers and/ or family members, and healthcare professionals from an IDDCP, in alleviating the burden carers experience and better enabling them to support the individual with an intellectual disability and dementia. It has also helped me to better understand the important role of the IDDCP in the support of people with an intellectual disability and dementia; this has predominately focused on the reactive diagnosis process in place and the IDDCPs attempts to ensure carers are dementia capable; trying to reduce the burden they experience and support their knowledge and skill needs.

There were categories which I had an inkling could emerge from the data, and they did; however, within these categories, the data presented unexpected findings. For instance, support was expected to be prominent throughout experiences, but carers discussing challenges of applying the dementia model to support, and how this could 'clash' with their understanding of an intellectual disability model, was unexpected.

In some cases, what the CGT helped to make explicit surprised me. For instance, how paid carers felt supported and generally happy with the level of dementia training received; though many still had knowledge gaps. As previously being an intellectual disability support worker, and experiencing little dementia training, this challenged my pre-held assumption. Perhaps one of the more surprising features of the data was the belief that carers were better equipped to cope with the dementia. This was something I had never considered, but illustrated a 'resilience', which was projected through the data. As I completed my analysis, I reflected on the influence this process had on me. It has helped me better appreciate the complexity of supporting someone with dementia; the factors which underpin experiences, and the daily challenges, but also the compassion shown by care providers, including carers

and healthcare professionals, and the commitment by people to ensure the impact of the dementia was limited, even when this came at a personal cost.

4.9. Summary

Within this Chapter, the experiences of supporting someone with an intellectual disability and dementia was found to be informed by five interrelated categories. The bidirectional relationships between the core category, *Impact of Dementia*, and its underpinning categories of *Challenging the Diagnosis*, *Continuum of Support*, *Continuum of Understanding*, and *Continuity* were discussed and supported through data extracts (see Figure 4.1., page 132, for further details of the properties of the core category, and its four underpinning categories). The *Impact of Dementia* highlighted the multiple forms of burden which impacted upon carers, including physical, emotional, and financial, and how this burden could differ between paid and family carers.

Challenging the Diagnosis illustrated the challenges which carers experienced with identifying the symptoms of dementia and distinguishing these symptoms from the individual's intellectual disability; and demonstrated the additional measures which an IDDCP had to take when implementing a reactive approach to the diagnosis. A combination of a delayed referral and reactive diagnosis process meant that the diagnosis of dementia, and the initiation of post-diagnosis support for carers and people with an intellectual disability took place once the dementia had deteriorated further.

Continuum of Support explicated the importance of social support and training for carers, to help alleviate the additional burden and better ensure they had the skill set to meet the needs of the person with an intellectual disability and dementia.

However, support was not always available to carers, and family carers had less access to the same level of support than paid carers. For paid carers, the important supportive role of an IDDCP was evident; though family carers reported not having access to the important support provided by the IDDCP.

Continuum of Understanding illustrated the importance of understanding the individual, intellectual disability, and dementia, to meet the person's needs. It highlighted carers' poor knowledge of dementia, and how paid carers received training and support, which improved this knowledge and translated into the delivery of support informed by elements of a person-centred approach. However, it demonstrated the challenges family carers' experienced when trying to understand dementia; again, they did not have the support and training which paid carers' received, which meant they had to do their own research. Furthermore, it highlighted how carers and IDDCP healthcare professionals could facilitate or impede the understanding and rights of people with an intellectual disability, as they decided whether a diagnosis should be shared and whether they actively involved the individual in the decision making process.

Continuity explained carers' commitment to ensuring a home for life for people with an intellectual disability and dementia through an 'ageing in place' model. Carers reported different strategies to help the individual remain in their home but also experienced barriers, such as lacking the appropriate skill set and being unable to adapt the environment, which meant it was not appropriate for the individual to remain in their home. For family carers, a point came when they recognised they could not provide a dementia friendly environment in which they could support their family member's needs; instead, they were more accepting of moving their family member into a residential setting, which was dementia capable. Knowing their family member

was safe relieved family carer burden. There was recognition that sometimes it was necessary to move the individual into a different setting, to ensure the safety of the individual and their peers. *Continuity* also referred to maintaining the important involvement of intellectual disability services, but also highlighted the need to collaborate with mainstream older psychiatric services, to ensure the needs of people with an intellectual disability and dementia are met.

Chapter Five presents the substantive literature review. The substantive literature review was used to engage in a critical conversation with previous ideas and research within the area this research study's CGT aimed to address: carers' views and experiences of supporting people with an intellectual disability and dementia, and the supportive role of a Dementia Care Pathway.

Chapter Five: Substantive Literature Review

5.1. Introduction

Within this Chapter, a focused, substantive literature review is presented. The literature review was undertaken after the participant interviews were analysed, in keeping with Constructivist Grounded Theory (CGT) methodology. This Chapter starts with a brief recap of the rationale for a delayed review of the literature, before stating the questions

(developed from the CGT) which this review sought to answer. The inclusion criteria are then detailed and the reason for each criterion highlighted. The literature search process is then explicated, with the databases used stated, before the selected literature is presented and critically reviewed, and the CGT is positioned within the substantive literature.

5.2. Literature Review Process

Applying the principles of CGT, the substantive literature review was carried out after this study's CGT was developed; this helped to avoid 'importing preconceived ideas and imposing them on your work' (Charmaz, 2006, p. 165) and encouraged the articulation of the researcher's own ideas, which are better informed and shaped by their understanding and the inductive data. The timing of the review entailed a thorough, systematic detailed approach which remained close to and was shaped by the data; subsequently, the CGT guided and informed the search strategy applied, as categories were used to develop questions and key search terms. These terms centred around: the impact of dementia upon carers; and the supportive role of carers and Dementia Care Pathways (DCPs) (see Chapter 2.6.1. for a detailed discussion of the use of literature within this thesis). Underpinning the literature review were four questions informed by this study's CGT:

1. What impact does supporting someone with an intellectual disability and dementia have upon paid and family carers?
2. What supports do paid and family carers draw upon to better cope and manage the impact of the dementia?

3. What is the role of paid and family carers in the support of people with an intellectual disability and dementia?
4. What is the role of dementia care pathways (DCPs) in the support of paid and family carers, and people with an intellectual disability and dementia?

To fully explore these questions, key search terms and their possible alternatives were developed (see Table 5.1., page 225). Terms were kept broad, whilst remaining close to the literature review questions.

5.2.1. Inclusion criteria.

Inclusion criteria were developed and applied to produce a focused search strategy, which included high quality literature and provided information on the remit of this review (Aveyard, 2014); indicating why literature was included and discarded. The literature included was:

1. Qualitative and quantitative research
2. Theses
3. English language only
4. Published 2000- 2018
5. Peer-reviewed
6. Abstract available

It was important to include both qualitative and quantitative research within the literature review. Though qualitative research, with its concern with experiences and perspectives, was well aligned with the current research study, quantitative research could provide pertinent information around aspects of how dementia is experienced, for example, numerical data on increased burden placed on carers.

The time frame 2000-2018 was selected to capture a period of UK service and policy developments which were informed by important White Papers (Valuing People [DH, 2001]; Valuing People Now [DH, 2009], and numerous reports (see Appendix O). This time frame also captured a period of increased focus on dementia within the intellectual disability research field (e.g. Courtenay, Jokinen, & Strydom, 2010; Doody & Clearly, 2017; Furniss et al., 2012; Herron & Priest, 2013; Iacono et al., 2014; Janicki et al., 2005; McLaughlin & Jones, 2010), and increased availability of guidance around service provision and support (BPS & RCP, 2015; Public Health England, 2018). It also captured increased awareness through government initiatives such as the Prime Minister's Dementia Challenge (Department of Health, 2012, 2015) which subsequently informed service developments.

5.2.2. Databases searched.

Two citation indexes, EBSCO and Web of Science, were used to search a variety of databases. EBSCO and Web of Science were selected as they host an extensive breadth of databases and subsequently, literature; this allowed for a thorough review of the literature. Within EBSCO, the options 'All Health Databases' and 'Psychology and Sociology Databases' were selected, resulting in the following databases being searched: Academic Search Complete, CINAHL Plus with full text, MEDLINE, PsycARTICLES, PsycINFO, and AgeLine. Within Web of Science, its core collection was searched; this is its most comprehensive collection of databases. In addition to EBSCO and Web of Science, EThOS was searched for relevant unpublished Theses. Finally, the key search terms were searched through Google Scholar.

Working closely with a senior librarian at Keele University, a database search strategy was developed to ensure that a focused exhaustive literature search was performed. The key terms, their alternatives, and how these have been used to search the databases is presented in Table 5.1. (see page 225). To maximise the amount of relevant literature and ensure the inclusion criteria were met, truncation (*) and Boolean operators 'AND/OR' were applied when searching databases (see Table 5.1., page 225).

Using the search strategy within EBSCO (141 papers), Web of science (195 papers) and EThOS (18 theses) produced 354 papers. Google Scholar produced over 12000+ returns. These were viewed in date order, with papers from 2018 being viewed first; this ensured that the most contemporary research was included in the screening and appraisal process. The first 200 returns were screened and appraised. Furthermore, to maximise the inclusion of relevant literature, after the development of the CGT's tentative categories, the researcher signed up to alerts from relevant journals. These alerts provided the researcher with six additional papers, which were included in the screening and review process.

The searches across all databases were combined, and a list of 560 papers was produced. See Figure 5.1. (page 226), which is a flow chart of the screening and appraisal process from the literature search to the final body of reviewed literature.

Table 5.1. Search terms and combinations.

Key term	Alternatives													
Intellectual disabilit*	OR	learning disabilit*	OR	learning difficult*	OR	Down* syndrome	OR	Mental deficienc*	OR	Mental retardation	OR	Developmental Disabilit*	OR	Mental Handicap*
AND														
Dementia	OR	Alzheimer's disease												
AND														
Carer*	OR	Paid carer*	OR	Professional carer*	OR	Family carer*	OR	Family caregiver*						
AND /OR														
Care pathwa*	OR	Clinical pathwa*	OR	Integrated care pathwa*	OR	Critical care pathwa*	OR	Care map*						
AND /OR														
Healthcare professional	OR	Nurse*	OR	Psychologist*	OR	Psychiatrist*								
AND /OR														
Impact of dementia	OR	Effect of dementia												
AND /OR														
Support*	OR	Care												
AND /OR														
Continuity	OR	Continuous												
AND /OR														
Diagnos*	OR	Assess*												

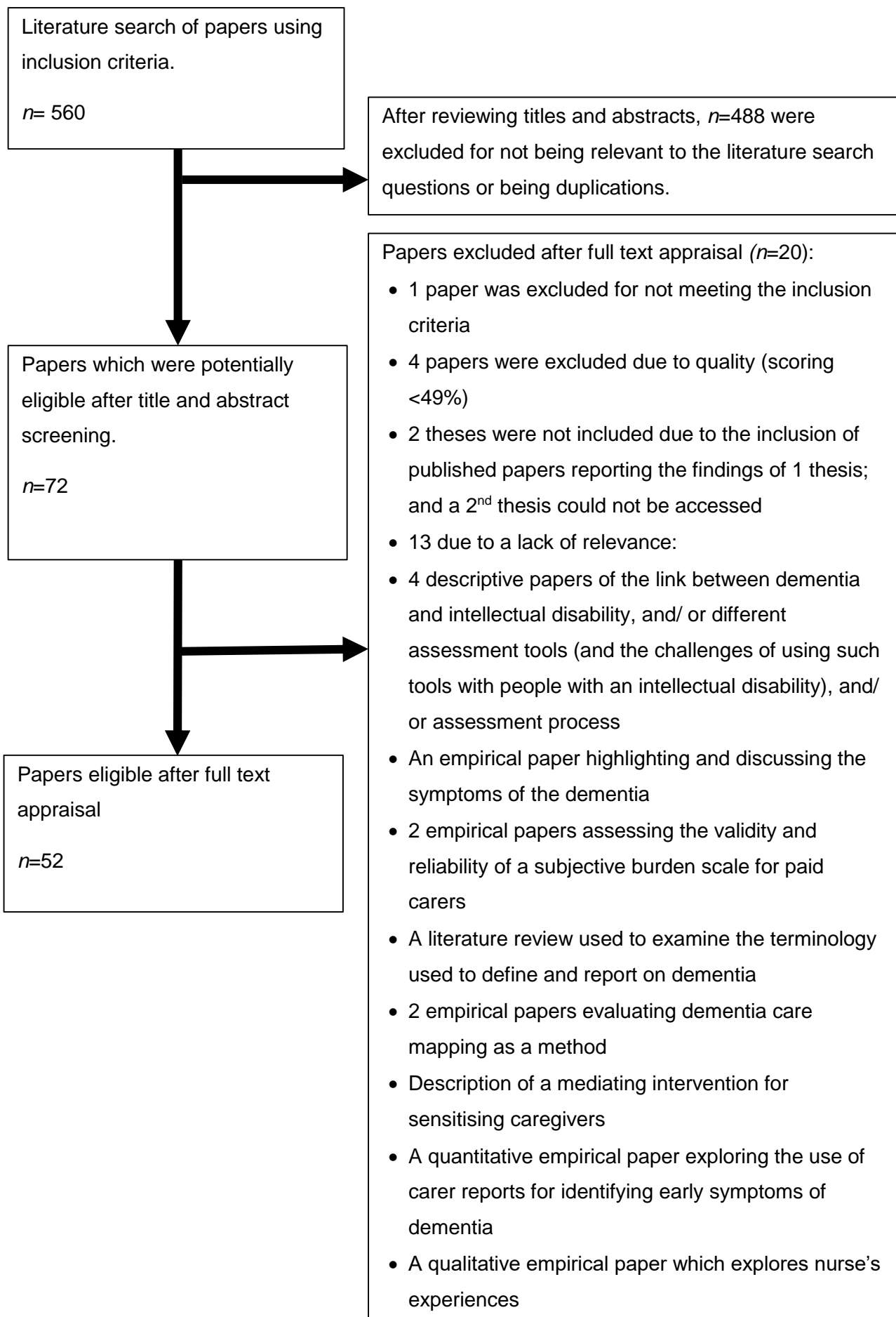


Figure 5.1. Literature Review Flow Chart.

5.2.3. Screening and appraising the literature.

All 560 papers were screened by reviewing their titles and abstracts; asking whether they were relevant to the literature search questions. Papers which were considered relevant to these questions were kept, those which were not relevant were discarded. Duplications were also discarded. This produced 72 papers; these comprised qualitative, quantitative and mixed method studies, literature reviews, and non-research papers (discussion, guidance, reports and theoretical papers). All 72 papers were full-text screened for their relevance by using the literature search questions, and their quality assessed by using appropriate appraisal tools:

- Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2017), which was used to evaluate qualitative research. This appraisal consisted of 10 questions.
- Case-control study version of the CASP appraisal checklist (CASP, 2017), which was used to evaluate case-control studies. This appraisal consisted of 11 questions.
- Modified version of a survey critical appraisal tool developed from Crombie (1996) (Centre for Evidence-Based Medicine (CEBM), 2017), which was used to evaluate surveys. This appraisal consisted of 11 questions.
- CASP Systematic review checklist (CASP, 2017), which was used to evaluate systematic reviews. This appraisal consisted of 10 questions.
- Modified version of a case study critical appraisal tool, developed from Crombie (1996) (Centre for Evidence-Based Medicine, 2017), which was used to evaluate case studies. This appraisal consisted of 10 questions.

- For non-research papers, Hek and Langton's (2000) criteria were applied. This appraisal consisted of 8 questions.

Using appraisal tools, each paper was given a value based on its quality. This value was obtained by scoring responses to each appraisal tool question. For answers where the criterion was fully met a score of two was given; where it was partially met or unclear, a score of one was given; where the criterion was not met, a score of zero was given. After each paper was appraised, points were tallied. The number of questions varied for different appraisal tools, so the total number of possible points varied. The point tally was therefore converted into percentages (with scores being rounded up to whole numbers, e.g. 73.5% to 74%). At this point a protocol was developed specifically for use within this research study, as no guidance was provided in the literature on the cut-off point for poor quality literature. Aveyard (2010) stated that poor quality research may not be included in a systematic review, but provided no further guidance. A cut-off point of 50% was deemed appropriate for this review and was decided upon after reviewing and scoring all the literature. Literature scoring below 50% generally lacked sufficient details and/ or did not meet enough of the criteria for key elements (e.g. the method) to be judged to have sufficient quality to be included.

From the 72 papers screened, 20 were excluded (See Figure 5.1., page 226, for the reasons why the 20 papers were excluded). In total, 52 papers were included in the substantive literature review (see Figure 5.1. page 226). See Appendix P for full details of the 52 reviewed pieces of literature.

5.3. Summary of 52 Reviewed Literature

Most of the reviewed papers were of UK origin (33 papers). Five papers came from the USA; five papers came from the Republic of Ireland; two papers came from Australia and seven papers informed from multiple national perspectives (see Appendix P for the table of reviewed literature).

The reviewed literature comprised of 17 qualitative papers; 11 quantitative papers; eight mixed method papers; and 16 papers which were not empirical, consisting of literature reviews; a theoretical paper; guidelines; reports and discussion papers, and descriptive papers (see Appendix P for the table of reviewed literature). The year of publication ranged from 2000-2018, with the year with the most papers published being 2018 (seven papers; see Appendix Q for a table with the chronological breakdown of the numbers of papers published each year of the review).

5.4. Discussion of the Literature

The substantive literature review was used to engage in a critical conversation with previous ideas and research within the area this research study's CGT aimed to address: carers' views and experiences of supporting people with an intellectual disability and dementia, and the supportive role of a Dementia Care Pathway (DCP). Following guidance from Charmaz (2006; 2014), the substantive literature review was used to:

- Make explicit connections between this study and earlier studies
- Make claims from this research study's CGT
- Evaluate earlier studies
- Reveal the gaps in the existing knowledge and state how the CGT answered them

- Position this study and explicate its contribution.

When discussing the literature, the extent to which the concepts from this research study's CGT supported, challenged and extended extant ideas and research, as well as the extent to which the literature supported, challenged and extended the research study's findings is explored. The core category (*Impact of Dementia*) and the four underpinning categories (*Challenging the Diagnosis Process; Continuum of Support; Continuum of Understanding; and Continuity*) of the CGT were used as a framework to review the literature, and to structure the discussion of the literature (see Figure 5.2., page 231, for a visual representation of how the discussion of the literature is structured). As illustrated in Figure 5.2., *Continuum of Understanding* is not discussed under a separate heading like the other four categories of the CGT, but instead discussion of the literature relevant to this category has been carefully woven throughout the literature review. The reason for this was to ensure a coherent discussion of the literature which did not contain needless repetition. Within the literature, understanding and knowledge were discussed alongside other categories. Discussing these concepts under separate headings would have meant repeating already discussed content.

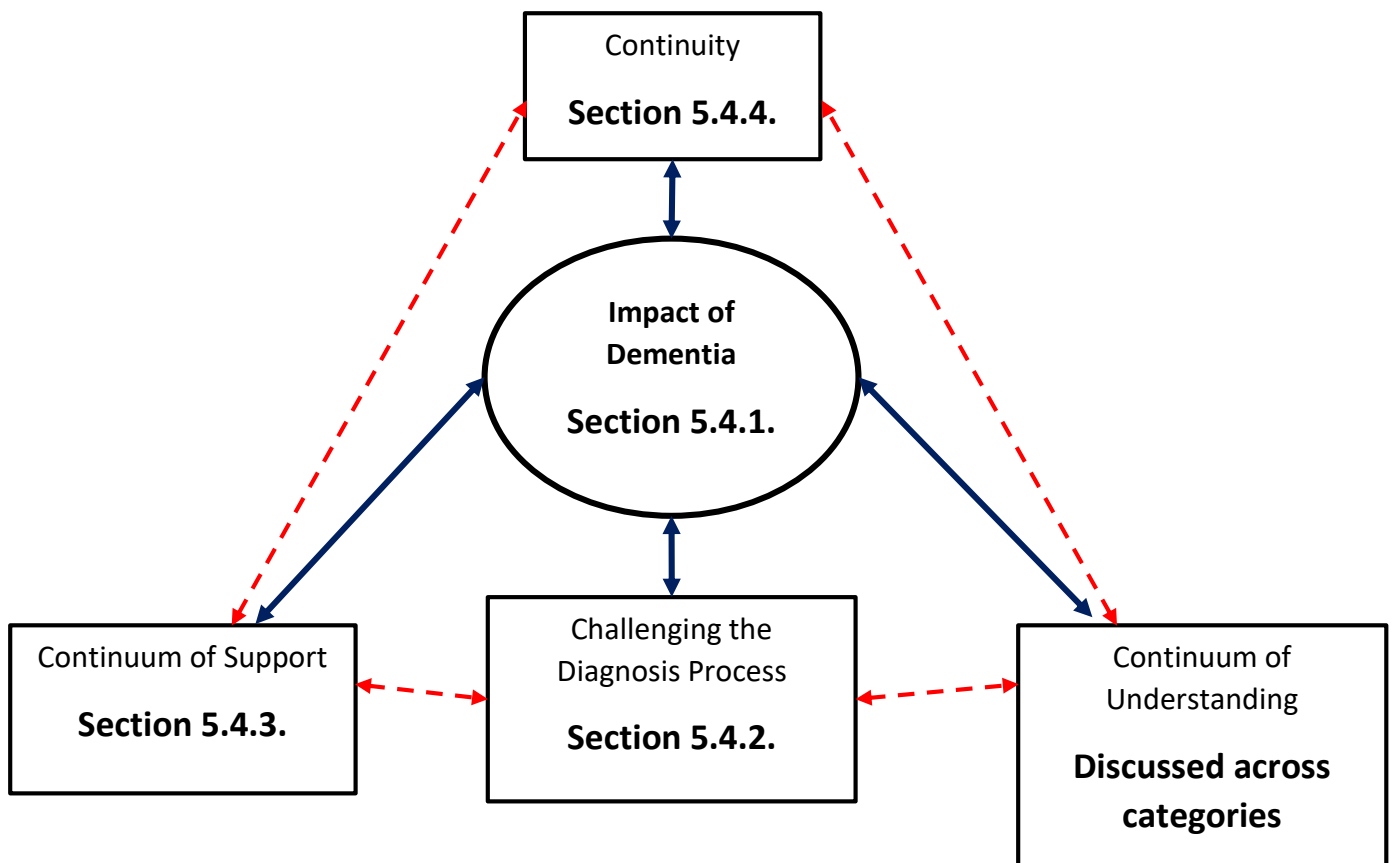


Figure 5.2. Visual Representation of the structure of discussion of the reviewed literature.

5.4.1. Core category: Impact of dementia.

The core concept of this study's CGT is the impact that the dementia has upon carers of people with an intellectual disability and dementia. As the dementia presented and worsened in the person with an intellectual disability, it was reported that they typically experienced behavioural and personality changes, and a loss of skills and ability. Consequently, this impacted upon carers, who experienced physical (increased and varied demands), emotional (sadness, loss, helplessness), and financial burden (hiring carers).

The added burden of supporting someone with an intellectual disability when dementia presented and worsened is also well documented within the reviewed literature (Cleary & Doody, 2017; Courtenay, Jokinen, & Strydom, 2010). As carers,

many of whom lack appropriate expertise in dementia and access to resources, face new and additional tasks and challenges, they experience increasing levels of burden (McLaughlin & Jones, 2010; Moore, 2012). McCarron and McCallion (2005) state that caregiver burden can be both objective and subjective. Objective burden is concerned with the observable elements of the carer's experience. Subjective burden is concerned with the carer's perceptions of the burden of care (McCarron & McCallion, 2005).

The literature search provides several survey-based papers which have illustrated caregiver burden. One indicator of objective burden is the increased amount of time spent on caregiving activities as dementia presents and worsens in the individual with an intellectual disability (Janicki, Dalton, McCallion, Baxley, & Zendell, 2005; McCarron, Gill, McCallion, & Begley, 2005; McCarron & McCallion, 2005). McCarron et al. (2005), through purposive sampling, investigated the amount of time formal carers spent supporting people with Down syndrome with (63 people) and without (61 people) Alzheimer's disease in daily activities. The authors compared staff burden using the Caregiver Activities Scale- Intellectual Disability (CAS-ID). When AD developed, staff time increased (from a mean of 2.66 hours to 8.18 hours); this was greater for people with a moderate intellectual disability compared to severe levels of intellectual disability. Staff caregiving time was similar between mid (8.40 hours) and end (7.84 hours) stage dementia; however, tasks altered significantly. At mid stage dementia, supporting behaviour and supervising eating and drinking were more time-consuming, compared to end stage where assisting with toilet use, and health-related care were more time consuming. These findings suggest the need for services, care organisations, and carers to adjust support to the dementia stage-specific care needs of the individual with an intellectual disability and dementia. The authors also found

that the presence of comorbid conditions, alongside the dementia, were associated with an increased amount of time spent providing support; highlighting the complexity of the carer's role, as they may be supporting the additional psychological, social, and medical needs which arise from the comorbidities.

Janicki, Zendall, and DeHaven's (2010) research findings, support and extend McCarron et al.'s (2005) study, showing similar findings but within family carers. 17 family carers (three supporting someone with Down syndrome and a confirmed diagnosis of dementia; one supporting someone with Down syndrome and a suspected case of dementia) were administered with the PCAD Participant Form, Modified Caregiver Index, Caregiver Burden Survey, Caregiver Concern Survey, Family Health Status Inventory, and the CAS-ID. The authors found that family carers of people with Down syndrome and dementia spend twice as many hours on support than those supporting people with Down syndrome without dementia (32.6 hours per week vs 14.2 hours per week). Like McCarron et al.'s (2005) study, this support was often greatest for people with a moderate intellectual disability impairment where there was a greater impact on abilities, as compared to people with severe impairments, whose functioning remains static. Interestingly, though engaged in increased hours on support, the authors found no degradation in carer viability, or increased health related problems associated with continued caregiving; demonstrating a resilience in what the authors call 'adaptive copers': family carers providing lifespan care at-home care.

McCallion, Nickle, and McCarron (2005) demonstrated the consistency of caregiver burden across different carer groups. The authors compared caregiver burden between 14 foster family carers and 14 staff carers across three scales: Dementia Questionnaire for Mentally Retarded Persons (DMR); Caregiver Activity Survey-Intellectual Disability (CAS-ID); and The Caregiving Difficulty Scale-ID (CDS-

ID). The results indicated that there were no significant differences for caregiver subjective burden; whilst for objective burden, only one item was significant, with staff in group homes spending more time supervising adults. Given the different living environments and the likely difference in resources available across the different settings, these findings are surprising. As proposed by the authors, the foster families' greater experience may act as a protective factor against experiences of subjective burden.

However, Lloyd, Kalsy, and Gatherer (2008) provide some contrasting evidence. Through the Caregiver Activities Scale- Intellectual disabilities (CAS-ID), the Caregiver Difficulties Scale- Intellectual Disabilities (CDS-ID), and the Maslach Burnout Inventory (MBI), the subjective and objective burden of dementia on residential carers was examined. 20 questionnaires were returned, with responses of carers of people with Down syndrome and dementia being compared with those caring for people with Down syndrome without any additional cognitive decline. In contrast to previous research (Janicki et al., 2005; McCarron et al., 2005), analysis of the CAS-ID results found no significant difference between the time spent on caregiving between both groups. However, Lloyd et al. illustrated the emotional impact of support through the MBI. Seven out of the nine carers of people with Down syndrome and dementia reported experiencing greater levels of emotional exhaustion compared with carers of people with Down syndrome without dementia; this may be somewhat surprising given that carers did not report significant differences in time spent on caregiving.

Other research has illustrated the impact which the individual's level of intellectual disability and comorbid conditions can have on both the objective and subjective burden experienced by carers. However, Lloyd et al. do not report

controlling for such factors. Consequently, their findings need to be considered with caution, as possible confounding variables have not been accounted for.

The available quantitative research offers useful insights into the objective and subjective burden experienced across carer groups. It has demonstrated the increased and changing role of paid and family carers, which is influenced by the level of intellectual disability, stage of the dementia, and comorbidities. The changing task type which presents as dementia worsens highlights a need for additional support for carers to enable them to utilise a stage-specific approach to delivering support. Nevertheless, much of this evidence is informed by small sample sizes which results in limited generalisability (Janicki et al., 2010; Lloyd et al., 2008; McCallion et al., 2005), and possible confounding variables (Lloyd et al., 2008). For instance, in Janicki et al.'s study (2010), only three of the 17 participants supported someone with a confirmed diagnosis of dementia, and one participant supported someone with a suspected diagnosis of dementia; making it difficult to judge the representativeness of the findings and preventing the generalisability of findings to the wider population of family carers of people with Down syndrome and dementia.

The reviewed literature provides a growing number of qualitative research studies, which add rich, in-depth context to the evidence provided by quantitative survey based studies. It has elucidated carer burden; highlighting the context under which this burden is experienced. For example, McLaughlin and Jones (2010) provide useful insight into how carers are negatively impacted through their supportive role. The authors carried out in-depth interviews with four sibling carers and two paid carers of people with Down syndrome and dementia. Participants had to have at least 12 months' experience of supporting the person with Down syndrome prior to noticeable deterioration in skills, and at least 6 months following the diagnosis with dementia;

therefore, excluding the views of less experienced carers. A thematic analysis indicated that carer experiences were underpinned by change. People with an intellectual disability and dementia were reported as losing their independence as the dementia worsened and they struggled with day-to-day tasks they could previously complete, resulting in increased dependency on carers. Consequently, individuals became almost unrecognisable to the carer; with carers reporting loss and adjustment. Small changes in the daily living environment (e.g. room being untidy) represented major changes in the day-to-day life of the person with dementia and their carers. McLaughlin and Jones also highlighted the importance of considering carers' informational needs, which increased as dementia worsened. Lacking the necessary information and knowledge can impact upon carers, who may not feel adequately informed to provide the necessary support to meet the needs of someone with an intellectual disability and dementia.

Carling-Jenkins, Torr, Iacono, and Bigby (2012) supported and extended McLaughlin and Jones' (2010) findings, illustrating the impact of dementia through multiple sources of burden. Data were collected through two semi-structured interviews conducted 6-12 months apart, with direct care staff (paid and unpaid carers) of three individuals with Down syndrome and Alzheimer's disease who had spent all or most of their lives living in the family home. The authors, through in-depth case studies of the three individuals, highlight examples of unpaid carers simultaneously experiencing multiple forms of burden. For instance, the emotional burden of observing the functional and cognitive decline of their child; financial burden, as they lacked funding and/ or resources; and physical burden, as they tried to manage the increasing demands of supporting their child, and their own complex medical needs.

Furniss, Loverseed, Lippold, and Dodd (2012), through a small-scale service evaluation, carried out semi-structured interviews with two family carers, three family members, and eight paid carers. Using IPA, the authors highlighted that the frequent emotional burden experienced by participants was influenced by changes in behaviour; for example, the person they cared for being uncooperative, verbally aggressive and waking through the night. Participants reported 'anticipatory grief', as they had to come to terms with the loss of the individual's skills and abilities, as well as planning for their death and funeral arrangements, thus increasing the emotional impact. However, the authors provided few details of the role of carers in this planning process, and whether they involved people with an intellectual disability and dementia.

Bromley (2014), in an unpublished thesis, extends the previous literature. Through the thematic analysis of semi-structured interviews with 12 carers (five family carers and seven paid carers), both paid and family carers discussed experiences of physical (injury) and mental health problems (stress related anxiety and depression) as the dementia presented and worsened in the person they supported; highlighting the need to ensure the health of carers is also supported in tandem with that of the people with an intellectual disability and dementia.

The qualitative research further highlights the importance of the reciprocal nature of the relationship (Bromley, 2014; Foster, 2012; McLaughlin & Jones, 2010; Moore, 2012). Moore (2012), through an unpublished thesis, used semi-structured interviews to explore the experiences of nine paid carers. An IPA analysis highlighted the participants' frustration with the loss of the reciprocal nature of their relationship with the individual they supported. Carers perceived this as the most difficult part of supporting the individual as the dementia worsened.

Foster (2012), through an unpublished thesis, further highlights the importance of this reciprocal relationship with carers. Semi-structured interviews were completed with six family carers and four paid carers and data were analysed using IPA. Foster, unlike Moore, explained that for some participants, the continued positive reciprocal nature of relationships between family carers and their family member with dementia were important to show that both the carer and individual with dementia were still there for each other. Family members reported giving their family member a lot of time and attention, but receiving little in return. In contrast to Moore, the importance of reciprocity was not reported for paid carers.

Interestingly, within her research, Foster further explicitly distinguishes family carer experiences from paid carer experiences; highlighting differences in the emotional intensity of these experiences. For instance, family carers experienced an intense sense of loss; both through their family member losing skills and personal loss when their family member did not recognise them. They felt hopeless and helpless, and felt there was nothing they could do to help. Similar to experiences reported by Furniss et al. (2012) in their study, family carers reported 'anticipatory grief' as they felt the loss of the person before they had died. Family carers had to sacrifice 'parts of their lives or future plans' (p. 74) to be there for their family member; and experienced a sense of fear of what may happen in the future. In contrast, Foster reported paid carers as discussing their challenges from an 'observer position' and having less of a personal involvement; consequently, the emotional impact was less intense than for family carers. However, in her research, Foster notes that paid carers did experience negative feelings as they saw the individual they were supporting decline.

The idea that the emotional intensity differs between family and paid carers is recognised within the literature. For instance, McCarron and McCallion (2005) state

that paid carers may have a level of protection against some of the impact of the dementia, such as depression and anxiety, as compared to family carers. This protection may be influenced by the differences in the carer groups' roles; for instance, paid carers are able to leave at the end of the shift. In support, the CGT suggests that the impact of dementia on family carers may be experienced more intensely; however, the CGT demonstrated that paid carers too experienced intense emotional burden which negatively influenced their experiences.

The reviewed qualitative literature has consistently demonstrated the multi-dimensional nature of burden for carers, which is experienced physically (Bromley, 2014; Carling-Jenkins et al., 2012; McLaughlin & Jones, 2010; Iacono et al., 2014), emotionally (Bromley, 2014; Carling-Jenkins et al., 2012; Furniss et al., 2012; McLaughlin & Jones, 2010; Iacono et al., 2014; Moore, 2012; Ryan, MacHale, & Hickey, 2018; Wilkinson, Kerr, & Cunningham, 2005) socially (Bromley, 2014; McLaughlin & Jones, 2010; Moore, 2012), and financially (Carling-Jenkins et al., 2012; Iacono et al., 2014). Much of this research has implemented methodological strategies to ensure greater trustworthiness, such as data source triangulation (Bromley, 2014; Carling-Jenkins et al., 2012; McLaughlin & Jones, 2010) and investigator triangulation (Bromley, 2014; Furniss et al., 2012; McLaughlin & Jones; Moore, 2012; Ryan et al., 2018). However, as outlined throughout, the transferability of the qualitative research is limited by a lack of quotes to support claims (Bromley, 2014), restricted selection criteria (McLaughlin & Jones, 2010), a small number of case studies (Carling-Jenkins et al), and small sample sizes (Bromley, 2014; Foster, 2012; Furniss et al, 2012; McLaughlin & Jones, 2010; Moore, 2014) that are predominately composed of paid carers (Bromley, 2014; Furniss et al., 2012); though it is recognised that studies which

apply IPA (Foster, 2012; Furniss et al., 2012; Moore, 2014) do not always aim to transfer findings but instead build a knowledge base.

Nonetheless, collectively this research has provided an evidence base which has demonstrated the negative impact of supporting someone with an intellectual disability and dementia. It has also illustrated the need for organisations and services to implement holistic supports which consider the multi-dimensional nature of burden. This is supported by the CGT which has illustrated different forms of burden which are experienced as dementia presents and worsens.

McCarron and McCallion (2005) provided a theoretical framework which helps to clarify the interrelated conditions which underpin and inform the impact of the dementia on carers. The authors adapted the Pearlin model of stress and coping (Pearlin, Mullan, Semple, & Skaff, 1990). McCarron and McCallion retained the four domains of Pearlin's model (background and contextual factors; primary and secondary strains, mediating factors, and outcomes or manifestation of stress) in their model, but introduced and removed components within each domain. For example, McCarron and McCallion introduce 'conflict with other staff' as a possible stressor within the model; whilst removing contextual factors which may not be relevant to paid carers.

Background and contextual factors, such as carer age and background, and the level of the intellectual disability of the person they are supporting, are recognised as components which influence caregiving demands and burden. A central domain of the framework and model are primary and secondary stressors. These stressors are described as 'the conditions, the experiences, and activities that are problematic for carers and are likely to generate both physical and mental fatigue' (Pearlin et al., 1990, p.586). Primary stressors are the core of the stress process, which are key instigators

of further stressors, and are likely to intensify with time. The reviewed literature, and this CGT, provide examples of primary stressors, such as observing the loss of skills, and behavioural and personality changes (McLaughlin & Jones, 2010), and an increase in the intensity of support and supervision provided (Carling-Jenkins et al., 2012), the task type and length of time taken to complete tasks (McCarron et al., 2005). Secondary stressors include 'role strains and intrapsychic strains/conflict generated by the caring process' (p, 143). A commonly cited secondary stressor within the reviewed literature and one that was present within this CGT is the role strain experienced by staff who feel unprepared or lack the necessary training, and/ or knowledge to meet the changing needs of the individual as dementia presents and worsens (McLaughlin & Jones, 2010).

A further central domain are mediating factors. Mediating factors help to explain why carers experiencing seemingly equivalent situations are impacted upon by different levels of burden. Mediating factors, such as coping strategies, the different ways carers cope with stressful events, and the availability and accessibility of social support and/ or training can elevate or compound this impact (McCarron & McCallion, 2005). The authors highlight the mediating potential of the physical environment of the home of the individual with an intellectual disability and dementia. A dementia-friendly home, which allows the individual with an intellectual disability to remain at home, can help to reduce carer stress; whilst a home without the appropriate adaptation, preventing the individual from ageing in place, can increase carer stress.

The interrelationship between these domains and their components influence the 'outcome'; which may result in psychological distress, physical illness, and/ or burnout (Bromley, 2014; Iacono et al., 2014; McLaughlin & Jones, 2010; Moore, 2012; Ryan, MacHale, & Hickey, 2018). Though McCarron and McCallion, (2005) adapt

Perlin's model to align more closely with paid carers, the domains have been applied within the family carer literature more widely (Pearlin et al., 1990) and are therefore applicable to family carers. One shortcoming of McCarron and McCallion's (2005) theoretical framework is the lack of research carried out to validate the adaptations they have made. However, the domains of the model have been validated within the wider caregiving literature (Pearlin et al., 1990).

The CGT, like McCarron and McCallion (2005) theoretical framework, illustrates how 'outcomes' are influenced by 'stressors' and 'mediators'; both explicate factors which may compound and/ or alleviator the impact of supporting someone with dementia. These interrelated factors are discussed further across the themes of the literature review.

Overall, this CGT has provided support for the reviewed literature on the impact of the dementia, illustrating the varying impact that dementia has on both paid and family carers, and how this can differ between both. Like the reviewed literature, the CGT has shown that how the worsening dementia introduced increased and varied demands, unpredictability, helplessness, loss, and negative emotions.

5.4.2. Underpinning category: Challenging the diagnosis process.

Pertinent within the CGT and widely discussed throughout the literature is the diagnosis process, and the challenges associated with providing an early diagnosis (Auty & Scior, 2008; Herron & Priest, 2013; McLaughlin & Jones, 2010; Watchman, 2003; Rowe, 2014). The literature highlights that a timely diagnosis allows for the implementation of dementia care planning, which provides a number of benefits including: allowing for the implementation of appropriate post-diagnostic support strategies and interventions for both carers and people with an intellectual disability

and dementia (Cairns, Lamb, & Smith, 2010; Chapman, Lacey, & Jervis, 2018; Watchman, 2003); providing an opportunity to implement person-centred strategies, such as advance care planning, to better understand the future care decisions and needs of the individual with an intellectual disability and dementia (Bayley, Amoako, & El-Tahir, 2017; Chapman, Lacey, & Jervis, 2018; Heller, Scott, Janicki, & Pre-summit workgroup on caregiving and intellectual/developmental disabilities, 2018; McKenzie, Metcalfe, Michie, & Murray, 2018); ending the uncertainty created by a lack of a diagnosis (McLaughlin & Jones, 2010) and improving the quality of care by providing clarity of the neuropathological conditions and ancillary factors (Janicki, 2011). However, the reviewed literature, like the CGT, has illustrated the difficulties of making an early and accurate diagnosis (Watchman, 2003; Rowe, 2014); and has explicated a manifold of challenges, considerations and variability across the diagnosis process from initiating a referral to obtaining a diagnosis, which influenced the likelihood of an early diagnosis (Auty & Scior, 2008). Section 5.4.2. discusses carer knowledge of dementia symptoms, diagnostic overshadowing, proactive screening and reactive assessments; whilst demonstrating the role of carers and DCPs within the diagnosis process.

One commonly cited challenge to initiating an early diagnosis is the lack of awareness and knowledge of dementia symptoms of those supporting people with an intellectual disability (Bromley, 2014; Herron & Priest, 2013; Iacono et al., 2014; McKenzie, Baxter, Paxton, & Murray, 2002). Research has illustrated the important role of carers' knowledge in initiating the diagnosis process and helping to ensure a timely diagnosis and appropriate post-diagnostic support (Cleary & Doody, 2017). Carers' close relationship with the individual means they are usually the first to notice dementia-related changes (Chapman et al., 2018). However, without the appropriate

knowledge, carers may mistakenly attribute dementia-related symptoms to the person's intellectual disability or other co-morbid conditions, which results in diagnostic overshadowing (Iacono, Bigby, Carling-Jenkins, & Torr, 2014); that is, where symptoms of the dementia are confused for characteristics associated with the individual's intellectual disability.

The literature, in conjunction with this CGT, illustrates that both family and paid carers commonly lack the awareness and knowledge to identify dementia-related changes. For instance, earlier research by Whitehouse, Chamberlian, and Tunna (2000) investigated the knowledge of dementia held by care staff working with older people with an intellectual disability. Each of the 21 participants completed three different questionnaires: The Facts on Ageing (FOA) Quiz (Palmore, 1977); the Dementia and Intellectual Disability (DID) Quiz (Hogg, J. unpublished data); and the Attributional Style Questionnaire (ASQ) (modified; Peterson et al, 1982); and a sample took part in a semi-structured interview investigating what behaviour carers would expect to observe in someone with dementia. Whitehouse et al. found that care staff, none of whom had received dementia training, obtained a mean score of 62% on the FOA questionnaire, indicating knowledge of ageing comparable to that of college students. Similar results were reported on the DID questionnaire with a mean score of 57%. Additionally, through semi-structured interviews, carers highlighted more noticeable and disruptive symptoms, such as forgetfulness, as the most prominent indicators of dementia; early signs, such as changes in sleeping patterns and withdrawal, were identified much less frequently. Being unable to identify the early symptoms of dementia is likely to result in a delayed referral and diagnosis.

More recently, research by Herron and Priest (2013) provided support, illustrating carers' lack of knowledge and the consequence of this. The authors

recruited 14 support workers across two research sites, all having to read three hypothetical case vignettes which depicted the progressive symptoms of dementia in the same person with an intellectual disability. After reading each vignette, the participants wrote answers to several open questions. Herron and Priest found that most participants lacked mental health training, and were unable to identify the early and intermediate indicators of dementia. They could identify the later indicators, but often incorrectly identified these as the onset of dementia. Like Whitehouse et al. (2000)'s findings, less intrusive and disruptive dementia-related changes initially went unnoticed or were wrongly attributed to the person's intellectual disability. It was not until more advanced, intrusive symptoms of dementia became present that alarms were raised. A consequence of this is a delayed referral, diagnosis, post-diagnosis support, and planning for life with dementia. Given the increased awareness and focus on dementia and the increasing contact between services and people with an intellectual disability and dementia, these findings may be somewhat surprising and concerning but illustrate a need for the ongoing commitment by services to ensure carers are dementia trained, as supported by Herron and Priest, who stressed the importance of carer training in the symptoms and trajectory of dementia.

Though both studies provide insight into paid carers' knowledge, a shortcoming of both Whitehouse et al. (2000) and Herron and Priest's (2013) studies are their small sample sizes, with Herron and Priest only recruiting participants from two sites, meaning it is difficult to transfer either set of findings beyond their contexts. Furthermore, Whitehouse et al., through their study's inclusion criteria, defined ageing individuals as those over 65 years old. This is problematic as people with an intellectual disability, specifically people with Down syndrome, may develop dementia prior to this age; consequently, excluding a proportion of carers with experience of supporting

someone with dementia and further weakening the findings' transferability. Neither of the studies explored knowledge within family carers; the differing environments of paid and family carers makes it difficult to apply these findings to the family carer population. Additionally, though both used a slightly different questionnaire format, it is recognised that how people respond to questionnaire questions may differ to how they behave in practice, illustrating a social desirability bias (Coolican, 2014).

Ryan, MacHale, and Hickey (2018), whose research explored the experiences of staff when supporting people with an intellectual disability and dementia, highlighted that poor carer awareness and knowledge is still a challenge to an early diagnosis. Data were collected through two focus groups with eight carers in each. The authors reported carer challenges of initially determining if the individual's change in behaviour could be attributed to dementia; instead considering other possible causes of behaviour changes, including ageing and mental health difficulties. A noteworthy shortcoming of this paper is that unlike other studies (e.g. McLaughlin & Jones, 2010), the participant recruitment criteria did not specify that carers needed to have supported people with an intellectual disability and dementia. This is compounded by the lack of details of whether participants have cared for someone with an intellectual disability and dementia, and whether the individual being supported had a confirmed diagnosis of dementia. Consequently, it is difficult to judge the extent to which the findings are informed by experiences of supporting someone with dementia.

McLaughlin and Jones (2010) found that family and paid carers' need for information was at its greatest in the time pre-diagnosis, as they noticed behavioural changes but were not aware of their significance. Therefore, carers did not discuss the changes with anyone else as they lacked the knowledge that they may have been caused by dementia. Consequently, a referral may be made at a more advanced stage

of dementia. Worryingly, research has illustrated that family carers were unaware of a link between Down syndrome and dementia (Carling-Jenkins et al., 2012; Furniss et al., 2012), which may contribute to them not attributing changes to dementia. Paid carers, understandably, appeared to be more aware of this link (Bromley, 2012; Furniss et al., 2012), which made them better prepared for recognising dementia related symptoms (Bromley, 2014).

The challenge of distinguishing dementia from the individual's intellectual disability is not exclusive to carers, but is also a challenge for healthcare professionals within services (Auty & Scior, 2008; Rowe, 2014). Carling-Jenkins et al.'s (2012) study showed that both families and services would commonly attribute behavioural changes to the person's Down syndrome: neglecting to consider dementia. This diagnostic overshadowing carried on even after a diagnosis of dementia was given. Consequently, this negatively impacted the individual with Down syndrome as it delayed their diagnosis, and once diagnosed, it still led to the implementation of inappropriate supports and mismanagement by both families and staff within care environments.

Supporting the literature, this CGT too illustrated the challenges which carers and to a lesser extent, healthcare professionals from the IDDCP, experienced when recognising signs of dementia and distinguishing them from the individual's intellectual disability; consequently, initiating the referral process happened when dementia had worsened. This has negative implications for planning care and person-centred strategies, such as involving people with an intellectual disability and dementia in advance care planning.

Other factors which increased the likelihood of diagnostic overshadowing occurring included: the increased severity of the individual's intellectual disability,

where there may be impaired communication and reduced ability to perform tasks independently (Herron & Priest, 2013; Rowe, 2014); an environment of over-supporting, where carers complete tasks the people they support could possibly do themselves, as the carer is not fully aware of the person's ability (Rowe, 2014); and where comorbid conditions are present (Bell, Turnbull, & Kidd, 2008; Rowe, 2014). A failure by carers and/or healthcare professionals to identify dementia early can complicate the diagnosis process (Auty & Scior, 2008), making it important to ensure they have knowledge of dementia symptoms and its progress.

Once referred and the diagnosis process initiated, further challenges may be experienced. Where individuals with an intellectual disability and dementia have impaired abilities or communication skills, which may be influenced by diagnostic overshadowing and a referral being made once the dementia has worsened, carers are likely to be relied upon by services, to access important information to make an accurate diagnosis (Rowe, 2014; Watchman, 2003). Rowe (2014) through her discussion paper, outlines the central role of carers in the diagnosis process and the challenge of collecting reliable information where there is high staff turnover or poor documentation procedures in place; this is compounded by the well-documented challenges carers have with being able to identify dementia-related changes and report these. The CGT concurred with the literature, as it captured examples of diagnostic overshadowing, which was heightened when impaired communication, co-morbid conditions and/or less disruptive symptoms were present.

Watchman (2003) too accentuates the reliance of the diagnosis process on carers, and the challenges of accessing reliable information, especially for paid carers, who in comparison to family carers, may not know the individual well or be able to access the necessary information. This central role of carers highlights the importance

of a knowledgeable, skilled workforce, and the implementation of an effective documentation protocol in the diagnosis process.

Services, such as those providing Dementia Care Pathways (DCPs), are integral to ending the uncertainty carers and people with an intellectual disability and dementia experience without a diagnosis. Well documented within the literature (Auty & Scior, 2008; Bell et al., 2008; Chapman et al., 2018; Cleary & Doody, 2017; Jervis & Prinsloo, 2007; Llewellyn, 2011; Rowe, 2014; Starkey, Bevins, & Bonell, 2014; Watchman, 2003) and increasingly used within services (Cairns et al., 2010; Chapman et al., 2018; Hobson et al. 2012; Jervis & Prinsloo, 2007; McKenzie, Metcalfe, Michie, & Murray, 2018), is the implementation of proactive baselining and screening processes (rather than reactive assessments) for people with Down syndrome, who are at risk of developing dementia at a younger age. Reactive assessments are when assessments are carried out once a referral of dementia is made to the appropriate services; when the individual is experiencing changes believed to be due to dementia. Proactive baselines and screening is when assessments are carried out prior to a dementia referral and changes associated with dementia, and repeated on a regular basis (McKenzie et al., 2018). Janicki (2011) through a framework for dementia care quality measurements in group homes, proposes that an early clinically relevant and periodic assessment is one indicator of high quality care. This is supported by Strydom, Al-Janabi, Houston, and Ridley (2016), who through a review of the intellectual disability and dementia literature, provided best practice guidelines; these included services providing proactive screening that enabled early recognition of deterioration, reduced delays in the diagnosis process, and improved outcomes (e.g. timely planning and treatment). One shortcoming of Strydom et al.'s paper is the lack of details provided on the literature search strategy and what literature was included; making it

difficult to judge the quality of the literature informing the best practice recommendations.

Proactive screening allows for the early detection and diagnosis of dementia; enabling timely planning of future support for individuals and their carers which are tailored to their changing needs (Chapman et al., 2018; Cleary & Doody, 2017; McKenzie et al., 2018; Wilkinson & Janicki, 2002). Furthermore, a proactive approach reduces the reliance placed upon carers' reporting observed changes and the challenges associated with this. However, McKenzie et al. (2018) demonstrate that proactive baselines and screening, even for people with Down syndrome who are known to have a greater risk of developing dementia, is not always implemented. The authors assessed service provision in Scotland for people with an intellectual disability and dementia, or who were at risk of developing dementia. Data were collected through an online survey of healthcare professionals across 12 intellectual disability services. Proactive baselining and screening and reactive assessments were implemented by seven services for people with Down syndrome, with five services providing reactive assessments only. For people with an intellectual disability other than Down syndrome, 11 services provided reactive assessments only; whilst only one area provided both proactive screening and reactive assessments. The authors do not provide contextual details or differences between the services, making it difficult to judge why a service implemented a reactive assessment or proactive screening; however, it is likely that resources influenced such decisions (Bayley, Amoako, & Omer El-Tahir, 2017). One shortcoming of McKenzie et al. is that only one healthcare professional from each service replied to the survey; consequently, the views and knowledge of other team members, which may have differed, were not included.

Furthermore, though a proactive baselining and screening approach is widely recommended, the reviewed literature provides few examples of empirical research that explores the use and the effectiveness of proactive baselining and screening, with most of the available evidence coming from small scale service evaluations and/or service development papers. Starkey, Bevins, and Bonell (2014) offer some supportive evidence for the use of proactive baselining and screening. The authors, through multiple assessments and a multi-disciplinary approach, provided a proactive baseline for individuals with Down syndrome known to the community learning disability team at approximately 20 years old. These individuals are then screened, from the age of 40 years, biennially, and from the age of 50 years, annually. The authors analysed all 26 case files of people with Down syndrome and dementia diagnosed between 2001-2013 to understand the effectiveness of their proactive process. In 56% of cases, concerns of dementia were raised through the screening process; whilst in 46% of cases concerns were raised in between screening. This data highlights the possible role of proactive screening in detecting dementia-related concerns for individuals with Down syndrome who were subsequently diagnosed with dementia. However, as the authors explain, since the findings were based on a small sample, no firm conclusion could be made.

More recently, in their study, Chapman, Lacey, and Jervis (2018), through one focus group with eight health and social care practitioners from a community intellectual disability service, explored the usefulness of Dementia Care Pathway (DCPs) in the screening and diagnosis process, and post-diagnosis interventions. The authors carried out an evaluation of an established specialised dementia service for people with an intellectual disability and their carers that made use of care pathways to provide services and supports. These services and supports consisted of dementia

screening, assessment and diagnosis pathway, dementia interventions pathway, training and dementia resources (e.g. dementia intervention checklist). People with Down syndrome are offered a baseline assessment between 25-30 years of age, followed by ongoing reassessment. Unlike the DCP in Starkey et al.'s (2014) research, the period between initial assessment and re-assessments was not detailed. Dementia screening and assessment pathways were reported to provide a 'common framework' and 'shared understanding' for participants which enabled an improved 'consistent, efficient, co-ordinated, multidisciplinary approach' (Chapman et al., 2018, p.38). Both the proactive screening (for people with Down syndrome), and the assessment and diagnosis pathways were reported as facilitating early detection and diagnosis of dementia; subsequently, this informed earlier intervention and made available detailed information that informed the provision of appropriate support. However, in contrast to Starkey et al. (2014), the authors provide few details of the screening and assessment process and little evidence to support this claim (e.g. statistical evidence detailing how many people were initially identified by the pathways as showing dementia-related changes, and at what stage of dementia this occurred); consequently, providing little context for the authors' claims. Furthermore, any findings from this service evaluation need to be considered with caution, as the results are informed by health and social care professionals from the DCP; meaning the findings may be influenced by participant bias.

A literature review by Llewellyn (2011) further supports the use of a proactive baseline assessments and screening process. The author's search, using six different databases (Psychinfo, Zetoc, Cinahl, Medline, Assia, and BNI) with the use of intellectual disability and dementia search terms, and an extensive amount of alternative terms for each, provided an elaborative search strategy and thorough

search of relevant literature. 170 papers published between 1996-2006, which focused on the needs of people with an intellectual disability and dementia, and their carers were reviewed by a team of academics using a proforma. Llewellyn found that the likelihood of an early diagnosis of dementia for people with an intellectual disability was compounded by a lack of established baseline information. It is likely to be more challenging to provide a definitive diagnosis of dementia without a proactive baseline assessment, taken prior to decline, to compare future assessments against. Where a definitive diagnosis cannot be given, there may be a need for longitudinal assessments, where the person is assessed multiple times over a period of time, rather than one-off assessments. This paper reported on an extensive review, which was drawn from a wide variety of alternative terms and multiple databases to increase the range and breadth of papers included.

Other literature consisted of papers which primarily described and reflected on the practicalities of developing and implementing a specialist service for proactive baselining and screening (Cairns et al., 2010; Hobson et al. 2012; Jervis & Prinsloo, 2007), and a service evaluation against set criteria (Bayley et al., 2017). These papers discussed some of the issues and considerations for implementing proactive screening services. For instance, the increased uptake of screening (Jervis & Prinsloo, 2007) and a service's ability to manage this within the available resources (Bayley et al., 2017). These papers also highlighted the need for and importance of using a multi-disciplinary approach and working across services (Bayley et al., 2017; Cairns et al., 2010; Jervis & Prinsloo, 2007; Rowe, 2014) to meet these demands and to ensure a holistic assessment. Hobson et al. (2012) reported the importance of intellectual disability and older age generic services working together to develop a proactive screening project. Reflecting on this process, the authors highlighted mutual learning between services,

and a developing relationship which enabled a 'quicker, earlier and more accurate diagnosis' (Hobson et al., p. 103).

Jervis and Prinsloo (2007) and Cairns et al. (2010), through their reflections of developing a proactive screening pathway for people with Down syndrome, illustrated additional benefits. For instance, involving carers and people with an intellectual disability within the screening process raised awareness about dementia; this was supplemented by the dementia training both services provided to carers. One shortcoming of Jervis and Prinsloo, Cairns et al., and Hobson et al.'s papers was the lack of formal evaluation of the proactive screening service and its implementation through care pathways. Most of the findings were based on informal feedback and/ or the authors' own reflections. Consequently, findings may be influenced by bias and need to be considered with caution.

In support of the literature, this CGT has highlighted a need for the implementation of a proactive baselining and screening process for people with Down syndrome, but also a proactive approach for people with an intellectual disability without Down syndrome, to provide a baseline assessment before the individual's cognitive and functional ability has been impaired by dementia. Unlike Chapman et al., Jervis and Prinsloo, and Cairns et al.'s studies, and adding to the limited literature, this CGT has explored the role of a care pathway which has utilised a reactive approach to assessment, where it was reported that individuals may have to wait more than a year after referral for a diagnosis. A consequence of this was a period of uncertainty, a lack of dementia care planning, including a delay in post-diagnostic support for people with an intellectual disability and their carer.

Bell et al. (2008), though not reporting on a DCP, do provide supporting evidence for the CGT's findings in relation to the challenges of providing a confirmed

diagnosis when a proactive screening process was not in place. Through an in-depth case study of Mr X, a 56 year old man with Down syndrome who had presented with memory problems for 6 years, they further highlighted that the diagnosis process 'is not that easy' (p.64) and illustrated many of the challenges discussed within this section. Mr X was referred for formal assessment due to observed changes by carers. Through this reactive assessment, it was thought Mr X could possibly have dementia but no confirmed diagnosis was given. However, due to not being able to conclusively confirm a diagnosis of dementia, there was a need to compare baseline functioning from the initial assessment with functioning six to 12 months later, to observe any decline, and make a precise diagnosis. Additionally, the authors demonstrated the added considerations and challenges of the diagnosis process, as although the individual was suspected of having dementia, other conditions which could mimic elements of dementia had to be ruled out. This required a high level of expertise throughout the screening process. Additionally, Mr X's severe intellectual disability and communication impairments compounded the difficulties.

The combined considerations and challenges could result in a prolonged diagnostic process. This paper also highlighted the length of time which someone with an intellectual disability may go without a referral. Mr X had presented with memory problems for nearly 6 years before a referral and assessments were delivered. As this is a descriptive case-study of the diagnosis process for one individual, and few details of the service context have been provided, it is difficult to extrapolate conclusions more widely across the relevant population and across services; however, they are likely to be common to other services.

The complexity of the diagnosis decision-making process is also compounded by having to negotiate the myriad of assessment tools and ensure those selected are

sensitive to intellectual disability (Heller et al., 2018). In their study, Auty and Scior (2008) aimed to examine the role of clinical psychologists in the dementia assessments of people with Down syndrome. A mixed method design was implemented. 64 respondents completed a questionnaire developed to capture the processes used across the assessment, consisting of closed and open questions, and Likert-scale answers. Two focus groups, consisting of five and six participants, were carried out to further explore findings from the questionnaire. The authors found that clinical psychologists reported various challenges throughout assessing people with an intellectual disability for dementia, including variations in assessment tools, a lack of accessible standardised tools, and lack of consistent informant. Participants also highlighted the need to utilise multiple dementia assessments to rule out any other possible conditions which may underline the individual's symptoms. This study used multiple methods to triangulate and better understand their findings. However, the low response rate (26%) weakens the strength of Auty and Scior's findings.

Consistent with Auty and Scior (2008), Llewellyn (2011) found that 27 different diagnosis assessments were mentioned within the literature, and that there was not one single test which was able to diagnose dementia across the varied population. The literature suggests a need to utilise multiple assessments and to include family and paid carers, as there may be poor agreement between assessment results.

Little of the reviewed literature provides evidence of how the screening and/or assessment process was experienced by carers. In her study, Foster (2014) illustrated that family carers found the diagnosis process lengthy but thorough, as it ruled out all other possibilities. It was also reported that a diagnosis provided family carers with control and the ability to use a proactive approach to care. However, the author provides no details of the diagnosis process experienced. This theme was not raised

for paid carers and no explanation as to why this difference occurred was present. Furthermore, McLaughlin and Jones (2010) found that a diagnosis ended the period of uncertainty; though again, few details of this were provided. The CGT provides some insight into how a reactive assessment process was experienced by paid carers; however, much of this understanding was reached from healthcare professional data.

Overall, the literature illuminated the importance of a timely diagnosis to start the process of planning for future needs of people with an intellectual disability and dementia, and their carers. However, it has also shown the complexity of the diagnosis process, which was underpinned by challenges and extra considerations; consequently, an early diagnosis may not always be possible. Similar findings were raised in this CGT, which demonstrated how diagnostic overshadowing, reactive assessments, impaired communication, and the sensitivity of dementia assessment tools acted to challenge the diagnosis process. Consequently, creating uncertainty for both carers and people with an intellectual disability and dementia, and delaying planning for the future care needs of people with an intellectual disability and their carers.

5.4.3. Underpinning category: Continuum of support.

A prominent feature of the CGT and the category, *Continuum of Support*, was carers' experiences of delivering support and how this changed as dementia presented and worsened. The literature too found that carers could find elements of their changing role challenging, such as being able to recognise and address pain (Cleary & Doody, 2016; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2011), support the individual's nutritional needs (Cleary & Doody, 2016; McCarron, McCallion, Fahey-

McCarthy, Connaire, & Dunn-Lane, 2010), and utilise elements of dementia care which contrasted with the ethos of care within intellectual disability services (Moore, 2014).

The reviewed literature expounds that dementia care needs to be informed by an individual, person-centred approach, which fosters and enhances the quality of life of people with an intellectual disability and dementia (Heller et al., 2018; Janicki, 2011; The Edinburgh Principles, 2002; Strydom et al. 2016; Jokinen et al., 2013). Through this person-centred approach, care should be tailored to the individual's changing needs as the dementia worsens, and help the person to live well with the dementia, ensuring they have the opportunity to engage in meaningful activities (Jokinen et al., 2013; Jokinen et al. 2018; Strydom et al. 2016;). Furthermore, support needs to consider social, physical, emotional, psychological, and spiritual care needs (Jokinen et al., 2013; McCallion et al. 2018; Strydom et al., 2016); and focus on skill maintenance rather than development of new skills (Jokinen et al., 2016; The Edinburgh Principles, 2002); whilst supporting as much autonomy as possible (Janicki, 2011). A key element of dementia care which fosters a person-centred approach is care planning. There needs to be long term care and service provision that considers and plans for the worsening impact of the dementia (Janicki, 2011; Jokinen et al., 2013; Jokinen et al, 2018; The Edinburgh Principles, 2002). Dementia care planning should be inclusive of both people with an intellectual disability and dementia, and their carers, to ensure support is proactive rather than reactive, and tailored to the wants and needs of the individual. Importantly, any planning should have people with an intellectual disability and dementia actively and meaningfully involved within the decision-making process in aspects of their care and own lives (Chapman et al., 2018; Jokinen et al., 2016). This is especially important in planning for a time when the individual with

dementia may not be able to make decisions, for instance, through advance care planning (Heller et al., 2018; Jokinen et al., 2013).

To implement a person-centred approach which supports the personhood of the individual with an intellectual disability and dementia, there is a need to ensure, where possible and wanted by the individual, they are supported to understand their diagnosis of dementia. Being provided with an accessible diagnosis, where the diagnosis is tailored to the individual's level of understanding, through a format they are familiar with, better enables the individual to be actively engaged within decisions and advance care planning. Furthermore, it allows carers to facilitate the engagement of individuals with an intellectual disability and dementia within the planning process, and draw on necessary support for themselves and the individual (Watchman, 2007; 2018). A lack of knowledge of if or how a diagnosis has been shared may act as a barrier to carers discussing care planning with the individual with an intellectual disability and dementia; consequently, a reactive approach instead of a proactive approach may be implemented (Watchman, 2007).

Little of the reviewed literature specifically explored supporting the understanding of people with an intellectual disability through their diagnosis of dementia. Nevertheless, the literature did explore whether a diagnosis was shared with the person with an intellectual disability, and to a lesser extent, how it was shared and the possible impact of a lack of a diagnosis. Watchman (2007), through a quantitative postal questionnaire, found that in 77% of the 35 returned questionnaires, people with Down syndrome were not provided with any information about the dementia-related changes they experienced, whilst only four individuals with Down syndrome in the study were given a diagnosis using the word dementia or alternative words, such as Alzheimer's disease. One reason for this, which Watchman proposed, was that those

sharing the diagnosis may have an underlying assumption that people with an intellectual disability would not have the ability to understand their diagnosis. Not sharing an accessible diagnosis can have a negative impact on the person and those around them; for instance, timely post-diagnosis support and where appropriate, medication, may not be delivered. However, the extent to which these findings can be generalised beyond this sample is difficult to judge, as conclusions were drawn from a small sample (35) and important contextual details of the individuals with an intellectual disability and dementia were not provided, such as their level of intellectual disability. As people with a more severe intellectual disability have less ability to communicate and understand information, detailing their level of intellectual disability would have provided further understanding of care provider decisions.

A lack of a shared accessible diagnosis was also explored by Watchman (2016), who reflected on two conceptual and practical issues drawn from qualitative case studies: a lack of awareness of a sense of 'self' or identity; and a lack of information about dementia being shared with the person with Down syndrome and dementia, post-diagnosis. Focusing on a lack of shared information for the diagnosis, Watchman highlighted that none of the three participants in her study had a diagnosis shared with them, and discussed the impact that this may have on the individual. For instance, one participant became more fearful as he was not getting information about his diagnosis, to better understand his experiences. The small sample size means that such findings cannot be transferred beyond these three participants, as recognised by Watchman; however, the findings do support this study's CGT, where carers and healthcare professionals gave examples of withholding a diagnosis from the individual with dementia.

Interestingly, Auty and Scior (2008) illustrated the clinical psychologists' uncertainty about how to broach and share a diagnosis, and the challenges they considered. The authors highlighted variability in whether participants explained to people with Down syndrome and dementia either the purpose of the assessment or, if found to have dementia, their diagnosis. Like research discussed in this Chapter (Watchman, 2007; 2016), people with Down syndrome were not actively included throughout their diagnosis. Auty and Scior found that they were the least likely to be told their diagnosis, with 20% of participants stating that they did not provide feedback to the client at all. Not understanding the purpose of the assessment may have implications for its accuracy; whilst not informing the individual of their diagnosis has implications for their ability, or their families and carers' ability, to actively collaborate and engaging in advance care planning. Through the focus groups, participants illustrated their struggle to approach dementia with the individual, and were unsure about whether the individual wanted to know the diagnosis or not. When dementia was discussed, most participants highlighted that instead of discussing the term dementia, they used pseudonyms or modified explanations to discuss the changes the individual had experienced. Two prominent reasons raised for this difficulty and/or reluctance to use the term dementia were: to protect the individual from unnecessary stress; and as in Watchman's (2007) findings, an assumption that the individual lacked the capacity to understand the shared information. However, more positively, 31% of respondents did indicate that they gave face-to-face and written feedback to clients, whilst adapting how this information was communicated to the individual's ability and preference.

In agreement with the literature, the CGT illustrated that many people with an intellectual disability and dementia are never provided with an accessible diagnosis; this was reported as having an impact on their understanding of the changes they

experienced. Both the literature and this CGT raised the role of others in this understanding, and their rationales for whether a diagnosis was shared. Salient in the literature and CGT was the perceived capability of the individual. Both illustrated that people with dementia had little say in whether their diagnosis was disclosed, which would act to disempower the individual. This CGT highlighted how a lack of knowledge about making a diagnosis meaningful influenced whether one was provided. Both the CGT and literature highlighted a range of shared tools and strategies which healthcare professionals and carers utilised to provide an individualised, shared diagnosis; however, these were rarely used.

Within the reviewed literature, few papers explored the support strategies implemented by carers and the philosophy which underpin these strategies. However, it was commonly reported that carers, in the absence of dementia training, felt unprepared to provide person-centred dementia support across the stages of dementia (McCarron et al., 2010; McKenzie et al., 2018). This is supported by Clearly and Doody (2016) who state that person-centred approaches are not always available to people with an intellectual disability as dementia presents and worsens.

When the support delivered by carers was discussed (usually briefly within papers and focusing on paid carers), the reviewed qualitative research illustrated that carers may experience challenges with delivering person-centred dementia care. Consequently, support may be reactive where it could be planned, and inappropriate support strategies may be used which negatively influence the personhood of the individual with an intellectual disability and dementia, and their carer (Perera & Standen, 2014; Wilkinson et al., 2005).

This is supported by McCarron, McCallion, Fahey-McCarthy, Connaire, and Dunn-Lane (2010), who carried out 13 focus group interviews with 57 paid carers

across six intellectual disability services (50 carers) and one specialist palliative care service. The authors aimed to explore the experience of staff carers in both intellectual disability and specialist care services in supporting people with an intellectual disability and advanced dementia. Paid carers reported not feeling ready to respond to the end of life needs of the person with an intellectual disability and dementia, and lacked the resources to support someone in the advanced stages of dementia. This highlighted the need for end of life training to address the carers' confidence in being able to adapt their roles to changing needs.

The challenges of implementing a person-centred approach within the advanced stages of dementia was further highlighted by Watchman (2005), who aimed to explore practitioner raised issues relating to the end-of-life care for people with intellectual disability and dementia. The author carried out interviews with 10 practitioners caring for adults with Down syndrome and dementia. Watchman found that there was a lack of future planning, and no planning had involved the individual with an intellectual disability. People with an intellectual disability were not involved in planning due to not being told they were dying and/or had dementia. This highlights the challenges of not providing important information to people with an intellectual disability about their diagnosis or the trajectory of dementia, as it could prevent discussions around future care preferences.

Though McCarron et al. (2010) aimed to explore the experiences of staff carers in both intellectual disability and specialist care services, only a small number of their participants from one palliative care service, contributed to the data, making the results less representative of staff views within palliative care services. Compounding this was the lack of transparency on which participant group/s informed the developed themes. Watchman's (2005) study had a small sample size, and like McCarron et al, only a

small sample of participants from a palliative care setting contributed to the data; again making the findings less representative of staff in palliative care services.

The carers' knowledge and understanding of dementia support influenced the appropriateness of the support strategies delivered (Clearly & Doody, 2016; McKenzie et al., 2018). Wilkinson et al. (2005) carried out interviews and focus groups across six case study sites with 10 managers, 22 direct care staff, 13 residents, and 5 relatives of people with an intellectual disability and dementia. The authors found that care staff, few of whom had prior dementia training, commonly felt uncertainty and lacked expertise to provide the best care and support. Care staff learnt as they went along, with no confirmation of whether what they were doing was correct, whilst many lacked dementia training; any experience of dementia was often obtained personally through caring for a family member. Consequently, support was reactive, with staff describing a sense of 'floundering'. The lack of reassurance may impact upon the carer's wellbeing, whilst a reactive approach would mean the appropriate support may not be received by the person with an intellectual disability and dementia.

Noteworthy were staff who received relevant, practice-based and person-centred training, had greater confidence, provided higher quality support, and reduced levels of stress. A strength of Wilkinson et al.'s (2005) research was its use of multiple key stakeholder perspectives and large sample size which provided a more holistic picture of carer experiences and ensured the findings were more easily transferable to different settings. However, this paper provides few methodological details.

Carling-Jenkins, Tor, Iacono, and Bigby (2012) illustrated that poor understanding of dementia, as demonstrated by overshadowing which continued post-diagnosis, resulted in the provision of poor or inappropriate support; this was only addressed when a crisis made professionals acknowledge that the increased support

was due to the impact of the dementia, rather than the individual's intellectual disability. It was not clear if participants had received any dementia training.

Supporting and furthering Carking-Jenkins et al.'s findings, Iacono et al. (2014) provide useful insights into the significance of carer understanding, and how this may inform the support strategies they apply. The authors illustrated the unpredictability paid carers experienced. As carers found it challenging to understand this unpredictably, they experienced varying success in the support strategies they implemented, and support was described as day-to-to-day; possibly illustrating the lack of long-term planning.

Interestingly, Iacono et al. (2014) explicate potential challenges that carers' experience when drawing on new dementia knowledge and support strategies. They found that even though many of the carers had received dementia training, their uncertainty of the underlying cause of the person's changing behaviour, influenced the appropriateness of applied support strategies. As carers attributed dementia-related changes to the individual's intellectual disability, they utilised their pre-established knowledge in intellectual disability and challenging behaviour to explain changes and to inform support strategies. As participants became more aware of the dementia, they implemented more appropriate strategies. This illustrates that even with training, carers, at least initially, need time to understand and reinforce new knowledge within practice. Importantly, Iacono et al. state that carers implemented strategies which provided comfort and reassurance for the people they supported.

Though little of the research explicitly explored person-centred care or labelled it as such, it provided examples of support strategies which are person-centred. When papers did explicitly explore or discuss person-centred support it was not always defined (Lord, 2015; Moore, 2012), sometimes making it difficult to understand the

findings of the paper. The few studies (Chapman et al., 2018; Foster, 2012) which did define person-centred care drew on the widely used definition provided by Kitwood (1997).

The literature illustrated positive examples of carers applying a person-centred approach to dementia care. McCarron et al. (2011) collected data through focus groups, field notes and reflective journals from nursing staff (34 participants), care workers (17 participants), doctors (five participants), and a social worker (one participant). The authors found that to ensure quality of care, carers would make efforts to ensure the people they supported participated in valued life activities. Participants felt it was also important to plan the care of the person with an intellectual disability and advanced dementia as early as possible, to ensure quality of life; however, no participant explicitly stated that the individual would be included in the planning process, meaning care may not reflect the individual's preferences. The use of method and data source triangulation proved a strength of this study, as it provided a rich description of experiences from multiple perspectives and methods; increasing the trustworthiness of the data.

The examples of a person-centred approach to dementia care mainly focused on carers' understanding the perspective of the person with dementia, by drawing on their pre-held knowledge of the person, and using this to inform the type of support they delivered. Foster (2012) found that both paid and family carers implemented elements of a person-centred care approach. The authors reported that family carers felt able to take into account the perspective of their family member with dementia and understand their changed behaviour; consequently, they could respond to their family member's needs in a 'thoughtful and helpful' (p.69) way to manage any difficulties. Paid carers too were reported as taking the individual's perspective and seeing the

individual rather than the dementia. However, Foster found that the quality of person-centeredness differed between family and paid carers; with it coming more naturally to family carers, whilst paid carers drew more upon their training. This highlights the usefulness of the close and long relationship family carers may have with their family member in being able to understand their perspective.

The carer's relationship with the individual played an important part in whether they could implement an individual approach. Where carers knew the person prior to the dementia, they felt able to implement a person-centred approach, where support was based on the individual's preferences (Moore, 2014). This is also demonstrated by Lord (2015), who explored the lived experiences of ten paid carers of people with an intellectual disability and dementia through semi-structured interview. Through their unpublished thesis, Lord explained the importance participants placed on the pre-existing relationship which provided them in-depth knowledge of the likes and dislikes of the person they were supporting; this knowledge enabled the participants to advocate for the person with dementia. Having knowledge of their client's idiosyncrasies enabled them to consider the finer details which they understood were important to their client previously. Interestingly, neither Moore nor Lord mention carers involving people with an intellectual disability and dementia in decisions around the type of support they receive; instead participants delivered care based on their own knowledge of the person. Within their research, Lord used an appropriate methodology (interpretative phenomenological analysis [IPA]), with an appropriate number of participants for IPA. However, as three paid carers worked with the same individual with an intellectual disability and dementia, and many of the participants worked within the same residential home and/ or organisation, findings may not reflect a wide range

of experiences of paid carers supporting different people with an intellectual disability and dementia across different settings.

Like some of the literature, this CGT drew on Kitwood's (1997) widely used definition of person-centred care which is underpinned by personhood, the Enriched Model of Dementia, the impact of Malignant Social Psychology, and taking the individual's standpoint (see Chapter 1.7.1.). Like the literature, it also found that carers attempted to utilise a person-centred approach by going into the world of the individual with dementia and understanding their perspective. Carers adapted their care and planned care around each individual's needs. However, the CGT, like the literature, also demonstrated that carers do not always involve people with an intellectual disability and dementia in the decision-making process; which contrasts with a person-centred approach. Furthermore, the unpredictability of the dementia sometimes made it difficult for carers to plan future support, which made support only reactive; consequently, support was not always appropriate and carers were stressed.

Carers may also find it challenging to implement the elements of dementia care which conflict with their philosophy of care within intellectual disability services (Moore, 2014; Watchman, 2005). In support of this, Watchman (2005) raised a possible 'care culture clash'. This occurred when there was conflict between different support models. Within intellectual disability support, care providers advocated an independent lifestyle through supporting development at a time when the individual would expect to experience a loss of skills due to the dementia and increased dependency on their carers. However, Watchman stated that unstructured development may not be beneficial for an individual experiencing dementia-related losses. At this point, an independent lifestyle may not be achievable or advisable. Instead, it may be more suitable to apply a dementia care model, which advocates methods of support for

coping with loss of abilities; whilst introducing increased dependency on structure and directive services.

Moore (2014) too highlights the difficulty some paid carers had with the change in 'culture' when dementia presented in the people they supported. Moore reports that paid carers reflected on the aim of the care they provided, which promoted independence, and ensured the individual with an intellectual disability could do everything they could do without the carer's assistance. However, when dementia presented, carers reported being distressed to see the individual lose their independence and ability to complete tasks without assistance. This loss of independence was something they felt did not fit with the 'ethos of the service' (p.74). Within the CGT, this 'culture clash' was evident through paid carers' actions and beliefs. There were examples of carers struggling with applying elements of dementia care which they felt conflicted with those used within their service; for instance, where the support was deemed age inappropriate or where following the individual's journey meant not reorienting them to reality.

A small amount of literature has also highlighted the role of Dementia Care Pathways (DCPs) in delivering support to people with an intellectual disability and dementia. This evidence highlights the use of some elements of a person-centred approach, but also the challenges services experienced with ensuring other elements. Tromans, Andrews, Wani, and Ganghadaran (2018) carried out an audit of a DCP to review the level of compliance with key standards of end of life care. The audit found low levels of compliance around advance care planning, specifically: 25% of people with an intellectual disability and dementia were involved in decision-making; 22% had their preferred place of death recorded; and 3% had their spiritual and cultural needs assessed. Again, common with previously discussed literature, people with an

intellectual disability were not actively involved in decisions around their future support. Due to this being an audit study which did not have a qualitative element embedded, it provides little understanding of why there was a low level of involvement of people with an intellectual disability and dementia in the future planning process.

Chapman, Lacey, and Jervis (2018) similarly highlighted that people with an intellectual disability and dementia were not always involved in dementia care planning, such as during reviews and in difficult discussion on end of life. This level of involvement was influenced by: the level of the individual's intellectual disability and dementia; whether the review team believed someone could understand and actively contribute within reviews; and the review location. However, elements of the care pathway and the supports it provided were viewed as maintaining independence and preserving the individual's personhood; though this paper provided few details of this.

The CGT too found that people with an intellectual disability and dementia were not always involved in important discussions and decisions, such as whether they wished to have their diagnosis shared and future planning. However, within the CGT, the IDDCP support was predominately aimed at paid carers, to shape the support they delivered and ensure this was person centred.

Both the CGT and literature have highlighted that paid and family carers are impacted upon by various forms of burden and may find it challenging to implement the appropriate person-centred dementia care. Given the central role of carers in ensuring a good quality of life for people with an intellectual disability and dementia (Wilkinson, Kerr, & Cunningham, 2005), it is important to make sure that carers' needs are also appropriately met. McCarron and McCallion (2005), within their adapted stress and coping framework, identify support as a mediating factor, which can help to alleviate caregiver burden and reduce negative outcomes, such as mental and physical

health problems. The importance of appropriate support for carers is outlined by Janicki et al. (2010), who illustrated that the impact of dementia is likely to be greater where there is a lack of support and ability to access appropriate services.

McLaughlin and Jones (2010) expound the importance of specialist health and social care professionals in understanding the varying information and support needs of both family and paid carers, to ensure timely support and information, which is provided in a person-centred manner. Further considerations are the nature of the role of the carer and the stage of the dementia (Jokinen et al., 2018; McCarron et al., 2005). As stated within the CGT core category *Impact of Dementia*, the caregiving tasks vary between the stages of dementia (McCarron et al., 2005); subsequently, so will the needs of the carer (McLaughlin & Jones, 2010). This is further supported by Jokinen et al. (2018), who proposed a support staging model for family caregiving. This model is composed of two elements. The first element consists of understanding the 'role and nature of the involvement of caregiving' (p.415); this can be either primary (direct supporting responsibilities, when the individual with dementia lives with their carer or are directly supervised by their carer) or secondary (where the individual does not live with their carer, and the carer's role is focused on 'advocacy, oversight, and planning [p.416]). The second element consists of the influence of the stage of dementia (diagnostic phase, explorative phase, adaptive phase, and closure phase). The authors provide carer factors and supports for each stage (e.g. in the adaptive stage, the need for carers to have ongoing advice for available supports and on how to ensure a dementia friendly home), which services and organisations can take into consideration when understanding and meeting the needs of carers. This model provides a framework for understanding the changing needs of family carers, and for organising and planning the appropriate supports for carers. This is important, as to

ensure carers are dementia capable, services and organisations need to be able to understand the future holistic needs of carers. However, due to the recent publication of this model, there is currently a lack of empirical research which has explored its use for carers of people with an intellectual disability and dementia.

The literature highlights and recommends that carers should have access to different forms of support. This includes services and organisations taking a person-centred approach, and providing 'psychoeducational sessions, planning and advocacy strategies, respite, and grief and loss counselling' (Jokinen et al., 2018, p. 429); support to navigate, negotiate and coordinate needed services across different sources; information on self-care strategies; information provision and signposting for carers; ensuring professionals are appropriately trained to identify and support the emotional needs of carers; and utilising varying formats to share detailed information with staff and service providers (Courtenay et al., 2010; Furniss et al., 2012; Heller et al., 2018; Jokinen et al., 2013; Strydom et al., 2016). The core category *Impact of Dementia* has illustrated burden which is experienced by both family and paid carers, making these recommendations relevant to both types of carers; however, the literature (Chapman et al., 2018; Jenkins et al. 2009; Perera & Standen, 2014) and the CGT highlight that the need to access such supports may sometimes differ between family and paid carers. For instance, the need to access support for negotiating services is likely to be greater for family carers compared to paid carers.

Interestingly, Courtenay et al. (2010) explicated the idea of needing support from multiple sources to alleviate the impact of the dementia on carers. From their review of the literature, the authors found various interventions that improved the quality of life for the person with an intellectual disability and dementia, and reduced the impact of the dementia on carers, such as the implementation of training,

education, support groups, counselling, and respite care. However, these interventions only produced significant reductions in carer burden when used in combination. This is unsurprising given the multiple forms of burden highlighted throughout the literature, as supported by the CGT. The use of multiple forms of support was not explicitly discussed within the study's CGT, although carers illustrated their use of multiple sources of support to help them better cope, and ensure the quality of life for the person with an intellectual disability and dementia.

In reality, the type and level of support received by carers may not reflect that recommended within the literature. Where supports are available, the carers' full range of caregiving needs are not always assessed (Heller et al., 2018). The type of support, the importance of support, and the variability of support can be gleaned from the small amount of available empirical evidence which has explored the experiences of paid and family carers (Bromley, 2014; Foster, 2012; McLaughlin & Jones, 2010; Moore, 2012; Perera & Standen, 2014; Ryan et al., 2018). Though little of this empirical research specifically aimed to explore the supports experienced and utilised by carers (Bromley, 2014), they have provided some understanding of support, as a mediating factor, and as something not always equally available and accessible for carers (Perera & Standen, 2014). All papers which explored the experiences of carers reported, to differing extents, the role of support and/ or lack of support. The reviewed literature, like the CGT, illustrated a continuum of support, as paid and family carers reported using informal and formal sources of support to varying degrees (Bromley, 2014; Foster, 2012; McLaughlin & Jones, 2010; Lord, 2015; Moore, 2012; Perera & Standen, 2014; Ryan et al., 2018), as well as their challenges of accessing and negotiating appropriate support, for example, through healthcare services (Perera & Standen, 2014).

Widely reported in the empirical research was the use of informal sources of supports by paid and family carers to meet their own needs and to ensure the quality of life for people with an intellectual disability and dementia. For instance, paid and family carers drew on peer support (e.g. team members [paid carers], family and friends [family carers] and support groups [family and paid carer]) to manage the additional stresses (Bromley, 2014; Foster, 2012; Ryan et al., 2018), emotional burden (Bromley, 2014; Foster, 2012; McLaughlin & Jones, 2010; Moore, 2012; Perera & Standen, 2014), and to help with practical challenges (Moore, 2012; Foster, 2012; McLaughlin & Jones, 2010; Perera & Standen, 2014). For instance, Carling-Jenkins et al. (2012) found that family carers mostly relied on other family members for support, as parents and siblings took shifts throughout the week to ensure their family member with an intellectual disability and dementia was adequately supported.

Supporting and furthering Carling-Jenkins et al.'s work, Perera and Standen (2014) explored the strategies that family and paid carers used to cope when supporting people with an intellectual disability and dementia. They carried out two focus groups with community intellectual disability nurses and nine semi-structure interviews with family and paid carers. However, it is not clear from the paper how intellectual disability nurse data has been included in the analysis and informed the findings. Nevertheless, Perera and Standen illustrated the use and importance of social support, as carers relied on others with common experiences to discuss their feelings and relieve the burden of their role, and to provide an 'extra pair of hands' when needed. However, being able to call on others was not always available to family carers; illustrating the challenges family carers may have with navigating and/or accessing needed support.

Perera and Standen's findings were drawn from a small sample and few specific details of the participants were provided. For instance, the precise number of paid and family carers was not given. This makes it difficult to judge the transferability of the findings to participant groups and different settings.

A small amount of the empirical evidence illustrates the use of formal sources of support (e.g. healthcare services) that helped to mediate caregiver burden (Foster, 2012; McLaughlin & Jones, 2010). For instance, McLaughlin and Jones (2010) stressed the importance of post-diagnosis emotional and practical support for family carers, including an increased need for support from professionals. Janicki et al. (2010) added to this, reporting that when necessary, such as when the needs of the person with the dementia become more demanding, family carers hired paid carers for extra support to help keep the person with dementia in their own home; this would help to alleviate the burden for carers.

Furthermore, Furniss et al. (2012) found that care staff received more support when the person presented with dementia; this enabled them to have a 'quicker and clearer diagnosis alongside additional information as required to meet the needs of the person' (p.324). The authors also found that all paid carers had received training and resources through the service they were evaluating; whether family carers received training was not reported. Family carers in Bromley's (2012) paper outlined the importance of having access to respite care; though few details of why this was important were provided. Of note, Perera and Standen (2014) highlighted the important role of formal supports, such as those provided by healthcare professionals, who supported carers by understanding and strengthening their existing coping strategies; to better help carers within their supportive role. A distinguishing element of paid carers' experiences, and an important source of support, was their ability to access

more senior members of the team (e.g. residential home manager and external services, such as local psychiatric services). This provided relief from stress as paid carers felt they had ease of access to these sources of support; however, this was reactive, not planned input, as it occurred when carers were faced with no other options. This source of support was not accessible to family carers. However, none of this research reported exploring the support provided by a specialised dementia service for people with an intellectual disability and dementia, and their carers.

Specialised support services, such as those offered by Dementia Care Pathways (DCPs), were highlighted as an important framework for the delivery of support for carers within the CGT. However, the literature was scant of empirical research which has explored the supportive role of DCPs for family and paid carers (Chapman et al., 2018; Jenkins et al., 2009). The quality of this limited evidence was also mixed. Jenkins et al. (2009), through semi-structured interviews with three family carers, two paid carers, one team leader, and two supported housing managers explored carers' experiences of the newly developed (at the time) DCP. Like this research study, Jenkins et al. used a grounded theory methodology; though it was not clear which form of grounded theory, and therefore what methodological strategies were applied to analysing the data. This lack of information made it difficult to understand how the grounded theory was constructed, and the philosophical underpinnings of the constructed grounded theory.

Jenkins et al. (2008) provided a descriptive account of participants' knowledge, engagement and views of the DCP. They reported that participants were generally positive about their experiences of the DCP and the services it provided. However, few reported receiving pathway review meetings, making it difficult to assess any long-term benefits. There was also a lack of clarity and knowledge of the DCP and its role.

Though training had been offered to paid carers, none had been offered to carers in a 'family' situation; though both groups of participants reported being provided either advice, literature, and/ or had contact with professionals.

As the service evaluation took place soon after the pathway had been implemented, it is difficult to truly understand the role and impact of the DCP for carers. Crucially, whilst Jenkins et al.'s (2008) grounded theory provided insight into carers' awareness of a DCP and its different components (e.g. training, access to case coordinator, and services), it does not fully explore and/ or provide details of the role of the DCP and the type of support (including the philosophical underpinning) it provided. Furthermore, it does not offer an extensive understanding of how carers' journeys are influenced by the DCP. This is compounded by Jenkins et al. (2008) not including healthcare professionals' views as data within the grounded theory; meaning less of a holistic picture was explored and poorer trustworthiness of the study.

Recently, Chapman et al. (2018) have provided further understanding of the usefulness of DCPs; illustrating their differing supportive role for carers. An important element of this pathway was a central contact point, the case co-ordinator, for carers to be able to contact for advice and support needs. It was reported that the co-ordinated service support and quick response helped paid carers to feel supported and better able to cope, alleviated feelings of anxiousness, and improved the support they delivered to people with an intellectual disability and dementia. The support offered to carers extended to dementia training for family and paid carers. Healthcare professionals reported that the training they provided improved carers' confidence and the quality of person-centred support delivered to people with an intellectual disability and dementia; though few details of what constituted 'quality' care, person-centred care, and how care was improved were reported.

It was reported that most of the training attendees were paid carers. However, paid carers could also experience barriers to accessing training, including: awareness of the training and being released to attend multiple training days. Here, Chapman et al. demonstrate the important need for services to work closely with care organisations to make training accessible. Conversely, and like other research within this review (Furniss et al., 2012), the authors reported that some family members may have found the amount of service input overwhelming; highlighting the need to tailor the support to the individual carer.

Through this empirical work, Chapman et al. (2018) have built on Jenkins et al. (2008)'s study to provide insight into the usefulness of well-established (seven years) specialised services. These processes and pathways were well-embedded within practice, with health and social care professionals having experience of utilising them within their role. This allowed for greater understanding of the role of these services and supports, as delivered through care pathways, within the support of people with an intellectual disability and dementia, and their family members and/ or paid carers. However, a shortcoming of this research is its failure to draw on different participant perspectives, such as family and paid carers, to triangulate data and provide a more holistic understanding of the role of these specialised services; this is especially important as claims, such as paid carers benefited from the provided training, are hard to substantiate and may reflect bias from the participant who may have a vested interest in the service's success. This is compounded by findings being based on a small amount of data, drawn from eight participants through only one focus group, where saturation of the data is unlikely to have been met.

The CGT, like Jenkins et al. and to a lesser extent, Chapman et al., found that family carers may not have the same level of access to support as paid carers, and not

receive the same level of support. Like Jenkins et al., within this research study paid carers, who did have access to DCP services, lacked awareness and understanding of the DCP and its role. Supporting Chapman et al., the CGT found that the DCP provided a central contact point which allowed them to express their concerns and have queries clarified. Additionally, the CGT supports Chapman et al.'s claim that the support through training was useful to carers. However, this CGT builds on the work of Jenkins et al. and Chapman et al. and adds understanding through multiple perspectives. For instance, the CGT, informed by both healthcare professionals working on the DCP and paid carers who have experienced support from the DCP, has provided insight into how the DCP focused its support on paid carers, to ensure they had the tools to provide person-centred support and ensure the quality of life of the individual with an intellectual disability; and how the DCP was utilised by paid carers, for instance, to better inform the person-centred care they delivered, but also to act as a mediating factor, which alleviated the concerns and answered the queries of paid carers.

At the other end of the category *Continuum of Support*, the CGT highlighted the challenges of accessing support and the impact of the loss of support. Similarly, the reviewed literature provides examples of a lack of support and barriers to accessing support (Janicki et al., 2010). Iacono et al. (2014), in contrast to McLaughlin and Jones (2010) and Perera and Standen (2014), illustrated that services appeared to play a limited and inconsistent supportive role in carers' experiences. They reported that carers were uncertain about the type of specialist support they may access; again, illustrating the need for support to navigate different services. Paid carers experienced varying level of success with accessing differing support from services. The authors reported a lack of a 'pattern' in the type of support received, and consistency in the

source of support, and its relationship to the stage of the dementia, Conversely, when the participants did receive informational support from professionals, where they did not agree with the advice, they did not always follow it. As Iacono et al. state, a potential outcome of this is ill-informed care that may place people with an intellectual disability at risk. However, in respect to the role of services, it is important to recognise that Iacono et al.'s study was based in Australia, where carers drew support from mainstream services; therefore, carers' experiences may be different for UK based carers, where in addition, support may be provided by intellectual disability services (Iacono et al., 2014).

Furniss et al. (2012) illustrated the uncertainty paid carers felt when deciding when to ask for support; highlighting a need for organisations and services to clarify their own role. This uncertainty may result in a delay between when support is needed and when support is requested; consequently, impacting upon carers and people with an intellectual disability and dementia. The authors also illustrated the challenges and mixed feelings that family carers and relatives experienced when supported by multiple professionals and services they had experienced. Family carers reported that the number of professionals involved was confusing and not always welcome.

Bromley (2012) supports and extends Furniss et al.'s (2012) findings, illustrating the barriers family carers experience in accessing support from services, including not being aware of services. However, Bromley illustrates how family carers' utilisation of services can be influenced by previous negative experiences. For instance, previous negative experiences of respite care made family carers more cautious of the service; whilst past experiences of support being unavailable meant family carers had a low expectation for supports being available in the present. These findings highlight that barriers to accessing support may sometimes be informed by the carers' views, and

the need for organisations and services to break down the negative views which carers may hold.

What can be gleaned from the collective evidence, is that family and paid carers have access, to varying degrees, to different forms of formal and informal sources of support; this support, when available, helps carers to both cope with the added burden, and better ensure the quality of life for people with an intellectual disability. However, support to meet the carers' holistic needs is not always in place, illustrating a lack of forward planning and/or adequate navigational support by organisations and services; family carers experience greater barriers to accessing and utilising support from these sources. Nevertheless, as highlighted throughout this Chapter, much of the reviewed research contains small samples of family carers, making it difficult to judge whether similar experiences would be experienced within larger samples.

Like the literature, the CGT has found that paid and family carers used formal and informal sources of support. Family carers predominately utilised support from other family members; though when their supportive role became too much, they hired paid carers. In contrast, paid carers had access to a range of supports, including fellow carers, care home management, and healthcare professionals as part of an Intellectual Disability Dementia Care Pathway (IDDCP). This support acted as a mediating factor which not only helped to elevate their negative feelings, it also better enabled them to deliver support. Furthermore, the CGT too highlighted negative experiences for both family and paid carers, who either lost essential support or could not access needed support.

Training was recognised as an important form of support for carers, which could act as a mediating factor, to alleviate the stress of the carer's role, but also improve the person-centred support they delivered (Heller et al., 2018; Jokinen et al., 2013;

Strydom et al., 2016). As part of the planning process, it is necessary to ensure carers are dementia capable, through appropriately tailored training which develops their skill set, and ensures they are knowledgeable and competent within person-centred dementia care. This is further illustrated by Janicki (2011), who includes 'quality training' and the degree to which paid carers feel able to apply this training, as a measure of quality care in group homes. Where carers received relevant, practice-based and person-centred training, they had greater confidence, provided higher quality support, and reduced levels of stress (Dicks, Jackson, Pasokhy, Catty, & Symes, 2015; Wilkinson et al. 2005); importantly, the literature highlights that the right training can address the previously mentioned challenges carers experience with implementing person-centred dementia care.

Kalsy, Heath, Adams, and Oliver (2007) examined the effects of a one day training session in ageing, dementia and people with intellectual disabilities on the controllability and optimism for change in behavioural deficits and excesses. 97 care staff from community day centres for adults with intellectual disabilities completed, pre and post training, an attribution questionnaire, the knowledge quiz and optimism scales (Dagnan, Grant, McDonnell, 2004; McCallion & Janicki, 2002). The authors found improved knowledge of ageing and dementia from pre to post-training, and a greater understanding that the person's changing behaviour was not always in their control. However, it is not clear within this paper what point post-training assessments took place. The timing is important, as long-term follow up instead of or in addition to immediate assessments would better indicate information retention and changes in thought process. Furthermore, such assessments do not illustrate changes in practice.

Supporting the important role of training in carer understanding, Dicks et al. (2015) in a small-scale study, developed and assessed a bespoke training workshop

for 17 paid carers across three staff teams. The training lasted four hours and focused on a person-centred approach to support. Key elements of the training included: the nature of dementia, communication, drinking and eating, the environment, engagement in activities, and support services. Paid carers completed a questionnaire specifically designed for this study, at both pre and post-training. The results highlighted increased confidence and understanding of the individual with an intellectual disability and dementia. However, any findings based on this training need to be considered with caution. The effect of this training on the delivery of person-centred support and the long terms effect of this training were not measured. Furthermore, the findings could be influenced by demand characteristics as paid carers completed the questionnaire at the training site, where the training provider was present.

Iacono et al. (2014) highlight the importance of the training being specific to people with an intellectual disability. Unlike Kalsy et al.'s and Dicks et al.'s research, staff carers were provided generic dementia care training by Alzheimer's Australia. Staff carers reported mixed feelings about the dementia training provided, with some participants believing that the training needed to be more specific to the needs of people with an intellectual disability.

Within the CGT, training was a central form of support for paid carers, which improved their knowledge and understanding of dementia, and better enabled them to apply the appropriate support strategies in a person-centred manner. However, training was not equally accessible, with family carers illustrating the lack of access to training and information.

5.4.4. Underpinning category: Continuity.

Within this study's CGT and throughout the literature, the accommodation of people with an intellectual disability and dementia was recognised as an important feature in maintaining personhood and a good quality of life for the individual. Within the literature, accommodation was discussed through three models of support: 'ageing in place'; 'in place progression'; and 'referral out' (Courtenay et al., 2010; Watchman, 2008). 'Ageing in place' is where care and support is adapted to the individual's changing needs within their home. 'In place progression' is where the person is provided with a 'range of accommodation options and support in a specialised setting' (Watchman, 2008, p. 65). A 'referral out' is where the person receives care and support from an alternative service; this means moving the individual into a generic social care facility or a nursing led facility (Watchman, 2008).

A common theme throughout the literature is the need to ensure people with an intellectual disability and dementia can remain in their home, under the principles of 'ageing in place', for as long as possible (Chapman et al., 2017; Strydom et al., 2016). Guidelines and recommendations (Jokinen et al., 2013; The Edinburgh Principles, 2002; Strydom et al., 2016) support this, and advocate the implementation of planning, supports, and services which increase the likelihood of people with an intellectual disability and dementia remaining in their chosen home. Furthermore, the literature expounds 'ageing in place' as the preferred model of support for both healthcare professionals and carers. Supporting people with an intellectual disability and dementia in their home under the systems and supports of 'ageing in place', until end-of-life, could help to maintain the personhood, quality of life, wellbeing, and independence of people with an intellectual disability and dementia (Jokinen et al., 2013; Strydom et al. 2016); whilst mediating the negative impact on carers, as they feel a sense of pride in

maintaining the individual's home (Iacono et al., 2014; McCarron & McCallion, 2005; Wilkinson et al., 2005).

There was a concern that moving the person with an intellectual disability and dementia out of their home and into other settings, predominately an aged/ older person care setting, would have a detrimental impact on their quality of life (Chapman et al., 2017; Furniss et al., 2012; Iacono et al., 2014; Janicki et al., 2010; Watchman, 2005). Aged/ older person care settings may not be able to meet the holistic needs of people with intellectual disabilities, for instance, for someone with Down syndrome who may develop dementia in their 40s or 50s, and be younger than other individuals within the setting (Watchman, 2003). Underpinning these concerns was the perceived inability and lack of suitability of staff and organisations outside the individual's care and intellectual disability services to provide the same necessary interaction and support which they received in their current setting. For instance, Iacono et al. (2014) found that care staff felt a sense of responsibility for maintaining the person in their home and doubted that others, within different settings such as residential care for older people, would provide the same, necessary support and care; an attitude influenced by previous negative experiences of people they supported moving into aged care. Participants felt that staff in such settings lacked disability-specific training and consequently, understanding. They believed that aged care settings did not have the appropriate staffing ratios and did not provide the necessary type of support, compared to group homes for people with an intellectual disability.

Supporting this, Watchman (2005) found that although carers believed that the living environment of group homes was not appropriate for people with Down syndrome and dementia, they also believed that the same quality of care would not be provided within other care settings, as the staff would not have the same level of

familiarity and understanding of the person. Both Iacono and Watchman illustrate the carers' belief that the individual needs continuity in their support, which is best provided by those who have prior knowledge of the individual and their needs.

Like the literature, the CGT found that participants had a strong commitment to supporting the individual in their home for as long as possible. Carers too were concerned about the detrimental impact of moving the individual from their familiar environment and supports, to other settings which the person was not familiar with and where those providing support were not familiar with the individual; this was believed to compound the impact of the dementia for the individual with an intellectual disability.

The successful implementation of an 'ageing in place' model requires care providers, including services, organisations, and their employees, to consider multiple factors. Collectively, the literature highlighted the need for a proactive, planned approach across care providers. There is a need to understand the positive or negative impact of the individual's living environment, and how functional modifications can be implemented to make it dementia friendly and better ensure the individual's wellbeing (Janicki, 2011; Strydom et al., 2016). This is particularly important, as supporting the needs of someone with dementia is relevantly new within intellectual disability services, so older homes are unlikely to be 'dementia capable'. Janicki (2011) states that there is a need to understand the trajectory of decline when dementia is present, and use this understanding to care plan and consider present and future modifications to meet the individual's changing needs. Any plans which promote a 'dementia capable' home also require meeting the present and future needs of carers (Watchman et al., 2017). As illustrated throughout this literature review, carers may not necessarily have the knowledge or skills to ensure a home for life; consequently, they need access to the necessary tools, supports and resources to ensure their needs are met and they are

able to provide person-centred dementia care (Jokinen et al., 2013; Janicki, 2011; Watchman et al., 2017). Adding to this, Courtenay et al. (2010) state that ensuring 'ageing in place' requires an early diagnosis and specialised care.

Carers are a central component to ensuring the 'ageing in place' process, and show a strong commitment to achieving 'ageing in place' (Furniss et al., 2012; Iacono et al., 2014; Janicki, 2011; Janicki et al., 2010; Llewellyn, 2011; Watchman, 2005). A small number of papers outlined the different strategies carers implemented, such as making modifications to the physical environment of the home, in their attempts to maintain 'ageing in place' to ensure the quality of life of the individual with an intellectual disability and dementia (Courtenay et al., 2010; Furniss et al., 2012; Janicki et al., 2010). However, it was recognised that sometimes it was not 'ageing in place' but instead 'staying at home': where the accommodation remained the same, but did not apply the principles of 'ageing in place' (Watchman, 2008). Furniss et al. (2012) found that family carers, family members, and paid carers changed and adapted to meet the person's individual needs, to ensure a home for them; for example, they worked extra hours, implemented more staffing, or more overt support for each other.

Janicki et al. (2010) found that to keep adults with an intellectual disability in their family home, parents would take steps such as seeking healthcare professional interventions, as well as personal care assistance, or help from a sibling. In addition, parents would look for guidance from carers, or 'try to cope and deal with things as they come' (p.399). Adaptations to the person's living environment were also implemented to ensure they could remain in their home for as long as possible. For instance, some participants made changes to their adult child's personal space in their home, for example, by moving their bedroom downstairs and installing a disability-accessible bathroom or improved access to the home.

Ryan et al. (2018) highlighted the importance of future planning modifications to make the living environment dementia friendly as early as possible. Within their study, paid carers raised concerns about the lack of forward planning when changing the individual's living environment. The individual with dementia had to cope with sudden changes, which removed familiarity and routine from their environment.

Though strategies were implemented to increase the likelihood of the individual with an intellectual disability and dementia remaining at home, when dementia presented and worsened, and the 'tipping point' (Janicki, 2011, p.767) was reached, alternative accommodation had to be considered. In many cases, this was to ensure the individual's safety and quality of life. Many factors influenced whether the person remained in their home or was moved to a different setting (Janicki et al., 2010; Watchman, 2005). For instance, Janicki et al. (2010) found that when considering whether the person could continue to live in their family home, their parents' decisions were influenced by their ability to continually provide support over time, the increased impact of medical needs of their adult child, and the impact of the deterioration in their own health. In addition, other influencing factors were how their adult child reacted to adaptations in their home environment, the added demands of safety issues, how much support the family member received from other family members, access to services which enabled them to meet their child's increasing needs, and whether there were other recipients of support and care within the house and their support needs too. Watchman (2005) found that a paid carer's decision to move the person to a new environment also depended on the impact on other housemates.

A small number of papers also explained the challenges and barriers of implementing and maintaining 'ageing in place'. An underlining issue was the lack of forward planning to address the future needs of people with an intellectual disability

and dementia. Modifications to ensure a dementia capable environment, including ensuring carers were dementia capable, were generally reactive; this is in contrast to person-centred dementia care which advocates a proactive approach. This is illustrated by Wilkinson et al. (2005), who found that organisations' attention to the environment was limited, with the environment being perceived by the researchers to be 'positively disabling' (p.395) to individuals with an intellectual disability and dementia. However, the authors illustrated the importance of training, as paid carers who had received training in relation to the environment were able to make dementia friendly modifications.

Iacono et al. (2014) found that paid carers felt a sense of inevitability in the person with an intellectual disability and dementia being moved to aged care/ older person care settings. Paid carers questioned their employer's commitment and preparedness, for instance, to provide sufficient resources, employ additional staff, or to implement the necessary structural adjustments to enable the person to remain in their home.

Similarly, Furniss et al. (2012) found that participants were concerned about the future; in particular, the appropriateness of the person's current physical environment, and the available resources provided by employers to ensure appropriate support and training to meet the individual's needs. Additionally, Janicki (2011) identified that a lack of an appropriate philosophy of care by care managers, and the individual's needs being greater than the care provider's capacity to continue to provide support and care, could result in the person being referred to a different living setting.

The challenges with implementing and sustaining 'ageing in place' are also seen within advanced dementia. McCarron et al. (2010) highlighted that intellectual disability services were not prepared to provide support that meets the increasing support needs

of people with an intellectual disability at the end stage of dementia. The authors found that services did not provide suitable environments or adequately prepare paid carers. Though the different intellectual disability sites generally supported 'ageing in place', this was difficult to maintain with advanced dementia which required greater assistive environments. Paid carers described the challenges of providing care with 'comfort or with safety' (p.292) in the individual's own home, which was compounded by inappropriate staff ratios to ensure the needs of the individual with dementia were met.

The poor future planning of appropriate staff skill mix is supported by McCarron et al. (2011), who reported that participants (predominately composed of nursing staff and paid carers) did not have the skills or support to provide optimal end-of-life care. Consequently, individuals were transferred to an acute hospital and died in the hospital.

As illustrated within the category *Continuum of Support*, a core tenet of a person-centred approach is the inclusion of people with an intellectual disability and dementia in the decision-making process; this includes decisions around where the individual wishes to live. Watchman (2008), through a predominately closed-question postal question which was sent out to 45 members of Down Syndrome Scotland, found that in only four cases, from the 35 questionnaires returned by family and paid carers, was 'ageing in place' observed. This was dependent on having a bedroom on the ground floor which could be adapted, as well as having sufficient staffing levels to enable a move within the same intellectual disability environment. Adversely, Watchman illustrated missed opportunities to involve people with Down syndrome and dementia in advance care planning, as discussion about future accommodation was not carried out in the early stages of dementia. Only three out of 16 people were included in discussions prior to moving. The underpinning reasons were the person's

inability to communicate or to participate in meetings. Not involving people in discussions of advance care planning, and specifically around where they want to live in the future, highlights poor adherence to person-centred care, which advocates early planning and the active participation of the individual with dementia. Though providing valuable information, the use of a predominately closed-question questionnaire does not provide the richness and understanding of other more qualitative formats, such as interviews. For instance, Watchman highlights how some respondents did not provide an answer for some questions; there could be multiple reasons for this which could not be explored.

The CGT largely agreed with the literature, as both revealed a strong commitment by paid and family carers in maintaining the home of the person with an intellectual disability and dementia, and a willingness to implement many of the same strategies to ensure this. Both illustrated carers' concerns that others could not provide the same, necessary support, especially accommodation and staff outside intellectual disability services. In addition, both demonstrated underlying reasons for moving someone out of their home and into new accommodation, as well as strategies to ensure 'ageing in place'. Furthermore, both the literature and CGT illustrated the importance and lack of future planning to ensure a dementia capable and friendly environment, including the need for timely adaptations to the environment and ensuring the needs of carers are met. In contrast to a person-centred approach, both the CGT and the literature also demonstrated that people with an intellectual disability and dementia have little say in their current and future accommodation: again, disempowering the individuals.

Service provision was a key factor discussed by carers and healthcare professionals in the support of people with an intellectual disability and dementia.

Within the study's CGT, continuity of the service provider enabled continuity in support, delivered by healthcare professionals and carers with an understanding of the individual, and their intellectual disability needs. The CGT illustrated how intellectual disability services could better enable a fulfilling quality of life.

Prominent throughout the literature were discussions around service provision. Little of this literature specifically states which services should be the main provider of services for people with an intellectual disability and/ or their carers; however, what can be gleaned from the literature is a need for intellectual disability services to have input in the support. Llewellyn (2011) highlighted that intellectual disability services should be the main service provider for people with an intellectual disability and dementia; though, the consensus is that people with an intellectual disability should have the same access to specialist dementia services as those without an intellectual disability (Llewellyn, 2011; Watchman, 2003). However, the evidence illuminates potential challenges that intellectual disability services may experience with supporting the individual's dementia needs. For instance, clinical psychologists believed that intellectual disability services lacked the appropriate resources, and were not designed to meet the needs of older people (Auty & Scior, 2008). Unlike older people's services in the general population, intellectual disability services were sometimes viewed as being fragmented, inappropriate, and lacking a consistent strategy for assessment and intervention. This highlighted the need to work collaboratively, to ensure the most appropriate support and expertise are received. Interestingly, participants believed that the specialist skills required to address the individual's dementia-related changes were present within intellectual disability teams and could be developed.

Like the literature, the CGT highlighted the important need for intellectual disability services to maintain their supportive role; specifically, there was a need for

specialised dementia services from within intellectual disability services which understood and could meet the individual's intellectual disability and dementia needs. The CGT somewhat contrasted with Auty and Scior (2008), as intellectual disability services, through the DCP, were viewed as appropriate and important in meeting the needs of people with an intellectual disability and dementia. This difference may be due to the specialised nature of the pathway, which consisted of intellectual disability healthcare professionals trained in the dementia assessment process. This difference also illustrated the strength of DCPs; which brought services and healthcare professionals together, within a multidisciplinary team, guided by a centralised, specialised framework. In support of Auty and Scior, this CGT has highlighted a belief that intellectual disability staff already have the skills and ethos to support the needs of someone when dementia presents.

A consistent theme across the literature, like the study's CGT, is the important need for collaboration between different healthcare professions and services. Across the severity range of dementia, it was important for input from a multidisciplinary team, to ensure a timely diagnosis and that the needs of people with an intellectual disability, where possible within their own home, and their carers, were met (Cairns, Lamb, & Smith, 2010; Chapman, Lacey, & Jervis, 2018; Hobson et al., 2012; Jervis & Prinsloo, 2007; McCarron et al. 2011; Watchman, 2005). Where intellectual disability services lacked the knowledge and/ or resources to meet the individual's dementia needs, there was a clear need for collaboration with other services which addressed these gaps in expertise and resources (Watchman et al., 2017; McCarron et al. 2011). However, within any collaboration, the active input of intellectual disability services was viewed as a necessity, as generic services did not have the expertise and experience to support the individual's intellectual disability needs (Llewellyn, 2011)

The Edinburgh Principles (2002) and its accompanying guidelines and recommendations illustrate the importance of clearly defining who holds responsibility and which services are accountable for the support and care of an individual with an intellectual disability who presents with dementia. The principles recommend collaboration between services to meet the individual's changing needs, but recognise the challenges of achieving this, such as the diversity of terminology used within and between intellectual disability and older adult systems.

The need for collaboration was supported by Rowe (2014), who highlighted the importance of collaboration between GPs, who may not have much experience with people with an intellectual disability, and intellectual disability practitioners who would bring a vast amount of experience, when screening for dementia for people with an intellectual disability. Professionals from generic and intellectual disability services could bring their separate expertise together to ensure a thorough and speedy diagnosis. Watchman (2003), throughout a discussion paper around critical issues with the support of people with Down syndrome and dementia, amongst other things, also stressed the importance of co-ordination and a multi-disciplinary approach between services. This approach was important to ensure appropriate support for people with an intellectual disability and dementia and their carers; for instance, to better ensure an early and accurate diagnosis of dementia.

Iacono et al. (2014) introduces the need for input from services trusted by paid carers within any collaboration. Whether paid carers adapted their support to the needs of people with an intellectual disability and dementia relied upon input from services which paid carers trusted. The authors argued that such trust may only be obtained through close collaboration between intellectual disability services and dementia services which would provide quality support. Iacono et al. recommend that any

collaborations need to reassure paid carers that dementia services understand the needs of people with an intellectual disability, and which would provide opportunities for training and support from healthcare professionals who have expertise in both intellectual disability and dementia. The benefits of this could be a greater ability to maintain the individual in their home, as well as greater levels of planned supports and transitions to needed care, such as end of life services, and a greater preparedness of paid carers to meet the individual's changing needs.

Collaboration was deemed essential to ensure quality support across the journey of dementia. This was particularly evident in the diagnosis process (Cairns, Lamb, & Smith, 2010; Chapman, Lacey, & Jervis, 2018; Hobson et al., 2012; Jervis & Prinsloo, 2007) and end-of-life care (McCarron et al. 2011; Watchman, 2005), where healthcare professionals, carers and intellectual disability services may lack knowledge, experience, and/or resources to meet the needs of people with an intellectual disability. For instance, collaborative practices between intellectual disability and adult mental health services enabled a timely and more accurate diagnosis of dementia for people with an intellectual disability (Hobson et al., 2012). Such collaborative practices were also important with Dementia Care Pathways for people with an intellectual disability. Working with generic services helped to support a robust follow-up process, which enabled people with an intellectual disability to access specialist services that people without an intellectual disability could access (Jervis & Prinsloo, 2007). Greater collaborative working also helped to develop working relationships with services that are central to dementia support but which people with an intellectual disability may previously have had little access to (Cairns et al, 2010).

McCarron et al. (2011) highlighted how participants felt early collaboration between intellectual disability services and specialist palliative care services may have

improved decisions, whilst helping to capitalise on each other's expertise. This was important, as the authors found that specialist palliative care staff experienced difficulties in communicating with people with an intellectual disability and understanding their support needs, understanding dementia, and the intellectual disability service structures. In contrast, participants from intellectual disability services commonly lacked the necessary knowledge and specific skills for end-of-life care, which resulted in anxiety in providing support through death. Consequently, McCarron et al. recommend increased collaboration between services, including opportunities for cross training, as well as a need to understand when and how to involve specialist palliative care input.

Watchman (2005) raised issues around a lack of collaboration between intellectual disability services and palliative care services in the support of people with an intellectual disability and dementia in need of end-of-life care. A consequence of this was that participants working in intellectual disability services were unaware of palliative care services available to them; whilst participants from palliative care services described the difficulties of caring for people with an intellectual disability and dementia.

Ultimately, collaboration between services served as a core underpinning to meeting the needs of people with an intellectual disability and dementia and to a lesser extent, their carers. There is a need for any collaborative working to consider both the individual's intellectual disability and dementia needs. Like the literature, the CGT illustrated the importance of collaboration, to bring together expertise from intellectual disability and dementia services, whilst ensuring access to services: preventing isolation within one service, where the individual's needs may not be appropriately met. Like Chapman et al., the DCP within this CGT provided continuity in support, and

maintained important input from intellectual disability services. The DCP's specialised knowledge and expertise within dementia also meant the individual's dementia needs were met; for instance, by providing training and support to carers. However, as illustrated through the literature, there was still a need to work in both multi and interdisciplinary ways, to ensure the necessary resources were available, such as working with the memory clinic within generic services to provide a timely diagnosis.

5.5. Summary

This Chapter has provided a critical review of the substantive literature; highlighting the quality of the available literature and areas where this CGT has contributed to further understanding. This Chapter has provided an account of the extent to which the concepts of this study's CGT were found throughout the substantive literature review. Through this Chapter, it has been shown that the previous literature supports much of the CGT, raising similar themes as the CGT's concepts. It has also demonstrated how this CGT has extended knowledge within intellectual disability and dementia; contributing original findings. For instance, it has provided new depth to findings in the literature, increasing understanding of DCPs as a framework for planning and delivering support and services. This empirical study has drawn on multiple perspectives and provided original findings, including how DCPs acts as a mediating factor, alleviating the impact of dementia upon paid carers. A further original finding is the implications of the IDDCP using a reactive assessment approach and not also implementing a proactive screening process, where baseline assessments are carried out prior to a dementia referral and changes associated with dementia, and repeated on a regular basis are. When dementia could not be confirmed or ruled out, the IDDCPs use of a reactive assessment, which meant baseline assessments were carried out

once a referral was made, created a period of uncertainty and delayed planning for the future support of carers and people with an intellectual disability. However, it must be noted that after data collection, the IDDCP was moving towards a proactive screening approach. Furthermore, no other study within the reviewed literature explored the experiences of engaging with a DCP, and the role of an established DCP in the planning and delivery of support from the perspective of both carers and healthcare professionals. This unique CGT has helped to better understand the experiences and views of carers and the role of DCPs. Chapter Six will present the critical discussion of the CGT and research study.

Chapter Six: Discussion

6.1. Introduction

The primary foci of this Chapter are to critically discuss this research study and the findings through its Constructivist Grounded Theory (CGT), and to demonstrate its unique contributions. To achieve this, Chapter Six starts with an overview of the study; reminding the reader of the aims and questions set out in Chapter 1. 11., alongside the methodology and methods used to achieve both. The CGT categories and key findings are consolidated and integrated in a meaningful manner to illustrate and critically reflect upon how they contribute to answering each research question.

This research study has provided unique theoretical, methodological, and empirical contributions; these contributions are critically explored and how they have furthered the intellectual disability and dementia field is explained. This study was meticulously planned to offer a piece of research which contributed an understanding of experiences; this has provided several strengths. However, like all research, this study has weakness; these have centred on the challenges experienced with recruitment. Chapter Six explicates the strengths and weakness of this study, before suggesting how the latter can be overcome in future research, as well as ideas for future research topics to build on the CGT. Recommendations, informed by this thesis (both the findings and explored literature), are outlined, before ending this Chapter with reflections and conclusions.

6.2. Overview of the Study

There is a growing awareness that people with intellectual disabilities are living longer, and consequently developing age related mental health problems, such as dementia.

Dementia is seldom experienced in isolation; it affects the family, family carers and paid carers; hence, new and significant challenges will be experienced by families, support staff and services (Watchman, 2014). Although there is an increasing amount of research exploring these experiences, there is a limited amount of qualitative empirical understanding of the support needs of carers, the support structures and strategies carers draw upon, and how these inform the support they deliver to meet the person's changing needs.

The use of a multi-disciplinary approach is advocated to providing services to support carers in their role with people with an intellectual disability and dementia throughout their journey. One recommended framework for planning and delivering services and supports is the Dementia Care Pathway (DCP). However, though DCPs are widely implemented, little empirical evidence has explored their role in supporting carers and the people or family members they support; furthermore, the quality of the available evidence is mixed. Therefore, this research aimed to:

1. Explore family and paid carers' experiences of supporting someone with an intellectual disability and dementia.
2. Explore the role of healthcare professionals and support systems, with a focus on one Intellectual Disability Dementia Care Pathway (IDDCP) in the support of carers and people with an intellectual disability and dementia.

Three primary research questions were identified:

- 1) How do family and/or paid carers view and experience supporting someone with an intellectual disability and dementia?
- 2) What support systems and strategies are in place for carers, and how do these strategies contribute to support for carers?

3) What is the role of an Intellectual Disability Dementia Care Pathway, and its healthcare professionals, in the support of carers and people with an intellectual disability and dementia?

To systematically address these research aims and questions, a qualitative methodology was applied through CGT, with data being collected through semi-structured interviews. This methodology was used to explore the experiences of multiple participant groups, consisting of family carers ($n=2$), paid carers ($n=8$), and healthcare professionals ($n=8$). Data source triangulation was thus used to construct a CGT which provided an understanding of the research aims.

6.3. Discussion of the Research Questions

Within this section, the CGT's categories and components are consolidated and integrated in a meaningful manner to illustrate how they have addressed the research aims and questions. It is important to note that the extent to which all research questions have been answered has been influenced by the small number of family carers recruited, and the lack of theoretical saturation with this participant group. As recognised and further discussed in sections 6.5. and 6.6., this means that any understanding offered by the CGT, in relation to family carers, has not fully addressed the research aims and answered the research questions.

6.3.1. Question 1: How do family and/or paid carers view and experience supporting someone with an intellectual disability and dementia?

This is the first empirical study to have applied CGT to develop an interpretive theory of how dementia is experienced by paid and family carers and the role of an

IDDCP in this context. This CGT has highlighted that dementia is not experienced in isolation. As carers observed the loss of the individual's skills and elements of their uniqueness, underpinned by changes in their behaviour and personality, they felt the loss of who the person once was. This perceived loss of the individual resulted in carers' experiencing multidimensional burden, as echoed throughout the previous literature (Lin, 2008). The CGT highlighted both objective (increased time spent on support) and subjective burden (emotional impact) which impacted upon carers. A prominent feature of the core category *Impact of Dementia* and the literature was the physical and psychological burden which carers' experienced as the dementia presented and worsened.

Similar to McCarron and McCallion's (2005) model of stress and coping, the CGT highlighted primary stressors which negatively impacted upon carers' experiences. For instance, the functional and cognitive decline of a family member or an individual with whom the carer had developed a close relationship induced negative emotions and increased and varied demands. People with an intellectual disability and dementia became increasingly more dependent on carers, who had to support existing needs, such as personal care, and newly introduced demands, such as support with meal times and the need to respond to new behaviours and increased wandering. Family and paid carers had to spend increasingly more time on support, which also impacted upon others. For paid carers, this meant less time being spent with others' sharing the accommodation, which could produce further negative feelings as seen in Furniss et al.'s (2012) paper. For family carers, who had to juggle other important roles with different foci, such as being a parent and helping to run a family business, the added demands compounded the strain on them and other family members.

The emotional burden was compounded by the strength of the carer's relationship with the individual. Carers, especially family carers within this study, reported strong bonds and commitment to the person they supported. Carers had been a part of the individual's journey, helping them to develop and maintain their skills. Observing the deterioration of these skills and independence evoked sadness and anxiety. In line with the literature (Foster, 2012; McCarron & McCallion, 2005), the CGT showed that the intensity of the sense of loss experienced by carers and the emotional burden this induced varied between family and paid carers. Family carers who experienced life alongside their relative, helping to develop their skills and abilities and acting as a lifelong advocate, expressed higher levels of distress; as McCarron and McCallion highlighted, this may be compounded by family carers not having the same level of protection as paid carers, who are able to leave at the end of their shift. Exclusive to family carers were feelings of helplessness. Family carers' perceived inability to do anything about the observed decline was in part informed by their lack of understanding of dementia and how to respond to dementia-related changes. As highlighted across the CGT and supported within the literature (Bromley; 2012; Furniss et al, 2012), family carers did not have the same access to formalised post-diagnostic support, such as person-centred training. Consequently, they struggled to understand how they could support independence, skill maintenance and the personhood of their family member. Without the appropriate post-diagnostic support and guidance to navigate such support, family carers felt helpless.

The literature demonstrated that paid carers may not have a personal involvement with their 'client' but instead take an 'observer' position, speaking about dementia and clients in general instead of the individual (Foster, 2012), and/ or understandably compartmentalised their role from their personal life (Foster, 2012;

Perera & Standen, 2014). This was not always the case within the CGT, as paid carers demonstrated a strong personal relationship, developed over many years, with the individual. Paid carers reported frequently worrying and checking on the health of the individual once they had left their place of work, illustrating that not all separated their role from their personal life. However, this may have further compounded the emotional burden paid carers' experienced.

The loss, change, and decline of the individual's usual personality, behaviours, functional and cognitive abilities created frequent unpredictability in what was once a routinised environment. In this CGT, carers' wellbeing and experiences of supporting someone with an intellectual disability and dementia were impacted upon by the uncertainty dementia induced. The changing predictability of the individual's needs and the frequency of this was also a primary stressor which induced uncertainty and stress in carers. A negative outcome of carers' difficulty with this unpredictability was a reactive approach to support, which reduced their ability to plan ahead for the changing needs of the individual as the dementia worsened.

The CGT has provided useful insight into the role of carers, adding to the small amount of available literature. It has demonstrated that the core category *Impact of Dementia* is influenced and informed through four underpinning categories: *Challenging the Diagnosis Process*; *Continuum of Support*, *Continuum of Understanding*; and *Continuity*. Prominent across these categories is the important role of carers, who were instigators of the referral process and the primary source of post-diagnostic support, which could facilitate the personhood and wellbeing of the individual with an intellectual disability and dementia. Similar to the literature (e.g. Herron & Priest, 2013; McCarron et al., 2011) the CGT illustrated that the level of understanding and skill set of carers influenced whether an individual with dementia

had a timely diagnosis, whether their diagnosis was disclosed and whether it was meaningful, whether they received planned, responsive, timely and appropriate support, and whether they remained in their home as the dementia worsened. Importantly, this understanding underpinned the wellbeing and personhood of the individual with an intellectual disability and dementia. It also underlined the importance of having dementia-capable carers, who are well-trained, informed, and have the appropriate skill set, so they are able to base decisions on an appropriate understanding of both intellectual disability and dementia. However, this CGT has demonstrated that carers experienced challenges with understanding dementia and dementia care, which they felt contrasted with an intellectual disability approach; this highlights the need for appropriate training.

A lack of understanding was pertinent in the delayed referral of individuals with an intellectual disability for assessments by the IDDCP team. As previously found by Herron and Priest (2013), diagnostic overshadowing was prevalent, where carers attributed changes as being part of the person's intellectual disability. In the CGT, diagnostic overshadowing was compounded, for some carers, by their belief that dementia was something which affected people when older. Whilst most paid carers were satisfied with the training they received, and demonstrated a developing understanding of supporting someone's dementia needs, it appeared that the training did not translate into practice when identifying symptoms of dementia. The underlying reasons for this were not explored through the interviews; consequently, it is difficult to draw from the data why, even when satisfied with their level of training, paid carers struggled to translate their training into practice. In contrast to paid carers, training was not accessible for family carers; the findings suggested that this was underpinned by family carers' poorly developed support structures.

A lack of understanding had implications for the support carers delivered to people with an intellectual disability and dementia. Here, personhood stood out as a key concept. At times within their journey, carers could undermine the personhood of the individual with an intellectual disability and dementia through Malignant Social Psychology (MSP; Kitwood, 1997), by making decisions without attempting to facilitate the meaningful input of the person, something echoed throughout the literature (Watchman, 2016). This process could disempower the individual, as they were not actively involved in decisions about their future. Similar to findings of Watchman's studies (2007; 2016), within the CGT, a prime example of this disempowerment was shown through a lack of disclosing a diagnosis. Carers based decisions on whether a diagnosis was shared with the person with an intellectual disability and dementia on their own beliefs and abilities. Consequently, many people were never given the chance to understand their dementia-related changes. More encouragingly, some carers demonstrated support which was planned and informed by elements of a person-centred approach; for example, carers often described trying to apply an individualised approach, informed by the person's preferences. Carers' ability to implement a person-centred approach was strengthened when they had received some form of dementia training.

Like the previously discussed literature (Janicki, 2011; Strydom et al., 2016), this CGT has illustrated the importance of future planning, and its integral role when maintaining continuity in the home and support for people with an intellectual disability and dementia. Carers were committed to providing a home for life; however, they faced challenges when maintaining an individual in their home, through an 'ageing in place' model, when dementia presented and worsened. Moving the person to a new setting impacted upon their wellbeing and induced negative feelings for carers. Ryan et al.

(2018) highlighted the potential impact of not planning a dementia friendly environment at an early stage. Within this CGT, many of the reasons why an individual had to move from their home were a result of poor future planning' due to a lack of awareness of the risk of dementia within the intellectual disability population. Older buildings were a particular challenge to adapt and make dementia-friendly, for example, when there were no bedrooms on the ground floor. For an individual who is losing their mobility, this would inhibit their ability to freely get to their room. However, the carers' understanding of the dementia also informed continuity in the person's home. For example, carers felt they lacked the knowledge and ability to support the end-of-life needs of an individual with dementia. These findings demonstrated the need for organisations, services, and their employees to consider and plan for, at an early stage, the person's home environment, including the physical environment (e.g. adaptations) and carers' skill set and knowledge.

6.3.2. Question 2: What support systems and strategies are in place for carers, and how do these strategies contribute to support for carers?

To manage the additional burden, knowledge needs, and challenges this CGT has highlighted, carers drew on the support of others. The carers' ability to support the needs of people with an intellectual disability and dementia was informed by their supportive environment. When carers felt supported, they were better able to fulfil their role. Having a supportive social environment acted as a mediating factor and helped to alleviate the impact of the dementia, by enabling carers to share their physical and emotional burden, and to ensure a warm, caring environment for the individual with dementia. However, how support was experienced and its role differed

between paid and family carers. Support was experienced along a continuum. At one end of the continuum were paid carers, who had access to more varied and better established support structures than family carers, who, at the opposite end of the continuum relied almost exclusively on their own resources and fellow family members. The carers' positioning on the continuum impacted upon the level of burden they experienced and their ability to support the individual with an intellectual disability and dementia.

Paid carers had access to better developed support structures, both formal and informal, including healthcare services, the organisation they worked for, the care management team, and the care team. Similar to the reviewed literature (Courtenay et al., 2010), having access to multiple forms of support helped to alleviate the physical and emotional burden of the dementia, but also enabled carers to deliver informed support. The context under which support was used varied. For instance, paid carers relied heavily on their peers, who were more easily accessible, to alleviate their emotional burden; however, they drew more upon formal sources such as care team managers and healthcare professionals from the IDDCP for their informational needs.

Training was an essential support for paid carers. Most paid carers reported undertaking some form of dementia training which guided and informed how they responded to the needs of the person with an intellectual disability and dementia (e.g. going into the person's world when required, rather than always reorienting them to reality). Training also shaped the proactive approach some paid carers adopted, as it informed the changes they made to the physical environment of the individual, to better enable continuity in the person's home and supports. However, one issue was the challenge paid carers reported, even after receiving training, in translating their training into distinguishing the symptoms of dementia from the individual's intellectual disability.

Paid carers' difficulties with identifying the early symptoms of dementia are well-established within the literature, though unlike this CGT, the participants in some of the previous research had no previous training (Herron & Priest, 2013; Whitehouse et al., 2000). As the contents of the training received by paid carers was not explored in depth, it is difficult to know whether carers experienced challenges due to inadequate training, which did not provide depth around dementia symptoms, or whether they received such information but struggled to translate it into practice.

Furthermore, some paid carers experienced conflict between what they perceived as contrasting elements of dementia care and intellectual disability care. The intellectual disability model of care is informed by a social model, which advocates individual rights and choice, and the development of personal abilities across the lifespan (Watchman, 2005). Whereas the dementia care model recognises that the individual's deteriorating abilities results in an 'increasing dependency on structure and directive services, as well as nursing and medical care' (Watchman, 2005, p. 160). The carer, being trained and/or experienced in applying certain principles, found it difficult to then incorporate additional principles which they felt went 'against the grain'. This highlights the need for a comprehensive training package to address carers' understanding.

The CGT's findings explicate the importance of understanding, planning and meeting the support needs of carers; to ensure their wellbeing and ongoing ability to support the wellbeing of people with an intellectual disability and dementia. However, carers' holistic needs are not always being planned for or supported, as illustrated within the underpinning category *Continuum of Support*, which highlighted examples of poor planning of supports for carers. This point is echoed within some of the literature (Heller et al., 2018; Janicki et al., 2010; Perera & Standen, 2014), and is in

contrast to available guidance which advocates planning for carers' needs alongside the needs of people with an intellectual disability and dementia (Heller et al., 2018; Jokinen et al., 2013; Strydom et al., 2016). A reactive approach to supporting paid carers underpinned some of the paid carers' experiences, and added to the prolonged burden they experienced and their uncertainty in their actions. A particular example of this reactive approach was the timing of training. For some paid carers, training was received some time into their role of supporting someone with an intellectual disability and dementia, and also required some paid carers to request their own training. Consequently, paid carers, at least initially, did not always have the appropriate knowledge to meet the needs of people with an intellectual disability and dementia, and were less prepared for the emotional impact of the deterioration they observed. However, it is recognised that care organisations were increasingly making training compulsory for paid carers.

This CGT has demonstrated that family carers' needs are not always addressed. Family carers relied exclusively on each other and other family members for support which helped to alleviate some of the burden they experienced, such as relieving stress by having other family members' check-up on their family member; however, without input from supports with the necessary expertise, the family could be strained emotionally and physically by the added responsibilities. Due to the lack of awareness of available support structures, family carers had to use their own financial resources to ensure their family member's needs were met and alleviated the added burden they experienced. Similar to Furniss et al. (2011), there was a clear need for family carers to be supported to navigate and access appropriate supports. Again, family carers' experiences highlighted a lack of planning to meet the full range of their needs. Consequently, this informed the intense burden they experienced. It appeared

that family carers, when not well known to intellectual disability services, were left with few formal sources of support to draw upon to act as mediators for the additional burden they experienced and to meet their knowledge needs. Their dementia knowledge was informed by their own research. Ultimately, the inability to draw on necessary expertise contributed to the family carer participants' decision to move their family member into a nursing home.

6.3.3. Question 3: What is the role of an Intellectual Disability Dementia Care Pathway (IDDCP), and its healthcare professionals, in the support of carers and people with an intellectual disability and dementia?

The CGT offered a unique insight into one IDDCP, as a framework for the planning and delivery of support and services for carers and people with an intellectual disability and dementia. The IDDCP's involvement or lack of involvement was a central feature of how the dementia was experienced by paid and family carers, echoing Chapman et al.'s (2018) findings. The IDDCP provided expert knowledge in both intellectual disability and dementia. It predominantly supported paid carers and the people they cared for, through the diagnosis process, although additionally it maintained an advisory role across the journey with dementia.

A timely diagnosis can better inform the dementia care planning process, ensuring carers and the people they are supporting receive the necessary holistic support to meet their needs at an early stage of the dementia. The CGT demonstrated the IDDCPs attempts and the processes they implemented to identify, assess, and diagnose dementia in a timely manner. Echoing the previous literature (Bell et al., 2008), the CGT also illustrated the IDDCP's thorough assessment process which was

informed by a package of assessments and the necessary additional considerations, such as ruling out other conditions (e.g. depression) which may mimic some of the symptoms of the dementia. This process was implemented to ensure an accurate diagnosis for people with an intellectual disability.

The CGT illustrated the IDDCPs use of a reactive approach to the assessment of dementia. The pathway relied on carers referring people with an intellectual disability to the IDDCP for an assessment once they noticed decline. The outcome from the assessment process was either a diagnosis of dementia, suspected dementia, or dementia was discounted. Where a diagnosis of dementia was given, the support needs of the individual with an intellectual disability and their carer were assessed, and post-diagnostic support provided. Where dementia was discounted, the collated information provided a baseline if any future dementia assessments were needed. However, as highlighted within the literature, one possible drawback to reactive assessments is the reduced reliability and usefulness of assessments when baseline information is not available to compare the assessments against (BPS & RCP, 2015; McKenzie et al., 2018). Consequently, within the IDDCP, as baseline assessments had not been proactively obtained, it was sometimes difficult to make a clear diagnosis of dementia. In these cases, where dementia was suspected, the initial assessments needed to be compared against longitudinal repeated assessments. As illustrated within the CGT, this repeated assessment could be up to a year later, meaning a period of uncertainty for both the individual with an intellectual disability suspected of having dementia, and their carer/s. Furthermore, this would delay important post-diagnostic planning and delivery of support and services for both carers (e.g. training) and people with an intellectual disability (e.g. advance care planning).

The reviewed literature has not explored the role of an IDDCP which has exclusively used reactive assessments. Where IDDCPs have been explored, the pathways implemented a combination of both a reactive assessment and a proactive baseline and screening process (Chapman et al., 2018; Jenkins et al., 2008). The potential benefits of implementing a proactive baseline and screening process, especially for people with Down syndrome who are at higher risk of developing dementia, are widely accepted within the literature (Janicki, 2011; Strydom et al., 2016). Janicki (2011) proposed that an early clinically relevant and periodic assessment is one indicator of high quality care. A proactive baseline and screening process can allow for a timely diagnosis of dementia; bringing certainty and timely support. However, a possible drawback of proactive baselining and screening is that it requires 'considerable clinical and administrative resources' (McKenzie et al., 2018, p.11). For instance, such a service requires access to and awareness of people with an intellectual disability and dementia. This may mean additional resources to develop and maintain a database of people to be baselined and routinely screened (Hobson et al., 2012); something which could be challenging if services have little contact and knowledge of such people. Additionally, early baseline assessments and repeated screening could be stressful for the individual with an intellectual disability (BPS & RCP, 2015; McKenzie et al., 2018).

The IDDCP's reasons for not using a proactive baselining and screening approach alongside reactive assessments were not explicitly explored within the CGT; however, as illustrated through the findings and supplemented by the literature (Hobson et al., 2012; McKenzie et al., 2018), a lack of financial resources, expertise and capacity were possible barriers.

It is important to note that the IDDCP team was in the process of implementing proactive screening every two years for people with Down syndrome aged 40-49 years old, or annually for people with Down syndrome aged 50 years or older. This development was in its early stages and was implemented near the completion of data collection; consequently, it did not impact on the experiences of any of the participants or influence the CGT.

Good dementia care planning also involves ensuring the carers' needs are identified, planned for and met; implementing structures and strategies which protect them against burden and develop their skill set and knowledge (Janicki, 2011; Strydom et al., 2016). As illustrated within the *Impact of Dementia*, carers were negatively impacted upon through multiple forms of burden and uncertainty within their role, highlighting the need for access to planned post-diagnosis support from the IDDCP. Beyond the diagnosis, in relation to paid carers, the IDDCP's primary role was to support paid carers' ongoing informational needs. The CGT illustrated the IDDCPs potential role in developing dementia capable carers, which would better ensure the development and implementation of appropriate care plans. To ensure the wellbeing of people with an intellectual disability and dementia, the IDDCP gave 'carers the tools' by developing their skill set and knowledge through being a central point of contact and advice, and providing information and training.

The IDDCP was responsive to paid carers' needs. The success of this relationship partly rested upon the approachability and accessibility of the IDDCP healthcare professionals; most paid carers had awareness of who to contact, and were able to, and felt confident in, contacting them with concerns and queries whenever necessary. This support structure acted as a mediating factor which alleviated stress

and burden of paid carers. Furthermore, it better informed the carers' approach to supporting the individual with an intellectual disability and dementia within their home.

Carer training and information was a planned post-diagnostic support, embedded within the IDDCP. This support strategy was used to meet the informational needs of carers who had not received dementia training. Training helped paid carers' feel more confident in providing appropriate person-centred dementia care, and implemented adaptations to ensure a more dementia-friendly home. However, post-diagnostic training and informational support relied on a timely diagnosis; something which was not always possible due to a delayed referral, as carers struggled to identify potential dementia-related changes, and/or the lack of a baseline assessment to compare the dementia assessments against. Consequently, the IDDCP post-diagnostic support could sometimes be a long time after the individual with an intellectual disability presented with dementia-related changes. As discussed within this section, one possible way to improve the likelihood of timely support from services, such as DCPs, is through proactive baselining and screening. Chapman et al. (2018), who assessed a specialised intellectual disability and dementia service, consisting of DCPs, several years after its development, found that proactive baselining and screening informed earlier implementation of post-diagnostic interventions, such as training, and consequently, more appropriate, effective support. Having a baseline and regular screening meant that the dementia would be identified and diagnosed earlier, and support could be delivered to carers and people with an intellectual disability and dementia.

One challenge faced by the IDDCP was ensuring inclusivity, so that all carers could access its vital supports and services. Access to the IDDCP, for paid carers, relied on how receptive the care organisation and its carers were to the IDDCP. Where

paid carers were not aware of the IDDCP, they could not draw on the post-diagnostic support the service offered. This presented the risk of carers not having their support needs met, raising the need to ensure all care organisations, within the locality of the IDDCP, have a formalised access route to the IDDCP. It is recognised this approach may present challenges to the IDDCP which was already struggling with resources.

In contrast to most paid carers, family carers received no services and support from the IDDCP; consequently, they felt helpless to support their family members' changing needs. Findings have illustrated the possible impact upon family carers and their family member with dementia, when such specialised support was not accessible, but they have also raised additional questions about the causes of this lack of accessibility; whether this would be the case for other family carers; and whether access to the IDDCP depended on the route of access to services. Findings suggest that intellectual disability services' lack of awareness of the person with an intellectual disability and dementia, and their family carers, and vice versa, may be the underlying reason for the lack of IDDCP involvement; however, conclusions were difficult to draw from the data, as the CGT only represented two family carers, from the same family, who appeared to draw dementia support from generic rather than specialist services. Experiences may have been different for family carers whose family member was already known to intellectual disability services. However, these findings do illustrate the challenges services, such as the IDDCP, may have when trying to provide an inclusive supportive structure, and provide support to individuals cared for by families with little contact with services.

Like this CGT, both Jenkins et al. (2008) and Chapman et al. (2018) provided insight into the post-diagnostic support IDDCPs provide to carers, including training and advice; however, their findings were limited as they either reported on a newly

implemented IDDCP (Jenkins et al.) or were not based on carer experiences (Chapman et al.). This CGT has provided richer insights as it has reported on the supports provided by an IDDCP which has been in place for several years, from the perspective of different carer groups and IDDCP healthcare professionals. In contrast to Chapman et al.'s (2018) findings, this CGT did not explore the role of the IDDCP in dementia care planning and delivery when people with an intellectual disability and dementia entered end-of-life.

Though the IDDCP provided specialised support, the CGT identified that the healthcare professionals did not exclusively work on the IDDCP, but also had to work more widely across other areas of intellectual disability services (e.g. supporting the health needs of people with an intellectual disability without dementia). Healthcare professionals from the IDDCP felt that this 'diluted' their knowledge of dementia, and wanted to be able to specialise and focus on dementia. Working on the IDDCP and other parts of intellectual disability services resulted in large, varied caseloads; this prevented the development of specialised knowledge of dementia. Compounding this feeling of a lack of specialism in dementia, was the lack of broader dementia training healthcare professionals received. Most of their training was specific to their role on the IDDCP, for instance, those involved in the diagnosis process were only trained to carry out the package of assessments which collated information for a diagnosis. The healthcare professionals' inability to specialise in dementia and a lack of in-depth dementia training may have acted as a barrier to providing greater specialised support for carers and people with an intellectual disability and dementia.

The extent to which these findings can be transferred beyond the geographical area the IDDCP covers needs to be considered. IDDCPs may be idiosyncratic, differing between NHS trusts, and dependent on available expertise, infrastructure, and

financial resources. This may make it difficult to transfer this CGT's findings to other NHS Trusts; however, it contributes new knowledge to the limited available empirically informed understanding of the use of IDDCPs.

6.4. Unique Contributions

This research study has provided unique empirical and theoretical contributions, which are informed by the application of well aligned, and systematic methodological processes. The study's unique contribution is the CGT, which is situated in time and context. This CGT has provided a unique perspective that has drawn together five distinct interrelated concepts which underpin how paid and family carers experience their role supporting someone with dementia, and the role of others within these experiences, such as the mediating effect of an IDDCP. The CGT concepts represent parts of the journey with dementia, such as the diagnosis process (*Challenging the Diagnosis Process*); or features which are interwoven across the whole experience, such as support (*Continuum of Support*), understanding (*Continuum of Understanding*) and *Continuity*. As highlighted in Chapter Five, some of these concepts and some of their associated properties have been identified within previous literature, though usually described differently. For example, McLaughlin and Jones (2010) illustrated properties of *Continuum of Support*, and *Continuum of Understanding* in their findings; whilst Carling-Jenkins et al. (2012) illustrated properties of *Impact of Dementia* and *Challenging the Diagnosis Process*. However, this is the first empirical study to contribute a CGT that integrates these five concepts and demonstrates their position and the interaction between them within carers' experiences of dementia in their context. It is the first study to explicate the influence the concepts of this unique CGT

have on the support of people with an intellectual disability and dementia, and the role of an IDDCP as a framework for dementia care and service planning and delivery.

The CGT provides a theory which has shed light on stressors and mediators, and how these inform, compound and/or alleviate the impact of dementia on carers' experiences; and subsequently, inform how carers support and maintain the wellbeing and personhood of people with an intellectual disability and dementia. It has provided unique empirical contributions around the role of an IDDCP. As discussed in section 6.3.3., these empirical findings centre around the IDDCP as a framework for dementia care planning and delivering support, and focus on the assessment process and post-diagnostic support for paid carers.

An important underpinning of CGT and therefore this unique theory was the constructivist paradigm, which sensitised the analysis to relationships; the relationships between people with an intellectual disability and dementia, family carers, paid carers, healthcare professionals, the IDDCP, and service and care providers, and the influence these had on experiences. For instance, how these relationships influenced the *Continuum of Support*, which illustrated the importance of others across support structures and strategies. This knowledge extended the small but developing body of knowledge around intellectual disability and dementia, by scrutinising and understanding the role and impact of others, specifically, an IDDCP in the carer's journey. This has produced a complex understanding which has scope, depth, and relevance.

A unique element of this research study and CGT is its exploration of an IDDCP. This CGT is the first to integrate data from multiple key participant groups, including paid carers, family carers, and healthcare professionals from the IDDCP, when addressing and progressing understanding of the role of an IDDCP, an advocated

support structure (BPS & RCP, 2015). Only two other studies have qualitatively explored the role of an IDDCP: Jenkins et al. (2008) and Chapman et al. (2017). As discussed throughout Chapter Five, the quality of this evidence and the level of understanding the findings provide for the role of IDDCPs are mixed. For instance, in Jenkins et al.'s study, data were drawn exclusively from the carers' perspective, who lacked awareness and understanding of the DCP. In Chapman et al.'s study, the authors drew exclusively on the experiences of healthcare professionals working on the DCP and its processes, which meant that claims around how these pathways informed carers' experiences could be biased and need to be used with caution.

The utilisation of data source triangulation in the current research study, in comparison to drawing upon carer or healthcare professional experiences alone, has enabled the construction of a theory which: provides a better understanding of relationships between carers and the IDDCP; explores the similarities and differences in paid and family carers' perceptions and needs (though it is recognised that theoretical saturation was not achieved for family carers; see Section 6.5.); and allowed for the integration of findings for understanding dementia care planning in the context of carers and a specialised IDDCP (Kendall et al., 2009). However, the transferability of this CGT has been reduced by the challenges with recruitment and the inclusion of experiences of just one IDDCP; these challenges are further discussed in Section 6.5. with suggestions for overcoming challenges explored in Section 6.6.

Utilising a CGT methodology to develop a substantive interpretative theory is unique within the reviewed empirical intellectual disability and dementia literature. Where a specific form of qualitative methodology was mentioned, it was generally a phenomenologically informed approach, such as IPA (Furniss, Loverseed, Dodd, & Lippold, 2011). Although Jenkins et al. (2008) implemented Grounded Theory methods

for the analysis of the data, in contrast to CGT, this may suggest a more positivist theoretical underpinning for understanding (Charmaz, 2014).

The CGT approach enabled the development of a theory which represented and was shaped by the participants' voices. CGT's combined methodological procedures produced a unique approach to developing a bottom-up theory. Its constant comparison methods, iterative approach, delayed literature review, theoretical sampling, simultaneous data collection and comparison combined to ensure the CGT was relevant to carers of people with an intellectual disability. These procedures emphasised following the path laid out by participants; for instance, theoretical sampling meant using content, codes and developing categories from one/ multiple participants, to explore this information in future interviews. This stimulated conceptualisation from the data, whilst its constructivist approach illustrated the role of the researcher and their prior knowledge and experiences in the final developed theory. This encouraged a critical approach to data, ensuring that its meaning was not taken for granted and alternatives were explored. Utilising this approach facilitated the development of a distinctive CGT, which had scope, depth, and relevance, and contributed a unique understanding of how dementia is experienced, to the intellectual disability and dementia literature.

6.5. Strengths and Limitations

As with most research, this qualitative study has employed strategies to ensure the trustworthiness and quality of its procedures and outcomes. Equally, it has revealed aspects which could have improved its quality and outcomes. A strength was the application of data source triangulation (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). The CGT was informed by collecting data from different participant

groups. The use of multiple perspectives allowed for a better understanding of relationships, exploration of similarities and differences in perceptions, an understanding of the individual needs of family carers and paid carers, and the integration of findings for improving supports (Kendall et al., 2009). As stated throughout this research study, and illustrated across the findings, dementia is not experienced in isolation. How paid and family carers, the person with an intellectual disability and dementia, and healthcare professional interact with each other plays a meaningful role in how the dementia is experienced. Each participant group viewed dementia through a different lens, which made it important to draw upon and understand their different experiences. This subsequently aided the development of a CGT which provided a wide-ranging understanding of the phenomenon. Furthermore, the inclusion of key voices across the experience of the dementia enhanced the holistic understanding of how supporting someone with dementia is experienced. Including senior figures from the IDDCP, IDDCP healthcare professionals, and carers, who all play a central role in support, within this research study meant that any recommendations (see Section 6.7.) are theoretically underpinned by a wealth of expertise and experience.

A further strength of this research is the steps taken to ensure the trustworthiness of the study and how this is reported throughout the thesis. As stated in Chapter 2.18., to ensure the criteria of trustworthiness (Lincoln & Guba, 1985) were met, processes such as investigator triangulation, and decisions and processes were transparently communicated within the thesis, providing an audit trail. Such considerations have ensured this research study has a greater level of credibility, transferability, dependability, and confirmability.

A limitation of this research was the lack of theoretical saturation achieved across the family carer participant group. Only a small sample size of family carers ($n=2$; 4 interviews in total) were recruited and these participants were siblings to the same person with an intellectual disability and dementia. Though every effort was made to recruit more participants across a two-year period and to reach saturation of the data, the pragmatic decision was taken to end this recruitment phase. This was not an easy decision, but one based on the practicalities of time, resources, and the level of saturation achieved across the four interviews. Although full saturation of the data was not achieved, the level of saturation obtained was deemed acceptable to be included in the CGT.

Not achieving theoretical saturation had implications for the quality of the CGT. This study has provided an interpretive theory, which is situated in time and context (Charmaz, 2014). The aim was never to provide a CGT which could be generalised to populations, but instead could be transferred to other similar settings and contexts. Nevertheless, not reaching theoretical saturation limited the transferability of the CGT to other family carer contexts, and meant that the relevant research questions, as discussed in section 6.3, were not fully explored from the perspective of family carers.

Furthermore, as the two family carer participants are sisters, it may have introduced bias as family carers may have discussed the research with one another, and further weakened the transferability of findings as they discussed the same individual; both potentially impacting upon the trustworthiness of some of the findings in this research.

This research aimed to explore the roles of carers and an intellectual disability dementia care pathway (IDDCP) in the support of people with an intellectual disability and dementia. Though rich data were collected from multiple participant groups, to fully

address the research aims, it would have been beneficial to have taken a more inclusive stance and meaningfully involved people with an intellectual disability and dementia; exploring their views and experiences. Since the 1990s the UK Government has advocated service user involvement in research and evaluation (Gibbs & Read, 2010), including marginalised groups such as people with mental health problems and people with an intellectual disability, who may previously have been excluded from being actively involved. This has been supported by UK health policies which have aimed to strengthen public and patient involvement in the NHS (e.g. Health & Social Care Act, 2001), and by the English Department of Health (DH, 2005). From a research perspective, this has meant enabling people with an intellectual disability to have greater input into research which is related to them. This input should run throughout the research process from the design, conduct, and analysis stages through to dissemination (DH, 2005). More recently, increased inclusive research has enabled people with an intellectual disability to have a louder voice (Nind & Vinha, 2012). Methods and methodologies have been developed and adapted which facilitate active and meaningful engagement (Walmsley, 2004; Watchman, 2016).

As reported within this thesis, exhaustive but ultimately fruitless attempts were made to identify and recruit people with an intellectual disability and dementia, despite extensive consultation with members of appropriate reference groups and the creation of appropriately adapted recruitment and study materials (see Herron, Priest, & Read, 2015). Exploring the views and experiences of people with an intellectual disability and dementia would have provided a platform for an under-researched voice, improved the quality of the CGT and any implications and/or recommendations drawn from it, by making the theory more relevant to people with an intellectual disability and dementia.

The trustworthiness and quality of this research study could have been improved further. For instance, method triangulation was not applied. Only one data collection method was used in this study. Though the use of semi-structured interviews was justified and proved to be an excellent method (Charmaz, 2014; DiCicco-Bloom & Crabtree, 2006), applying additional complementary research methods would have captured methods triangulation, provided greater scrutiny of experiences, and improved the trustworthiness of the study. For instance, a salient finding was the relationship between carers and people with an intellectual disability and dementia, and examples of how carers may support or undermine the individual's personhood. Utilising ethnographic methods would have allowed a greater exploration of the social environment (Brooker, 2007), and the potential for Malignant Social Psychology (MSP) (Kitwood, 1997). Additionally, member checking was not utilised. For this technique, 'data or results are returned to participants to check for accuracy and resonance with their experiences' (Birt, Scott, Cavers, Campbell, & Walter, 2016, p2). Using member checking to explore the credibility of results would have improved its trustworthiness, and better ensured the researcher's voice did not take precedence over the participants' voices. However, as described in Chapter 2.17., steps were taken to ensure trustworthiness and that the CGT closely reflected the participants' voices, such as applying investigator triangulation.

6.6. Future research

Although this study has provided contributions to the field of knowledge within intellectual disability and dementia, the limitations of the research study and the findings explicated through the CGT have illuminated opportunities to extend it in multiple directions. As detailed in section 6.5., one shortcoming of this research was

the development of a CGT not informed and shaped around the views and experiences of people with an intellectual disability. Compounding this lack of inclusivity was the absence of people with an intellectual disability throughout the generation of the research aims and questions. The research aims and questions were developed from the perspective of the researcher, to explore areas of research drawn from their own interests and the literature; this was necessary for the current PhD. Future research could implement an emancipatory approach (Walmsley & Johnson, 2003), including people with an intellectual disability living with dementia, and people with an intellectual disability and experience of supporting or living with someone with dementia, from the start of the research process; ensuring the aims of the research are also shaped around their needs and interests. This approach will not only ensure the research and CGT is fit for purpose, it will also provide an empowering experience, where collaborators will learn the new skills necessary to develop, carry out, have active involvement in and take more control of the research. This will also enable the development of research which reflects the interests and concerns of those the research is concerned about. It is recognised that emancipatory research may be more of a challenging process for people with an intellectual disability and more advanced stages of dementia, which makes it particularly pertinent to implement inclusive practices.

As illustrated through this thesis, one shortcoming of the literature has been the lack of extensive qualitative empirical research which explored the experiences of family carers. Where family carer experiences are explored, it is through a small number of participants, which makes the findings less transferable. This research study attempted to address this and add to the small field of understanding; however, challenges were experienced when recruiting family carer participants and saturation

was not achieved. Consequently, future research needs to be carried out to further understand the experiences of family carers and the stressors and mediators which influence their journey supporting a family member with an intellectual disability and dementia. Such research requires further careful consideration of the practicalities of recruitment and the difficulties of recruiting research sites. For researchers without relevant clinical contacts to people with an intellectual disability and their carers, an alternative method may be the use of support group forums and message boards. Both deliver a flexible and robust approach (Weslowski, 2014), and may offer direct access to carers, and subsequently, routes to people with an intellectual disability and dementia.

In terms of research topics, this CGT's five concepts have illuminated a manifold of routes to further explore. The CGT has captured the need for the implementation of effective dementia care planning to ensure carers are supported in a timely manner, and that stressors are planned for and addressed. However, this research study did not explicitly explore this across the different stages of dementia. This CGT and the extant literature (Jokinen et al, 2018) have illustrated a need for future research to explore the changing needs of carers across the stages of dementia, and how dementia care planning can proactively address the stressors within their supportive role and better ensure carers are prepared to provide person-centred dementia care. Part of this future research will entail gaining an in-depth understanding of what person-centred care means in the context of dementia, from different perspectives. Therefore, this future research needs to take an inclusive approach, bringing together healthcare professionals, carers, and people with an intellectual disability, to provide a holistic understanding. It may be beneficial to implement a participatory action research approach (Jurkowski, 2008), drawing together key stakeholders which will better

ensure change is enacted. Such research would better enable services and organisations to implement a proactive approach to ensure carers' wellbeing, knowledge and skills are prioritised.

A further example of future research is exploring the impact of the dementia on the peers of people with an intellectual disability and dementia, and the influence of their relationship on experiences of dementia. This impact was briefly noted within the CGT (see Chapter Four), around continuity of the home, but not fully explored. This area is of importance, as more people are presenting with dementia, their peers are more likely to be impacted upon by the dementia. It would be of interest and importance to carry out further research exploring these experiences from the perspective of people with an intellectual disability, and carers. Again, using ethnographic research methods, drawing upon both interviews and observations, exploratory research could investigate the experiences of living with someone who has dementia: how it impacts upon the individual and their impact upon the individual with dementia; their understanding of the changes in their peer; and their coping strategies.

Additionally, this research study has provided insight into the role of a local IDDCP, and in doing so, has contributed new knowledge to a field with limited empirical understanding of its use. IDDCPs may be idiosyncratic, differing between NHS trusts. Nevertheless, it is important that future empirical research, utilising a mixed method approach, is carried out to better understand their delivery and function within the lives of paid and family carers, and people with an intellectual disability and dementia. The acquired knowledge can then be translated into service improvements and an understanding of key tenets to inform the development of future guidance for IDDCPs.

6.7. Recommendations

Both the research design and the CGT have extended knowledge within the field of intellectual disability and dementia, from which many implications for policy, practice, and research can be drawn. These implications are of relevance to many people, including paid carers, family carers, people with an intellectual disability with and without dementia, healthcare professionals, service providers, care and housing organisations, policy developers, and researchers. The CGT has highlighted the importance and usefulness of effective dementia care planning which considers the needs and role of carers, and the role of IDDCPs in this planning process.

The recommendations from this research study are that:

- There is further development and implementation of guidance and policy which advocates the application of both reactive assessments and proactive baselining and screening to better ensure a timely diagnosis. It is recognised that implementing a proactive approach may be difficult for some service providers, as it would require investment of resources, which in the current climate may be challenging. Some services may also already implement a proactive diagnosis approach. Additionally, it is important that people with an intellectual disability and their carers are involved in any decisions around whether they want baseline assessments and future monitoring.
- Services develop specialised IDDCPs. There is currently guidance available (BPS & Royal College and Psychiatrists, 2015), but this needs to be added to through empirical research, and the development of best practice guidelines, especially around the diagnosis, post-diagnosis support, and end-of-life care.
- IDDCPs support the assessment and planning of the full range of carers' needs, and where applicable, in collaboration with other services and organisations,

strengthening and formalising the support they offer (including training), and providing an inclusive, accessible central source of contact for carers.

- There is investment in IDDCP staff; this needs to include the encouragement, development and training of intellectual disability nurses to specialise in dementia. This would ensure nurses were able to provide specialised support and guidance.
- There is greater collaboration between service providers to ensure that both family carers and their family members accessed generic dementia services, where their support needs were not met. There needs to be better communication between services, as part of a collaborative process, to ensure that people with an intellectual disability and dementia are known to intellectual disability services and the IDDCP.
- IDDCPs take a proactive approach to ensuring awareness of the support available; for instance, by providing local services and organisations, GP practices and support groups with leaflets which highlight the services provided by the IDDCP. Such steps would help to provide a specialised service within intellectual disability which is equally accessible for all. However, practical considerations of such a service would need to be considered. A small specialised service, such as the IDDCP discussed in this research study, may experience challenges of managing increased referrals. Having specialised nurses and improved interdisciplinary collaboration would help to relieve this burden.
- There is further development of policy which ensures the active input of people with an intellectual disability and dementia in any decisions about their own lives. Simultaneously, services and organisations need to ensure appropriate guidelines and procedures are in place for their staff, to underpin a care culture which emphasises the active inclusion and contribution of people with an intellectual disability and dementia at necessary points.

- Organisations and services need to address the reactive approach which has sometimes been seen across the CGT and implement procedures for effective dementia care planning. Whilst the individual has the capacity, it is important to discuss their future, and their individual preferences (BPS & Royal College and Psychiatrists, 2015).
- A comprehensive training package, informed by the CGT's findings, to address carer needs, is developed to ensure personhood and wellbeing of the individual with an intellectual disability and dementia. Any training needs to be informed by the CGT and the principles of PCC (Brooker & Latham, 2016; Kitwood, 1997), and underpinned by a strong theoretical and evidence-base. This training needs to instil a clear understanding of how dementia is experienced by people with an intellectual disability and dementia, and the role carers can have in these experiences; this can be aided through utilising different models and frameworks as described in Chapter 1.4.2., and the concepts of this CGT.
- Within research, an appropriate qualitative methodology, such as CGT, which emphasises inductivity and prioritises the participant's voice should be utilised; whilst drawing upon multiple perspectives from key figures across relevant contexts, including people with an intellectual disability and dementia, who should be at the heart of any research which is exploring their experiences of dementia.
- Further research studies are carried out to explore a multitude of areas, including the changing needs of both family and paid carers, and the experiences of people with an intellectual disability and dementia; and needs to be informed by inclusive practices, such as including people with an intellectual disability in the development of the design and development of the research study.

Ultimately, these recommendations should not be seen in isolation, but instead as a collective, which need to be implemented simultaneously. For instance, guidance which emphasises a focus on ensuring personhood would not be as effective without an extensive training package and support for carers to undertake this training.

6.8. Reflections

In Chapter One, I illustrated my motivation for this PhD study. I started this journey from the position of a support worker, a group facilitator, a novice researcher. These experiences informed my beliefs about dementia and the impact it has on people. The knowledge I had collated through these roles made me more inquisitive; I wanted to understand experiences of dementia from the perspective of the people I supported and worked with. Ultimately, I wanted to gain this understanding to inform the literature and practice; helping people with an intellectual disability and their carers to live a good life with the dementia: making an impact. As I end my PhD journey, it is pertinent that I reflect on my experiences of my PhD and the research process; how my training, thoughts, and beliefs informed this research study, and the influence this research study has had on me.

My initial belief of dementia was that it had a destructive impact on people with an intellectual disability and their carers. I had some understanding of the role of paid carers in this process, mainly, within the referral process; still, I was uncertain of the factors which informed these experiences. Challenges were experienced across this research, resulting in the perspective of people with an intellectual disability and dementia not being included in this PhD study. Consequently, the study's focus evolved; now focusing exclusively on carers' experiences, their role in the personhood and quality of life of someone with dementia, and the role of an IDDCP and its

healthcare professionals in the planning and deliver of support. I was disappointed and frustrated that despite my best efforts I could not achieve the inclusion of the perspective of people with an intellectual disability and dementia.

Analysing the data, and as categories were developed, it soon became clear that this CGT was one which was underpinned by interrelated factors that played both a compounding and an alleviating role within experiences. I learnt that these factors, whilst individual, collectively provided an understanding of carers' experiences, and the mediating role of an IDDCP. I learnt that weaving through these factors was the social environment. People with an intellectual disability and dementia became increasingly reliant on carers. This reliance impacted upon carers, who drew on support, when available, from their social environment. Importantly, and something I had not previously considered, was the extent to which the social environment underpinned both negative and positive experiences of the dementia. How services, healthcare professionals, and carers, reacted to the dementia influenced the carers' journey and the type of support delivered to people with an intellectual disability and dementia.

I started to understand that at the heart of decisions were relationships. For instance, carers had strong, well-established friendships with the person/ family member they supported. These strong relationships, which were informed by respect and compassion, informed decisions; though not all of these decisions followed the best practice advocated by key guidance. I was struck by the scope of the concepts, ranging from before the diagnosis process to end-of-life. An unexpected finding was the vast differences between paid and family carers. I did not consider the lack of support structures in place for family carers and the impact this had on their experiences and their supportive role. However, I also found some of what I learnt

challenging to process, such as family carer experiences of seeing their family member decline and lose the 'spark' in their eyes. Hearing the participant's emotion, the desperation in their words when they described their helplessness, whilst emotionally challenging for me, only increased my conviction to develop a research study which could inform research and practice and help improve their experiences.

I started this journey aiming to gain an understanding of how dementia was experienced. I have ended it with an understanding of the realities of dementia: the impact of dementia and concepts which underpin this impact. However, this learning process went beyond my understanding of these experiences and entailed my development as a researcher. Equally important to my understanding and development as a researcher and academic, has been the extensive use of my PhD learning plan, which I have methodically used to develop my skills and broaden my experience. I have proactively sought-out training and expertise to develop important research skills, which have underpinned my research study. For instance, understanding my lack of expertise in CGT, I applied and attended four different CGT workshops. This also provided me with experiences of common processes within academia, such as applying for funding. However, I have also taken opportunities to attend training which broadened skills that were not necessarily, or directly related to my research study, such as thematic analysis training in order to appreciate the strengths and limitations of my own methodological approach. I have tried to become a more whole researcher, equipped for my PhD and a career after my PhD.

I have also sought-out opportunities to disseminate my knowledge across a wide and varied audience, including healthcare professionals, academics, students and the public. The experience of presenting through various formats at international and national conferences has developed essential skills for my future career, such as

communication skills and an understanding of how to present and adapt information to specific audiences. My time teaching psychology in China for Keele University's School of Psychology reinforced the importance of communication, and the need to make sure it is appropriately adapted to ensure inclusivity. These opportunities have also provided experiences which have helped me develop as a researcher, such as applying for internal and external funding, networking, and to me, most importantly, my confidence to talk in-front of an audience.

Some of the most influential elements of development came through spontaneous opportunities, such as working with my supervisor, Professor Sue Read, on a project to develop a healthcare toolkit through a collaborative process. This experience further progressed my thinking and desire to work collaboratively with people with an intellectual disability.

I started this process as a novice researcher. Uncertain about myself and the decisions I made. Uncertain about how to apply the research methods. However, as I end this journey, I feel a more established researcher, one with growing confidence, knowledge and skills. One salient learning experience was my attempt to implement inclusive processes. Trying to apply these processes introduced me to the administrative and practical challenges of including others in research design. Though intensive, the lessons I learnt from these experiences have profoundly changed my perspective of the research process, and the need to practice and demonstrate inclusivity within research across all populations.

I end this reflection with my experience of disseminating this research study at a national dementia conference. At the conference, I presented within an intellectual disability and dementia strand, whose diverse audience consisted of: people with an intellectual disability, family members, carers, healthcare professionals, and support

organisation representatives. As I presented my CGT, I considered the relevance of my findings; will these concepts and experiences resonate with the audience? As I ended my talk, which was at the last slot of the symposium, I was overwhelmed by the support of the audience. Having attended and presented at many conferences which were either dementia or intellectual disability specific, never before have I had so many members of the audience wanting to discuss their experiences, which reverberated with my findings. However, I also reflected on how far I had come as a researcher, and how my skills and experience informed how I presented. I was now able to adapt my communication to different audiences, explaining complex terminology in clear language, and I was confident.

At the start of my PhD journey, I detailed how I wanted to carry out my research to help people: make a difference. As I ended my PhD journey, I felt that I was on the road to achieving this.

6.9. Conclusions

In conclusion, findings of the CGT have presented a clear argument: carers are impacted upon by multiple forms of burden, and may find their role challenging; and intellectual disability services, specifically IDDCPs, can have an important role in supporting carers through the planning and delivery of support and services. This is reflected through the CGT's five interrelated concepts: *Impact of Dementia*, *Challenging the Diagnosis Process*; *Continuum of Support*, *Continuum of Understanding*, and *Continuity*.

Utilising an inductive, methodical CGT methodology, these findings have enabled the research questions and broad aims to be addressed; though as critically discussed throughout Chapter Six, the extent to which these were addressed was

negatively impacted upon by the challenges with recruitment. However, applying an advanced qualitative methodology and appropriately aligned methods, and employing data source triangulation, has provided a CGT which has relevance, scope and depth. It has offered a unique contribution to understanding of carers' experiences and the role of an IDDCP in planning and delivery of support and services. This research study and CGT have made unique contributions empirically, methodological, and theoretically. It has extended knowledge, provided routes for future research to explore, and suggested practical recommendations.

References

- Adams, T. (1996). Kitwood's approach to dementia and dementia care: A critical but appreciative review. *Journal of Advanced Nursing*, 23, 949–953.
- Adams, R. E., Boscarino, J. A., & Figley, C. (2006). Compassion fatigue and psychological distress among social workers: A validation study. *American Journal of Orthopsychiatry*, 76(1), 103-108.
- Adler, P., & Adler, P. (2012). 'Expert voice'. In S. E. Baker & R. Edwards (Eds.), *How many qualitative interviews are enough?* (pp. 8-11). National Centre for Research Methods Review Discussion Paper.
- Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: Mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy*, 10(3), 173-182.
- Allen, D., Gillen, E., & Rixson, L. (2009). The effectiveness of integrated care pathways for adults and children in health care settings: a systematic review. *JBIR Reports*, 7(3), 80-129
- Ahmad, F., Roy, A., Brady, S., Belgeonne, S., Dunn, L., & Pitts, J. (2007). Care pathway initiative for people with intellectual disabilities: Impact evaluation. *Journal of Nursing Management*, 15(7), 700-702.

Allen, C. (1997). *Nursing Process in collaborative practice*. Stamford: Appleton and Lange.

Alzheimer's Research UK (2012a). Dementia statistics. Retrieved from:
<http://www.alzheimersresearchuk.org/dementia-statistics>

Alzheimer's Research UK (2012b). Dementia symptoms. Retrieved from:
<http://www.alzheimersresearchuk.org/general-symptoms/#acc1/>

Alzheimer's Research UK (2018). Dementia with lewy body. Retrieved from:
<https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/dementia-with-lewy-bodies/about/>

Alzheimer's Society (2011). Learning disabilities and dementia. Retrieved from:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

Alzheimer's Society (2012a). Dementia 2012 infographic. Retrieved from:
<http://alzheimers.org.uk/infographic>

Alzheimer's Society (2012b). Learning disabilities and dementia. Retrieved from:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

Alzheimer's Society (2013). What is vascular dementia? Retrieved from:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=16

1

Alzheimer's Society (2015). Rights based approach to dementia? Retrieved from:
<https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/equality-discrimination-human-rights>

Alzheimer's Society (2018). Vascular dementia, what is it? What causes it? Retrieved from:
<https://www.alzheimers.org.uk/about-dementia/types-dementia/vascular-dementia>

Alzheimer's Society (2018). Frontotemporal dementia: what is it? Retrieved from:
https://www.alzheimers.org.uk/about-dementia/types_dementia/frontotemporal-dementia

Atherton, H. (2007). A history of learning disabilities. In B. Gates (Ed.), *Learning disabilities: Towards inclusion* (pp21-42). Edinburgh: Elsevier/Churchill Livingstone.

Atkinson, P., Coffey, A. and Delamont, S. (2003). *Key Themes in Qualitative Research: Continuities and Change*. Walnut Creek, CA: Alta Mira.

- Atwal, A., & Caldwell, K. (2006). Do multidisciplinary integrated care pathways improve interprofessional collaboration?. *Scandinavian Journal of Caring Sciences*, 16, 360–367.
- Auty, E., & Scior, K. (2008). Psychologists' clinical practices in assessing dementia in individuals with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 259–268.
- Ballard, C., Lowery, K., & Powell, I. (2000). Impact of behavioural and psychological symptoms of dementia on caregivers. *International Psychogeriatrics*, 12(1), 93–105.
- Bayley, A., Amoako, A., & El-Tahir, M. O. (2017). Service evaluation of a Specialist Memory Clinic for adults with ID in South Wales. *Advances in Mental Health and Intellectual Disabilities*, 11(4), pp.145-154
- BBC News (2006). Life expectancy hits record high. Retrieved from: <http://news.bbc.co.uk/1/hi/health/6168466.stm>
- Beck, E., McIlfratrick, S., Hasson, F., & Leavey, G. (2017). Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature. *Dementia*, 16(4), 486-512.

- Bell, D. M., Tumbull, A., & Kidd, W. B. (2008). Differential diagnosis of dementia in the field of learning disabilities: A case study. *British Journal of Learning Disabilities*, 37, 56–65.
- Benbow, S. M., Grizzell, M., & Griffiths, A. (2014). Intellectual disability and dementia services - Better together or apart? In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 270-285). London: Jessica Kingsley Publishers.
- Berg, B. L., & Lune, H. (2012). *Qualitative research methods for the social sciences*. Boston: Pearson.
- Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*: Garden City, New York: Anchor Books
- Bialon, L., & Coke, S. (2012). A study on caregiver burden: stressors, challenges, and possible solutions. *American Journal of Hospice & Palliative Medicine*, 29(3), 210–218.
- Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide* (2nd ed.). Los Angeles, CA: SAGE Publications.
- Bisson, J., Hampton, V., Rosser, A., & Holm, S. (2009). Developing a care pathway for advance decisions and powers of attorney: Qualitative study. *British Journal of Psychiatry*, 194(1), 55-61.

- Bittles, A., Petterson, B., Sullivan, G., Hussain, R., Glasson, E., & Montgomery, P. (2002). The influence of intellectual disability of life expectancy. *Journal of Gerontology: Medical Sciences, 57A*, 470-472.
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research, 26*, 1802-1811
- Black, L. A. (2013). *Health inequalities and people with a learning disability*. Northern Belfast: Ireland Assembly.
- Blaire, M., & Perry, B. (2017). Family caregiving and compassion fatigue: A literature review. *Perspectives, 39*(2), 14-19.
- Blumer, H. (1954). What is wrong with social theory? *American Sociological Review, 18*, 3-10.
- Bouras, N. & Holt, G. (2004). Mental health services for adults with learning disabilities. *British Journal of Psychiatry, 184*, 291-292.
- Breckenridge, J. P., Jones, D., Elliott, I., & Nicol, M. (2012). Choosing a methodological path: Reflections on the constructivist turn. *Grounded Theory Review, 14*(1).

Brigham, L. (2000). *Crossing boundaries: change and continuity in the history of learning disability*. Kidderminster: BILD Publications.

British Psychological Society (BPS) (2011). *Code of Ethics and Conduct Guidance*. London: BPS.

British Psychological Society (BPS) Dementia Advisory Group (2016). *Psychological dimensions of dementia: Putting the person at the centre of care*. London: BPS.

British Psychological Society (BPS) & Royal College of Psychiatrists (RCP) (2015). *Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia*. London: BPS.

Brooker, D. (2007). *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers.

Brooker, D., & Latham, I. (2016). *Person-centred dementia care: Making services better with the VIPS framework*. London: Jessica Kingsley Publishers.

Bromley, L. (2014). *How do carers of people with an intellectual disability with dementia experience their role and the support they receive through services?* (Unpublished Thesis). Exeter: University of Exeter.

- Bryant, A. (2003). A constructive/ist response to Glaser. *Forum for Qualitative Social Research*, 4(1). Retrieved from www.qualitative-research.net/fqs/-texte/1-03/1-03bryant-e.htm
- Bryant, A., & Charmaz, K. (2007). *The SAGE handbook of grounded theory*. London: SAGE Publications.
- Bryman, A. (2012). How many qualitative interviews is enough? In S.E. Baker, & R. Edwards, R. (Eds.), *How Many Qualitative Interviews is Enough? Expert Voices and Early Career Reflections on Sampling and Cases in Qualitative Research*, (pp. 18–20). Southampton: ESRC National Centre for Research Methods, University of Southampton.
- Bubb, S., Brittan, K., & Dixon, S. (2016). *Time for change: The challenge ahead*. London: Aveco.
- Buijssen, H. (2005). *The Simplicity of Dementia*. London: Jessica Kingsley Publishers.
- Bulmer, M. (1979). *Censuses, surveys and privacy*. London; Macmillan.
- Bunn, F., Burn, A. M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, 12, 192-207.
- Burgess, R. G. (1984). *In the Field*. London: Allen & Unwin.

Burr, V. (2015). *Social Constructionism*. London: Routledge.

Bush, N.J. (2009). Compassion fatigue: Are you at risk? *Oncology Nursing Forum*, 36(1), 24-28.

Buunk, B. P., & Schaufeli, W. B. (1993). Burnout: A perspective from social comparison theory. In W. B. Schaufeli, C. Maslach, & T. Marek (Eds.), *Professional burnout: Recent developments in theory and research* (pp. 53-66). Washington, DC: Taylor & Francis.

Cairns, V., Lamb, I., & Smith, E. (2010). Reflections upon the development of a dementia screening service for individuals with Down's syndrome across the Hyndburn and Ribble Valley Area. *British Journal of Learning Disabilities*, 39, 198–208.

CASP (2017). CASP checklists. Retrieved from: <http://www.casp-uk.net/casp-tools-checklists>

Carling-Jenkins, R., Tor, J., Iacono, T., & Bigby, C. (2012). Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. *Journal of Intellectual and Developmental Disability*, 37(1), 54-60.

- Carnaby, S. (2007). The bigger picture- understanding approaches to learning disability. In S. Carnaby (Ed.), *Learning disability today* (pp. 7-16). Brighton: Pavilion Publishing.
- Campbell, H., Hotchkiss, R., Bradshaw, N., & Porteous, M. (1998). Integrated care pathways. *BMJ: British Medical Journal (International Edition)*, 316(7125), 133-137.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, 41(5), 545-547.
- Centre for Evidence-Based Medicine (2017). Critical appraisal tools. Retrieved from: <http://www.cebm.net/blog/2014/06/10/critical-appraisal/>
- Chamberlain, K. (2004). Reflexivity: Fostering research quality, ethicality, criticality and creativity. In M. Murray. (Ed.), *Critical health psychology* (pp. 165-181). Hampshire: Palgrave MacMillan.
- Chambers, M., Ryan, A. A., & Connor, S. L. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing*, 8, 99–106.
- Chaplin, E., Paschos, D., & O'Hara, J. (2010). The specialist mental health model and other services in a changing environment. In N. Bouras & G. Holt (Eds.), *Mental*

health services for adults with intellectual disability; strategies and solutions (pp. 9-21). Hove: Psychology Press.

Chapman, M., Lacey, H., & Jervis, N. (2017). Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals. *British Journal of Learning Disability*, 46(1), 33-44.

Charmaz, K. (1990). Discovering chrome illness: Using grounded theory. *Social Science and Medicine*, 30, 1161-1172.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. Lincoln (Eds.), *The Handbook of Qualitative Research* (pp 509-535). Thousand Oaks, CA: SAGE Publications.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE Publications.

Charmaz, K. (2014). *Constructing Grounded Theory*. London: SAGE Publications.

Charmaz, K., & Belgrave, L. L. (2012). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti & K. D. McKinney (Eds), *The SAGE Handbook of interview research: The complexity of the craft* (pp. 347-366). London: SAGE Publications

- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: SAGE Publications.
- Cleary, J., & Doodly, O. (2017). Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature. *Journal of Intellectual Disabilities, 21*(1), 1-19.
- Coetzee, S. K., & Klopper, H. C. (2009). Compassion fatigue within nursing practice: A concept analysis. *Nursing and Health Sciences, 12*, 235-243.
- Cooper, S., McLean, G., Guthrie B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: Population-based cross-sectional analysis. *BMC Family Practice, 16*, 110-121.
- Coolican, H. (2009). *Research methods and statistics in psychology*. London: Hodder Education.
- Cooper, S., & Holland, A. J. (2007). Dementia and mental ill-health in older people with intellectual disabilities. In N. Bouras, & G. Holt (Eds.), *Psychiatric and behavioural disorders in intellectual and developmental disabilities* (pp. 154-172). Cambridge: Cambridge University Press.

- Courtenay, K., Jokinen, N. S., & Strydom, A. (2010). Caregiving and adults with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 26-33.
- Coyne, I. (2009). Accessing children as research participants: Examining the role of gatekeepers. *Child: care, health and development*, 36(4), 452-454.
- Crotty, M. (1998; 2015). *The foundations of social research*. London: SAGE Publications.
- Crow, G., & Wiles, R. (2008). *Managing anonymity and confidentiality in social research: the case of visual data in community research*. Southampton: ESRC National Centre for Research Methods.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.
- Day, J. R., & Anderson, R. A. (2011). Compassion fatigue: An application of the concept to informal caregivers of family members with dementia. *Nurse Research and Practice*, 2011, 1-10.
- Day, J. R., Anderson, R. A., & Davis, L. L. (2014). Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues in Mental Health Nursing*, 35(10), 796- 804.

- De Luc, K., Kitchiner, D., Layton, A., Morris, E., Murray, Y., & Overill, S. (2001). *Developing care pathways: The handbook*. Oxon: Radcliffe Medical Press.
- Dempsey, D. (2013). Advance care planning for people with dementia: Benefits and challenges. *International Journal Palliative Nurse*, 19(5), 227-34.
- Denzin, N. K. (2002). *Interpretive Interactionism*. London: SAGE Publications.
- Denzin, N. K., & Lincoln, Y. S. (1994). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *Handbook of Qualitative Research* (pp. 1-18). Thousand Oaks: SAGE Publications.
- Denzin, N. K. & Lincoln, Y. S. (2000). *Handbook of qualitative research*. London: SAGE Publications.
- Denzin, N. K. & Lincoln, Y. S. (2003). *Collecting and interpreting qualitative materials*. London: SAGE Publications.
- Derbyshire County Council & Derbyshire Healthcare NHS Foundation Trust (2014). *Derbyshire joint dementia strategy: Living well with dementia*. Derbyshire: NHS
- Detering, K., Hancock, A., Reade, M., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *The British Medical Journal*, 340, 1-9.

Dey, I. (1999) *Grounding Grounded theory: Guidelines for Qualitative Inquiry*. London: Academic Press.

Devapriam, J., Alexander, R., Gumber, R., Pither, J., & Gangadharan, S (2014). Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. *Journal of Intellectual Disabilities*, 18(3), 211- 220.

Dicks, S., Jackson, S., Pasokhy, A., & Symes, M. (2015). Training for staff who care for clients with dementia. *Learning Disability Practice*, 18(9), 28-32.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321.

Digby, A. (1996). Contexts and perspectives. In D. Wright & A. Digby (Eds.), *From idiocy to mental deficiency: Historical perspectives on people with learning disabilities* (pp. 1-21). London: Routledge.

Department of Health (2001). *Valuing people: A new strategy for learning disability for the 21st century*. London: Department of Health.

Department of Health (2005). *Research governance framework for health and social care* (2nd ed.). London: Department of Health.

Department of Health (2008). End of life care strategy. Retrieved from:
<https://www.gov.uk/government/policies/improving-care-for-people-at-the-end-of-their-life>

Department of Health (2009a). *Valuing people now: A three year strategy for people with learning disabilities*. London: Department of Health.

Department of Health (2009b). *Living well with dementia: a national dementia strategy*. London: Department of Health.

Department of Health (2010). *Making written information easier to understand for people with learning disabilities*. London: Department of Health.

Department of Health. (2012a). *Transforming care: A national response to winterbourne view hospital: Department of health review final report*. London: Department of Health.

Department of Health. (2012b). *Prime Minister's challenge on dementia*. London: Department of Health.

Department of Health. (2015). *The Prime Minister's Challenge on Dementia 2020*. London: Department of Health.

Department of Health and Social Security (1971). *Better Services for the Mentally Handicapped*. London: HMSO.

Department of Health Social Services and Public Safety (2003). *Research Governance Framework for Health and Social Care*. Belfast: DHSSPS

Dewing, J. (2004). Concerns relating to the application of frameworks to promote person-centredness in nursing with older people. *Journal of Clinical Nursing*, 13(1), 39-44.

Dewing, J. (2008), Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, 3, 3-13.

Dey, I. (2007) Grounding categories. In A. Bryant & K. Charmaz (Eds.). *The Sage Handbook of Grounded Theory* (pp.167-190). London: SAGE Publications.

Disability Rights Commission. (2006). *Equal treatment: Closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems*. London: Disability Rights Commission.

Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *Journal of Pain Symptom Manage*, 55(1), 132-150.

- Dodd, K. (2014). Staff Knowledge and Training. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice*. London: Jessica Kingsley Publisher.
- Dodd, K., Watchman, K., Janicki, J., Coppus, A., Gaertner, C., Fortea, J.,...Strydom, A. (2017). Consensus statement of the international summit on intellectual disability and Dementia related to post-diagnostic support. *Journal of Aging & Mental Health, 22*(11), 1406-1415.
- Down Syndrome Extra 21. (2012). Facts and figures. Retrieved from: <http://www.extra21.org.uk/facts-and-figures-faqs/>
- Dowling, S., Manthorpe, J., Cowley, S., King, S., Raymond, V., Perez, W., & Weinstein, P. (2006). *Person-centred planning in social care: A scoping review*. York: York Publishing.
- Duffy, B., Oyebode, J. R., & Allen, J. (2009). Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors. *Dementia, 8*(4), 515- 541.
- Dunne, C., (2011). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology, 14*(2), 111-124.

- Ely, M., Anzul, M., Friedman, T., Garner, D., & Steinmetz, A. M. (1991). *Doing qualitative research: Circles within circles*. Philadelphia: Falmer.
- Emerson, E., Baines, S., Allerton, L., & Welch, V. (2011). *Health inequalities and people with learning disabilities in the UK*. London: Department of Health.
- Edvardsson, D., Fetherstonhaugh, D., Gibson, S., & Nay, R. (2010). Development and initial testing of the person-centered care assessment tool (PCAT). *International Psychogeriatrics*, 22, 101-108.
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, 58(1), 10-19.
- Flick, U. (2006). *An introduction to qualitative research*. Thousands Oaks, CA: SAGE Publications.
- Flowers, P. (2008) Temporal tales: The use of multiple interviews with the same participant. *Qualitative Methods in Psychology Newsletter*, 5, 24-27.
- Foster, L. A. (2014). *The experience of carers of people with Down Syndrome who develop dementia*. (Unpublished Thesis). Birmingham: University of Birmingham.

- Furniss, K. A, Loverseed, A., Lippold, T., & Dodd, K. (2012). The views of people who care for adults with Down's syndrome and dementia: A service evaluation. *British Journal of Learning Disabilities* 40(4), 318–327.
- Garfinkel, H. (1967). *Studies in Ethnomethodology*. Cambridge: Polity Press.
- Gibbs, M., & Read S. C. (2010). Involving people with intellectual disabilities in research: Participation and emancipation. In P. M. Roberts & H. M. Priest (Eds.), *Healthcare research: A textbook for students and practitioners* (pp. 247-255). London: Wiley.
- Given, L. M. (2016). *100 Questions (and Answers) About Qualitative Research*. Thousand Oaks: SAGE Publications
- Glaser, B. G. (1992). *Basics of Grounded Theory Analysis*. Mill Valley, Ca: Sociology Press.
- Glaser, B.G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Goffman, E. (1968). *Asylums: Essays on the social situation of mental patients and other inmates*. London: Penguin.

- Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia care in England and the social model of disability: Lessons and issues. *Dementia*, 4(4), 571-586.
- Graham, N., Lindesay, J., Katona, C., Bertolote, J. M., Camus, V., Copeland, J. R. M., & Wancata, J. (2003). Reducing stigma and discrimination against older people with mental disorders: A technical consensus statement. *International Journal of Geriatric Psychiatry*, 18(8), 670-678.
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. London: SAGE Publications.
- Guba, E. G. & Lincoln, Y. S. (2005). Paradigmatic Controversies, Contradictions, and Emerging Confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (3rd Ed) (pp. 191-215). Thousand Oaks: SAGE Publications.
- Hall, I., Higgins, A., Hassiotis, A., & Samuels, S. (2006). The development of a new integrated mental health service for people with learning disabilities. *British Journal of Learning Disabilities*, 34, 82-87.
- Hamlin, A., & Oakes, P. (2008). Reflections on deinstitutionalization in the United Kingdom. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 112-121.

- Hassiotis, A., Guinn, A., Tanzarella, M., McCarthy, J., & Roy, A. (2015). *Community-based services for people with intellectual disability and mental health problems: Literature review and survey results*. London: Faculty of Psychiatry of Intellectual Disability.
- Hek, G., Langton, H., & Blunden, G. (2000). Systematically searching and reviewing literature. *Nurse Researcher*, 7(3), 40-57.
- Heller, T., Scott, H. M., Janicki, M. P., & Pre-summit workgroup on caregiving and intellectual and developmental disabilities (2018). Caregiving, intellectual disability, and dementia: Report of the Summit workgroup on caregiving and intellectual and developmental disabilities. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 4, 272-282.
- Henwood, K., & Pidgeon, N. (2003). Grounded theory in psychological research. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 131-155). Washington, DC: American Psychological Association.
- Herron, D., & Priest, H. (2013). Support workers' knowledge about dementia: A vignette study. *Advances in Mental Health and Intellectual Disabilities*, 7(1), 27-40.

Herron, D., Priest, H. M., & Read, S. (2015). Working alongside older people with a learning disability: Informing and shaping research design. *British Journal of Learning Disabilities*, 43, 261-269.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). *Confidential enquiry into premature deaths of people with learning disabilities*. University of Bristol: Norah Fry Research Centre.

Hobson, B., Webb, D., Sprague, L., Grizzell, M., Hawkins, C., & Benbow, S. (2012). Establishing a database for proactive screening for adults with Down's syndrome: When services work together. *Advances in Mental Health and Intellectual Disabilities*, 6(2), 99-105.

Holland, K. (2011). *Factsheet: Learning disability*. Worcestershire: British Institute of Learning disabilities.

Holland, A. J. (2000). Ageing and learning disability. *The British Journal of Psychiatry*, 176, 26-31.

Holton, J. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265–289). London: SAGE Publications.

- Hood, J. C. (2007) Orthodoxy vs. Power: The Defining Traits of Grounded Theory. In Bryant, A., Charmaz, K. (Eds.) *The Sage Handbook of Grounded Theory* (pp.151-164). London: SAGE Publications.
- Howitt, D. (2010). *Introduction to qualitative methods in psychology*. Harlow: Prentice Hall.
- Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigating the grounded theory terrain. Part 1. *Nurse Researcher*, 18(4), 6-10.
- Hussein, M. E., Hirst, S., Salyers, V., & Osuji, J. (2014). Using Grounded Theory as a method of inquiry: Advantages and disadvantages. *The Qualitative Report*, 19(27), 1-15.
- Iacono, T., Bigby, C., Carling-Jenkins, R., & Torr, J. (2014). Taking each day as it comes: Staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. *Journal of Intellectual Disability Research* 58(6), 521–533.
- Jackson, M. (1996). Institutional provision for the feeble-minded in Edwardian England: Sandlebridge and the scientific morality of permanent care. In D. Wright & A. Digby (Eds.), *From idiocy to mental deficiency: Historical perspectives on people with learning disabilities* (pp. 161-183). London: Routledge.

Janicki, M. P. (2011). Quality outcomes in group home dementia care for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 55(8), 763–776.

Janicki, M. P., & Dalton, A. J. (1999). Aging and dementia. In M. P. Janicki, & A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities: A handbook* (pp. 7-26). Philadelphia, Pa; London: Brunner/Mazel.

Janicki, M. P., Dalton, A. J., McCallion, P., Baxley, D., & Zendell, A. (2005). Group home care for adults with intellectual disabilities and Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, 4(3), 361-385.

Janicki, M. P., Zendell, A., & DeHaven, K. (2010). Coping with dementia and older families of adults with Down syndrome. *Dementia*, 9(3), 391-407.

Jenkins, R., Davies, R., Sardi, I., Llewellyn, P., Northway, R., O'Conner, C,...Keeling, D. (2008). Adults with learning disabilities presenting with dementia. Retrieved from:
[http://udid.research.glam.ac.uk/media/files/documents/20100316Presenting_w
ith_Dementia_Final_June_2009.pdf](http://udid.research.glam.ac.uk/media/files/documents/20100316Presenting_w
ith_Dementia_Final_June_2009.pdf)

Jervis, N., & Prinsloo, L. (2008). How we developed a multidisciplinary screening project for people with Down's syndrome given the increased prevalence of early onset dementia. *British Journal of Learning Disabilities*, 36, 13–21.

- Jokinen, N., Gomiero, T., Watchman, K., Janicki, M.P. Hogan, M...Crowe, J. (2018). Perspectives on family caregiving of people ageing with intellectual disability affected by dementia: Commentary from the international summit on intellectual disability and dementia. *Journal of Gerontological Social Work*, 61(4), 411-431.
- Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force., L. T., & the National Task Group on Intellectual Disabilities and Dementia Practices (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10(1), 1-24.
- Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1-11.
- Kalsy, S., McQuillan, S., Adams, D., Tarvinder, B., Konstantinidi, E., Broquard, M., ... Oliver, C. (2005). A proactive psychological strategy for determining the presence of dementia in adults with Down Syndrome: Preliminary description of service use and evaluation. *Journal of Policy and Practice in Intellectual Disabilities*, 2, 116–125.
- Kalsy, S., Heath, R., Adams, D., & Oliver, C. (2007). Effects of training on controllability attributions of behavioural excesses and deficits shown by adults with down

syndrome and dementia. *Journal of Applied Research in Intellectual Disabilities*, 20(1), 64-68.

Kars, M. C., van Thiel, G., van der Graff, R., Moors, M., de Graeff, A., & van Delden, J. (2016). A systematic review of reasons for gatekeeping in palliative care research. *Palliative Medicine*, 20(6), 533-548.

Keele University (2013). Keele University Code of Good Research Practice. Retrieved from:

<https://www.keele.ac.uk/media/keeleuniversity/policyzone/sas/Approved%20Code%20of%20Good%20Practice%20Version%204-0%20April%202017.pdf>

Keidel, G. (2002). Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice and Palliative Medicine*, 19(3), 200-205.

Kelle, U. (2007). The Development of categories: Different approaches in Grounded Theory. In K. Charmaz & A. Bryant (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 191–214). Los Angeles: SAGE Publications.

Kendall, J. (1999). Axial coding and grounded theory controversy. *Western Journal of Nursing Research*, 21, 743-757,

Kerr, D. (1997). *Down's syndrome and dementia: Practitioner's guide*. Birmingham: Venture Press.

- Kerr, D. (2007). *Understanding learning disability and dementia: Developing effective interventions*. London: Jessica Kingsley Publishers.
- Kerr, M., Fraser, W., & Felce, D. (1996). Primary healthcare for people with a learning disability. *British Journal of Learning Disabilities*, 24(1), 2–8.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Knox, S., & Burkard, A. W. (2009). Qualitative research interviews. *Psychotherapy Research*, 19(4-5), 566-575.
- Kuhn, T. S. (1962). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Kulakkottu, S. (2016). Role of the care pathways in interprofessional teamwork. *Nursing Standard*, 30(50), 42-47.
- Kwan, J., & Sandercock, P. (2005). In-hospital care pathways for stroke. *Stroke*, 36(6), 1348–1349.
- Lay, J., & Kirk, L. (2012). Person-centred strategies for planning. In H. Atherton & D. Crickmore (Eds.), *Learning disability: Towards inclusion* (pp. 145-160). Oxford: Elsevier.

- Lee, C-J. G. (2012). Reconsidering Constructivism in Qualitative Research. *Educational Philosophy and Theory*, 44(4), 403-412.
- Lempert, L. B. (2007). Asking Questions of the Data: Memo writing in the Grounded Theory tradition. In K. Charmaz & A. Bryant (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 245–265). Los Angeles: SAGE Publications.
- Levers, M-J. D. (2013). Philosophical paradigms, grounded theory, and perspectives on emergence. *SAGE Open*, 1-6.
- Llewellyn, P. (2011). The needs of people with learning disabilities who develop dementia: a literature review. *Dementia*, 10(2), 235–247.
- Lin, M. C. (2008). *A comparison of carers' experiences of caring for individuals with dementia or intellectual disability: A longitudinal grounded theory study*. Edinburgh: Napier University.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. London: SAGE Publications.
- Lindgren, C. L., Pass, C. M., & Sime, A. M. (1990). Burnout and social support in family caregivers. *Western Journal of Nursing Research*, 12(4), 469-487.
- Livingston G, Lewis-Holmes E, Pitfield C, Manela M, Chan D, Constant, E.,...Morris, J. (2013). Improving the end-of-life for people with dementia living in a care home: an intervention study. *International Psychogeriatric*, 25, 1849–1858.

- Local Government Association, Association of Directors of Adult Social Services, & NHS England (2015). *Building the right support*. London: NHS England.
- Lloyd, V., Kalsy, S., & Gatherer, A. (2008). Impact of dementia upon residential care for individuals with down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 5(1), 33-38 5.
- Lord, A. (2015). *The experiences of staff supporting people with intellectual disabilities with dementia, death, and bereavement*. (Unpublished Thesis). Lancaster: Lancaster University.
- Mander, R. (1992). Seeking approval for research access: The gatekeeper's role in facilitating a study of the care of the relinquishing mother. *Journal of Advanced Nursing*, 17, 1460-1464.
- Mann, D. M. (1988). Alzheimer's disease and down's syndrome. *Histopathology*, 13(2), 125-137.
- Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-9.
- Manthorpe, J., & Samsi, K. (2016). Person-centered dementia care: Current perspectives. *Clinical interventions in aging*, 11, 1733-1740.

- Maslach, C., Jackson, S.E. and Leiter, M.P. (1996). *MBI: The Maslach Burnout Inventory: Manual*. Palo Alto, CA: Consulting Psychologists Press.
- Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job burnout. *Annual Review of Psychology*, 52, 397– 422.
- Mason, J., & Scior, K. (2007). 'Diagnostic Overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17, 85-90.
- Matousova-Done, S., & Gates, B. (2006). The nature of care planning and delivery in intellectual disability nursing. In B. Gates (Ed.), *Care planning and delivery in intellectual disability Nursing* (pp. 1-20). Oxford: Blackwell.
- Mattson, M., & Hall, J. G. (2011). Linking health communication with social support. In M. Mattson & J. G. Hall (Eds.), *Health as communication nexus* (pp. 181–218). Kendall Hunt Publishing Co.
- McCann, T., & Clark, E. (2003). Grounded theory in nursing research: Part 3— Application. *Nurse Researcher*, 11(2), 29-39.
- McCarron, M., & McCallion, P. (2005). A revised stress and coping framework for staff carers of persons with intellectual disabilities and dementia. *Journal of Policy and Practice in Intellectual disabilities*, 2(2), 139-148.

- McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Alzheimer's dementia in persons with Down's syndrome: Predicting time spent on day-to-day caregiving. *Dementia, 4*(4), 521-538.
- McCarron, M., McCallion, P., Coppus, A., Fortea, J., Step, S., & Janicki, M. (2018). Supporting advanced dementia in people with Down syndrome and other intellectual disability: Consensus statement of the International Summit on Intellectual Disability and Dementia. *Journal of Intellectual Disability Research, 62*(7), 617-624.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K., & Dunn-Lane, J. (2010). Supporting persons with Down syndrome and advanced dementia: Challenges and care concerns. *Dementia, 9*, 285–298.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., & Connaire, K. (2011). The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia. *Journal of Applied Research in Intellectual Disabilities, 24*, 189-198.
- McCarron, M., McCallion, P., Reilly, E., & Mulryan, N. (2014). Responding to the challenges of service development to address dementia needs for people with an intellectual disability and their caregivers. In K. Watchman (Eds.), *Intellectual disability and dementia: Research into practice* (pp. 241-269). London, Jessica Kingsley Publisher.

- McCallion, P., Nickle, T., & McCarron, M. (2005). A comparison of reports of caregiver burden between foster family care providers and staff caregivers in other settings: A pilot study. *Dementia*, 4(3), 401-412.
- McGhee, G., Marland, G.R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60(3), 334–342.
- McKenzie, K., Baxter, S., Paxton, D., & Murray, G. (2002). Picking up the signs. *Learning Disability Practice*, 5(3), 16-19.
- McKenzie, K., Metcalfe, D., Michie, A., & Murray, G. (2018). Service provision in Scotland for people with an intellectual disability who have, or are at risk of developing, dementia. *Dementia*, 0(0), 1-14.
- McLaughlin, K. & Jones, A. (2010). 'It's all changed:' carers' experiences of caring for adults who have Down's syndrome and dementia. *British Journal of Learning Disabilities*, 39, 57-63.
- McNally, S. (2006). Person centred planning in intellectual disability nursing. In B. Gates (Ed.), *Care planning and delivery in intellectual disability nursing* (pp. 68-74). Oxford: Blackwell.

Mencap. (2004). *Treat me right: Better healthcare for people with a learning disability*.
London: Mencap.

Mencap (2007). Death by indifference. Retrieved from:
<http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=0CDIQFjAB&url=http%3A%2F%2Fwww.mencap.org.uk%2Fsites%2Fdefault%2Ffiles%2Fdocuments%2F2008-03%2FDBIreport.pdf&ei=zEO7UdKbNsKIhQe55YHADw&usq=AFQjCNGeJzqN9llsUoKxTpGGw7fFABUNiA&bvm=bv.47883778,d.ZG4>

Mental Health Foundation (2015a). Social Model of disability. Retrieved from:
<https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/s/social-model-disability>

Mental Health Foundation (2015b). *Dementia, rights, and the social model of disability*.
London: Mental Health Foundation.

Michael, J., & Richardson, A. (2008). Healthcare for all: The independent inquiry into access to healthcare for people with learning disabilities. *Tizard Learning Disability Review*, 13(4), 28-34.

Millard, C. (2015). *The Authenticity of person centred planning for people who use learning disability services*. (Unpublished Thesis). Exeter: University of Exeter.

Mills, C. W. (1959). *The sociological imagination*. New York: Oxford University Press.

- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12(1), 8-13.
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, 30(7), 46-50.
- Moore, C. L. (2012). *The caring experience of staff carers working with adults with learning disability and dementia*. (Unpublished Thesis). Hull: University of Hull.
- Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M., & Wolf, A. (2017). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences*, 31(4), 662-673.
- Mutkins, E., Brown, R. F., & Thorsteinsson, E. B. (2011). Stress, depression, workplace and social supports and burnout in intellectual disability support staff. *Journal of Intellectual Disability Research*, 55(5), 500-510.
- Naegeli, A.N., Flood, E., Tucker, J., Devlen, J., & Edson-Heredia, E. (2013). The patient experience with fatigue and content validity of a measure to assess fatigue severity: Qualitative research in patients with ankylosing spondylitis (AS). *Health and Quality of Life Outcomes*, 11, 192.

National Institute for Health and Clinical Excellence's (NICE; 2004). Dementia: supporting people with dementia and their carers in health and social care.

Retrieved from: <https://www.nice.org.uk/guidance/cg42>

National Institute for Health and Clinical Excellence's (NICE; 2018). Dementia.

Retrieved from:

<https://www.nice.org.uk/guidance/ng97/chapter/Recommendations>

NCH Software (2015). Express scribe transcription software. Retrieved from:

<http://www.nch.com.au/scribe/index.html>

Nelson, J. (2016). Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research. *Qualitative Research*, 17(5), 554-570.

Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. Southampton, University of Southampton: National Centre for Research Methods.

Nind, M., & Vinha, H. (2012). *Doing research inclusively, doing research well? Report of the study: Quality and capacity in inclusive research with people with learning disabilities*. University of Southampton.

Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: A new vision for gerontological nursing. *International Journal of Older People Nursing*, 13, 45-53.

Norman, I., & Redfern, S. (1997). *Mental healthcare for elderly people*. London: Churchill Livingstone.

NHS England (2017). *Dementia: Good Care Planning*. Leeds: NHS.

NHS (2018). Care and support plans. Retrieved from: <https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/care-and-support-plans/>

Nunkeosing, K. (2011). The social construction of learning disability. In H. Atherton, & D. Crickmore (Eds.), *Learning disabilities: Towards inclusion* (pp. 3-16). London: Churchill Livingstone.

O'Brien, J., & Tyne, A. (1981). *The principle of normalization: A foundation for effective services*. London: Campaign for the Mentally Handicapped.

Office of Public Sector Information (1990). *National Health Service and Community Care Act 1990* (c. 19). London: HMSO.

- O'Hara, R., Hull, J., Lyons, K., Bakitas, M., Hegel, M., Li, Z., & Ahles, T. (2010). Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. *Palliative Support Care*, 8, 395–404.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. London: Red Globe Press.
- Parkinson, M., Carr, S., Rushmer, R., & Abley, C. (2017). Investigating what works to support family carers of people with dementia: A rapid realist review. *Journal of Public Health*, 39(4), 290-301.
- Percy Report (1954-1957). *Report of the Royal Commission on the law relating to mental illness and mental deficiency, 1954-57, Cmnd 169*. London: HMSO.
- Perera, B., & Standen, P. (2014). Exploring coping strategies of carers looking after people with intellectual disabilities and dementia. *Advances in Mental Health and Intellectual Disabilities*, 8(5), 292-301
- Poppe, M., Burleigh, S., & Banerjee, S. (2013). Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS One*, 8(4).
- Potter, P., Deshields, T., Divanbeigi, J., Berger, J., Cipriano, D., Norris, L., & Olsen, S. (2010). Compassion fatigue and burnout: Prevalence among oncology nurses. *Clinical Journal of Oncology Nursing*, 14(5), 56-62.

- Powell, H., & Kwiatek, E. (2006). Integrated care pathways in intellectual disability nursing. In B. Gates (Ed.), *Care planning and delivery in intellectual disability nursing* (pp. 21-52). Oxford: Blackwell.
- Prasher, V. P. (2005). *Alzheimer's disease and dementia in down syndrome and intellectual disabilities*. Oxford: Radcliffe.
- Priest, H., & Gibbs, M. (2004). *Mental health care for people with learning disabilities*. Edinburgh: Churchill Livingstone.
- Rahman, S. (2017). *Enhancing health and wellbeing in dementia: A person-centred and integrated care approach*. London: Jessica Kingsley Publishers.
- Reeves, S, Kuper A, Hodges BD. (2008). Qualitative research methodologies: Ethnography. *BMJ*, 337, 512–514
- Reeves, S., Peller, J., Goldman, J., & Kitto. S. (2013). Ethnography in qualitative educational research: AMEE Guide No. 80. *Medical Teacher*, 8, e1365–e1379.
- Reiss, S., Levitan, G., & Szyszko, J., (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency*, 86, 567-574.
- Roberts, P. M. & Priest, H. M. (2010). *Healthcare research: A textbook for students and practitioners*. London: Wiley.

- Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., Howel, D., & Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing, 41*(2), 263-269.
- Rotter, T., Kinsman, L., James, E., Machotta, A., & Steyerberg, E. (2012). The quality of the evidence base for clinical pathway effectiveness: Room for improvement in the design of evaluation trials. *BMC Medical Research Methodology, 12*(80), 1-8.
- Royal College of Psychiatrists Working Group (2004). *The interface between General and Community Psychiatry and Old Age Psychiatry services: Report of a working group*. London: Royal College of Psychiatry.
- Royal College of Psychiatrists Working Group (2017). Mental health care pathways. Retrieved from: <https://www.rcpsych.ac.uk/workinpsychiatry/nccmh/mentalhealthcarepathways.aspx>
- Royal College of Psychiatrists (2013). *National Audit of Dementia Care in General Hospitals 2012-13*. London: Royal College of Psychiatry.
- Royal College of Psychiatrists (2014). *Care pathways for people with intellectual disability*. London: Royal College of Psychiatrists.

Royal College of Nursing (2016). Care Plans. Retrieved from: <https://rcni.com/hosted-content/rcn/first-steps/care-plans>

Royal Geographical Society (2013). Why are people living longer? Retrieved from: <http://www.rgs.org/OurWork/Schools/Teaching+resources/Key+Stage+3+resources/Who+wants+to+live+forever/Why+are+people+living+longer.htm>

Rowe, M. (2014). Will General Practitioners be adequately prepared to meet the complexities of enhanced dementia screening for people with learning disabilities and Down syndrome: key considerations. *British Journal of Learning Disabilities*, 44, 43–48.

Ryan, C., MacHale, R., & Hickey, E. (2018). “Forgetting familiar faces”: Staff perceptions of dementia in people with intellectual disabilities. *British Journal of Learning Disabilities*, 46(3), 155-162.

Ryan, J., & Carey, E. (2009). Developing person-centred planning in dementia care. *Learning Disability Practice*. 12(5), 24-28.

Saldana, J., (2015). *The coding manual for qualitative researchers*. London: SAGE Publications.

- Samsi, K., & Manthorpe, J. (2014), Care pathways for dementia: Current perspectives. *Clinical interventions in aging*, 9, 2055-2063.
- Saunders, B., Sim, J., Kingston, T., Baker, S., Waterfield, J., Bartlam, B.,... & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893-1907.
- Schaufeli, W.B., & Enzmann, D. (1998). *The burnout companion to study and research: A critical analysis*. London: Taylor & Francis.
- Schiffer, K. & Schatz, E. (2008). *Marginalisation, social inclusion and health*. Amsterdam: Correlation Network.
- Sharkey, S., & Larsen, J. A. (2005). Ethnographic exploration: Participation and meaning in everyday life. In I. Holloway (Ed.), *Qualitative research in health care* (pp. 168 – 190). Maidenhead: Open University Press.
- Singer, P., Martin, D., Lavery, J., Thiel, E., Kelner, M., & Mendelssohn, D. (1998). Reconceptualizing advance care planning from the patient's perspective. *Archives of Internal Medicine*, 158(8), 879-884.
- Sleeman, K., Koffman, J., Bristowe, K., Rumble, C., Burman, R., Leonard, S.,... Higginson, I. (2015). 'It doesn't do the care for you': a qualitative study of health

care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care. *BMJ Open*, 5.

Social Care Institute for Excellence [SCIE], (2018). Advance care planning. Retrieved from: <https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/advance-care-planning.asp>

Smebye, K., & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: A qualitative, hermeneutic study. *BMC Nursing*, 12 (29), 1-13.

Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: An update. *Advances in Psychiatric Treatment*, 11, 214-222.

Smith, J. & Osborn, M. (2003). Interpretive phenomenological analysis. In J. A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods* (pp.51-80). London: SAGE Publications.

Smith, K. & Biley, F. (1997). Understanding grounded theory: Principles and evaluation. *Nurse Researcher*, 4(3), 17-29.

Stalker K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, 13, 5–19.

- Starkey, H., Bevins, S., & Bonell, S. (2014). The role of prospective screening in the diagnosis of dementia in people with Down's syndrome. *Advances in Mental Health and Intellectual Disabilities, 8*(5), 283-291.
- van der Steen, J., van Soest-Poortvliet, M., Hallie-Heierman, M., Onwuteaka-Philipsen B., Deliens, L., de Boer, M.,...de Vet, H. (2014). Factors associated with initiation of advance care planning in dementia: A systematic review. *Journal of Alzheimer's Disease, 40*(3), 743-757
- Schreiber, R. S., & Stern, P. N. (2001). *Using Grounded Theory in Nursing*. New York: Springer.
- Stern, P.N. (1994). Eroding grounded theory. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 212-223). Thousand Oaks, CA: SAGE Publications.
- Strauss, A. L. & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: SAGE Publications.
- Strauss, A. L. & Corbin, J. M. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks, CA: SAGE Publications.
- Strydom, A., Al-Janabi, T., Houston, M., & Ridley, J. (2016). Best practice in caring for adults with dementia and learning disabilities. *Nursing Standard, 31*(6), 42-51.

- Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., . . . Maaskant, M. (2010). Dementia in older adults with intellectual disabilities-epidemiology, presentation, and diagnosis. *Journal of Policy & Practice in Intellectual Disabilities*, 7(2), 96-110.
- Suchman, J. (2006). A new theoretical foundation for relationship-centered care complex responsive processes of relating. *Journal of the Society of General Internal Medicine*, 21(1), 40-44.
- Sulch, D. & Kalra, L. (2000). Integrated care pathways in stroke management. *Age and Ageing*, 29, 349-52.
- Sullivan, D., Mannix, M., & Timmons, S. (2017). Integrated care pathways and care bundles for dementia in acute care: Concept versus evidence. *American Journal of Alzheimer's Disease & Other Dementias*, 32(4), 189-193.
- Taft L, Fazio S, Seman D, Stansell J. (1997). A psychosocial model of dementia care: Theoretical and empirical support. *Archives of Psychiatric Nursing*, 11, 13–20.
- Taylor, C. M. (2005). Interviewing. In I. Holloway (Ed.), *Qualitative research in health care* (pp. 39-53). Maidenhead: Open University Press.
- Taylor, J. (2016). *Making sense of sunbed tanning: A social representations approach* (Unpublished Thesis). Keele: Keele University.

The Mental Health Act (1959). London, TSO.

Thornberg, R. & Charmaz, K. (2011) Grounded theory. In S. Lapan, M. Quartaroli, & F. Riemer (Eds.), *Qualitative research: An introduction to methods and designs* (pp. 41-68). San Francisco: Jossey-Bass.

Tierney, W., Dexter, P., Gramelspacher, G., Perkins, A., Zhou, X., & Wolinsky, F. (2001). The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16, 32-40.

Tromans, S., Andrews, H., Wani, A., & Ganghadaran, S. (2018). The ELCIDD project: An audit of end-of-life care in persons with intellectual disabilities and dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 16(1), 88-92.

Truzzi, A., Valente, L., Ulstein, I., Engelhardt, E., Laks, J., & Engedal, K. (2012). Burnout in family caregivers of patients with dementia. *Rev Bras Psiquiatr*, 34(4), 405-412.

Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (2008). Doing research on people with learning disabilities, cancer, and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, 36, 185-190.

- Tuffrey-Wijne, I., Bernal, J., Jones, A., Butler, G., & Hollins, S. (2006). People with intellectual disabilities and their need for cancer information. *European Journal of Oncology Nursing*, *10*, 106–116.
- Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (2008). Doing research on people with learning disabilities, cancer, and dying: Ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, *36*, 185-190.
- Turner, B. A. (1981). Some practical aspects of qualitative data analysis: One way of organizing the cognitive processes associated with the generation of grounded theory. *Quality and Quantity*, *15*, 225–247.
- Turning Point (2004). *Hidden lives: Improving life chances of people with a learning disability*. London: Turning Point.
- Urquhart, C. (2007). The evolving nature of grounded theory method: The case of the information systems discipline. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 339-359). London: SAGE Publication.
- UK National Statistics (2013a). Life expectancies: UK national statistics publication hub. Retrieved from: <http://www.statistics.gov.uk/hub/population/deaths/life-expectancies/index.html>

UK National Statistics (2013b). Older people: UK national statistics publication hub.

Retrieved from: <http://www.statistics.gov.uk/hub/population/ageing/older-people>

Union of the Physically Impaired Against Segregation (1976). *Fundamental principles of disability*. London: The Disability Alliance.

Urquhart, C. (2007). The evolving nature of grounded theory method: The case of the information systems discipline. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 339-359). Thousand Oaks, CA: SAGE Publications.

Urquhart, C. (2013). *Grounded theory for qualitative research: A practical guide*. London, United Kingdom: SAGE Publications.

Vanhaecht, K., Panella, M., van Zelm, R., & Sermeus, W. (2010). An overview on the history and concept of care pathways as complex interventions. *International Journal of Care Pathways*, 14(3), 117-123.

Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32, 65-71.

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. London: Jessica Kingsley.

Wang, J., Xiao, L., He, G. P., Ullah, S., & De Bellis, A. (2014). Factors contributing to caregiver burden in dementia in a country without formal caregiver support. *Aging Mental Health, 18*(8), 986–96.

Watchman, K. (2003). Critical issues for service planners and providers of care for people with Down's syndrome and dementia. *British Journal of Learning Disabilities, 31*(2), 81-84.

Watchman, K. (2005). Practitioner-raised issues and end-of-life care for adults with Down syndrome and dementia. *Journal of Policy and Practice in Intellectual Disabilities, 2*(2), 156-162.

Watchman, K. (2007). Dementia and Down syndrome: The diagnosis and support needed. *Learning Disability Practice, 10*(2), 10-14.

Watchman, K. (2008). Changes in accommodation experienced by people with Down syndrome and dementia in the first five years after diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, 5*(1), 65-68.

Watchman, K. (2014). *Intellectual disability and dementia: Research into practice*. London, Jessica Kingsley Publisher.

Watchman, K. (2016). Investigating the lived experience of people with Down syndrome with dementia: Overcoming methodological and ethical challenges. *Journal of Policy and Practice in Intellectual Disabilities, 13*(2), 190-198.

Watchman, K., Janicki, M. P., Splaine, M., Larsen, F. K., Gomiero, T., & Lucchino, R. (2017). International summit consensus statement: Intellectual disability inclusion in national dementia plans. *American Journal of Alzheimer's Disease & Other Dementias*, 34(4), 230-237.

Watchman, K. (2017). *Intellectual disability and dementia: A guide for families*. London: Jessica Kingsley Publisher.

Watson, D. (2007). Causes and manifestation of learning disabilities. In H. Atherton & D. Crickmore (Eds.), *Learning disabilities: Towards inclusion* (pp. 3-15). Edinburgh: Elsevier/Churchill Livingstone.

Webster, J. & Watson, R. T. (2002). Analyzing the past to prepare for the future: Writing a literature review. *MIS Quarterly*, 26(2), xiii – xxiii.

Wells, C., & Smith, S. (2017). Diagnostic care pathways in Dementia: A review of the involvement of primary care in practice and innovation. *Journal of Primary Care and Community Health*. 8(2), 103-111.

Weslowski, P. (2014). Using forums and message boards to recruit study participants in qualitative research. *The Qualitative Report*, 19(23), 1-15.

- Whitehouse, R., Chamberlain, P., & Tunna, K. (2000). Dementia in people with learning disability: A preliminary study into care staff knowledge and attributions. *British Journal of Learning Disabilities*, 28, 148-153.
- Wiles, R. (2013). *What are qualitative research ethics*. London: Bloomsbury Academic.
- Wilkinson, H., Kerr, D., & Cunningham, C. (2005). Equipping staff to support people with an intellectual disability and dementia in care home settings. *Dementia*, 4, 387.
- Wilkinson, H., & Janicki, M. P. (2002). The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46(3), 279-284.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wills, P., Claesson, C., Fratiglioni, L., Fastborn, L., Thorslund, M., & Winblad, B. (1997). Drug use by demented and non-demented elderly people. *Age and Ageing*, 26(5), 383-391.
- Wills, W. J. (2012). Using spoken and written qualitative methods to explore children and young people's food and eating practices. *Sociological Research Online* 17(3), 16.

Wilson, C., Swarbrick, C., Pilling, M., & Keady, J. (2012). The senses in practice: Enhancing the quality of care for residents with dementia in care homes. *Journal of Advanced Nursing*, 69(1), 77-90.

Wood, S., Gangadharan, S., Tyrer, F., Gumber, R., Devaproam, J., Hiremath, A., & Bhaumik, S. (2014). Success and challenges in the implementation of care pathways in an intellectual disability service: Health professionals' experiences. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 1-7.

Wolfensberger, W. (1972). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation.

World Health Organisation (2010). ICD-10: Block F00-F09. Retrieved from: <http://thcc.or.th/ICD-10TM/gf00.htm>

World Health Organisation (2015). Ensuring a human rights-based approach for people living with dementia. Retrieved from: http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf

World Health Organisation (2016). ICD-10: Block F70-F79. Retrieved from: <http://apps.who.int/classifications/icd10/browse/2016/en#/F70-F79>

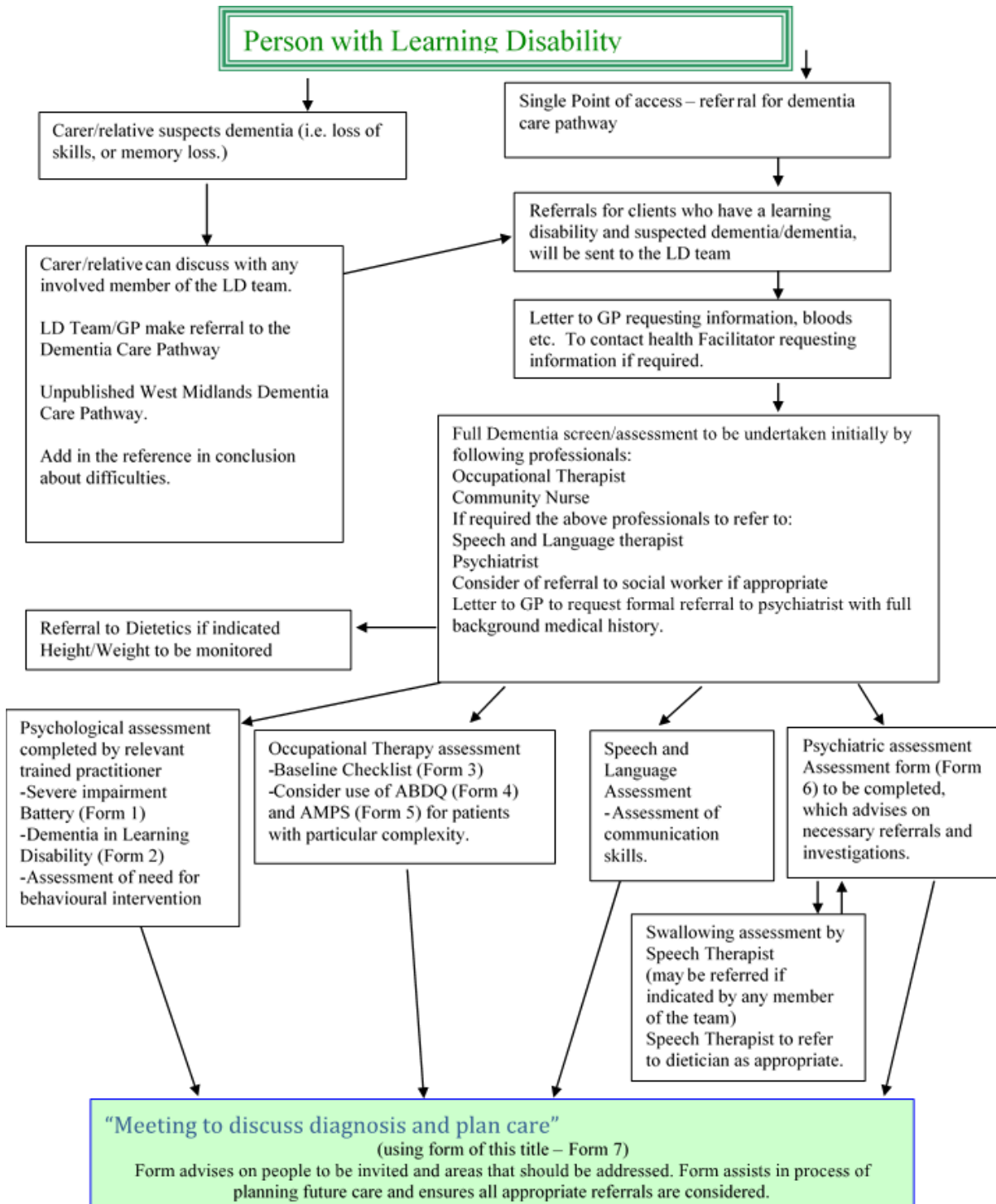
Appendices

Appendix A

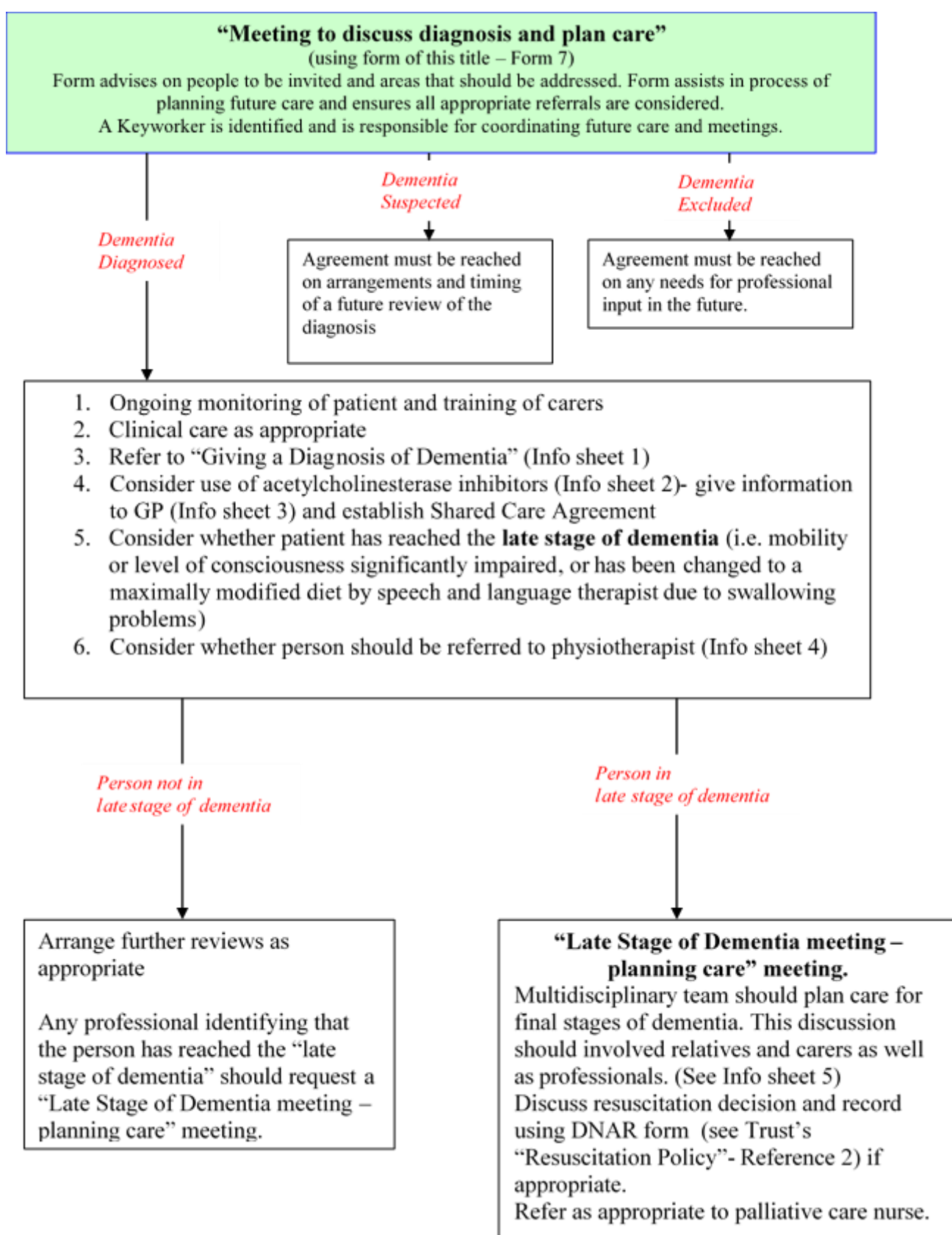
- A West Midlands Intellectual Disability Dementia Care Pathway (IDDCP)

This document has been edited to ensure anonymity

Stage 1. Initial Assessment



Stage 2. Diagnosis and Planning Care



Appendix B

- Peer Review Comments from 1st Application of Independent Peer Review

PEER REVIEWER'S PROFORMA

Research Project Details	
Project title	People with intellectual disabilities and dementia: Exploring the holistic care and support provided by a care pathway
Name of principal investigator	Daniel Herron
Institution of principal investigator	

The important or relevance of the problem to be addressed in relation to either or both of:

The particular field of research as a whole

The value of this research for health or social care

The quality and relevance of the background information provided

This proposal identifies the relevant literature with regard to looking at Dementia Care pathways with people with intellectual disabilities. However there is an additional small research literature looking at views of carers and staff with regard to people with intellectual disabilities and dementia that has not been referred to. This needs to be considered in the literature review and design of the semi-structured questionnaires.

Design, methods and strengths and weakness of the proposed plan of investigation

The design and methods are appropriate for this sort of study. An Easy Read Information sheet and consent form are essential for the people with intellectual disabilities and dementia.

The proposal talks about gaining obtained consent from people with intellectual disabilities and dementia – this may be difficult and needs to be addressed in the proposal. The proposal also needs to outline how the researcher will explore issues of dementia if the person has not been told, or if they become distressed.

It is also unclear from the proposal how many people from each of the four groups will be recruited to make the analysis meaningful.

The quality of analysis provided (statistical or qualitative, as appropriate)

This seems appropriate for this study.

The capacity and expertise of the research team in the context of the proposed study

This seems appropriate.

Appropriateness of resource requirements

Appropriate,

General feedback (indicate major areas where changes will be required, indicate whether any weaknesses indicated in any of the above categories are major or minor areas of concern)

I think this is an important piece of research which will add to the limited evidence base with regard to our understanding of dementia and people with intellectual disabilities. More detail is needed with regard to consent issues, and what happens if none of the prospective participants identified with dementia can give informed consent. Also how people with intellectual disabilities and family carers will be

supported if they become distressed either at the time of the interview or later having talked about their issues.

Assessment of Merit

Grading	Description	Please tick
1	Proceed without any revision. Project may be submitted for appropriate NHS/University approval and then to either the Local or the Multi-Centre Research Ethics Committee.	
2	Minor amendments or Further information required. Revise project according to reviewer(s) recommendations. Document to be checked by Internal Committee Member prior to Chairman's approval to proceed.	Yes
3	Complete major revision required. Principal Investigator to discuss outcome with Centre/Programme Director and agree plan to complete substantive revision of the project (with support as agreed). Resubmission will need to be reviewed and approved by Internal Committee Member, prior to Chairman's approval to proceed.	
4	Reject on the basis that the project has major scientific flaws	

Appendix C

- Independent Peer Review Grade after Replying to Comments



21st November 2013

Daniel Herron

RESEARCH AND ENTERPRISE SERVICES

Dear Daniel,

'People with intellectual disabilities and dementia: Exploring the holistic care and support provided by a care pathway'

As you know the above project was initially awarded a grade 2 but following assessment of your response to the issues raised the project now has received final approval from the Independent Peer Review Committee and can be submitted for ethical approval.

I am attaching a letter addressed to the Chair of the NHS REC along with the original peer review comments which you can enclose with your NHS REC application.

Management approval You should arrange for all relevant NHS care organisations to be notified that the research will

be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Clinical trial of a medicinal product

Please remember that, if your project is a clinical trial of a medicinal product, MHRA approval is required. You must submit a request for a clinical trial authorisation under the Medicines for Human Use (Clinical Trials) Regulations 2004. Further details can be found at <http://www.mhra.gov.uk/home/groups/l-unit1/documents/websiteresources/con2022633.pdf>

Appendix D

- Research Ethics Committees (REC) Provisional Opinion Letter and ethical approval

Dear Mr Herron

Study Title:

REC reference: Protocol number: IRAS project ID:

People with both Intellectual Disabilities and Dementia: Exploring Holistic Care and Support 13/WM/0513 N/A

140593

[National Research Ethics Service](#)

NRES Committee West Midlands - The Black Country

The Research Ethics Committee reviewed the above application at the meeting held on 03 February 2014. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

HRA NRES Centre Manchester 3rd Floor, Barlow House 4 Minshull Street
Manchester M1 3DZ

Telephone: 0161 625 7821 Facsimile: 0161 625 7299

Document	Version	Date
Evidence of insurance or indemnity		23 July 2013
GP/Consultant Information Sheets	1	28 November 2013
Interview Schedules/Topic Guides	(Intellectual Disability and Dementia) 1	28 November 2013
Interview Schedules/Topic Guides	(Family Carer) 1	28 November 2013

Interview Schedules/Topic Guides	(Professional Carer) 1	28 November 2013
Interview Schedules/Topic Guides	(Professional Members of Dementia Care Pathway) 1	28 November 2013
Investigator CV		
Letter from Sponsor	1	28 November 2013
Letter of invitation to participant	1 (People with Intellectual Disabilities and Dementia)	28 November 2013
Letter of invitation to participant	1 (Both Carer Groups and Dementia Care Pathway Professionals)	28 November 2013

A Research Ethics Committee established by the Health Research Authority

Other: Academic Supervisor CV: Dr Helen Priest		28 November 2013
Other: Flowchart	1	29 November 2013
Other: Poster	1	28 November 2013
Other: Academic Supervisor CV: Professor Susan Read		
Participant Consent Form: Intellectual Difficulties and Dementia	1	28 November 2013
Participant Consent Form: Family and Professional Carers	1	28 November 2013
Participant Consent Form: Professionals from Dementia Care Pathway	1	28 November 2013
Participant Information Sheet: Intellectual Disability and Dementia	1	28 November 2013

Participant Information Sheet: Family Carer	1	28 November 2013
Participant Information Sheet: Professional Carer	1	28 November 2013
Participant Information Sheet: Professionals from Dementia Care Pathway	1	28 November 2013
Protocol	1	28 November 2013
REC application	140593/540009/1/978	12 December 2013
Referees or other scientific critique report		21 November 2013

Provisional opinion

1. The Committee made reference to the peer review and in particular how the issues of dementia will be handled if the individual has not been told that they have it. You clarified that you work closely with the pathway team and they have informed you that all participants recruited to this study will know that they have dementia.
2. The Committee pointed out that the wording on the information sheet for the Professional carers is identical to the wording used for the family carers; some of it will not be applicable e.g. the decision will have no influence on the support they receive...etc. You clarified that the professionals will receive training which could count as support; the Committee clarified that it is making reference to the treatment patients would receive. You agreed to amend the Information Sheet accordingly.
3. The Committee pointed out that there should be a statement on the consent form making reference to the GP being informed. The Committee also pointed out that there need not be a separate consent form for the use of quotes; the statements on the consent form can be merged into the main

consent form. You agreed.

4. The Committee queried what would happen if anybody became distressed. You clarified that you would stop the interview and see how they feel. If they need to be referred then you will do that. The Committee advised that it would be helpful to name an individual as a point of contact on the information sheet. You agreed.

You were thanked for attending and left the meeting room. The Committee considered your responses.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Alternate Vice-Chair.

A Research Ethics Committee established by the Health Research Authority

Further information or clarification required

1. The Committee would like to see the Professional carers information sheet revised to ensure it is applicable to them. Some of the wording used applies to the family carers such as; '...discuss it with family and relatives if you wish.' And also 'Your decision will have no influence on the services and support you receive.' And 'supportive figure of your choice. The information sheet needs to be proof read and corrected where appropriate.
2. Both Information Sheets for the family carer and professional carer require amending where the title should be 'What will happen if I take part?' currently the word 'part?' is missing. They also require a statement that the patients GP will be informed of their taking part in the study.
3. The information sheets for people with ID should have a named contact point for anybody who requires help and

support. Currently and organisation is named which is fine, but there should be an individual named person.

4. The Committee would like to see the Consent Form revised as follows;

Incorporate the 'use of quotes' section of the form into the main consent form.

Insert the following standard mandatory paragraph 'I understand that relevant data collected during the study, may be looked at by individuals from [\[COMPANY NAME\]](#), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these



Health Research Authority

National Research Ethics Service

NRES Committee West Midlands - The Black Country

HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7269

19 February 2014

Mr Daniel Herron
PhD student
Keele University
Centre for Psychological Research, Dorothy Hodgkin Building
Keele University, Keele
Staffordshire
ST5 5BG

Dear Mr Herron

Study title:	People with both Intellectual Disabilities and Dementia: Exploring Holistic Care and Support
REC reference:	13/WM/0513
Protocol number:	N/A
IRAS project ID:	140593

Thank you for your letter of 18 February 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Miss Shehnaz Ishaq, nrescommittee.westmidlands-blackcountry@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

A Research Ethics Committee established by the Health Research Authority

Appendix E

- Ethical Approval Process

The Process of Gaining Ethical Approval

The first step was to gain ethical approval. This process started with identifying the appropriate ethics panel to review the research. Initial searches identified a local dementia register specifically for people with an intellectual disability, attached to an intellectual disability dementia care pathway team (IDDCP). As this was part of an NHS organisation, and participants consisted of service users, their carers and healthcare professionals working within the NHS, the research needed to be reviewed by an NHS Research Ethics Committee.

As stated by the Department of Health (DH) (2005) in the Research Governance Framework for Health and Social Care, research which involves service users is required to be reviewed independently; therefore, the process for gaining ethical approval began with an Independent Peer Review (IPR) of the research proposal.

Independent peer review.

This independent review was conducted by a senior representative of Keele University's Joint Independent Peer Review Committee, who assessed the quality of the then proposed research, before giving feedback (see Appendix E) in the form of one of four grades: grade one, the application has been successful and needs no amendments; grade two, the application needs minor amendments or further information, before being resubmitted; grade three, major revisions are needed; and grade four, the application has been rejected. Following independent peer review approval (see Appendix F) from the University, NHS ethical approval was sought.

Integrated Research Application System (IRAS).

IRAS is a 'single system for applying for the permissions and approvals for health and social care / community care research in the UK' (IRAS, 2014, para. 1). This application required details on every aspect of the project across eleven areas using the IRAS system; each section required thorough planning.

Research Ethics Committees (REC).

The REC reviews applications for research, before giving an opinion about potential participant involvement and the ethical nature of the research (NHS, 2013). These committees can consist of up to 18 members, where one third are lay members. Their role includes safeguarding the 'rights, safety, dignity and well-being of research participants, independently of research sponsors' (NHS, 2013, para. 1). The proposal went through the Black Country REC, who initially provided a provisional opinion letter (see Appendix G), which detailed the committee's requirements before they could give a favourable ethical opinion. A favourable opinion was provided in response to changes.

Substantial amendment.

At the time of the REC application, the research was also going through the internal process of PhD progression, which reviewed the project to date. From this process, it was decided that a second interview for all participants, apart from the IDDCP healthcare professionals and paid carers, would be beneficial to the research process. As this was altering the research method, a substantial amendment form was completed, and reviewed by the REC, before a favourable opinion given (see Appendix H).

Minor amendments.

As the research study progressed it was necessary to make two minor amendments. The first related to extending the duration of access to the research site. Due to a change in the mode of attendance from full-time to part-time for the researcher, the timeline of the research study was altered to correspond with part-time studying. Additionally, access and recruitment were significantly delayed (see Chapter Four). In response to the aforementioned challenges, the second amendment was adding a further research site, a housing and care organisation. Both minor amendments were approved.

NHS Trust Research and Development (R&D) approval.

NHS R&D approval relates to a 'risk proportionate process of reviewing research applications to take place within an NHS organisation' (NHS, 2013, para. 1). The application was reviewed and permission to conduct the research in the local Trust was granted. A contact within the NHS North Staffordshire Combined Healthcare Research and Development (R&D) was contacted in relation to minor amendments, and where necessary they sent updated documents to the researcher.

Site Specific Information (SSI).

The R&D SSI forms are intended to be completed for each NHS site where the research is being carried out. As the current research project had only one NHS research site, no adapted versions were required for documents submitted with the main application. The SSI form was included with the R&D application.

Research passport.

A further requirement before research could begin was the completion and approval of a research passport; this is a 'streamlined procedure for issuing honorary research contracts or letters of access to researchers who do not have a contractual relationship with the NHS who carry out research in the NHS that affects patient care or requires access to NHS Facilities' (Keele University, 2014, para. 1)

Appendix F¹

- Information Sheet for Healthcare Professionals

DCP



Information Sheet

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Aims of the Research

The proposed research aims to:

- explore the experiences and journeys of people with a learning disability living with dementia.
- explore the experiences and journeys of family and professional carers.
- critically explore how services and the support systems in place influence their journey, experience of holistic care and support, and how this may be best utilised.

Invitation

You are being invited to consider taking part in the research study on 'People with Learning Disabilities and Dementia: Exploring Holistic Care and Support'. This project is being undertaken by Dan Herron, Dr Helena Priest and Professor Sue Read.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being carried out and what it will involve. **Please take time to read this information carefully and discuss it with friends and relatives if you wish.**

Ask us if there is anything that is unclear or if you would like more information.

Why have I been chosen?

As a professional with a role in the Dementia Care Pathway for people with learning disabilities, you have been chosen to take part in this study

10

Do I have to take part?

You are free to decide whether you wish to take part or not.

If you do decide to take part you will be asked to sign **two consent forms**, one is for you to keep and the other is for our records.

You are free to withdraw from this study at any time and without giving reasons.

What will happen if I take

You will take part in an interview. The time and location of the interview will be entirely your choice. You should choose a location where you feel comfortable to openly speak about your experiences, views and opinions. Space will be made available at Keele University if required.

If I take part what will I have to do?

You will take part in an interview.

The interview will be an informal conversation about your experiences, views and opinions of the Dementia Care Pathway, dementia services, care and support for people with both learning disabilities and dementia, and their carer.

What are the benefits (if any) of taking part?

You will be helping us to understand more about how people with learning disabilities experience dementia, and the presentation of dementia. Additionally, you will be providing much needed information on dementia care, support and services.

Taking part in this research will also give you an opportunity to have your say, no matter what it may be, in a secure and confidential environment. What you say may help to shape future services and support in North Staffordshire for people with learning disabilities and carers.

What are the risks (if any) of taking part?

There are no risks we can anticipate of you taking part in this study.

How will the information I provide be used?

During the interviews we will be digitally recording your conversation. Categories will be pulled from this data which best represent your experiences and opinions.

The data you provide will be used in the researcher's thesis which will be handed in at the end of their PhD. It will also be used in academic conference presentations and used for publications in journals. **A report will be produced and made available to you.**

All of your data will remain **confidential and anonymous**. Your name will be replaced with a code throughout, and any identifiable information will be avoided in the write up.

If you **lose the ability to give consent** during any part of the study the data you have provided prior to this will be kept, but no other data will be collected.

Who will have access to this information?

All the information you provide will remain confidential. Only the research team will have access, this includes Dan Herron (Chief researcher), Dr Helena Priest and Prof Sue Read, and individuals from regulatory authorities or from the NHS Trust.

- You will give us your full name when signing the consent form, but all participants' names will be replaced with codes for use in analysis and the reports (unless you opt to have your real name used).
- All of the information will be kept in a locked office.
- Digital information will be kept on a password protected computer which is located in a locked office.
- Hard copies will be kept in a locked filing cabinet in a locked office.
- Following good practice research, your data will be kept secure for at least five years after the conclusion of the study, and when appropriate the data will be securely destroyed.

Who is funding and organising the research?

This research has no external funding and is being organised by the Chief Researcher, Dan Herron, for part of his PhD.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the researcher(s), who will do their best to answer your questions; you should contact Dan Herron on d.l.herron@keele.ac.uk or 01782 734402. Alternatively, you may wish to contact the researcher's project supervisor, if so you may contact Dr Helena Priest, at H.M.Priest@staffs.ac.uk or 01782-294580/4007

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact Nicola Leighton, who is Keele University's contact for complaints regarding research, at the following address:-

Nicola Leighton

**Research Governance Officer
Research & Enterprise Services
IC1
Keele University
ST5 5BG**

E-mail: n.leighton@keele.ac.uk

Tel: 01782 733306

Contact for further information

Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology
Dorothy Hodgkin Building, Keele University
Keele, Staffordshire
ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number: 01782 734402

Contact for Support Services

Approach

Helpline: 01782 214999

Email: enquiries@approachstaffordshire.co.uk

Appendix F²

- Consent Form for Healthcare Professionals



Consent Form

Study Title

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Name and Contact details of Chief investigator

Dan Herron, School of Psychology, Dorothy Hodgkin Building, Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone: 01782 734402

Please tick box if you agree with the statement

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time.
3. I agree to take part in this study.
4. I understand that data collected about me during this study will be anonymised before it is submitted for publication.
5. I agree to the interview being recorded.
6. I agree for any anonymised quotes from me to be used in reports and conferences.
7. I understand that relevant data collected during the study, may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

Name of participant

Date

Signature

Daniel Herron

Name of researcher

Date

Signature

Appendix F³

- Invitation Letter for Healthcare Professionals

Invitation Letter

People with both Learning Disabilities and Dementia: Holistic Care and Support

Dear insert

You are invited to take part in our research project which wishes to:

- explore the experiences and journeys of people with learning disabilities living with dementia.
- explore the experiences and journeys of family and professional carers.
- critically explore how the support systems in place influence both your journey and the person with both a learning disability and dementia, experience of care and support, and how this may be best utilised.

In this project you will take part in an **informal interview** speaking about your experiences and opinions. This may take place in a location of your choice and you may have a supportive figure of your choice present.

With this letter I have enclosed a reply slip and an addressed envelope.

After you have had time to read this letter please consider if you would like to know more about this research project. If you would like to know more, then please return the completed slip below in the enclosed envelope. This slip asks if you wish to speak further about this research, and if so, for your permission to use your contact details for further communication; only the research team will have access to this information, which will be stored in a locked filing cabinet, in a locked office.

If you have further questions then please contact me: Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology, Dorothy Hodgkin Building,
Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number:

With thanks for your time

.....

Delete as appropriate*

I would / would not* like to speak further about the research project on **People with both Learning Disabilities and Dementia: Holistic Care and Support**

Name.....

Postal
Address
.....
.....
.....

Contact Telephone Number.....

Date.....

Signature.....

Appendix G¹

- Information Sheet, Consent Form, and Invitation Letter for Paid Carers

Paid carer information sheet



Information Sheet

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Aims of the Research

The proposed research aims to:

- explore the experiences and journeys of people with a learning disability living with dementia.
- explore the experiences and journeys of carers, caring for someone with an learning disability and dementia.
- critically explore how services and the support systems in place influence their journey, experience of holistic care and support, and how this may be best utilised.

Invitation

You are being invited to consider taking part in the research study on People with both learning Disabilities and Dementia: Exploring Holistic Care and Support. This project is being undertaken by Dan Herron, Dr Helena Priest and Professor Sue Read.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being carried out and what it will involve. **Please take time to read this information.**

Ask us if there is anything that is unclear or if you would like more information.

Why have I been chosen?

As a carer of someone with both a learning disability and dementia, your experiences of providing care and support, and of dementia services are very important to us.

Do I have to take part?

You are free to decide whether you wish to take part or not.

If you do decide to take part you will be asked to sign **two consent forms**, one is for you to keep and the other is for our records.

You are free to withdraw from this study at any time and without giving reasons.

What will happen if I take part?

You will take part in two interviews. The time and location of the interviews will be entirely your choice. You should choose a location where you feel comfortable to openly speak about your experiences, views and opinions. Space will be made available at Keele University if required.

If I take part what will I have to do?

You will take part in two interviews.

The interviews will be an informal conversation about your experiences, views and opinions of caring for someone with a learning disability and dementia, dementia care and services, and the support they provide the service user. **It is important to remember that anything you say will be confidential and anonymous.**

What are the benefits (if any) of taking part?

You will be helping us to understand more about your experiences of caring for a family member with both a learning disability and dementia, and their experience of dementia. Additionally, you will be providing much needed information on dementia care, support and services.

Taking part in this research will also give you an opportunity to have your say, no matter what it may be, in a secure and confidential environment. What you say may help to shape future dementia services and support in North Staffordshire for people with learning disabilities and carers.

What are the risks (if any) of taking part?

There are no risks we can anticipate of you taking part in this study. However, you may speak about scenarios and experiences which you **may find emotionally challenging**.

- You will have the ability to stop the interview and withdraw from the study.
- You may have a supportive figure of your choice present.
- Information on support services will also be provided in the contact section at the end of this sheet.

How will the information I provide be used?

During the interviews we will be digitally recording our conversation. Categories will be pulled from this data which best represent your experiences and opinions.

The data you provide will be used in the researcher's thesis which will be handed in at the end of their PhD. It will also be used in academic conference presentations and used for publications in journals. **A report will be produced and made available to you.**

All of your data will remain **confidential and anonymous**. Your name will be replaced with a code throughout, and any identifiable information will be avoid in the write up.

If you **lose the ability to give consent** during any part of the study the data you have provided prior to this will be kept, but no other data will be collected.

Who will have access to this information?

All the information you provide will remain confidential. Only the research team will have access, this includes Dan Herron (Chief researcher), Dr Helena Priest and Prof Sue Read, and individuals from regulatory authorities or from the NHS Trust.

- You will give us your full name when signing the consent form, but participants' names will be replaced with codes for use in analysis and the reports (unless you opt to have your real name used).
- All of the information will be kept in a locked office.
- Digital information will be kept on a password protected computer which is located in a locked office.
- Hard copies will be kept in a locked filing cabinet in a locked office.
- Following good practice research, your data will be kept secure for at least five years after the conclusion of the study, and when appropriate the data will be securely destroyed.

Who is funding and organising the research?

This research has no external funding and is being organised by the Chief Researcher, Dan Herron, for part of his PhD.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the researcher(s), who will do their best to answer your questions. You should contact Dan Herron on d.i.herron@keele.ac.uk or 01782 734402. Alternatively, you may wish to contact the researcher's project supervisor, if so you may contact Dr Helena Priest, at H.M.Priest@staffs.ac.uk or 01782-294580/4007

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact Nicola Leighton, who is Keele University's contact for complaints regarding research, at the following address:-

Nicola Leighton

**Research Governance Officer
Research & Enterprise Services
IC1**

**Keele University
ST5 5BG**

E-mail: n.leighton@keele.ac.uk

Tel: 01782 733306

Contact for further information

Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology
Dorothy Hodgkin Building, Keele University
Keele, Staffordshire
ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number: 01782 734402

Contact for Support Services

Carers Direct

Website: www.nhs.uk/carersdirect

Carers Direct helpline: **0808 802 0202**

An online and telephone service providing information advice and support for carers.

Approach

Helpline: 01782 214999

Email: enquiries@approachstaffordshire.co.uk

Appendix G²

- Consent Form for Paid Carers



Consent Form

Study Title

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Name and Contact details of Chief investigator

Dan Herron, School of Psychology, Dorothy Hodgkin Building, Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone: 01782 734402

Please tick box if you agree with the statement

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time.
3. I agree to take part in this study.
4. I understand that data collected about me during this study will be anonymised before it is submitted for publication.
5. I agree to the interview being recorded.
6. I agree for any anonymised quotes from me to be used in reports and conferences.
7. I understand that relevant data collected during the study, may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix G³

- Invitation Letter for Paid Carers

Invitation Letter

People with both Learning Disabilities and Dementia: Holistic Care and Support

Dear insert

You are invited to take part in our research project which wishes to:

- explore the experiences and journeys of people with learning disabilities living with dementia.
- explore the experiences and journeys of family and professional carers.
- critically explore how the support systems in place influence both your journey and the person with both a learning disability and dementia, experience of care and support, and how this may be best utilised.

In this project you will take part in an **informal interview** speaking about your experiences and opinions. This may take place in a location of your choice and you may have a supportive figure of your choice present.

With this letter I have enclosed a reply slip and an addressed envelope.

After you have had time to read this letter please consider if you would like to know more about this research project. If you would like to know more, then please return the completed slip below in the enclosed envelope. This slip asks if you wish to speak further about this research, and if so, for your permission to use your contact details for further communication; only the research team will have access to this information, which will be stored in a locked filing cabinet, in a locked office.

If you have further questions then please contact me: Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology, Dorothy Hodgkin Building,

Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number:

With thanks for your time

.....

Delete as appropriate*

I would / would not* like to speak further about the research project on **People with both Learning Disabilities and Dementia: Holistic Care and Support**

Name.....

Postal

Address
.....
.....
.....

Contact Telephone Number.....

Date.....

Signature.....

Appendix H¹

- Information Sheet for Family Carers

Family Carer information sheet



Information Sheet

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Aims of the Research

The proposed research aims to:

- explore the experiences and journeys of people with learning disabilities living with dementia.
- explore the experiences and journeys of carers, caring for someone with both a learning disability and dementia.
- critically explore how services and the support systems in place influence their journey, experience of holistic care and support, and how this may be best utilised.

Invitation

You are being invited to consider taking part in the research study on People with both Learning Disabilities and Dementia: Exploring Holistic and Support. This project is being undertaken by Dan Herron, Dr Helena Priest and Professor Sue Read.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being carried out and what it will involve. **Please take time to read this information carefully and discuss it with friends and relatives if you wish.**

Ask us if there is anything that is unclear or if you would like more information.

Why have I been chosen?

As a carer of a family member with both a learning disability and dementia, your experiences of providing care and support, and of dementia services are very important to us.

Do I have to take part?

You are free to decide whether you wish to take part or not.

Your decision will have no influence on the services and support you receive.

If you do decide to take part you will be asked to sign **two consent forms**, one is for you to keep and the other is for our records.

You are free to withdraw from this study at any time and without giving reasons.

What will happen if I take part?

You will take part in two interviews. The time and location of these interviews will be entirely your choice. You should choose a location where you feel comfortable to openly speak about your experiences, views and opinions. Space will be made available at Keele University if required.

If I take part what will I have to do?

You will take part in two interviews.

These interviews will be an informal conversation on your experiences, views and opinions of caring for a family member with both a learning disability and dementia, dementia care and services, and the support they provide for you and your family member. **It is important to remember that anything you say will be confidential**

What are the benefits (if any) of taking part?

You will be helping us to understand more about your experiences of caring for a family member with both a learning disability and dementia, and their experience of dementia. Additionally, you will be providing much needed information on dementia care, support and services.

Taking part in this research will also give you an opportunity to have your say, no matter what it may be, in a secure and confidential environment. What you say may help to shape future dementia services and support in North Staffordshire for people with learning disabilities and carers.

What are the risks (if any) of taking part?

There are no risks we can anticipate of you taking parting this study. However, you may speak about scenarios and experiences which you **may find emotionally challenging**.

- You will have the ability to stop the interview and withdraw from the study.
- You may have a supportive figure of your choice present.
- Information on support services will also be provided in the contact section at the end of this sheet.

How will the information I provide be used?

During the interviews we will be digitally recording our conversation. Categories will be pulled from this data which best represent your experiences and opinions.

The data you provide will be used in the researcher's thesis which will be handed in at the end of their PhD. It will also be used in academic conference presentations and used for publications in journals. **A report will be produced and made available to you.**

All of your data will remain **confidential and anonymous**. Your name will be replaced with a code throughout, and any identifiable information will be avoided in the write up.

If you **lose the ability to give consent** during any part of the study the data you have provided prior to this will be kept, but no other data will be collected.

Who will have access to this information?

All the information you provide will remain confidential. Only the research team will have access, this includes Dan Herron (Chief researcher), Dr Helena Priest and Prof Sue Read, and individuals from regulatory authorities or from the NHS Trust.

- You will give us your full name when signing the consent form, but all participants' names will be replaced with codes for use in the analysis and reports (unless you opt to have your real name used).
- All of the information will be kept in a locked office.
- Digital information will be kept on a password protected computer, located in a locked office.
- Hard copies will be kept in a locked filing cabinet, in a locked office.
- Following good practice research, your research data will be kept secure for at least five years after the conclusion of the study, and when appropriate the data will be securely destroyed.

Who is funding and organising the research?

This research has no external funding and is being organised by the Chief Researcher, Dan Herron, for part of his PhD.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the researcher(s), who will do their best to answer your questions. You should contact Dan Herron on d.l.herron@keele.ac.uk or 01782 734402. Alternatively, you may wish to contact the researcher's project supervisor, if so you may contact Dr Helena Priest, at H.M.Priest@staffs.ac.uk or 01782-294580/4007

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact Nicola Leighton, who is Keele University's contact for complaints regarding research, at the following address:-

Nicola Leighton

**Research Governance Officer
Research & Enterprise Services
IC1
Keele University
ST5 5BG**

E-mail: n.leighton@keele.ac.uk

Tel: 01782 733306

Contact for further information

Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology
Dorothy Hodgkin Building, Keele University
Keele, Staffordshire
ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number: 01782 734402

Contact Support Services

Carers Direct

Website: www.nhs.uk/carersdirect

Carers Direct helpline: **0808 802 0202**

An online and telephone service providing information advice and support for carers.

The Alzheimer's Society (England, Wales and Northern Ireland)

Website: www.alzheimers.org.uk

Helpline: **0300 222 1122**

The Alzheimer's Society offers information, advice and support for people with dementia and their families.

Appendix H²

-Consent Form for Family Carers



Consent Form

Study Title

People with both Learning Disabilities and Dementia: Exploring Holistic Care and Support

Name and Contact details of Chief investigator

Dan Herron, School of Psychology, Dorothy Hodgkin Building, Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone: 01782 734402

Please tick box if you agree with the statement

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time.
3. I agree to take part in this study.
4. I understand that data collected about me during this study will be anonymised before it is submitted for publication.
5. I agree to the interview being recorded.
6. I agree for any anonymised quotes from me to be used in reports and conferences.
7. I understand that relevant data collected during the study, may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix H³

- Invitation Letter for Family Carers

Invitation Letter

People with both Learning Disabilities and Dementia: Holistic Care and Support

Dear insert

You are invited to take part in our research project which wishes to:

- explore the experiences and journeys of people with learning disabilities living with dementia.
- explore the experiences and journeys of family and professional carers.
- critically explore how the support systems in place influence both your journey and the person with both a learning disability and dementia, experience of care and support, and how this may be best utilised.

In this project you will take part in an **informal interview** speaking about your experiences and opinions. This may take place in a location of your choice and you may have a supportive figure of your choice present.

With this letter I have enclosed a reply slip and an addressed envelope.

After you have had time to read this letter please consider if you would like to know more about this research project. If you would like to know more, then please return the completed slip below in the enclosed envelope. This slip asks if you wish to speak further about this research, and if so, for your permission to use your contact details for further communication; only the research team will have access to this information, which will be stored in a locked filing cabinet, in a locked office.

If you have further questions then please contact me: Daniel Herron (**Chief Researcher**)

Contact Address

School of Psychology, Dorothy Hodgkin Building,
Keele University, Keele, Staffordshire, ST5 5BG

Email: d.l.herron@keele.ac.uk

Telephone number:

With thanks for your time

.....

Delete as appropriate*

I would / would not* like to speak further about the research project on **People with both Learning Disabilities and Dementia: Holistic Care and Support**

Name.....

Postal

Address
.....
.....
.....

Contact Telephone Number.....

Date.....

Signature.....

Appendix I

- Pre-Interview Check List

People with both Intellectual Disabilities and Dementia: Exploring Holistic Care and Support

Date:

Introduction to the process

- Thank the study participant for agreeing to be interviewed regarding this study.
- Provide the participant with a study information sheet and ensure that they have adequate time to read the information thoroughly.
- Answer any questions that may arise as comprehensively as possible.

Emphasise to the participant that:

1. The interview should take no longer than one hour to complete
 2. To accurately capture what is being said the interview will be audiotaped
 3. All information that is collected about the participant during the course of the research will be kept strictly confidential and
 4. Any information about the participant which leaves the university/hospital will have the participant's name and address removed so that the participant cannot be recognised from it
 5. In addition to consenting to be interviewed, the participant will also be asked to give consent for direct quotations from the interview to be used in the write up of the research
 6. Any quotations that are used will be completely anonymous
 7. The information provided by the participant will be used to help to improve understanding of the experiences of dementia of people with ID and their carers.
- Ensure that the above points have been fully considered by the participant, prior to asking the participant to complete a consent form.
 - Ask if anyone has any questions.
 - When written consent has been obtained, ask the participant if it is satisfactory to turn on the tape recorder and conduct the interview.

- Switch on the audiotape

Healthcare Professional Interview Schedule

1. Can you tell me a bit about you? What's your role on the DCP?
2. What does dementia mean to you?
3. What are the usual reasons for PWID being referred to the DCP? What are the less common reasons?
4. Could you describe the process that people with ID suspected of dementia go through to get a diagnosis?
 - a. How long does it usually take for the person to get a diagnosis? How does the dementia develop over this period? How are PWID and their carers affected over this period?
5. Could you describe how PWID are given their diagnosis?
6. What is the typical journey that PWID and dementia after diagnosis?
7. What services are in place for family and professional carers? How do you think these help them?
8. How do you think the DCP has helped PWID and dementia, and their carers? Could you describe any changes you would like to see?
9. Could you describe what you think are the most important services and/or support for PWID and dementia, and their carers?
10. Is there anything you would like to see in place to help PWID and dementia, and their carers
11. What do you think the most influential aspect is in how PWID experience dementia?

- a. What you think the most influential aspect is in how carers experience caring for someone with dementia?

12. What do think the biggest challenge is for someone with an ID and dementia?
How do you think this could be overcome?

- a. What do think the biggest challenge is for the carer of someone with an ID and dementia? How do you think this could be overcome?

13. What do you see as the biggest challenge for you in the future? How do you think this will affect PWID and dementia, and carers? What would you like to overcome this?

14. Is there something that you might not have thought about before, that occurred to you during this interview?

15. Is there anything you would like to ask me?

Appendix J²

- Initial Interview Guides for Family Carers

1. Can you tell me a bit about yourself?
 - How long have you cared for _____?
 - Since you have been a carer for _____ has your relationship changed? How?
2. Can you tell me what dementia means to you?
3. Could you describe what made you first ask for help about _____?
 - Can you describe what you went through for _____ to get a diagnosis?
 - How did this help?
 - How did you feel?
 - How did you feel when you found out about _____ diagnosis?
 - Could you describe how _____ responded to being told their diagnosis?
4. Could you describe a typical day for you when you are caring for _____?
 - Could you describe how _____ has changed since having dementia?
 - Could you describe anything which has helped you?
 - How has this helped you?
5. What other services, if any, have you experienced since caring for _____?
 - Have they helped you?
 - How have they helped you?
6. Have you heard of the North Staffordshire learning disability dementia care pathway? [
 - [if so] how has it helped you?
 - How have you been supported by these services?
 - How would you like to be supported?

If not,
7. Would you like to know more about the ID DCP?
 - What would you like to be told about the ID DCP?
 - What services and support would you like them to provide?

8. Is there anything that you would like to help you to care for _____ in the future that you are not getting now?
9. Is there something that you might not have thought about before, that occurred to you during this interview?
10. Is there anything you would like to ask me

Appendix J³

- Initial Interview Guides for Paid Carers

1. Can you tell me a bit about yourself?
 - How long have you cared for _____?
 - Since you have been a carer for _____ has your relationship changed? How?
2. Can you tell me what dementia means to you?
3. Could you describe what made you first ask for advice about _____?
 - Can you describe what you went through for _____ to get a diagnosis?
 - How did this help?
 - How did you feel?
 - How did you feel when you found out about _____ diagnosis?
 - Could you describe how _____ responded to being told their diagnosis?
4. Could you describe a typical day for you when you are caring for _____?
 - Could you describe how _____ has changed since having dementia?
 - Could you describe anything which has helped you?
 - How has this helped you?
 - How has your employer helped to support you?
 - Could you describe anything you would like your employer to do to help you?
5. Have you heard of the North Staffordshire learning disability dementia care pathway?
 - [if so] how has it helped you?
 - How have you been supported by these services?
 - How would you like to be supported?

If not,

6. Would you like to know more about the ID DCP?
 - What would you like to be told about the ID DCP?
 - What services and support would you like them to provide?
7. What other services, if any, have you experienced since caring for _____?
 - Have they helped you?
 - How have they helped you?

8. Is there anything that you would like to help you to care for _____ in the future that you are not getting now?
9. Is there something that you might not have thought about before, that occurred to you during this interview?
10. Is there anything you would like to ask me?

Appendix K

- Participant Analysis Document

Participant Number: Pat	Participant Group: Paid Carer	Interview number (where applicable): 1 and 2		
Quotes	Overarching Focused code	Cluster of focused codes	Initial codes	Brief description
<p>we as a team, we obviously have hand overs and that's a crucial part. I think it helps staff to vent at the end of their day, you know if either of them or any service user if they've had a particularly bad day or upsetting day or challenging day. It allows them time to get it off their chests so they can unwind <u>an</u> they leave work so they're not taking the pressures home (PX 9, interview 2, lines 244-249).</p> <p><u>Erm</u> so you know we had as much advice and support from everybody we can think of you know, and as an employer obviously, the company, the company <u>as a whole, we've</u> got the, the, the staff training (PX 9, interview 2, lines 271-273).</p> <p>I know the other day the male service user was a little bit anxious, or appears to be a little bit anxious and confused and displayed a new behaviour and he spat at the member of staff. <u>Erm</u> so that's something totally new so we amended his care plan and his behaviour monitoring plans so all staff knew he may do this as well as anything else, so anything new we see behaviour wise we record that on, in their paper work (PX 9, interview 2, lines 159-165).</p>	1. Continuum of support	<p>Being supported by external services</p> <p>'Responsive to us'</p> <p>Importance of health care facilitation team</p> <p>Sharing information with staff</p> <p>Supported by company</p> <p>Feeling supported</p> <p>Being able to 'just pick up the phone' for support</p> <p>Supporting each other</p> <p>Supporting each other as a team</p> <p>Encourage staff to reflect</p> <p>Communicate own support needs</p> <p>Missing previously provided support</p> <p>Missing a stepping stone</p> <p>Having to manage without facilitation team</p> <p>Wanting lost support back</p> <p>Lack of staff</p> <p>Supporting staff awareness</p> <p>Communicating changes to staff</p> <p>Losing support x 2</p> <p>Losing expertise losing the expertise of health facilitation team</p> <p>Losing continuity</p>	<p>Being supported, external services.</p> <p>Supported by a team, regular reviews, responsive to requests.</p> <p>Came out to the home, Importance of HFT.</p> <p>Sharing information with staff.</p> <p>Leading by the heart, exhausting all options, provided with advice and training.</p> <p>The company supporting staff requests, feeling comfortable to approach management.</p> <p>Being able to 'just pick up the phone' for support</p> <p>Hand overs, Staff venting, Unwind</p> <p>Deal with it as a team, Communicating issues</p> <p>Encourage staff to reflect</p> <p>Upskill and keeping informed</p> <p>Missing previously provided support</p> <p>Missing a stepping stone</p> <p>Harder without the facilitation team, Managing on own</p> <p>Wanting their support back</p> <p>Short on senior staff, we've bin dipping in to a bit of everything</p> <p>Communicating changes to staff, Recording behaviour</p> <p>Losing support</p>	<p>Support was a prominent focused code for this participant. It entails experience support across levels, from services, management, and within care teams. The focus is on carer support and how this support enables them to provide care and support for clients. Support strategies can come in many forms and communication appears to be a key element of it- for instance, care teams would have meetings where they would communicate through the team any changes, this is <u>similar to</u> the hand overs they have, which enables them to discuss any issues. Support from services and management appear to differ in part from that provided within care teams. For instance, services and management seem to provide more advice and training <u>in order to</u> support the carers' actions; whereas, care teams seem to allow carers to vent and unwind as they discuss their days. However, it seems that no matter the support it is important to feel supported, to be able to approach management, or to be able to 'just pick up the phone' when there are difficulties.</p> <p>Support also entails loss of support and the implications this has on the team and client. The participant highlights the devastating loss of support from services which understood their clients. This support acted as the gatekeeper to other services and provided much needed advice, but the services were taken away from the care team which took away their 'stepping stone'.</p> <p>The participant also highlights their role in the support as they try to keep the care team from becoming demoralised. To ensure this they play a reassuring figure who will reward carers where possible. Without this, carers may become demoralised and this has implications for care.</p> <p>Overall, there are <u>a number of</u> interlinking elements to support. Support better enables carers to manage the challenges presented by dementia in clients. Without this support, further challenges are presented both for the carer and ultimately for the client.</p>

		<p>Consequence of loss of support (Feeling the loss of support) Adapting to support client's needs (adapting to help client)</p> <p>Constantly thinking what else we can do</p> <p>Barrier to support</p> <p>Constantly trying to support client</p> <p>Support based on individual need</p> <p>Trying to keep staff motivated</p> <p>Staff demoralisation</p> <p>Trying to reward staff</p>	<p>Losing the expertise of health facilitation team</p> <p>Affected 'terribly' with the loss of the HFT</p> <p>Adapting to help the service user, <u>Using</u> visual prompts to get over barriers, just another way of trying to communicate, Using picture cards to prep service users for appointments, Adapting to facilitate the client's care</p> <p>Constantly thinking what else we can do</p> <p>Barrier to better care</p> <p>constantly trying to see what else we can do</p> <p>Facilitating appropriate staff</p> <p>Trying to keep staff motivated</p> <p>We try not get stressed because then that demoralises them, <u>Feeling</u> demoralised and threatening to leave, Staff want constant reassurance</p> <p>Trying to reward good staff</p>	
<p>just to have a little bit more of an understanding and flexibility around individuals with dementia I think is the biggest thing, and a little bit of leeway (PX 9, interview 2, lines 312-313).</p> <p>So I feel that GPs are less understanding, well not just necessarily GPs. People who aren't aware of learning disabilities and dementia, service users or patients whatever you wish to call them. You don't it's just the small things which would make thing so much more successful like a double appointment at the doctors you know sometimes they're willing to and sometimes they aren't (PX 9, interview 2, lines 288-293).</p>	2. Understanding	<p>Treated the client as an individual</p> <p>GP not adapted</p> <p>Services lack understanding of ID</p> <p>Varied understanding (<u>Not being supported by the GP practice</u>)</p> <p>Wanting services to adapt to clients</p>	<p>Trying to help the client, trying to help the client in a person-centred way, not seeing them as a 'statistic like GPs'</p> <p>Not adapted for the client</p> <p>Not all services are understanding of LD 'let alone LD and dementia'</p> <p>Not being understood by the GP practice, management accommodating clients</p>	<p>Understanding was an important element to this participant's interviews. Throughout they highlighted the importance of understanding for the client's experience. This understanding varied and was discussed in relation to services, carers, and the <u>general public</u>. The key message was that when there was an understanding of intellectual disabilities, clients were better accommodated for. There were highlighted examples of how services and carers would use their understanding to adapt and implement changes which would provide better support for clients. However, when understanding of intellectual disabilities were</p>

<p>Obviously, you're in the community, you're under the public eye but they're not always so understanding when you've got to have maybe a firm approach and its cared planned, its risked assessed, it's from the behavioural management plan. You know, then staff could be worried with how it could be relayed, are they going to get a phone call, a complaint, it will have to be investigated (PX 9, interview 2, lines 328-333).</p>		<p>Services accommodating client</p> <p>Interview 2 Lack of understanding results in lack of adaptations</p> <p>Need for more understanding in professionals for client's benefit</p> <p>Need for professionals to have understanding</p> <p>Need for <u>general public</u> to have understanding</p> <p>Need more knowledge in the care industry</p> <p>Clients' lacking ability to understand diagnosis</p> <p>Worried about distress of sharing diagnosis</p> <p>Communicating the process to client</p> <p>Caution about giving a diagnosis</p> <p>Giving as much information as think client needs</p> <p>Explaining the process</p>	<p>Wanting services to be more accommodating, they don't adapt their ways, could make things a lot easier by taking the LD and/ or dementia into consideration</p> <p>Services working in partnership to accommodate, trying to understand and accommodate the client</p> <p>People who aren't aware are less understanding, Small things that would make things more successful, <u>Not</u> being responsive</p> <p>Understanding the difference needs of people, Dementia makes things more difficult, Having more understanding and flexibility</p> <p>More understanding</p> <p>Worrying about the <u>general public</u> views, Under the public eye, Feeling worried</p> <p>Need continued knowledge in the care industry</p> <p>Not being able to understand diagnosis, telling them wouldn't make a difference, we don't feel they would understand what it means</p> <p>Haven't gone out of the way to explain to them, not wanting to distress them with a diagnosis</p> <p>Explain the services they experience</p> <p>Caution about giving a diagnosis</p> <p>Amount information depends on client, Lack understanding</p>	<p>lacking, there were implications for clients. The services were not adapted.</p> <p>Understanding also refers to the clients understanding and the implications this had for being informed. Carers played an important role in this as it appears that when they felt that the client lacked the necessary ability to understand, they would not go out of their way to disclose the individual's diagnosis. This withholding of the diagnosis coincided with a fear that telling them, with their lack of understanding, would only hurt the client in some way. This meant that decisions on what the client was told were based on their perceived level of understanding. However, carers also played an important role in client understanding as they would adapt the information process to explain services to them- this was to enable them to visit the service and to receive the necessary treatment.</p> <p>Understanding also had implications for carers. There was a fear that the <u>general public</u> would not understand the support and care strategies implemented by carers for clients with an intellectual disability and dementia- a fear which they felt would result in some kind of action being taken against the care.</p>
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<p>Obviously, you're in the community, you're under the public eye but they're not always so understanding when you've got to have maybe a firm approach and its cared planned, its risked assessed, it's from the behavioural management plan. You know, then staff could be worried with how it could be relayed, are they going to get a phone call, a complaint, it will have to be investigated (PX 9, interview 2, lines 328-333).</p>		<p>Services accommodating client</p> <p>Interview 2 Lack of understanding results in lack of adaptations</p> <p>Need for more understanding in professionals for client's benefit</p> <p>Need for professionals to have understanding</p> <p>Need for <u>general public</u> to have understanding</p> <p>Need more knowledge in the care industry</p> <p>Clients' lacking ability to understand diagnosis</p> <p>Worried about distress of sharing diagnosis</p> <p>Communicating the process to client</p> <p>Caution about giving a diagnosis</p> <p>Giving as much information as think client needs</p> <p>Explaining the process</p>	<p>Wanting services to be more accommodating, they don't adapt their ways, could make things a lot easier by taking the LD and/ or dementia into consideration</p> <p>Services working in partnership to accommodate, trying to understand and accommodate the client</p> <p>People who aren't aware are less understanding, Small things that would make things more successful, <u>Not</u> being responsive</p> <p>Understanding the difference needs of people, Dementia makes things more difficult, Having more understanding and flexibility</p> <p>More understanding</p> <p>Worrying about the general <u>public's</u> views, Under the public eye, Feeling worried</p> <p>Need continued knowledge in the care industry</p> <p>Not being able to understand diagnosis, telling them wouldn't make a difference, we don't feel they would understand what it means</p> <p>Haven't gone out of the way to explain to them, not wanting to distress them with a diagnosis</p> <p>Explain the services they experience</p> <p>Caution about giving a diagnosis</p> <p>Amount information depends on client, Lack understanding</p>	<p>lacking, there were implications for clients. The services were not adapted.</p> <p>Understanding also refers to the clients understanding and the implications this had for being informed. Carers played an important role in this as it appears that when they felt that the client lacked the necessary ability to understand, they would not go out of their way to disclose the individual's diagnosis. This withholding of the diagnosis coincided with a fear that telling them, with their lack of understanding, would only hurt the client in some way. This meant that decisions on what the client was told were based on their perceived level of understanding. However, carers also played an important role in client understanding as they would adapt the information process to explain services to them- this was to enable them to visit the service and to receive the necessary treatment.</p> <p>Understanding also had implications for carers. There was a fear that the <u>general public</u> would not understand the support and care strategies implemented by carers for clients with an intellectual disability and dementia- a fear which they felt would result in some kind of action being taken against the care.</p>
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<p>So I think staff have found it a little bit hard emotional because each week we see a little bit less of that person because the dementias changing him (PX 9, interview 2, lines 217-219).</p> <p>things take a lot longer with them, personal care, <u>erm</u> obviously there's more incidents with them, they don't slot in too the group living as much (PX 9, interview 2, lines 116-118).</p> <p>they come across here in floods of tears, they can't believe how much they're changing an it breaks <u>me</u> heart and I want <u>make</u> sure that everything's done for them (PX 9, interview 2, lines 275-277).</p> <p>However, yes it creates a little bit more work, but you do it because you want the best outcome for them. You just, you just <u>have to</u> adapt and make time and complete all the things you wouldn't have thought of doing, <u>erm</u> so yeah, training and a little bit more of a work load (PX 9, interview 2, lines 204-208).</p> <p>Impact of dementia refers to both the emotional impact, such as being sad when they found out the diagnosis or worrying more when the client has a diagnosis; and the physical impact where the carer must make more considerations and has increased demands throughout their role. <u>It is clear that seeing</u> the loss of what the client was has a big emotional impact on carers who struggle with this (is this why carers need support?). Dementia also impacts on the carers routine and level of support they provide.</p>	<p>3. Impact of dementia (emotional and physical)</p>	<p>Burden of dementia</p> <p>Feeling negative emotions after diagnosis</p> <p>Uncertainty of change</p> <p>Added demands of dementia for carer</p> <p>Having to document everything</p> <p>Taking more time due to extra considerations</p> <p>Having to consider the environment</p> <p>(Interview 2) Demands of dementia</p> <p>Emotionally demanding (losing client, emotion of seeing parts of the client disappear)</p> <p>Emotionally and physically challenging</p> <p>Want best outcome for client (so don't mind demands)</p> <p>Adapting to client change (because <u>have to</u>)</p> <p>Impacts others (affects others)</p> <p>Losing skills</p> <p>Reliving their past</p>	<p>You worry more, extra precautions, extra aware</p> <p>Feeling sad after diagnosis, you worry it will affect the lifespan, worried sad apprehensive</p> <p>We never know how they may change next, unknown,</p> <p>Having to think of the environment, need more time to complete personal care, having to be in arm's length because of risk, having to spend more time with clients</p> <p>Having to document 'all of this'</p> <p>Taking more time due to extra considerations, more support for daily living</p> <p>Having to think of wheelchair access, having to avoid busy period, trying to accommodate the client, you <u>have to</u> be more thoughtful throughout the day</p> <p>Care takes a lot longer, Personal care takes longer, bin tested a little bit</p> <p>Finding it hard emotionally, <u>Seeing</u> less of who that person was, Hard to see them change</p> <p>Emotionally and physically challenging</p> <p>Putting the service user first</p> <p><u>Have to</u> adapt</p> <p>Lashing out at others, Impact others, <u>Removing</u> other service users, Can disrupt others' routines, Interfering with day to day activities</p>	<p>mpact of dementia was prominent throughout the participant's interviews and focused on the impact on carers. This impact was both emotional and physical. Emotionally, the clients found it difficult to see the loss of the client: their skills and parts of who they used to be. However, through this emotional challenge, the participant highlights how in some <u>cares</u> this strengthens their commitment to do whatever they can to support the client through their dementia.</p> <p>Impact of dementia also increases demands on carers in their role. This includes extra time spent giving personal care and extra considerations, such as the environment. However, when dementia presents, the uncertainty it creates means carers feel apprehensive and like they <u>have to be at arms length</u> to make sure the client is OK and is in no danger.</p> <p>Impact of dementia also refers to other clients without dementia and how the dementia related changes in their housemate has disrupted their routine.</p>
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<p>It's nice to see and think that they've not had to go to a dementia home and I'm not saying that every dementia home is bad, it's just, it's not home for them. It wouldn't be home. To move them would, they've all said it would have such a dramatic negative effect on their wellbeing, it's likely to increase the deterioration quicker <u>erm</u> (PX 9, interview 2, lines 363-368).</p> <p><u>erm</u>, for that I think I'm quite proud that we can say, we've not just said that we don't just look after people with dementia, you know we've adapted to their needs (PX 9, interview 2, lines 343-345).</p> <p>obviously it's still very rewarding know that they are safe, as happy as they can be in a <u>place</u> that they are familiar with, with staff that know them well and genuinely care (PX 9, interview 2, lines 240-242).</p> <p><u>erm</u> am more awareness <u>er</u> of dementia, <u>erm</u> especially <u>erm</u> in LD, it's made me realise that you can with input from others, and team work, you can help to keep somebody in their home and not automatically think "oh god they've got dementia and they can't live here anymore, we're not a registered dementia home". We actually <u>went</u> to look at a <u>erm</u> another residential home, <u>erm</u> which was for Learning disability/ dementia. The one we went we actually thought, it was a lovely home, fairly local, but we actually thought there's nothing they do that we can't, so with the correct training, team work and <u>erm</u> willing to learn and adapt, we feel that we can accommodate just as much as that other home could (PX 9, interview 1, lines 254-264).</p> <p>but if ever we felt the incidents were becoming too frequent or they're having too much of an affect then obviously we'd look at suitable alternative replacement, but were not there yet, you know <u>erm</u>, nowhere near that, and you know we want it be a home for life and we've been told that if we were to move either of the service users it would have a negative detrimental effect on their wellbeing, and obviously that's paramount so until we come to a point where the incidents are having too much of a negative impact or too risky for all involved (PX 9, interview 2, lines 150-157)</p>	<p>4. Continuity</p>	<p>Ensuring client can stay at home</p> <p>Upskilling ourselves so they can stay at home</p> <p>Wanting to ensure a home for life</p> <p>Ensuring the client is kept at home</p> <p>Support enabling to keep the client at home</p> <p>Interview 2 Making it work</p> <p>Proud to have adapted to their needs</p> <p>Fulfilment in keeping them at home</p> <p>Wanting to keep clients at home to maintain wellbeing</p> <p>Wanting it to be a home for life, unless last resort</p> <p>Rewarding to see continuity and clients happy</p>	<p><u>NWe</u> wanted to make sure we were doing everything we could, wanting to keep the client at home,</p> <p>Wanting to upskill to keep them at home, knowledge allowing client to stay at home,</p> <p>Wanting to ensure a home for life, looking to the future, having end of life support when required, determined to upskill to accommodate</p> <p>Working together to keep the client at home, fear sending clients with dementia away, there's nothing they do that we can't, keeping the client at home</p> <p>The company wanting to provide specialised <u>accommodation</u>, managing to support clients in their home</p> <p>.....</p> <p>Making it work</p> <p>Proud to have adapted to their needs</p> <p>Fulfilment in keeping them home</p> <p>Wanting to keep services users at home</p> <p>Wanting it to be a home for life, Negative effects of moving them, A last resort, <u>Having</u> to look for alternative placements</p> <p>Rewarding role</p>	<p>Continuity is the participants focus on ensuring the client is kept in-place. <u>In order to</u> achieve this, the participant highlights how they take steps- such as working in collaboration with services, upskilling themselves and adapting the environment. Being able to provide this continuity is important to the participant and they take great pride and happiness in being able to achieve this. The impetus behind this want for continuity is the belief that moving the client would not be in their best interest and would see greater decline in the client. However, the participant does highlight that moving the client is possible in the last resort, if incidents became too frequent and they had too much of an affect- implying that if they were unable to manage or adapt to the changes they would need to look for a more suitable home. Again, at the centre of this focused code is the desire to maintain and ensure the client receives the best support.</p>
<p>Yeah, <u>erm</u> but we would just generally, again I would like to think we've got a good relationship with the nurses up and you know we could always just ring up and say do you have any support that you could offer for this (PX 9, interview1, lines 302-305).)</p>	<p>5. Awareness of DCP</p>	<p>Being unaware of DCP's involvement</p> <p>Having a good working relationship with DCP staff</p> <p>Awareness of DCP at an organisational level</p>	<p><u>GLacking</u> awareness of DCP terminology, being unaware of the DCPs involvement</p> <p>Having a good working relationship with the DCP staff, being able to contact the DCP for support being able to 'just pick up the phone' for support</p> <p>Well established with the DCP, being aware of them as a company</p>	<p>Awareness of the DCP refers to awareness at both a care and organisational level. The participant lacks the awareness that they are being supported by the DCP, seemingly unaware of the name but being aware that they are being supported by ID services. Though they are unaware of the DCP role in support, they frequently discuss being supported by the team up 'broom street' and how they can contact them for advice. They also highlight how they are established with the DCP</p>






















<p><u>erm</u> obviously, <u>erm</u> am more awareness <u>er</u> of dementia, <u>erm</u> especially <u>erm</u> in LD, it's made me realise that you can with input from others, and team work, you can help to keep somebody in their home (PX 9, interview1, lines 254-257).</p> <p>The training, the training which was provided, the distance learning and the actual presentation and delivery of some, <u>erm</u> I believe it was just the basic dementia training which makes you think of other little things which you take for granted (PX 9, interview1, lines 238-241).</p> <p><u>erm</u>, I wouldn't say we had to push for it, <u>erm</u> and then since then, we have had, as a company, as part of <u>erm</u>, or we have started looking at providing training the trainers, so we've got a couple of our trainers at head office which can now deliver dementia training, so we wouldn't rely so much on people coming in. We've had distance learning, <u>erm</u> booklets on, <u>erm</u> you know these free courses (PX 9, interview1, lines 131-137).</p>	<p>6. Experience of services</p>	<p>Training influences client's experience</p> <p>Training helping to enact change</p> <p>Training developing awareness</p> <p>Training through organisation</p> <p>Wanting further training</p>	<p>The importance of training</p> <p>Being helped by training</p> <p>Having more awareness</p> <p>Training through organisation</p> <p>Wanting further training</p>	<p>as an organisation- with the organisation being on their radar.</p> <p>Throughout, the Participant highlights the training they have received and the benefits of this. For instance, as a tool to enact change and raise awareness of dementia.</p>
<p>Thoughts</p>				
<p>As I have read and analysed this transcript, it is evident that the dementia is new to the Participant and much of their actions are in response to this change in the client. The overarching theme is 'Ensuring the quality of life' for the person with an intellectual disability and dementia. <u>It is clear that the</u> participant wants what is best for the client and there are a number of elements which help to ensure this, such as understanding across services and carers, support from services, management and within care team, and continuity- keeping the client at home, as well as the important role of training to raise understanding and also to enact change and ensure the client is receiving appropriate care. Many of these elements also help the carer to overcome the challenges which dementia produce- such as the emotional impact and the increase in demands. However, there are elements which impact both the carer and client, such as a lack of understanding by services and the <u>general public</u> which increase challenges for both carers and clients. The role of understanding is pertinent throughout, and the power which the carer holds is also evidence in their decision to only give the client information they deem to be important- though this decision is always in the <u>clients</u> best interest and in order to prevent any distress. Though the DCP's role is not explicitly acknowledge, as the carer does not know the service as the DCP, they provide an important role in supporting carers to support clients, and in supporting clients. There is also an identification of what makes a good carer- I am assuming this is what the participant wants to see in their colleagues.</p>				

Appendix L

- Participant (Pat) Analysed Transcription

Gained varied experience	<p>1 DH: So, can you tell me a bit about yourself?</p> <p>2 P1, i1: <i>erm</i>, yeah, so what name and...</p>	<p> PsyPG Worked with a variety of clients</p>
Love job	<p>3 DH: Yeah that's fine</p> <p>4 P1, i1: Yeah, so my name is ****. I started off as a support worker and then over the years developed my career, <i>erm</i>, and become a senior, well an acting senior then a senior support worker, I've seen many service users and staff come <i>ah</i> go over the years, from all varieties of personalities and <i>erm</i>, diagnosed conditions. I love my job, <i>erm</i>, what else, I've just completed my level 5 and we're just trying to catch up with all the changes around the care act, and care certificate and all of the other bits of legislation which comes with that as well as the running of the home, so <i>erm</i>, yeah.</p>	<p> PsyPG Trying to keep up with legislation changes</p>
Years of experience	<p>13 DH: That's great, so have you got much experience of caring for people with learning disabilities?</p> <p>14</p> <p>15 P1, i1: Learning disabilities, yeah, I've been in learning disabilities since I was 18. Here at *** **** and I've never been anywhere else. <i>erm</i>, I did do a week at a care home at **** prior to that but that was elderly care home and I wasn't really enjoying it and I was offered this job and decided to go for this, so I've got 14 years of experience from here at **** with learning disabilities.</p>	<p> User A lot of experience</p>
Years of experience	<p>16</p> <p>17</p>	<p> User Continuity</p>
Years of experience	<p>18</p> <p>19</p> <p>20</p>	<p> User Many years of experience</p>
Recent experience of LD and dementia	<p>21 DH: Have you cared for many people with [learning disabilities and] dementia?</p> <p>22</p> <p>23 P1, i1: <i>erm</i>, in this, in the time at ****, we've only recently, <i>erm</i>, well I'll say 12 months ago, have had two of our service users we've had for many years diagnosed with dementia. Prior to that no, <i>erm</i>, so the past I'd say 12-18 months <i>er</i>, is when we've seen changes to the services users and they've been diagnosed with it.</p>	<p> User Only recent experience of LD and dementia</p>
Recent experience of LD and dementia	<p>24</p> <p>25</p> <p>26</p> <p>27</p>	<p> User Noticing changes resulted in a diagnosis</p>
Recent experience of LD and dementia	<p>28 DH: Ok, so has your relationship changed with service users since....</p> <p>29</p>	<p> User You worry more</p>
Recent experience of LD and dementia	<p>30 P1, i1: The service users with dementia?</p> <p>31</p>	<p> User Extra precautionous</p>
Burden of dementia	<p>32 DH: Yeah</p> <p>33 P1, i1: Definitely, <i>erm</i>, you worry more, <i>erm</i>, you're on your toes more. <i>erm</i>, you're extra, not, yeah extra, <i>erm</i>, precautionous, and extra aware, <i>erm</i>, because when the service users were diagnosed with dementia, we <i>erm</i>, sought as much advice as we could at the time, we had the health facilitation team on board, one of the LD nurses and she actually, <i>erm</i>, provided us with some in-house training for the staff team, cause dementia was a new condition to us. <i>erm</i>, you know, <i>else where</i>, <i>erm</i>, were aware of it, but it was new to us, so we had <i>er</i> in-house training, and then we've followed lots of advice and guidance, from the consultants who</p>	<p> User Extra aware</p>
Seeking advice	<p>34</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p>	<p> User Seeking out advice when diagnosed</p>
Being supported by external services	<p>41</p>	<p> Daniel Herron Being supported</p>
Being supported by external services	<p>42</p>	<p> Daniel Herron External training</p>
Being supported by external services	<p>43</p>	<p> Daniel Herron a 'new condition'</p>
Being supported by external services	<p>44</p>	<p> Daniel Herron Taking steps to overcome shortcomings</p>
Being supported by external services	<p>45</p>	<p> Daniel Herron Following advice and guidance from consultant</p>

Addressing shortcomings	41 have been on boards. You know who have obviously seen to the medication side of things, but that health facilitation team has now been decommissioned so we've not got any, that role stopped, so we've not got any support from them. Ern it would have to go straight to, usual route, GPs and so on.
Losing support	46 [Interruption] 47 Where was a?
Feeling the loss of support	48 DH: Ern , just before I forget, I was going to ask, you said that the service [facilitation team] has been decommissioned so now you had to go through your GP, so how has that affected you? 49 50
Treated client as an individual	51 P1, i1: Terribly, ern , we relied heavily on the support from the health facilitation team. It was ** and ** mainly, and they were absolutely fantastic, they would come out to the home, ern , and they would support us with any queries that we've got. For example, with the gentleman that's been diagnosed. They started doing desensitisation work on him. Tried to do it, however, that was unsuccessful because every time he was coming to visit the service user was forgetting who he was and what had been done. But they tried all these things, but trying to do it in a person centred way, ern , and not just seeing them as individuals or a statistic like GPs do when you go down with them. It wasn't adapted to them, they would do 62 ern , they would prescribe ern , mild sedation so we could do things like blood tests that were needed, they would refer to other services, ern , they would liaise and they would even come on appointments with us, because they are nurses they obviously knew the medical side to it. They worked with, the partnership we had with them, the service is sadly missed, not just by services users with dementia, but you know all service users with LD, because not all services out there, your first point of contact like your GPs, are understanding of services users with LD, never mind services users with LD and dementia. So yeah it greatly missed.
GP not adapted	64 65 66 67 68 69
Services lacking understanding of ID	70 DH: So it was a good service? 71 P1, i1: It was a brilliant service, it was yeah. Ern and now we just have to refer in to, ern , learning disability up **** ern , and they, and they will, ern , delegate who they feel could help, ern , but at the moment, for our service users who have dementia, we've got the consultation, Dr ****, ern , she has, she does, three monthly, or 6 monthly reviews. However, she has bin very responsive to us, I have often dropped her an email and said have you got any appointments or give us any advice, were noticing a decline. However, one of our service users is unable to have any medication for his ern , dementia because of his heart condition, ern , whereas the other, there's a lady who does, can have medication and has been on it since early diagnosis and it does appear to have kept her on level, whereas the gentleman who can't have medication because of his
'Responsive to us'	80 81 82

-  **Daniel Herron**
Losing support
-  **Daniel Herron**
Changing route to GP
-  **Daniel Herron**
Affected 'terribly' with the loss of the health facilitation team
-  **Daniel Herron**
Appreciating support
-  **Daniel Herron**
Support with queries
-  **Daniel Herron**
Trying to help the service user
-  **Daniel Herron**
Forgetting who the person was
-  **Daniel Herron**
Trying to help the client in a person centred way
-  **Daniel Herron**
Not seeing them as a 'statistic like GPs'
-  **Daniel Herron**
Not adapted for the client
-  **Daniel Herron**
Overcoming challenges with help
-  **Daniel Herron**
The importance of the health facilitation team
-  **Daniel Herron**
Working in partnership
-  **Daniel Herron**
A sadly missed form of support
-  **Daniel Herron**
Not all services are understanding of LD 'let alone LD and dementia'
-  **Daniel Herron**
Supported by a team
-  **Daniel Herron**
Regular reviews
-  **Daniel Herron**
Responsive to requests
-  **Daniel Herron**
Unable to take medication because of a heart condition
-  **Daniel Herron**
The benefits of medication
-  **Daniel Herron**
A decline without medication

	83	heart condition, we've noticed a change more, a more dramatic change,
	84	in his health and social skills in general wellbeing really.
Benefits of taking medication	85	DH: OK then, that's great thank you. Erm can you tell me what dementia means to you? Personally to you?
	86	
Losing skills	87	P1, i1: Forgetfulness, dementia is forgetfulness, confusion, erm, losing
	88	erm, bodily functions, erm, or having an effect on the whatever ability they
	89	had, so obviously they had a lower level of ability because of the LD,
	90	however, the dementia has reduced that even more. Erm, but the, you
	91	know, disorientation, erm, even you know, down to sensory things, so
	92	visual, how they see things, erm, and again I suppose it comes to, the
	93	training we were given as well. Noises, I know noises can affect erm, I
	94	know there's different types of dementia, I don't know the medical term,
Training influence client's experience	95	but I know there's different types depending on which part of the brain, is
	96	that right? Front lobe and all things like that. One of our ladies has got
	97	picks, picks dementia. Erm, but yeah I'd say mainly forgetfulness and
	98	confusion. Going back to your past. They seem to relive their youth and
	99	remember things when they were a child. That's the same with one of our,
	100	the male service user. If he saw a photo of himself as he presents today,
	101	it wouldn't ring a bell with him. If he looked at a picture of when he was a
	102	lot younger, he'd say 'oh thats me' and he can remember years and years
	103	ago, to not so good our days, and that's the same for photos of his
	104	relatives and his sister in particular.
Reliving their past	105	DH: Erm, so can you describe what made you first ask for advice, it
	106	may not have been you, for the individuals with dementia.
	107	P1, i1: Erm, because here at *****, up until those two services users, we
	108	noticed lots and lots of changes in their behaviours and how they
	109	presented. A bit like confusion and one service user was particularly
	110	more, anxious, and we noticed, erm, some of the behaviours that were,
Responding to dementia related changes	111	erm, causing concern, bit more challenging behaviour, what ever
	112	erm, causing concern, bit more challenging behaviour, what ever
	113	labelled downer days, and then we quickly got people on board, and they
	114	referred into baseline dementia assessment, and from them, erm, we
	115	obviously, we were told then given a diagnosis. But it was because we'd
	116	not supported anyone with dementia before we wanted to make sure we
Getting people on board	117	were doing everything we could. We didn't want to have to, erm, say that
	118	they couldn't live here any longer because we couldn't accommodate it
	119	because we weren't knowledgeable on it, so we wanted to up skill
	120	ourselves, so you know make sure the staff team felt comfy, and obviously
	121	allowed the service users to stay here for as long as it was safe for all to
Ensuring client can stay at home	122	do so.
	123	DH: So is that something you, or the team had pushed for this kind
	124	of training?
	125	P1, i1: No again, it came through the health facilitation team and she
		came and did it. She came here to the home, erm, I think we had two or


 Daniel Herron
Dementia related decline in across social skills and health

 Daniel Herron
Effect of dementia

 Daniel Herron
Dementia reduces their ability

 Daniel Herron
Affects all the senses

 Daniel Herron
The importance of training

 Daniel Herron
They seem to relive their youth and remember things when they were a child

 Daniel Herron
Unable to recognise themselves

 Daniel Herron
Reliving the past


 Daniel Herron
Changes resulted in asking for advice

 Daniel Herron
Becoming anxious

 Daniel Herron
Increase in challenging behaviour


 Daniel Herron
Labelled behaviour

 Daniel Herron
Getting people on board

 Daniel Herron
we wanted to make sure we were doing everything we could

 Daniel Herron
Wanting to keep them at home















 Daniel Herron
Wanting to upskill to keep them at home


 Daniel Herron
Knowledge allowing the client to stay at home




 Daniel Herron
Importance of health facilitation support


 Daniel Herron
Came out to the home

Importance of health facilitation team	126 three, she did put two or three on a period of time. Em , I wouldn't say we had to push for it, em , and then since then, we have had, as a company, as part of *** group, er , we have started looking at providing training the trainers, so we've got a couple of our trainers at head office which can now deliver dementia training, so we wouldn't rely so much on people coming in. We've had distance learning, em , booklets on, em , you know these free courses. Em we've had a lot of staff who've done these dementia course, because we've realised that service user with LD, service with LD and dementia can be totally different, em and they do need them extra levels of support, you know just the same as somebody with LD and autism and LD and epilepsy. We've had to upskill ourselves. Em so that they can stay here as long as possible really.
Training through organisation	134 135 136 137
Responding to challenges of ID and dementia	138 DH: That's answered a few of my other questions [laugh]. So did the, are the individuals with the diagnosis, how did they kind of react when they were given the diagnosis?
Upskill ourselves so they can stay at home	141 P1, it: Em, that's tricky, I think the level of understanding prior to the diagnosis, I don't think they could em, understand what dementia is. Em, and I think the service users', em, close relatives, ourselves as a staff team that's supported them for many years and professionals from broad haven't gone out of the way to try and explain to them because we wouldn't want to distress them anymore, or make any more changes to their life you know. We've kind of fought so hard to try and keep them here in their home, em, so we don't see that telling them would make any difference. Em, obviously you know, we have to, were thoroughly explain different processes and why they've been done and obviously we look around. We do, we are aware of deprivation of liberties for certain issues, which both service users are, do have an authorises em, deprivation of liberty for, em, their accommodation and treatment. Is it Lord Havles, a guiled cage is still a cage, so we're aware that they do obviously lack capacity in certain areas, but they're fully aware of, their, or this, thoroughly involved in their daily living, em, but we just don't feel they would understand what it means.
Clients lacking ability to understand diagnosis	142 143 144 145 146 147 148 149 150
Worried about distress of sharing diagnosis	151 152 153 154 155 156 157
Communicating the process to clients	158 DH: So do you believe it could have maybe a negative impact if you told them...
Lacking ability to understand	159 160 P1, it: Yeah, then I think they just won't think they would have the capacity to understand, em, I don't think they fully understand their learning disability, never mind what dementia is as well. Em, both service users have lived in care for a very, very long time, so that's kind of normal living to them. 161 162 163 164 165 DH: So how did you feel when you found out about the diagnosis? 166 P1, it: Very sad, em, because we, you know, we've I've cared for these service users since they've moved in. Obviously it can be, it is a life limited condition, em, and a long side other conditions that particularly the 167 168

-  **Daniel Herron**
Training provided
-  **Daniel Herron**
The company training trainers
-  **Daniel Herron**
Not relying on people coming in
-  **Daniel Herron**
Distance learning training
-  **Daniel Herron**
Staff have carried out dementia courses
-  **Daniel Herron**
Realised the challenges of LD and dementia
-  **Daniel Herron**
Client needs extra support
-  **Daniel Herron**
Upskill ourselves so they can stay at home
-  **Daniel Herron**
Not being able to understand their diagnosis
-  **Daniel Herron**
Haven't gone out of their way to explain to them
-  **Daniel Herron**
Not wanting to distress them with a diagnosis
-  **Daniel Herron**
Fought hard to keep them [happy](#)
-  **Daniel Herron**
Telling them wouldn't make any difference
-  **Daniel Herron**
Explain the services they experience

-  **Daniel Herron**
We don't feel they would understand what it means

-  **Daniel Herron**
Don't have the capacity to understand
-  **Daniel Herron**
I don't think they fully understand their learning disability, never mind what dementia
-  **Daniel Herron**
Used to being cared for, normal living to them

-  **Daniel Herron**
Feeling sad after the diagnosis

169 gentleman has, you obviously worry that **erm**, that it will, **erm** it will affect
170 their life span. We wanted to make sure we were doing everything we
171 could. I.e. the training and you know we had staff meeting, but worried,
172 sad, apprehensive, you know we never know how they may change next.
173 You know we saw the female service user change within her behaviour,
174 it became slightly challenging, then her medication got reviewed and she
175 was put on the dementia medication and she seemed to, **erm**, be on a
176 level. Whereas the gentleman, **erm**, he become very emotional, **erm**,
177 constantly cry, wanting reassurance, **erm** just company, **erm** you saw a
178 lot of confusion and for us with that gentleman we're slightly more
179 apprehensive about his deterioration, decline since the diagnosis, **erm**, so
180 yeah, suppose it's the unknown as a care provider and someone who has
181 cared for them for year, we also want to try and ensure it is a home for
182 life. **Erm** you know, so no doubt, we have had basic end of life training as
183 well, and we have when the health facilitation team were on board, they
184 have said for us to refer in to palliative support towards, when required for
185 either or both of the service users, so **erm**, but we're determined to you
186 know, upskill ourselves, so that we can accommodate.

187 **DH: Erm**, so could you describe a typical day for when you are caring
188 for a service user with dementia?

189 P1, it: Due to safeguarding issues that were brought up from, **er**, the lady
190 with dementia because she **become** challenging, **erm** she was granted
191 someone to one hours, **erm** so from that we had to put **erm** lots of one to
192 one support in throughout the day at key times when it was the busiest,
193 cause we noticed obviously noise, lots of movement, people. **Erm** they
194 were the key points, so one particular, the lady service user has one to
195 one hours so we noticed that person care needed more, they needed
196 more time to complete personal care. Meal times, **erm**, preparing the
197 person for the day, **erm**, because the safe guarding we've got to be in
198 arm's length because of any risk, potential risk to anyone, especially if
199 she is anxious. We have to look at medication. There are, that one service
200 had PRM medication to help with anxiety. So any sign, the first sign of
201 any anxiety or any that we noticed in her that is a possible trigger then we
202 would, **pres**, you know following protocols, care plans about the
203 administration of PRM medication. **Erm** they'd get, I'd say you constantly
204 got to be reminding them **erm** where they are sometimes, the time of day
205 it is, **erm** sitting with them through meal times because they seem to
206 sometimes even forgetting that they were eating or drinking. Obviously
207 when to evidence to all of this, we have to update person centred plans,
208 care plans, risk assessments, protocols, **erm**, you know we have staff
209 meetings as well to discuss these things for the staff training, but the, the
210 daily occurrence obviously more support with personal care, meal times,
211 medication, **erm**, activities can sometimes **erm** take longer, because you
212 have to be more mindful of like where you're going, how you're getting
213 there, is it a large group, a small group, can they tolerate being with any
214 group at all, does it have to be on a one to one.

Feeling negative emotions after diagnosis
























Wanting to ensure their care

Uncertainty of change

Wanting to ensure a home for life

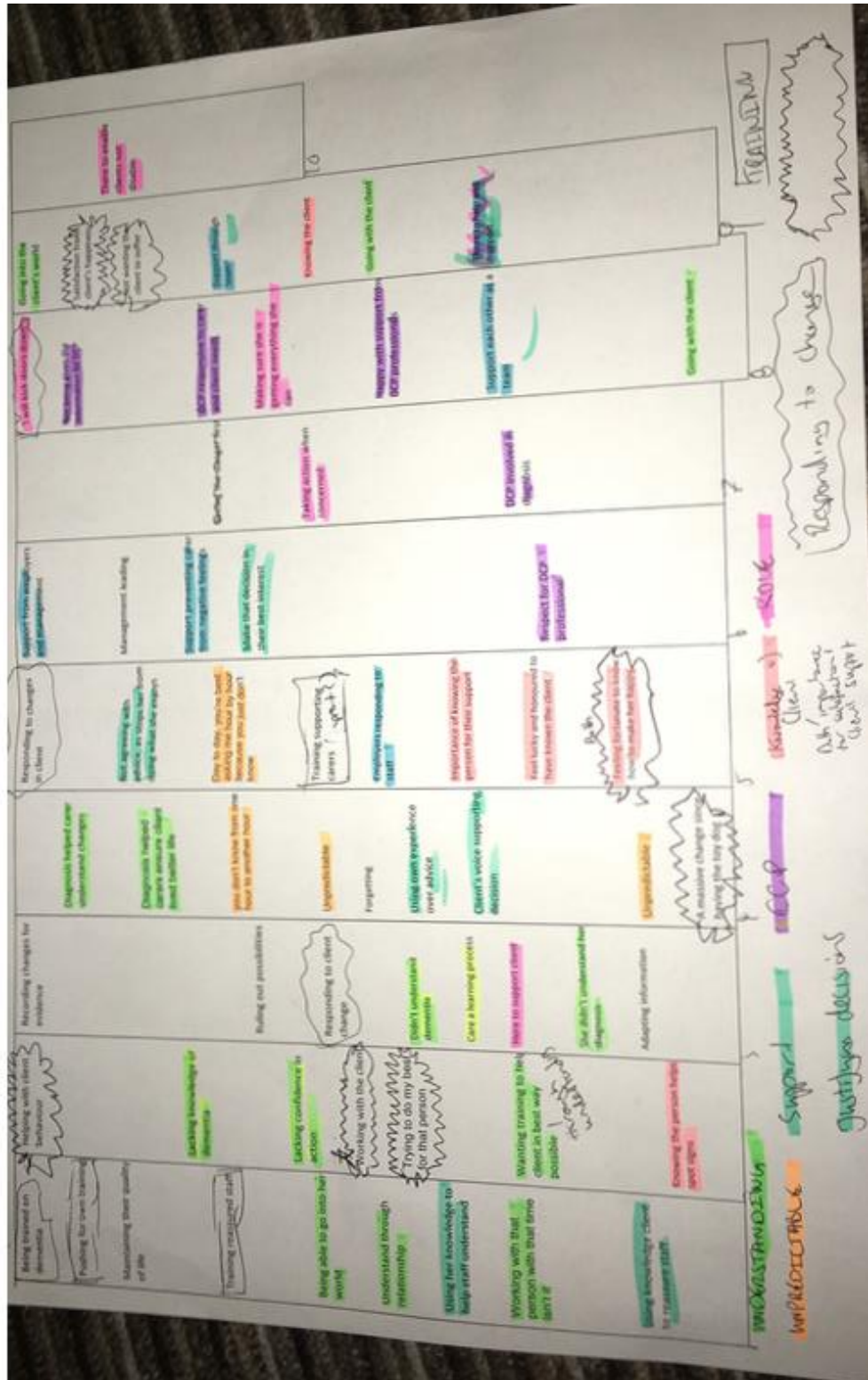
Added demands of dementia for carer

Having to document everything

-  **Daniel Herron**
You worry it will affect the lifespan
-  **Daniel Herron**
Wanting to do everything they could
-  **Daniel Herron**
worried, sad, apprehensive
-  **Daniel Herron**
we never know how they may change next
-  **Daniel Herron**
Using medication to help the client
-  **Daniel Herron**
Dementia related changes
-  **Daniel Herron**
Becoming apprehensive seeing dementia related change
-  **Daniel Herron**
unknown
-  **Daniel Herron**
Wanting to ensure a home for life
-  **Daniel Herron**
Looking to the future
-  **Daniel Herron**
Having end of life support when required
-  **Daniel Herron**
Determined to upskill to accommodate
-  **Daniel Herron**
Client being granted one-to-one support
-  **Daniel Herron**
Being strategic with one-to-one support
-  **Daniel Herron**
Having to think of the environment
-  **Daniel Herron**
Needing more time to complete personal care
-  **Daniel Herron**
Having to be in 'safety' because of risk
-  **Daniel Herron**
Considerations for better living
-  **Daniel Herron**
Having to spend more time with clients
-  **Daniel Herron**
Taking the time to document everything
-  **Daniel Herron**
Sharing information with staff
-  **Daniel Herron**
More support for daily living
-  **Daniel Herron**
Taking more time due to extra considerations

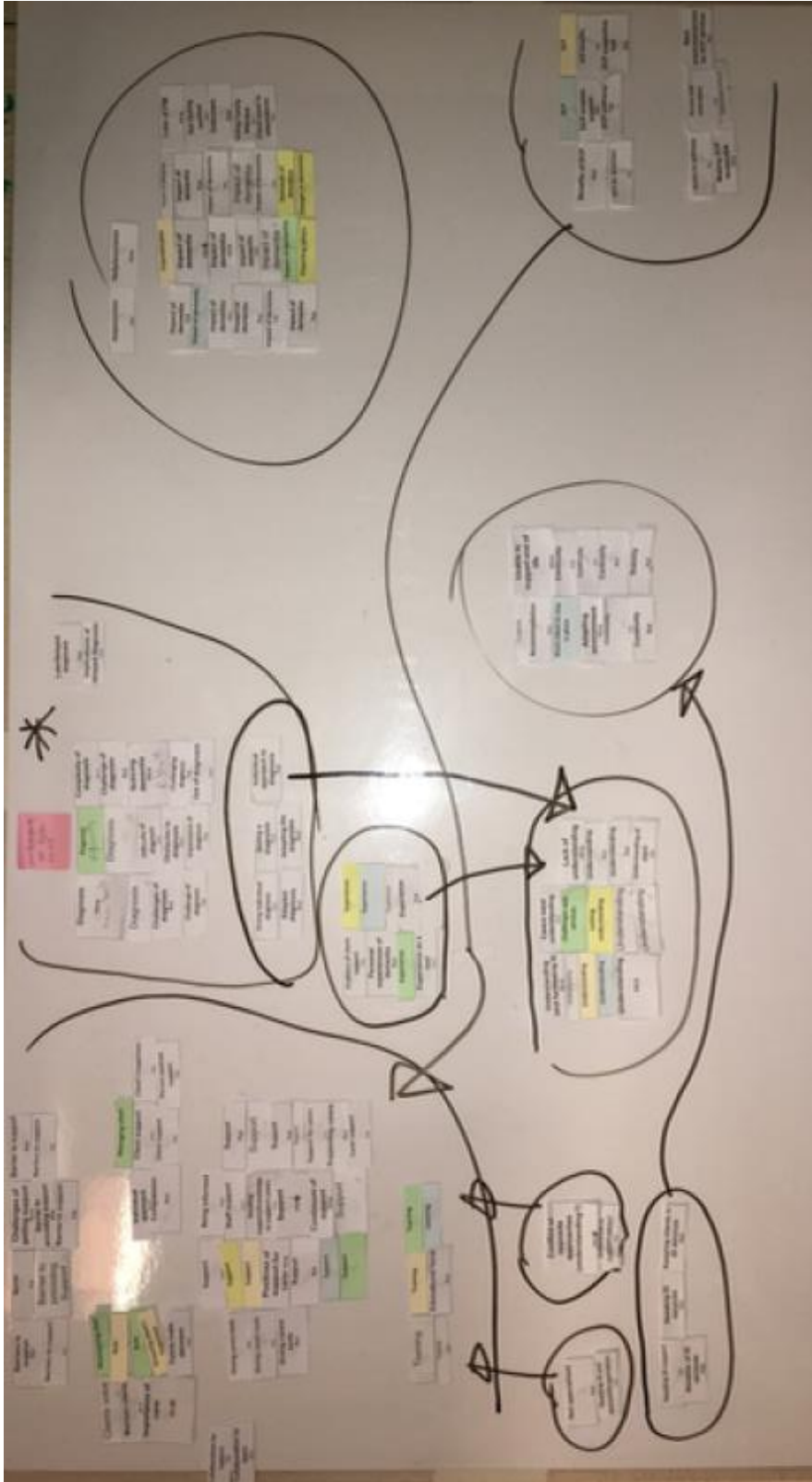
Appendix M

- List of Overarching Focused Codes



Appendix N

- Picture of Overarching Focused Codes Clustered



Appendix O

- List of Reports to Support use of Timeframe in Literature Search

- Treat Me Right (Mencap, 2004)
- Death by Indifference (Mencap, 2007)
- Winterbourne View Hospital (Department of Health, 2012)
- Confidential Enquiry into Premature Deaths of People with Learning Disabilities report (Heslop et al., 2013)
- Building the Right Support report (Local Government Association, Association of Directors of Adult Social Services, & NHS England, 2015)
- Transforming Care programme national plan, the Time for Change: The Challenge Ahead report (Bubb, Brittan, & Dixon, 2016)

Appendix P
- Literature Review Table

	Author (year), Country of focus, Title	Methods	Key Findings	Strengths and Limitations	Quality Score
1.	Auty, E., & Scior, K. (2008). (UK). Psychologists' clinical practices in assessing dementia in individuals with Down syndrome.	Mixed methods: quantitative, questionnaires; qualitative, focus groups. Participants <i>n</i> =64 clinical psychologists. Descriptive statistics.	Variability in practice, assessment methods, and the explanations given by clinicians to people with intellectual disability and their carers. Lack of resources and options for referral purposes after people showed signs of dementia.	Methodology and methods appropriate. Credibility of qualitative analysis improved through member validation. Low response rate (26%). Lack of objective measures within questionnaire.	80%
2.	Bayley, A., Amoako, A., & El-Tahir, M. O. (2017). (UK). Service evaluation of a Specialist Memory Clinic for adults with ID in South Wales	A predominately quantitative study with a small number of open-ended questions within questionnaires. Data were collected through three methods: an audit of the Memory Clinic and professional's records of activities at 2011 and 2015, using published guidelines as a criterion; carers feedback and evaluation of training sessions.	Findings highlighted full compliance with guidelines apart from delivering a baseline assessment for people with Down syndrome. Carers provided positive feedback about the service. Evaluation of training highlighted improvement in knowledge.	Findings were developed from a small amount of data (four carer feedback forms; training feedback from 20 staff; 11 cases within the audit), meaning poor generalizability. There was a lack of detail of how assessments were developed and whether they were validated.	65%

<p>3. Bell, D. M., Tumbull, A., & Kidd, W. B. (2008). (UK). Differential diagnosis of dementia in the field of learning disabilities: a case study.</p>	<p>Case study- individual with Down syndrome and suspected dementia. Description of the assessment and intervention process.</p>	<p>Highlighted difficulties around a speedy diagnosis, and the usefulness of assessing other complex situations to rule out conditions which could mimic dementia. Importance of a baseline in the assessment process.</p>	<p>Draws on multiple sources of data. Uses validated and reliable measures. Recruitment strategy is not described. Informed consent stated, but ethical approval is not.</p>	<p>75%</p>
<p>4. Bromley, L. (2014). (UK). How do carers of people with an intellectual disability with dementia experience their role and the support they receive through services?</p>	<p>Thesis. Qualitative study. Utilises semi-structured interviews with five family and seven paid carers. Data were analysed using thematic analysis.</p>	<p>9 meta-themes were developed: including carers' identity; transitions in the carer experience, self-care, difficulties in caring, changes to services, recommendations for change, barriers to accessing carer support, sources of support and resources, and sharing carers' best practice. Many of these themes were shared across carer groups</p>	<p>Use of investigator triangulation to improve trustworthiness of findings- though no detail of how this was achieved or with who were provided. Methods allowed aim to be achieved. Few to no quotes were used to support points, making it difficult to judge the trustworthiness of findings.</p>	<p>80%</p>
<p>5. Cairns, Lamb, & Smith (2010). (UK). Reflections upon the development of a dementia screening service for individuals with Down's syndrome across the Hyndburn and Ribble Valley Area</p>	<p>Paper offering reflections on feedback on the development of a screening and post-diagnostic pathway for dementia in people with Down syndrome.</p>	<p>At the time of publication 27 individuals had been screened with six were identified as moderate to high risk of dementia. Feedback highlighted that engagement with the pathway and the training they provided increased</p>	<p>Little details were provided of the measures used to collect feedback. Formal research methods were not used to collect data. Much of the data appeared to be collected through informal feedback and the authors' reflections.</p>	<p>58%</p>

			knowledge and awareness in carers		
6.	Carling-Jenkins, R., Tor, J., Iacono, T., & Bigby, C. (2012). (Australia). Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments	Case studies: semi-structured interviews; written diaries; medical file audits. Participants $n=3$ people with Down syndrome and Alzheimer's disease, and their families. Qualitative data analysis strategies were applied.	Families of adults with Down syndrome and Alzheimer's disease experienced stress and confusion negotiating services not adequately equipped to meet their needs. Diagnostic overshadowing was present and masked increased care needs due to dementia.	Data collection appropriate and were well detailed. Data analysis was appropriate but lacked detail. No attempts mentioned to improve rigour of coding. Themes convincingly supported with quotes. Experiences of participants based on a small number- 3 people with Down syndrome and Alzheimer's disease, making transferability challenging.	75%
7.	Chapman, M., Lacey, H., & Jervis, N. (2017). (UK). Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals.	Qualitative study, Focus group with eight health and social care practitioners working in community learning disability services. Data were analysed using thematic analysis.	The dementia screening, pathways and processes provided a common framework, which instilled an efficient, multidisciplinary, proactive approach. The training and information provided by services and participants were reported as improving care quality and reduce carer anxiety.	Appropriate methodology used to answer the research question. A clear description of the analysis. Use of investigator triangulation to improve trustworthiness. Claims around carers could have been strengthened by recruiting carers. Findings based on pathway HCPs meaning could be influenced by bias.	80%

<p>8. Cleary, J. & Doody, O. (2017). (Republic of Ireland). Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature</p>	<p>Systematic narrative literature review, searching for papers between January 2000- May 2015 in the following electronic databases: Academic Search Complete, CINAHL Plus with full text, MEDLINE, PsycARTICLES, PsycINFO, UK and Ireland Reference Centre and British Education Index.</p>	<p>7 themes outlined: staff knowledge of dementia; staff training in dementia; caregiving; challenging behaviour; pain recognition; mealtime support; coping strategies.</p>	<p>Method of systematic review detailed. Numerous electronic databases used. Inclusion of relevant studies to address the review's questions. Little detail provided on evaluating the quality of included studies.</p>	<p>90%</p>
<p>9. Courtenay, K., Jokinen, N. S., & Strydom, A. (2010). (International). Caregiving and adults with intellectual disabilities affected by dementia.</p>	<p>Literature review, period 1997-2008, searched across Medline, EMBASE, and PsycINFO. Papers selected could be in English, Dutch or German. Included were also relevant publications from the author's personal collection.</p>	<p>Dearth of research reporting on caregiving in the family context. Families have limited involvement regarding dementia care. Greater burden for paid carers supporting people with Down syndrome and dementia. Carers lacked experience in dementia support. Importance of training was highlighted.</p>	<p>Use of international papers and author's personal collection. Authors internationally recognised experts. Search results were clearly written and displayed. A full description of the methodology not provided. Small number of databases used.</p>	<p>80%</p>

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| <p>10. Dicks, S., Jackson, S., Pasokhy, A., & Symes, M. (2015). (UK).
Training for staff who care for clients with dementia.</p> | <p>Mixed method. A small-scale study which assessed a bespoke training workshop. Participants n=17 paid carers across three staff teams. Paid carers completed a questionnaire specifically designed for this study, at both pre and post-training.</p> | <p>The results highlighted increased confidence and understanding of the individual with an intellectual disability and dementia</p> | <p>Ethical approval not detailed. The long terms effect of training was not measured making it difficult to judge usefulness. The findings could be influenced by demand characteristics as paid carers completed the questionnaire at the training site, where the training provider was present. Small sample size reducing generalisability of findings.</p> | <p>55%</p> |
| <p>11. Foster, L. A. (2014). (UK).
The experience of carers of people with Down Syndrome who develop dementia.</p> | <p>Qualitative methods: semi-structured interviews. Participants n= 6 family carers and n=4 paid carers. Data were analysed using interpretative phenomenological analysis.</p> | <p>Key findings included: similar themes developed for family members and paid carers. However, the emotional intensity of experiences differed between carers: family members experienced higher level of emotional burden compared to paid carers who took an observer position.</p> | <p>Use of appropriate methods to answer research questions. Transparent analytical process. Small sample size reducing representativeness of the findings. Ethical approval detailed.</p> | <p>85%</p> |

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|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| <p>12. Furniss, K. A., Loverseed, A., Dodd, K., & Lippold, T. (2012). (UK).
The views of people who care for adults with Down's syndrome and dementia: a service evaluation.</p> | <p>Semi-structured interviews. Checklist to indicate participants' interests in a range of services. Participants $n=13$ ($n=2$ family carers; $n=3$ family members; $n= 8$ care staff members). Data analysed using interpretative phenomenological analysis.</p> | <p>Three themes developed: knowledge and information; coping and support; concerns about the future. Analysis highlighted better knowledge of dementia for staff members compared to family carers and relatives.</p> | <p>Methodology and methods appropriate for research questions. Clear, detailed description of participants and recruitment. No attempts to improve rigour through peer examination. Participants did not need to support someone with a confirmed diagnosis of dementia. Small number of family carers.</p> | <p>85%</p> |
| <p>13. Heller, T., Scott, H. M., Janicki, M. P. & Pre-summit workgroup on caregiving and intellectual and developmental disabilities. (2018). (USA).
Caregiving, intellectual disability, and dementia: Report of the Summit workgroup on caregiving and intellectual and developmental disabilities.</p> | <p>This report aimed to: assess the quality of research, policy, and practice whilst developing recommendations related to supports for carers of older adults with an intellectual disability; 'to translate the contributions of these findings to the greater dementia care agenda; and to promote inclusion of issues particularly relevant to IDD and dementia as part of the summit platform' (p.273).</p> | <p>Five themes in relation to programs and caregiving were assessed: 'challenges of dementia; family caregiving interventions; supportive care settings; effects of diversity; and bridging service networks of ageing in disability' (p.272).</p> | <p>This report was developed by experts within caregiving, dementia, and intellectual disabilities. However, details of whether caregivers themselves were involved were not provided. Report was developed through experts in the USA, meaning some elements, such as services, may not be relevant to caregivers and people with intellectual disabilities and dementia in the UK.</p> | <p>80%</p> |

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| <p>14. Herron, D. L., & Priest, H. M. (2013). (UK).
Support workers' knowledge about dementia: a vignette study.</p> | <p>Qualitative vignette study with a semi- structured questionnaire. Participants $n=14$ support workers who had supported someone with an intellectual disability and dementia. Data analysed through thematic analysis.</p> | <p>Few participants received any mental health training. Generally poor at judging early and intermediate symptoms of dementia, but better able to identify more explicit symptoms seen in the later stages of the dementia. Need to combine training with experience.</p> | <p>Appropriate method. Detailed sample and recruitment section. Ethical approval stated. The design was described and justified. Clear details of the analysis were provided. Small sample size was used. Use of vignettes lacks ecological validity.</p> | <p>85%</p> |
| <p>15. Hobson, B., Webb, D., Sprague, L., Grizzell, M., Hawkins, C., & Benbow, S. (2012). (UK).
Establishing a database for proactive screening for adults with Down's syndrome: when services work together.</p> | <p>This paper describes a service improvement project which aimed to proactively screen adults with Down's syndrome aged over 30 years, for dementia. The service established a functional baseline and develop a database to facilitate a timely diagnosis.</p> | <p>The key findings included: through contact with health, social, third sector and housing services, a defined group of people with Down syndrome; a proactive screening process can be successfully implemented; and the importance of intellectual disability and older age generic services working together to develop a proactive screening project.</p> | <p>Lack of formal evaluation of the proactive screening service and its implementation through care pathways. Most of the findings were based on informal feedback and/ or the authors' own reflections. Consequently, findings may be influenced by bias and need to be considered with caution.</p> | <p>65%</p> |

<p>16. Iacono, T., Bigby, C., Carling-Jenkins, R., & Torr, J. (2014). (Australia). Taking each day as it comes: staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes</p>	<p>Two semi-structured interviews conducted 6-12 months apart with direct care staff. Participants: direct care staff who supported each of the nine people with Down syndrome and dementia. Data analysed thematically with guidance from Creswell (2009).</p>	<p>Three themes developed: struggling to understand change; taking each day as it comes; commitment; care staff had limited understanding of the impact of Alzheimer's disease; Responses were reactive, and strategies were used on a trial and error basis.</p>	<p>Detailed sampling and recruitment section. Themes well supported by quotes. Detailed comparison to previous literature. Coding by multiple authors to improve rigour. Lacked sufficient details of direct care staff participants.</p>	<p>95%</p>
<p>17. Janicki, M. P. (2011). (USA). Quality outcomes in group home dementia care for adults with intellectual disabilities.</p>	<p>Literature review of relevant policy and practice organisational guidelines, and applied research service provision critical to quality care. Developed quality outcome measures.</p>	<p>Contributing factors of quality dementia care, which have the potential to alleviate or compound the impact of the dementia, were discussed in relation to structural features. Four components of quality dementia care were stated: 'clinically relevant early and periodic assessment; functional modifications in the living setting; constructive staff education and functionality for stage-adapted care; an flexible long-term services provision that recognises and plans for progression of decline and loss of function' (p.763).</p>	<p>Use of relevant types of literature. Supported with evidence. Systematic review strategy not described. Quality of literature unclear.</p>	<p>70%</p>

<p>18. Janicki, M. P., Dalton, A. J., McCallion, P., Baxley, D. D., & Zendell, A. (2005). (International). Group home care for adults with intellectual disabilities and Alzheimer's disease.</p>	<p>Mixed methods. Ethnographic suvery. Two samples of group homes (sample one: 12 group homes across five countries. Sample two: 10 group homes drawn from the UK and USA.</p>	<p>Key results included: group homes, though varying in staffing and design, generally implemented general practices of dementia care; as homes experienced changes through the presentation and deterioration of dementia, group homes managed by relying on their existing resources; as dementia worsened, group homes implemented environmental and program adaptations; compared to residents without dementia, staff burden increased when supporting people with dementia, with increase time spent on hygiene maintenance and behaviour management.</p>	<p>Use of data source and method triangulation to improve the quality of the research and findings. Data drawn across different countries which improved the cross-cultural generalisability of the findings.</p> <p>Ethical approval reported and some ethical considerations reports.</p> <p>Member checking was employed to improve the trustworthiness of the findings.</p> <p>The analysis strategy was not adequately reported. For instance, the form of analysis for the qualitative data was not stated. Furthermore, how the qualitative data was used within the findings section is not clear.</p>	<p>90%</p>
<p>In sample one, data were collected through observations and semi-structured interviews with key informants.</p>	<p>In sample two, each home completed questionnaires, including, The Caregiver Activity Survey-Intellectual Disabilities (CASID); The Assessment for Adults with Developmental Disabilities (AADS) scale; The Dementia Status Questionnaire (DSQ); and The Group Home Site Questionnaire (GHSQ)</p>			

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| <p>19. Janicki, M. P., Zendell, A., & DeHaven, K. (2010). (USA)
Coping with dementia and older families of adults with Down syndrome.</p> | <p>Survey design. Participants $n=17$ primary carers of people with Down syndrome (mostly parents and siblings). Data were statistically analysed through ANOVAs and correlations.</p> | <p>Carers expressed strong commitment to keeping their child at home. Implemented changes to ensure their child stayed at home. No burn-out or significant health problems due to continued caregiving. Concerns about the day-to-day strains and the future.</p> | <p>Research method appropriate. Validated measures used and detailed. Small sample over large geographical area preventing generalisation. Response rate not reported. Sample size calculation not given.</p> | <p>80%</p> |
| <p>20. Jenkins, R., Davies, R., Sardi, I., Llewellyn, P., Northway, R...Keeling, D. (2008). (UK).
Adults with learning disabilities presenting with dementia</p> | <p>Qualitative methods: semi-structured interviews. Participants: $n=3$ family carers, $n=2$ paid carers, $n=1$ team leader, and $n=2$ supported housing managers. Explored carers' experiences of the newly developed (at the time) DCP. Data analysed through Grounded Theory.</p> | <p>participants generally positive about their experiences of the DCP and the services it provided. Few reported receiving pathway review meetings, making it difficult to assess any long-term benefits. A lack of clarity and knowledge of the DCP and its role. Training offered to paid carers, none had been offered to carers in a 'family' situation.</p> | <p>A lack of clarity around which form of Grounded Theory was used and the methodological strategies applied. Service evaluation took place shortly after implementation of DCP making it difficult to judge its role and usefulness. Implementation of investigator triangulation which Improved trustworthiness of the findings.</p> | <p>75%</p> |
| <p>21. Jervis, N. & Prinsloo, L. (2007). (UK).
How we developed a multidisciplinary screening project for people with Downs syndrome given the increased prevalence of early onset dementia</p> | <p>This article provides details and reflects on lessons learnt from how the Manchester Learning Disability Partnership approached screening 135 people with Down syndrome.</p> | <p>This paper illustrated the importance of proactively screening people with Down syndrome for dementia, and provides a blue print to others on how this was achieved. The authors reflect on the benefits of this process, including raising</p> | <p>Paper provides no details on the outcome of this proactive approach, making it difficult to judge the effectiveness of the screening process. Other claims around raising awareness not based on a formal systematic approach,</p> | <p>60%</p> |

			awareness of dementia in carers and family members, and the use of a multi-disciplinary approach used to bring services together.	making it difficult to judge the trustworthiness of such claims.	
22.	<p>Jokinen, N., Gomiero, T., Watchman, K., Janicki, M.P. Hogan, M...Crowe, J. (2018). (International).</p> <p>Perspectives on family caregiving of people ageing with intellectual disability affected by dementia: Commentary from the international summit on intellectual disability and dementia.</p>	A discussion paper examining family caregiving situations through the lens of a support-staging model for adults with an intellectual disability and dementia.	The proposed support staging model for family caregiving was composed of two elements: the 'role and nature of the involvement of caregiving' (p.415), which can be either primary or secondary; and the influence of the stage of dementia (diagnostic phase, explorative phase, adaptive phase, and closure phase).	The authors of the paper are experts within the relevant field. Points and claims are supported by relevant literature from both the intellectual disability and non-intellectual disability literature.	90%
23.	<p>Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force., L. T., & the National Task Group on Intellectual Disabilities and Dementia Practices (2013). (USA).</p> <p>Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia.</p>	Paper discussing practice guidelines of dementia care.	These guidelines are drawn from the literature, clinical experience, and best practice. The guidelines provide guidance on what actions should be taken across the journey of dementia, from initial suspicions to end-of-life care. Underpinning the guidance is a staging model.	The authors of the paper are experts within the relevant field. Some elements of the guidance were specific to the USA and not relevant to a UK context.	

<p>24. Kalsy, S., Heath, R., Adams, D., & Oliver, C. (2007). (UK). Effects of training on controllability attributions of behavioural excesses and deficits shown by adults with down syndrome and dementia</p>	<p>Quantitative method. Mixed factorial design. Examined the effects of a one day training session in ageing, dementia and people with intellectual disabilities on the controllability and optimism for change in behavioural deficits and excesses. Participants <i>n</i>= 97 care staff from community day centres for adults with intellectual disabilities completed, pre and post training, an attribution questionnaire, the knowledge quiz and optimism scales.</p>	<p>Results showed improved knowledge of ageing and dementia from pre to post-training, and a greater understanding that the person's changing behaviour was not always in their control.</p>	<p>The use of validated surveys improved the quality of the research. The use of a large sample size making the results more generalizable.</p> <p>It is not clear within this paper what point post-training assessments took place. The timing is important, as long-term follow up instead of or in addition to immediate assessments would better indicate information retention and changes in thought process. Furthermore, such assessments and surveys do not illustrate changes in practice.</p>	
<p>25. Llewellyn, P. (2011). (UK). The needs of people with learning disabilities who develop dementia: a literature review</p>	<p>Literature review. Papers published between 1996-2006. Databases used: Psychinfo, Zetoc, Cinahl, Medline, Assia, and BNI. 170 papers were included in the review.</p>	<p>Primary medical need is timely and accurate diagnosis. Carers' needs entwined with people with an intellectual disability and dementia. Intellectual disability services should be the main provider of services. Family carers approached services once unable to cope.</p>	<p>Clear description of search strategy. Rigorous method used to review articles. Inclusion of quality literature. Some key databases not searched. Only searched up to 2006, which meant some key studies were not included.</p>	80%

<p>26. Lloyd, V., Kalsy, S., & Gatherer, A. (2008). (UK), Impact of dementia upon residential care for individuals with Down syndrome.</p>	<p>Between-groups questionnaire design. Participants $n=20$ paraprofessional paid carers (71% response rate) within residential care ($n=9$ cared for individuals with Down syndrome and dementia [dementia group]; $n=11$ care for people with Down syndrome only [non-decline group]). Data statistically analysed using t-tests.</p>	<p>No significant differences found when comparing dementia group against the non-decline group for all measures across objective or subjective burden. Carers in dementia group reported significantly increased levels of emotional exhaustion.</p>	<p>Response rate was reported and adequate. Use of valid and reliable measures which are detailed. Sample may have high care needs regardless of dementia. Small sample size.</p>	<p>83%</p>
<p>27. Lord, A. (2015). (UK). The experiences of staff supporting people with intellectual disabilities with dementia, death, and bereavement</p>	<p>Qualitative methods: semi-structured interviews. Participants: $n= 10$ paid carers. Data analysed using IPA. Aimed to explore the lived experiences of paid carers in residential or supported living environments with a focus on their relationship with people with an intellectual disability and dementia.</p>	<p>The analysis produced four themes: the value of the pre-existing relationship to carers as dementia progresses; finding ways to connect when reciprocity has gone; resisting dementia “creeping in” and taking control; and the stronger the pre-existing relationship, the greater the emotional cost of dementia.</p>	<p>Use of appropriate methodology to explore the study aims. Small sample size reduced the transferability of the findings. As carers worked with the same individual and many worked within the same residential home and/ or organisation, findings are not representative of paid carers within different contexts. Ethics recorded. Steps to enhance quality of research were detailed.</p>	<p>90%</p>

<p>28. McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). (Republic of Ireland). Alzheimer's dementia in persons with Down's syndrome.</p>	<p>Survey design. Participants-caregivers of 63 persons with Down syndrome and Alzheimer's disease, and 61 persons with Down syndrome without Alzheimer's disease, the Caregiving Activity Survey-Intellectual Disability (CAS-ID). Data were also gathered on co-morbid conditions.</p>	<p>When Alzheimer's disease developed, staff time increased (from a mean of 2.66 hours to 8.18 hours); this was greater for people with a moderate intellectual disability compared to other levels of intellectual disability. Staff caregiving time was similar between mid (8.40 hours) and end (7.84 hours) stage dementia; however, tasks altered significantly.</p>	<p>Use of validated surveys. The authors recruited participants across different living settings, including community based group homes, specialist units, campus based group homes, and residential units, making the findings more representative; however, the use a purposive sampling strategy over random sampling meant the sample was less representative.</p>	<p>85%</p>
<p>29. McCarron, M., & McCallion, P. (2005). (Interational). A revises stress and coping framework for staff carers of persons with intellectual disabilities and dementia.</p>	<p>Theoretical paper explicating a theoretical framework, adapted from Pearlin model of stress and coping (Pearlin, Mullan, Semple, & Skaff, 1990), which helps to clarify the interrelated conditions which underpin and inform the impact of the dementia on carers.</p>	<p>The authors retained the four domains of Pearlin's model (background and contextual factors; primary and secondary strains, mediating factors, and outcomes or manifestation of stress), but introduced and removed components within each domain. For example, McCarron and McCallion introduce 'conflict with other staff' as a possible stressor within the model; whilst removing contextual factors which may not be relevant to paid carers.</p>	<p>One shortcoming of this theoretical framework is the lack of research carried out to validate the adaptations made by McCarron and McCallion. However, the domains of the model have been validated within the wider caregiving literature (Pearlin et al., 1990). Adaptations have been informed by reviewing the relevant literature. Literature search strategy not clearly explicated.</p>	<p>80%</p>

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| <p>30. McCarron, M., McCallion, P., Coppus, A., Fortea, J., Step, S., & Janicki, M. (2018). (International).
Supporting advanced dementia in people with Down syndrome and other intellectual disability: consensus statement of the International Summit on Intellectual Disability and Dementia.</p> | <p>Discussion paper identifying the similarities and differences in 'expressions of advanced dementia between adults with intellectual disability (and adults in the general population' (p. 617).</p> | <p>This paper reported that it is important, when identifying advanced dementia, that any change should be measured from the person's prior functioning in 'combination with clinical impressions of continuing and marked decline and of increasing co-morbidity' (p.617). Additionally, care planning needs to recognise the increased likelihood of 'physical symptoms, co-morbidities, immobility and neuropathological deterioration' (p.617).</p> | <p>Use of literature to support arguments. Points appear credible and coheres with previous literature. The article is peer-reviewed and well written. This paper is written and informed by the perspectives of leading experts within the relevant area.</p> | <p>90%</p> |
| <p>31. McCarron, M., McCallion, P., Fahey-McCarthy, E., & Connaire, K. (2011). (IRepublic of Ireland)
The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia.</p> | <p>Qualitative descriptive design- focus groups, field notes, reflective journals. Participants <i>n</i>=57 (<i>n</i>=34 nursing staff; <i>n</i>=17 care workers; <i>n</i>=5 doctors; <i>n</i>=1 social worker). Data analysed using a qualitative descriptive approach.</p> | <p>Seven inter-related influences on the role and timing of palliative care: dignity, comfort and quality in care; when should palliative care begin; pain and symptom management; collaboration and accessing specialist support; challenges of hospital placement; co-ordinating care; supporting the person through death.</p> | <p>Appropriate method which was justified. Large sample size was recruited. Improved trustworthiness of analysis through methods triangulation. Findings supported through quotes. Triangulation through multiple data sources.</p> | <p>95%</p> |

<p>32. McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K., & Dunn-Lane, J. (2011). (Republic of Ireland). Supporting persons with Down syndrome and advanced dementia</p>	<p>Qualitative methods. Thirteen focus group interviews. Participants n= 50 staff in six ID services and seven staff in one specialist palliative care provider. Data analysed through a qualitative descriptive approach.</p>	<p>Results highlighted that intellectual disability services were not prepared to provide support that meets the increasing support needs of people with an intellectual disability at the end stage of dementia. Services did not provide suitable environments or adequately prepare paid carers. Though the different intellectual disability sites generally supported 'ageing in place', this was difficult to maintain with advanced dementia which required greater assistive environments. Paid carers described the challenges of providing care with 'comfort or with safety' (p.292) in the individual's own home.</p>	<p>Data collected from a large sample, though a small number of these participants were from one palliative care service, making the results less representative of palliative care specific views. Compounding this was the lack of transparency on which participant group/s informed the developed themes.</p> <p>The trustworthiness of the findings was improved through the implementation of investigator triangulation.</p> <p>Claims are well supported with appropriate illustrative quotes.</p>	<p>90%</p>
<p>33. McCallion, P., Nickle, T., & McCarron, M. (2005). (USA). A comparison of reports of caregiver burden between foster family care providers and staff caregivers in other settings: A pilot study.</p>	<p>Survey design with matched participants. Participants n=28 were split into two groups (n=14 people with an intellectual disability and Alzheimer's disease living in foster family care settings; n=14 people with an intellectual disability and</p>	<p>No significant difference found between group home staff and family care providers on the CDS-ID. Group home staff spent more time supervising adults with an intellectual disability, and addressing behavioural concerns. Group home staff</p>	<p>Detailed sample, recruitment, and setting section. Measures were valid and reliable, and adequately described. Statistical tests stated. Small sample, though was a pilot study. Results not clearly explained.</p>	<p>75%</p>

	Alzheimer's disease, living in out-of-home settings). Statistical analysis using <i>t</i> -tests and comparable non-parametric statistics	spent more time on activities associated with bathing, eating, and nursing care.		
34. McKenzie, K., Baxter, S., Paxton, D., & Murray, G. (2002). (UK). Picking up the signs.	Questionnaire, predominately closed-questioned, with one open-question. Participants <i>n</i> =88 social care staff working in intellectual disability services (two groups: <i>n</i> =50 worked with people with Down syndrome; and <i>n</i> =34 those who did not).	Level of knowledge, although significantly higher in staff who supported clients with Down syndrome, suggested staff may not be aware of health problems or potential signs of Alzheimer's disease in people with Down syndrome.	Method appropriate for research questions. Anonymity and confidentiality mentioned, but ethical approval not stated. Recruitment strategy and analytical method not described.	58%
35. McKenzie, K., Metcalfe, D., Michie, A., & Murray, G. (2018). (UK). Service provision in Scotland for people with an intellectual disability who have, or are at risk of developing, dementia.	Survey design. Participants <i>n</i> = 12 staff from 12 intellectual disability services, representing 11 main health board areas in Scotland.	Proactive screening and reactive assessments were implemented by seven services for people with Down syndrome, with five services providing reactive assessments only. For people with an intellectual disability other than Down syndrome, 11 services provided reactive assessments only; whilst only one area provided both proactive screening and reactive assessments	Ethical approval was stated. The sample was drawn from a high proportion of health board areas. There was a lack of detail of the survey used and whether it was validated. Contextual details or differences between the services were not provided, making it difficult to judge why a service implemented a reactive assessment or proactive screening.	65%

				Only one healthcare professional from each service replied to the survey; consequently, the views and knowledge of other team members, which may have differed, were not included.	
36.	McLaughlin, K. & Jones, A. (2010). (UK). 'It's all changed:' carers' experiences of caring for adults who have Down's syndrome and dementia.	In-depth, unstructured qualitative interviews with individuals caring for adults with Down syndrome at differing stages of dementia. Participants <i>n</i> =6 (Siblings <i>n</i> =4; Paid carers <i>n</i> =2). Data analysed using thematic analysis.	Participants described changing informational needs and experiences from pre- to post-diagnosis. Carers experienced changing support needs as the dementia worsened in the people they supported.	Methodology was appropriate to answer the research questions. Ethical approval reported but insufficient detail was given around ethical considerations. Analysis was peer-reviewed.	85%
37.	Moore, C. L. (2012). (UK). The caring experience of staff carers working with adults with learning disability and dementia	Qualitative methods: semi-structured interviews. Participants <i>n</i> =9 paid carers. Data analysed through IPA.	Four overarching themes were identified: 1. Reciprocity and Relationships, 2. Culture of LD Services, 3. Emotional Impact, 4. Knowledge and Understanding.	Investigator triangulation applied which improved trustworthiness of findings. Appropriate methods used to answer research questions. Small sample size reducing transferability of findings. Ethical approval stated. Use of respondent validation and investigator triangulation strengthened the trustworthiness of findings.	88%

<p>38. Perera, B. D., & Standen, P. J. (2014). (UK). Exploring coping strategies of carers looking after people with intellectual disabilities and dementia</p>	<p>Semi-structured interviews with carers. Focus groups with community learning disability nurses. Participants $n=9$ carers ($n=3$ family; $n=6$ paid carers). Community learning disability nurses (number unknown). Data analysed through thematic analysis.</p>	<p>Three themes developed, participants: used narratives to develop meaning and cope better; developed tools and coping strategies over their career; departmentalised their jobs from their personal life.</p>	<p>Multiple researchers coded together to improve rigour. Themes were clearly described and supported by quotes. Lacked details of participants. Not clear how some of the data has been used. Small sample size of carers for form of analysis.</p>	<p>85%</p>
<p>39. Rowe, M. (2014). (UK). Will General Practitioners be adequately prepared to meet the complexities of enhanced dementia screening for people with learning disabilities and Down syndrome: key considerations</p>	<p>Discussion paper about the dementia screening process and the difficulties GPs may encounter.</p>	<p>Article outlined GP aims within a dementia screening process and the difficulties they may encounter, and considerations they need to make.</p>	<p>Use of literature to support arguments. Points appear credible and coheres with previous literature. The article is peer-reviewed and well written.</p>	<p>90%</p>
<p>40. Ryan, C., MacHale, R., & Hickey, E. (2018). (Republic of Ireland). "Forgetting familiar faces": Staff perceptions of dementia in people with intellectual disabilities</p>	<p>Qualitative study. Two focus groups, with eight frontline staff members in both day and residential services, at various levels of training, from a large voluntary organisation that provides services to people with intellectual disabilities. Data were analysed using thematic analysis.</p>	<p>Four key themes were developed: the difficulty of recognising symptoms of dementia in people with intellectual disabilities; the process of diagnosis; the challenge of dementia for the person; the emotional impact of dementia for other people. A key finding was the lack of involvement of people with intellectual disability in future care.</p>	<p>A clear description of the methods used. Ethical approval detailed. Themes supported with appropriate quotes. More appropriate research methods could have been used to collect data. Participant criteria did not specify whether participants had supported someone with a diagnosis of dementia. Use of investigator triangulation improved trustworthiness of findings.</p>	<p>76%</p>

<p>41. Starkey, H., Bevins, S., & Bonell, S. (2014). (Republic of Ireland). The role of prospective screening in the diagnosis of dementia in people with Down's syndrome.</p>	<p>Quantitative paper. Analysed 26 files of people with Down syndrome and dementia diagnosed between 2001-2013 to understand the effectiveness of their proactive screening process</p>	<p>In 56% of cases, concerns of dementia were raised through the screening process; whilst in 46% of cases concerns were raised in between screening.</p>	<p>The findings were based on a small sample and only one diagnosis service, so no firm conclusion could be made and findings cannot be generalised to other services.</p>	<p>75%</p>
<p>42. Strydom, A., Al-Janabi, T., Houston, M., & Ridley, J. (2016). (UK). Best practice in caring for adults with dementia and learning disabilities.</p>	<p>Literature review focusing on old people with intellectual disabilities; examining presentation and diagnosis of dementia, and its implications for management and service provision.</p>	<p>Literature searched in relation to screening, diagnosis, management, environmental considerations, end of life care, and training issues for nursing staff.</p>	<p>Recommendations informed by relevant literature and leading experts within the intellectual disability and dementia field.</p>	<p>70%</p>
	<p>Literature review search strategy not reported.</p>	<p>The paper provided recommendations for best practice and service improvements which focused on the areas searched in the review.</p>	<p>Literature search strategy not detailed, which makes it difficult to judge the exhaustiveness of the search.</p>	

<p>43. Tromans, S., Andrews, H., Wani, A., & Ganghadaran, S. (2018). (UK). The ELCIDD project: An audit of end-of-life care in persons with intellectual disabilities and dementia.</p>	<p>Audit of a Dementia Care Pathway to review the level of compliance using a bespoke data collection form informed by key standards of end of life care [Department of Health, Gold Standards Framework and National Institute for Health and Care Excellence (2010)].</p>	<p>The audit found low levels of compliance around advanced care planning, specifically: 25% of people with an intellectual disability and dementia were involved in decision-making; 22% had their preferred place of death recorded; and 3% had their spiritual and cultural needs assessed. Again, common with previously discussed literature, people with an intellectual disability were not actively involved in decisions around their future support.</p>	<p>A systematic approach was utilised, with a predefined compliant document.</p> <p>Due to this being an audit study which did not have a qualitative element embedded, it provided little understanding for some of the quantitative findings.</p> <p>Analysis strategy not clearly detailed.</p>	<p>75%</p>
<p>44. Watchman, K. (2003). (UK). Critical issues for service planners and providers of care for people with Down's syndrome and dementia.</p>	<p><i>n</i>= 32 patient cases were included within the analysis. Discussion paper about critical issues for service planners and providers of care for people with Down syndrome and dementia</p>	<p>Discussed critical issues around accommodation, diagnosis of dementia, training and experience of staff, the role of the family, the advantages of health screening, and difficulties of collating accurate information.</p>	<p>The paper was written by a leading expert. Reputable literature drawn upon. Points supported by empirical evidence.</p>	<p>100%</p>

<p>45. Watchman, K. (2005). (UK). Practitioner-raised issues and end-of-life care for adults with Down syndrome and dementia.</p>	<p>Semi-structured qualitative interviews with 10 practitioners ($n=8$ intellectual disability services; $n=2$ palliative care services- all had experience of supporting someone with an intellectual disability and dementia). No details of the data analysis were provided.</p>	<p>Key findings included: a need to involve people with Down syndrome in the planning of their own end-of-life care; a lack of communication between those working in palliative care and intellectual disability settings; identification of a "care culture clash;" and deficits in training programs for staff involving dying, death, and bereavement.</p>	<p>Sample and recruitment detailed. Findings evaluated with previous literature. Ethical considerations or approval not detailed. Little amount of quotes to support claims. Small number of participants mainly from voluntary sector.</p>	<p>75%</p>
<p>46. Watchman, K. (2007). (UK). Dementia and Down syndrome: the diagnosis and support needed</p>	<p>Quantitative postal questionnaire. Participants $n=35$ questionnaires returned (80% response rate) ($n=12$ family carer; $n=23$ paid carers).</p>	<p>Changes in behaviour (80%), living skills (71%) and confusion (66%) were first signs of dementia noticed by carers. 77% of people with Down syndrome not provided information about the dementia-related changes they experienced.</p>	<p>A high response rate. Ethical consideration reported. Lack of detail is provided for the research question. Cannot judge validity or reliability of questionnaire. Small sample size.</p>	<p>65%</p>
<p>47. Watchman, K. (2008). (UK). Changes in accommodation experienced by people with Down syndrome and dementia in the first five years after diagnosis.</p>	<p>Postal questionnaire. Participants $n=35$ (response rate 77.8%) composed of family and paid carers.</p>	<p>20 out of 35 people with an intellectual disability and dementia not changed accommodation since diagnosis. Ageing in place was present in four cases. Adults with Down syndrome were often prevented chance</p>	<p>Methodology and method appropriate and justified. Small sample size which negatively impacted upon generalisability.</p>	<p>75%</p>

			to discuss their future accommodations.		
48.	Watchman, K. (2016). (UK). Investigating the lived experience of people with Down syndrome with dementia: overcoming methodological and ethical challenges.	Qualitative case studies-data collected through recorded conversations, detailed field notes based on participant observations. Participants $n=3$ people with Down syndrome and dementia. Data analysed through a phenomenological approach identifying themes.	Two key findings discussed: lack of awareness of a sense of self; impact of a lack of information being shared with the individual with Down syndrome post-diagnosis about diagnosis of dementia.	Methodology and methods appropriate and justified. Sample and recruitment technique were detailed. Good level of description for case studies. Appropriately compared with previous literature. Small sample size and inability to transfer data beyond these participants is recognised.	95%
49.	Watchman, K., Janicki, M. P., Splaine, M., Larsen, F. K., Gomiero, T., & Lucchino, R. (2017). (International). International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans.	Discussion paper. Reviewed national plans and reports on dementia to judge the inclusion of intellectual disability in national plans.	National plans and reports provided minimal consideration of intellectual disability and the challenges that carers may experience. Recommendations included: that people with an intellectual disability and their family carer, need to be actively involved in the consultation processes; national organisations needing to provide greater advocacy on behalf of families; and the need for health and social care to provide a infrastructure that	Use of literature to support arguments. Points appear credible and coheres with previous literature. The article is peer-reviewed and well written.	85%

			supports quality care for dementia.		
50.	Wilkinson, H., Kerr, D., & Cunningham, C. (2005). (UK). Equipping staff to support people with an intellectual disability and dementia in care home settings.	Qualitative methods: semi-structured interviews and focus groups across six case study sites. Participants n=10 managers, n=22 direct care staff, n=13 residents, and n=5 relatives of a people with an intellectual disability and dementia.	Care staff, few of whom had prior dementia training, commonly felt uncertainty and lacked expertise to provide the best care and support. Support was reactive, with staff describing a sense of 'floundering'. Staff who received relevant, practice-based and person-centred training, had greater confidence, provided higher quality support, and reduced levels of stress.	There is a lack of description around methods used to collect and analyse data. Use of multiple perspectives and large sample size to improve transferability of findings. Transferability was improved by the use of illustrative quotes.	55%
51.	Wilkinson, H., & Janicki, M. P. (2002). (International). The Edinburgh Principles with accompanying guidelines and recommendations.	Communication paper of principles within intellectual disability and dementia support and services.	The document discusses seven principles which governments, organisations and care provides can adopt and use to aid people with an intellectual disability and dementia.	Authors are leading experts in field. Content coheres with the literature and informed by a panel of experts. Little use of literature to support points or recommendations.	90%

<p>52. Whitehouse, R., Chamberlian, P., & Tunna, K. (2000). (UK). Dementia in people with learning disability: a preliminary study into care staff knowledge and attributions</p>	<p>Mixed Methods: Surveys (The Facts on Ageing (FOA) Quiz; the Dementia and Intellectual Disability (DID) Quiz; and the Attributional Style Questionnaire (ASQ), and semi-structured interviews. Participants $n=21$ care staff</p>	<p>Staff knowledge of ageing comparable to college students. Participants most expect to see forgetfulness if they believed someone was presenting with dementia.</p>	<p>Appropriate methods used. Use of valid and reliable measures. Detailed information for sampling and recruitment. Small sample size, though it was a preliminary study.</p>	<p>90%</p>
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Appendix R

- Table of Review Literature's Year of Publications

2000	Whitehouse, Chamberlain, & Tuna, 2000
2001	NONE
2002	McKenzie, Baxter, Paxton, & Murray, 2002; Wilkinson & Janicki, 2002
2003	Watchman, 2003
2004	NONE
2005	McCallion, Nickle, & McCarron, 2005; McCarron & McCallion, 2005; McCarron, Gill, McCallion, & Begley, 2005; Watchman, 2005; Wilkinson, Kerr, & Cunninham, 2005; Janicki, Dalton, McCallion, Baxley, & Zendell, 2005
2006	NONE
2007	Jervis & Prinsloo, 2007; Kalsy, Heath, Adams, & Oliver, 2007; Watchman, 2007
2008	Auty & Scior, 2008; Bell, Turnbull, & Kidd, 2008; Lloyd, Kalsy, & Gatherer, 2008; Watchman, 2008; Jenkins et al. 2008
2009	NONE
2010	Cairns, Lamb, & Smith, 2010; Courtenay, Jokinen, & Strydom, 2010; Janicki, Zendell, & DeHaven, 2010; McCarron, McCallion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010; McLaughlin & Jones, 2010
2011	Janicki, 2011; Llewellyn, 2011; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2011
2012	Carling-Jenkins, Tor, Iacono, & Bigby, 2012; Foster, 2012; Hobson et al., 2012; Moore, 2012; Furniss, Loverseed, Lippold, & Dodd, 2012
2013	Herron & Priest, 2013; Jokinen et al., 2013
2014	Bromley, 2014; Iacono, Bigby, Carling-Jenkins, & Torr, 2014; Perera, & Standen, 2014; Rowe, 2014; Starkey, Bevins, & Bonell, 2014)
2015	Dicks, Jackson, Pasokhy, Catty, & Symes, 2015; Lord, 2015
2016	Strydom, Al-Janabi, Houston, & Ridley, 2016; Watchman, 2016; Clearly & Doody, 2016
2017	Bayley, Amoako, & El-Tahir, 2017; Watchman et al., 2017
2018	Chapman, Lacey, & Jervis, 2018; Heller et al., 2018; Jokinen et al., 2018; McCarron et al., 2018; McKenzie, Metcalfe, Michie, & Murray, 2018; Ryan, MacHale, & Hickey, 2018; Tromans, Andrews, Wani, & Ganghadaran, 2018