DOCTOR OF PHILOSOPHY

Determining the Informational Needs of Family Caregivers of People With Learning Disabilities Who Require Palliative Care: A Qualitative Study

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DETERMINING THE INFORMATIONAL NEEDS OF FAMILY CAREGIVERS OF PEOPLE WITH LEARNING DISABILITIES WHO REQUIRE PALLIATIVE CARE: A QUALITATIVE STUDY

Laurie McKibben, BSc (Hons) Nursing

A thesis submitted to the School of Nursing and Midwifery, Queen's University Belfast for the degree of Doctor of Philosophy (PhD)

23 April 2018
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LIST OF ABBREVIATIONS

CIPOLD Confidential Inquiry into Premature Deaths of People with Learning Disabilities
DH Department of Health
DHSSPS Department of Health, Social Services and Public Safety
DisDAT Disability Distress Assessment Tool
EAPC European Association for Palliative Care
EBCD Experience Based Co-Design
FCA Family Caregiver Alliance
GCP Good Clinical Practice
IQ Intelligence Quotient
LACDP Leadership Alliance for the Care of Dying People
NCPC National Council for Palliative Care
NHPCO National Hospice and Palliative Care Organisation
NHS National Health Service
NICaN Northern Ireland Cancer Network
NICE National Institute for Health and Care Excellence
NIHR National Institute for Health Research
NISRA Northern Ireland Statistics and Research Agency
NPSA National Patient Safety Agency
ONS Office for National Statistics
ORECNI Office for Research Ethics Committee Northern Ireland
PCPLD Palliative Care for People with Learning Disabilities Network
PHSO Parliamentary and Health Service Ombudsman
PPI Personal and Public Involvement
WHO World Health Organisation
WPCA Worldwide Palliative Care Alliance
GLOSSARY

Learning Disability- The presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development’ (Department of Health, Social Services and Public Safety (DHSSPS), 2005, p.18).

Palliative Care- Is an approach to improve the quality of life of patients and their families who face life- threatening illness, focusing on prevention and relief of suffering and treatment of pain and other problems, physical, psychosocial, and spiritual (World Health Organization, 2017).

End of Life Care- Is provided to people who are likely to die within the next 12 months and this is inclusive of people who are approaching death within days or hours (Leadership Alliance for the Care of Dying People (LACDP), 2014).

Family Caregiver- Someone who provides unpaid care by looking after an ill, older, or disabled family member, friend or partner (Carers UK, 2015).

Information Needs- Needs arising from the poor provision or receipt of information, representing a gap in someone’s knowledge (Beaver and Witham, 2007; Timmons, 2006).

Qualitative Research- Exploratory research concerned with lived experiences, and seeks to understand perceptions, behaviours, values or beliefs (Parahoo, 2014).

Logic Model- A logic model is a pictorial version of an initiative or a program in response to a particular situation; it presents logical relationships, planned changes, and for whom these changes apply (University of Wisconsin-Extension, 2003).

Expert Reference Group- A group of people who have experience or knowledge of the subject, who consult with research findings and advise on how recommendations can be promoted amongst services and networks.

Advance Care Planning- Describes conversations between people and those looking after them in relation to their future wishes and care (Gold Standards Framework, 2013).
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- The active and bereaved family caregivers who so graciously gave up their time in order to participate in this study, to contribute to the research evidence and promote better outcomes for other family carers of people with learning disabilities requiring palliative care. These expert voices have truly been the threads that make up the tapestry of this thesis. Let's hope that together we can facilitate change in not only the learning disability and palliative care sectors, but in wider primary care services.

- The Health and Social Care professionals who participated in the study and contributed to this research. Their input has realised valuable insights into the perceived needs of these family carers and how they can be best supported.

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- My expert reference group members including service users, staff, academics and an HSC Commissioner. Special thanks to Laura Collins’ contribution.

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Her legacy to me is my passion and drive, and inability to give up or give in. To fight for what is good and what is right. It is a privilege to follow in her footsteps and research an area of health and social care that is close to my heart.

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- My father Thomas and brother Robert for championing me to the end, despite mastering their own bereavement. Daddy, I love you. To Robert, thank you for understanding my ADHD brain and all its workings. I think we both truly have a gift, rather than a label. Let’s change the World one step at a time.

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‘The marvelous richness of human experience would lose something of rewarding joy if there were no limitations to overcome. The hilltop hour would not be half so wonderful if there were no dark valleys to traverse.’

Helen Keller (1880-1968)
ABSTRACT

Increased life expectancy has given rise to a greater number of people at risk of developing advanced, progressive diseases that require palliative care. The population requiring palliative care will include people with learning disabilities, who are also living longer. People with learning disabilities are often cared for by a family member. International research literature reports inadequate support of family caregivers and demonstrates caregiving in learning disability is a long continuum before end of life. A wide scope of informational need is thought to exist for family caregivers of people with learning disabilities who require palliative care, however, there is a paucity of research to evidence their specific information needs. This study aimed to determine the informational needs of family caregivers of people with learning disabilities who require palliative care, with logic model development providing a visual representation of these needs and how they could be met. A qualitative, exploratory design was implemented. Semi-structured interviews were conducted with a purposive sample of family caregivers (n=10), and six focus groups were composed of purposefully sampled Health and Social Care professionals (n=28), from across the province of Northern Ireland. Following consultations with an expert advisory group, findings informed the co-design of a logic model reflecting the information needs reported and how family caregivers can be best supported in having their information needs met.
Findings revealed four themes from family caregiver interviews: ‘Changing and diverse nature of information need’, ‘Consistent communication and joint working’, ‘Navigating care across settings’ and ‘Evolution and components of the caring role.’ Three themes evolved from focus groups with Health and Social Care professionals which were: ‘Information needs at the interface of services’, ‘Interplay of services across settings’ and ‘Decision making dilemmas.’ Family caregivers reported multiple information needs, which were changeable over the disease trajectory and remained into the bereavement period. Services played an integral role in enabling access to the right information at the right time. Conclusively the most reported information needs surrounded educational information on the disease and palliative care, and information relating to financial assistance. Other reported information needs applied to practical support and respite. Information needs surrounding psychosocial support were cited by some, however these were not considered a priority. Family caregivers of this population require consistency and continuity, with recommendations for co-ordinators or link staff, who can provide information on a personalised, one to one basis. An increased number of people with learning disabilities will be in receipt of services from primary care and acute services, due to their palliative diagnosis; this research shows a lack of preparedness and training amongst staff who appear to require more knowledge and skill to deal with this area of practice. This increases the strain on the family caregiver, and increases the level of information and support that they will require.
Chapter 1 Introduction

This chapter introduces the philosophies and concepts underpinning learning disability and palliative care services, the importance of joint working between these fields and family caregivers, and the research aims and objectives. The chapter finishes with a structured layout of the thesis.

Family caregivers of people with learning disabilities remain under-researched, notably those caring for someone who also requires palliative care. Informational needs of family caregivers in learning disability and palliative care were sought following a broad review of the literature. This research aimed to determine specific informational needs which existed for family caregivers of people with learning disabilities who required palliative care. This research, integrating the experience based co-design (EBCD) (National Health Service (NHS), 2009) approach, has provided a platform for family caregivers to have a voice through personal and public involvement.

Future recommendations for service improvements are based on a co-designed logic model (University of Wisconsin-Extension, 2017), visually representing the informational needs reported by family caregivers, the views and perceptions of Health and Social Care professionals, and their recommendations. No previous research exists which targets this very specific population of family caregivers with respect to their informational needs and this study aimed to address this gap.
1.1 Context of the study

Life expectancy is increasing as are the number of people diagnosed with advanced disease requiring palliative care (Worldwide Palliative Care Alliance (WPCA) and World Health Organisation (WHO), 2014). The Northern Ireland (N.I.) Statistics and Research Agency’s (NISRA) General Annual Report for deaths concluded that 15,430 deaths were recorded in 2016, which is much the same from the Northern Ireland Cancer Network’s (NICaN) statement in 2008 that approximately 15,000 people die every year in Northern Ireland.

NISRA’s most recent statistical projections from mid-2016 to 2041 show there will be a rise of people aged 65 or over from 297,800 to 491,700. Furthermore, the proportion of people aged 85 or over in the population will have doubled from 2% to 4.1% (NISRA, 2017). N.I. projections are in line with those for the rest of the United Kingdom (Hospice UK, 2017). The group of people aged 65 or over contains the greatest incidence of deaths from chronic conditions and cancer (NISRA, 2017; NICaN, 2008). NISRA (2017) also reported that in 2016 the top three causes of death were cancer (29%), circulatory disease (24%) and respiratory disease (13%), with 48% of deaths registered at hospital, 33% at home or other places and 20% in Nursing Homes and 5% elsewhere. Estimations are that approximately 3,000 people in N.I who would benefit from palliative care but do not receive it (Dixon et al, 2015).
Figures show that although there has been an increase in the percentage of people receiving palliative care for a non-malignant condition evidence still shows that the majority of people who access palliative care services have cancer (Marie Curie, 2015). Across the United Kingdom a diagnosis of Cancer is a principal determinant of access to palliative care services (Dixon et al, 2015). Within the United Kingdom palliative care has been chiefly funded in the past by cancer charities, this has resulted in systemic inequities, leaving those with non-malignant illnesses in receipt of unequal services (Boland and Johnson, 2013; National Council for Hospice and Specialist Palliative Care Services 2004).

The European Association of Palliative Care (EAPC) White Paper on Standards and Norms for Hospice and Palliative Care in Europe concurred revealing that within the European Union (EU) palliative care provision is predominantly served towards people with advanced cancer, despite many people with non-malignant diseases having the same palliative care requirements (Radbruch and Payne, 2010). This is important when considering marginalised populations such as those with learning disabilities, who may already be at a disadvantage due to reported existing health inequalities and already poor access to palliative care services (Heslop et al, 2013).
The current population of people requiring palliative care, including people with learning disabilities, are living longer with more complex needs and this directly impacts those informally caring for this populace, with increased pressure and stress if the correct services and support are not in place (Uppal et al, 2015; Heslop et al, 2013; Carlander et al, 2011; Department of Health Social Services and Public Services (DHSSPS), 2010b).

The National Palliative and End of Life Care Partnership (2017) published ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’ in response to reports which have demanded change in palliative and end of life care. This framework recommends individualised care, equitable access to care, with coordinated care from staff who are ‘prepared to care’ in order that a person’s wellbeing and comfort is maximised. It stresses the importance of involving and supporting those who are important to the person requiring palliative and end of life care.

The 2011 census reported that there were 43,674 carers in Belfast alone, which constitutes 12% of the population, meaning almost 1 in 8 people have a caring role (Carers UK, 2012). Carers UK (2015) provided a definition of a carer as someone who provides “unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week, or round the clock, in your own home or down the motorway” (p.1). Hudson and Hudson (2012) defined family caregivers as someone who may be a relative, spouse or friend, who supports the person who requires care.
The unpaid carer can also be considered an informal carer (Collins and Swartz, 2011). The term ‘family’ caregiver is used for the purposes of this research, rather than ‘informal’, as it has been used frequently in the international caregiving literature (Rainsford et al, 2017; McCabe et al, 2016; Dikkers et al, 2013; Hudson and Aranda, 2013). It is also appropriate to research in the field of learning disability, as within the learning disability community care is often provided by a family member (Tuffrey-Wijne et al, 2016; Michael, 2008). Furthermore, it is also used by organizations such as the Family Caregiver Alliance (FCA).

The World Health Organization (WHO) (2008) reports more people want to be cared for at home, and recognized the contribution of informal care provided by family or friends, in enabling sustainable community care and reducing the strain on acute care services. The WHO (2008) recommended that policies are directed toward supporting family caregivers, as well as the care recipient, focusing on alleviation of the burden associated with providing care informally. Formal services should support family caregivers through emotional and professional support, to enable them to continue in their role. Cash payments have been promoted for individuals, to pay for their informal care. The WHO also acknowledge that a care system could not professionally meet all care needs of service users, long term (WHO, 2008).
International literature highlights the importance of addressing the needs of family caregivers who provide palliative care, particularly in relation to information and signposting to respite, finance, education and psychosocial support (Lewis, 2014; Harrop et al, 2014; Cowan, 2014; Hudson et al, 2013). There should be key principles where family caregivers that provide palliative and end of life care are concerned. Caregivers must be central in the team, with their own needs recognised. Policy and regulatory guidelines promote local authorities’ implementation of needs assessments for family caregivers. UK guidelines endorse equality of assessment and support for all family caregivers, regardless of where the family member they are caring for is on the illness trajectory (DHSSPS, 2010b).

In response to the increasing numbers of family members providing care, the Family Caregiver Alliance (FCA) (2012) developed assessment tools for family carers to have their own needs assessed, with suggested implementation of appropriate provisions. Increased life expectancy for people with learning disabilities, and their complexity of needs can impose an even greater burden on family caregivers, socially, financially, and on society in general (Heslop et al, 2013; Kirkendall et al, 2012; Michael, 2008).
European policy and guidelines promote involvement and support of family caregivers in the learning disability field, as historically it has been flawed with barriers and inequalities (Tuffrey-Wijne and McLaughlin, 2015; Michael, 2008; DHSSPS, 2005). ‘Death by Indifference’ (Mencap, 2007), the Michael Report (2008) and the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) (Heslop et al, 2013) highlighted healthcare inequalities for people with learning disabilities. Concerns about the quality of care and support that people with learning disabilities and their family caregivers received were also raised.

National policy and recommendations have however attempted to address marginalisation, promoting the involvement of family caregivers and recognition of their needs (Care Act, 2014; Disability Discrimination Act, 2005). It should be acknowledged that not all family caregivers will feel comfortable in their role, and sources agree that society can place inordinate responsibility on family caregivers as their role is more often than not undertaken out of duty and love (Blum and Sherman, 2010; Department of Health (DH), 2006). In fulfilling a caregiving role family caregivers often neglect their own social identity, personal lives and employment, and can be left isolated and with unmet needs of their own (Walton, 2011; Blum and Sherman, 2010; DH 2006, Thompson and Mathias, 1998; Barnes, 1991). As a result of social isolation and individual information needs not being adequately addressed, family caregivers are not provided with adequate information that could be invaluable.
The National Collaboration for Integrated Care and Support (2013) recommended that service provision is integrated and co-operation between Health and Social Care, public health and local services is ensured with accessible and transparent information on available support. Within the UK, the Department of Health suggests family caregivers, across disciplines, would benefit from holistic carer’s assessments, incorporating physical, psychological, emotional, social and financial needs. Information in relation to support and services should then be signposted where appropriate (DHSSPS, 2010b; DH, 2008b). Supporting family caregivers by recognising their holistic informational needs; whether it is information on financial, emotional, educational or psychosocial support, enables them to contribute to society and the economy (DH, 2008a).

The importance of this research is based on the following considerations: the population of people with learning disabilities are living longer, with an increased likelihood of palliative care requirements. There is a paucity of research studies explicit to the informational requirements of family caregivers of people with learning disabilities who require palliative care (Tuffrey-Wijne et al, 2016; Payne et al, 2010). Furthermore, no research has been conducted in the island of Ireland, with this specific population, in order to establish their informational needs.
1.2 Definition, concept and philosophy of palliative care and end of life care

The concept of palliative care is a complex and multifaceted one that may be explained slightly differently depending on the country, the setting (for example hospital, hospice or community), the person (non-professional or professional) or the organisation defining it (ten. Have and Janssens, 2001).

Palliative Care is defined by the World Health Organisation (WHO) (2017, para. 1) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.’ Another recognised and commonly used definition is given below:

‘Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.’ (National Institute for Health and Care Excellence (NICE), 2004, p.20).
Diseases that warrant palliative care are categorised. These include Cancer, Neurological disease (Multiple Sclerosis, Parkinson’s Disease, Motor Neurone Disease and Huntington’s Disease), Organ Failure (Heart and Lung Failure, End Stage Respiratory and Renal Disease or Liver Failure), Elderly and Frail (Dementia and Stroke), HIV/AIDS and rare genetic disorders (WPCA and WHO, 2014; National Collaboration for Integrated Care and Support, 2013; Gold Standards Framework, 2006).

The Leadership Alliance for the Care of Dying People (LACDP) (2014) suggest that palliative care involves an approach which recognises not only the relief of any suffering, but also the prevention of it by timely assessment and identification of any holistic health and wellbeing problems. Palliative care is delivered across a range of settings including hospital, hospice, nursing homes and community environments (Kelley and Meier, 2010). Palliative care is delivered following a prognosis of an advanced, incurable, and progressive or end stage illness and centres on alleviation of suffering and optimising quality of remaining life (DHSSPS, 2010b; Kelley and Meier, 2010).
1.2.1 Philosophy of palliative care

Palliative care is described in ‘Living Matters Dying Matters’ published by the NI Department of Health (DHSSPS, 2010b) as aiming to affirm life and accept dying as something of a normal process. Palliative care provides a system of support for patients and their family members, to enable the person who is dying to live as active a life as possible, and to help families cope in their time of bereavement through counselling or other therapies.

Palliative care considers the spiritual and psychological elements of patient care, Cicely Saunders introduced the concept of ‘total pain’ in relation to acknowledging and treating not just the physical pain a person who is dying may experience (Saunders, 1996). The complexity of other symptoms such as: social, emotional and spiritual elements, causing depression, fear, guilt, anxiety and concerns for the family in the bereavement period, are all recognised in palliative care philosophy (Saunders, 1996). Palliative care ultimately encompasses a team approach, to enhance the quality of life of the person and to support the family members (DHSSPS, 2010b).
1.2.2 End of life care

Definitions of end of life care are variable across the world, but in the United Kingdom this is defined by the Gold Standards Framework (2013) as the final year of life, when death is expected within the following 12 months and is the end stage of the palliative care trajectory. More recently the LACDP (2014) have stated that end of life care is provided to people who are ‘likely to die within the next 12 months and this is inclusive of people who are approaching death within days or hours.

Hospice care is end of life care delivered by specialist Health and Social Care professionals and volunteers. Modern hospice services were introduced following the opening in London of St Christopher’s Hospice in 1967 by Dame Cicely Saunders (National Hospice and Palliative Care Organisation (NHPCO), 2015). The goal of hospice care is to enable peace, comfort and dignity for the person who is dying whilst supporting the family (WPCA and WHO, 2014; Radbruch and Payne, 2009).

1.2.2.1 Recognition of dying and the end of life stage

The Leadership Alliance for the Care of Dying People (LADCP) (2014) published ‘One chance to get it right’ in response to expressed concerns by family members of people who had died in 2012, supporting an independent review in 2013 of the previously used Liverpool Care Pathway (LCP), used when caring for those who were dying.
The alliance established priorities for caring for someone who is in the final days or hours of life, these include: recognition of when someone may die within hours or days, decisions should be made taking into account the needs and wishes of the person who is dying, communication is sensitive, holistic individualised care plans are implemented, and identification of the needs of the family members, or important people, to the person who is dying.

Recognising when a person is actively dying and at end of life is important, and this requires timely communication to family members. Health and Social Care professionals should, where possible, communicate clearly to the person and those important to them, when it is felt that the end of life stage is approaching.

1.2.3 The palliative and end of life continuum of care

Palliative and end of life care form a total care continuum, commencing from the point of diagnosis of an advanced, progressive disease, until the last part of life (NHPCO, 2015; DHSSPS, 2010b). Macmillan Cancer Support (2017) recognize both palliative and end of life care, with reference to five of their nine outcomes: personalized care, coordinated care, support for carers, emphasizing quality of life and finally wanting to die well, or to have a good death. This final outcome is the main underpinning for Macmillan Cancer Support’s (2017) End of Life Care Strategy.
In Northern Ireland ‘Living Matters, Dying Matters’ (DHSSPS, 2010b) recognised that palliative or end of life care engaged a holistic care continuum for people with life limited or advanced progressive disease or illness. Ultimately there has been a shift from the old philosophy of a cure only attitude, towards a more holistic promotion of quality of life and symptom palliation as the disease progresses (Lynn and Adamson, 2003).

Generalist palliative care can now be delivered in primary care facilitated by community nursing services and General Practitioner (GP) practices, allowing people with more complex palliative and end of life needs, which require more intense care and expertise, to be managed via the specialist palliative care teams and Hospice services (DHSSPS, 2010b). Importantly there is also now a consensus that most people want to die in familiar surroundings, surrounded by those that are important to them, with the correct support in place (DHSSPS, 2010b; Lynn and Adamson, 2003). The below figure 1.1 demonstrates the trajectory of a chronic, progressive or life limiting illness, and how this links in with where a person is on the palliative and end of life care continuum.
1.2.3.1 Levels of palliative care

The report of the National Advisory Committee on Palliative Care (NACPC) report (2001, p32) introduced the three levels of palliative care services, in reference to the expertise and specialism of the professionals delivering palliative care. Level one is the ‘Palliative Care Approach, where the principles of palliative care are demonstrated by all professionals within Health and Social care, and by every hospital and community clinician. This enables people with advanced disease to have their care managed without a referral to specialist palliative care services. Level two is ‘General Palliative Care’ at intermediate level, where professionals have had enhanced training and palliative care experience and can offer this expertise within the community or in hospital.
Level three is ‘Specialist Palliative Care’, in which services are specific to palliative care provision for complex patients. Specialist palliative care is delivered by specially trained professionals, who will support care delivery across all care settings regionally, and provide support and advice to other health care professionals. All levels should be available and accessible to staff and patients (NACPC, 2001, p 32).

1.2.4 Family caregivers in palliative and end of life care

Within the United Kingdom the DHSSPS (2010a; 2010b) recommended family caregivers should have accessibility to information that is relevant and appropriate to ensure that they are prepared and confident in their role. Collaboration between Health and Social Care professionals and family caregivers should also be promoted. Family caregivers should have their support requirements identified and acted upon, to ensure provisions are accessible and interventions are supportive. Access to information should also be available across care settings, 24 hours a day, seven days a week (DHSSPS, 2010b).

The National Council for Hospice and Specialist Palliative Care Services (2004) state the provision of information and support to family carers should be consistent during an illness trajectory and in the bereavement period. Post bereavement information on emotional and psychological support is important, as a person’s identity and role as carer is instantly diminished once the person they cared for has died, hence bereavement care must be signposted comprehensively and delivered in a timely manner (DH, 2008b).
1.3 Definition, concept and philosophy of learning disability

There is a general absence of statistics on the prevalence of learning disability due to a lack of standardisation between countries on definitions and terms (WHO, 2010). It is approximated that 1-3% of the population have a learning disability (Mash and Wolfe, 2004). Within the European Union it is estimated that there are between 5 million and 15 million people with a learning disability (Pomona, 2008).

However, it should be noted that prevalence studies focus on people with a learning disability known to services, not taking into account the hidden population particularly people with mild intellectual disability who may be an invisible population within the field of Health and Social Care due to a lack of identification (Tuffrey-Wijne and McLaughlin, 2015). McConkey et al. (2006) published further prevalence figures in relation to people with learning disabilities in the Island of Ireland.
Figures revealed that 25,134 people with a learning disability were known to services across the Republic and Northern Ireland in 2002, a prevalence of 6.34 per 1000, with 8,340 of the 25,134 people living within N.I. It was estimated that this population would rise by over 20% by 2021 (McConkey et al, 2006). McConkey et al. (2006) also highlighted that there were more people with learning disabilities living with family caregivers in Northern Ireland.

When defining learning disability terms can vary globally; in the UK the term ‘learning disability’ is used within government policy and Health and Social Care, whilst in other parts of the world the term ‘intellectual disability’ is used (Holland, 2011; Emerson and Heslop, 2010). Internationally it is agreed that learning disability can be identified when three criteria are present: ‘intellectual impairment (IQ), social or adaptive dysfunction combined with IQ and early onset’ (Holland, 2011, p.3).

These criteria are reflected in a commonly used definition which states that learning disability is: ‘the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development’ (DHSSPS, 2005, p.18).
Historically people with learning disabilities have been considered a marginalised group, often in receipt of inequitable care and health care services (NHS and Palliative Care for People with Learning Disabilities (PCPLD) Network, 2017; Michael, 2008; DHSSPS, 2005). The complex needs of people with learning disabilities may not be detected, thus resulting in substandard care (Michael, 2008). Reports have highlighted discrimination and access inequalities that exist in the healthcare system for people with learning disabilities and their family caregivers (Michael, 2008; Mencap, 2007; DHSSPS, 2005).

Acts of Parliament are now under scrutiny to ensure a society comprehensive of equality, inclusion and the right to services, with needs assessments and appropriate provisions to enable family members’ work as carers to be respected and supported (DHSSPS, 2011; The Northern Ireland Assembly, 2008; The Human Rights Act, 1998). This is applicable for all family caregivers equally.

The DHSSPS ‘Equal Lives’ (2005) review in N.I. expressed root values to underpin policy and service provisions. These were that people with learning disabilities have the right to be treated equally as citizens and as respected members of society. People with learning disabilities should be exposed to the same mainstream provisions as those without disabilities; inclusive of empowerment through community involvement, active participation in decisions made about their lives with multidisciplinary work and partnership work. Any care and support should be individualised (DHSSPS, 2005).
The review incorporated feedback from family carers in Northern Ireland and feedback stated getting the right support from social services was appreciated, valued and essential. The review was conducted in the N.I. context, however reflected the overall state of affairs of national policy in the wider UK. However, despite recommendations from ‘Equal Lives’ (DHSSPS, 2005) ‘Death by Indifference’ was published in 2007 by Mencap, this report was in response to the deaths of six people with learning disabilities in the UK, which resulted from the alluded inadequate and inappropriate care from healthcare professionals.

Reduced access to information and service provisions for people with learning disabilities was explicitly highlighted and the dangers of healthcare professionals not listening to the families of those with learning disabilities were also emphasized. In failing to listen to those providing care to people with learning disabilities, medical needs were neglected and serious conditions ignored, which led to substandard care and deaths (Mencap, 2007). Following on from this, an independent inquiry ‘Healthcare for All’ (2008) was conducted by Sir Jonathan Michael.

Statistical findings declared that around 60% of carers in England and Wales looked after someone with learning disabilities. It was also found that people with learning disabilities have notably worse health and receive inadequate care. As a result this population have an increased level of unmet needs.
Findings also accede that carers are often ignored and healthcare professionals do not have sufficient knowledge, training or awareness of learning disability. The report illustrated gaps in communication as some healthcare staff did not communicate at all with the carer (Michael, 2008). It was indicated that carers may have other family responsibilities and unmet needs of their own and it is for this reason that information and signposting are important.

The main family carer should be identified and healthcare professionals must be aware of their needs, these may include but are not exclusive to: education, entitlements, support, knowing how much is expected from them and knowing how much control they have. The report recommended that ‘reasonable adjustments’ to care should be implemented in relation to the provision of care for people with learning disabilities as a vulnerable group (Michael, 2008).

The following year ‘Six Lives’ (2009) was released from the UK Parliamentary and Health Service Ombudsman (PHSO) in partnership with the Local Government Ombudsman. This report was in direct response to complaints made by Mencap in support of the families of the people who died in the ‘Death by Indifference’ publication. Complaints were received against 20 local councils and NHS bodies concerning quality of care and service failures. The investigation illustrated the disastrous consequences of poor leadership and unfamiliarity with the law in respect to disabilities and human rights.
Four of the complaints were upheld in that the people concerned were treated unequally and the public bodies had failed to comply with basic human rights principles. Communication, partnership working, and relationships with carers were areas of concern. The report recommended that systems and services were reviewed, Health and Social Care organisations were meeting regulatory requirements, and that the Department of Health supported the implementation of these recommendations (PHSO, 2009). In the wake of ‘Death by Indifference’ (2007) Mencap published ‘Getting it Right’ (2010).

This charter was to educate healthcare providers and front line workers with information, training and policy, to better equip them to work with people with learning disabilities. It acknowledged family caregivers and stressed the importance of information and practical support, as often family caregivers are confused with their role and have a lack of education and signposting to services that would benefit them (Mencap, 2010).

Further endorsement followed in the DHSSPS review on Health and Social Care in N.I., ‘Transforming Your Care’ (2011). This provided a model for integration of Health and Social Care services, recognising the need for information and access to services for people with learning disabilities and their family carers (DHSSPS, 2011). However, Mencap published ‘Death by indifference: 74 deaths and counting:'
A progress report 5 years on’ in 2012, reflecting the succession of deaths between 2007-2011 reported by families following the 2007 Death by Indifference campaign, as a result of continued failings within the UK National Health Service to provide adequate care for people with learning disabilities. Succeeding this was the UK Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (2013), which reported care remained fragmented, despite people with learning disabilities living with multiple health conditions (Heslop et al, 2013).

Following 247 deaths between 2010-2012 the inquiry recommended better adherence of health professionals to the Mental Capacity Act (2005), with individualised care and advance care planning (Heslop et al, 2013). Emergent evidence from published literature and facts around services and care delivery concur that systemic barriers to services and professionals remain, with the same evidence highlighting the importance of supporting family caregivers of people with learning disabilities, acknowledging their role and expertise (McLaughlin et al, 2014a; 2014b; Stajduhar et al, 2013; Payne et al, 2010; Mencap, 2007; Daw, 2005; Botsford, 2000).
1.3.1 Family caregivers in learning disability

As with palliative care, when caring for someone with learning disability, a person’s ability and competence to provide care should be assessed (DH, 2008b; DH, 2006). In the healthcare system both patients and their caregivers should have a care plan, and both be involved in the decision making process in relation to healthcare choices (Carers UK, 2014a; DH, 2008b; DH, 2006). Research as far back as the National Patient Safety Agency (NPSA) Report (2004) ‘Listening to people with learning difficulties and family carers talk about patient safety’ showed that people with learning disabilities were more at risk of adverse incidents in relation to their health and wellbeing. As a result this report recommended priorities which included ease of access to information regarding illness and treatments, and supportive interventions for family caregivers.

1.4 Learning disability and palliative care

Evidence that palliative care includes appropriate provisions for someone with learning disability is reportedly lacking and referrals to palliative care and hospice services are minimal (McLaughlin et al, 2014a; 2014b; DH, 2006). Late diagnoses for a palliative prognosis can also occur in relation to people with learning disability, as there may be lack of screening for this population or ‘diagnostic overshadowing’ attributing symptoms to the learning disability as opposed to advanced co-morbid disease (Tuffrey-Wijne and McLaughlin, 2015; Heslop et al, 2013; Reiss et al, 1982).
People with a learning disability are not a homogenous cohort, each person is individual and on a wide ranging spectrum from mild to profound intellectual impairment and they can also be found at various stages of the palliative care trajectory. Moreover, certain conditions requiring palliative care are specifically linked to ageing in people with learning disability, for example people with Down syndrome having a greater risk of developing dementia (Towers and Glover, 2015).

1.4.1 Family caregivers of people with a learning disability who require palliative care

Palliative care services and learning disability services have a responsibility to collaborate and include family caregivers as ‘experts’ (Tuffrey-Wijne et al, 2016). It is important that family caregivers are involved as partners in decision making in regards to their loved one’s end of life care and wishes (Mencap, 2010; DH, 2006).

Olson (2008) concurs approaching the importance of advance care planning and of family members as ‘translators’ who can interpret behaviours and language. The most contemporary recommendations at European level are that palliative care provision must cover the entire learning disability spectrum and all palliative care settings, and include support for family members providing (Tuffrey-Wijne et al, 2016).
A positive example of learning disability and palliative care services working together with caregivers has resulted in the co-production of an informational resource in Northumberland (St Oswald’s Hospice, 2015). The resource was developed to support people with learning disability and their carers, formal or informal, at end of life. The guide includes the Disability Distress Assessment Tool (DisDAT), and delivers practical information for carers to support them in the identification and management of particular symptoms (St Oswald’s Hospice, 2015).

Elsewhere in the United Kingdom initiatives such as the ‘When I Die’ leaflet produced by Calderstones NHS Trust in 2008 provide a template for a person centred plan for those with learning disabilities to express their wishes in an easy to understand format. This incorporates the family caregivers, hence alleviating some of the difficult decisions they may have faced, and improving psychological wellbeing. As information can aid signposting to support, or as a means of simply educating, it serves as important component of providing care in both palliative care, and across the learning disability spectrum (Philip et al, 2014; Kirkendall et al, 2012).

By determining ‘information need’ there is recognition and an assertion of poor provision of information (Beaver and Witham, 2007). Eysenbach (2000) argued that tailored information aided choice in respect to support and the provision of services.
The Department of Health concur that supporting caregivers, in recognising their informational needs can promote quality of life, wellbeing, and contribution to society (DH, 2008a). This study was undertaken as information is considered a conduit to supporting family caregivers across disciplines, and little is known about the specific information needs of family caregivers who provide care at the learning disability and palliative care interface.

1.5 The concept of information needs

The term ‘information need’ involves the recognition of poor provision or receipt of information, in a general context (Beaver and Witham, 2007). When interpreting the term information need, it has been suggested that simply this is what a person needs to know (Timmins, 2006; Knowles, 1989). Timmons (2006) argues that information need also represents a knowledge gap, which may be remedied through information provision.

Timmins (2006) supports the work of Lazarus and Folkman (1984) in recognising precursory events leading to information need in a person, with an individual reacting to a stimulus for example, a major life event or diagnosis of illness. Lazarus and Folkman (1984) determine information seeking as part of problem based coping behaviours, with information assisting adaptation to a situation. Timmons (2006) elaborates that information need is individualised and based on the particular needs of the person, with information needs expressed through questioning.
1.6 Aim and objectives of the study

The aims of this research were to determine the informational needs of family caregivers of people with learning disabilities who require palliative care and to develop a logic model providing a visual representation of the information needs reported and how they can be best addressed.

In order to achieve the research aims, the objectives were to:

1. Complete a review of the literature on family caregiving in palliative care and in learning disability in general to determine what informational needs may currently exist.

2. Explore the specific information needs of family caregivers of people with learning disabilities who require palliative care.

3. Establish Health and Social Care professionals’ perceptions of the information needs which exist for these family caregivers.

4. Co-design with family caregivers and Health and Social Care professionals, a logic model which visually represents the information needs reported and how they can be addressed.

5. Generate recommendations from both family caregivers and Health and Social Care professionals to inform education and policy, further research and service development in this practice area.
The outcome development of a logic model, as a visual representation of how family caregivers can be best supported, involved the experience based co design (EBCD) approach prescribed by the National Health Service (2009). It refers to partnerships between the researcher, family caregivers, and professionals and incorporates functionality, safety, and usability, to predict desired outcomes (Donetto et al., 2014).

Co-designed recommendations are based on the voice of family caregivers, multi-disciplinary Health and Social Care professionals, and an expert reference group. The approach was service user centred and evidence based. This logic model reflects the information needs reported by family caregiver participants, and how these information needs can be addressed, based on input and liaisons with an expert reference group comprised of service users, field specific Health and Social Care professionals, academics and policy makers.

1.7 Researcher background

Prior to conducting this research the researcher completed professional training in adult nursing, with enhanced learning disability experience. This study was undertaken following knowledge and interest in the proposal, and coming from many years personal experience of learning disability. The researcher had a personal connection to the study through caring for a sibling with Down Syndrome, and with an interest in working with disenfranchised groups such as family caregivers in learning disability.
The decision to undertake the study was also influenced by the active campaigning work completed by the researcher’s late mother in the preceding years, promoting equality and inclusion for those with learning disabilities and their family carers.

1.8 Thesis structure

The thesis is comprised of qualitative exploration of the experience of family caregivers who have provided palliative care to someone important to them with a learning disability, via semi-structured interviews, in order to ascertain their information needs. Data collection via focus groups also sought the perceptions of Health and Social Care professionals in providing insights from their own experiences and perspectives, around the information needs of family care givers of people with learning disabilities requiring palliative and end of life care.

Through co-design this research study was also concerned with developing a logic model which visually represented the information needs reported by family caregivers, and how they could be best addressed and supported by Health and Social Care services. Recommendations for best practice and outcomes via liaison with an expert advisory panel consisting of service users, academia, Health and Social Care staff and policy makers have also taken place.

The thesis comprises of eight chapters a summary of which can be seen below:
**Chapter 1** is an introductory chapter, providing background and context to the study. This chapter provides a synopsis of approaches, philosophy and fundamentals central to palliative care and learning disability services. It also explains the rationale for integration of both of these specialties in respect to the information needs of family caregivers of people with learning disabilities who require palliative care.

**Chapter 2** explores literature and published research on family caregiving across the palliative care and learning disability fields, from regional to international level. The chapter highlights what is known, what is not known, and what the review adds to the existing evidence base. Study context is further developed, establishing the research gap and therefore leading into the rationale for this study.

**Chapter 3** presents and discusses the theoretical underpinnings and research design and provides discussion and background on the selected theories. The aims and objectives of the study are represented in this chapter. It provides an outline for the use of a qualitative, exploratory research design and this chapter discusses the rationale for the purely qualitative methods adopted for this study.

The pertinence and relevance of using the underpinning Lazarus and Folkman (1984) model for this family caregiving research alongside the Transformative Paradigm is discussed (Mertens, 2005; 2009) along with the principles of co-design (Donetto et al, 2014).
Chapter 4 outlines and discusses the data collection methods and analysis. It provides the rationale for the data collection methods used in this study, with in depth discussion around the choice of methods and their limitations. The chapter discusses in detail the method of recruitment and how data were analysed, with procedural transparency which was used. Ethical considerations are examined and rigour considered in this chapter.

Chapter 5 presents the findings from both the semi structured interviews with family caregivers and focus groups with Health and Social Care professionals, from across both the learning disability and palliative care fields. Findings are translated into a visual logic model based on the Wisconsin model (University of Wisconsin, 2016), with co-designed recommendations for service development, further research and education. The chapter discusses the logic model which drawn up with expert advisory panel consultation and input, in relation to finalisation and how to best present and disseminate the findings.

Chapter 6 discusses the research findings from both the family caregiver and Health and Social Care professional participants and the chapter discusses similarities and differences of findings within these two datasets. Discussion also considers how the study findings link in with, build on and add to previous literature published nationally, and at European and International level. Study limitations are provided at the end of this chapter.
Chapter 7 summarises the main research findings and the chapter discusses implications for practice, service development, education, policy and future research. Recommendations for the above are also provided and integrated into the final presented version of the co-designed logic model.
Chapter 2 Integrative Literature Review

2.1 Background

The global population are living longer (WPCA and WHO, 2014) with Age UK (2017) asserting that only one in seven people will be free from a long term condition by the time they reach their eighties. Furthermore, one in three people will require care assistance with at least five tasks of daily living by the time they reach their late eighties (Age UK, 2017). Consequently the number of people providing unpaid care at home to a family member or friend is expeditiously increasing, with recent figures reporting an increase from 16.6% to 17.8% of the population between 2011 and 2015 (Office for National Statistics (ONS), 2016a; University of Essex, 2015). Moreover, Carers UK and University of Leeds (2011) report that there are approximately six million unpaid carers in the United Kingdom, with Carers UK (2014) forecasting this to rise to nine million by 2037.

Family caregivers are people who provide care for neighbours, relatives or friends who are dependent on them and who do not take payment for these services and they can also be known as informal carers (Thompson and Mathias, 2008). These caregivers are now providing exceeding levels of care to people with increased complexity of needs (Age UK, 2017).
In the UK there has been recognition of the role of family caregivers, with recommendations for support to meet their own individual needs (National Council for Palliative Care (NCPC), 2010; DH, 2008a; Harding and Higginson, 2003). The Department of Health’s (2008a) Carer’s Strategy promoted carer support to allow for a life outside of the caring role, whether that is through working, respite or social engagement. The literature describes the burden associated with unpaid caring, with many undertaking the role out of duty, and in doing so neglecting their own needs (Walton, 2011; Blum and Sherman, 2010; DH, 2006; Thompson and Mathias, 1998; Barnes, 1991).

Carer or caregiver burden is frequently cited in the literature and covers the spectrum of burdens that may be associated with providing care informally including psychological, financial, social, emotional and physical stresses and strains (González-Fraile et al. 2015; Collins, 2011). Within England, Scotland and Wales, local Health and Social Care authorities are duty bound to offer carer’s needs assessments incorporating physical, psychological, emotional, social and financial need (Carers UK, 2014a; DH, 2008a). Within NI assessments are discretionary only at present, therefore information that signposts caregivers to various supports are important (Care Act 2014, Carers UK, 2014; DH, 2006).
As the population live longer they are also at increased risk of developing an advanced disease such as Cancer, Dementia, organ failure (including heart failure, end stage respiratory disease, liver failure or renal disease) or degenerative neurological disease, which requires palliative care (WPCA and WHO, 2014; Radbruch and Payne, 2009). Palliative care is described as a team approach and support system for a person who is dying and their family, and continues into the bereavement period (DHSSPS, 2010b).

Existing evidence emphasises the needs of family caregivers specifically in palliative care, reporting also on the impact of caregiving in relation to the physical, mental, social and financial burden, and the impact of this on their lives and society in general (Candy et al, 2011; Payne et al, 2010). Lazarus and Folkman (1984) provide some theoretical understanding as to the burden associated with caring in offering prediction and explanations as to how stress and availability of resources may affect the unmet needs of family caregivers and how they cope in their role.

*Rationale for a two phase integrative review*

Initial scoping searches of the literature for this study revealed a paucity of evidence surrounding family caregivers of people with learning disabilities who require palliative care. People with learning disabilities are living longer with increasingly complex needs, their family caregivers may have a broad scope of unmet needs.
Hence, searching the literature to identify information needs of this cohort was undertaken. There were no studies identified explicit to the information needs of this cohort of family caregivers, which revealed the gap in the research literature providing rationale for this research. An integrative review was considered appropriate as it involves critical evaluation of studies, of varying methodologies to address a specific area of practice. Analysis of qualitative and quantitative research, discussed in context to relevant practice guidelines and policy, enables a more comprehensive overview of concepts or problems (Noble and Smith, 2018; Souza et al, 2010).

Phase 1 was undertaken in order to initially scope the wider literature concerning the broader needs of family caregivers, of which there was a vast amount. This was to enable retrieval of studies that may not explicitly cite ‘information needs’ in the title or abstract, but may reference them within the main bodies of research. This phase also helps to identify those which may indeed be considered ‘information needs’, however authors may not have classified them as such. Through undertaking phase 1, the gaps in the research literature are highlighted, informing the search undertaken for phase 2. Phase 1 review of systematic reviews of the needs of family caregivers across settings, aimed to retrieve all possible studies concerned with caregiving in both palliative care and those who have provided longer term care at home, for example to someone with a learning disability in general.
Phase 1 covers all family caregiving subgroups, to reveal the most commonly reported needs and identify which populations are under-researched and where the research gaps exist. Systematic reviews have been chosen due to the sheer volume of literature retrieved during searches. Phase 2 was informed by the gap in the literature identified as rationale for this research study, it is supported by the evidence from phase 1. Phase 2 sought to further explore the commonly reported ‘information needs’ from reviewing the broader literature in phase 1, in relation to people with learning disabilities who require palliative care.
2.2 Aim

The overall aim of the two phase literature review was to identify the most common reported needs of family caregivers in general; to highlight any gaps in the literature, and subsequently distinguish the ‘information needs’ of family caregivers of people with learning disabilities who require palliative care. The individual objectives of each phase are presented below:

Phase 1 review of systematic reviews in order to:

- Examine systematic reviews on the broader area of general ‘needs’ of family caregivers providing care to adults, from palliative care extending to those providing longer term care in chronic illness or learning disability.
- Reveal commonly cited needs of family caregivers.
- Identify under-researched subgroups of family caregivers.

Phase 2 literature review, adjunct to and informed by phase 1 in order to:

- Seek out what published research exists around the information needs of family caregivers of people with learning disabilities who require palliative care.
- Identify further gaps in the literature.
2.3 Methods

As recommended by Smith et al. (2011), to first collate the overwhelming volume of existing evidence around needs in the family caregiving field, a review of systematic reviews was conducted systematically, as per Aveyard (2014). This provided prioritisation of a particular aspect of the literature, which in this review were the identified needs family caregivers (Arksey and O’Malley, 2005).

Phase 1 follows guidelines for systematic conduct and reporting, in line with Aveyard’s (2014) systematic approach and the PRISMA reporting method recommended by Moher et al. (2014).

2.3.1 Search strategy

For both phases this involved inspection of five electronic databases (CINAHL, PsycINFO, Medline, Cochrane and Pubmed).

*Phase 1 keywords:*

- Family care* (* to include carers and caregivers) OR Informal care* (* to include carers and caregivers) AND Needs AND Systematic Review.

*Inclusion:* Informal or family caregivers of adults over the age of 18. Systematic Reviews or systematically conducted integrative reviews, as these are considered a subset of systematic reviews (Gunnarsson, 2014). There were no restrictions applied on date or language.
**Exclusion:** Papers that did not meet the search criteria. Reviews that involved formal or paid caregivers, or caring for children rather than adults. Narrative and literature reviews.

Further relevant literature was obtained through a hand search of pertinent journals and reference lists. Abstracts meeting initial criteria were screened and selected for full text retrieval.

**Selection and quality appraisal:**

Each review was critically appraised for relevance and methodology audited for quality using the 10 question Critical Appraisal Skills Programme (CASP) (2018) systematic review checklist tool ([www.casp-uk.net](http://www.casp-uk.net)). The quality of papers reviewed ranged from moderate to high quality (7-10), see Table 2.1.

Papers falling outside of the criteria in any form were rejected. Irrelevant or duplicate papers were also dismissed (see Figure 2.1).

**2.4 Phase 1 results**

Whilst there were many literature reviews and primary studies, a total of 16 systematic reviews were identified concerning the needs of family caregivers.
Figure 2.1 Phase 1 PRISMA

Records identified through database searching (n = 521)

Additional records identified through other sources (n = 1)

Records screened after duplicates removed (n=507)

Records excluded (n = 484)

Full text articles assessed for eligibility (n = 23)

Full-text articles excluded (n = 6)

Systematic Review Papers (n = 15)
Protocol for Systematic Review (n=1)

Identification

Screening

Eligibility

Included

CINAHL (41)
PsycInfo (40)
Medline (76)
Pubmed (358)
Cochrane (6)
Extraction of the data

Retrieved systematic reviews revealed a good demographic spread internationally across various countries: UK= 4, Australia= 3, Canada= 3, United States (US) = 2, Spain= 1, Portugal= 1, France= 1 and the Netherlands= 1. Key characteristics of each review is presented in the data extraction table (Table 2.1, p.63-66).
<table>
<thead>
<tr>
<th>Author(s)/Year</th>
<th>Country/ Setting</th>
<th>Aims &amp; Objectives</th>
<th>Number of studies included</th>
<th>Population of caregivers concerned</th>
<th>Outcome/Findings</th>
<th>CASP Quality Score (1-10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Docherty et al. (2008)</td>
<td>United Kingdom</td>
<td>A systematic review considering the knowledge and information needs of informal caregivers in palliative settings</td>
<td>34 studies</td>
<td>Informal caregivers in Palliative care</td>
<td>Inadequacies highlighted in relation to knowledge and education, in particular around pain management. Weaker evidence of knowledge and information needs in relation to welfare and social support. Effective communication significant in information sharing</td>
<td>9</td>
</tr>
<tr>
<td>Bee et al. (2009)</td>
<td>United Kingdom</td>
<td>A systematic review examining practical information needs of informal caregivers who provide home-based palliative and end-of-life care to people with advanced stage cancer</td>
<td>26 studies</td>
<td>Informal caregivers of people in receipt of palliative and end of life care for advanced cancer</td>
<td>A general lack of practical support related often times to inadequate information provision or exchange. Family members as a result adopt a 'trial and error' approach, despite needing a wide scope practical-focused information</td>
<td>7</td>
</tr>
<tr>
<td>Innes et al. (2011)</td>
<td>Canada</td>
<td>A systematic review to evaluate existing evidence surrounding informal/family caregiving in remote or rural settings to ascertain state of caregiver knowledge</td>
<td>26 studies</td>
<td>Informal/family caregivers of people with Dementia living rurally or remotely</td>
<td>Four themes: Service use, carer experience, rural perceptions of dementia, and support and education</td>
<td>7</td>
</tr>
<tr>
<td>Washington et al. (2011)</td>
<td>United States</td>
<td>A systematic examination of the information needs of informal caregivers of older adults with chronic conditions</td>
<td>62 articles</td>
<td>Informal caregivers of older people with chronic illness</td>
<td>Lack of education and information in general: disease specific information, treatment options, and information around services. Two kinds of information need: general factual information, explanations and advice; specific individualised information</td>
<td>7</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Location</td>
<td>Study Type</td>
<td>Study Population</td>
<td>Methodology</td>
<td>Key Findings</td>
<td></td>
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<tr>
<td>Forster et al. (2012)</td>
<td>United Kingdom</td>
<td>Cochrane systematic review on information provision for stroke patients and their caregivers</td>
<td>21 Randomised Control Trials</td>
<td>Family caregivers of someone who had suffered a stroke</td>
<td>9 trials = passive information intervention, 12 = active information intervention. Information had a significant effect on caregiver knowledge (P = 0.03). No significant effect on carer satisfaction or mood. Sufficient information provision following discharge back to the home setting</td>
<td></td>
</tr>
<tr>
<td>Silva et al. (2013)</td>
<td>Portugal</td>
<td>To review the needs of informal caregivers providing care to people who are elderly (integrative)</td>
<td>14 articles</td>
<td>Informal caregivers providing care to elderly people in the home setting</td>
<td>Four core themes: professional support, legal and financial support, effective communication, and information and training</td>
<td></td>
</tr>
<tr>
<td>Lunsky et al. (2014)</td>
<td>Canada</td>
<td>Systematic scoping review of the literature surrounding family carers of people with intellectual/developmental disabilities</td>
<td>87 papers</td>
<td>Family carers of someone with intellectual or learning disability</td>
<td>Authors reported carer burden, depression, and stress. The need for respite care and information on available services for family caregivers. Financial planning, future planning, and awareness of financial entitlements were distinguished needs</td>
<td></td>
</tr>
<tr>
<td>Afram et al. (2015)</td>
<td>The Netherlands</td>
<td>A systematic review on the needs of informal caregivers of people with Dementia during transition from home to institutional care</td>
<td>13 publications</td>
<td>Informal carers of people with Dementia</td>
<td>14 topics of ‘need’ from the literature, with the most prominent topics including ‘knowledge and information’, ‘emotional concerns’ and ‘support.’</td>
<td></td>
</tr>
<tr>
<td>Gonzalez-fraile et al. (2015)</td>
<td>Spain</td>
<td>Cochrane systematic review on information, support and training of those caring informally for people with Dementia [protocol]</td>
<td>N/a protocol only</td>
<td>Informal caregivers of people with Dementia</td>
<td>Information was one of three priority areas identified by the authors, which supports other evidence and reflects the current status of caregiver information needs. Authors argue information needs of family/informal caregivers should be a priority for future research</td>
<td></td>
</tr>
<tr>
<td>Authors (Year)</td>
<td>Country</td>
<td>Study Type</td>
<td>Number of Studies</td>
<td>Population</td>
<td>Key Themes</td>
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<tr>
<td>Wheelright et al. (2015)</td>
<td>United Kingdom</td>
<td>A systematic review on quality of life of informal carers of patients with cancer cachexia</td>
<td>16</td>
<td>Informal carers of people with cancer cachexia</td>
<td>Five key themes: impact on everyday life, the need for healthcare professionals' input, conflict with patient/negative emotions, and attempts of some carers to take charge. Acknowledgement of carer burden and importance of provision of education around cachexia</td>
<td></td>
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<tr>
<td>Balogh et al. (2009; 2016)</td>
<td>Canada</td>
<td>Cochrane review (updated) of how healthcare systems are organised for people with an intellectual disability and their caregivers</td>
<td>2009: 8 studies, 2016: 7 studies (6 already included in 2009 review)</td>
<td>Family caregivers/relatives of someone with an intellectual or learning disability</td>
<td>In relation to the family caregivers, caregiver burden and financial costs of providing care were acknowledged. Extended care into the community is recommended, with integrated care teams, to support the person and their family caregiver</td>
<td></td>
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<tr>
<td>McCabe et al. (2016)</td>
<td>United States</td>
<td>A systematic review of the needs of family caregivers of people with Dementia</td>
<td>12</td>
<td>Family caregivers of people with Dementia</td>
<td>Two main themes: caregivers' personal needs and caregiver needs related to the management of older people with Dementia. Subthemes included: information and knowledge needs, caregivers' own needs, and addressing caregivers' physical and psychological needs</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Methodology</td>
<td>Articles</td>
<td>Sample Description</td>
<td>Key Findings</td>
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<tr>
<td>Cagle et al. (2017)</td>
<td>United States</td>
<td>Systematic review examining the psychosocial needs and interventions specific to families and patients receiving palliative care for Heart Failure</td>
<td>17 articles</td>
<td>Family caregivers of people receiving palliative care for Heart Failure</td>
<td>Provision of information relating to the disease, symptoms, pain management deemed important. Poor provision of information = emotional distress. Educating via information suggested to reduce distress and caregiver burden</td>
<td></td>
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<tr>
<td>Novais et al. (2017)</td>
<td>France</td>
<td>A systematic review of the methodologies used to identify the needs, instruments of needs assessment and the general topic of needs of caregivers of people with cognitive impairment in Alzheimer's or related diseases</td>
<td>70 studies</td>
<td>Informal caregivers of people with cognitive impairment in Alzheimer's disease, or related diseases</td>
<td>Top topic of needs explored within instruments was 'information needs'; on the disease, medications, treatment options and available services. Psychological and psychoeducational needs were rated, however information needs were particularly important</td>
<td></td>
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<tr>
<td>Parker et al. (2017)</td>
<td>Australia</td>
<td>A systematic review of patient/caregiver preferences for information around prognostic or end of life communication at the end stage of a person's illness</td>
<td>123 articles</td>
<td>Family caregivers of people at the end of life stage of illness</td>
<td>Information needs concerning stage of disease, symptom management, and treatment options. Information following a diagnosis was key, alongside its delivered and by whom. Content and scope of information need was negotiated depending on the individual caregiver</td>
<td></td>
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<tr>
<td>Rainsford et al. (2017)</td>
<td>Australia</td>
<td>A systematic literature review on rural end of life care from the perspective of family caregivers and patients</td>
<td>27 articles</td>
<td>Family caregivers of people receiving palliative and end of life care within rural areas</td>
<td>Increased responsibility with the need for coordinating and advocating for the person at end of life. Many caregivers were unprepared physically, emotionally and educationally. Accurate information was the main identified need along with medication needs</td>
<td></td>
</tr>
</tbody>
</table>
There was some variation in family caregiving groups: Dementia/Alzheimer's (5), Palliative care and End of life care (4), Cancer or end of life stage of Cancer (2), Intellectual/Learning Disability (2), Stroke (1), Chronic health conditions (1) and Elderly (1). The following reviews are grouped by the condition, or type of caregiving provided.

**Family caregiving in dementia/alzheimer's disease**

Four systematic reviews (Novais et al, 2017; McCabe et al, 2016; Afram et al, 2015; Innes et al, 2011) and one protocol for systematic review (González-Fraile et al, 2015) were concerned with needs of informal or family caregivers of people with Dementia, or more specifically Alzheimer’s. A Canadian systematic review of 26 articles by Innes et al. (2011) looked at family caregivers of people with Dementia in a rural setting. This review showed that rural caregivers were more educated on the disease generally, and expressed more interest in learning how to implement coping strategies than urban family caregivers.
In relation to information and service needs both rural and urban family caregivers similarly conveyed the most interest, and need, for information on the disease, and access to training. Information needs around financial planning, legal planning and caregiver support were also reported by Innes et al. (2011), they demonstrated that use of services, or the ability of services to meet the needs of family caregivers, was relatively poor for those living in more remote areas. Conclusive recommendations were for a coordinated family centred approach to further examine the needs of these rural family caregivers supporting someone with Dementia (Innes et al, 2011).

Also focusing on the needs of caregivers of someone living with Dementia was Afram et al. (2015) in the Netherlands, who systematically reviewed 13 papers focusing on the needs of the informal caregivers. Afram et al. (2015) concur with Innes et al. (2011) in recognising that caregivers of this population have needs of their own, identifying 14 topics of ‘need’ from the literature, with the most prominent topics including ‘knowledge and information’, ‘emotional concerns’ and ‘support.’

This review showed that collectively, caregivers expressed information and knowledge needs regarding care options, facilities, the care system, and policies. The review acknowledged the importance of information and signposting to social welfare and financial assistance. Afram et al. (2015) demonstrated relationships between the most reported needs and emotional distress and caregiver burden.
Both caregiver burden and emotional distress can be directly influenced by information provision and knowledge, these are also linked to timely support and access to appropriate supportive services. Information and knowledge, delivered in a one to one individualised manner, were seen as important facilitators to decision making (Afram et al, 2015). Comparatively, McCabe et al. (2016) also reviewed studies in relation to the needs of family caregivers of people with Dementia.

12 studies were included for review and results revealed two main themes: caregivers’ personal needs and caregiver needs related to the management of older people with Dementia. The first theme contained four subthemes comprised of: activities of daily living, information (and knowledge) needs, formal and informal care support needs and instrumental activities of daily living and Behavioural and Psychological Symptoms of Dementia support needs. The second main theme was comprised of only two subthemes on the need to manage caregivers’ own lives’, and the need to address their psychological and physical health (McCabe et al, 2016).

Authors report that information and knowledge needs were raised in 9 of the reviewed studies; information on the disease and its progression, health and behavioural problems in Dementia, strategies to manage care and cognitive function, and medications and access to supportive services in a timely fashion were identified (McCabe et al, 2016).
McCabe et al. (2016) agree with Innes et al. (2011) and Afram et al. (2015) in acknowledging the importance of individualised assessment of caregiver needs and person centred support. Afram et al. (2015) appreciated the existing provision of information from groups, websites, flyers and other channels in Dementia, however suggested consideration of timing of when information is given, and the volume if information required depending on the individual. In France, Novais et al. (2017) completed a systematic review specific to the needs of informal caregivers of people with Alzheimer’s disease. 70 studies were reviewed and included qualitative, quantitative and mixed methods designs.

Although the review considered instruments of measurement of need, the top topic of needs explored within the instruments in each of the studies reviewed was ‘information needs’; specifically information needs on the disease, medications, other treatment options and available services. Psychological and psychoeducational needs were also rated, however information needs were deemed particularly important. The fact these instruments prioritise information needs of caregivers is reflective of the other literature concerning other caregiving populations (Lunsky et al, 2014; Silva et al, 2013 Washington et al, 2011; Docherty et al, 2008). Novais et al. (2017) argue that caregivers of people with Alzheimer’s disease have more specific information needs than other informal or family caregivers.
The authors recommended the development of a validated instrument to assess the needs of informal caregivers of people with any cognitive impairment, and at any stage of its progression (Novais et al, 2017). The Spanish González-Fraile et al. (2015) protocol of systematic review centres on information, alongside training and support based interventions. González-Fraile et al. (2015) argue the efficacy of such interventions in reducing the burden associated with providing care informally to people with Dementia.

Information interventions are described as addressing disease specific information; care in general; difficulties with care; and available community resources. Recognised information delivery was through avenues such as lectures, leaflets, audio-visual aids or manuals. Support interventions included participants actively discussing care issues and feelings with fellow caregivers and professionals, through counselling or peer support groups (González-Fraile et al, 2015).

Training interventions were aimed to equip caregivers with practical skills to help alleviate caregiver burden, through more effective communication or via self-management of psychological stress and coping. Conclusively, information was one of three priority areas identified by the authors, which supports other evidence in the systematic review repository, and reflects the current status of caregiver needs around information. The authors assert that the information needs of family and informal caregivers should be a priority for further research (González-Fraile et al, 2015).
Family caregiving in palliative and end of life care

Similar findings to family caregiving in Dementia were deduced from Docherty et al’s (2008) systematic review of 34 articles, relating specifically to the knowledge and information needs of informal caregivers in palliative care. Information and knowledge related domains of communication, information and education, information on social welfare and psychological issues were examined, and the problem of inadequate information on disease progression, pain and side effects of new medications was identified (Docherty et al, 2008). Communication between caregivers and staff was deemed key in facilitating informational provision. Also, caregivers’ understanding of the information they were being given was significant. The holistic information needs approach was supported in this review (Docherty et al, 2008). Assessment and delivery of information was said to promote caregiver efficacy through reassurance and support, which ultimately enhanced the process of coping (Docherty et al, 2008).

Cagle et al. (2017) also considered information provision in their systematic review of 17 articles, specific to families and patients receiving palliative care for Heart Failure in the USA. Psychosocial needs and interventions were examined, and the provision of information was highlighted as important in relation to the disease, symptoms, pain management. How effectively this information was communicated and exchanged between health care providers and family caregivers, had an impact upon how the needs of family caregivers were addressed.
Poor provision of information contributed to emotional distress through misunderstanding and miscommunication. Education was considered an effective means to counteract distress and poor psychosocial outcomes, involving strategies to manage caregiver burden (Cagle et al, 2017).

An Australian systematic review conducted by Parker et al. (2007) concurred in recognising caregiver preferences for communication and information. The review examined 123 articles concerning patient/caregiver preferences for information around prognostic or end of life communication at the end stage of a person’s illness. 46 articles provided caregiver preferences in respect to end of life communication and information; information need was at the forefront of this review, with a particularly high need concerning information on the stages of the life limiting disease’s trajectory, for both patient and caregiver.

Information needs around symptom management and treatment options were similar for the patient and caregiver. Conversely, as the disease progressed the caregiver required more information than the patient. The provision of information following a diagnosis was pertinent, in conjunction with discussion with a trusted health care professional. In agreement with Afram et al. (2015), how the information was delivered was also important in end of life care, as was negotiation of the content and scope of the information (Parker et al, 2007).
Similar to Innes et al. (2011), Rainsford et al. (2017) explored the needs of rural family caregivers, however this systematic review of 27 articles concerned end of life care in Australia. Summary findings may not be generalizable or applicable to family caregiving populations in UK settings including N.I., due to potential differences in culture, availability of services, and what is considered ‘rural’ in the UK. Family caregivers overall acknowledged the responsibility of caring, and coordinating and advocating for the person who was at end of life. Inadequate knowledge was reported, with few family caregivers feeling emotionally, physically, or educationally prepared for the responsibility and tasks associated with caregiving.

Later in the caregiving journey, disease progression inspired a need to have someone to turn to and talk with. The greatest identified support need for family caregivers was for accurate information. Effective communication and information were seen to empower caregivers in their role, reduce distress, and help prepare patients and their families for death (Rainsford et al, 2017). In 9 of the review studies, poor communication was reported involving ill-timed information, conflicting information, and not receiving information from the experts. Honesty, support at time of death, and social support were important requirements and needs for caregivers at the end of life stage (Rainsford et al, 2017).
As the Rainsford et al. (2017) findings are confined to Australia it limits generalisability to other geographical areas, where there may be different infrastructures or cultures which may influence the provision of care and the needs of family caregivers.

**Family caregiving in cancer or end of life stage of cancer**

In the UK, Wheelright et al. (2015) completed a systematic review of 16 sources, on the quality of life of informal carers of patients with Cancer and who were cachexic. Cachexia is characterized by an involuntary loss of weight and skeletal muscle (Wheelright et al, 2015). As with previous literature (Afram et al, 2015; González-Fraile et al, 2015; Docherty et al, 2008) caregiver burden was discussed in relation to role responsibilities. Fear, guilt, worry, helplessness and anger were some of the recognised emotional burdens associated with providing care in general to a family member.

Wheelright et al. (2015) highlighted the conflict between the person and their caregiver in relation to nutritional expectations in cancer cachexia. The presence of conflict around nutrition and caregiver expectations were argued to aggravate existing pressures of delivering care, with family caregivers’ quality of life being directly influenced by person’s disease symptoms. Education was a key caregiver need, with proposition for Health and Social Care professionals’ to consider the needs of family caregivers as part of the management of cancer cachexia.
Wheelright et al. (2015) recommend the patient and family caregiver are approached as a dyad, with interventions aimed at both the person and their family caregiver. It is suggested this may facilitate the resolution of existing conflict, and in turn increase the quality of life of the family caregiver by reducing caregiver burden. Similar to Rainsford et al. (2017) there is the issue of generalisability of findings from Wheelright et al. (2015) to other populations in other geographical regions.

All studies in this review were conducted in Europe or the United States of America (USA), this is particularly important when it comes to the concept of nutrition and cancer cachexia in other cultures, such as those in underdeveloped countries in Asia or Africa. Correspondingly there was an overall identified need in relation to information provision on practical support in a UK based systematic review conducted by Bee et al. (2009). Recommendations were made based on their systematic review of 8 research studies, specific to end of life carers of people with cancer.

The review linked reduced practical support to poor exchange of information. The authors recommended increased information on practical support for this population of caregivers, specifically in relation to nursing skills. Bee et al. (2009) suggest the provision of information promoted the efficacy and confidence of the caregiver and reduced carer distress, which agrees with other systematic reviews (Afram et al, 2015; Wheelright et al. 2015; Docherty et al, 2008).
Family caregiving needs in learning or intellectual disability

A Canadian systematic review identified from scoping the literature by Lunsky et al. (2014) examined 87 papers concerning system wide information about family caregivers of people with intellectual/developmental disabilities. The aims were to ascertain who required services, type of services, and perceptions of the caregiver. These perceptions included subjective impression of stress, capacity, and burden.

Quality indicators for services for adults with intellectual disability were comprehensive in acknowledging the perspectives of the family, and recognition of their individualised needs. The review found that each country had its own particular services and Health and Social Care policies and there was unequal availability in service provision. However, this was dependent on provider supply and population characteristics (Lunsky et al, 2014).

Lunsky et al. (2014) reported on the well documented carer burden, and presence of depression and stress experienced by family caregivers of people with intellectual/developmental disabilities. The need for respite care and information on available services for family caregivers was identified. Financial future planning, funding of services, and awareness of financial entitlements were distinguished needs.
This review acknowledged the expanding body of literature in relation to the experiences of caregivers, however state there is no review explicitly identifying information needs of family caregivers. Longitudinal research was suggested with this population of family caregivers, to provide a better understanding of the long term effects of caring for someone with intellectual/developmental or learning disability. Also in Canada Balogh et al. (2016) updated their 2009 Cochrane review of the same title. The authors evaluated how care was organized care for people with intellectual disability and their caregivers.

The original review findings identified people with intellectual or learning disabilities as having: a lower life expectancy, higher rates of morbidity, more unmet needs, and problems accessing care. Studies reviewed (n=8) included RCTs (6), controlled before and after (1) and interrupted time series (1) studies. Findings recommended deinstitutionalization and extending care into the community, with widened community learning disability teams supporting the person and their family caregiver (Balogh et al, 2009).

Speculations as to the most effective way to organize services for people with learning disabilities (specialist or mainstream) were suggested similar to that services for people with chronic conditions such as heart failure, diabetes and chronic obstructive pulmonary disease (Balogh et al, 2009). The 2009 review found scant evidence in relation to guide suitable interventions and services for people with learning disabilities.
Specialist and integrated care was recommended to address these issues, particularly if the person bridged varying service sectors or teams, for example a specialist palliative care team. Results from measures of caregiver burden and QOL were not significant (Balogh et al, 2009). The 2016 update reported scant evidence on how healthcare is organized for people with learning disabilities and their family caregivers. Seven trials with a total of n=347 participants met criteria for selection for this review. 6 of the studies were already included in the last review. Studies show interventions helped behavioural issues, caregiver burden, and financial costs (Balogh et al, 2016). Balogh et al. (2016) argued that the evidence there was on financial and caregiver burden was limited and suggested further research.

**Family caregiving needs post stroke**

Congruent to other family caregiving literature (Novais et al, 2017 McCabe et al, 2016; Afram et al, 2015; Washington et al, 2011; Bee et al, 2009; Docherty et al, 2008; Parker et al, 2007) information was spearheaded in a UK based Cochrane review on information provision for stroke patients and their carers (Forster et al, 2012). Forster et al. (2012) assessed the strategies of information provision and how effective they were in improving outcomes for patients with a stroke and their family caregivers. 21 randomised control trials, involving comparisons between information based interventions and standard care, were selected for inclusion in this Cochrane review. The total amount of carers involved as participants was 1290.
Knowledge of stroke, stroke services, and the impact of this on mood were examined outcomes. 9 of the trials involved passive information intervention compared to 12 involving active information intervention. Meta-analysis revealed that an intervention had a significant effect on the patient (P <0.001) and carer knowledge (P= 0.03). However, there was no significant effect on carer satisfaction or mood. Studies demonstrated that sufficient information provision following a stroke was important to patients and their carers, following discharge back to the home setting.

Forster et al. (2012) support the evidence that information improves the knowledge of the carer and patient, however, acknowledges that the best way to deliver information to this population of patients’ with stroke and carers remains unclear (Rainsford et al, 2017 Bee et al, 2009; Docherty et al, 2008).

**Family caregiving in chronic health conditions**

Washington et al. (2011) explored the information needs of informal caregivers of older adults with chronic health conditions in the US. This systematic review examined 62 papers. When caring for someone with a chronic illness, lack of education and information was a frequently reported need. There were a variety of topics on which caregivers wished to have information provision. Synthesis of the evidence revealed two kinds of information that a caregiver would prefer: general factual information including explanations and advice; or information that is specific to an individual caregiver's needs.
General information included disease specific information and treatment options, information around services and support (Washington et al, 2011). Specific information needs were based on the individual’s personalised need for information, which varied from person to person and depended on the situation. Washington et al. (2011) suggest online delivery of information was suggested as an accessible option for some, however, in agreement with Afram et al. (2015) acknowledgement was that information should include varying levels of depth depending on the individual preference of the caregiver.

Concurring with Rainsford et al. (2017) and Afram et al. (2015) this review highlighted information needs will change over the course of an illness or a period of time. Furthermore, information should be delivered in a timely manner to adequately prepare the caregiver (Washington et al, 2011). Supporting caregiving literature in other conditions (Novais et al, 2017 Afram et al, 2015; Docherty et al, 2008) information need in this review was reported in relation to end stage disease, death and dying, financial assistance, respite, practical support, and advance planning. Information was seen as preparatory and a priority for health care providers, with recommendations for tailored information designed to meet the individual needs of family caregivers (Washington et al, 2011).
**Family caregiving needs in elderly care**

Silva et al.’s (2013) integrative review on the needs of informal caregivers of the elderly also identified information need. Four themes were developed from 14 articles and the scant literature authors reported was available: Information and training, effective communication, financial and legal support, and professional support. The predominant theme of information and training needs was identified.

Silva et al. (2013) concur with the other authors within the caregiving literature highlighting that informal caregivers require information on the likes of a disease and diagnosis, disease trajectory, medications, treatments, symptoms, and behaviours (Afram et al, 2015; Wheelright et al, 2015; Washington et al, 2011; Bee et al, 2009; Docherty et al, 2008). Although the Silva et al. (2013) review was specific to informal caregivers of people who were elderly, it is important to recognise that a percentage of the elderly population will have a chronic or life limiting illness, or a learning disability.

**Commonly identified need for information**

Analysis of all systematic reviews identified a strong running theme of information/information need/information provision for family caregivers. Information regarding available services, access to services and support, information on self-care, and information and signposting to psychosocial support were deemed important for family caregivers.
Beaver and Witham (2007) suggest that the term ‘information need’ entails the recognition and assertion of poor provision or receipt of information. Sources agree that information has a recognised impact on how well a caregiver copes with the stress and burden associated with their role, including how information is delivered and by whom (Afram et al, 2015; Lunsky et al, 2014; Washington et al, 2011; Bee et al, 2009; Rose, 1999).

McCabe et al. (2016) concur with their predecessors Afram et al. (2015), Parker et al. (2007), Docherty et al. (2008) and Bee et al. (2009), in recognising information as an important facilitator of services, support, and knowledge, to promote and enable caregiver competency. Information is individualised depending on each family caregiver (Afram et al, 2015; Lunsky et al, 2014; Silva et al, 2013; Forster et al, 2012).

Tailored information aids choice (Eysenbach, 2000) and tailored information can facilitate holistic support including respite, education and training, financial assistance, and psychosocial support (Philip et al, 2014; DH, 2008a). Docherty et al. (2008) concur that information provision should be tailored, continuous and timely. Information need for disease specific education and knowledge was similar across the caregiving populations (Afram et al, 2015; Lunsky et al, 2014; Silva et al, 2013; Forster et al, 2012; Bee et al, 2009).
The same assertion may be applied to other family caregivers providing care to people with varying chronic, progressive, or life limiting conditions. Due to the common presence, information needs are suggested to be regularly assessed, alongside how a caregiver is coping and what supports and services are required (Novais et al, 2017; Afram et al, 2015; Lunsky et al, 2014; Silva et al, 2013; Forster et al, 2012).

Discussion

The majority of the papers retrieved for this review concerned family caregiving in Dementia/Alzheimer’s (5) and palliative and end of life care (4). WPCA and WHO (2014) acknowledge Dementia in categorising it as a progressive disease which may require palliative care in the advanced stages. Dementia is also a co-morbid disease frequently associated with the ageing population of people with Down Syndrome (Towers and Glover, 2015).

Furthermore, despite prevalence, cancer cachexia is poorly assessed and documented by specialist palliative care services (Lorton et al, 2016). Moreover, findings relating to caregiving in cancer cachexia may be useful to caregivers in a palliative care context due to the involvement of multi agencies and the identification of similar needs. Palliative care can also be delivered in acute stroke (Singh et al, 2017), however, in this review of reviews post stroke and longer term survivorship were considered only (Forster et al, 2012).
Findings from each systematic review were limited to the specific disease populations of the people they were caring for, with their own individualised needs. However, when it concerns information needs findings across settings this may overlap and be applicable to other caregiving populations, depending on the similarities of the characteristics of the person who is being cared for. All reviews reported a similar spectrum of needs ranging from psychological need and respite requirements to educational needs on the illness, practical support, and the need for financial assistance. This review of systematic reviews shows that information is a common need and priority for family caregivers comprehensively, across caregiving populations.

Moreover, a common identified information need across systematic reviews was the need for information on the disease, illness trajectory, and its management. There were however no systematic reviews explicit to the information needs of family caregivers of people with learning disabilities in palliative care.

Across all settings reviewed information was seen as preparatory and a priority for health care providers. Recommendations call for the provision and delivery of tailored information, designed to meet the individual needs family caregivers (Afram et al, 2015; Lunksy et al, 2014; Washington et al, 2011; Docherty et al, 2008).
Despite the breadth of insight and knowledge gained, there were limitations identified through the Critical Appraisal Skills Programme (CASP) (2018) appraisal tool for systematic reviews, which should be acknowledged. All systematic reviews followed a systematic method with transparency of reporting, however, structured quality assessment was not explicitly reported by Innes et al. (2011), Novais et al. (2017), Washington et al. (2011), Cagle et al. (2017) and Lunsky et al. (2014).

Some of the reviews were limited to date (Rainsford et al, 2017; McCabe et al, 2016; Balogh et al, 2016; Innes et al, 2011), whilst others were included published works only (Rainsford et al, 2017; McCabe et al, 2016; Innes et al, 2011; Docherty et al, 2008; Parker et al, 2007). Other reviews were limited to inclusion of English language evidence (Rainsford et al, 2017; Bee et al, 2009; Docherty et al, 2008). Whilst many of the reviews incorporated mixed methodologies of studies and literature reviews, a small number of the systematic reviews included only randomised control trials (Balogh et al, 2016 González-Fraile et al, 2015; Forster et al, 2012), and some only qualitative studies (McCabe et al, 2016; Wheelright et al, 2016; Afram et al, 2015; Docherty et al, 2008).
Restrictions on inclusion of particular evidence may have excluded valuable evidence that could provide interesting insight to support or oppose other research included in the review. Furthermore, it limits the generalisability of findings to similar populations, however the majority of reviews did include a wide geographical spread (Novais et al, 2017; McCabe et al, 2016; Afram et al, 2015; González-Fraile et al, 2015; Lunsky et al, 2014; Silva et al, 2013; Innes et al, 2011; Washington et al, 2011; Docherty et al, 2008; Parker et al, 2007).

McCabe et al. (2016) and Wheelright et al. (2016) specifically reported on the fact that the majority of studies were based in the United States of America and Europe however. González-Fraile et al. (2015) identified the risk of bias as did Parker et al. (2007) and Balogh et al. (2016), adding increased methodological rigour to their reviews. Findings are useful and may be applied to other populations in part, however they cannot be generalised (Innes et al, 2011).

Overall this review focused on medium to high quality systematic reviews, each of which provided individual insight into specific family caregiving groups. There were similarities in unmet family caregiver needs identified, as well as corroborating evidence of the commonly reported need for information. This review of systematic reviews highlights that family caregivers of people with learning disabilities are under-researched compared to other caregiving groups.
Moreover, the two systematic reviews in relation to people with learning disabilities and their family caregivers were both conducted in Canada. As previously highlighted, it is not certain findings would then be applicable to other cultures or geographical locations. The importance of conducting such research with this sub group of family caregivers is strengthened by the recent population statistics suggesting that long term family caregivers of people with learning disabilities may also be faced with problems similar to that of a caregiver in dementia, palliative care, cancer, stroke or chronic illness as the person they care for grows older (Age UK, 2017; Tuffrey-Wijne et al., 2016; Kirkendall et al, 2012; Michael, 2008).

Furthermore, certain conditions requiring palliative care are specifically linked to ageing in people with a learning disability, as people with Down syndrome have a greater risk of developing dementia (Towers and Glover, 2015). This initial phase of review confirms the gap in research in relation to the information needs of family caregivers of people with learning disabilities who require palliative care. A European Association of Palliative Care (EAPC) Taskforce has highlighted that particularly people with mild learning or intellectual disability may be an invisible population within the field of Health and Social Care as they may not be known to services thus a lack of identification may occur (Tuffrey-Wijne et al, 2016). If there is a lack of data on people with learning disabilities who require palliative care there will also be little research conducted with their family caregivers.
2.5 Phase 1 conclusion

Increased global life expectancy means more people will require assistance with activities of daily living as they age, with most being assisted by a family caregiver. We know information is an important facilitator in supporting family caregivers. Using this knowledge and applying it to the under researched population identified as family caregivers of people with learning disabilities who require palliative care, will help scope the specific information needs of this cohort of family caregivers. Phase 2 seeks to examine the specific research area of information needs of family caregivers of people with learning disabilities who require palliative care.
2.6 Phase 2 introduction (Integrative literature review)

As phase 1 reports, the population is living longer with increasing palliative diagnoses (WPCA and WHO, 2014). Many people require palliative care, some of whom include people with learning disabilities (Michael, 2008). Many of the family caregivers of people with learning disabilities have been providing care for many years prior to any diagnosis of a life limiting or advanced illness requiring palliative care (Michael, 2008). The transactional model of stress and coping introduced by Lazarus and Folkman (1984), and advocated by Hudson (2003), offers theoretical insight, explanations and predictions in relation to the lived experience of family caregivers.

This is particularly important when it comes to the family caregiving experience in a palliative care setting and the increased carer burden which may be present.

How stress is perceived, and coping processes implemented have a bearing upon and potential to influence unmet needs and support requirements. Stress and coping and the Lazarus and Folkman (1984) model have been acknowledged in primary palliative caregiving studies in recognising the impact of carer burden on unmet needs (Harrop et al, 2014; Sherman et al, 2014; Hudson and Aranda, 2013). Role demands, availability of resources, and access to information can positively or negatively influence how a caregiver perceives stress, adapts to stress and implements coping mechanisms (Harrop et al, 2014; Sherman et al, 2014; Hudson and Aranda, 2013).
2.6.1 Phase 2 background

Historically, in the UK, Health and Social Care professionals have reportedly demonstrated insufficient knowledge, training or awareness of intellectual disability (PHSO, 2014; 2009; Heslop et al, 2013; Mencap, 2007). Recommendations for ‘reasonable adjustments’ to care and support to be implemented have previously been made in relation to the provision of meaningful care for people with learning disabilities and their caregivers as vulnerable groups (PHSO, 2009).

It is important to recognize marginalized subpopulations such as people with intellectual disabilities and their family caregivers within the palliative care setting, as they may have different informational needs, and face different barriers to general family caregivers. It is important to acknowledge that a late diagnosis for a palliative prognosis can occur in relation to people with an intellectual disability, as there may be lack of screening for this population, or ‘diagnostic overshadowing’, the latter is the term given to where people may attribute symptoms or changes in behaviour to the learning disability, as opposed to an advanced co-morbid disease (Tuffrey-Wijne et al, 2016; Heslop et al, 2013; Reiss et al, 1982).
UK reports such as “Equal Lives” (DHSSPS, 2005), “Healthcare for All” (Michael, 2008), “Six Lives” (PHSO, 2009), the “Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)” (Heslop et al, 2013), “Dying without dignity” (PHSO, 2014) and the more recent EAPC white paper (Tuffrey-Wijne et al, 2016) have highlighted historical discrimination and access inequalities that have existed in the healthcare system for people with intellectual disabilities. These issues can have a profound impact upon the family caregivers of people with intellectual disabilities, who often play an important and central role in the lives of this population.

Reduced access to information and service provisions are frequently cited issues (PHSO, 2014; 2009; Michael, 2008; DHSSPS, 2005). “Living Matters, Dying Matters” (DHSSPS, 2010b), was developed as a regional palliative and end of life care strategy in Northern Ireland. The strategy acknowledged the contribution of family caregivers in palliative care. It also recognised the prevalence of chronic conditions and the similar burden of symptoms to that of a malignant condition. Tuffrey-Wijne and Mclaughlin (2015) then provided consensus norms and standards for the provision of palliative care for people with intellectual disability and this is reflected in their EAPC White Paper (Tuffrey-Wijne et al, 2016).
European level policy and recommendations have attempted to reduce pockets of marginalisation and assumptions, promoting the involvement with and needs of family caregivers in palliative care, and learning disability (Tuffrey-Wijne et al, 2016; Radbruch and Payne, 2010; DH, 2008a; 2008b). UK Acts of Parliament are also under scrutiny to ensure a society comprehensive of equality, inclusion and the right to services, with appropriate provisions to enable family members' work as carers to be respected and supported (Disability Discrimination Act, 2005; Human Rights Act, 1998).

However, services remain fragmented and difficult to access (Tuffrey-Wijne et al, 2016; McLaughlin et al, 2014b). This extends to the international arena (Balogh et al, 2016; Kirkendall et al, 2012). Olson (2008) concurs approaching the importance of advance planning and of family members as ‘translators’ who can interpret behaviours and language. The most contemporary recommendations at European level are that provision of palliative services must cover the entire learning disability spectrum, all palliative care settings and all care provided by family members (Tuffrey-Wijne et al, 2016).

**Phase 2 aim and keywords**: to retrieve papers specific to information needs and to family caregivers of people with learning disabilities requiring palliative care:
Family care* OR Informal care*

AND

Learning Disabilit* OR Intellectual disabilit* OR Developmental disabilit*

AND

OR Information OR Information needs

AND

Palliative care OR End of life OR Hospice

Inclusion: Published papers. Informal or family caregivers. Caregivers of adults over the age of 18. There were no date restrictions applied.

Exclusion: Papers that did not meet the search criteria. Papers that involved formal caregivers, or caring for children rather than adults.

Literature reviews, quantitative, qualitative and mixed methods studies were included. Additional records identified were retrieved from hand searches of reference lists. Abstracts meeting initial criteria were screened and selected for full text retrieval.

Selection and quality appraisal: Papers were assessed for quality and scored using the relevant CASP (2018) checklist (www.casp-uk.net) or using the Mixed Methods Assessment Tool (MMAT) (Pluye et al, 2011). Quality of studies included ranged from moderate to high quality (6-9 CASP; 100% MMAT), see Table 2.2. Poor quality, irrelevant or duplicate papers were dismissed (Figure 2.2).
Figure 2.2 Phase 2 PRISMA

All search terms
- CINAHL (9)
- PsycInfo (14)
- Pubmed (20)
- Cochrane (1)
- Medline (64)

Additional records identified through other sources (n = 2)

Records identified through database searching (n = 108)

Records screened after duplicates removed (n = 105) + (n = 2)

Records excluded = (n = 99)

Full text articles assessed for eligibility (n = 8)

Papers included in review (n = 8)

Qualitative (4)
Mixed Methods (2)
Review (2)
2.7 Phase 2 results

A final number of eight published papers were retrieved from searching the keywords from concerning information needs of family caregivers of people with learning disabilities who require palliative care. The resulting papers reviewed are discussed alongside, and in context to, other relevant literature including government policies and reports. Demography of retrieved articles revealed that these studies had taken place across a variety of countries, but were weighted within the UK: UK = 5, United States (US) = 1, New Zealand = 1 and the Netherlands = 1. Details of the selected papers are provided in the data extraction table (Table 2.2, p. 97-99).
<table>
<thead>
<tr>
<th>Author(s)/Year</th>
<th>Country/Setting</th>
<th>Aim</th>
<th>Design and Sample</th>
<th>Data Collection</th>
<th>Data Analysis</th>
<th>Outcome/Findings</th>
<th>Quality Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuffrey-Wijne et al.</td>
<td>United Kingdom</td>
<td>A review of the literature on palliative care and end of life care for people with intellectual disabilities</td>
<td>Literature review of 45 sources</td>
<td>Not applicable</td>
<td>Not applicable</td>
<td>Issues reported: prognostic disclosures and presentation of symptoms, late diagnoses, and poor communication. Training and information needs of family carers identified as well as access to palliative care services. Importance of service planning</td>
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<td>(2007a)</td>
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<tr>
<td>Tuffrey-Wijne et al.</td>
<td>United Kingdom: Specialist Palliative Care Services</td>
<td>An investigative study into the issues and difficulties experienced by palliative care staff in relation to the provision of palliative care for people with intellectual disabilities</td>
<td>Qualitative: 32 palliative care professionals</td>
<td>Semi-structured interviews</td>
<td>Thematic Analysis</td>
<td>Identification of: family issues, assessment problems, emotional fears, and the effectiveness of good communication between staff, patient and carers, were promoted</td>
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<td>(2007b)</td>
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<td>Marlow and Martin</td>
<td>New Zealand: Community</td>
<td>To provide understanding of inner meanings of the experience of supporting a dying family member with an intellectual or learning disability</td>
<td>Qualitative Hermeneutic Heideggerian phenomenological : 5 family caregivers</td>
<td>Semi-structured interviews</td>
<td>Hermeneutic Phenomenological</td>
<td>Themes - (1) interlocked companionship (2) Search for new balance (3) permeable interaction</td>
<td>8</td>
</tr>
<tr>
<td>Authors</td>
<td>Country</td>
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<td>Kirkdendall et al. (2012)</td>
<td>United States</td>
<td>Peer reviewed article on caring for people with intellectual or learning disabilities and life limiting illness</td>
<td>Intellectual/learning Disability and Palliative care services need to build relationships, share goals and merge philosophies to be successful</td>
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<td>McLaughlin et al. (2014a)</td>
<td>United Kingdom: advocacy network and community</td>
<td>To explore service user perspectives on palliative care education for Health and Social Care professionals supporting people with intellectual/learning disabilities</td>
<td>Themes - (1) Partnership between practices (2) shared learning (3) support and empowerment and (4) challenges at end of life</td>
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<td>McLaughlin et al. (2014b)</td>
<td>United Kingdom: primary and secondary care settings (specialist palliative care and intellectual/learning disability services)</td>
<td>Developing a best practice model for partnership practice between specialist palliative care and intellectual/learning disability services</td>
<td>Positive partnership working, however referrals for palliative services were limited. Better understanding of intellectual/learning disability required with supporting the carer coping with the aftermath of a palliative diagnosis and death</td>
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<td>Bekkema et al. (2015)</td>
<td>Netherlands: community, intellectual/learning disability intensive care unit, hospital and hospice</td>
<td>To explore the perspectives of relatives, care staff and physicians on shifts in care approaches at the end of life of people with intellectual/learning disabilities</td>
<td>End of life care for people with intellectual/learning disability requires increased teamwork and fostering of collaborative relationships among professionals and relatives. Joint decision making, cooperation and shared care in the best interests of the person</td>
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<td>Study</td>
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<tr>
<td>Tuffrey-Wijne et al. (2016)</td>
<td>United Kingdom: involving experts from 15 European countries</td>
<td>To define consensus norms for palliative care of people with intellectual/learning disabilities in Europe</td>
<td>Mixed Methods Delphi study composed of four rounds</td>
<td>(1) taskforce drafting of norms (2) Online survey to evaluate norms (3) modification and recommendations from taskforce (4) Review and approval from the European Association for Palliative Care</td>
<td>Equity of access to palliative care services; recognition of palliative care need; needs assessment; involving important people; support for family carers; preparation for death and support in bereavement; and education and training</td>
<td>100%</td>
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Connecting services and joint working

The search retrieved a literature review conduct by Tuffrey-Wijne et al. (2007a) concerning people with learning disabilities who required palliative care. The review included 45 sources where the primary focus was palliative care issues for people with learning disabilities. Reported issues included diagnostic and prognostic disclosures, presentation of symptoms, late diagnoses, poor communication, and ethical issues around end of life decision making. The review addresses the importance of collaborative practice between learning disability and palliative care services and partnership working with family caregivers. Training needs were identified as were information needs of the carer; accessible information on the disease and how to access palliative care services were important. Service planning, end of life decision making and recognition of the psychosocial issues experienced by the person with a learning disability and their family caregivers were also discussed (Tuffrey-Wijne, 2007a).

A further study conducted by Tuffrey-Wijne et al. (2007b), investigating similar issues for the provision of palliative care for people with learning disabilities, considered the role of paid staff. The UK based qualitative study recruited 32 palliative care professionals for interviews. Study findings support that of Tuffrey-Wijne et al. (2007a), Lunsky et al. (2014) and Balogh et al. (2016) in promoting the identification of family issues, assessment problems, emotional fears and the effectiveness of good communication between staff, patient and carers.
Collaboration between palliative care and learning disability services was also championed by Tuffrey-Wijne et al. (2007b), amongst others (Bekkema et al, 2015; McLaughlin et al, 2014a; 2014b). Tuffrey-Wijne et al. (2007b) recommended that palliative care staff have enhanced training on learning disability, with raised awareness of the expertise of the family carer. The impact of a palliative diagnosis must also be considered in respect to the emotional and psychological needs of family carers. McLaughlin et al. (2014b) found that partnership working was positive, however, referrals from the learning disability field for palliative care services were limited.

The mixed methods study incorporated two phases within the UK with questionnaires (n=47 received) to scope end of life care in learning disability, and semi-structured interviews (n=30) with Health and Social Care professionals from either care fields (McLaughlin et al, 2014b). McLaughlin et al. (2014b) discussed the context in which care was being delivered and partnerships that would be pertinent in these cases, for example respiratory services and primary care services. Learning needs highlighted concur with Tuffrey-Wijne et al. (2007a; 2007b) suggesting staff need to have a better understanding of: learning disability, supporting the carer, and coping with the aftermath of a palliative diagnosis and death.
A best practice model for partnership working, with the person with learning disability and family carer at the centre, was proposed with development of improved training and education for professionals (McLaughlin et al, 2014b). Similarly concerning integration of learning disability and palliative care services, Kirkendall et al (2012) published a peer reviewed article in the US evaluating care for people with a learning disability and life limiting illness. Although this retrieved paper did not look into the information needs of the carers of this population, it recognised that people with learning disabilities were living longer and identified little was known about their end of life needs.

This article also focused on care in the US, therefore there may be some similarities of insight and knowledge in comparison to other international literature, it is uncertain however whether the barriers to care and service provision cited in this paper are assigned to the country and how Health and Social Care services are funded (Kirkendall et al, 2012). Kirkendall et al. (2012) acknowledged that partnerships between learning disability services and palliative services were on the increase, yet the effectiveness of these collaborations remained under researched. The authors argued that managing the care of people with a learning disability in the community employed divergent ideologies of care, in comparison to palliative and end of life care services (Kirkendall et al, 2012).
Kirkendall et al. (2012) further postulate that it is a disparity between these two fields and their approaches that creates issues for both disciplines in respect to the client set and their family caregivers. Therefore collaborative partnership working between both fields is promoted to ensure information sharing and shared awareness of palliative care and learning disability (Kirkendall et al, 2012).

More recently Bekkema et al. (2015) conducted a study in the Netherlands to evaluate perspectives of the family and Health and Social Care professionals at the end of life of people with learning disability. A retrospective case study design was adopted and semi-structured interviews were employed. Participants (n=45) included relatives and professionals who had been involved with a recently deceased person (n=12) with a learning disability.

Bekkema et al. (2015) highlighted the importance of enhanced therapeutic relationships between the informal and paid carers. Important values were: being responsive, being reflective, taking responsibility and cooperating in shared care. This study highlighted the importance of the professionals and family working together; however, this is dependent on knowledge and skills. Teamwork and cooperation were essential, with family carers requiring support from professionals to make difficult decisions. (Bekkema et al, 2015).
Accessibility and equity of information and services

McLaughlin et al. (2014b) attested to a gap in services and alluded to a lack of accessibility for people with learning disability to quality end of life care. Recommendations from the study were for services to be intertwined enabling the care recipient and their family caregiver to access the right services and information, and to die in their place of choice, with the continuation of care delivered by those familiar to them. Recommendations from the Marlow and Martin (2008) study in New Zealand revealed 24 hour ongoing information and support for families was of pertinence. The qualitative study interviewed family caregivers (n=5) of someone with a learning disability who required palliative or end of life care. This study suggested that there should be sensitive communication between professionals and family caregivers, and that where possible the family caregiver should be able to remain in close proximity to the person they are caring for at end of life.

Marlow and Martin (2008) offer a window, albeit a small and limited one into the world of a caregiver of someone caring for a loved one with learning disability who is dying, however, the research remains limited as this is a small sample size and more exploratory work with this family caregiving population should take place. The study also looked at the experience rather than the informational needs of this caregiving group.
It did however uncover some insight into what informational needs may be present such as information requirements relating to a palliative diagnosis, decision making and advance care planning, or information needs surrounding bereavement and counselling. McLaughlin et al. (2014a) conducted a qualitative study, in the UK, to explore perspectives of people with a learning disability, in relation to the education of professionals in palliative care and the support of people with learning disabilities.

Two focus groups were convened consisting of people with a learning disability (n=17) alongside semi structured interviews with family caregivers who were either actively caregiving or bereaved (n=5). Interviews revealed four key themes involving partnership between practices, shared learning, support and empowerment and issues and challenges at end of life. Recognition of the challenges were highlighted as important, hence promoting the need for early referrals to enable adequate provision of information, collaborative work and the formation of trusting relationships (McLaughlin et al, 2014a).

Late referrals, however, remained an apparent barrier to collaboration and information and signposting to supportive interventions in general (McLaughlin et al, 2014a). This study used a small sample of family caregivers of people with learning disabilities in the context of end of life care specifically, however, given these insights it is clear that work is still outstanding to establish their specific information needs across the wider palliative care continuum.
Accordingly, Bekkema et al. (2015) recognised that it may be difficult for carers and staff to adapt from task management and symptom control to comfort measures. There will also be increased responsibility around interpretation of pain and distress, increased emotional burden, and greater informational requirements to foster decision making at end of life.

A European Delphi study conducted by Tuffrey-Wijne et al. (2016) involved a mixed methods research focusing on four rounds. This involved experts from various European countries who took part in a taskforce and helped draft the norms for people with intellectual or learning disabilities who require palliative care in Europe. A survey was also utilised by further experts (n=34) from a further 18 countries across Europe. 80 experts from across Europe then evaluated 13 norms including 52 items.

Tuffrey-Wijne et al. (2016) developed norms which included ‘communication; equity of access; recognising the need for palliative care; assessment of total needs; end of life decision making, symptom management, involving those who matter; support for family and carers; collaboration; preparing for death; bereavement support; education and training, and developing and managing services.’ (p. 452-453). Recommendations were made and the European Association for Palliative Care (EAPC) approved this as an EAPC White Paper (Tuffrey-Wijne and McLaughlin, 2015).
Tuffrey-Wijne et al. (2016) concluded that there is a lack of data on people with a learning disability who require palliative or end of life care, and highlight that good practice is dependent on the commitment and dedication of individuals, not simply policy. Recommendations include the sharing of best practice, inclusive of family caregivers, and modifications in policy in order for change. The recent white paper suggests that palliative care services actively reach out in order to uncover this ‘hidden’ population.

Issues of pertinence include equity of provision, access to services, optimal needs assessments, and communication assimilating informed decision making. Therefore the family caregivers of this population will no longer be invisible and their involvement will be encouraged as ‘expert care partners’ (p. 54). Furthermore the emotional bond that exists and the grief suffered by the family caregiver will be recognised and bereavement support offered as a standard norm (Tuffrey-Wijne et al, 2016).
Discussion

The amount of research around family caregivers in the learning disability field and palliative care is limited in comparison to caregiving in palliative care generally. There was no literature identified specific to the information needs of family caregivers of people with learning disabilities who require palliative care. The majority of literature was based in the UK, which as previously highlighted may not be a reflection of the status of the needs of family caregivers in other countries, due to the nature of how government systems and health care services are organised.

There can be no certainty as to the quality of the material reviewed in the Tuffrey-Wijne (2007a) paper, as there was no reporting of such, dates were also limited from 1995-2005 meaning useful material may have been overlooked. As there was such little research at the interface of learning disability and palliative care services at the time the evidence is useful nonetheless. Moreover, Tuffrey-Wijne (2007a) focused on the person with a disability as opposed to the family caregiver, however did provide some insight and knowledge into the role and importance of supporting family caregivers.

Tuffrey-Wijne’s (2007b) primary study explored the role of paid staff only which is a limitation given this review examines informal family caregivers. McLaughlin et al. (2014b), although a robust mixed methods study, examined partnership working between services with Health and Social Care professionals only.
Focus was also on paid carers in the Bekkema et al. (2015) study, this research did however uncover obstacles, but did not address unmet needs, in particular information needs of the family caregivers. The study was also completed retrospectively which introduces the element of potential recall bias. Some studies had very small numbers of participants (McLaughlin et al, 2014a; Marlow and Martin, 2012), however, due to the exploratory nature of these qualitatively designed studies there was rich information important to understanding the experience and potential unmet needs of family caregivers of people with learning disabilities who have required palliative or end of life care.

The larger Delphi study reported by Tuffrey-Wijne et al. (2016) provides the most robust evidence supporting equitable palliative care for people with learning disabilities, incorporating support for their family caregivers. There was precise research direction, with wider European level collaboration of recommendations for policy changes and best practice. Tuffrey-Wijne et al. (2016) also recognised this hidden population of family caregivers and the need for bereavement care in particular. Results from this study not only apply and help locally, but at a European level, setting consistent standards by which all European countries should follow.
The literature retrieved however shows us that planned support through information provision enables healthcare providers, as partners, to help relieve the burden associated with providing care to someone with a learning disability who requires palliative care (Tuffrey-Wijne et al, 2016; Bekkema et al, 2015; Kirkendall et al, 2012).

The scope of information required may be extensive and dependent on the individual caregiver at the interface of learning disability and palliative care services. The literature affirms that holistic information needs exist in respect to family caregivers in general in palliative care, and can range from information and education on the illness, nursing care, psychological support, financial assistance and respite (Harrop et al, 2014; Philip et al, 2014; Rose, 1999).

Information needs have also been reported in the general learning disability literature, however, centre more on general practical and emotional support (Chadwick et al, 2013; Wilson and Mansell, 2010). It can be surmised from this review of the literature that the receipt of information and signposting to a multitude of supports such as financial relief, counselling, education on disease, medication, or basic nursing care may be hindered by barriers such as reduced access to appropriate services and poor communication between Health and Social Care professionals (McLaughlin et al, 2014a; 2014b; Kirkendall et al, 2012).
In the primary caregiving literature professionals across fields have played a significant role in ensuring that appropriate information and resources are signposted, as they are viewed as gatekeepers to valuable support and services (Wilson and Mansell, 2010; Harrop et al, 2014; Mclaughlin et al, 2014a; Philip et al, 2014). Kirkendall et al. (2012) agree with Tuffrey-Wijne et al. (2016) that if each field identifies the other’s similar philosophy of care then there will be intermutual agreements. In the UK the philosophy of a ‘good death’ (DH, 2010b) in palliative care is similar to the philosophy of living a ‘good life’ within the learning disability field (British Institute of Learning Disabilities (BILD), 2015). The congruent philosophies suggests the benefits of partnerships and joint working, which has also been promoted in the literature (Kirkendall, 2012; McLaughlin et al, 2014a).

2.8 Phase 2 conclusion

There is a wide body of literature concerning palliative caregiving; however, there remains a dearth of literature relating to family caregivers of people with learning disabilities in general, in this particular context. At present there is no apparent published research identifying the information needs of family caregivers of people with learning disabilities who require palliative care.
We may be guided by the larger bodies of literature in generic palliative caregiving which allude to a spectrum of information needs including disease specific information, practical information and financial information (Harrop et al, 2014; Philip et al, 2014; Sherman et al, 2014; Dikkers et al, 2013; Ewing and Grande, 2012; Shanley et al, 2011).

The learning disability literature also tells us that there is a need for information in general for family caregivers, whilst hinting that information need around emotional and psychological support may be present (Chadwick et al, 2013; Wilson and Mansell, 2010). In palliative care and learning disability, Kirkendall et al. (2012) and McLaughlin et al (2014a) both discuss family caregiving in learning disability and end of life care, promoting adequate information provision with good communication and partnership work across fields.

This review highlights the gap in the research in relation to the informational needs of family caregivers of people with learning disabilities who require palliative care, it sheds light on what informational needs may exist based on the studies retrieved. The exploratory qualitative design of this research seeks to address this gap and determine the informational needs of these family caregivers, which can provide insight into the ramifications and significance of negotiating both the learning disability and palliative care constituents of a person’s care.
Implications for practice

As predictions suggest many more of the population will be living with long term conditions in the future with family or informal caregivers providing care in the home setting (Age UK, 2017). Increased life expectancy for people with learning disabilities and their increased risk of developing a condition which will require palliative care justifies the need for family caregivers of this population to be a priority for future research.

The complexity of care involved in learning disability, and in palliative care may compound already existing carer burden (Kirkendall et al, 2012). In supporting under researched populations of family caregivers by recognising their informational needs we can enable them to have a better quality of life and contribute to society and the economy (DH, 2008a).

The needs of people with learning disabilities who require palliative care and their family caregivers are of paramount importance at European level, and a policy direction priority (Tuffrey-Wijne et al, 2016). It is imperative that the informational needs of this marginalised cohort are a priority for future research, in order to support and improve best outcomes. Until then, as a result of this gap in the research, crucial elements of policy and practice are not being guided or influenced.
2.8.1 Reflexivity through literature reviewing

Through preliminary scoping of the literature prior to the review being conducted, the researcher became aware of existing problems and needs within the family caregiving field across disciplines. Following critical reflection, this influenced the direction of the study and contributed to the evolvement of the research aims around information need.

2.9 Chapter summary and rationale for this research study

Family caregivers of people with learning disabilities who require palliative care remain an under researched group, with scant literature available on this population and their needs. It is also apparent from the literature review that ‘information needs’ are a commonly identified family caregiver ‘need’, across the general caregiving literature. This review highlights that information is an important conduit to, and facilitator of, supportive interventions. Information may be key to signposting family caregivers to individualised support. Information needs are not limited and can be in relation to: education on the disease, death, dying and bereavement, financial entitlements, practical assistance, psychological support and respite.
Access to information and equity of available services remain barriers to meeting the information needs of family caregivers across fields, this has been identified from the caregiving literature and is evident from UK based reports and government policy. In summary, the review identifies the gap in the literature in respect to information needs of family caregivers of people with learning disabilities who require palliative care and suggests further research in this area as a future priority in Health and Social Care. The aim of this study is to therefore determine these information needs, through exploratory interviews with family caregivers. The perceptions of Health and Social Care professionals, around which information needs they feel exist, and how they can best addressed, will also be established.

This chapter has critically examined the literature, and highlighted the gap in the research literature in relation to the information needs of family caregivers of people with learning disabilities who require palliative care. The review chapter provides justification for conducting this study. The following chapter will discuss the theoretical underpinnings for this study, why they are relevant and why they were chosen for this research.
Chapter 3 Theoretical Underpinnings and Research Design

3.1 Introduction

This chapter will discuss the theoretical underpinnings and the research design of the study. It will examine why theory is important in research, the rationale for the chosen theory underpinning this study, and how theory is embedded within different stages of this research study.

3.2 Importance of theory in research

It is important that the theory fits with the design and methods of a research study; underlying conceptualization of behaviour and characteristics, influences and contexts allow for development of sound research design decisions (Parahoo, 2014). Theories can explain a particular phenomenon or reality in an abstract and systematic manner, combining concepts to explain or describe an aspect of the world or reality. How phenomena are interrelated and also the characteristics of the phenomena can be explained by theory (Polit and Beck, 2014). Theory provides structure to knowledge and can also provide a framework for means of data collection in order to describe and predict. It can provide clarity and either challenge or confirm existing knowledge or intuition (McEwen and Wills, 2007).
Parahoo (2014) asserts that theories link known bodies of knowledge to research, with evidential findings from research either confirming, adapting or discounting existing theories, to enable development of new theories. In relation to research findings the underpinning theory enables meaning to be derived from results, which in turn can foster interpretation and understanding into the how and why of a phenomenon (Polit and Beck, 2014).

For the purpose of this research, theory underpins and guides the study and provides context in respect to offering some explanation or understanding as to why certain phenomena exist in certain situations. Underpinning theory assists navigation of the research, it may generate new ideas, and may be examined through the research process.

3.3 Conceptual frameworks and models

Models highlight processes which develop outcomes, including relationships and concepts (McEwen and Wills, 2007). Closely linked to theory, models can demonstrate a simplified version of phenomena, or an element of phenomena (Per Nilson, 2015). A conceptual model, however, assembles concepts relevant to a particular theme or themes and can provide a broader understanding of what is being studied; reflecting the underlying philosophy, assumptions or views of the person who formulated the model (McEwen and Wills, 2007).
McEwen and Wills (2007) describe conceptual models as representing an aspect of the real world, adding that they can be diagrammatic, formulas, objects or simply narrative. Models have been described as highlighting the processes which develop outcomes, including relationships and concepts (McEwen and Wills. 2007). Using a model can inform thinking through enabling one to make sense of a concept, and allow for effective decisions, strategies and forecasts.

3.3.1 Theoretical frameworks

Theoretical framework, conceptual framework and conceptual model are seen to be used interchangeably within research (Polit and Beck, 2014). Some sources disagree, stating there is a distinction in that theoretical frameworks provide an overview of categories which are descriptive rather than explanatory (Nilson, 2015; Frankfort-Nachmias and Nachmias, 2008). A theory of explanatory nature better assists the researcher to understand a phenomenon, and why it occurs.

3.4 Stress and society

Stress has been defined as ‘a particular relationship between the person and the environment that is appraised by the person taxing and or exceeding his/her resources’ (Lazarus and Folkman, 1984, p18). Supplementary to this Lazarus published ‘Psychological stress and the coping process’ in 1966, and the field of stress expanded in the years following.
Lazarus (1966) discussed how the amount of stress experienced by an individual was dependent upon how the individual perceived the meaning of the stress stimulus. Impetus was on how stress was managed whilst taking into account appraisal and coping. Later work completed by Toffler in 1970 made some suggestion that stress was a manifestation of a rapidly changing society and industrial growth whereas succeeding work by Lazarus and Cohen (1977) introduced the notion of internal and external environmental demands and how these affect wellbeing and balance.

By the 1960s and 1970s sources recognised that stress was a potential causal factor in emotional and physical ill health, it was therefore imperative that psychological and social factors were considered in the management of stress (Lazarus, 1966; Lazarus and Cohen, 1977). As stress was becoming such a prevalent issue in society that needed addressed Lazarus and Folkman (1984) developed the transactional model of stress and coping. This is pertinent to this study, as caregiving is associated with stressors related to the role, and carer burden.
3.4.1 The transactional model of stress and coping

The selection of the transactional model was appropriate for this research due to the often reported stressors and carer burden associated with the role of a family caregiver. Furthermore, it is allowing greater understanding of how resources such as information play a part in enhancing family caregivers’ ability to deal with stress and coping. Moreover, stress and coping were important themes highlighted during the initial scoping review of the literature, and it is a prominently used conceptual model within nursing research (Harrop et al, 2014; Philip et al, 2014; Hudson and Aranda, 2013).

Lazarus and Folkman’s (1984) Transactional Model of Stress and Coping was originally aimed towards an audience including clinicians within the healthcare sphere, as a theoretical analysis of how stress may be prevented, managed or eliminated altogether. The model is dynamic and specific to each encounter of a ‘stressor’, the model appreciates the transactions between a person and their environment, and how resources play a role in coping processes. Figure 3.1 shows the processes involved in the 1984 stress and coping model.
Figure 3.1 Lazarus & Folkman (1984) model of stress and coping

(Adapted from Lazarus and Folkman, 1984)
In the context of palliative care, Lazarus and Folkman’s (1984) model was modified by Folkman (1997) to include positive psychological states, relating to meaning and how it is related to coping processes. For example, in an end of life scenario, despite an important person nearing end of life, caregivers can still maintain positive emotion by deriving meaning from an unfavourable event or situation or feeling that they have the privilege of caring for their loved one at end of life. Hudson (2003) developed a further variation of the model processes, influences and outcomes (Figure 3.2).

**Figure 3.2 Hudson’s (2003) revised model of stress and coping**

*(Hudson, 2003)*
The revised version assimilated emotion and meaning into the coping processes and also incorporated meaning based coping derived from negative stress and episodes of no resolution. The difference from the original Lazarus and Folkman (1984) model is in positive reappraisal, spiritual beliefs, and positive events and revised goals, which all eventually lead to favourable resolution despite the original unfavourable outcome of negative stress. Meaning based coping then provides more sustainable coping processes by which the person can utilise in future encounters with what they perceive as a threat or challenge.

### 3.4.2 Carer burden, stress and coping

Caregiver burden is frequently cited in the caregiving literature (Totman et al, 2015; Cowan, 2014; Sherman et al, 2014; Grant et al, 2013). The transactional model offers insight into the lived experience of family caregivers, whilst providing explanations and predictors as to if and how they cope with the stressful demands of the role. In relation to information need the transactional model appreciates how access to information and availability of resources can impact on how much stress a caregiver will experience and how they adapt and cope with it. This conceptual model offers further explanation in how people deal with stress and proposes that coping mechanisms are learned. The mechanisms provide a strategy that enables adaption or the ability to change the said stressor(s) (Lazarus and Folkman, 1984).
Sources support the assertion from Polit and Beck (2014) that in relation to health the model links a person’s own perception of their physical and mental health, to how they cope with stress, factoring in their evaluation of stress and subsequent coping strategies (Totman et al, 2015; Sherman et al, 2014; Grant et al, 2013). Hudson (2003) advocated the transactional model in its application to family caregiving research in guiding interventions in palliative care. Cognitive appraisal and coping processes are integral components of the model in family caregiving, with cognitive appraisal involving evaluation of the environment and its impact on physical and mental wellbeing. If a situation or environment is deemed challenging, a decision based on a caregiver’s values and goals will be made in order that harm is minimized and adaptations made to overcome problems and these efforts to manage challenges are seen as coping (Hudson, 2003).

3.4.3 Cognitive appraisal

The stress adaption proposed in the revised conceptual model developed by Hudson (2003) provides a cognitive representation of stress, with the model tying together the concepts of appraisal, coping and outcomes. The model focuses on the psychological processes and responses involving thoughts, actions and how they change as a result of an event. This process is dynamic and consists of continuous appraisal and reappraisal depending on the situation, environment or relationship.
The model of stress and coping proposes that coping is a result of how a person responds and perceives a threat, with this evaluation demonstrating cognitive appraisal. Lazarus and Folkman (1984) previously described coping as how a person manages this appraisal. Coping can be defined as either ‘emotion-focused’ or ‘problem-focused’, the former when a person modifies the meaning of a situation, the latter when the change involves the relationship between the person and their environment (Lazarus and Folkman, 1984). Reappraisal follows a successful episode or period of coping, this incorporates reflection on how the situation was managed and adjustments that may need to be made to new information (Hudson, 2003).

3.4.4 Coping and Stress Adaption

Adaption is defined by Lazarus and Folkman (1984, p182) as ‘the capacity of a person to survive and flourish.’ As a result of successful coping a person adapts which is important when it comes to health and wellbeing and how a person functions on a social level, in particular family caregivers within the fields of palliative care and learning disability. Sources agree these areas can affect one another due to their interdependency, for example if a person becomes unwell this can impact upon their social lives, self-esteem or their ability to deliver safe effective care (Carers UK, 2014a; Carlander et al, 2011; DH, 2008a).
Health and Social Care professionals can help family caregivers facilitate more effective, or new coping strategies, by understanding, assisting, or supporting them with their coping processes (Sherman et al, 2014). In the context of family caregiving, information may be viewed as a coping resource, it can also facilitate increased competence and confidence of a caregiver in their role which in turn influences variables such as anxiety and lack of self-efficacy (Philip et al, 2014; Hudson, 2003).

The modified Folkman (1997) version of the transactional model is supported by palliative caregiving research (Cowan, 2014; Hudson and Aranda, 2013). For example, meaning enhanced coping was employed by family members caring for a dying relative in a small qualitative study conducted within a small community of Sikh caregivers in the United Kingdom (Cowan, 2014). Cowan (2014) conducted semi-structured interviews (n=6) with carers from the Sikh population. This cohort of family caregivers used their faith to reconcile them with death and claimed this helped with the process of coping with their role. However, this sole reliance on faith may have influenced the family caregivers’ decision whether to seek further support, if they felt meaning based coping was sufficient.
3.4.5 Variables in stress, coping and adaption

The variables touched upon, suggested by Hudson (2003), conceptualise the experience of family caregivers in a palliative care context. Appraisal variables which include self-efficacy, health and wellbeing, role by default, preparedness, mastery, depression and anxiety, competence, mutuality, optimism, patient dependency, and social support (Hudson, 2003). Variables which may be applicable to family caregivers of people with learning disabilities, who require palliative care, may also be more complex due to the diversification of experience of these family caregivers.

Hudson (2003) argues preparedness and its perception can influence outcomes positively, or negatively, depending on the level of support and knowledge one has. Consequently, the concept of mastery, resulting from adaptation to an environment or mastery of new skills, can enhance control, self-esteem and satisfaction. Conversely, a lack of mastery can manifest as strain and stress, and competence in performance as a caregiver may also directly influence the ability to adapt and master (Hudson, 2003). Self-efficacy lies in a caregiver’s belief in their ability, in particular, their ability to manage a situation and overcome obstacles. If there is low self-efficacy the resulting low self-esteem and helplessness may develop into anxiety and depression, conditions commonly associated with the burdensome role of palliative caregiving (Harrop et al, 2014; Grant et al, 2013; Hudson et al, 2011).
Respite for caregivers is viewed as a variable, Hudson (2003) asserts in protecting one’s social realm and maintaining a life outside of the caring role, the role is seen as less threatening and less stressful. The same may also be said in a learning disability context, where respite is considered important to family caregivers (Balogh et al, 2016; DHSSPS, 2005).

Caregiver burden and its impact on a person emotionally, psychologically, financially, socially or physically can be greatly influenced by a person’s choice to take on a caregiving role (Lewis, 2014). This is motivated by the caregiver’s relationship to the care recipient, as often those taking on a caregiving role, do so with commitment (Hudson, 2003).

Finally, disease status can influence caregiving in distress potential, education and knowledge of a disease and its trajectory is therefore paramount to relieve stress, empower the caregiver and support their decisions (Harrop et al, 2014; Philip et al, 2014). These variables are influenced by the provision and delivery of care provided by specialist learning disability and palliative care services, where there remain recommendations for improvements (Tuffrey-Wijne et al, 2016; McLaughlin et al, 2014a; 2014b).
3.4.6 Considerations for other models

When selecting this model to underpin the study the researcher considered whether an information or family caregiving based model would be more appropriate than the transactional model of stress and coping; rationale for selection of the latter was based on consideration of a number of points. Initial visualisation for the study was based upon antecedent family caregiving research in palliative care, completed by Hudson and Aranda (2013) on the Melbourne Family Support Program. This program was based on Transactional Model of Stress and Coping, which proved successful in guiding the study.

The Caregiving Stress Process Model proposed by Pearlin et al. (1981) assesses how the processes involved with caregiving affect the health of the caregiver, caregiver health was not the focus of the research question in this study. The Family Caregiving Model introduced by Zerwekh (1991) was modelled around public health nursing, however this focused more on the role of the professional when working with families. The Family Caregiving Health Model (CGHM) (Weierbach and Cao, 2017) may have been appropriate, however it was introduced later in the study timeline.
In relation to information, Ellis (1989) developed the Model of Information Seeking Behaviour. This model refers to how information is sought and used. Information seeking is dependent on how motivated an individual is to self-seek information, or recognise the gap in their knowledge. This study sought to identify information needs rather than identify how caregivers find and utilise information.

3.4.7 Guiding support for family caregivers

Psychological distress can result from the isolating nature of caregiving, compounded by the reported guilt, grief and fatigue that can arise when caregiving has been a long continuum before end of life, such as in the field of learning disability (Marlow and Martin, 2008). It is therefore important that this is recognised and acted upon, whether that be via information or signposting to supportive interventions. Support should incorporate social availability and dependability of people on whom caregivers can rely upon (Hudson, 2003).

Information being a sentinel factor in this research, caregivers can often display information seeking behaviour which is viewed in itself as a coping mechanism (Philip et al, 2014; Wilson and Mansell, 2010). However, informational provision must be available otherwise decision making can be compromised which can impact on outcomes (Chadwick et al, 2013).
The 1984 transactional model of stress and coping, and the revised versions by Lazarus (1997) and Hudson (2003), show insight into the importance of factors relating to positive, or negative outcomes for family caregivers, why they may manifest and how outcomes can be improved. This theoretical underpinning serves as both explanatory and predictive, based on its application to family caregiving at the learning disability and palliative care interface. In combination with the Transformative paradigm this theory influenced and determined the conduct and processes of this study. Paradigms are discussed in further detail in section 3.5.

3.5 Paradigms

The notion of a ‘paradigm’ was introduced by Kuhn (1970), describing how a set a beliefs and values can steer and influence research, highlighting a set of beliefs and a particular world view. McEwen and Wills (2007) concur that a paradigm is comprised of concepts, assumptions, theories and principles. Parahoo (2014) further considers a paradigm as an overarching set of ideas or beliefs about phenomena, and the chosen methodologies adopted in order to study them. A theoretical framework has been suggested as sometimes being referred to as the research paradigm (Mackenzie and Knipe, 2006; Mertens, 2005). MacKenzie and Knipe (2006) discuss a paradigm as a reflection of the ‘philosophical intent’ of the researcher, or the research motivation.
Fundamental philosophical debates and issues underlie qualitative research and these include acknowledgement of ontology and epistemology; George (2014) describes ontology as a study of ‘the nature of being and of reality’ (p8), and epistemology as the study of ‘knowledge, including the origin, nature, methods, and limitations of knowledge development’ (p5).

Epistemology has also been associated with the relationship between participant and researcher (Teddle and Takkashori, 2009). Sources agree that the way researchers approach the research they are undertaking is based upon their inner, ontological and epistemological assumptions and therefore must be acknowledged (Creswell, 2007; Guba and Lincoln, 1994). Polit and Beck (2014) assert paradigms sharpen the area of interest. However, research in nursing is dependent upon several factors, including the cooperation of the human participants, and ethical considerations, regardless of paradigm choice.

3.5.1 Recognised research paradigms

Existing theoretical paradigms that have been referred to in the literature include: positivist, post positivist, constructivist, interpretivist, pragmatic and transformative paradigms (Mackenzie and Knipe, 2006).
Positivism and postpositivism are aligned with scientific research and quantitative methods; constructivists/interpretivists seek to understand the reality of individuals (how individuals construct their own reality with varying interpretations) using qualitative methods; the pragmatic paradigm focuses on research problem and aligns with mixed methods research, and the transformative paradigm is suited to both qualitative and quantitative methods and encourages involvement of participants to minimize inequality and social injustice (Teddlie and Takkashori, 2009; Mackenzie and Knipe, 2006).

Within traditional research paradigms, qualitative research is considered to be based on constructivism, as it employs an interpretation when researching individual phenomena (Parahoo, 2014). Although the constructivist approach considers human experience and a ‘socially constructed’ reality (Mertens, 2005, p12.) the transformative paradigm goes further in addressing social injustices and inequalities within marginalised groups (Mackenzie and Knipe, 2006; Mertens, 2005). Cresswell (2003) posits that transformative researchers consider political agendas and action for reform in provoking change in the lives of the participants and the researcher. For this reason, the research was underpinned by the transformative paradigm alongside the transactional model of stress and coping, as this research considered inequalities and culturally complex issues within the field of learning disability whilst giving a marginalised population of family caregivers a voice.
3.5.2 The transformative paradigm

The transformative paradigm, adopted and changed from the previous term ‘emanicipatory’ by Mertens (2005) provides a world view emphasizing culturally complex issues and reform (Mackenzie and Knipe, 2006; Mertens, 2005). It has been historically affiliated with research within the field of learning disability, and is concerned with inclusion of people in marginalised groups, such as those with learning disabilities (McLaughlin et al, 2014a; 2014b; Mertens, 2005).

Government policies, reports and statutes have demonstrated that historically people with learning disabilities have been marginalised alongside their family caregivers (Michael, 2008; DHSSPS, 2005; DDA, 2005). The Transformative Paradigm involves participants in the methods and decisions made throughout the research process, guided by the principle of social justice. Moreover, interaction between the participant and researcher is appreciated, valuing the variety of viewpoints and explanations (Teddlie and Tashakkori, 2009). The main philosophical assumptions of the Transformative Paradigm are provided by Mertens (2007):

**Axiology (Ethical assumption):**

- **Respect** - of cultural norms of interactions across a community.
- **Beneficence** - by promoting human rights.
- **Justice** – by promoting an increase in social justice.
These central principles govern research ethics and Mertens (2007) argues the transformative paradigm drives these three assumptions in a number of ways: respect being expressed and considered through the cultural norms of a community and their interactions; beneficence is examined in relation to the advocacy of human rights and social justice; justice is delivered following the processes or outcomes of the research and the overall furthering of an agenda promoting social justice.

**Ontology (Assumption of the nature of reality):**

Describes how our version of reality is shaped by values including: political, social, cultural, ethnic, gender, age and disability. The exact influence that these values have on our realities, and how we conduct research should be explicit (Mertens, 2007).

**Epistemology (Assumption about the nature of knowledge):**

In order to recognise what is known there must be interaction between the participants and the researcher. Knowledge is viewed as culturally contextual, as it is socially and historically placed. Power issues must be addressed and cultural awareness is crucial (Mertens, 2007).
**Methodology (Assumption about methods of inquiry):**

The inclusion of qualitative methodology is important; the interactive link between researcher and participants must be included in the definition of the research focus, methods should accommodate cultural complexities; history and context should be acknowledged and issues relating to discrimination and oppression recognised (Mertens, 2007). The transformative paradigm matched the methods of this study as it allows for either quantitative or qualitative methods to be applied (Teddle and Tashakkori, 2009). Qualitative study design is discussed in further detail in section 3.8.
3.6 Application of transactional model of stress and coping and transformative paradigm to the study

Theoretical concepts steer research and link data from findings to a theoretical framework (Parahoo, 2014). McEwen and Wills (2007) have stated research underpinned by theory may enable validation of theory, or modify or disprove the theory. In this research study, to justify the choice of theory, a conceptual model was applied and integrated into the study. The theoretical underpinnings were incorporated within the research process, influencing the research question, how the literature was reviewed and interpreted, and the methods by which data was collected with the participants in this study. Such processes were cognisant of and took into account of stress encounters and influences, carer burden, and coping mechanisms in relation to unmet information needs. Furthermore, this research was concerned with giving a minority group of family caregivers a voice, and addressing inequalities which may be considered culturally complex. The underpinnings supporting these processes and strategies are discussed in more detail below.

The choices of two theoretical underpinnings were chosen as lenses through which the study was viewed and conducted. Firstly, Lazarus and Folkman’s conceptual model, the Transactional Model of Stress and Coping (1984), as it is suited to family caregiving research and is referenced in previous research in family caregiving (section 3.4).
The application of this theory in the field of healthcare is of further importance as it provides a method of assessing stressors, effects of stress, coping processes, and how these coping processes can be supported by means of resources such as information and meeting information needs (Philip et al, 2014; DH, 2008a). The Transactional Model of Stress and Coping (1984) has been applied to the study via incorporation of, and in reference to, other family caregiving research within the literature that has cited stress and coping as important factors underpinning the caregiving experience, and acknowledging how they influence caregiver burden (Totman et al, 2015; Harrop et al, 2014; Philip et al, 2014; Sherman et al, 2014; Grant et al, 2013; Hudson and Aranda, 2013).

The second underpinning is the Transformative paradigm, as a world view, as historically it has been affiliated in learning disability research and literature (Mertens, 2009; 2005). Within the Transformative paradigm sits the co-design approach (section 3.7), which has enabled inclusion of participants throughout this study. Thus, reflecting personal and public involvement. Through application of the transformative paradigm incorporating the co-design principles of experience based co-design (EBCD) in particular, family caregivers of people with learning disabilities as a marginalised group, are provided a platform whereby inclusion and self-efficacy is supported in having an active role and voice throughout the study (Carers UK, 2014a; Mertens, 2005).
In this research study, family caregivers were incorporated from the beginning, from development of the study material, which involved consultation with two family caregivers of people with learning disabilities who have required palliative care in order to give feedback on clarity, format and general readability. Both family caregivers independently concurred with the format, clarity and readability of the information sheets that had been developed for use within this study. All participants were involved throughout the co-design element of a logic model through implementation of family caregiver voice and recommendations from the data into the model. An expert reference group comprised of service users, Health and Social Care professionals and policy makers were consulted throughout the co-design process.

3.6.1 Logic model application

In keeping with the Transformative paradigm and inclusion of service user voices, the logic model presents a plan that communicates the family caregivers’ informational needs identified from the data findings, and how these needs will be addressed to incite change to stakeholders such as those who would be benefitted from this program or plan (Evaluation Support Scotland, 2017). Development involving co-design with the expert reference group ensured the consolidated voice of family caregivers was reflected in the final logic model. Logic models and co-design are discussed in more detail in chapter 5.
3.7 Research design and methodology

Qualitative research and the rationale for applying a qualitative approach will be explored in the following sections. Other distinct methodologies and designs in research will be discussed and the reasoning behind exclusion of their choice for this research.

3.8 Methodologies in research

Research design sets out the approach, methods of data collection, ethical considerations and how data were analysed (Parahoo, 2014). There are three categories within research methodology: qualitative, quantitative and mixed methodology (Leedy and Ormrod, 2010).

3.8.1 Choice of quantitative or qualitative methodology

As quantitative methodology is concerned with measurements and variables of interest, qualitative methodology was suitable for this study as the researcher was concerned with particular qualities of interest, or characteristics (Parahoo, 2014). Green and Thorogood (2009) describe the latter as being suited to complex phenomena such as perceptions, experiences and behaviours. Sources agree that a quantitative researcher may seek only to explain or predict something they can generalise to populations or places, to validate existing theories and generalisations (Leedy and Ormrod, 2010; George, 2014).
Qualitative work in contrast seeks understanding and incorporates observations (Leedy and Ormrod, 2010). Some researchers utilise mixed methods incorporating both quantitative and qualitative methodologies. The chosen methodology is dependent on the nature of the research question, timeframe, and resources that are available to the researcher (Creswell and Clark, 2011). The literature also influenced the choice of qualitative methodology, due to the plethora of studies utilizing this exploratory design in the generic family caregiving research.

### 3.8.2 Qualitative methodology

As Qualitative research is exploratory and concerned with lived experiences, phenomena and meaning, it was the suitable choice for this research. The experiences of the family caregiver participants were explored in depth, in order to ascertain what informational needs existed. Aveyard (2014) asserts this method of research appreciates an understanding of phenomena through narratives and descriptions.

The rich data gained from use of qualitative methodology offered insight that may not have been be gained from quantitative methods. Qualitative research also seeks to understand perceptions, beliefs, values and behaviours (Parahoo, 2014). This is suited for healthcare research in considering how family caregivers of people with learning disabilities who require palliative care live and behave based on their experiences. Within qualitative methods the researcher is seen as a tool, to facilitate the research (Leedy and Ormrod, 2010).
Within this research study, using qualitative methodology prescribed the researcher’s individual ability to make sense and interpret information, which was crucial to enable understanding of what was being studied. The researcher applied requisite methods of semi-structured interviews and focus groups to collect the qualitative data, with participants that were chosen purposefully based on their exposure to the phenomena being studied (Aveyard, 2014).

The researcher sought to answer the research question from a smaller purposive sample. The literature cites the importance of researcher reflexivity within qualitative research, this was employed through the suggested use of reflexive memos throughout the research process which documented the researcher’s own perceptions and beliefs, and how this may impact on the interpretation of the data they collected (Newbury, 2011; Leedy and Ormrod, 2010).

3.8.2.1 Common qualitative approaches

Common qualitative approaches or research designs include; phenomenology, discourse analysis, case studies, ethnography and grounded theory. The employment of a particular design should best answer the research question, and will best fit the study. The design chosen for this study was an exploratory qualitative design. The rationale for this choice and exclusion of others is now discussed.
**Phenomenology** – This approach involves the interpretation of the lived experience, how that person experiences particular phenomena (Parahoo, 2014).

The phenomenological approach was introduced by the philosopher Husserl (1970) and is based upon everything being subjective to perception, with understanding being derived from one’s subjective experience and consciousness. In order to understand phenomena, we must first understand the experience of the lived social reality (Green and Thorogood, 2009).

Phenomenology, looking at the lived experience of the population being studied is only applicable if participants are currently still ‘living through’ the experience; in the case of this qualitative research study, with both current and bereaved caregivers, this design was not suitable as the bereaved population were no longer in an active caregiving role.

**Discourse analysis** – Incorporates analysis of communication and narratives, what is said, how it is said, word choice, timing, and tone to determine meaning and uncover values. An example of this is conversational analysis (Parahoo, 2014). The design of this study is such where review and analysis of a conversation, observation or interaction alone would not be enough to answer the research question. Discourse analysis was therefore not an appropriate method to use in the case of this study.
Case studies – The objective of a case study approach is to explore a case or cases through various sources of information including observations, interviews and documents. It may involve one person, several, or a group. An issue is examined with a case (bounded system) or cases chosen to illustrate this (Cresswell, 2007). This research was not an in depth inquiry into a case or of multiple cases therefore this was not selected as an appropriate approach.

Ethnography – Ethnography involves collection of information and data in the natural surroundings of participants and immersion in the culture of those being studied (Green and Thorogood, 2009). This approach is reliant upon the data being collected from within the natural setting and how the setting and culture influences people and their behaviour. Ethnography posits that we can only understand human behaviour by way of observing in the setting it occurs. Rooted in cultural anthropology, researchers adopt similar rituals working alongside participants (Parahoo, 2014).

As ethnography involves immersion within the culture, surroundings and community of the participants and the researcher in this study was not living alongside participants, nor involving oneself within the local systems and culture, this approach could not be adopted.

Grounded theory – This is an inductive method of conducting research, in which new theories or hypotheses emerge that are grounded in the research data (Parahoo, 2014).
Grounded theory was introduced by Glaser and Strauss (1967), to explain hypothesis and theory generating data. The inductive process involves observations and data providing fresh explanations and theories that can be tested. Any new research has the potential to generate new theory or provide an avenue for new concepts to emerge (Parahoo, 2014).

This study does not primarily seek to generate new theory or provide explanation for a hypothesis, it instead seeks to explore in order to answer the research question, and therefore a grounded theory was not used to underpin this research. However, new theory that may be generated as a result of the study findings will be acknowledged.

3.9 Chosen research design

Based on the exploratory nature of the research aim and following the scoping review of the literature in chapter 2, of mostly qualitative studies, the most appropriate research design for this study was an exploratory, qualitative research design. This exploratory qualitative design involved semi-structured interviews with family caregivers and focus groups with Health and Social Care professionals. The qualitative data was then analysed thematically as per Braun and Clarke’s (2006) six-step framework. The exploratory qualitative design has been guided by the discussed theoretical underpinnings of Lazarus and Folkman’s (1984) Transactional Model of Stress and Coping and the Transformative Paradigm.
In order to obtain rich data and to give the participants a voice without the confines of quantitative methods, semi structured interviews and focus groups were chosen, to help focus participation with the purpose of answering the research question. It also allowed for the use of an interview and topic guide to be developed with the involvement of service users, being mindful of potential stressors and which realms of information may be important to enhancing coping mechanisms for family. Cognisance of the various holistic realms of physical, mental, emotional, spiritual and social health and wellbeing and the effects of stress upon these and how information on resources including, but not limited to financial aid and respite and psychosocial support can enhance and enable more meaningful coping processes as suggested by the stress and coping theory.

3.10 Reflexive annotation

It was important as a reflexive practitioner through this chapter to consider the researcher’s personal stance on caregiving as a concept. The researcher was mindful of how their own personal caregiving experience was influenced by stress and coping, and similarly by the need for information, to reduce stress and enhance coping mechanisms.
3.11 Summary rationale for qualitative methodology and design

An exploratory, qualitative approach using qualitative data collection methods of semi structured interviews and focus groups fostered a rich understanding of the extracted narratives, providing a more in depth understanding of the experiences, values and beliefs of the participants. The purely qualitative design cultivated detailed understanding of the information needs reported by participants, in order to directly address the research question, and in turn the research gap.
3.12 Chapter summary

The chapter has discussed the importance and relevance of underpinning theory in order to guide and steer research (Parahoo, 2014). The theoretical underpinnings of the study and narrative on the background have been discussed and the constituents of qualitative traditions. The chosen research design chosen for the study has been explained including rationale for why this was the appropriate choice to fit the research question, aims and objectives.

This research builds upon previous research in family caregiving in palliative care and learning disability, adds new knowledge to the evidence base, and provides fresh insight and improved understanding into the experience and informational needs of family caregivers who negotiate both palliative care and learning disability services. The co-designed recommendations for policy, practice and further research from this study presents areas for improvements and suggested best outcomes have been identified for this population of family caregivers.
Chapter 4 Methods, Data Collection and Analysis

4.1 Introduction

The previous chapter has discussed the exploratory qualitative research design implemented for this study and presented the rationale behind this choice. The following chapter examines in more detail the qualitative methods used for data collection in this study and how the data was analysed. Ethical issues with the study are also described and how concerns were addressed. Firstly, the research aims and objectives are outlined.

Aims and objectives

The aims of this research were to determine the informational needs of family caregivers of people with learning disabilities who require palliative care and to develop a logic model providing a visual representation of the information needs reported and how they can be best addressed.

The specific objectives were to:

1. Complete a review of the literature on family caregiving in palliative care and in learning disability in general to determine what informational needs may currently exist.

2. Explore the information needs of family caregivers of people with learning disabilities who require palliative care.
3. Establish Health and Social Care professionals’ perceptions of the information needs which exist for these family caregivers.

4. Co-design with family caregivers and Health and Social Care professionals a logic model, which visually represents the information needs reported and how they can be addressed.

5. Generate recommendations from both family caregivers and Health and Social Care professionals to inform education and policy, further research and service development in this practice area.

4.2 Ethical considerations

When considering ethics in research, approaches to conduct should adhere to ethical principles. The four principles of Beauchamp and Childress (2001) were adhered to when carrying out this research:

**Autonomy** – the right for a person make their own informed choices.

**Beneficence** – acting with the best interests of the person.

**Non-maleficence** – to do no harm.

**Justice** – ensures equality and fairness for all.

Participants' autonomy was assured though written informed consent. Participants were also made aware of how they would benefit from participation. The research gained approval from Research Ethics Committees, safeguarding participants from harm. Lastly, all participants were treated equally throughout the research process.
The study has been fully approved by the Office of Research Ethics Committee Northern Ireland in July 2016 (ORECNI, Reference 16/NI/0111), and Research Governance for the relevant Health and Social Care Trusts (IRAS 19778). Governance committee permissions were also granted from the Northern Ireland Health and Social Care Board, the Northern Ireland Hospice, and Marie Curie. Each site was designated an approved local collaborator or principle investigator. Favourable ethical approval was given for a substantial amendment in March 2017 for circulation of study information to the Health and Social Care Trusts and advocacy groups social media sites.

4.2.1 Consent

The researcher, and the research supervisory team at Queen’s University’s School of Nursing and Midwifery were certified in Good Clinical Practice (GCP) in accordance with National Institute for Health Research (NIHR) (2017) guidelines. GCP certification ensured that researchers were qualified and competent to carry out research activities with adequate and appropriate training, education and experience (NIHR, 2017). All participants were provided with verbal and written information on the study, carried out by the primary researcher and achieved through the following means: Information sessions at team meetings with Health and Social Care professionals, participant information sheets, opportunities for potential participants to contact the research team via email or telephone. Written informed consent was obtained before interviews and focus groups proceeded.
Consent was continuous and the participant was reminded they were free to withdraw at any stage. If potential participants did not fully understand what the study entailed there was opportunity for them to ask further questions and speak directly to the research team, to provide clarity and understanding. There was no requirement for an interpreter or an appropriate person, as no participants had additional communication needs.

4.2.2 Confidentiality and anonymity

Confidentiality was maintained in keeping with the Data Protection Act (1998) and Good Clinical Practice (GCP) guidelines (NIHR, 2017). With participants’ permission interviews were audio recorded with a digital voice recorder. This data was only accessible to the research team. All recorded interview information was written down word for word by the primary researcher in the School of Nursing and Midwifery at Queen’s University, Belfast. Hard copies of this information were stored in a locked filing cabinet to which only the research team had access. Electronic copies of the information were also stored on a secure computer that was password protected.

Names were removed from the transcripts and each participant was designated a unique code. Names, addresses and contact details with the allocated code were stored in a separate locked filing cabinet in a locked room within the university, only accessible by the research team. Direct quotations were used to illustrate themes, but these were anonymised and no names were linked to these quotations.
Steps were also being taken to remove information related to specific roles, as this may identify a particular individual. All information was stored legally as set out in the Data Protection Act (1998). All data will be kept for five years and destroyed after that period by the research team, in accordance with University regulations.

### 4.2.3 Disclosure protocol

In such circumstances during data collection where there was disclosure of any illegal activities, or activities which may have caused risk to self or others, this would have necessitated breach of confidentiality, for the safety of the participant and of others. The supervisory team would have been made aware of the situation and the information passed on to the relevant authorities, for example, the Northern Ireland Social Care Council (NISCC), the Nursing and Midwifery Council (NMC) or the Police Service of Northern Ireland (PSNI). This information was provided to participants through the information sheet in the section ‘Will my taking part in the study be confidential?’ (Appendix 9) and reiterated in the consent form (Appendix 11). There were no disclosures of illegal activities, or activities that would have caused harm during this research.
4.2.4 Benefits of participation

For family caregivers it may have been very important that they were part of a study that will help family caregivers of people with learning disabilities who require palliative care. As a result of this study, information will be available as to how family caregivers of people with learning disabilities can be best supported in their role and what information they feel would be most helpful. It will help improve and inform Health and Social Care services in providing the correct information and support these family caregivers. Participants can ask to see the results of the study and what we recommend following study completion, by contacting the researcher via email or telephone.

Health and Social Care participants may have found it beneficial to be part of a research project which was aiming to improve services and enhance collaboration between family caregivers and services. A summary of findings and recommendations to inform education, policy, practice and further research can be requested by any participant once the study is complete. Involvement in research related activities may also be used as professional development hours and count towards a Continued Professional Development (CPD) portfolio.

4.2.5 Distress

It was recognised that there was potential for participants to become upset during the interviews due to the sensitive nature of discussions associated with palliative and end of life care. In this instance the researcher would offer to suspend or terminate the interview.
All participants of the study were provided with a support pack (Appendices 16-17) containing contact details for further information, telephone advice lines and names and numbers of professional organisations should they wish to contact someone following the interview. It was noted that researcher distress may develop following discussion around the sensitive subjects of palliative and end of life care, in this event the researcher would notify the supervisory research team and discuss. If required the researcher could also avail of Queen's University counselling services.

4.2.6 Lone worker protocol

When conducting face to face interviews in participants’ own homes a Lone Worker protocol was adhered to with the primary researcher carrying a mobile telephone on their person for each interview in case of emergency. An agreed timeline for contact was established with the research supervisory team. There were no issues with lone working in this study.

4.3 Data collection methods

In principle, it is of pertinence in research that data collection methods are the most appropriate for the design of the research. The aims and objectives and the research questions must be answerable by the method chosen. Time frame and availability of resources must also be considered.
Furthermore, the data collection methods needed to be appropriate to the sensitive nature of palliative and end of life care. Ethical considerations were applied in relation to the sensitivity required to explore these study objectives and this in turn influenced the methods chosen. The review of the literature presented in chapter 2, on family caregiving in learning disability and palliative care, revealed that most studies were qualitative in nature, or at least involved a qualitative aspect within a mixed methods study.

The two most popular methods of data collection in exploratory inquiry were semi structured interviews and focus groups. Furthermore, methods were also akin to the applied philosophies of the underpinning theories of stress and coping and the Transformative paradigm. The methods chosen for this study and how they were influenced by theory are further described in the following sections.

4.3.1 Semi-structured interviews

Sources concur that semi-structured interviews provide a structured framework, however they retain an element of flexibility. For example, interview guide domains can be focused on the phenomena being studied (Holloway and Wheeler, 2010). However, open questions with prompts allow the researcher an element of flexibility (Parahoo, 2014). The interview is structured with pre-determined questions and key domains however the questions themselves are open ended, allowing potential for exploring meanings (Parahoo, 2014).
The domains were influenced by the Transactional theory of stress and coping (Lazarus and Folkman, 1984), considering particular stress variables and how they impacted upon the holistic realms of a caregiver's health and wellbeing, whilst factoring in the role of information in delivery of support and to identify particular information needs.

In this study, semi-structured interviews were conducted face to face with family caregivers, this enabled the researcher to consider any contextual factors that were present at the time of interview, and enabled the opportunity for founding trust and rapport between the researcher and the participant. Trust and rapport can be important benefactors and prerequisites to an open, data rich interview (Råheim et al, 2016). This in turn is essential to fostering a therapeutic relationship and provision of a platform for participants from minority groups to have their say, in particular about complex issues.

The use of semi-structured interviews has its limitations as well as advantages. Despite the method being a flexible means of data collection, allowing prompting and further exploration of what is being discussed, there are the issues of objectivity and time constraints when transcribing and analysing interview data. Leedy and Ormrod (2010) propose the researcher is a tool in qualitative research and by making sense of and interpreting the data they enable facilitation of the research.
Parahoo (2014) suggests that objectivity can be addressed by researcher reflexivity, as previously described, this is the process whereby the beliefs, values and perceptions of the researcher are acknowledged, and how they may influence the interpretation of results (Newbury, 2011). Reflexivity was employed in this study through use of reflexive memos, written within a journal following each interview and focus group, documenting thoughts and feelings that were present at the time of each particular data collection session. As recommended by Holloway and Wheeler (2010), fellow members of the research team also examined the data to compare themes, which ensured inter coder reliability and increased trustworthiness of the research findings.

Each member of the research team independently analysed a portion of the interview and focus group transcripts, in order that there was consensus with interpretation of data, and accuracy. Holloway and Wheeler (2010) argue that time is something that cannot be compromised on when analysing rich data transcripts and so this was factored into the research time-frame. The method of semi-structured interviews was used with both active and bereaved family caregivers in the study. In keeping with the research question this was considered an appropriate method of exploring the sensitive issues surrounding palliative care in this context.
4.3.2 Focus groups

Focus groups were chosen as a research method to obtain data from the Health and Social Care professionals in this study. Focus groups are a group interview consisting of people who have similar characteristics or experiences and it is also appropriate technique in qualitative research for data collection (Parahoo, 2014; Krueger and Casey, 2009).

Group conversations and discussion allowed for thoughts and perceptions to be identified and explored and this in turn can generate ideas in relation to the questions being discussed (Parahoo, 2014). Holloway and Wheeler (2010) suggest that there can be between four and twelve people within a focus group, however they acknowledge that data generated from focus groups is reliant upon group dynamics. It was important to consider that interaction needed to be facilitated and moderated by the researcher.

In respect to confidentiality complete anonymity in a focus group could not be guaranteed due to the nature of group discussion, however, participants were reminded of the importance of keeping discussion within the focus group confidential. It was envisaged that the synergy of discussion within the focus groups would generate rich data relevant to the aims and objectives of the study and the information needs of family caregivers of people with learning disabilities who require palliative care.
Focus groups were chosen as the method for data collection from Health and Social Care professionals across both the learning disability and palliative care fields, as a method that allowed for a meeting of minds of those who shared an experience that they could discuss with others who were similar. Focus groups provided a suggested space for debate and idea generation through discussion of thoughts, beliefs and perceptions surrounding the subject being explored by the researcher (Holloway and wheeler, 2010).

4.4 Sampling

Participants were purposefully sampled from across three Health and Social Care Trusts and two Hospices within Northern Ireland. Purposive sampling selected participants with experience of the phenomena being studied, to ensure that the research questions could be answered (Ritchie et al, 2003). The rationale for this choice of purposive sampling was to ensure that those with the relevant experience and who met the inclusion and exclusion criteria were included. This warranted the collection of data relevant to the study aim and objectives, which would in turn answer the research question.

Health and Social Care professionals

Six focus groups comprising of a total purposive sample of n=28 Health and Social Care professionals were convened. Each focus group was comprised of four to six multidisciplinary Health and Social Care professionals from both the learning disability and palliative care sectors which ensured a recommended blend of disciplines (Krueger and Casey, 2009).
The sample was also within the recommended parameters for numbers for focus groups, based on the literature (Holloway and Wheeler, 2010; Kruger and Casey, 2009).

Inclusion criteria for Health and Social Care professionals were that they:

- Were a registered professional currently working within a specialist learning disability or palliative care service.
- Had been involved in the provision of palliative care to adults with learning disabilities and their family caregivers.
- Had provided written informed consent.

**Family caregivers**

A purposive sample of family caregivers, who were or had been involved with a family member with a learning disability who required palliative care, were recruited to participate in individual semi-structured interviews. Individual interviews rather than focus groups provided a sensitive method to collect data with family caregivers who had cared for, or were currently caring for someone with a learning disability who required palliative care. Baker and Edwards (2012) suggest n=12 interviews is practical for time constraints whilst Green and Thorogood (2009) emphasise that most qualitative studies reach data saturation after n=20 interviews. Whilst anticipating this, interviews were forecast to continue until data saturation occurred with no new themes emerging.
Inclusion Criteria for family caregivers were that they:

- Had been or were actively involved with an adult family member with a learning disability who has required palliative care.
- Were 18 years old or over.
- Had provided written informed consent.

Exclusion criteria for family caregivers were that they:

- Had experienced a recent bereavement (within the past 3 months). Three months exclusion is supported by recent literature (Bentley and O’Connor, 2014; Koffman et al, 2011; Beck and Konnert, 2007).
- Were under 18 years of age.

4.5 Recruitment

Recruitment of participants took place concurrently across all five Health and Social Care Trusts and two Hospices in Northern Ireland.

4.5.1 Health and Social Care professionals

Following permission from the Service Leads responsible for each of the learning disability and palliative care services in the Health and Social Care Trusts and Hospices (Appendix 1) the researcher visited each community learning disability and specialist palliative care service within the five Health and Social Care Trusts and in-patient and community services attached to the two Hospices.
Visits provided opportunity for the researcher to inform professionals about the study, answer any questions and distribute information packs (Appendices 4-7) containing a covering letter, participant information sheets, stamped addressed envelopes and a reply slip requesting their contact details.

Recruitment was carried out via interested Health and Social Care professionals, who met the inclusion criteria, either returning the completed reply slip or via email or telephone call, indicating that they had read and understood the information about the study, and were willing to participate in a focus group or an expression of interest via email or telephone call. The researcher then contacted participants who responded and arranged the focus group that they would be attending for a suitable time and place.

4.5.2 Family caregivers

As the evidence from the literature has demonstrated, palliative care referrals for people with learning disabilities have historically been minimal, with diagnostic overshadowing potentially causing delays to diagnosis of illnesses that require palliative care (McLaughlin et al, 2014a; 2014b; Heslop et al, 2013; DH, 2006; Reiss et al, 1982). Therefore, this population of family caregivers who were known to services were potentially very small, with the very real situation that many were not known to services, provoked cross province recruitment for one to one interviews.
Family caregivers were recruited to semi-structured interviews through five Health and Social Care services Trusts and two Hospices, who were asked to circulate information about the study (Appendices 2-3), to people known to their service who met the criteria, asking them to contact the researcher if they wished to take part. Services were asked to forward the letter (Appendix 3) to family caregivers who were or had been known to their service. This letter informed family caregivers that the study was happening and provided the researcher’s details so that they could contact the researcher for further information if they wished to take part.

The advocacy groups Mencap and the Bamford Monitoring Group were also asked to circulate initial participant letters and information to family caregivers known to them who met the inclusion criteria for the study, asking them to contact the researcher, if they wished to take part. The researcher forwarded each interested family caregiver who responded an information pack (Appendices 8-11) with a covering letter, participant information sheet, stamped addressed envelope and a reply slip requesting contact details.

Recruitment was carried out via participants either returning the completed reply slip or contacting the researcher via email or telephone call, indicating that they had read and understood the information about the study, met the inclusion criteria and were willing to take part in an interview. The researcher then contacted the family caregivers to answer any queries about the study and to arrange the interview for a suitable date, time and place.
4.6 Data collection

Data collection for all participants commenced in October 2016, and was completed in April 2017. Data collection for each layer of participants was concurrent.

4.6.1 Health and Social Care professionals

Focus groups for Health and Social Care participants were chosen based on the qualitative design of the study, the nature of the research aim and objectives, and the wide geographical region that the study was being conducted across. Practically, focus groups provided better logistical means of collecting the data from Health and Social Care professionals from across the province of Northern Ireland. Health and Social Care professionals’ focus groups were held in private, accessible environments within premises of Health and Social Care Trusts or local Hospices. They were convened at a suitable time and place for all attendees for each group. Health and Social Care professionals’ participation was voluntary.

The researcher facilitated the focus groups and prior to the focus groups commencing answered any questions about the study which participants had. Each participant was also asked to sign a consent form prior to the focus group commencing and complete their anonymous participant demographic form (Appendix 15). A focus group topic guide informed by the literature was used (Appendix 13). The focus groups lasted between 55-85 minutes (with an average of 65 minutes) and were audio recorded with participants’ permission with the use of a digital recorder.
4.6.2 Family caregivers

Semi-structured interviews provided a sensitive means for data collection in this study. A semi-structured interview guide (Appendix 12) was used for each one to one interview. The guide was informed by the literature and adapted based upon an interview guide used in a previous study with a small sample of family caregivers of people with learning disabilities who required end of life care (McLaughlin et al, 2014b). The choice of semi-structured interviews provided opportunity for the family caregivers to have their voice heard in a more meaningful way, exploring the role and influence of the stresses of the caregiver role, carer burden, and the influence information and resources have on a caregiver's ability to cope in their role.

To simply limit data collection to quantitative confines through use of a questionnaire or survey would not have provided sufficient means to fully involve participants. Through use of this data collection method there was cognisance of the theoretical underpinnings of the 1984 stress and coping theory by Lazarus and Folkman, involving participants in a method that aligns also with the Transformative paradigm. The guide was adapted to integrate the holistic realms of information need uncovered from the literature, which, with some added questions and prompts sought to better answer the research question of this study.
Embedded within the questions were prompts to explore events which may lead to favourable or unfavourable outcomes for the family caregivers, which were dependent upon the previously discussed stress and coping variables and how resources would enhance coping. The guide explored the areas of information as a resource to enhance coping in relation to education, practical support, financial support, psychological support, social support, decision making and collaborative practice between the learning disability and palliative care services.

The first two interviews with family caregivers who met the inclusion criteria for the study were used as a pilot test. This equalised the position of the participants and their involvement in the study as per the Transformative paradigm. Following the pilot test there was no reasoning to modify any further, therefore the data from both interviews was included in the study. Interviews lasted between 60-140 minutes and with participants’ permission were audio recorded with the use of a digital recorder. Participation was voluntary and each family caregiver was asked for written informed consent and to fill in an anonymous demographic form (Appendix 14) prior to the interviews commencing. Interviews took place in the participants’ own homes, and in one case, in a private room on the university campus at the participant’s request.
Following initial issues with recruitment, due to low numbers of potential family caregivers known to Health and Social Care services who met the inclusion criteria, a substantial amendment was granted through the Office for Research Ethics Committee Northern Ireland (ORECNI) and through the subsequent research and development offices for each Health and Social Care Trust, in order that a recruitment post could be circulated through each Trust’s social media sites and the Mencap social media site. This was to ensure further potential candidates across Northern Ireland could be reached, such as those not known to services or those who had been bereaved a number of years.

No further family caregivers were recruited through these posts, however, following interview number 10 a level of data saturation was apparent, where no further new information was emerging. Consistent themes were emerging from the data, with no new data outside of this. Interview transcripts were producing the same themes and data was sufficient to meet and answer the research aim question (Walker, 2012).
4.7 Data analysis

Demographic data was collected from all participants and this data was analysed using frequencies to present the characteristics of each of the family caregivers, and Health and Social Care professionals. Qualitative data generated from the face to face interviews and focus group transcripts were subjected to thematic analysis using the six-step framework advocated by Braun and Clarke (2006). The Braun and Clarke (2006) framework is one of the most widely used frameworks for thematic analysis in the last decade, it has been used successfully in previous studies to analyse qualitative data and it provides a more pragmatic framework to guide the researcher through use of comprehensive guidelines. Interpretation of the data from the transcripts and initial coding was driven in part by awareness of the theory of stress and coping and how family caregivers identified information needs in respect to enhancing how they would cope in their role delivering care.

Through awareness of this theory the researcher could link and interpret identified information needs to how they enhanced variables in how family caregivers appraised stressors, how particular information needs related to adaption of coping processes, and how deriving meaning from the caregiving role enabled more sustainable coping mechanisms. Data from interviews and focus groups were transcribed verbatim by the primary researcher and analysed using this recognised framework to generate themes for thematic analysis.

Stage 1: Following each interview with a family caregiver and focus group with Health and Social Care professionals, the researcher compiled an initial memo of thoughts and notes on the interview or group. These memos served as reflective pieces related to a particular group or interview, and acknowledged any issues including how the researcher felt, and how the scenario went in general. The transcript was then played through twice before transcription verbatim of the recordings word for word. Recordings were checked again for accuracy against the transcript and the researcher read through the transcript several times to become familiar with the data.

Stage 2: All transcriptions were then uploaded onto the data management system NVIVO, as well as being printed on hard copy. The transcripts were re-read once again and then initial codes were created for sections of each transcript to conceptualise the data content and its meaning. This was completed for each separate interview and each separate focus group. The other members of the research team took a proportion of the anonymised transcripts and independently analysed to ensure inter rater reliability, to improve rigour and determine consensus over codes.
Stage 3: Any codes which could be unified under a broader category and theme or a code which encompassed more than one other were combined. Data was further analysed to check whether the designated codes/categories adequately reflected the data, and whether the annotations were adequately displaying the theme. Themes were also inter-rater checked by members of the research team, again to determine consensus and improve rigour.

Stage 4: Codes, categories and themes were reviewed again for relevance, or whether they could be amalgamated or discarded.

Stage 5: Themes were finalised for discussion, with designated titles and extracts that best displayed the theme.

Stage 6: The organised data was put onto paper, with each theme displayed and discussed with the research supervisory team members, with associated categories of data, in relation to reporting the qualitative findings.
4.8 Expert reference group

The co-design within this research incorporated liaisons and consultations with an expert reference group, ensuring service user involvement through the Transformative paradigm lens through which the study was underpinned by. The researcher invited potential members who had experience of learning disability or palliative care in a professional or commissioning capacity, or as a service user. Those who were invited were provided with Terms of Reference (Appendix18) which explained what would be involved. Invited members made a voluntary decision whether to participate in the group.

The group was composed of a learning disability social care commissioner for Northern Ireland, an expert carer of someone with a learning disability, a palliative care specialist lead nurse, a learning disability lead, academic research professionals in palliative care and learning disability, and a member from the Bamford monitoring advocacy group (n=7).

4.8.1 Preliminary co-design of logic model

Underpinned by the Transformative paradigm the study integrated the fundamentals of co-design through involving service users, professionals and policy makers from the expert reference group in development of the logic model, ensuring public and personal involvement. This is described in more detail in the following results chapter. Co-design involves partnerships and is seen as transformative in a variety of ways (Donetto et al, 2014).
Bate and Robert (2007) initially described experience based design (EBD), to reform healthcare by involving carers and professionals in respect to improving healthcare services. The NHS (2009) later prescribed experience based co-design (EBCD) in relation to involving service users in Health and Social Care research projects. Co-designed projects such as this then reflect the needs of service users/patients/carers and how Health and Social Care services can best respond to these needs (Donetto et al, 2014).

4.9 Rigor and validity

Qualitative research is considered less objective and more subjective than quantitative research, which can be a positive aspect when it comes to interpreting data from interviews and focus groups, and factors in observations, feelings and context (Parahoo, 2014). There are recognised protocols such as the adoption of reflexivity in which a qualitative researcher can employ rigor. In quantitative research validity and reliability of the results are based on measurement, internal validity and external validity, reliability, objectivity and generalizability (Holloway and Wheeler, 2010). However, qualitative research such as this study relies on trustworthiness via credibility, confirmability, dependability and transferability (Holloway and Wheeler, 2010). Guba (1981) introduced these qualitative naturalistic equivalents to the scientific quantitative terms: credibility being the qualitative commensurate to internal validity; transferability instead of generalizability or external validity; confirmability rather than objectivity; and dependability in the place of reliability.
In quantitative research, validity is commonly used for assessing quality. Nachmias and Nachmias (2008) argue in order for validity there must be evidence that an instrument of measurement does what is supposed to do. However, as the researcher is seen as the tool in qualitative research, Guba (1981) suggests the alternative requirement for credibility may be achieved by the researcher presenting as best possible a full picture of what is being studied and transparency of the processes implemented to do this, for example audit trail, employment of reflexivity and triangulation or peer review. Transferability in qualitative research ensures there is enough information and detail to make a decision as to whether the findings are applicable to other settings (Shenton, 2004).

Shenton (2004) argues dependability infers if the study was repeated using the same methods, the results be similar, which supports the importance of maintaining an audit trail and transparent reporting of methods. Confirmability involves researchers being cognisant of their own beliefs and perceptions and how these may influence interpretation of the data (Shenton, 2004). Guba (1981) suggests the practice of reflexivity to remedy this alongside triangulation with full description and peer review or member checking. All of the above enable improved rigour of conduct and study methods, and trustworthiness of findings.
Rigour was ensured in this study through 1) An audit trail in terms of field notes made during and after interviews and focus groups, 2) Researcher reflexivity in relation to management of own preconceptions and beliefs. To enable this the researcher completed reflective memos following each interview and focus group and wrote into a reflective diary in some instances when more elaboration was required, and discussed issues with the research team when necessary, and 3) Independent analysis of a portion of transcripts from the interviews and focus groups by the researcher and her supervisory team, to ensure inter-rater reliability and accuracy of data interpretation.

4.9.1 Audit trail

Transparency through providing detailed information such as a well explained audit trail provides information on the research process and steps of analysis, so that is clear to the reader (Parahoo, 2014). Explicitness with respect to sampling, a systematic approach to data analysis and full explanations are provided to show competence (Parahoo, 2014; Holloway and Wheeler, 2010).
4.9.2 Reflexivity

Researcher reflexivity has been argued to increase credibility when analysing data by demonstrating a less biased, more objective analysis (Newbury, 2011). Researcher reflexivity is employed through mindfulness of own perceptions and beliefs, and how this may impact on the interpretation of the data that has been collected (Leedy and Ormrod, 2010).

4.9.2.1 Reflexive annotation

During data collection the researcher completed reflexive memos following each interview and focus group, and continued to document thoughts and feelings further in a reflexive diary in instances where an interview was particularly difficult or upsetting. A benefit of this was through sharing some initial information with participants, as to the researcher’s personal experience as a carer of a sibling with Down Syndrome, and being recently bereaved; this enabled trust to be established and a rapport based on commonalities.

4.9.3 Peer review

Peer review by the more experienced research supervisory team involved independent analysis of proportions of the transcripts (five interview transcripts and three focus group transcripts). Iterative feedback on all elements of this research was consistent throughout the study from the research supervisory team.
4.9.4 Member checks

Member checks improve rigour and trustworthiness of qualitative data analysis (Leedy and Ormrod, 2010). Member checking occurred through involvement of the expert reference group, where members included service users independent from the research and two Health and Social Care professionals that were involved in focus groups, who were asked to feedback regarding the logic model and co-designed recommendations, and if they were a close reflection of the collective voice of participants in this study. The expert reference group was consulted on the study findings and translation into the logic model only, each member was provided a synopsis of the findings.

The two Health and Social Care professionals were involved in the group as there was a small pool of professionals to recruit from for this study. These Health and Social Care staff proved integral to the logic model development and how it would be accepted amongst Health and Social Care services. They did not however have involvement on how the study was to be conducted and were therefore independent in this role. The potential for conflict of interest was checked and considered ethically sound from a Research and Development perspective.
4.10 Chapter summary

This chapter discussed the data collection methods used within this exploratory qualitative study, using semi-structured interviews and focus groups. Ethical considerations were outlined, and how ethical issues were acknowledged and addressed. The chapter concluded with consultation around rigour and how this was established and upheld. The following chapter will provide an outline and discussion of study findings.
Chapter 5 Findings of the Study

5.1 Introduction

The previous chapter outlined the data collection and data analysis methods utilised within this study. This chapter presents findings from the interviews with family caregivers of people with learning disabilities and focus groups with Health and Social Care professionals. Following on from this, the final section of the chapter provides an overview of the logic model that has been developed and co-designed with the expert reference group. This logic model is informed by the findings of the study, centred on the information needs identified for family caregivers of people with learning disabilities who require palliative care, and how they can be best addressed.

5.2 Data collection with family caregivers and Health and Social Care professionals

Data collection for the study involved semi structured interviews with family caregivers of people with learning disabilities who required palliative care (n=10), and six focus groups comprised of multidisciplinary Health and Social Care professionals (n=28) from both the community learning disability and specialist palliative care teams/ hospices across Northern Ireland. The data from these sources are now presented.
5.2.1 Semi-structured interviews with family caregivers

Ten family caregivers of people with learning disabilities who had required palliative care, and who met the inclusion criteria (outlined in Appendix 9), took part in face to face interviews. These included family caregivers who were actively providing care (n=3) and those who were bereaved (n=7). There were no withdrawals. Table 5.1 presents a socio-demographic profile of those who took part.

Retrospective information about close persons with learning disabilities who required palliative care:

70% has passed away (bereaved family caregivers) prior to the study.
70% had a learning disability of Down Syndrome, 30% had a neurological condition.

Age at the time of caregivers’ study participation (or age at death):
30% were 18-25 years old, 10% were 26-40 years old, and 60% were 41-65 years old.

In relation to condition: 50% had a diagnosis of Cancer, 30% were diagnosed with life-limiting, progressive neurological conditions, and 20% had a diagnosis of Dementia.
Table 5.1 Demography of family caregivers

<table>
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<tr>
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<th>n=10</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<td>Male</td>
<td>2</td>
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<tr>
<td>Female</td>
<td>8</td>
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<td><strong>Age</strong></td>
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<td>40-49 years</td>
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<td>50-59 years</td>
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<td>60-69 years</td>
<td>5</td>
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<tr>
<td>70+ years</td>
<td>1</td>
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<tr>
<td><strong>Years caregiving</strong></td>
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<tr>
<td>10-14 years</td>
<td>2</td>
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<tr>
<td>15-19 years</td>
<td>1</td>
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<tr>
<td>20+ years</td>
<td>7</td>
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<tr>
<td><strong>Relationship of caregiver to person</strong></td>
<td></td>
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<tr>
<td>Parent</td>
<td>4</td>
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<tr>
<td>Sibling</td>
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5.2.1.1 Categories and themes from semi structured interviews

Thematic analysis of the family caregiver transcripts generated four main themes which are presented in Figure 5.1. Each main theme comprised of categories that were unveiled from the data. Themes incorporated and addressed support needs and issues reported from the transcripts. The four themes developed were:

- ‘Changing and diverse nature of information needs’
- ‘Consistent communication and joint working’
- ‘Navigating care across settings’
- ‘Evolution and components of the caring role’

Information needs reported in this study varied and were dependent on the stage of the disease progression. Information needs also changed over time were influenced by communication and joint working of professionals across primary care, palliative care, and learning disability services. How care was coordinated across settings also influenced which information needs were present for each family caregiver, with existing systemic problems giving rise to particular issues with information provision. The determination of information needs was also shaped by how each family caregiver perceived their identity, role, responsibility and competence.
Figure 5.1 Themes and categories from interviews with family caregivers

Categories:
Various information needs;
Information needs changing over time;
Information needs influencing carer burden;
Impact of diagnosis, death and dying.

Categories:
Respecting wishes and best interests;
Proactive advocacy role;
Increased responsibility and upskilling;
Identity as a carer.

Categories:
Communication facilitating service provision;
Breaking bad news appropriately;
Shared learning and awareness.

Categories:
Transition between child and adult services;
Early recognition of palliative care need;
Service provider’s responsibility in meeting information needs of family caregivers;
Importance of familiar staff;
Training needs for service provision of information.

Theme 1: Changing and diverse nature of information needs
Theme 2: Consistent communication and joint working
Theme 3: Navigating care across settings
Theme 4: Evolution and components of the caring role
5.2.1.2 Changing and diverse nature of information needs

This theme represents the variation of information needs reported and acknowledges the dynamic nature of information need over a trajectory of time. Unmet information needs can be influenced by the associated burden experienced when coping with a caring role, and in the case of palliative care, the impact of death and dying on the family caregiver. This theme was comprised of four categories: ‘Various information needs’, ‘Information needs changing over time’, ‘Information needs influencing carer burden’ and ‘Impact of diagnosis, death and dying.’

Various information needs

This category took account of the varying information needs reported by each family caregiver including information needs relating to education on the disease or illness, finances, practical support such as training and equipment, respite and psychosocial support. The presence of varied and unmet information needs was generally cited from all family caregivers:

‘I’ve had no support at all. Nothing… We’ve just had to get on with it… I wouldn’t know what’s available.’ (P5)
Caregivers perceived that unless they actively asked for information, it often was not offered, resulting in unmet information needs:

‘...some people want to know and some don’t, I think if you’re saying, look anything you want to know? I don’t think anyone ever sort of said, that you know? (P4)

‘People will not come to you with advice… you’ll not always know who to ask for… or you know social workers are told, don’t tell anybody anything, don’t tell them they can get this…’ (P10)

Information around financial entitlements such as government funded benefits, allowances, grants or financial aid, was a frequently cited need identified by family caregivers:

‘I knew nothing, I didn’t know anything I was entitled to… this girl that lived in our street… stopped in the street and said to me, are you getting carers allowance? I’d never heard of it before in my life...’ (P6)

There was the larger issue of government funding and general awareness of what caregivers should be entitled to:
‘There’s nowhere to turn to, even if you work there’s no funds that would help you with things… I was told to ask for an emergency payment…they gave me the wrong information… I mean all over Christmas it was as well we were in hospice because there was nothing here.’ (P10)

In the case where there was financial relief, this was down to the good communication of Health and Social Care professionals:

‘Though the social worker, who I really have to praise… she was able to get us financial help from the independent living fund…’ (P7)

Family caregivers further reported needs in relation to educational information on the illness and what it would entail and the need for sensitive communication from Health and Social Care professionals, particularly around death and dying:

‘…or say, look now, this could be cancer but he has to go on this medication, and it may keep him awake, and it might do this and it might do that. I don’t remember being told that at all… he just started getting medication.’ (P1)
Information need around medication management was reported and how it should be delivered:

‘the medication… get them to write out exactly how you’re to deliver it, written out… because sometimes… I wouldn’t exactly hear what I was to do.’ (P1)

The importance of adequate practical information was highlighted, without practical information some family caregivers were left with nursing care problems:

‘He sat for so long, if somebody had said to me look, to avoid what’s called a bedsore… I didn’t know to do that...’ (P1)

Family carer training needs, and the importance of information around equipment use were raised:

‘I was given the suction machine, with no training, not showed how to switch it on, not shown how to use it, nothing. I was given an oxygen bottle, no training... I wasn’t even given any manual handling training.’ (P5)
Family caregivers considered the importance of respite and psychosocial support, and correspondingly, information and signposting to these supports:

‘we got a bit of respite… they were able to do that… once he went in through the respite route into ********, the respite door closed, because government didn’t agree with some protocol…’ (P3)

‘I couldn’t depend on anyone because my brother would have said he would have turned up, he didn’t.’ (P9)

Some participants reflected on the most important piece of information they received:

‘I said how are we going to know what time he has left? I forget who it was but she said, “I’m going to tell you this… whenever you see monthly, you have months left, if you see changes weekly you have weeks left, and if you see changes daily you’ve days left.” And I thought that was the most wonderful piece of information to have, because it happened, that’s how it happened.’ (P3)
‘…when he first got the diagnosis and we went to that training course [on Dementia and Learning Disability]... it just prepared us so much and let us understand what he was going through and why.’ (P7)

Recommendations were proposed by some participants as to how information needs could be addressed and conjecture was that there needed to be a central person that linked in or coordinated:

‘…to try and get information out to everyone is a very difficult job… it would make more sense to have that one co-ordinated person…’ (P2)

‘…a link professional, a coordinator that gets to know the person… or a team lead or a group of professionals… I think a good team that has good continuity… like, would you rather maybe me come with a person and explain palliative care to you?’ (P10)

One to one and face to face were suggested as to how information could be best delivered; given the isolating and burdensome nature of caregiving, the sensitivity of palliative care, and the need for continuity when working with people with learning disabilities:
‘face to face, every time, because you’re in such a threadbare place at the time, and you don’t know that and all these other things are so impersonal…” (P3)

‘Somebody needs to sit down with people and tell what exactly it is they’re entitled to…” (p6)

Furthermore, there was acknowledgement that a lot of family caregivers of people with learning disabilities who require palliative care will be older, as they are often elderly parents, who have provided care for a long time. It was highlighted that certain modes of informational delivery may not work for elderly caregivers:

‘One to one... at the end of the day the biggest majority of carers is older people... people don’t know how to pick up emails you know?’ (P9)

**Information needs changing over time**

This category represents the dynamic nature of information need and how this can vary over a period, for example earlier in the disease trajectory the information need may be related to education on the illness, whereas as time goes on the need may change to information on practical and financial support followed by information on social and psychological support towards the end of life.
Reassessment of need over time is essential, in order that adequate provisions can be implemented, or existing supports adapted:

‘...benefits started changing... I would ask questions... still learning now even...’ (P1)

When family caregivers anticipated the bereavement phase they acknowledged a loss of role and how this would impact upon them:

‘Because of my age I’ll probably be unemployable, I’ll lose my house, I’ll lose my car... I wouldn’t even know where to start… it’ll all be gone... I know it happens within days, you’re lucky to get time to breathe. You lose everything.’ (P6)

Moving into the bereavement phase orientation shifted more towards emotional, psychological and spiritual support which prior to death was overshadowed by the more practical information needs around education on the disease, finances and practical support:
'…we help in church… we were working towards retirement… and X was so tied into what we were going to do… but this is two years later, we’re finding our way now… for the first year, maybe more… we were sort of drifting…we were just trying to cope with the missing [the brother].’ (P1)

**Information needs influencing carer burden**

This category reflects how the concept of carer burden is influenced by information provision and unmet support needs. Lack of information has the potential to influence carer burden negatively, by compounding it. Family caregivers reflect on how lack of information on respite or financial assistance added to the burden associated with caregiving:

‘we would never take a holiday... because we didn’t ever want to leave him... I used to say we have the money but we don’t have the time and I know when we have the time we’re not going to have the money.’ (P8)

Family caregivers were unable to ask for certain information due to the nature of the illness, its trajectory, and how this was consuming:
‘…but then when you’re in the middle of somebody who has an illness, and they’re going down rapidly, you’re dealing with every moment very quickly … so I wasn’t thinking up questions at the time.’ (P1)

The absence of information on respite support appeared to have a negative influence on carer burden:

‘We don’t go out, we never get out… my home is between a cocoon and a prison… the only time I go out, I go shopping… I don’t go out and socialise… all I am… I feel at times, is a giver.’ (P10)

The physical impact of the caregiver role was intertwined with the psychological burden of caring for someone who was at end of life:

‘…you weren’t maybe getting the rest that you were used…I was tired, and yes I did get crotchety at times but I think, you were just waiting every day on something bad happening.’ (P3)

**Impact of diagnosis, death and dying**

Following a diagnosis, all family caregivers were faced with the premature situation of death and the process of dying.
In some cases, there was an endeavour to accept and understand in order to enhance the process of coping. Acceptance of having limited time left with their family member was difficult for family caregivers who had not previously imagined or expected to be in such a situation:

‘…just accepting it… this was a scenario you’d heard other people had been involved in it and now it was coming to you, you know? It was just acceptance of it was difficult.’ (P3)

For some, there was an element of guilt involved in their acceptance of the situation:

‘The advertisement where the face comes off, well that was me…I knew that he needed to go in and accepted that… but at the same time I felt as if I wasn’t looking after him...’ (P7)

Whereas for others, there was an element of denial in recognising the reality of a palliative diagnosis:
‘When he said a mass I said, oh he’s got an infection, we can clear this up...I always pick the best outcome, I didn’t think cancer at all... it became clear that it was a tumour and I just thought, I don’t want to know about this.’ (P1)

‘We didn’t want to know and we didn’t want to fully understand either.’ (P4)

Family caregivers reported a lack of information on the palliative and end of life care progression and confirmation of what to expect at the end:

‘Nobody tells you anything. We have watched him deteriorate...’ (P5)

The significance of finding meaning in the end of life and bereavement stages seemingly enhanced coping:

‘We were not in control of those things so I’d lots of bittersweet stuff going on… I often say he taught me how to live, but he taught me how to die.’ (P3)
5.2.1.3 Consistent communication and joint working

This theme considers communication between the specialist palliative care teams, learning disability professionals, primary care staff, general hospital staff, and the family caregivers. Ongoing communication can facilitate effective co-ordination of care, and influence the provision of information and support. The importance of familiar relationships and partnerships are cited by family caregivers as an enabling factor for good communication and subsequent provision of information and support. Shared education and awareness amongst services and family caregivers is also reported to promote communication, and thereby co-ordination of support and services in a timely fashion. This theme is composed of the categories ‘Communication facilitating service provision’, ‘Breaking bad news appropriately’, and ‘Shared learning and awareness.’

**Communication facilitating service provision**

This explains the assertion from the family caregivers that to be informed, there must be adequate and optimum communication from information or support providers. Family caregivers identified that until information needs are assessed, identified, or communicated effectively, they could not be addressed:
‘...the social workers... they weren’t proactive...they would say they would go and do something, and didn’t… I couldn’t understand…asking for help and not getting it.’ (P1)

If family caregivers were well informed, there was less delay in referrals and initiation of services and supports:

‘she was the first nurse, I mean nurse, that I had been in contact with…. she had gone up to the social worker and she asked about his learning difficulties... she got in touch with the GP… I couldn’t believe the difference, but it was too late by this time.’ (P4)

Optimum communication also promoted consistent delivery of care and provision of information:

‘the rapport that was built up within I think, within the GP practice, was central.’ (P2)

‘the only thing the hospital didn’t set up was they didn’t communicate with the community mental disability team...it was just lack of communication, but once my daughter communicated through some avenues... everyone appeared at the door.’ (P3)
Breaking bad news appropriately

Breaking bad news was a frequently cited issue. Breaking bad news inappropriately included the delivery of a prognosis in a non-private area:

‘the Doctor was coming out and said… he’s had a bad seizure and if it happens again there will be no intervention, and it was as brutal as that. In fact, it was in a corridor.’ (P7)

This impacted upon the caregivers psychologically, and therefore on their ability to cope:

‘I’ll never forget that day… now he never asked us do you want to go into a side room, I’ve something to tell you. He stood in that corridor… he looked at me and he said your brother has a tumour and I could feel myself falling backwards…’ (P9)

Family caregivers felt that the person delivering the news should provide adequate and appropriate information, depending on the holistic information need of the individual:
‘One thing the consultant said to me and I was surprised by it, she said you know dementia is a terminal illness? And you never think about it like that… the consultant had come back after a week or so… just told us they were discharging him for end of life care.’ (P7)

In the case of family caregivers who transitioned from children’s services to adult services, insensitivity was apparent, and the use of language was inappropriate:

‘When he was two and a half, as my husband and I walked through a hospital door, a consultant happened to say to us “don’t worry about him, because he will probably not live to see three” … that was the conversation….’ (P5)

**Shared learning and awareness**

This reflects the importance of recognising the family caregivers as experts, and the value of Health and Social Care professionals listening and learning from their expertise, whilst employing a willingness to provide appropriate and relevant information, education and training to them when needed:

‘I think a lot of the caring profession… it’s a very difficult job, they need to have a session with the carer.’ (P2)
Family caregivers praised some of the partnership work demonstrated across primary care, learning disability and palliative care services:

‘The GPs, the doctors… brilliant… the district nurses were fantastic, they tapped into things… hospice, I tell you they were brilliant…it was just like X being in a big family.’ (P1)

In some cases the GP in particular was an important facilitator in sharing information:

‘the GP helped… she introduced me to the palliative care nurse.’ (P5)

There were reported issues with initial communications; however, once the appropriate people were made aware of the situation the person and their family caregiver were then identified:

‘We had the team coming in… OT… social work…a community mental health nurse… it was a good enough team… it was just that glitch… that the team didn’t even know he was in the community, didn’t know he was in hospital even.’ (P3)
5.2.1.4 Navigating care across settings

Navigating care across settings represents the issues reported by the family caregivers in respect to the wider systemic problem within Health and Social Care services of insufficient staffing, poor training in learning disability of generic Health and Social Care professionals, gaps between child and adult services in learning disability, and needing to consistently ‘fight’ for entitlements and services. This theme is based on the categories ‘Transition between child and adult services’, ‘Early recognition of palliative care need’, ‘Service provider’s responsibility in meeting information needs of family caregivers’, ‘Importance of familiar staff’ and ‘Training needs for service provision of information.’

Transition between child and adult services

In the cases of adults who had transitioned from children’s services, there was a reported divergence between what services and support were available in childhood compared to in adulthood, particularly in respect to hospice services. In these cases when children had transitioned from the care of children’s hospice, there was found to be no equivalent in adult hospice services, as often they did no longer meet hospice criteria or adult services were underdeveloped:
‘Neurology is the only consultant that we have. We don’t have anybody else, once we moved to adults we lost everybody… there’s no equivalent in adults… when we got to 18… they hadn’t a clue, they didn’t know him’ (P5)

One parental family caregiver perceived that adult inpatient Hospice services focused on pain control more than the holistic needs approach experienced under Children’s Hospice services:

‘He was one of the patients in children’s hospice but becoming over 18 and a vulnerable adult he then becomes under the adult hospice, which was mainly for pain control, nothing more...’ (P10)

This impacted upon respite, leaving family caregivers without information on what was now available, or not available to them:

‘She had respite up until she was 20 and then it all stopped… You get everything when they are children, to me they need more when they are adults, and you get nothing… that’s my experience...’(P6)
Further to that, decision making became more complex, with parents feeling disenfranchised and redundant in their role, which had previously involved their voice in decision making:

‘When he’s in children’s, I’m his advocate, when he’s in social services, their decision counts more than mine does… As he’s seen as an individual adult, I’m only a parent… I don’t have his rights when he’s that age, they can make a decision, and I can’t over rule it.’ (P5)

Early recognition of palliative care need

This category reflects the inconsistency reported from caregivers when it came to their family member’s diagnosis, in respect to incorrect diagnosis or delayed diagnosis due the apparent presence of diagnostic overshadowing. Diagnostic overshadowing has been said to occur in people with learning disabilities when professionals interpret a change in behaviour or symptoms of an advanced disease to part of the person’s disability, instead of an illness which may require screening, further investigation and treatment (Reiss et al, 1982).
Family caregivers would be better prepared through the timely provision of information following an earlier diagnosis, however a delayed diagnosis will prevent this and increase distress and carer burden:

‘I think maybe, had it actually been treated properly, he wouldn’t have ended up the way he did.’ (P4)

This was often attributed to generic medical staff being unable to recognise symptoms correctly, in a timely manner:

‘I took him straight to A&E, he was yellow… went into the triage nurse… ah she said, maybe it’s the light, I said it’s not the light, he is yellow, I said he’s jaundice, look at his eyes, the whites of his eyes.’ (P9)

In some cases clinical agreement on a diagnosis and prognosis were not made until later in the disease trajectory:

‘…it took nearly two years before they agreed, and I think the wording was… exhibiting signs of Dementia of the Alzheimer’s type.’ (P7)
Service providers’ responsibility in meeting the information needs of family caregivers

Family caregivers reported a lack of monitoring and support in the community, with antagonistic systems and barriers to support:

‘Social workers… there’s just not enough… they’ve too big a number to look after… in our community there just not enough people all round and it’s down to money…’ (P1)

‘he doesn’t fit…from the day and hour he was born…we contacted the cerebral palsy support group…they referred us to Mencap…they referred us back…when he transitioned, it was all about learning disabled… but I said no, he’s also physically disabled… well, the learning disability comes first apparently.’ (P5)

Healthcare systems at times were unresponsive, gave mixed messages, or did not take responsibility:

‘I could never get to speak to a Doctor afterwards, so I never found out exactly what they did... this plaque had been growing... had turned cancerous... he then said, “that’s not my field, so I’ll have to refer you to a consultant who would deal with that”’ (P4)
Some family caregivers had to access information and support independently:

‘I put in for DLA [Disability Living Allowance]… I had to go in front of a tribunal, the DHSS were fighting me… I didn’t get any tax credits, I went to my MP… no, you’ve to get income support not tax credits… so, I lost all that money.’ (P6)

There was an expressed need to employ patient navigators, to support family caregivers through the system when negotiating both learning disability and palliative care services:

‘…day centre were struggling with him, as they needed two people to look after him… they didn’t have the staff… we actually asked about Hospice… they said they could organise for him… that was the Monday, but it took up until the Thursday…’ (P7)

**Importance of familiar staff**

This category reflected that in the case of providing care for someone with a learning disability, there was an emphasis on consistency and continuity of care, for the person and the caregiver.
Familiar staff providing consistent care enabled the family member opportunity to see professionals regularly, in order that they could seek information and support on or following a diagnosis:

‘Once he was diagnosed he was prioritized, because of the practice, and the relationship that they had built up… it was the same two doctors that saw him each time… it’s continuity of the whole process.’ (P2)

Interactions with familiar staff were shown to alleviate carer burden; information needs were likely to be identified and addressed in relation to practical information and support:

‘I had to fight to get [enhanced care at home nurse] support, but she’s wonderful…she’s there when I know he needs help… she has learned his breath sounds, she knows when he’s well because she’s made the effort to come out… to get to know him and to get to know me.’ (P5)


**Staff training needs for service provision of information**

This was an issue raised by all participants \((n=10)\), and for this reason has been highlighted. All family caregivers interviewed had experience of being in hospital with their family member at some stage during their illness.

In order for family caregivers to be identified and subsequently supported in meeting their individualised information needs, staff had to be adequately trained on learning disability and palliative care. Despite some pockets of good practice, overall, it appeared that general hospital staff were unprepared for people with learning disabilities. Ultimately this resulted in family caregivers being left without information that would have relieved distress and burden, or helped support them practically:

‘…any nursing staff I came across during the two weeks of his hospitalisation, not one was able for his disability... he was in a general medical ward... they were at a loss...he could not be coped with.’ (P3)

Issues were reported with emergency department staff in particular, information exchange and good communication were lacking:
‘...my first experience of A&E... whoa... interesting, not good. We had a consultant who said, “get this child out of my resus area”, I said he’s not a child, he’s twenty-two... “he’ll be going to a children’s ward”, I said no he won’t and he said to me “what would you know?”... the whole experience was awful... they left him for about two hours and he deteriorated.’ (P5)

This was extremely important information when it came to the communication of pain and recognition of symptoms, and in turn how this was treated, for the family caregiver:

‘...he was very agitated and obviously in pain...A&E were not prepared for him...they were not in any shape or form able for him... I said, “my son’s dying, what are you going to do?” ... because nobody could do anything.’ (P3)

It was also alluded that as hospital staff did not know how to deal with the person with learning disability, care duties were left to the family caregiver who was present, which naturally impacted upon the carer burden in a time of crisis:
'I took him to the bathroom this time, and although they had been changing him, they hadn't been washing him… he was soiled… I’d to say to them he hasn’t been looked after.’ (P7)

‘He was wetting the bed; the nurses weren’t taking him to the toilet. And then he was getting upset… you get your eyes open whenever you sit in hospital for a while. Unbelievable. Some of them knew how to work with him, other ones didn’t know how to work with him.’ (P9)

As community services are involved in palliative care delivery, it was suggested the district nursing staff were made aware when a person has a learning disability in order that the person and their family caregiver are identified and supported appropriately, which was an important influence unmet information needs:

‘…district nurses… they should know what they’re dealing with… if they’re dealing with people with learning difficulties… this needs to be something that’s written in big letters… as you can lift a chart…’ (P4)

However, specialist community palliative care services’ awareness of learning disability was praised, as a result information needs were met in respect to education on the illness and its trajectory:
‘There was one in the hospital [specialist palliative care nurse], I don’t know who she was but she came in and out but… she just didn’t get it with us, where the girl that came out to the community was completely different, she was amazing.’ (P8)

5.2.1.5 Evolution and components of the caring role

The role of the family caregiver of someone with a learning disability is often more complex than that of family caregivers of non-disabled people requiring palliative care. For example, the family member has been providing care for a longer period of time, and the person with a disability often has sometimes multiple existing health complexities prior to a palliative diagnosis. As a result, they become the experts and the voice of the family member. In modern society caregivers are seen to provide above and beyond what would be expected from a paid or informal carer. This has implications for the unmet information and support needs experience by the family caregivers. This theme is comprised of the categories, ‘Respecting wishes and best interests’, ‘Proactive advocacy role’, ‘Increased responsibility and upskilling’, and ‘Identity as a carer.’
Respecting wishes and best interests

In cases where the person with a learning disability had reduced or no capacity, family caregivers took on the role of advocates when it came to best interest decision making. This was difficult when it came to end of life care or decisions to have or withdraw treatment, interventions in the event of cardiac arrest, or admittance into a nursing home, hospital or hospice. The family caregivers had to weigh up expressed wishes of the person with a disability with what was in their best interests, which often interfered with their own objective decision making:

‘...we do have a code one in his chart, that came after a lot of soul searching and quite a nasty illness... we talked at length to a couple of Doctors about what’s right for X.’ (P5)

This entailed the family caregiver being reflective on what the family member would want, what they wanted, and what was best for their family member:

‘I said to the staff do you really need X to be in tonight? They said no and I said, right I’ll take him home… he loves home and it was just more normal and we wanted to keep everything normal.’ (P1)
This internal tension presented emotional and psychological challenges such as whether the person with a learning disability should know what is wrong with them or how decisions were made in respect to interventions:

‘…parents of the learning disabled… want to protect… is it right? Should you protect them? Or should you try and involve them in as much as possible? That comes back to that person’s ability and their capacity to take on the total understanding.’ (P2)

‘…we never wanted him to know… I knew we were at the stage where there was nothing more could be done.’ (P4)

However, respecting the person’s wishes allowed family caregivers to find meaning, in the difficult end of life stage and into bereavement:

‘…he always wanted cremated and so we did that and we picked his hymns and he had full say in everything that happened…but you see sort of organising his funeral…doing that, all that he wanted… fulfilling his wishes.’ (P4)
**Proactive advocacy role**

This category represents the proactivity that some family caregivers employed in seeking information, services and support, whilst being anticipatory of issues:

‘I was ready to start and say look, what’s going on here? X needs a scan, there’s something not right here... they recognised we were extremely proactive.’ (P1)

‘I would be a very proactive parent and I’m not scared of anybody... but I don’t care, because he doesn’t have a voice.’ (P5)

This category also reflects the family caregiver as the person’s advocate, interpreter, and voice:

‘I had to answer for him. I was interpreter... I thought, if I wasn’t sitting here, what would happen here?’ (P3)

Family caregivers vocalised the need to ‘fight’ for services and support in the field of learning disability:
'I had to say to social services, what about respite? ... you know it’s a fight all the time... you have to learn how to fight... you have to shout... you are doing so much caring, you get too tired to shout...’ (P5)

‘I’ve had to fight for everything. You think you’re going mental.’ (P6)

‘...the problem is, there’s nobody loud enough to shout, because at the end of the day you’re maybe talking to one person, and then the next time... that person is off on holidays... you have to start and tell them over again and I hate repeating myself.’ (P9)

**Increased responsibility and upskilling**

Family caregivers of people with learning disabilities reported to have provided care for a long period of time, already dealing with complex health needs before a palliative prognosis was ever made:

‘I mean that’s what we do, I have a wee sats [oxygen saturation] monitor that I use on his finger, so I’m keeping an eye on that, I’ve got his oxygen bottle, I’ve got his nebs, I’ve got his suction...’ (P5)
Family caregivers felt that they learned from their caring role, and did so independently. They perceived that they developed their skills by default, in being the expert carer for their family member:

‘...it was just an extension of being a carer... my daughter was wonderful, she set out everything to do with the meds and we had a table on the wall... and tick boxes, it was all very methodical...it was the learning’ (P3)

Increased responsibility compounded stress and carer burden:

‘We’d be told what meds to give him... and they were very trusting of us to give him some really big sort of stuff... I felt scared, yes scared to be in control of these meds.’ (P3)

Identity as a carer

This category reflected the long-term family caregivers’ role as part of their identity, woven into the fabric of their day to day existence:

‘I became the old parent, and now they are all turning to me... they’re all watching you, because he’s the first complex child to transfer from day-care, because none of the rest of them have survived.’ (P5)
The caregiving role was viewed as a ‘privilege’ and rewarding by some:

‘I think we were really privileged to be able to do it to tell you the truth… to know he had the best, that he wasn’t getting ill-treated anywhere, or left.’ (P8)

Caregiving appeared to consume the lives of other family caregivers leaving very little remaining for a life outside of this:

‘I think the last two years of my life has been taken... I was going to decorate... that stopped because my whole life was on that phone, because so many people were involved with him.’ (P4)

‘That’s the fear…you’ve got to keep a part of you that does something else… if something happens to him… I’ve nothing else to hold on to. I fear that you go down too quickly.’ (P5)
5.2.1.6 Summary of findings from interviews with family caregivers

Family caregivers reported a variation of information need, which differed from person to person, depending on individual circumstances. The most frequently expressed information needs were surrounding education on the disease, palliative care and the illness trajectory; this was followed by information on financial entitlements, assistance or aid. Information around practical support, respite and psychosocial support was considered important, but was not prioritised as highly by the family caregivers. Multiple coexisting information needs were present for all participants, which could potentially change over the disease trajectory and remain into the bereavement period.

The presence of unmet information needs impacted upon how much stress family caregivers perceived, consequently the increased stress and absence of needs being met resulted in unfavourable outcomes and negative stress. This was particularly important in relation to information on the disease or information educating the family caregivers about palliative care, death and dying. Stress and lack of coping due to uncertainty and worry was fostered by a clear lack of appropriate and timely information.
Information was seen as a conduit to understanding and acceptance of the process of death and dying. It has been highlighted that information needs are influenced by a number of factors including the early identification and prognosis of advanced illness that would require palliative care, adequately trained staff, and the good communication of staff across primary care, acute services, learning disability, and palliative care fields.

Unmet information needs has been show to influence and increase carer burden and stress by leaving caregivers without important information which may signpost them to support, or alleviate distress around unanswered questions. Adequate information provision can support family caregivers to avail of support appropriate to their individual needs and support them to develop more meaningful, sustainable coping processes. Participants recommended that assessment of need and subsequent delivery of information took place on a one to one, face to face basis.

5.2.2 Focus groups with Health and Social Care Professionals

A total of twenty-eight Health and Social Care professionals from both the community learning disability, and specialist palliative care teams, participated over six focus groups. Each group comprised of between four and six participants and ran for a period of between sixty to seventy-five minutes. Table 5.2 represents the demographic detail of all focus group participants.
Table 5.2 Demography of Health and Social Care Professionals

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<td>50-59 years</td>
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<tr>
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<td>Palliative care Services</td>
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<td>15+ years</td>
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5.2.2.1 Themes from focus groups with Health and Social Care professionals

Following analysis of transcripts from each of the focus groups, three themes emerged. These themes are presented in Figure 5.2 and reflect the perceptions and views Health and Social Care professionals had in relation to the information needs which may exist for family caregivers of people with learning disabilities who require palliative care. The three themes were ‘Information need at the interface of services’, ‘Interplay of services across settings’, and ‘Decision making dilemmas.’
Figure 5.2 Themes and categories from the focus groups with Health and Social Care professionals

Theme 1: Information needs at the interface of services
- Individual information and support needs;
- Generation of need from crisis;
- Increased psychological needs in palliative care.

Theme 2: Interplay of services across settings
- Remit, responsibility and joint working;
- Learning needs of staff across disciplines;
- Core multi-disciplinary staff.

Theme 3: Decision making dilemmas
- Death dialogue as a barrier;
- Advance care planning;
- Capacity and consent.

Categories:
- Individual information and support needs;
- Generation of need from crisis;
- Increased psychological needs in palliative care.

Categories:
- Remit, responsibility and joint working;
- Learning needs of staff across disciplines;
- Core multi-disciplinary staff.

Categories:
- Death dialogue as a barrier;
- Advance care planning;
- Capacity and consent.
5.2.2.2 Information need at the interface of services

This theme reflects the acknowledgement of Health and Social Care professionals in relation to the variety of cases that straddle learning disability and palliative care services, in respect to severity of disability, palliative prognosis, and how each family caregiver copes differently. Categories include ‘Individual information and support needs’, ‘Generation of need from crisis’, and ‘Increased psychological needs in palliative care.’

*Individual information and support needs*

Health and Social Care professionals reflected that depending on the individual, there will be different information need and support requirements:

‘… it depends on the individual, some people are just hungry for the facts and some people just want to bury their head in the sand, but to certain degree they want emotional support… it’s a very individualised thing…’ (FG7 Community Learning Disability Nurse)

Particular needs were identified for those who transition from children’s services into adult services, where there are not always equivalent services:
‘We have had a few people come to us through transition or just they come into adulthood, they had a regular placement in the children’s Hospice, and that stops full stop as there is no replacement for it.’

(FG2 Community Learning Disability Nurse)

The need for carers’ assessments was reinforced to identify information needs:

‘If somebody has taken really ill and they don’t know what they’re entitled to… like a bereavement entitlement… it’s letting people know what they’re entitled to.’ (FG1 Learning Disability Social Worker)

‘I think if circumstances change it is up to the professional most involved to offer a reassessment.’

(FG7 Community Learning Disability Nurse)

It was felt that family caregivers may not be in receipt of enough information and training and this was the responsibility of Health and Social Care professionals and wider services:

‘I think one of the biggest probably omissions professionals make is the fact there’s not enough information shared with the family…’

(FG7 Community Learning Disability Nurse)
‘…we’re not giving families the tools… brilliant training for staff…but we don’t have it for family members… for the carers and that’s a big gap.’ (FG24 Carers’ Coordinator)

However, there was recognition that Health and Social Care professionals may not always be able to meet the information needs of every individual:

‘…I would lack knowledge of the resources out there or services out there if somebody did need palliative care… if I had information, then you know, I can offer more support and direct them where they should be going.’ (FG1 Learning Disability Social Worker)

‘…these people have had to fight for everything… and actually continue in fighting mode because that’s all they know… sometimes you think you don’t do enough… we support families… but if these people have more need than that, I don’t know that we necessarily have the time or the recognition to give them what they may need.’ (FG10 Palliative Care Consultant)

Health and Social Care professionals felt information on financial entitlements was important:
‘even with carer’s allowance… carers would say it’s not enough, especially as needs increase… there’s not a lot of money for what our carers do… with carers we’re really not good, I don’t even think even as society… they’ve been forgotten nearly.’

(FG9 Palliative Care Social Worker)

‘…finance is just an issue for carers in general… in learning disability especially, someone will have reduced hours or else left employment altogether… there’s a lot of lone parenting now of adults with learning disability.’ (FG24 Carers’ Coordinator)

Health and Social Care professionals also felt information around practical, social, and emotional support was important:

‘It could be combination of things…enabling them to have a break sometimes from their caring role so there could be some practical things that we could put in place.’

(FG14 Learning Disability Social Worker)

‘…it’s making sure that the carers have enough support themselves and feel that they know where to go and have those key kinds of contacts.’ (FG7 Community Learning Disability Nurse)
‘…there’s so much anxiety you could reduce immediately just with that very practical stuff.’ (FG28 Learning Disability Clinical Psychologist)

As communication and pain were acknowledged caveats of caregiving in learning disability, information on the disease and medications were deemed important when the person was in receipt of palliative care:

‘…they have got to know the condition their relative has, and yes they need to know a bit more about it… they need to know what is out there that they can access.’ (FG1 Learning Disability Social Worker)

‘…there’d have been a couple of medications just that she (person with learning disability) had been prescribed and mummy was “I’m not giving her that, that’s morphine and I’m going to, I’m going to kill her” … it was just constant reassurance.

(FG22 Community Learning Disability Nurse)

Some Health and Social Care professionals surmised what the most important piece of information communicated would be:
‘…they want to know what they are dealing with from the word go… I think that’s basically what most families want to know. How much time do we have?’ (FG15 Learning Disability Social Worker)

Health and Social Care professionals appreciated potential difficulties family caregivers of people with learning disabilities may have navigating palliative care services, and obtaining information in general:

‘…if they want the patient assessed it’s the Hospice, for sitting services, for Marie Curie, Macmillan… that’s all very hard to navigate… we try to keep ourselves up to date, but as a family member… I don’t know how they find out who does what, there’s so many overlapping services.’ (FG19 Specialist Palliative Care Nurse)

‘…sometimes you can give someone too much information at the beginning and it doesn’t sink in… we’ve had people we’ve given loads of information to and found out afterwards there was major literacy issues there… some people devour every piece of information…there’s people that want you to tell them, there’s people that don’t, people want to write things down.’

(FG19 Specialist Palliative Care Nurse)
‘there’s so much we haven’t done, we haven’t really thought about you know getting specific information for carers of someone with a learning disability around that whole palliative issue.’

(FG24 Carers’ Coordinator)

Health and Social Care participants identified ways in which they felt information could be best delivered to these family caregivers:

‘…a person, somebody to support… to help you go through whatever it is you need, rather than a pack of leaflets… liaison person… like a regional coordinator for palliative care for people with learning disabilities’ (FG6 Learning Disability Social Worker)

‘…upskilling should be within teams, as opposed to an individual.’

(FG14 Learning Disability Social Worker)

‘I think you need to see a face, you need a person, and develop a relationship.’ (FG20 Palliative Care Social Worker)

‘…a key worker… one person who knows where to go, who can link in, who can react to every issue and be proactive and anticipate problems.’ (FG19 Specialist Palliative Care Nurse)
**Generation of need from crisis**

This category reflects the fact that often family caregivers of people with learning disabilities, who require palliative care, are often not visible to services until they are at crisis point with outstanding information and support needs:

‘…we aren’t aware that they have an issue, unless they contact us and tell us, then we don’t know… they need to be actively involved in the services, or at least at the point of crises where they contact us and say, listen, I need a bit of help now. I didn’t need it for 30 years but I do now.’ (FG15 Learning Disability Social Worker)

It was felt some family caregivers would not ask for help due to feelings of guilt, or lack of insight into their needs, or what is available:

‘…they don’t want to avail of services… there’s a whole guilt thing … they go until they are nearly on their knees… there are people out there that I’m sure learning disability services don’t know. I think it’s a cultural thing as well.’ (FG9 Palliative Care Social Worker)
It was perceived that unmet information needs until this point could be unknown, as often family caregivers feel that asking for help is an admission of not coping, therefore things have to get to this stage before they will ask for help:

‘the elderly carers I’ve spoken to… would nearly see kind of taking any kind of benefit of any kind almost like an admission of failure or… you know, I'll not be begging.’ (FG24 Carers’ Coordinator)

Participants perceived that the reality of family caregivers asking for help at crisis point could have wider implications for the person, the family caregiver, and health care services in general:

‘…people then end up being rushed to hospital… and end up you know ending their days in a clinical environment.’

(FG24 Carers’ Coordinator)

‘You end up looking after two people, because they don’t look after themselves.’ (FG8 Palliative Care Occupational Therapist)
‘... the time they do tend to talk about it is when there is some kind of crisis going on, then they can't really listen... their focus of the conversation is about a problem that isn't really necessarily the issue, it's an outcome of the issue.’ (FG24 Carers' Coordinator)

**Increased psychological needs in palliative care**

This category acknowledges that family caregivers providing care to someone with a learning disability will have an element of carer burden and unmet information needs existing already, as in most cases there have been many years of caregiving:

‘I think they were distraught at losing a very focal person in the family, the person that sort of kept them all together.’

(FG10 Palliative Care Consultant)

‘It’s another new road that they’ve gone down. This is now palliation and they have been used to all the other supporting...so it’s getting used to that one.’ (FG12 Palliative Care Nurse)

It is understood that when their family member is then diagnosed with another condition that is advanced and progressive, there may be new information need in respect to psychological support:
‘…they’re kind of grasping at straws a lot of the time and with very limited knowledge and hearsay, their whole perspective on really what the future holds can be very blurred.’

(FG7 Community Learning Disability Nurse)

‘You’ve sent them in a twirl with the latest diagnosis or news, and you’re expecting them to function, and be able to go and find information…when they’re just unravelling…’

(FG10 Palliative Care Consultant)

It was recognised that information need extended into the bereavement phase, and there were responsibilities of Health and Social Care staff in this instance:

‘…it’s about the support offered to the people after [death] as well, sometimes they don’t know what’s available.’

(FG21 Community Learning Disability Nurse)

‘…for the family members left behind, a good experience makes the difference between a good bereavement and a difficult bereavement. So, we recognise the need for family care.’

(FG10 Palliative Care Consultant)
Health and Social Care professionals offered recommendations as to how services can respond to these family caregivers in these circumstances, to meet their information needs:

‘I think if somebody’s health deteriorates, which obviously would be the case if it’s life limiting, the frequency of meetings should increase because family have an actual presence more.’

(FG7 Community Learning Disability Nurse)

‘…a kind of guidance sheet for staff who are working with people with learning disabilities… I would love to see a kind of information sheet on future planning for carers…’ (FG24 Carers' Coordinator)

5.2.2.3 Interplay of services across settings

This theme represents the role that learning disability and palliative care services have in working together, and in partnership with the family caregiver in order to meet their information needs. It is categorised by ‘Remit, responsibility and joint working’, ‘Learning needs of staff across disciplines’ and ‘Core multi-disciplinary staff.’
**Remit, responsibility and joint working**

Responds to the issue of services and Health and Social Care professionals knowing whose responsibility and role it is to provide certain information, services and support, whilst working together with other professionals who are involved with the individual and their family caregiver:

‘I think we don’t know when to refer and to who, there’s Macmillan… hospice… district nursing… there’s no real guidance on who we should be linking in with… when and where, and why?’

*(FG4 Learning Disability Social Worker)*

‘…there’s a lot of fantastic information floating round everybody’s kind of area and I think it is just typical of Northern Ireland as a whole, everybody regionally are doing different things, and you know, reinventing the wheel.’ *(FG7 Community Learning Disability Nurse)*

Remit and responsibility of the Health and Social Care professional role is important in relation to referrals, assessments and ultimately provision of information:

‘I think we need more involvement of Hospice, for children and adults… that is a service we don’t access…’

*(FG1 Learning Disability Social Worker)*
‘… a palliative nurse came to our team and talked to us about things like that… I would like to think she would have the information… she would tell me who, when and whatever.’

(FG2 Community Learning Disability Nurse)

‘GPs here aren’t making appropriate onward referrals to the right people … I think that that is building relationships and is hopefully going to bridge and improve services.’

(FG4 Learning Disability Social Worker)

Professionals from both learning disability and palliative care services acknowledged the need to take part in joint up working to adequately support the person and their family caregiver and provide appropriate information and signposting, with each person’s role and expertise respected, including the family caregiver:

‘…the district nurses would say, I’ll do the nursing, you do the rest…if we weren’t doing things with gloves on, weren’t actually nursing… they couldn’t see that value of what we were doing.’

(FG2 Community Learning Disability Nurse)

‘If we’re involved with somebody who is end of life we end up being that coordinator, but we are not the experts in the areas we are dealing with...’ (FG4 Learning Disability Social Worker)
'I think sometimes there’s a danger in learning disability… that we create this dependency on us, when really we need to start thinking more about everybody working together.’

(FG6 Learning Disability Social Worker)

Pockets of good practice were acknowledged by professionals from two of the Health and Social Care Trusts:

‘…there’s a lot of good joint up working which I thought was lovely to see, because it’s not always positive experiences out there.’

(FG7 Community Learning Disability Nurse)

‘the health facilitator… excellent…she’s a go to. Very useful.’

(FG5 Learning Disability Social Worker)

‘…in my experience… the minute anyone mentions palliative care, everyone pulls the stops out, there’s no ifs buts or maybes about funding or delays.’ (FG17 Learning Disability Social Worker)
However, correct identification of palliative care need was a reported issue by Health and Social Care professionals:

‘About 2% of a GPs practice population over a year will be palliative care… it’s not something they will probably do every day… identification issues are difficult in the non-malignancy… if as a specialist team we are still getting two thirds of our cause as Cancer, there’s a problem still with identification.’ (FG19 Specialist Palliative Care Nurse)
Learning needs of staff across disciplines

Staff working with people with learning disabilities with a palliative diagnosis and their family caregivers should be trained and prepared for working with someone with a learning disability, and should take the lead from the ‘expert’ family caregivers, in order to effectively meet the person with a disability’s needs and their carer’s information needs:

‘… lack of insight from probably our mainstream services… into what learning disability is, even at the stage of being diagnosed… there is still a lack of knowledge when it comes to A&E staff on how to manage, on how to deal…’ (FG4 Learning Disability Social Worker)

‘… they felt hospital staff were so poorly trained in learning disability… they had no idea how to work with the person… they felt the treatment they got was very poor…also that they were not necessary being listened to…’ (FG24 Carers’ Coordinator)
There should also be education and awareness on what palliative and end of life care is, and who and what is involved. This was something everyone was aware of, but this was not always happening in practice:

‘I would have gone to district nursing and said this person really only has a couple of days and should be eligible for whatever it is service… they’ve said to me no, that client is up and got up and went to the toilet, therefore they are not approaching death just yet… and the person did die, without the service.’ (FG4 Learning Disability Social Worker)

‘I would like more information, I would like to have read that book [Understanding Learning Disability and Dementia by Diana Kerr], because I think in our everyday work we are going at 90 miles an hour… you don’t have time to stop and look at resources until the situation actually happens and then sometimes you’re way down the path.’ (FG5 Learning Disability Social Worker)

‘Staff don’t see their role in supportive and palliative care, they think if they’re not giving an injection or something, that they don’t have a role… the emotional, not just the physical, the psychological…”

(FG19 Specialist Palliative Care Nurse)
Core multidisciplinary staff

Health and Social Care professionals felt that there should be central staff known to the person and the family caregiver, from both learning disability and palliative care services, and dedicated staff in primary care. This was to enable effective care, support, and to facilitate information giving:

‘…we had supported this young man since he was seven…he died at 43…to her we were his family. She wanted us involved.’
(FG6 Learning Disability Social Worker)

‘Palliative and end of life care is such an important part of a person’s life… you’re never more vulnerable, you’re never in more need of security, care and compassion, and love that at any other stage in your life… it’s important that people get it right.’
(FG27 Learning Disability Clinical Psychologist)

A central core team of dedicated staff enables appropriate and adequate information provision, timely referrals and easier navigation of the various services and agencies:

‘…you can be that link person who is trying to maybe facilitate getting somebody home from hospital…’
(FG4 Learning Disability Social Worker)
‘I think if I referred her to a stranger… she probably wouldn’t have gone. She just wanted familiarity of the people she knew and who would understand.’ (FG5 Learning Disability Social Worker)

It was felt that familiar staff, with consistent communication, improved the endeavour of Health and Social Care professionals to meet the information and supports needs of the family caregivers:

‘it’s not only the information that we have, but actually access we might have to other individuals who may have further information, which kind of works but I know that’s probably not the model of teams across the region.’ (FG14 Learning Disability Social Worker)

Key workers and face to face interactions were suggested by participants:

‘It’s access to the people that they want to speak to… the nurses here, they will know a name, a nurse by name.’

(FG10 Palliative Care Consultant)
Ultimately, the involvement of familiar staff was suggested to relieve psychological stress, and introduce meaning to the end of life event:

‘…it comes down to relationships… the right people who had the strong relationships…he felt safe, secure, his life had meaning, they reminisced with him… that’s what you want at the end of your life, what was the point? Did I mean anything to anybody?’

(FG27 Learning Disability Clinical Psychologist)

Some professionals reflected on what worked well, and made recommendations:

‘Our overall experience was just so positive…just how excellently they coordinated everything and really at the heart of that was just how person centred they were.’

(FG28 Learning Disability Clinical Psychologist)

‘…it came down to the relationships… everybody respected everybody’s opinion, and I do think there is an important role for psychology in this as well.’

(FG27 Learning Disability Clinical Psychologist)
5.2.2.4 Decision making dilemmas

This theme emerged due to the weight of discussion around this area during the focus groups with Health and Social Care professionals, from both fields. It was felt that issues with decision making were linked with information, and information need. Categories include ‘Death dialogue as a barrier’, ‘Advance care planning’, ‘Capacity and consent.’

**Death dialogue as a barrier**

Health and Social Care professionals reported that, in their experience, death remained a taboo subject in general:

‘…the other thing with carers is they’re trying to protect the person with the diagnosis… they’re sort of brushing over it…’

(FG3 Learning Disability Occupational Therapist)

‘There is a fear around dying, and even Cancer, it used to be referred to and still is as the C word, you couldn’t say the word.’

(FG25 Community Learning Disability Nurse)
As a result, important conversations were not taking place, or inadequate information was being communicated in relation to a palliative prognosis:

‘…the Doctor just turned round and said… well you know he will not be home? …did he mean he was going to die? So, it’s other professionals and how they approach people and talk to people.’
(FG1 Learning Disability Social Worker)

‘I think there is a tendency where people give false promises to people…’ (FG7 Community Learning Disability Nurse)

‘… it’s a cultural thing that we don’t talk about death and dying… to tell someone they have palliative Cancer or that they are dying… those are not the words that are used… it’s just not clear for people and they’re left wondering… staff aren’t confident in having those conversations… if you say that they’re dying then they’ll give up.’
(FG19 Specialist Palliative Care Nurse)

Some professionals gave their perceptions on how death and dying should be communicated:

‘You can’t sugar coat anything, you can’t dance around with flowery language… you have to be black and white and as straight to the point and as simplified as you possibly can.’
(FG28 Learning Disability Clinical Psychologist)
‘...there’s no excuse for kind of heads down, ignoring the elephant in the room if someone is especially, as a lot of the carers now are, in their 80s.’ (FG24 Carers’ Coordinator)

‘...not to shy away from it... we have a tendency in our culture to somebody mentioning fear of dying “awk you’ll be... you’ll outlive us” and that leaves the person in the loneliest, isolated place...there’s nobody that will meet them where they are at.’

(FG27 Learning Disability Clinical Psychologist)
**Advance care planning**

The value of providing family caregivers with enough information early on, to advance plan for the end of life and bereavement stage was suggested to enhance coping, leaving family caregivers with less unmet needs than if they were making decisions in a crisis:

‘…in general reviews, if somebody is not ill, there would be a point in the review where we would talk about forward planning… it makes it more natural to talk about these things.’

*(FG5 Learning Disability Social Worker)*

‘Nobody wants to think about those sort of things... at the end of the day you need to make them decisions early on, so people have their choices and wishes known early on.’

*(FG23 Learning Disability Nurse)*
However, end of life decisions such as do not attempt resuscitation (DNAR) orders, have proved a challenge, with family caregivers not always being involved in the decision making process and provided adequate information to educate them on such decisions:

‘I’ve had two or three cases… where the carers were informed that there was a DNAR in place, the hospital told me that this had been well explained to the carers… when I went to the carers, they hadn’t a notion… they did not understand the significance of what it meant.’ (FG2 Community Learning Disability Nurse)

‘…the family struggled with the hospital experience…they felt that the teams were communicating poorly with the brother and then with them and making decisions about him.’ (FG10 Palliative Care Consultant)

There were instances where family caregivers were involved in decisions, and actively promoted the involvement of staff familiar to them in the decisions also:

‘Family were wanting us very much involved with the GP and his DNR order that was very much a MDT group discussion and the family, they wanted us to really inform the decision as well.’ (FG7 Community Learning Disability Nurse)
However, it was demonstrated that staff should be provided information to appropriately educate on advance planning, and DNR/DNAR (Do not resuscitate/Do not attempt resuscitation) orders:

‘…DNAR…the staff were terrified of this document…they found a big responsibility with the form… it just makes you think we have our learning, we have our experience…’

(FG13 Community Learning Disability Nurse)

‘I think for the carers especially…it’s too hard to think about…yet they know they have a need for future planning as well…we shouldn’t be afraid to grasp the nettle…actually have the conversation even if we don’t have the solutions.’ (FG24 Carers’ Coordinator)

There were identification issues with the ‘end of life’ stage of the palliative care journey which impacted on information giving, decision making and the ability to future plan:

‘I had to call a meeting with the GP, the family, and the Consultant…to say you know this young man is at end of life… they didn’t want to be making that decision… he died two weeks later.’

(FG19 Specialist Palliative Care Nurse)
**Capacity and consent**

Represents challenges with capacity and consent either for or against intervention for someone with a learning disability who requires palliative care. The provision of information to the family caregiver of exactly what the palliative illness entailed, how it would progress, and treatment options were cited as important when it came to assisting the consent process:

‘…we have had a few cases where people have declined treatment, and that’s very difficult, to think do they fully understand what the implications are?’ (FG3 Learning Disability Occupational Therapist)

‘I think there is a degree of paternalism in healthcare and in families toward the person with disability…I think the motivation is about overprotecting them… but it can override their rights a little bit.’ (FG10 Palliative Care Consultant)

‘…she had got her capacity assessed…she had commenced her treatment…she then withdrew her consent…that was respected, was very important.’ (FG18 Community Learning Disability Nurse)
There were cases reported where the family member did not consider the capacity of their family member, or had conflicting views due to lack of educative information or adequate information on the illness, in order to make an informed choice on what was best for the person important to them:

‘...it can often be fraught with difficulty...you maybe have conflicting views between say the client and the family, in relation to whatever it might be... maybe what the person knows or understands about their condition. So, it can be a mine field.’

(FG5 Learning Disability Social Worker)

‘...he did get worried... like one time two of his brothers visited and said, he was raging, he said, they’re going to stop this... they’re going to wreck my plans. They can’t, don’t you worry.’

(FG23 Learning Disability Nurse)

Family caregivers had themselves to accept death and dying; with lack of educative information again clouding decision making due to issues with acceptance, denial, and overprotection:

‘...he was a man who lived quite independently and functioned very, very well... the family were not for giving in, but they couldn’t cope themselves. I think there was an awful lot of guilt, there was all sorts of emotions going on, muddying the water.’

(FG5 Learning Disability Social Worker)
‘…she did have capacity… she wanted to discuss end of life… but her mum didn’t want to discuss it with her…this woman needed support as well… she was fearful of losing her daughter.’

(FG20 Palliative Care Social Worker)

‘Carers themselves… a lot of them call adults with learning disabilities their children, they still see them as in that kind of young children bracket, and therefore wanting to protect them always from the truth.’

(FG24 Carers’ Coordinator)
5.2.2.5 Summary of focus group findings

Health and Social Care professionals, across the learning disability and palliative care sectors, acknowledged the spectrum of unmet needs they perceived which existed for family caregivers of this population. Analogous to findings from family caregivers, Health and Social Care professionals perceived unmet needs including information needs in respect to the disease itself, illness trajectory, medications, practical and psychosocial support, palliative and end of life care, death and dying and advance care planning, respite, and finances.

Information, and information need, was considered crucial to facilitate referrals for the right support, from the right professionals. Information provision around education on the disease itself, financial support, practical support and social or emotional support was considered important. It was felt an awareness of core staff, across teams, would enhance consistency and communication; in order that the family caregivers' information needs are addressed in a timely fashion, with adequate supports and provisions established.

Early intervention, through adequate information provision was seen to promote effective support and potentially reduce the amount of crisis point situations in acute settings. Talking more around the subject of death and dying was also important in removing barriers to advance care planning and consent issues in palliative care for this population.
Findings highlighted the importance of addressing the learning needs of Health and Social Care professionals, to ensure that they are equipped to identify and work with people with learning disabilities and their family caregivers, and to listen and learn from the expertise of these family caregivers. Participants acknowledged the unique challenges faced by this specific population of family caregivers at the interface of palliative care and learning disability services. Findings reflect suggestions of one to one, face to face interventions from familiar link or key workers, which would improve overall coordination of care and address any outstanding information needs present for the family caregivers.

5.2.3 Comparative analysis

Data from interviews and focus groups similarly identified, or perceived the need for information chiefly on the disease and its trajectory. Financial information need was not perceived as strongly from focus group data, whereas this was the second most commonly identified information need from family caregivers. Health professionals recognised they play an integral role in enabling access to the right information in a timely manner, but also identified barriers to information and influences on information need. Rhetoric around death was acknowledged as a barrier from both family caregivers and Health and Social Care Professionals.
Similar systematic barriers to information and support were reported, such as poor partnership working, learning needs of professionals, and lack of awareness of existing resources. Family caregivers reported a lack of assessments, which was also identified by focus group participants. Both family caregivers and Health and Social Care professionals also supporting the view that informational materials would improve knowledge of the disease, and practically assist the role of the family caregiver.

Furthermore, participant groups agreed that information facilitated decision making in relation to advance care planning for people with learning disabilities. All participants agreed that development of information specific to palliative care for people with learning disabilities was warranted. Moreover, both family caregivers and professionals concurred this would be best delivered one to one, and by someone familiar to the person with a learning disability and their family caregiver.
5.2.4 Good Models of Practice

Data from one family caregiver praised the involvement of services at the end of life stages, suggesting professionals who were involved were communicative and informative. However, this was dependent on the good communication between community and specialist teams, which only happened in the later stages. This was a positive example nonetheless of teams working together to meet the needs of the person, and the information needs of the family caregiver. Earlier intervention would have promoted information needs earlier in the disease trajectory.

Data from one of the focus groups revealed that one Health Care Trust in Northern Ireland had delivered care to a person with a learning disability and those he was close to at end of life. The gentleman had his wishes respected and met as best possible, his end of life involved gold standard care and involved those close to him. This particular case utilized and involved clinical psychology professionals throughout and into the bereavement stages, for paid staff and those close to the gentleman. All multidisciplinary staff involved in this case found it meaningful and fulfilling, and feel it will inform future work with people with learning disabilities who require palliative care.
5.2.5 Overall findings from study data

- The overarching findings from the study have arisen from the collective voice of the family caregivers and Health and Social Care professionals who participated. This has provided a wider perspective of what information needs exist for this population, and how Health and Social Care professionals across the palliative care and learning disability disciplines can work together to address this. The findings display the following key messages:

- New insights have been obtained around the specific information needs of family caregivers of people with learning disabilities who require palliative and end of life care which may be numerous and change over time. The most commonly identified information needs pertaining to education on the disease and its trajectory, followed by information relating to financial aid, entitlements and benefits. Information needs around practical support and respite were identified, but not as common.

- There is an identified need for consistent one to one holistic needs assessments for family caregivers of people with learning disabilities at end of life, implemented by core or familiar staff such as link or key workers.

- There is a reported lack of awareness of existing materials that may help address unmet palliative and end of life care information needs of family caregivers.
• There is a need for Health and Social Care professionals to work in close partnership with family caregivers of people with learning disabilities who require palliative and end of life care and learn from their expertise.

• A need has been identified for front line staff to be adequately trained in learning disability and for learning disability staff and carers to have enhanced training on palliative care.

5.3 Logic modelling using research data findings

The logic model application to this study was initially introduced in chapter 3 and the co-design element mentioned in chapter 4. The logic model visually represents a proposed framework and conjectures of the key stakeholders that were involved in the study. Donetto et al. (2014) cite that good logic model design incorporates functionality (How well it performs or is fit for purpose), safety (how safe and reliable it is) and usability (how interaction with the service or product is experienced). The logic model developed in this study and presented in this chapter is based on the Wisconsin Model, which is one of the most used and common configurations for logic modelling, which serves as a tool to articulate the current status of informational need for family caregivers, logical relationships, planned changes, and for whom these changes apply (University of Wisconsin, 2016).
The University of Wisconsin (2003) identified a logic model as a simple pictorial version of an initiative, intervention, or a program in response to a particular situation, or more simply as a way of thinking (University of Wisconsin-Extension, 2003). The other commonly used logic models ‘The Weaver’s Triangle’ was not chosen as the translation of findings from this study would be limited in this smaller format, underlying assumptions would not be questioned and visually it is more difficult to connect the various components of the model processes (Evaluation Support Scotland, 2017). Activities that will support the best outcomes are also communicated, alongside the resources required. Assumptions and external factors that may influence the end result are also presented.

Dorsey et al. (2014) supports the use of the logic model as a representation of a situation, or a problem used to help answer a specific question, in this case identifying and addressing the information needs of family caregivers of people with learning disabilities who require palliative care. Essentially the logic model examines a specific question in order to offer ways of resolution and steer decision makers and stakeholders in the right direction for planned change (University of Wisconsin-Extension, 2016). The logic model logically presents a manual or blueprint of how a program or processes are to be developed, demonstrating how components of the model sit together, their relationships and how these contribute to the predicted outcomes (Dorsey et al, 2014).
The model essentially communicates a way of thinking, represented in a pictorial form (University of Wisconsin-Extension, 2003; 2016). Linking to the aim of the study the logic model communicates how certain inputs and initiatives can help address the current situation of unmet information needs in this population of family caregivers. The final logic model serves as an easy read, visual, diagrammatic representation of what information needs were present for family caregivers of people with learning disabilities, what support they should receive, and what it should look like, using the evidence from the study.

The rationale to co-design a logic model as a blueprint for potential development of a future intervention, rather than simple narrative recommendations alone, evolved from the literature (Donetto et al, 2014; National Health Service (NHS), 2009; Bate and Robert, 2007). Furthermore, the outcomes of this logic model promote transformation in the individual family caregivers, Health and Social Care professionals, Health and Social Care services, and the wider system. This transformation process is supported by the transformative lens through which this study was conducted, promoting the voice of family caregivers and reform guided by the social justice principle (Teddle and Tashakkori, 2009).
Following data analysis the voice of family caregivers and Health and Social Care professionals across the learning disability and palliative care disciplines were translated from findings into the logic model. The co-design process involved three consultations with an expert reference group consisting of service users, professionals and policy makers. The group were consulted on three occasions to review study findings and to facilitate the model co-design. The expert reference group provided feedback and suggestions, and assisted in how the research findings and recommendations were to be disseminated.

**Composition of the logic model**

Expanding on the previous section the model was composed of a framework of inputs, outputs and short, medium and long-term outcomes in relation to the information needs of these family caregivers, whilst taking into consideration external influences and assumptions, which conceptualised an effort for change (University of Wisconsin-Extension, 2016).

The inputs illustrate investments, for example, funding, knowledge, or staff time. Outputs involve activities showing what we do and participation showing who we reach. Outcomes then show what the results will be from the inputs and outputs over the short term to long term, based on the projected order in which they will be achieved.
The model altogether provides a sequence of events, which will result in change over a period of time, rather than limited to specific time frames, and over the longer time period can help steer the direction of future policy and service development. Integrating the findings from this study into the model presents the information needs and other issues identified, and how they could be best addressed and via which methods.

The logic model was co-developed in consultation with the previously discussed expert reference group. Through 3 consultations (one face to face, and two electronic) with the expert reference group, thoughts and ideas were discussed in relation to the integration of findings into the logic model format, iterations followed adaptions and changes based on the liaisons with the panel members. The final logic model was drawn up as to what realistically could be done to address the varying information needs reported and the influences upon these; the components of the logic model are discussed further towards the end of this chapter.
5.3.1 Initial consultation with expert reference group

It was important that the expert reference group was open to involvement from people with learning disabilities, and recruitment for such members was promoted at the attendance of a monitoring group for people with learning disabilities and their caregivers. One monitoring group member expressed interest, and was recruited to the group.

The expert reference group were consulted on three occasions and consisted of seven members: a social care commissioning lead for mental health and learning disability services, a community palliative care nurse lead, a service user and member of a monitoring/advocacy group, a team leader in adult learning disability services, a lecturer in palliative care and chronic illness, a lecturer in learning disability nursing, and an expert carer who was a member of various patient and public involvement (PPI) groups (Social Work Research and Service Improvement Strategy PPI Group, Integrated Care Partnership PPI Reference Group, Carers Reference Group).

The members were provided with a synopsis of the research findings and this generated initial discussion on information needs and influences on this. This was to enable co-development of the initial drawing up of the logic model, based on how the findings could be integrated into the model to reflect the needs reported and how they could be met. This included discussion around investments, what we could do, who would we reach, and potential outcomes from short to long term based on the data from family caregivers.
Minutes were taken from the initial meeting and informed how and what was represented in the initial logic model, based on the Wisconsin (2016) template, an example of which all the expert reference group were provided with. Summarised information was then communicated back to the group to ensure it adequately and accurately reflected the variables and processes discussed.
5.3.2 Second consultation stage (electronic)

The first draft of the logic model communicating the findings from the family caregivers and considering discussion and feedback from the first expert advisory meeting was sent back to each member of the group for feedback. There were some suggestions for adaptions and changes, however the remainder of the group agreed the model provided a good representation of study findings and a reflection of the original consultation. At this stage, the logic model was adapted and redrafted following the feedback from the expert panel to reflect the suggested changes and inputs.

5.3.3 Final consultation stage (electronic)

The amended version 2 of the logic model was sent to the expert reference group for final comments. Following final iteration and feedback the logic model articulated the situation and priorities in relation to this research, inputs and outputs that address the presence of information needs reported and suggestions as to how they can be identified, addressed and sustainably met. The logic model ultimately provides a pictorial presentation of processes that seek resolution and can steer service improvements, and potential changes in policy long term. This model enables a visual understanding of the issues, context, influences and goals for addressing the information needs of this population.
Current situation and priorities at threshold of logic model

First, there was establishment of the current situation and priorities were identified. The situation being that family caregivers of people with learning disabilities who require palliative care have various unmet information needs, there are also outstanding training needs of professionals which influence the information needs of family caregivers. Some training needs of Health and Social Care professionals may be met through listening to and learning from the family caregivers as experts. Moreover, there is an identified lack of awareness of learning disability in Health and Social Care settings, influencing the information needs of these family caregivers.

Priorities identified from findings and upon consultation from the expert reference group included reducing unmet information needs, increasing awareness and education whilst promoting collaborative practice across Health and Social Care fields, improved awareness and signposting to information services and support, maximising resources in meeting information needs, and establishing a realistic vision in communicating the values of these family caregivers and how they can be best supported in meeting their information needs as care partners.
**Inputs, Outputs and Outcomes**

Following the initial consultation version 1 of the logic model was drafted, incorporating inputs, outputs and outcomes suggested from the data findings and the initial face to face meeting with the expert reference group. The input investments were noted in relation to what we must invest in order to meet the information needs of the family carers of people with learning disabilities. Outputs involved activities and who would participate. Inputs and outputs promoted short term goals. Medium term outcomes were identified and long term goals and objectives.

Outcomes provided the direction and sequence of short-medium-long term goals, in the order that they would most likely be achieved, rather than mapping a specific timeframe, as suggested by the University of Wisconsin (2003). The logic model draft concluded with identified assumptions and external factors which may influence the logic model processes and components. Figure 5.3 below provides the full presentation of the logic model followed by narrative treatment of the logic model framework and contents.
Identifying and addressing the information needs of family caregivers of people with learning disabilities who require palliative care

SITUATION:
Family caregivers of this population have various unmet information needs. There are outstanding training needs of health and social care professionals which influences the information needs of caregivers. There is a decreased awareness of Learning Disability in general in health and social care settings.

PRIORITIES:
- Reducing unmet information needs of this family caregiving population
- Increase awareness, education whilst promoting collaborative practice across health and social care multi-disciplines
- Improve awareness and signposting to information, services and support
- Maximize resources in meeting information needs
- Establishing a realistic vision communicating the values of this caregiving population in how they can be best supported
**Figure 5.1 Logic Model continued.**

<table>
<thead>
<tr>
<th>INVESTMENT</th>
<th>WHAT WE DO</th>
<th>WHO WE REACH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inputs</strong></td>
<td><strong>Outputs</strong></td>
<td><strong>Participation</strong></td>
</tr>
<tr>
<td>Early identification of family carers</td>
<td>Clinician training on diagnosing palliative illness in learning disability (LD) (“annual health check”) to identify family carers as early as possible.</td>
<td>Wider health and social care services</td>
</tr>
<tr>
<td>Adequate human resources &amp; staffing</td>
<td>Family carers should be linked to at least one named health &amp; social care professional who has regular contact.</td>
<td>Clinicians including GPs</td>
</tr>
<tr>
<td>Planning for assessment &amp; care plan development</td>
<td>Individualised carer’s support planning to identify &amp; meet information needs including advance care planning (ACP) with regular reassessment of changing needs to facilitate support into bereavement &amp; beyond</td>
<td>People with learning disabilities &amp; their family carers &amp; Specialist services (LD and Palliative Care teams)</td>
</tr>
<tr>
<td>Shared expertise of specialist services and family carers</td>
<td>Promote &amp; facilitate joint working &amp; shared learning carried into the bereavement stage</td>
<td>People with learning disabilities &amp; their family carers &amp; Specialist services (LD and Palliative Care teams)</td>
</tr>
<tr>
<td>Awareness &amp; availability of existing resources</td>
<td>Promotion &amp; circulation of Carers’ strategies &amp; existing informational resources for carers</td>
<td>Specialist services (LD and Palliative Care/Hospice), individual health &amp; social care staff &amp; family carers</td>
</tr>
<tr>
<td>Training for family carers &amp; staff</td>
<td>Carer training on palliative care &amp; advance care planning. Front line staff &amp; palliative care professionals adequately trained on LD.</td>
<td>People with learning disabilities &amp; their family carers, Specialist services (LD and Palliative Care teams), primary care &amp; front line staff and the general public</td>
</tr>
<tr>
<td>Application of new knowledge from research &amp; Funding</td>
<td>Development of information specific to family carers of people with LD who require palliative care based on new knowledge from this research</td>
<td>Family carers, the general public, decision makers, policy makers &amp; all health &amp; social care staff</td>
</tr>
</tbody>
</table>

**Assumptions** Learning Disability and Palliative Care services are committed to working together, and in partnership with family caregivers whilst being responsive. Family caregivers are willing to work and share their expertise as care partners with health and social care professionals and wider services.

**External Factors** Funding for staffing, resources, staff training. Consistency of preparedness of stakeholders (service users, service providers, health and social care professionals and policy makers) and availability to carry out sustainable long term solutions.

<table>
<thead>
<tr>
<th>Outputs</th>
<th>Short</th>
<th>Medium</th>
<th>Long</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased early identification of palliative care need &amp; awareness of the involved family carer</td>
<td>Change in behaviours and practice. Increase in palliative care &amp; hospice referrals. Early assessment of family carer need</td>
<td>Sustainable practices &amp; partnerships</td>
<td></td>
</tr>
<tr>
<td>Suggestion of link staff/key staff. Continuity of care into bereavement</td>
<td>Pilot &amp; audit of link staff or core staff. Increased trust. Coordinated care</td>
<td>Sustainable &amp; permanent positioned link or key staff/Coordinators/Core teams</td>
<td></td>
</tr>
<tr>
<td>Consistent assessment &amp; identification of information needs of family carers &amp; adequate information provision &amp; support planning to meet these needs. ACPs offered to all family carers</td>
<td>Facilitation of coordinated holistic support based on the reported information needs of family carers &amp; reduction in unmet information needs.</td>
<td>Good working relationships and provision of optimum care delivery &amp; majority of information needs met</td>
<td></td>
</tr>
<tr>
<td>Increase in skills, attitudes &amp; formation of working partnerships &amp; trust. Shared expertise reducing training &amp; learning needs</td>
<td>Enhanced partnerships and role respect</td>
<td>Testing &amp; improving existing systems for meeting family carer information needs met</td>
<td></td>
</tr>
<tr>
<td>Effective use of existing resources to meet information needs</td>
<td>Evaluation of existing resources, planning for next steps, development of new resources</td>
<td>Financial focus on addressing persistent information gaps</td>
<td></td>
</tr>
<tr>
<td>Increased knowledge &amp; capabilities. Reduction of carer burden. Promotion of trusting relationships between family carers &amp; staff</td>
<td>Sustainable decrease in carer burden &amp; further reduction of unmet information needs</td>
<td>Evaluating training and resources</td>
<td></td>
</tr>
<tr>
<td>Information needs specific to LD/palliative care can be met more efficiently</td>
<td>Further research or resource development</td>
<td>Economic benefits through reduction of hospital admissions and more efficient use of services and resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Influences on policy, education and further research</td>
<td></td>
</tr>
</tbody>
</table>
5.3.4 Logic model narrative

The purpose of the model is to communicate study findings, presenting complex findings and reducing them to a simplified version that is understandable for any lay person who reads it. The model is primarily targeted at family caregivers of people with learning disabilities who require palliative care and the multidisciplinary Health and Social Care staff who work across the learning disability, palliative care and primary care sectors. However, it is also intended to address unmet information needs and the wider issues with service development, policy and changes in practice therefore it is of relevance to policy makers and future application of new knowledge to health care research. Family caregivers, Health and Social Care professionals and policy makers hold the responsibility for enacting components of the model and have their roles in doing so.

Input investments of the logic model included staff numbers, staff time, planning time, research and knowledge, expertise and funding to enable better identification of information needs and direction to support for family caregivers. Some of the above may be resourced more readily, for example staff time more so than human resources or funding. Investments could be realised with the simple presence of motivation and increased awareness of staff and management levels of organisations.
Outputs involved activities and who would participate in identifying and addressing information needs suggesting consistent needs or support assessments and planning for early identification and timely intervention, participants being chiefly the family caregivers and Health and Social Care staff. Output activities included training and development of specific information tailored to the individual. Tailored information may include disease specific information, promotion and awareness of existing resources and materials through signposting to specific disease charities or groups, and multidisciplinary working.

Training and information on advance care planning for staff and family carers are also suggested, with early initiation of this advance planning offered to all family caregivers. Suggested activities also include reactive training for family caregivers and staff, depending on their individual training needs. Promoting family caregivers sharing their expertise with Health and Social Care professionals will help minimize professional learning needs when working with someone with a learning disability.

Inputs and outputs promoted short term goals and included effective use of existing resources to determine the specific information needs of individual family caregivers and meet them wherever stage they are on the palliative care trajectory. Existing resources discussed included carer support plans and assessments, and existing informational resources developed by charities such as Marie Curie, or Carers UK.
A further short term goal was a general increased awareness of the information needs of this population, which would be in part fulfilled by the findings and dissemination of this research. Medium term outcomes identified included a reduction of the amount and level of unmet information needs; development of new informational resources on a budget or that did not require additional funding, for example information sheets for family caregivers or for staff working with family caregivers of this population. Continued promotion and circulation of regional or national Carers’ strategies should also be undertaken by key staff or carer’s coordinators coming into contact with these family caregivers, which may signpost existing informational resources.

Consensus for longer term goal and achievements concluded with increased trust between caregivers and staff, with sustainable partnerships promoting information giving with key staff or co-ordinators which would ultimately reduce the presence of unmet information needs for a larger number of family caregivers. Longer term goals are for changes in behaviours and practice and for better trained staff (beginning at university level) with consistent and continued sharing of expertise between specialisms in partnership with family caregivers.
It is also the suggestion of the family caregivers in this study, that there be dedicated staff or co-ordinators for people with learning disabilities who require palliative care, to assist navigation of the Health Care system and services for the family caregivers. The reduction of unmet information needs may in the longer term reduce unnecessary hospital admissions for people with learning disabilities at end of life, enabling them to die in their own surroundings, surrounded by those important to them. Being able to carry out this advanced plan reduces distress for family caregivers and promotes more meaningful coping and wellbeing into the bereavement phase. Overall outcomes provided this direction and sequence of short- medium-long term goals, in the order that they would most likely be achieved, rather than mapping a specific timeframe, as suggested by the University of Wisconsin (2003).

The logic model draft concluded with identified assumptions: that learning disability and palliative care services are committed to working together in partnership with family caregivers; that family caregivers are willing to work as care partners; that there are external factors which may influence the logic model processes and components including resources, funding, staff training; and that there is consistent preparedness of stakeholders and availability to employ sustainable long term solutions.
Evaluation of existing resources, planning for next steps such as piloting of co-ordinators for people with learning disabilities who require palliative care, or development of new resources that are specific to the information needs of this population such as a one stop information sheet are all suggested, but require further funding, development and research in order to progress these recommendations further.

In the interim this logic model communicates recommendations that can realistically improve existing systems for family caregivers in meeting their information needs and addressing the more common information gaps in relation to advanced diseases. It is hoped this logic model will have positive influences on policy, education and further research. These are further discussed in chapter 7.

5.4 Reflexive Annotation

Iterative consultation with members of the research supervisory team helped to ensure categories and themes were a fair representation of the data findings, and that quotes displayed were appropriately communicating these. Due to personal experience the researcher was aware of the often talked about ‘fight’ for services, and so whilst making sure this point was highlighted, existing knowledge of historical problems was kept separate from the data.
5.5 Chapter summary

This chapter presented the qualitative research findings from both the family caregivers and the Health and Social Care professionals who participated in this study. The aim of determining the information needs of this population has been addressed, and the information needs reported, and how they can be best addressed visually presented in the co-designed logic model.

Findings from family caregivers showed there is a variation of information need which was shown in some cases to change over time. The most important information need identified was concerning information and education on the disease and palliative and end of life care. Information need around finances, practical support, psychosocial support and respite was also identified. At times there were also more than one existing information need for participants, which compounded the burden associated with caring.

Information was seen as a facilitator for support and also influenced by factors such as early identification of palliative care need, staff training needs and communication across Health and Social Care disciplines. Participants from the interviews recommended that information need should be assessed and delivered face to face. Health and Social Care professionals agreed in acknowledging the multiple and changing information needs that they perceived existed for these family caregivers.
Findings from focus groups concurred that information was important to facilitate timely referrals for the right support. Focus group participants also identified the pertinence of information on the disease, on financial support, practical support, and emotional support. As with the family caregivers focus group findings alluded that this community of carers would benefit from core staff, in order that important information need was identified and delivered by familiar staff, whilst enhancing communication and consistency of care.

Adequate information provision was perceived to reduce family caregivers reaching crisis point and subsequently presenting to acute hospital settings. Staff also identified the need for open discussions and information giving around death and dying in palliative care, particularly in learning disability where there are frequent issues with capacity and consent. Both family caregivers and Health and Social Care professionals promoted the use of advance care planning.

Findings from all participants highlighted the learning needs of professionals to equip them work with people with learning disabilities and subsequently their family caregivers in order to meet their information needs. Ultimately new insights are presented on the information needs of family carers of this specific population, of people with learning disabilities who require palliative care.
Findings reflect the need for consistent holistic needs assessments and support planning for family carers, which are carried out one to one, by core staff or key workers, in order to identify the information needs present and organise support to meet these. There are existing materials circulated by Health and Social Care Trusts that may support family carers in meeting their information needs, however these are not readily available and there is a reported lack of awareness from family caregivers and staff of what is actually out there.

The final findings support other research findings suggesting joint working and partnership working between multidisciplinary staff and family carers in order to facilitate good communication, coordination of care and assessments, all of which assist staff to meet the information needs of the family carers. Front line staff also have identified training needs around learning disability, and carers have outstanding training needs for palliative care training and education.

The logic model in Figure 5.3 lays out these findings and translation into a format that communicates what we can do, through what means, and to promote which outcomes. The following chapter discusses, compares and contrasts the research findings in context to existing regional, national, and international research literature and policy.
Chapter 6 Discussion of findings

6.1 Introduction

The aim of this study was to determine the informational needs of family caregivers who provided care to someone with a learning disability who required palliative care. Further objectives of the study were to establish the perceptions held by Health and Social Care professionals of the information needs which existed for this family caregiving population. Thesis findings have brought to light the multifaceted information needs of family caregivers which are influenced by several factors at the interface of palliative care and learning disability services. Through also providing multidisciplinary Health and Social Care professionals a platform, the study has gained insight into the similarities and disparities between what information needs existed for these family caregivers and what information needs Health and Social Care professionals perceived existed.

This study collaborated with family caregivers, of people with learning disability requiring palliative care, from the beginning in adhering to the EBCD approach as previously discussed. Accordingly, the final stages of the study involved liaisons with an expert reference group facilitating the translation and transference of study findings to practice, reflected visually in the co-designed logic model.
Study conclusions are summarised into main fundamental points:

- A key finding is that new insights not previously explored with this family caregiving population have been obtained, and identification of the various and co-existing information needs of family caregivers of people with learning disabilities who require palliative and end of life care, which are individualised and can change over time. Information needs pertaining chiefly to the disease and its trajectory, followed by information regarding financial assistance or aid, and practical support and respite.

- There is a need identified for these family caregivers to have consistent one to one individualised holistic needs assessments and support planning in relation to the spectrum of potential information needs, carried out by familiar staff such as key workers. Appointment of dedicated co-ordinators has been suggested, for people with learning disabilities who require palliative care and their family caregivers.

- Findings report poor awareness of materials that are already available and that could be used to address the information needs of family caregivers providing care to people with learning disabilities in a palliative care context.
• Partnership working and collaboration of staff across learning
disability and palliative care disciplines with family caregivers
as experts at the centre, is required to connect services through
positive communications, whilst promoting shared learning to
identify and meet the information needs of this population.

• There is an identified need for front line staff to undertake
training in learning disability in primary care settings utilising
the expertise of family caregivers, and in a palliative care
context, and for family caregivers in learning disability to be
offered training on palliative and end of life care.

Conclusions from this study are further discussed in this chapter in
context to previous research, how it compares and contrasts, links in
with relevant policy, and how it adds to earlier research and provides
new insight in an area little was known about. Following discussion of
each finding, recommendations will be drawn and presented in the
following chapter in the format of research recommendations and
implications.
6.2 Various co-existing information needs

The findings of the study show that family caregivers of people with learning disabilities who require palliative care have many information needs, sometimes more than one, and information needs that can change over time. The presence of unmet information needs was cited by all family caregivers.

The leadership alliance for the care of dying people’s ‘One chance to get it right’ document (Leadership Alliance for the Care of Dying People (LACDP), 2014) outlined within its five priorities that the needs of family caregivers should be identified and explored. Findings from this study provide new evidence on the identification of particular information needs of this population of family caregivers. The data from this study can also help inform regional carer initiatives, by facilitating input, from this caregiver group, throughout this study and contributing to the evidence supporting carer involvement.

Family caregivers, who participated in the study, were presented with a situation where the person they cared for was diagnosed with an advanced disease warranting palliative care. As a result of this event there were reported unmet information needs pertaining to the disease, the illness trajectory, palliative care, and the dying process. These information needs were not met by Health and Social Care Services.
Other information needs which were unmet concerned financial support, entitlements or benefits, practical support and psychosocial support. This resonates with Carers UK’s (2014a) previous deposition that health and social care services may inadvertently neglect the needs of family carers, leading to unmet financial, psychosocial, educational, practical and information needs.

These holistic support and information needs are important when considering the theoretical underpinning of the Stress and Coping theory (Lazarus and Folkman, 1984) as they are influential in determining whether or not a family caregiver positively adapts to this unfavourable event or outcome, to promote sustainable coping mechanisms in the event of other every day stressors which contribute to overall carer burden.

The presence of unmet information needs compromises the ability of a family caregiver to utilise emotional and problem based problem solving, depending on the type of information required. Supported by the work of Hudson (2003) lack of appropriate, useful and timely information can be a barrier to meaningful appraisal and re-appraisal of stressful events, which then lead to more unmet needs, uncertainty and negative stress.
This study supports these assumptions and how understanding of them is crucial to supporting family caregivers in their role in caring for someone with a learning disability who requires palliative care, as lack of information and unmet information needs impact upon how much of a threat of harm they perceive from stressful events and situations associated with their role. If they are unequipped they will not cope favourably, which will potentiate and perpetuate existing needs for information and increase carer burden.

Study findings concur with previous research in the international palliative caregiving literature such as that of UK based Rose (1999), Japan based Fukui (2002) and Lin and Tsao (2004) in Taiwan, in respect to information needs. All three of these studies looked at informal or family carers of people with Cancer. In this study, however family caregivers were providing care for a spectrum of conditions requiring palliative care, inclusive of Cancer, but also including end stage dementia and neurodegenerative conditions. The limitations of information needs relating only to cancer caregiving are that they may not be generalizable to family caregivers of people with other advanced diseases or with learning disabilities.
How certain diseases manifest and the supports that are in place for other illnesses may not be as well recognised or available for family caregivers, furthermore, as Cancer is one of the top causes of death in NI (NISRA, 2017) people with cancer and their family caregivers are more easily identified and referred to specialist palliative care services in a timely manner. Aspects of the results from these Cancer based studies; however support findings from the family caregivers in this study, in identifying that information on the disease and prognosis were paramount. Rose (1999) also concurred that information needs can change over time.

Similar to findings from this research Rose (1999) also acknowledged information needs as individualised and that they may be different from carer to carer. As well as this, two systematic reviews conducted in the UK, also within the context of informal caregiving in palliative care (Docherty et al, 2008) and end of life Cancer (Bee et al. (2009), suggested that poor exchange of information led to a reduction in practical supports and that there was an existing problem of inadequate information on disease progression and education.
Supporting research conducted in Australia and Sweden (Janze and Henriksson, 2014; Carlander et al, 2011; Hudson et al, 2010) also found that family caregivers explicitly reported the need for informational materials to educate caregivers through knowledge on the disease, practical instructive information to assist in the role practically, information relating to training on medication or equipment, information on coping, respite and psychosocial support was also identified within these studies.

Educative information was highly regarded as with this study to reduce uncertainty around how the disease would manifest and how much time a person would have left to live. Also corroborating this evidence was a review specifically looking at the information needs of people with Diabetes at end of life in the Netherlands (Dikkers et al, 2013), recurrent themes included the need for information on end of life stages, decision making involving carers, and preparation for end of life, all of which were issues raised by the family caregivers in this study. From a theoretical perspective, this preparatory information parallels with Lazarus and Folkman (1984) and Hudson (1984) and may be seen as a tool to facilitate more effective problem and emotion based coping, reducing uncertainties and enhancing meaning in an end of life scenario.
Nationally, a UK study looking at family caregiver experiences in relation to non-malignant chronic kidney disease also showed findings consistent with this study, with information needs reported in respect to education on the illness or disease and the importance of how the disease was managed practically, taking into account symptom management, medications and basic nursing care (Low et al, 2014).

A further UK study conducted by Harrop et al. (2014) exploring the information and support needs of family carers at end of life similarly found unmet information needs in relation to education on the disease and death and dying. Similarly carers in this study also reported gaps in relation to information on basic nursing care, equipment, medication, manual handling, and dietetics. Participants in the Harrop et al. (2014) study asserted that at times there was uncertainty as to their caregiver role and competence level and similar issues were highlighted in this study in that family caregivers were providing care beyond what would be expected from a paid carer.
Ambiguity and uncertainty around what was expected from the role and what to do practically in the home setting was also highlighted by the family caregivers in this study, attributable in part to the involvement of Health and Social Care professionals from both learning disability and palliative care services, with no definitive consensus on who was responsible for certain tasks and implementation of particular services and supports. Subsequently for the caregivers in this study and those in the Harrop et al. (2014) study, this manifested in information needs in relation to how to manage care practically alongside the increased responsibility of administering new medications and in some cases dietetics and oxygen therapy.

As with the participants in the Harrop et al. (2014) study there was supporting evidence from this study that knowing what to expect in relation to the disease trajectory reduced anxiety and distress, and increased preparedness and competence. Philip et al. (2014) also concur that lack of information on the disease or practical nursing care and services contributed to gaps in caregiver knowledge, uncertainty in relation to disease trajectory, poor awareness of services, and late referral to specialist palliative care services. Therefore, despite family caregivers in this study being caregivers of someone with a learning disability, there were similar issues reported and similar information needs.
Further evidence from the US sought to understand the experiences of family caregivers seeking hospice services when supporting someone with Dementia (Lewis, 2014). Findings from Lewis (2014) are consistent with this research in raising issues about inexplicit or inconsistent information around palliative care and the financial burden involved in providing care. In this current study, insight was gained into how existing provision of care was ineffective at meeting the information needs of family caregivers in relation to palliative care and education on the disease, for reasons including late referrals to specialist palliative care services and poor communication between professionals and family caregivers.

Participants perspectives revealed a lack of assessments completed with family caregivers once they entered into palliative care services, with the few caregivers who had assessments of need completed by learning disability services prior having no reassessment. There were identified inconsistencies around whose responsibility it was to complete these assessments or to provide information. Discussion of death and dying provided barriers to information sharing. Some family caregivers were not accepting of a diagnosis and not open to receiving information on the disease and its trajectory at point of diagnosis, information was not offered at the later stages as a result. This compromised the ability for family caregivers to earlier appraisal of what they perceived theoretically as a harmful event, which impacted upon capacity to then implement meaningful re appraisal and positive coping mechanisms.
In learning disability services and palliative care services there was some professional knowledge of what resources and entitlements were available to family caregivers, however this was not always transparent and participants reported having to be proactive in asking for information and support. Less earnest and resolute caregivers did not receive information if they did not ask. The inability of the family caregivers of people with learning disabilities in this study to work or hold down part time employment introduced financial hardship due to the full time commitment of caregiving over several years. Many reported that they were never informed verbally, or provided with any information on financial relief that they may be entitled to.

The financial strain may be more pronounced for the caregivers in this study, as there was a longer period of time caregiving. New knowledge generated from this research shows family caregivers providing care to someone without a disability in a palliative care context may not have such issues with continuing employment, or the shorter time period of providing care may not introduce as many financial issues.
In support of findings that lack of information often led to family caregivers reaching crisis point and presenting to acute hospital services, this unfavourable outcome or negative stress is predicted as a result of a perceived inability to cope in a situation (Lazarus and Folkman, 1984), or a lack of problem based coping (Hudson, 2003). Harrop et al. (2014) also found that the information gaps led to unnecessary hospital admissions.

The participants within this study reported similar situations in presenting to Accident and Emergency (A&E) departments at a time of crisis, leading to caregiver distress and in some occasions full admissions, which may have been avoided with adequate information provision. As with the family caregivers in this research, Philip et al. (2014) also found that information was seen as a facilitating factor for caregiving, by assisting the role practically. More recent research also supports study findings that there is a general lack of information or resources, or the presence of unmet information needs amongst family caregivers in a palliative care context (Towers and Glover, 2015; Kaltenbaugh et al, 2015).
The pertinence of information for family caregivers is consistent across the international research literature in palliative care, with White Paper recommendations (Payne et al, 2010) at European Level for family caregivers in palliative care. The DHSSPS (2010a) have also highlighted that information alongside the correct support is essential to facilitating shared decision making, better care and outcomes, whilst reducing costs for the economy. Existing literature in palliative care agrees that caregiver needs and autonomy may be neglected due to lack of information on support, particularly in respect to coping and respite (Philip et al, 2014; Carlander et al, 2011).

Findings from this study are supported by evidence from the palliative caregiving literature (Kaltenbaugh et al, 2015; Towers and Glover, 2015; Harrop et al, 2014; Lewis, 2014; Low et al, 2014; Philip et al, 2014; Payne et al, 2010). This existing literature also provides interesting insight into the information needs of family caregivers of people who have Cancer or who require palliative care and end of life care. However, family caregivers of people with learning disabilities who require palliative care have been shown in this study to have a wider scope of unmet information needs due to the involvement of multiple agencies and inadequate communication and training needs of professionals.
In the literature family caregivers of people with learning disabilities who require palliative care remain under studied. However, within the learning disability literature there is supporting evidence from McLaughlin et al. (2014a; 2014b) that there is a requirement for an increased provision of information, delivered in a timely manner, for family caregivers of people with learning disabilities who require end of life care. As with the participants from the interviews in this current study, information around benefits, financial entitlements and about the diagnosis itself was important to the family caregivers. Moreover, McLaughlin et al. (2014a; 2014b) reported in their findings that any information that was obtained by the family carers was self-sought, which was the case with some of the family caregivers interviewed for this study.

Following an independent investigation into reports of substandard care for people with learning disabilities at their end of life, the Michael (2008) report recommended that Health and Social Care services are responsible for providing the correct information to family caregivers to enable them to avail of the support that they need. Within the general learning disability literature, a Canadian based systematic review conducted by Balogh et al. (2016) concurs with Health and Social Care professionals in this study in speculating that the most effective way to organise services for people with learning disabilities and their family caregivers.
Findings from Balogh et al. (2016) suggest that organising care for people with learning disabilities and their caregivers should be similar to care provision for service users with chronic conditions such as heart failure, diabetes and chronic obstructive pulmonary disease. The systematic review agrees with data from this study that integrated care across settings, offers a solution as to how the specific needs of people with learning disabilities and their caregivers can be met.

Similar to findings in this study, in other learning disability literature Chadwick et al. (2013) found that communication and availability of information surrounding services, supports and entitlements were pertinent to family caregivers. Participants also concurred with family caregivers in this study in citing lack of respite and the need for their role as advocate when it came to ‘fighting for services’ (p.125) and information.

In Taiwan Chou et al. (2007) investigated specific stresses and difficulties faced by family carers of people with intellectual disability. Similar to participants in this research, study findings highlighted that information and signposting to financial support was considered significant. However, the study by Chou et al (2007) only explored carers of people with intellectual disabilities, without a palliative care diagnosis.
The Chou et al. (2007) study does however go some way to support that there will be an already existing financial burden and, therefore need for information on financial support once the person with a disability receives a palliative diagnosis. The Department of Health’s (2013) ‘Transforming your Care vision to action report’ recommended that carers receive direct payments and highlighted the Carers and Direct Payments Act (NI) 2002 in relation to Health and Social Care trusts’ responsibility to meet the financial needs of family carers.

In a palliative care context, Bekkema et al. (2015) evaluated perspectives of relatives, paid carers, and Health and Social Care professionals at the end of life of people with intellectual disability in the Netherlands. Findings support those reported by family caregivers in this study in recognising the importance of how pain and distress are interpreted and the increased responsibility for decision making.

Despite not looking at the information needs of family caregivers, Bekkema et al.’s (2015) results confirm data from this research in suggesting therapeutic relationships between family caregivers, paid carers and professionals, fosters responsive co-operation and shared care. The focus however of Bekkema et al.’s (2015) research was on paid carers and recommendations for how to better support them only.
Findings presented in this thesis provides evidence that family caregivers of people with learning disabilities who require palliative care have similar information needs to other family caregiving groups in a palliative care context, such as information need in relation to a diagnosis or education on a disease. However, what this study adds is to highlight that the information needs of this population are more individualised and complex due to the increased psychological and financial burden of providing care to someone for many years.

For some family caregivers who participated in this study, there was a diagnosis of life limiting illness before the person with a learning disability reached adulthood. Consequently their increasing complex caregiving role extended over an even longer period of time. As a result these family caregivers had the added physical and psychological burden of providing care over this lifespan, as well as the presence of financial hardship. This is of importance at policy level as there are currently 72,630 carer applications for financial allowance in NI, with only 46,090 in receipt of this entitlement (Northern Ireland Assembly (NIA), 2016).

This leaves a large remainder of carers in need of financial aid who are not meeting the criteria for these entitlements. Financial hardship may intensify the level of threat of harm a family caregiver perceive and their ability or inability to cope with it. Financial stress leading to poor coping mechanisms can lead to further stress creating more unmet psychological needs.
Considering the transactional model of stress and coping by Lazarus and Folkman (1984), an increase in unmet needs may compound carer burden which may ultimately prevent successful adaption to the situation and role as a family caregiver. In order to effectively provide care for person who is important to them the caregiver must also be supported. Findings from this research build on the assertion that information is an important resource in the provision of support for family caregivers.

Findings from this study also showed that holistic supports that were in place in children’s services were not maintained once the person transitioned into adult services. Family caregivers reported there to be no equivalent and as a result they were left with unmet information needs in relation to practical support, financial assistance and respite. The emotional and social impact upon a family caregiver who identified only as a caregiver rather than a husband, wife, mother, father, sibling or friend, with no life outside of this role, was evident from participants in this study.

Additional information needs were revealed in respect to emotional support such as counselling or practical support such as respite. This is recognised by the national Carer’s Strategy (DH, 2008a) in promoting a central concept of carers having ‘a life outside of their caring role’ (p.10).
Collins and Swartz (2011) agree and recognise that as conditions become more complex with around the clock care, the caregiver can suffer physically, psychologically and financially whilst undertaking their normal everyday activities of living such as managing existing responsibilities and household tasks.

Again, there may be a distinction between the family caregivers in this study, and those who are providing care to someone without a learning disability who requires palliative care, due to the much shorter associated trajectory of care, and so the burden associated with caregiving and the impact it has upon the individual’s information needs may be greater. There was an identified need for advance care planning for people with learning disabilities, participants promoted the provision of information that was anticipatory of issues that may arise in palliative care.

Anticipatory information has been previously endorsed by Lazarus and Folkman (1984) in planning ahead for practical, financial, emotional or psychological support. In the palliative caregiving literature Grant et al. (2013) further supports this assertion reporting that information is important and central to decision making in preparing carers for what to expect. In general, lack of information and support has been shown to compound the burden of caregiving responsibility in the palliative care literature (Harrop et al, 2014; Lewis, 2014; Philip et al, 2014; Hudson and Aranda, 2013).
Participants from this study confirm that information can help alleviate carer burden, and report a wider scope of informational need when providing care to someone with a learning disability who requires palliative care. With family caregivers of people with learning disabilities who require palliative care there appears to be a greater fallout when entering the bereavement phase, due to loss of a longer term identity and role as a care provider. As a result family caregivers are more vulnerable to psychological distress and financial suffering into and after the bereavement period. After the death of the person, the family caregiver may drop off the radar of existing services such as learning disability services that may have previously been central to the person and family, and provided support.

In New Zealand, Marlow and Martin (2008) conducted a small qualitative study with family carers (n=5) of people with intellectual disability who were dying. Recommendations from this study included ongoing information for family caregivers, accessible over the 24 hour period, and to continue once the person has died as often there is a reported disconnect from intellectual disability services at this stage; all of which confirm the data from this study. As discussed, due to the many years spent caring and the increasing age of this population of caregivers there is a struggle to find employment post bereavement, as well as mend relationships, or forge new social circles, all whilst grieving the loss of the person who was central to them and their life.
It is at this stage of the palliative and end of life care continuum that the family caregiver’s information needs may transition to information on psychological or social supports and there may be increased need for financial assistance or aid, or simply employment advice required. There is a dearth of published research in relation to family caregivers of people with learning disabilities in a palliative care context, with no identifiable evidence relating to their information needs. This research provides confirmation in support of previous caregiving research, demonstrating similar information needs in this particular population of caregivers to others, whilst adding fresh evidence and new insight as to the different information needs that exist.

6.2.1 Identification of information needs

In order to determine the information needs of family caregivers, they must first be identified. This is supported by the recent ‘Power to People’ proposal (Kelly and Kennedy, 2017) that there must be earlier identification of carers in order that important information can be shared with them. A census conducted in 2011 identified 43,674 caregivers within Belfast alone, meaning almost one in eight people of the population in Belfast have a caring role (Northern Ireland Statistics and Research Agency (NISRA), 2011).
In researching the information needs of family caregivers of people with learning disabilities who require palliative care, study findings also revealed the lack of identification of palliative care need in people with learning disabilities, which was suggested as the result of poor training and awareness of learning disability and the challenge of assessing someone with a learning disability for a palliative illness. Issues reported from the family caregivers in this research around late diagnoses due to misdiagnosed symptoms support previous assertions in the literature that late palliative diagnoses can occur in people with a learning disability due to a lack of adequate screening by, for example, General Practitioners (GPs), or due to diagnostic overshadowing (Tuffrey-Wijne and Mclaughlin, 2015; Heslop et al, 2013; Reiss et al, 1982).

This was the case with some family caregivers in this study, where the person with a learning disability was diagnosed at the later stages of the disease due to symptoms being overlooked. Initial manifestations and symptoms were attributed to the person’s learning disability, which resulted in the presence of unmet information needs in relation to the disease and the prognosis. Towers and Glover (2015) agree with family caregivers who participated in this study that if the person being cared for had an advanced disease that was specifically linked to ageing in learning disability, such as Down Syndrome and Dementia, then early signs of this should be identified by a GP or a Consultant in a timely manner.
Family caregivers expressed reported mixed relationships with GPs in their interviews, alluding to mistrust and unwillingness to attend the GP surgery on a regular basis for health surveillance. Late diagnoses led to late referrals to palliative care services; the family caregiver by this stage was without important information about the disease and its trajectory. However, in the case of Wilson and Mansell’s (2010) study exploring access to information and services for caregivers of people with intellectual disabilities, the GP was viewed as a positive point of contact, though this was in relation to obtaining information regarding services and not in respect to a palliative diagnosis.

McLaughlin et al.’s (2014a) research supports this with findings from this study promoting early referrals of people with learning disabilities to palliative care services, with the building of trusting relationships between family caregivers and professionals. Participants in the McLaughlin et al. (2014a) study were similar to the family caregivers in this study in that they provided care to people with learning disabilities at end of life, however this study adds new data in relation to the family caregiver information needs which exist.
This study reinforces previous research and practice standards that once a GP or a hospital Consultant makes a palliative diagnosis the family caregiver should then have a full needs assessment, where the study builds on this previous knowledge is to promote the early identification of specific information needs, in order that tailored support can be put in place earlier which can enhance and foster sustainable meaning based coping strategies.

Due to the increasing number of people with learning disabilities developing life threatening illnesses which require palliative care Vrijmoeth et al. (2016) explored how physicians identified a need for palliative care in people with learning disabilities in the Netherlands. In agreement with this study it was found that there are identification issues and uncertainties around diagnosis, which can rely upon how the patient communicates, and dependence on learning disability physicians.

Vrijmoeth et al. (2016) suggest their study findings provide insight into how this can be remedied and palliative care need better identified. Awareness of signals from someone with a learning disability such as changes in normal behaviour(s), decline of daily function or quality of life, poor recovery from an illness, or recurrent somatic issues can assist in the earlier recognition of palliative care need.
These findings support the data from participants in this study that there needs to be earlier recognition palliative care need and subsequent referrals. Vrijmoeth et al. (2016) also concur with findings from this study that earlier identification can facilitate early intervention and family caregivers should be listened to as a source of information, as the experts on their family member’s behaviour(s) and characteristics.

Existing sources in both the learning disability and palliative care literature concur with participants in this study that Health and Social Care professionals have a significant role in identifying and addressing information needs, as they may be the gatekeepers to valuable services and support, particularly in specialist service areas such as learning disability and palliative care (Harrop et al, 2014; Philip et al, 2014; Wilson and Mansell, 2010). Kirkendall et al. (2012) also provide supporting evidence stating that open and honest communication to identify the needs of caregivers of people with learning disabilities, in a palliative care context; will in turn foster a more therapeutic relationship between caregivers and professionals, which therefore promotes the identification of information needs early.
Late identification of a palliative disease in people with learning disabilities has implications for the care and support that they and their family caregivers receive, which may be minimal, rushed, or short term due to the later stages of the disease. This study supports previous evidence for more robust early screening needs and consistent surveillance during the course of the disease and its progression (Tuffrey-Wijne et al, 2016; McLaughlin et al, 2014a; 2014b).

Other research in learning disability has recognised this in promoting breast mammography screening for early detection and intervention of breast cancer, whilst increasing awareness and knowledge of breast cancer in females with learning or intellectual disabilities (McIlfatrick et al, 2011; Taggart et al, 2011), however it is clear years later from these study findings that this remains an issue for the learning disability population in Northern Ireland.

Participants in this study suggest better communication and joint working between the family caregivers, primary care and learning disability services, in order that identification problems are reduced. These important influences on information needs can promote more effective and consistent assessment of need and delivery of support, particularly in respect to those caring for adults who have transitioned from child services. As well as timely identification of advanced disease requiring palliative care there were other influences that had an impact upon the information needs identified in this study.
General access to information was a reported barrier from family caregivers and identified by Health and Social Care professionals, this supports previous research such as that of Lunsky et al. (2014) conducted in Canada, in recognising that there was unequal provision of services and supports for family carers of adults with intellectual disabilities. This system wide scoping review recognised that each country had its own services and policies; however, service provision was dependent on population characteristics and provider supply. Lunsky et al. (2014) highlighted similar issues with the use of services and permanency planning, which is consistent with the wider issue of navigating care across settings identified in this study.

In respect to systemic barriers reported in this study findings concur with Afram et al. (2015) in caregivers issues with navigating the care system and access to services. This is in accordance with the DHSSPS (2010b) recommendation that family caregivers should have access to relevant and appropriate information. The DHSSPS (2010b) also agree that family caregivers must have 24 hour, 7 day a week access to information across all care settings. In relation to access to information, family caregivers in this study are supported by previous literature in feeling that they had to ‘fight’ in order to get information, services or support (Chadwick et al, 2013). This is further supported in the literature by Washington et al. (2011) in that health care providers must prioritise family caregivers’ access to information and support in order to meet their individualised needs.
6.2.2 Influence of Carer Burden on information needs

Lazarus and Folkman (1984) and Hudson (2003) provided theoretical insight into the demands of family caregiving as a stressful role in connecting stress and coping, demands and burden, availability of resources, and access to information. Previously Payne et al. (2010) recognised that the grief associated with someone being diagnosed with a life limiting diagnosis would have a substantial impact upon a caregiver, with common manifestations such as anxiety, stress or depression, which would impact on carer burden.

Findings from this study resonate with the stress and coping theory and family caregivers reported manifestations such as those predicted by Payne et al. (2010) which led to information needs relating to psychological and practical support, and respite. Policy and literature have formerly acknowledged the burden associated with providing care in general (Carers UK, 2014a; DH, 2008a). In supporting the existing discussed literature (Low et al, 2014; Philip et al, 2014; Grant et al, 2013; Payne et al, 2010) findings from this research study demonstrates that unmet needs such as information needs influence carer burden, and the presence of carer burden can in turn influence the scope of information required to support caregivers to cope in their role. For example, poor provision of information in relation to finances, entitlements and benefits can increase financial strain, which then impacts upon the quality of life and emotional wellbeing of the family caregiver.
Another influence on information need is the willingness of the family caregivers to engage with services and Health and Social Care professionals. As previously mentioned there was the presence of mistrust towards professionals and an element of protection of the person being cared for, particularly in relation to shielding the person from the diagnosis, the existence of family caregiver denial, and feeling that any engagement with services to request an assessment for help would be an admission of not coping in their role as family caregiver.

Wilson and Mansell (2010) support this with their findings that family caregivers of people with learning disabilities had poor access to and relationships with allied health professionals outside of the GP, and that only those caregivers who were emphatic and assertive were able to gain information. However, this information and support was self-sought from friends, family, charities or groups rather than from health professionals.

Individualised information needs reported in the data from the study were further influenced by the situation of each family caregiver, taking into account where the person with a learning disability was on the palliative care trajectory, if existing supports were in place, the caregiver’s coping mechanisms, level of carer burden, and the age and relationship of the caregiver to the person with a learning disability.
Participants in this study cited the existence of difficulties around breaking bad news, diagnosis and talking about death and dying. Participants inferred this created a barrier to identification of informational needs and the provision of informational support in relation to palliative care and bereavement; advance care planning was also hindered by these difficulties. Bekkema et al. (2015) provides some supporting evidence for this evaluating the perspectives of relatives and professionals at end of life for people with intellectual disabilities and findings showed shifts in the approach of care at end of life including overlap of emotion and professional involvement and increased responsibility for decision making.

The Department of Health (DH, 2008b) previously highlighted the issues with open discussion around death and dying in Health and Social Care, stating staff may not be adequately trained to have these conversations. Findings from this study suggest that there is an element of protection and willingness to advocate decisions for the person. This family collusion may be present in similar situations where a person is receiving palliative care, however there seems to be already existing overprotection of the family caregiver towards the person with a learning disability, which is only heightened once a palliative diagnosis is made.
As a result, the person who requires palliative care can be hidden from Hospice and health care facilities, which may be able to provide the right care and support needed, including the provision of information that may be important to the family caregiver, particularly as palliative care incorporates holistic care of the family (NCPC, 2015). This supports the recommendations from Michael (2008) for an increased understanding of learning disabilities in palliative care and end of life care, with specific education for palliative care staff in order that they can work effectively in partnership with family caregivers at the end of life stage.

Participants in this study associated palliative care with Cancer and imminent death, which in 2017 corroborates a much older assertion by the National Council for Hospice and Specialist Palliative Care Services (2004) that palliative care in the UK has been historically funded by cancer charities resulting in systemic inequities, leaving those with non-malignant disease in receipt of unequal Health and Social Care services and supports.
Moreover, Radbruch and Payne (2010; 2009) reported that inequities still existed in that palliative care provision was predominantly supplied to people with advanced Cancer, despite many people with non-malignant diseases having the same palliative care requirements. It is important that now the direction of policy is served towards palliative care for all chronic diseases, with reasonable adjustments for those with learning disabilities in order that their family caregivers are supported in having their information needs met (Tuffrey-Wijne et al, 2016; DHSSPS, 2010b).

6.3 Holistic assessment and support planning to meet information needs

The majority of family caregivers in this study were either not offered an assessment; a few had received an assessment, but had no subsequent support as a result. Health and Social Care participants on the whole were aware they existed, but were not utilized routinely. As family caregivers cited multiple information needs across the holistic support spectrum it was important that an assessment took place to identify these, however this was not the case. Kelly and Kennedy’s (2017) ‘Power to People’ proposal to ‘reboot adult care and support in NI’ published by the Department of Health supports this in one of its priorities ‘Supporting Carers’ (p.26), in addressing the limited information and support available to carers.
It also reports that there is a lack of a statutory basis for caregivers’ assessments and support plans in N.I., with attention brought to the fact that in N.I. Health and Social Care Trusts have no binding obligations to support caregivers (Kelley and Kennedy, 2017). It is for this reason information and resources must be readily available to respond to these assessments. It is this information that may go some way in explaining the lack of awareness and of assessments offered to the caregivers in this study, and the under usage and lack of assessments undertaken by appropriate Health and Social Care professionals.

As well as this Carers UK (2016) highlighted that 22% of carers (1 in 5) reported they did not know where to find the information they needed, nor were they offered information that was helpful in relation to caring which impacted upon their physical health, mental health, social lives and ability to work. Previous sources affirm that local authorities should have a duty of care to family caregivers in offering holistic needs assessments and identifying information needs (Carers UK, 2014a; DH, 2008a; DH, 2006). In the UK, Ewing and Grande (2013) developed the evidence based carers’ support needs assessment tool (CSNAT) which aimed to measure holistic support needs, to meet the information and support needs of caregivers of people with life limiting illnesses.
Through a five stage approach, 14 broad topic areas in relation to education on the presenting illness, death and dying, financial entitlements, work issues/social issues, practical support, respite and emotional support are assessed (Ewing and Grande, 2013). Ewing and Grande (2013) showed the importance of a named contact to direct carers to information, services and support.

Study findings approve the findings of Ewing and Grande (2013) and support the wider literature in recognizing that caregivers require a consistently utilized needs assessment tool in practice, which recognizes the full spectrum of holistic needs and acknowledges the importance of assessing the need for tailored information. A systematic review by Hudson et al (2010) concerning family caregivers in palliative care in Australia also provided evidence at that time that there were inadequate and inconsistent assessments for family caregivers in order to provide information and education, and direct them to therapeutic interventions and support.

More recently ‘Transforming your Care’ (DHSSPS, 2011) provided guidance on recognition of information and access to services for people with learning disabilities and their caregivers. Further to this the ‘Transforming your Care Vision to Action Report’ (DHSSPS, 2013) recommended that Health and Social Care Trusts assess information and support needs and provide services to meet these needs.
However, this research demonstrates that assessments, support planning and access to certain services is not regular practice. Accessing information and support through the medium of assessments were also key themes in the Chadwick et al. (2013) study with family caregivers of people with intellectual disabilities in Ireland. Although the family caregivers in the Chadwick study were not involved in palliative care, this study supports conjecture that once a palliative diagnosis is made in someone with a learning disability, such as with those in this study, then the importance of assessments and support planning to identify information needs becomes an increased priority.

6.4 Lack of awareness of existing family caregiver resources
Findings from multidisciplinary Health and Social Care participants in this study highlighted that there were existing resources available for family caregivers, in both palliative care and learning disability. These resources that may have met at least some of the information needs of the family caregiver participants in this study, and these included information packs and websites run by charitable organisations such as Marie Curie and MacMillan. Signposting to existing informational resources was dependent upon the Health and Social Care professional’s knowledge of the resources or materials.
One family caregiver was signposted to information and training specific to the disease itself (Dementia) and how it manifested in someone with a learning disability; however, this was not common practice and was due to the knowledge and good communication of one Health and Social Care professional in the community learning disability team. Some family caregivers were aware of some generic websites, which they could access such as that of Carers UK (www.carersuk.org). However, many felt that this was not suitable or relevant informational resources to their particular situation of providing care to someone with a learning disability with a palliative diagnosis. Most family caregivers were not aware of the resources and information on financial assistance such as the direct payments initiative (DHSSPS, 2013; Carers and Direct Payments Act (NI), 2002).

Rose (1999) agrees in that family caregivers are unaware of what is out there and in doing so recognised that Health and Social Care professionals should be responsible for providing existing informational resources or signposting to them, thereby facilitating the meeting of information needs via use of existing resources. Shanley et al. (2011) support this in reporting that caregivers could not access existing information and resources due to lack of co-ordinated support. Specifically, in NI, Carers at the heart of Belfast (DHSSPSNI, 2010) introduced carer postcards to reach carers and give them an opportunity for engagement with services.
Stands were set up at hospital sites and there was also social media promotion. None of the family caregivers in this study were aware of this. Nor was it raised by Health and Social Care professionals. One caregiver recognised that there was a carers’ register, but this was simply a mailing list and not a point of support where information, guidance or signposting could be availed of. A recent trust initiative (Belfast Health and Social Care Trust (BHSCT), 2017) developed a one point of contact for carers, which would incorporate support planning and subsequent information giving, training and post caring support. Again, this is not something that was recognised nor identified by any of the participants in this study.

Evidence from this study reflects that despite existing initiatives, information and resources, the awareness of such resources is poor in this population of family caregivers. Study findings support the benefits of using an existing assessment tool, such as the Carer Support Needs Assessment Tool (CSNAT), to help identify any information needs which may be present for these family caregivers. However, the current awareness of the CSNAT, or consistency of use in this context remains poor.
6.5 Improving partnership working and connection of services

Family caregivers suggested in their interview that how effectively Health and Social Care professionals communicated across settings and worked in partnership had an important influence upon whether information needs were identified, and also upon what information needs were present. In the case of this study, and supporting findings from McLaughlin et al. (2014a; 2014b), this entails each service (learning disability and palliative care) being aware of the other and what the remit is of each service whilst respecting the role each service, professional, and individual has in the person’s care.

Kirkendall et al. (2012) also provides supporting evidence for this suggesting that learning disability and palliative care services need to work in partnership to support the person with a learning disability and to meet the needs of their family caregivers. However, Kirkndendall et al. (2012) reported that although these partnerships were on the increase, their effectiveness remained an area in need of more research and promotion. Findings from this research study builds on previous evidence such as that of Kirkendall et al. (2012), and provides corroborating evidence on this population of family caregivers at the interface of palliative care and learning disability services in reporting that there is still an element of disparity between these services in N.I., and how they connect in providing support for family caregivers of this population and meet their information needs.
Research findings from this study advocates previous literature that professionals across disciplines must work in partnership with family caregivers (Kirkendall et al, 2012; Wilson and Mansell, 2010) and that as with participants in this study, other research (Chadwick et al, 2013) demonstrates that through partnership working and collaboration carers want to be respected, valued, consulted, listened to, and importantly, informed. GPs and Social Workers were identified as central to those with learning disabilities and their family caregivers in this study, GPs were also identified as central and important in the Wilson and Mansell (2010) study, however, this study brings attention to the fact that social workers are key to facilitating information giving and support planning.

Findings reflect that family caregivers must be recognised as care partners, supported to have a voice, and have their own needs assessed and that Health and Social Care services play an integral role in enabling access to the right information at the right time, following an appropriate needs assessment, with consistent surveillance and re-assessment of need. This is supported in the policy and reports in relation to carers and initiatives to support carers (Tuffrey-Wijne and McLaughlin, 2015; DHSSPS, 2011; 2010b; DH, 2008a; 2008b).
Family caregivers who participated in this study wanted their long-term role, identities, and the psychosocial impact of being a family caregiver of someone with a learning disability who requires palliative care acknowledged and respected by professionals. It was suggested that this would in turn enhance communication and facilitation of tailored information and support. In order to facilitate these partnerships staff from both the learning disability and palliative care fields need to communicate effectively and engage in joint working to facilitate optimum coordination of care for the person and support for their family caregiver. Previous sources in the research literature have also highlighted these suggestions (Tuffrey-Wijne et al, 2016; McLaughlin et al, 2014a; Kirkendall et al, 2012).

Family caregivers suggested, in interviews, the allocation of a central person or coordinator, who would bridge both learning disability and palliative care services in providing the correct information for appropriate supports, at the right time. One to one support was also suggested by Ewing and Grande (2013) in relation to meeting the information, services and support needs of family carers in palliative and end of life care through use of the CSNAT. This is even more crucial when the person being cared for has a learning disability, due the increased carer burden and wider scope of information need. This substantiates Docherty et al.’s (2008) admission that for information provision to be facilitated or communicated there must be a relationship or partnership between the caregiver and staff.
A positive example of services working together across the palliative care and learning disability settings was displayed by the co-production of an informational resource in Northumberland called the Disability Distress Assessment Tool (DisDAT). DisDAT was co-developed to support people with learning disabilities and their caregivers at end of life, delivering practical information for carers in order to support them to identify and manage particular symptoms (St Oswald’s Hospice, 2015).
Elsewhere in the UK initiatives such as the ‘When I die’ leaflet produced by Calderstones NHS Trust in 2008 also recognised the need expressed by participants within this study for person centred advance care planning for those with learning disabilities, to express their wishes whilst incorporating their family caregivers. The reasoning behind advance care planning with the family caregivers is that it can enhance the earlier provision of information that can help alleviate the distress, uncertainty, and assist with difficult decisions whilst promoting psychological wellbeing. Findings presented in this thesis provide insight into the willingness of family caregivers and professionals to work in partnership in order to meet the needs of the person and the caregiver themselves.

The professionals involved in this study spoke of their respect for the role and expertise of the family caregivers, and how collaborative working would enhance shared learning and awareness. Family caregivers were willing to work in partnership in order to meet their information needs to enable them to better deliver care to their family member. However, the reality from findings demonstrates collaborative practice is minimal from the perspective of family caregivers, despite their willingness to engage. There were good pockets of practice of which other practice areas could learn from, however these were the minority and there remains room for improvement.
This research study supports previous literature and European recommendations that learning needs of staff must be identified to provide education based on knowledge deficits, with improved integration of services and promotion of interdisciplinary practice (Tuffrey-Wijne and McLaughlin, 2015; McLaughlin et al, 2014a; 2014b; DHSSPS, 2011). Study findings also suggested benefit of staff learning from the expertise of family caregivers, as experts. Due to their long term caregiving role and experience family caregivers of someone with a learning disability hold the expertise and best knowledge of the person with a learning disability.

Whilst these family caregivers have specific information needs, they also have expertise which can help to address the information needs of Health and Social Care professionals caring for the person with learning disability. This concurs with previous literature that the carer is the expert in the person with a learning disability’s care and can interpret their behaviours, such as how they communicate pain (Tuffrey-Wijne et al, 2016; McLaughlin et al, 2014a; 2014b; Michael, 2008; DHSSPS, 2005). The importance of familiar staff was clear from findings in this study in facilitating good working partnerships and delivery of care and provision of information. However, some reported issues around various staff being involved in the person’s care, staff changeovers, and sickness or absence reduced consistency and impacted upon opportunities to form familiar relationships between staff and caregivers.
On the other hand, there were some family caregivers who had good working relationships with the learning disability nurse or social worker, which proved important in establishing links with palliative care services, and for the provision of information, in one case on the disease itself and were then provided training on this. Organisational failures such as staff shortages and limited training opportunities need to be addressed at a higher level of service area development and human resources, however, if individuals and collective teams make small changes and promote shared learning and awareness, and better communication and needs assessments with family caregivers there will be more positive examples of practice and positive situations of family caregivers having their information needs met across Health and Social Care Trust areas.

Hospice staff participants in this study provided information and signposting to support in relation to palliative and end of life care for family caregivers, which continued into the bereavement stage. However, there was a lack of referrals of people with learning disabilities. This is supported by previous research that referrals were minimal for hospice for people with learning disabilities (McLaughlin et al, 2014a). For this reason a lot of family caregivers were not able to access this important information and support, particularly around bereavement support.
In relation to bereavement in a few cases family caregivers dealt with this alone and without the support of services, as they were unaware of what support there was, if any. Whereas in another case the family were able to avail of bereavement support, as in this case this were adequately informed about bereavement support run by the local hospice in which their loved one passed away. The presence of better awareness, connection of services and collaborative practice between learning disability, primary care, and palliative care services may go some way to improve the volume of referrals made to hospice, in order that the family caregivers can avail of information and support, importantly into the bereavement phase.

6.6 Identified training needs of staff and family caregivers

As discussed in the previous section information needs that were reported in the data were externally influenced by communication and partnerships, as well as awareness of learning disability in general, with identified systemic barriers to information, support and partnership working, such as staff training needs. An issue raised by participants, that has been previously highlighted in the literature (McLaughlin et al, 2014a; 2014b; Wilson and Mansell, 2010) was that many of the family caregivers had experienced being in hospital with their family member at some stage during their illness.
Despite some pockets of good practice, overall, there was a perceived lack of staff training on how to care for someone with a learning disability and family caregiver participants perceived that general hospital staff were unprepared for people with learning disabilities when they presented to accident and emergency departments in times of crisis. There was also an identified need for an increased awareness of what palliative care is and entails for some primary care staff, learning disability staff, and family caregivers.

The provision of educative information and specific training was suggested by participants to promote this in practice. Specifically educating professionals in primary care and learning disability services on when a palliative diagnosis should be made has been suggested as a driver to widen access to palliative care services for people with learning disabilities and their family caregivers, and educating general front line staff on learning disability has been suggested to reduce distress during presentations to hospital settings in times of emergency or crisis point.
Further identified learning needs of professionals in this study include knowing which information to provide at the time of diagnosis, and how much information. Findings reflect that general primary care staff should be more adequately trained in learning disability, to enhance communication with family caregivers and timely identification of information needs, concurring with Wilson and Mansell. (2010). As GPs and Social Workers were identified by participants in this study as central to people with learning disabilities and their family caregivers, training on palliative care and learning disability for these professionals was deemed paramount. Study findings promote interdisciplinary learning across primary care settings and palliative care and learning disability services, supported by European recommendations (Tuffrey-Wijne and McLaughlin, 2015).

Interdisciplinary training has been recommended in this study to inspire confidence in staff working with people with learning disabilities who require palliative care, which in turn will foster a better working partnership with their family caregivers and thus help them to meet the information needs of family caregivers. Similarly, Kirkendall et al. (2012) have agreed this cultivation of intermutual care will foster agreements and shared learning, which will improve what has been said by the EAPC as a ‘cross-fertilisation of expertise’ (Tuffrey-Wijne and McLaughlin, 2015, p.76).
The requirement for palliative care services to make reasonable adjustments in assessments and communication with people with learning disabilities, whilst including their family caregivers has previously been highlighted in UK policy (DHSSPS, 2010b). This present study builds on research carried out by McLaughlin et al. (2014a; 2014b) providing a wide perspective on staff training needs identified from both family caregiver and Health and Social Care professional participants which still exist in Northern Ireland.

A carer’s coordinator, who bridged all services who participated in this current study, promoted the benefits of a grab sheet documenting information related to palliative care for people with learning disabilities, with important contacts, departments and numbers as a go to for the coordinators themselves. A grab sheet could provide the correct information to direct family caregivers to the correct support and in a timely manner, given the nature of the palliative care trajectory. This finding is a fresh signal for a small and efficient resource that could be utilised widely across settings and by all Health and Social Care professionals. It has also been suggested as beneficial to provide information on a grab sheet directly to the family caregivers themselves once they are identified by services.
Health and Social Care participants from both palliative care and learning disability services acknowledged that there is existing professional educative information and training that is disease specific for example, which could be utilised by Health and Social Care professionals with a view to then passing on to family caregivers, however this is difficult to locate and awareness of how to access certain information is poor.

A small number of learning disability professionals had attended some training with palliative care professionals in one trust area, however this was not province wide, or common practice. This was deemed as beneficial and essential, and there was acknowledgement that this should be rolled out across all Health and Social Care Trusts routinely. Liaison working and exchanges between professionals in each discipline were suggested as a practical solution in the McLaughlin et al. (2014a) study. Other Health and Social Care participants recommended sharing a physical space with the other discipline such as an office or building, as the close proximity would allow for easier communication and more efficient coordination of care and support.
Conclusively, if professionals are adequately trained on elements of both disciplines, they will better informed of what information and services are available to support the family caregivers of the person with a learning disability in a palliative care scenario. Training needs of staff and caregivers are dependent on the good communication and joint working of services, and connecting these services in order to share learning, and to learn from the family caregivers as the experts. In return the caregivers can have their information needs met, and continuously reassessed depending on where the person with the learning disability is on their palliative care continuum.

Currently, some training on learning disability and palliative care are provided for general adult nurses and social worker students in Northern Ireland, however, there was uncertainty from participants around whether medics received any training on learning disability as undergraduates, or during GP training. It was identified from participants that knowledge of any current training that is rolled out in relation to these specialties at undergraduate level is minimal, and there is a call for more comprehensive training for adult nursing students and social work students, as a running thread throughout their training.
It is this rhetoric surrounding grass roots training which may help address these training needs, which in turn will impact on the future information needs of family caregivers at the coalface of palliative care and learning disability services, as it will be commonplace for professionals to be adequately equipped and trained. Further building upon the work of McLaughlin et al (2014a; 2014b) study findings from this current research support the assertion that information pertaining to specific diseases (malignant and non-malignant) should be shared across the specialist palliative care and community learning disability professionals. This may include enhanced training on Chronic Obstructive Pulmonary Disorder or Dementia for example.

Research findings presented in this thesis have suggested this may involve multidisciplinary workshops providing training to professionals, to ensure they are adequately equipped to then provide information on the disease to the family caregivers. There was no awareness from any participants of specific organisations concerning palliative care for people with learning disabilities, despite there being an existing network (Palliative Care for People with Learning Disabilities (PCPLD)), with a representative based in Northern Ireland. This finding advocates for a greater promotion of this organisation across the province, for the benefit of staff and the family caregivers.
6.7 Co-design in steering provision of information

Nationally the involvement of family caregivers in research has been promoted in palliative and end of life care (National Council for Palliative Care and NHS Centre for Involvement (NCPC and NCI), 2009). The new ‘Caring Together in Belfast’ carers’ strategy headed by the Belfast Health concurs recommending the involvement of caregivers as partners, implementing co-design and co-development in planning and resource development (BHSCT, 2017). Read and Maslin-Prothero (2011) agree that the involvement of carers in research is of upmost importance in linking theory to practice, enabling meaningful provision of support.

This study involved the voice of family caregivers from across the province of N.I. in as early an opportunity as possible and has incorporated suggestions and feedback from an expert reference group in communicating study findings through a co-designed logic model using the experienced based co-design (EBCD) approach (NHS, 2009). The study was also conducted through the lens of the Transformative paradigm to involve family caregivers and promoting their voice and involvement in this research. Participation of family caregivers and expert reference group involvement in co-design has enabled the identification of information needs with recommendations communicated in relation to how they felt services could improve and develop in meeting their information needs in palliative care.
Family caregiver participants have been accustomed to ‘fighting’ for services, support, and entitlements in the learning disability field (Chadwick et al, 2013; Wilson and Mansell, 2010), however, access to information and support in a palliative care context should be equitable and readily available. The added burden of a palliative diagnosis, to someone with a learning disability, can add to a family member’s already existing stress and influence their ability to cope, despite their expertise from a long-term caring role. Information is pivotal in educating family caregivers, meeting their training needs, and in satisfying outstanding holistic support requirements around finances, psychosocial, and practical support and respite.

The logic model developed from study findings communicates the multiple and changing information needs reported in this study and how these can be met in order to reduce stress and enhance how caregivers implement meaningful and sustainable coping mechanisms. Activities through which short, medium and long-term outcomes should be are also presented. There has been an identified need for increased awareness of existing carers’ strategies and initiatives, with proposed development of information and support specific to family caregivers of people with learning disabilities who require palliative care. The logic model further communicates what needs to be invested from Health and Social Care services and then government in relation to funding and resources.
The logic model presents activities that will address the information needs reported, who will take part in these activities in order to produce favourable outcomes in meeting the information needs of these family caregivers. Naturally the processes of the model, including inputs, outputs and outcomes, are all dependent on the assumptions that each individual service and family caregiver are committed to working together, and taking into account external factors such as preparedness of all involved to invest in and carry out sustainable long-term solutions to meet the information needs of family caregivers of people with learning disabilities who require palliative care.

Study findings recognise the benefit of specialist palliative care, learning disability and primary care services working together and with family caregivers, in order to steer policy direction, education, service development and further research. In essence, some of the research findings confirm those from previous research in the palliative caregiving literature, and builds on findings from the growing body of evidence in the learning disability literature. It is also supported by the small body of research existing within the palliative care for people with learning disabilities literature.
However, this study addresses the gap in the literature specifically concerning the information needs of family caregivers of people with learning disabilities in a palliative care context, which provides new insights and knowledge, and adds to the limited evidence base that exists for this population of family caregivers. As information is an important conduit to support, this research provides valuable observations and recognition of the very real issues faced by this population, and how they can be alleviated through the adequate provision of information that is delivered at the right time and from the right people.

As family caregivers were involved from the beginning of the study in development of documentation, through to the co-design of research findings and recommendations, this research affiliates with the current philosophy within our National Healthcare system, which is invested in involving service users and promoting public and personal involvement in driving research and Health Care reform.

### 6.8 Reflexive Annotation

Through writing this chapter the researcher was cognisant of ensuring all identified evidence which supported study findings was presented, and any contrasting evidence was also considered and presented. Reflexive practice ensured discussion communicated how this study sits within the larger evidence base, whilst being mindful of own thoughts and beliefs in relation to study findings.
6.9 Chapter summary

This chapter presented a discussion of study findings which aimed to feed into a co-designed logic model representing the identified information needs and how outcomes could be influenced by strategizing how information needs can be met. Findings have been compared with existing literature and policy in order to identify similarities and differences. Research findings are understood in the context of the underlying theory of stress and coping first introduced by Lazarus and Folkman (1984) in presenting how outcomes relating to how a family caregiver appraises stressful events associated with their role are influenced positively or negatively by the provision of resources such as information.

The provision of information can help family caregivers cope with their role by promoting competence and confidence in their role, whilst reducing the uncertainties associated with providing care to someone with advanced illness requiring palliative care and end of life care. The discussion also highlights what this study adds to the existing evidence, which was not known before, and why this is relevant. The following chapter presents study limitations, recommendations, and implications for practice, policy, education and further research.
Chapter 7 Research recommendations, implications and limitations

There are several research recommendations and implications elicited from the study findings in relation to practice, service development, policy, education and further research. Limitations of the study should first be acknowledged and below is a summary of the limitations that arose during the course of the study.

7.1 Study Limitations

It is recognised that there are a number of limitations to this study. These will now be discussed.

Study Design

As the study was exploratory seeking to address the study aim and objectives through semi-structured interviews with family caregivers and focus groups with Health and Social Care Professionals, a qualitative study design was employed as a best fit for the research. A qualitative design was chosen based upon the knowledge sought from study participants, how it was to be gathered, and how this knowledge would be analysed (Howe, 2004).
Through a qualitative study design the research question sought to contribute to the understanding and advancement of wider knowledge concerning a particular area of Health and Social Care, which would have potential to impact upon current practice, policy, education and further research (Northcote, 2012). A limitation of using this design may be argued through the traditional Muir Grey (1997) hierarchy of evidence, which suggested that those designs which are experimental and robust can produce superior evidence to that of other research designs. However, use of experimental methods which were not qualitative in nature would not have answered the research question and therefore an exploratory qualitative design was the best method to utilise in order to do this, based on the nature of the research and the research aim and objectives.

Jonas (2001) supports the view that exploratory research surrounding experiences, such as that in this study, may only be apprehended through qualitatively conducted research rather than quantitative means such as questionnaires. Qualitative research is considered appropriate when conducting research within fields such as nursing, as it accounts for the holistic and patient centred nature of care delivery (Coates, 2004; Parahoo, 2014).
Sources suggest rigorous and systematic conduct of qualitative research will ensure as good quality results with rich detail (Coates, 2004; Cohen and Crabtree, 2008). This study aimed to achieve rigour via transparent and systematic methods of data collection and analysis, whilst openly reporting findings.

Family Caregivers

The sample of family caregivers (n=10) who participated were purposefully selected, which is in line with the study aim and design in which the experiences of participants were sought in relation to a very specific population of service users. The original forecast was to recruit 12-20 family caregivers, based on the literature, however, this was not possible despite exhausting all known and authorised avenues possible for recruitment.

Data saturation did occur around interview number 8 as no new themes were being presented. Advocacy groups in learning disability services did engage in the initial recruitment phase, however, this ceased, and no participants were gleaned via this recruitment avenue. Naturally this was disappointing and provides conjecture around whether more family caregivers could have been recruited if more services had reached out to them.
There was a minority of male caregiver participants (n=2), therefore gender bias must be acknowledged. Most family caregiver participants were aged between 60-69 years old (n=5), it is important to acknowledge that age may have a bearing on which information needs may exist and therefore further research with a wider age range of caregivers would provide better insight into this. All participants were also of Caucasian ethnicity and again family caregivers from different cultural backgrounds may also have different information needs. It is therefore suggested that further research could be conducted with a larger, more varied sample of age groups, gender and ethnicity to further explore the information needs of family caregivers of people with learning disability.

**Health and Social Care Professionals**

All participants for focus groups were female and again an element of gender bias must be acknowledged. There was a satisfactory mixed sample of cross discipline professionals; however, staff from only three of the five trusts in Northern Ireland actively participated in the study, despite recruitment drives. Two hospices also participated in the study. Due to the positive recruitment of professionals through services there was no engagement with the full four proposed Hospices in the region, as sufficient staff and subsequent data were gleaned from the existing focus group participants.
7.2 Study Strengths

A strength of the study was the recruitment success of family caregivers \((n=10)\), from what is considered a small and often hidden cohort in Northern Ireland. Due to positive recruitment of family caregivers and multidisciplinary professionals, data saturation was reached and the research aim and objectives were met.

A further strength was the co-design element of the study, involving family caregivers from early stages of study documentation development, through to co-development of the logic model with involvement of an expert reference group. The ethical considerations around this study were also a strength, with commendation given from the Office for Research Ethics N.I. in relation to documentation and application for ethical approval to conduct the study.

Prior to this study there was no other research conducted in the United Kingdom, or internationally, to explore the informational needs of family caregivers of people with learning disabilities who require palliative care. It is also the only known study to seek the perceptions of health professionals in respect to what information needs may exist for this cohort, and how they can addressed in practice. This contributes to the evidence supporting caregiver involvement, and can inform regional carer initiatives.
7.3 Recommendations and implications for practice and service development

- There should be early identification of family caregivers of people with learning disabilities who require palliative care, promoted by more robust screening and health checks of people with learning disabilities by GPs in order that referrals are made earlier and information needs are identified at the earliest opportunity. This may include adaptions to the existing Royal College of General Practitioners (2017) annual health check for people with learning disabilities (www.rcgp.co.uk).

- Recommendation for amendment(s) to the Public Health Agency’s (2017) Hospital Passport for People with Learning Disabilities (www.publichealth.hscni.net), to contain any information on advance care planning, preferred place of care at end of life, a palliative diagnosis or other important information about the family carer. This recommendation also applies to Hospital Passports for People with Learning Disabilities in other geographical regions.

- There should be early identification and acknowledgement of the varying and changeable information needs of family caregivers of people with learning disabilities who require palliative care through holistic needs assessments and support planning.
• Information provision should be delivered one to one where possible, from familiar key staff or members of a core team known to the person and their family caregiver.

• Information on palliative care and learning disability should be understood by the multidisciplinary team involved with the person and their family carer.

• Health and Social Care professionals should readily joint work in partnership with family caregivers taking into account the expertise and knowledge of the family carer.

• Interdisciplinary training, upskilling of current staff or piloting of dedicated co-ordinator roles for people with learning disabilities who require palliative care are suggested.

• There should be equivalent care and support for young adults transitioning from children’s to adult learning disability services who require palliative care and their family caregivers. Currently there is a void and no adult equivalent in Hospice services.
7.4 Recommendations and implications for policy

- Family caregivers of people with learning disabilities who require palliative care have in some cases not been informed about, or been allocated carer’s allowance, giving rise to unmet information needs around financial assistance and support. A review of how carers allowance is allocated is suggested.

- The Carers and Direct Payments Act (NI) (2002) is out of date in comparison to other carer legislation such as the Care Act (2014) and the Carers Act (Scotland) (2016). As a result services and provision of care is not being steered in the right direction, it is recommended eligibility criteria be reviewed.

- In NI the last development in policy or law for carers ‘Caring for Carers’ (2006) falls behind its counterparts in Scotland, Wales and England, who have published updated strategies (NIA, 2016). A more recent strategy needs to be in place for carers in NI in relation to recognition of needs, inclusive of information needs in palliative care, whilst recognising the expertise skillset of this particular population of family carers.

- This study reported a lack of adequate assessments and unmet information needs. In NI services offered by the Health and Social Care Trusts to meet identified needs from a carers assessment is discretionary only. In England the Care Act (2014) stipulates these authorities have a duty of care to provide these (NIA, 2016).
It is recommended that local authorities in N.I. have the same obligation, which can only be remedied through a change in policy.

- It is recommended that the new DHSSPSNI Reform of Adult Care includes consultation around the assessment and identification of all carers in NI and their information needs, particularly at the interface of palliative care services, with proposals of how the Health and Social Care Trusts can help meet these needs.

- It is recommended that policy makers use evidence from research such as this to influence policy direction as principles of government action directly impact upon family caregivers who in turn save the economy £132 billion each year (Carers UK, 2015b).
7.5 Recommendations and implications for education

- Learning and training needs have been identified for all Health and Social Care professionals to have some level of training on learning disability and on palliative care. Particularly in acute care settings such as accident and emergency departments, and by primary care staff such as GPs and district nurses.

- For GPs, this includes the importance of annual health checks (Royal College of General Practitioners, 2017) for people with learning disabilities and what to look for to identify signs and symptoms of a disease which requires palliative care.

- Generalist and specialist palliative care professionals should undertake enhanced training on learning disability as how they treat the person and their carer’s holistic needs will be different to that of a non-learning disabled person.

- More comprehensive training and education on learning disability, palliative care, and the role of family caregivers should be delivered to Nursing, Social Work and Medical students.

- Family caregivers can meet the information needs of professionals through sharing their expertise in adding to new knowledge on how the person with a learning disability communicates pain and how the person has been cared over a lifetime care trajectory.
• Family caregivers should be offered enhanced education on palliative and end of life care and advance care planning.

• Partnership working and shared awareness between professionals and family caregivers should be promoted through joint training events.

• There should be development of family carer information specific to palliative care for people with learning disabilities.

• There should be increased community awareness and educating the public around palliative care for people with learning disabilities, and the added burden this has on the family caregivers.

• An increase in educational awareness of this population is recommended to promote change and social action in relation to a culture shift in attitudes, behaviours and practice.
7.6 Recommendations for further research

- There is a general lack of population statistics on people with learning disabilities who require palliative care, particularly in NI. Further auditing and statistical surveillance is suggested to promote early identification.
- Current use of needs assessments and support planning with this population of family caregivers should be further explored, and the effectiveness of such assessments and support plans.
- Further research into the use of hospital passports in relation to people with learning disabilities and their efficacy in alleviating the burden for the family carers when presenting to acute services in crisis situations.
- Further research employing mixed methods and a larger sample of family caregivers, across a larger geographical area is recommended to further explore education and information needs around particular diseases that require palliative care in people with learning disabilities, to compare any cultural and economic impacts variables on information needs.
• Further research incorporating the voice of family caregivers through co-design in strategic planning for service development at the interface of palliative care and learning disability services is recommended.

• Further research is required to pilot the appointment of dedicated coordinators for people with learning disabilities who require palliative care, across Health and Social Care Trusts. This could enable signposting family carers to the appropriate information, support and services when required.

• Finally, the logic model should be implemented and evaluated with the development of an informational resource pack for carers, carer’s coordinators and professionals, specifically on palliative care for people with learning disabilities, with important or useful contacts and signposting to relevant support.
7.7 Study Summary and thesis conclusion

This exploratory, qualitative study has incorporated the principles of co-design in co-development of a logic model, reflecting the information needs reported by family caregivers of people with learning disabilities who require palliative care in Northern Ireland and suggested inputs and outputs to produce favourable outcomes. As discussed previously this co-design involved public and personal involvement through an expert reference group and integrating the voice of the family caregiver participants into the model. The logic model provides recommendations for education, service development, practice, and the potential for development of an informational resource or an intervention.

The voices of the family caregivers and Health and Social Care professionals across both specialist palliative care and learning disability services in Northern Ireland have been given a platform to be heard. The logic model has been consulted and adapted following liaisons with an expert reference group, to best communicate what the family carers were reporting as information needs, and what realistically could be done to address and meet the information needs of this population in future.
Study findings demonstrate poor communication and lack of education remain issues and barriers to support, leading to unmet information needs. Communication and education are fundamental to ensuring family carers and their needs are identified, with adequate and appropriate information then shared in order to meet any outstanding support needs at the interface of learning disability and specialist palliative care services. Greater awareness of learning disability and palliative care, earlier identification of the person with a palliative diagnosis and their family carer, efficient use of existing resources, and each family caregiver and professional respecting the role of one another as experts in their own rights, and working together as a team, can all help reduce unmet information needs and reduce carer burden as a result.

It is remembering that palliative care is also about the family caregiver and the spectrum of information needs that they may have, and that they must be identified and addressed as best possible. Information can be a conduit to varying levels and types of support, and professionals are gatekeepers of this important information. In this study, the most important information need was that around the disease that the person with a learning disability was suffering from, this included signs, symptoms, medications, side effects, how long the person had left to live, what to expect at the end, what palliative care entailed, and information on bereavement.
The next most commonly reported information need was around financial support, practical assistance and respite, with pertinent view that it was essential that information was delivered in a timely manner, one to one, and by someone known to themselves and the person they cared for.
7.8 Thesis contribution

This research study has made several contributions. In the first instance, the study has shown that a qualitative design was, as recommended by the literature, the best method to gain the rich and new insights from this study population based on the research aim. As the study sought to explore a sensitive subject area and from participants in their natural setting, it has shown to be successful in contributing to the growing body of qualitative research in providing valuable evidence with a worthy sample number, considering the very specific characteristics and inclusion criteria for study participants.

Through qualitative means, and from the sample who participated, the research question has been answered, with enough data gathered to satisfy the research objectives in order to contribute to the evidence base. The study has contributed to learning and education by unveiling the information needs of these family caregivers and highlighting outstanding education and learning needs of Health and Social Care staff, and of family caregivers of this specific population. The learning needs of staff across the learning disability and palliative care fields is not new information (McLaughlin et al, 2014a; 2014b Kirkendall et al, 2012; Cartlidge and Read, 2010; Tuffrey-Wijne et al, 2007a; 2007b), however it is a study finding which supports this previous research nonetheless.
Early identification of a palliative diagnosis has been identified as an issue in learning disability, with many people with learning disability getting diagnosed later in the disease trajectory with late hospice and palliative care referrals, which has a detrimental impact on the family caregiver and increases their information needs. The study contributes to the recommendation for a review of the GP annual health checks for people with learning disabilities, to include criteria which may indicate a palliative disease in someone with a learning disability, in consultation with palliative care and learning disability specialists.

It is known that in previous research literature in family caregiving in palliative care, education on the disease was also deemed very important to family caregivers and this research brings fresh supporting evidence of similar needs of disease specific information and information on death and dying. However, it is acknowledged that there are differences when it comes to caring for someone with a learning disability in a palliative care context, as there will be greater carer burden and more complex information needs.
The voice of family caregivers and the insights of professionals from learning disability and palliative care have combined with the reflections of an expert reference group, which provided a unique public and personal involvement element to this study, with co-design of the logic model of findings and recommendations. There has been a practice contribution through findings highlighting there are multiple information needs present for these family caregivers, and those which are most frequently cited, which can inform how Health and Social Care professionals view and complete needs assessments and support plans in future.

In support of previous literature, this study has also promoted the partnership working between family carers and professionals, with shared learning and awareness. In the case of this study this was joint working and shared learning, training and awareness in relation to meeting the information needs of the family caregivers of this population. The study has provided ultimate findings of dedicated staff, core teams or link/key staff that will work with family caregivers and coordinate any information and support, as and when the needs arise. It has been suggested upskilling in existing teams, use of existing resources and enhanced training in the absence of a dedicated role or post for a coordinator for people with learning disabilities who require palliative care, per trust area.
It has also been suggested that the existing hospital passport in NI be adapted to incorporate information on any advance care planning or palliative care diagnosis, and extra information on the family carer. Finally, the study has provided a logic model which is a visual depiction of the voice of the family caregivers in this study and what they need to have their information needs addressed and met. The model takes into account assumptions and external factors and ultimately predicts the short, medium and long-term outcomes of implementing suggested inputs, activities and participation.

Prior to this research being conducted there was an existing paucity of research in family caregiving in learning disability in general and there was no research seeking the information needs of family caregivers of people with learning disabilities who require palliative care. It is known from the little research that is available in this field that unmet needs are almost always present, that more needs to be done in the health care system for people with learning disabilities, and inequalities and access issues remain in regard to equitable care, in particular in relation to palliative and end of life care. This study supports the existing literature, providing evidence that there is still a lot to be done in this area of health care and there are still problems which exist despite European level recommendations and policy requirements.
Findings contribute new knowledge by addressing the gap on what information needs exist for this very specific population of family caregivers. The fact that the participants will benefit from this research is also significant. By raising awareness of this hidden population and unveiling their information needs, the study findings promote training initiatives across disciplines to improve awareness and knowledge of palliative care for people with learning disabilities in Northern Ireland.

This research is valuable and important to staff across all multidisciplinary Health and Social Care professional teams, and across health care fields including community services, primary care, learning disability and specialist palliative care services, including Hospices. It is valuable to the family caregivers who participated in knowing that their voice has been heard and translated into something which can inspire change for them, and for those family caregivers coming behind them. In future it will be the norm for Health and Social Care teams to come across more and more people with learning disabilities who require palliative care, due to the global population living longer. Now we know what the most important information is to this population of family caregivers and important influences on these information needs.
The ‘Valuing Carers 2015’ report states: unpaid family caregivers provide most of the care delivered in the UK; the government has come to rely on this contribution to the health economy; the value of carers’ contribution to the economy has virtually doubled from £68 billion in 2001 to £132 billion in 2015; family caregivers save the government £15.1 million per hour (Carers UK, 2015b). It is with this knowledge in mind that the importance of family caregivers’ contribution to research is illuminated, in making information and data known.

These research findings are usable in helping to inform education, training and service development. Due to the small number of parental caregivers of children who had transitioned to adult palliative care services, findings may provide some transferable knowledge that may be applied to family caregivers of children with learning disabilities who require palliative care; however, this would require further exploration. Results also illuminate potential information needs that may be present for family caregivers of people with learning disabilities who require palliative care in other countries, however, further research with a greater sample size and across varying geographical regions and countries would provide interesting insight into whether information on the disease was priority over information on psychological or spiritual support for example, something which may be dependent on the country itself and the culture.
7.9 Dissemination Strategy

Results of the literature review have been presented at the European Association for Palliative Care (EAPC) World Research Congress in Dublin (June, 2016). The literature review and research protocol were presented at the Palliative Care for People with Learning Disabilities (PCPLD) annual conferences (November, 2015; November 2016). Results have been presented to Queen’s University’s School of Nursing and Midwifery’s Research showcase (September, 2017), Marie Curie Hospice (May, 2018), and at the EAPC World Research Congress in Switzerland (May, 2018). Further conference dissemination is planned for the 2018 PCPLD conference.

The integrative review of the literature has been submitted for publication to the International Journal of Palliative Nursing (August, 2018). Results paper to be submitted to Palliative Medicine for publication (Forecast submission for September, 2018). A paper concerning rigour, relationships and reflexive practice in learning disability research has been submitted to Learning Disability Practice (September 2018). All participants and Trusts involved will be sent links to the above papers once published. Results will also be delivered at invited meetings across the specialist palliative care and learning disability teams in Northern Ireland. This will foster regional, national and international awareness of study findings.
7.10 Reflexive conclusion

As this research study was qualitative in nature it required, as discussed, the researcher to become the research tool. Thus, reflexivity was employed following each data collection session and through utilising the reflexive process the researcher further developed qualitative researching skills and knowledge in relation to the research process.

Being reflexive also entailed being aware of the role theory played in this research and understanding how the chosen underpinnings and theoretical lenses shaped and informed the research. There was reflection on how research findings fed into the underpinning theory in supporting elements and justifying certain processes within frameworks.

Keeping a reflexive memo and being cognisant of thoughts and feelings was deeply important for the researcher to remain reflexive as the research tool, in acknowledging their own role as a family carer of someone with a learning disability, and having recently experienced bereavement of a close family member. Working with such a sensitive subject area at times raised some upset within the researcher, in particular as it was very close to home and something in future that they may experience. This was why it was important to debrief by documenting these feelings into memos and a diary following each session of data collection and transcription, in the awareness that it should not affect interpretation.
The researcher also had the opportunity to debrief with members of the research supervisory team if necessary. An advantage of having a brother with Down Syndrome and experience of learning disability services, however, was knowing it had helped increased rapport with participants, in having some shared experience, this appeared to be an advantage in facilitating participants to open up, whereas perhaps with others they may not have. The overriding cognisance was that by carrying out this research, there would be real life issues brought to the surface, which could be addressed to ensure better outcomes for the family caregivers interviewed by allowing their voice to be heard. This was an issue extremely close to the researcher.

This involvement of the family caregiver’s voice is promoted by new strategies by the NCPC (2009) and EAPC (2015) and locally by the BHSCT (2017). Through facilitating the collective voice of family caregivers they were able to comfortably communicate the information needs present for them and how they felt they could be met effectively. The all too familiar ‘fight’ for services and support still exists and the researcher was aware of this in the learning disability field, and this requires to be addressed by the existence of equitable and accessible information in the palliative care context. Information has been shown as pivotal and of influence to carer burden, it is therefore imperative that services, professionals and policy makers oversee changes and adaptations to current education, training, practices, frameworks, models and resources.
Ultimately it is through implementation of the above that will help change attitudes, behaviours and practices, and reduce the custom of ‘fighting’ for information or services in learning disability. This study will raise awareness and promote early identification of these family caregivers, in order that any information needs, along with any other support needs identified are addressed and met.
References


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Appendix 1 Letter to Director of Clinical Services/Director of Medical Care in Trusts and Hospices to access sample

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Funded by Queen’s University School of Nursing and Midwifery: Special Research Scholarship (PhD)

Date:

Dear

I am a registered Nurse undertaking a PhD at Queen’s University Belfast. The aim of the study is to explore the information needs of family caregivers of people with learning disabilities who require palliative care. A further objective is to identify health and social care professionals’ perceptions of the information needs which exist for these family caregivers. Approval to conduct the study has been sought from the QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern Ireland (ORECNI) (July 2016), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.

This is a qualitative study involving semi structured interviews with active and bereaved family caregivers of people with learning disabilities who have required palliative care. Focus groups will also take place with multidisciplinary health and social care professionals who have experience supporting family caregivers of people with learning disabilities who have required palliative care. Interviews and focus groups will inform a model of supportive care, as a visual representation of the information needs reported by family caregivers, and how they can be addressed. It is hoped the study will inform priorities and best outcomes for this population of family caregivers.

I am writing to ask permission to contact staff within your Trust/Organisation to arrange to visit learning disability/specialist palliative care services to present information about the study and to ask if they wish to consider participating. All staff who wish to participate will be required to give informed consent and all information and data collected will be held securely and in confidence. I would be very grateful if you could please forward me your response to this request using the reply section overleaf, or if you have any queries or would like more information about the study please feel free to contact me. My email address, telephone number and mailing address are listed below:

Thanking you for your help,

Yours sincerely,

Laurie McKibben
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Medical Biology Centre: Room 07.323
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E: ltturner12@qub.ac.uk
T: 0289097576
Reply Slip

I give permission for the primary researcher (Laurie McKibben) to contact staff within (Insert name of Trust/Organisation) __________________ to present information about the study and to ask if they wish to participate.

Please add signature to the appropriate box

YES

NO

Name ____________________________________________

Work Address: ___________________________________

_____________________________________________

_____________________________________________

_____________________________________________

Contact details

Please contact me at:

Phone number (work) ____________________________

Phone number (mobile) __________________________

Email address ___________________________
Appendix 2 Letter to Trusts, Hospices and Advocacy groups to recruit caregivers

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Date:

Dear Sir/Madam

I am a registered Nurse undertaking a PhD at Queen's University Belfast. The aim of my study is to explore the information needs of family caregivers of people with learning disabilities who require palliative care. People who require palliative care may have a diagnosis of cancer, heart, lung or kidney failure, neurological disease or elderly frail/dementia. Palliative care incorporates care and support that enables the person and their family to maintain a good quality of life while living with an advanced incurable disease and includes care given from the point of diagnosis through to the bereavement period. Approval to conduct the study has been sought from the QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern Ireland (ORECNI) (July 2016), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.

In order to recruit family caregivers to the study I am asking Learning Disability and Palliative Care Services and Advocacy Groups if they would be willing to circulate the attached letter to family caregivers, known to their services, who are currently (or have previously cared for) someone with a learning disability who has required palliative care. The purpose of recruiting active and bereaved family caregivers for the study is to obtain their views on their information needs through interviews. Family caregivers' perceptions and experiences of the informational provision and support they have or have not received, when caring for someone with a learning disability at end of life, is important in this study.

If you have any queries or wish to discuss things further please feel free to contact me. My email address, telephone number and mailing address are listed below:

Thanking you for your help,

Yours Sincerely,

Laurie McKibben
PhD Student, Queen's University School of Nursing and Midwifery
Medical Biology Centre: Room 07.323 E: Iturner12@qub.ac.uk
Lisburn Road, BT9 7BL
T: 02890975761
Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Dear Sir/Madam

I am a registered Nurse undertaking research for my PhD at Queen’s University Belfast. My study will be looking at your role and experience of being a family caregiver of someone with a learning disability who requires palliative care. Palliative care is care given by nurses, doctors, social workers and other professionals to people who have a disease which cannot be cured and is life-limiting, it is about making the quality of someone’s life as good as it can be and it helps with all parts of their life- their physical needs (such as pain and sickness), emotional needs, social needs and spiritual needs. Palliative care also, importantly, incorporates support of the family and carers. The research hopes to find out, by giving you a voice, what information you need in order to get the right support from the right places and right people. I would also like to know if you have had trouble receiving information that may have been important to you. Approval to conduct the study has been sought from the QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern Ireland (ORECNI) (July 2016), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.

This letter is being sent out so that people who have experience of being a family caregiver of someone with a learning disability, who requires palliative care, can be told about the study, and consider whether or not they would like to take part in an interview. Your views and contributions on palliative care is very important in health and social care research, education, and for improvements in health care. If you are currently a family caregiver of someone with a learning a learning disability who requires palliative care and feel that you would like to take part in an interview, or that you would like more information about the study please contact me either by telephone, email or letter, with your address and I will then forward you an information pack about the study. My email address, telephone number and mailing address are listed below:

Thanking you for your help,

Yours faithfully,

Laurie McKibben

PhD Student, Queen's University School of Nursing and Midwifery

Medical Biology Centre: Room 07.323 E: lturner12@qub.ac.uk

Lisburn Road, BT9 7BL

T: 02890975761
Dear Sir/Madam

I am a registered Nurse undertaking research for my PhD at Queen’s University Belfast. My study will be looking at your role and experience of having been a family caregiver of someone with a learning disability who required palliative care. Palliative care is care given by nurses, doctors, social workers and other professionals to people who have a disease which cannot be cured and is life-limiting, it is about making the quality of someone’s life as good as it can be and it helps with all parts of their life- their physical needs (such as pain and sickness), emotional needs, social needs and spiritual needs. Palliative care also, importantly, incorporates support of the family and carers. The research hopes to find out, by giving you and your experience a voice, what information family caregivers would need in order to get the right support from the right places and right people. I would also like to know if anything prevented you from receiving information that may have been important during your time as a family caregiver. Approval to conduct the study has been sought from the QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern Ireland (ORECNI) (July 2016), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.

This letter is being sent out so that people who have experience of being a family caregiver of someone with a learning disability, who has required palliative care, can be told about the study, and consider whether or not they would like to take part in an interview. Your views and contributions on palliative care are very important in health and social care research, education, and for improvements in health care. If you have previous experience of being a family caregiver of someone with a learning disability who required palliative care (and have been bereaved of that family member more than three months ago) and feel that you would like to take part, or that you would like more information about the study please contact me either by telephone, email or letter, with your address and I will then forward you an information pack about the study. My email address, telephone number and mailing address are listed below:

Thanking you for your help,

Yours faithfully,

Laurie McKibben
PhD Student, Queen’s University School of Nursing and Midwifery
Medical Biology Centre: Room 07.323 Lisburn Road, BT9 7BL
E:ltturner12@qub.ac.uk T: 028 90975761
Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

My name is Laurie McKibben and I am a registered Nurse undertaking research for my PhD at Queen’s University Belfast. My research team consists of Professor Kevin Brazil (Primary Supervisor) and Dr Dorry McLaughlin (Secondary Supervisor) within the School of Nursing and Midwifery at Queen’s University Belfast. Below is a brief synopsis of the study and how your involvement can be of purpose. An additional information sheet provides further details.

Background: Life expectancy is on the rise, this also means the risk of developing advanced, progressive diseases that require palliative care is also increased. People who require palliative care may also have a learning disability, with a family member providing their care. Recent reports suggest that these family caregivers are not receiving the information and support they require in order to care effectively for their loved one at end of life.

Objective: The aim of this study is to determine the informational needs of family caregivers of people with learning disabilities who require palliative care.

Method: Health and Social Care Professionals within learning disability and palliative care services in Northern Ireland are invited to take part in focus group interviews. Family caregivers will take part in separate interviews.

Get involved: Please read through the information sheet which will provide further details about the study. If you would like to take part in this research opportunity, please send us your details and an expression of interest to be involved via email or using the reply slip in the stamped addressed envelope supplied.

If you have any questions or would like to inquire further about details of the study please feel free to contact myself, Ms Laurie McKibben (E:ltturner12@qub.ac.uk / Tel: 02890975761), or the Chief Investigator, Professor Kevin Brazil (k.brazil@qub.ac.uk)
Appendix 5 Information sheet for HSC professionals

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Participant Information Sheet for Health and Social Care Professionals

You are being invited to take part in a research study which is part of a PhD project in the School of Nursing and Midwifery at Queen’s University, Belfast. Before you decide it is important for you to understand why the research is being done and what it will involve.

What is the purpose of the study?

The aim of this study is to explore the role of family caregivers of people with learning disabilities who require palliative care. Health and Social Care Professionals working within the learning disability and palliative care fields will take part so the research team can find out what information needs they feel exist for these family caregivers, and how they can be addressed. Results and recommendations from this study for service improvements will be based on the voice of family caregivers and input from Health and Social Care Professionals.

What do we mean by ‘Learning Disability’ and ‘Palliative Care’?

People with a learning disability are those individuals in receipt of services from the learning disability programme of care of the Health and Social Care Trusts or from private and voluntary agencies and Housing Associations acting on their behalf. The Equal Lives Report (2005) defined learning disability as follows:

‘Learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.’

Palliative care is normally relevant to people suffering from disease such as contained in three broad categories: Cancer, Organ Failure (Heart, Lung, Kidney, and Neurological Disease) and Elderly Frail/ Dementia and the goal is to achieve the best quality of life for patients and families. It incorporates the active holistic care of patients from diagnosis. Pain and symptom management and the provision of psychological, social and spiritual support are paramount. End of life care is defined by the Gold Standards Framework as the final year of life and is the end stage of palliative care.
Why have I been chosen?

You are currently working within a specialist learning disability or palliative care service and have been involved in the delivery of palliative care to adults with learning disabilities and their family caregivers. You therefore meet the criteria for participation in a focus group and we would appreciate your input.

Do I have to take part?

It is your decision whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time with no negative consequences.

What will happen if I take part?

Please complete the attached reply slip with your contact details and forward them to me. Or you can forward this information to me by email. I will then contact you to arrange the focus group at a time and place convenient for you. If you agree to take part in the focus group you will be asked first to complete an information sheet that records details such as your age, gender and professional background and second you will be asked to take part in one focus group. The focus group will last between 40-60 minutes and will be recorded with the use of an audio recorder. The focus group will take place in a private room within a venue suitable for all attendees.

What happens if I want to withdraw from the study?

You are free to withdraw from the study at any point, but the nature of focus groups such that it would not be possible to ensure that all of your data is withdrawn from the study.

What are the possible benefits and disadvantages of taking part?

It may be beneficial to be part of a research project that aims to improve services and enhance collaboration between family caregivers and services. Information from the study will be used to develop a model of supportive care which will visually reflect the information needs of these family caregivers and how they can be best supported. Results and recommendations from the study have potential to inform service improvement, education, policy and further research. You can request to see a summary of results once the study is complete. Your involvement in research related activities can also be used towards your Continued Professional Development (CPD) portfolio.

Due to the sensitive nature of palliative care participants may become upset during discussion, if this occurs the researcher will offer to suspend the focus group and you will have the choice of withdrawing if that is what you wish. All participants of the study will be provided with a support pack containing contact details for further information, telephone advice lines and names and numbers of professional organizations should they wish to contact someone following the focus group.
Where will my data be stored?
All focus group data will be transcribed by the primary researcher (Laurie Mckibben) in the School of Nursing and Midwifery at Queen’s University, Belfast.

Hard copies of transcripts will be stored in a locked filing cabinet to which only the research team will have access. Electronic copies of transcripts will also be stored on a secure server that is password protected.

All data will be stored in line with Data Protection Act 1998 requirements for 5 years following completion of the study, data will then be destroyed by the research team (by the Principal Investigator in the first instance).

Will my taking part in this study be confidential?

The information you offer is between you, focus group members and the research team, and will be kept private. Anonymity within a face to face focus group is difficult to maintain among participants, however the research team will keep all data anonymous and confidential, all participants in the focus group will be reminded of the need to ensure this. Confidentiality will only be broken if you tell us about any illegal activity or something which means someone is at risk of harm and requires action. This would then have to be reported to the relevant person or authorities. However, your transcript will not be made available to anyone outside the research team and any quotes published will be anonymous. All data collection, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection.

What will happen to the results of the study?

The results will be published in research papers and presented at professional conferences and meetings. Any quotes in the results section will be anonymised and untraceable to a specific person. These results are likely to be published in 2018.

What if there is a problem?

Any complaints should be directed to the Chief Investigator (Kevin Brazil) in the first instance (details below), followed by the Chair of the School Research Ethics Committee, Dr Oliver Perra. If you do not wish to make a complaint to the research team or they are the object of complaint and you wish to make a formal complaint, you can contact Dr Oliver Perra directly at the School of Nursing and Midwifery (details below).

Who is organising and funding the research?

This study is funded by Queen’s University, Belfast

Who has reviewed the study?

This study has received ethical approval from QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern Ireland (ORECNI) (date to be inserted), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.
Contact for Further Information

- Laurie McKibben
  Telephone- (028) 9097 5761
  Email- lturner12@qub.ac.uk

If you wish to make a complaint

- Professor Kevin Brazil (Chief Investigator)
  Telephone- (028) 90975782
  Email - k.brazil@qub.ac.uk
- Dr Oliver Perra (Chair of the School of Nursing and Midwifery Research Ethics Committee)
  Telephone – (028) 9097 2313
  Email – o.perra@qub.ac.uk

Thank you for taking the time to read this information sheet

You will be given a copy of this information sheet and a signed consent form to keep
Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Reply Slip

If you are interested in taking part please complete this reply slip and send it back in the stamped addressed envelope provided. Alternatively send your information via email to the primary investigator, Laurie McKibben (ltturner12@qub.ac.uk).

Please add signature to the appropriate box

I am interested in being contacted about participating in this research study

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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Name__________________________________________

Work Address: __________________________________

____________________________________________

____________________________________________

____________________________________________

Contact details

Please contact me at:

Phone number (work) ____________________________

Phone number (mobile) __________________________

Email address __________________________________
Appendix 7 Consent form for HSC professionals

Consent Form

Title of the project: Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Please initial the appropriate box yes/no.

<table>
<thead>
<tr>
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<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I confirm that I have been given, and have read and understand, the Information Leaflet for the above study. I have had the opportunity to ask, and receive answers to any questions I may have had</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. I understand that my participation is voluntary and that I am free to withdraw at any stage, without giving any reason</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. I agree to take part in the above study, inclusive of the procedures mentioned in the Information leaflet</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. I agree for the focus group to be audio-recorded</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. I understand that my participation or non-participation will not affect my career progression or my legal rights in any way</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. I understand that any disclosure of illegal activity or something which requires action must be reported by the researcher to the relevant authorities</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. I understand all data will be treated securely as described by Data Protection and stored appropriately as required by the University</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. I understand that I will not be identifiable in any data published in relation to this project</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

I agree to take part in this project

Name of Participant: Laurie McKibben
Date: ____________
Signature: ____________

Name of Researcher: ____________
Date: ____________
Signature: ____________

Contact Details of the researcher:
Telephone: (028) 9097 5761
Email: ltumer12@qub.ac.uk
Address: School of Nursing and Midwifery, Queen’s University Belfast Medical Biology Centre
97 Lisburn Road
Belfast BT9 7BL

One copy for Researcher and one copy for the participant
Appendix 8 Cover letter for family caregivers

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

My name is Laurie McKibben and I am a registered Nurse undertaking research for my PhD at Queen’s University Belfast. My research team consists of Professor Kevin Brazil and Dr Dorry McLaughlin within the School of Nursing and Midwifery at Queen’s University Belfast. Below is a brief summary of the study and how your involvement can be of purpose. An additional information sheet provides further details.

Background: Life expectancy is increasing, this means the risk of developing life threatening or life limiting diseases that require palliative care is also increased. People who require palliative care may also have a learning disability, with a family member providing their care. Recent reports suggest that these family caregivers are not receiving the information and support they need.

Objective: The aim of this study is to determine the informational needs of family caregivers of people with learning disabilities who require palliative care.

Method: Family caregivers, who have experience caring for people with learning disabilities who have required palliative care, are invited to take part in a face to face interview. Health and social care professionals working in learning disability and palliative care fields will also give their views through separate focus group discussions.

Get involved: Please read through the information sheet which will provide further details about the study. If you would like to take part in this research opportunity, please send us your details, and an expression of interest to be involved, via email or using the reply slip in the stamped addressed envelope supplied.

If you have any questions or would like to inquire further about details of the study please feel free to contact myself, Ms Laurie McKibben (E:ltturner12@qub.ac.uk / Tel: 02890975761), or the Chief Investigator, Professor Kevin Brazil (k.brazil@qub.ac.uk)
Appendix 9 Information sheet for family caregivers

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Participant Information Sheet for Family Caregivers

You are being invited to take part in a research study which is part of a PhD project in the School of Nursing and Midwifery at Queen’s University, Belfast. Before you decide it is important for you to understand why the research is being done and what it will involve.

What is the purpose of the study?

This study is being carried out as we would like to explore the role and experience of family caregivers of people with learning disabilities who require palliative care. We hope to find out what information you need in order to get the right support from the right places and right people. We also want to know if anything has prevented you from receiving information that may have been important to you. Results from this study could influence and guide improvements in Health and Social Care services by providing the correct information to family caregivers of people with learning disabilities who require palliative care. Recommendations from this study for improvements will be based on the voice of family caregivers and input from Health and Social Care Professionals.

What do we mean by ‘Palliative Care’?

Palliative care is care given by nurses, doctors, social workers and other professionals to people who have a disease which cannot be cured and is life-limiting. Palliative care is about making the last part of someone’s life as good as it can be and it helps with all parts of their life - their physical needs (such as pain and sickness), emotional needs, social needs and spiritual needs.

Why have I been chosen?

You are looking after or have looked after an adult family member with a learning disability who has required palliative care. You therefore meet the criteria for individual interview with the primary researcher (Laurie McKibben) and we would like to have you involved, if that is what you decide.
Do I have to take part?

It is your decision whether or not to take part. If you decide to take part you are still free to change your mind at any time and, there will be no problems if you decide to say no. If you do not take part this will not in anyway affect the care or support which you or your family member currently receive or will receive in the future.

What will happen if I take part?

Please complete the attached reply slip with your contact details and forward them to me. Or you can forward this information to me by email. I will then contact you to arrange the interview at a time and place convenient for you. First, you will be asked to sign a consent form telling us that you understand what you have read in the Information Sheet about the study and you agree to take part. If you agree to take part in the study you will be asked to complete an information sheet that records details such as your age, if you are male or female, and how long you have been a family caregiver. Secondly you will be asked to take part in one face-to-face interview. The interview will last between 40-60 minutes and with your permission, it will be audio recorded by the primary researcher (LM). All information you give us will be kept anonymous and private. In the interview you will be asked questions that will help us understand what it is like, or was like for you to care for a loved one with a learning disability who requires palliative care, and what information you need so that you are best supported.

What happens if I want to withdraw from the study?

You are free to stop the interview at any point and all information from your interview will be removed from the study if that is what you would like. We will give you contact information for people and organisations that will help support you.

What are the possible benefits and disadvantages of taking part?

It may be very important to you that you are part of a study that will help family caregivers of people with learning disabilities who require palliative care. As a result of this study, information will be available as to how family caregivers of people with learning disabilities can be best supported in their role and what information they feel would be most helpful. It will help improve Health and Social Care services so they can provide the correct information and support to family caregivers. You can ask to see the results of the study and what we recommend once the study is complete.

Sometimes people can become upset when discussing information that is very personal to them. If you become upset during the interview we will offer to stop the interview. You will be provided with a support pack containing contact details for further information, telephone advice lines and names and numbers of professional organizations. This means you can get support following the interview if you feel you need it.
Where will my data be stored?

All interview information that is recorded will be written down word for word by the primary researcher (LM) in the School of Nursing and Midwifery at Queen’s University, Belfast. Hard copies of this information will be stored in a locked filing cabinet to which only the research team will have access. Electronic copies of the information will also be stored on a secure computer that is protected with a password. All information will be stored legally as set out in the Data Protection Act 1998 and destroyed 5 years following the completion of the study by the research team (by the Principal Investigator in the first instance).

Will my taking part in this study be confidential?

The information you offer is between you and the research team and will be kept private. This confidentiality will only be broken if you tell us about any illegal activity or something which means someone is at risk of harm and requires action. This would then have to be reported to the relevant person or authorities. However your information will not be made available to anyone outside the research team and any quotes used in publications will be anonymous. All information, storage and processing will comply with the principles of the Data Protection Act 1998 and the EU Directive 95/46 on Data Protection.

What will happen to the results of the study?

The results will be published in research papers and presented at professional conferences and meetings. Any quotes in the results section will be made anonymous and untraceable to a specific person. The results are likely to be published in 2018.

What if there is a problem?

Any complaints should be directed to the Chief Investigator (Kevin Brazil) in the first instance (details below), followed by the Chair of the School Research Ethics Committee, Dr Oliver Perra. If you do not wish to make a complaint to the research team or they are the object of complaint and you wish to make a formal complaint, you can contact Dr Oliver Perra directly at the School of Nursing and Midwifery (details below).

Who is organising and funding the research?

This study is funded by Queen’s University, Belfast.

Who has reviewed the study?

This study has received ethical approval from QUB School of Nursing and Midwifery Research Ethics Committee, Office for Research Ethics Committees Northern
Ireland (ORECNI) (date to be inserted), and the Research Governance procedures of Health and Social Care Trusts and Hospices in Northern Ireland.

**Contact for Further Information**

- Laurie McKibben  
  Telephone: (028) 9097 5761  
  Email: iturner12@qub.ac.uk

**If you wish to make a complaint**

- Professor Kevin Brazil (Chief Investigator)  
  Telephone: (028) 9097 5782  
  Email: k.brazil@qub.ac.uk

- Dr Oliver Perra (Chair of the School of Nursing and Midwifery Research Ethics Committee)  
  Telephone: (028) 9097 2313  
  Email: o.perra@qub.ac.uk

Thank you for taking the time to read this information sheet

You will be given a copy of this information sheet and a signed consent form to keep if you decide to take part in an interview
Appendix 10 Reply slip for family caregivers

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Reply Slip

If you are interested in taking part please complete this reply slip and send it back in the stamped addressed envelope provided. Alternatively send your information via email to the primary investigator, Laurie McKibben (lturner12@qub.ac.uk).

Please add signature to the appropriate box

| I am interested in being contacted about participating in this research study |
|-------------------------|-------------------------|
| YES                     | NO                      |

Name__________________________________________________________

Home Address: ________________________________

______________________________________________

______________________________________________

Contact details

Please contact me at:

Phone number (home) ________________________________

Phone number (mobile) ________________________________

Email address ________________________________
Appendix 11 Consent form for family caregivers

Title of the project: Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Please initial the appropriate box yes/no.

YES NO

1. I confirm that I have been given, and have read and [ ] understand, the Information Leaflet for the above study. I have had the opportunity to ask, and receive answers to any questions I may have had

2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason

3. I agree to take part in the above study, inclusive of the procedures mentioned in the Information leaflet

4. I agree for my interview to be audio-recorded

5. I understand that my participation or non-participation will not affect my legal rights in any way

6. I understand that any disclosure of illegal activity or something which requires action must be reported by the researcher to the relevant authorities

7. I understand all data will be treated securely as described by Data Protection and stored appropriately as required by the University

8. I understand that any data collected will be anonymized to remove data that may identify a particular person in the published project

I agree to take part in this project

Name of Participant Date Signature

Laurie McKibben Date Signature

Name of Researcher Date Signature

Contact Details of the researcher

Telephone: (028) 9097 5761 Email: ltturner12@qub.ac.uk

Address: School of Nursing and Midwifery, Queen's University Belfast
Medical Biology Centre
97 Lisburn Road
Belfast BT9 7BL

One copy for Researcher and one copy for the participant
Appendix 12 – Interview guide active family caregivers

Interview Guide for Active Family Caregivers
Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A Qualitative study

Background

Thankyou for agreeing to take part in this face to face interview. I will be asking you questions that relate to your experience as a family caregiver, they will help enable me to identify what informational needs existed for you and what health care services could do to help. The interview should last between 40-60 minutes and will be audio recorded with your informed consent.

Can you start by telling me a bit about your family member’s current medical/health status?

Prompts:

- How long have you been providing care for your relative/spouse/friend?
- How did you feel when you were told the person you care for had developed an illness that required palliative care?
- How do you feel generally about the palliative care and support your relative/spouse/friend has received?
- How do you feel generally about the care and support that you have received to date as a family caregiver?

Information about the patient

Can you tell me about any verbal or written information you received on your relative/spouse/friend’s illness?

Prompts:

If yes –

- Who provided you with this information and how was it delivered?
- What types of information and education did you find most helpful?
- What further information would have helped you?

If no –

- What information and education do you think you would benefit from having?

Information about the family caregiver

Were you provided with any information to prepare you for your role as a caregiver and would it would entail?
Prompts:
If yes –
- What type of information did you receive?
- Who provided this information?
- Do you feel there was any other information that would have helped to prepare you?
- In what form do you prefer to receive information? (verbal/written/internet/mixture)

If No –
- What types of information do you feel would help to prepare you in your role as a caregiver?
- In what form would you prefer to receive information? (verbal/written/internet/mixture)

**Information on Practical Support**

Can you tell me about any information you were given to help you practically with the care of your family member? (i.e Home care workers, equipment, advice)

**Prompts:**
If yes -
- How were you provided with this information?
- Can you tell me about how the information you received enabled you to get practical support?

If no-
- What practical support do you feel you need to help you in your caregiving role?
- What information do you think you would benefit from in relation to practical support?

**Information on Social Support**

Can you tell me about any information you may have received about social support such as respite or support groups?

**Prompts:**
If yes –
- What services where you informed of?
- Who informed you of these services?
- What do you, as a caregiver, find most beneficial?
• Can you tell me about any extra information you may have received from palliative care services, on social support, from the palliative diagnosis was made?
  If no –
  • What do you think you think stopped you from receiving information on social support?
  • How do you feel you would benefit from social support?
  • What information do you feel you require to be best supported socially?

Information on Financial Entitlements
Can you tell me about any information you may have received about benefits or financial support you may be entitled to as a caregiver?

Prompts:
If Yes –
  • Who provided this information?
  • How were you able to access the financial support you were entitled to as a result?
  • Can you tell me about any problems you encountered?
If no-
  • What information do you feel you would require to be best supported financially?

Information on Psychological Support
How do you feel you are coping emotionally in relation to your relative/spouse/friend requiring palliative care?
Have you received information on emotional, psychological or spiritual support?

Prompts:
If yes –
  • What type(s) of information did you receive?
  • How were you able to access this?
If no –
  • What kind of emotional, psychological or spiritual support do you feel would be helpful?
  • How do you feel this would be best delivered (face to face/written/internet/mixture)?
  • What information do you feel you would require to enable you to access this emotional or psychological support?

Care-Giving Experience and Involvement
How have you found caregiving general?
Prompts:
- What aspects of caregiving do you find satisfying?
- What aspects of caregiving do you find difficult?
- Can you tell me about how you have, or have not been included, as a carer, in decisions about your family member?

If yes –
- How have you been included? - For example can you describe how services have worked in partnership with you?
- What could be done better?

If no –
- How could you have been more included?
- What do you feel has prevented this?

Experience of Services
Can you tell me about new or additional services that you have, as a caregiver, received since the diagnosis of this palliative illness?

Prompts:
- What professionals have been or are involved?
- Can you tell me about any support you have received from learning disability services?
- Can you tell me about any support you have received from palliative care services?
- What information and support did you find the most beneficial?
- Is there anything that you felt did not work well?
- Was there anything missing from the services you have received?
- Do you have any more thoughts on information that would improve support for caregivers of people with learning disabilities who require palliative care?

Are there any other points you feel are important to raise?
- If a programme to provide information and support for family caregivers of people with learning disabilities at end of life were to be developed how do you think this could best be delivered so that family carers could have access to it?
- Are there any other comments that you would like to make about information and support for family caregivers of people with learning disabilities?

Thank you for agreeing to take part in this interview and for giving your views and time. It is much appreciated.
Appendix 12 – Interview guide bereaved caregivers – version 3 09/05/2016

Interview Guide for Bereaved Family Caregivers

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study

Background

Thankyou for agreeing to take part in this face to face interview. I will be asking you questions that relate to your experience as a family caregiver, they will help enable me to identify what informational needs existed for you and what health care services could have done to help. The interview should last between 40-60 minutes and will be audio recorded with your informed consent.

Can you start by telling me a bit about your relative/spouse/friend’s illness?

Prompts:

• How many years had you been providing care for your relative/spouse/friend?
• How did you feel when you were told the person you provided care for had developed an illness that required palliative care?

• How do you feel generally about the palliative care and support your relative/spouse/friend received?

• How do you feel generally about the care and support that you received as a caregiver?

Information about the patient

Looking back do you feel you were able to find out all that you had wanted to know about your relative/spouse/friend’s illness, verbal or written?

Prompts:
If yes -

• How do you feel about the information and education you received on the illness, throughout the time you were a caregiver?
• Can you tell me what types of information and education you found the most helpful?
• How were you able to get this?
If no –
- What information and education do you think you would have benefited from having?

**Information about the family caregiver**

Were you ever provided with any information to prepare you for your role as a caregiver and would it entail?

**Prompts:**
If yes –
- What type of information did you receive?
- Who provided this information?
- Do you feel there was any other information that would have helped to prepare you?
- In what form do you prefer to receive information? (verbal/written/internet/mixture)

If No –
- What types of information do you feel would have helped to prepare you in your role as a caregiver?
- In what form would you have preferred to receive information? (verbal/written/internet/mixture)

**Information on Practical Support**

Can you tell me about any information you were given to help you practically with the care of your relative/spouse/friend (i.e. home care workers, equipment, advice)?

**Prompts:**
If yes -
- How were you provided with this information?
- Can you tell me about how the information you received enabled you to get practical support?

If no –
- What practical support do you feel you would have needed to help better care for your relative/spouse/friend?
- What information do you think you would have benefited from in relation to practical support?

**Information on Social Support**
Can you tell me about any information you may have received about social support such as respite or support groups?

**Prompts:**
If yes –
- What services were you informed of?
- Who informed you of these services?
- What did you, as a caregiver, find most beneficial?
- Can you tell me about any extra information you received from palliative care services, on social support, from the palliative diagnosis was made?

If no –
- What do you think stopped you from receiving information on social support?
- How do you feel you would have benefited from social support?
- What information do you feel you would have required to be best supported socially?

**Information on Financial Entitlements**

Can you tell me about any information you may have received about benefits, or financial support you may have been entitled to as a caregiver?

**Prompts:**
If Yes –
- Who provided this information?
  - How were you able to access the financial support you were entitled to?
- Can you tell me about any problems you encountered?
If no-
- What information do you feel you would have required, to have been best supported financially?

**Information on Psychological Support**

Did you receive any information or guidance for emotional, spiritual or psychological support during your relative/spouse/friend’s illness including the final stages and in your bereavement?
Prompts:
If yes –
  • What type(s) of support were you provided with?
  • Can you tell me how you were able to access it?

If no –
  • What kind of emotional, spiritual or psychological support do you feel would have been helpful?
  • How do you feel this would have been best delivered?
  • What information do you feel you would have required to enable you to access this support?

Care-Giving Experience and Involvement

Can you tell me how you found caregiving in general?

Prompts:
  • Can you tell me what aspects of caregiving you found satisfying?
  • Can you tell me what aspects of caregiving you found difficult?

If yes –
  • How were you included?
    • Can you tell me about how you have, or have not been included, as a caregiver, in decisions about your relative/spouse/friend – including the last stage of life?

If yes –
  • How were you included? - For example can you describe how services have worked in partnership with you?
  • What could have been done better?

If no –
  • How could you have been more included?
  • What do you feel prevented this?

Experience of Services

Can you tell me about new or additional services that you were offered, as a caregiver, once the diagnosis of palliative illness was made?

Prompts:
  • What professionals were involved?
  • Can you tell me about any support you received from learning disability services?
• Can you tell me about any support you received from palliative care services?
• What information and support was most beneficial?
• Is there anything that you felt did not work well?
• Was there anything missing from the services you received?
• Do you have any more thoughts on information that would improve support for caregivers of people with learning disabilities who require palliative care?
• Are there any other points that you feel are important to raise or any other comments that you would like to make?

• If a programme to provide information and support for family caregivers of people with learning disabilities at end of life were to be developed how do you think this could best be delivered so that family carers could have access to it?

• Are there any other comments that you would like to make about information and support for family caregivers of people with learning disabilities?

Thank you for agreeing to take part in this interview and for giving your views and time. It is much appreciated.
Appendix 13 – focus group schedule HSC professionals

**Topic Guide for Focus Groups with Health and Social Care Professionals**

Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study.

- What does the term palliative and end of life care mean to you?
- How do you feel family caregiver support fits into palliative care?
- Can you tell me about how you support a family caregiver of someone with a learning disability who has required palliative care?
- In your experience of supporting family caregivers can you describe any formal carer’s assessments?
- In your experience of supporting family caregivers can you describe what kind of information they needed?
- In your experience of supporting family caregivers can you describe any difficulties?
- What information do you feel should be provided to a family caregiver of someone with a learning disability following their loved one’s palliative diagnosis?
- Can you explain why this information in particular?
- Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to the education on either the disease the family member has, medication, death and dying and basic nursing care?
- Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to financial entitlements and benefits?
- Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to practical support such as: respite, sitting services, nursing care assistance such as homecare services?
• Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to psychosocial support such as counselling, spiritual/religious support, support groups and websites?

• What helped, or would help your team in supporting someone with a learning disability who required palliative care, and their family caregiver?

• Can you tell me how family caregivers are involved in the decision making process, if at all?
• What informational provision is there to enable collaborative decision making with services if any?
• How much have you found that partnership working between family caregivers of people with learning disabilities at end of life and services takes place? Can you give examples of where this partnership has taken place?
• What do you think would help promote partnership working between family caregivers and services?

• What has been your overall experience of working with family caregivers?

• Are there any other comments that anyone would like to make?

• If a programme to provide information and support for family carers of people with learning disabilities at end of life were to be developed how do you think this could best be delivered so that family carers could have access to it?

• Are there any other comments that you would like to make about information and support for family caregivers of people with learning disabilities?

Thank you all for agreeing to take part in this focus group and for giving your views and time. It is much appreciated.
Appendix 14 – Demographic sheet for family caregivers (v2 4/7/16)

Demographic Information Sheet for family caregivers

Participant Number:

Please tick the appropriate box

1. Are you Male? □ Female? □

2. Please indicate your age group below by ticking the appropriate box

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18-29 years</td>
<td></td>
</tr>
<tr>
<td>30-39 years</td>
<td></td>
</tr>
<tr>
<td>40-49 years</td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td></td>
</tr>
<tr>
<td>60-69 years</td>
<td></td>
</tr>
<tr>
<td>70+ years</td>
<td></td>
</tr>
</tbody>
</table>

3. Please indicate the number of years that you have cared for your family member with learning disability by ticking the appropriate box below

<table>
<thead>
<tr>
<th>Number of years caregiving</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 years</td>
<td></td>
</tr>
<tr>
<td>5-9 years</td>
<td></td>
</tr>
<tr>
<td>10-14 years</td>
<td></td>
</tr>
<tr>
<td>15-19 years</td>
<td></td>
</tr>
<tr>
<td>20+ years</td>
<td></td>
</tr>
</tbody>
</table>

Thank you for taking the time to complete this information sheet
Appendix 15 – Demographic sheet for HSC professionals

Demographic Information Sheet for Health and Social Care Professionals

Participant Number:

Please tick the appropriate box

1. Are you Male? □ Female? □

2. Please indicate below by ticking the appropriate box your age group and your professional background

<table>
<thead>
<tr>
<th>Professional Background</th>
<th>Age 20-29yrs</th>
<th>Age 30-39yrs</th>
<th>Age 40-49 yrs</th>
<th>Age 50-59yrs</th>
<th>Age 60-69yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Work</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Medicine</td>
<td></td>
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</tr>
<tr>
<td>Physiotherapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Speech and Language</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Physiology</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Psychology</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify below)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. Please state below:

(a) Where you currently work?

(b) What position you hold?

4. How long have you worked altogether in learning disability or specialist palliative care services, both in present and previous roles? Please tick the appropriate box(es)

I have worked in:

- Learning Disability Services
- Specialist Palliative Care Services
- Less than a year
- Between 1 and 5 years
- Between 6 and 10 years
- Between 11 and 15 years
- More than 15 years

5. Have you ever had any training on any aspects of providing palliative and end-of-life care to people with learning disabilities? Please tick the appropriate box

Yes  □  No  □

If yes please specify below

Thank you for taking the time to complete this information sheet
Information and Support Pack for Family Caregivers

If you would like to find out more about palliative care or seek professional advice and personal support, see below list of contact organisations.

If you have any queries or concerns arising from this interview or from the research process, there are a number of people and organisations who would be happy to help you. They can provide information and support to you and clarify any issues which might have arisen. You can contact them at any time.

- **The National Council for Palliative Care**

  If you would like more information about palliative and end of life care the National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative and end of life and hospice care in England, Wales and Northern Ireland.

  Address: The Fitzpatrick Building  
  188-194 York Way  
  London N7 9AS

  Telephone: 020 7697 1520

  Website: [http://www.ncpc.org.uk/](http://www.ncpc.org.uk/)

- **Palliative Care of People with Learning Disabilities Network**

  This national network aims to:

  - Enhance partnership working between services, family carers and people with learning disabilities
  - Promote best practice
  - Contribute to policy and standards
  - Support people with learning disabilities in making decisions and in using services through providing accessible information
  - Compile information in relation to training and other resources
Area meetings and national study days are also facilitated.

Website: http://www.pcpld.org/

- **Marie Curie Support Line**

Marie Curie Support Line Advisors are there to help, support and advise people who have palliative care needs and their family carers.

Telephone: 0800 090 2309

Website: www.mariecurie.org.uk/help

- **Cruse Bereavement Care**

Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable them to understand their grief and cope with their loss. The organisation provides counselling and support. It offers information, advice, education and training services.

The main Cruse website has even more information for you and can be reached at: www.crusebereavementcare.org.uk.

Alternatively, you can always contact the Helpline which is a confidential service.

Day by Day Service: 0870 167 1677

- **Carers UK (Northern Ireland Branch)**

Carers Northern Ireland is the regional office for Carers UK. It is a membership organisation run by carers, for carers across the whole of Northern Ireland. There are approximately 250,000 carers in Northern Ireland. Carers look after family, friends, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid. Carers Northern Ireland is the leading provider of information on all matters related to caring. For more information please contact:

58 Howard Street

Belfast BT1 6PJ

Telephone: 02890439843

Website: http://www.carersuk.org/northernireland
• **Samaritans**

Samaritans are a 24 hour confidential helpline who offer support for anyone experiencing distress. The core of their work is a telephone hotline however they also offer confidential email support.

Telephone: (028) 90664422

Email: jo@samaritans.org

*If you wish to make a complaint about the research:*

• **Complaints procedure**

Any complaints should be directed to the Chief Investigator (Kevin Brazil) in the first instance, followed by the Chair of the School Research Ethics Committee, Dr Oliver Perra. If you do not wish to make a complaint to the research team or they are the object of complaint and you wish to make a formal complaint, you can contact Dr Oliver Perra directly at the School of Nursing and Midwifery (details below).

**Professor Kevin Brazil (Chief Investigator)**

Telephone- (028) 9097

Email- k.brazil@qub.ac.uk

**Dr Oliver Perra (Chair of the School of Nursing and Midwifery Research Ethics Committee)**

Telephone – (028) 9097 2313

Email –o.perra@qub.ac.uk
Information and Support Pack for Health and Social Care Professionals

If you would like to find out more about palliative care or seek professional advice and personal support, see below list of contact organisations.

If you have any queries or concerns arising from this interview or from the research process, there are a number of people and organisations who would be happy to help you. They can provide information and support to you and clarify any issues which might have arisen. You can contact them at any time.

- **The National Council for Palliative Care**

  If you would like more information on palliative care the National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative and end of life and hospice care in England, Wales and Northern Ireland.

  Address: The Fitzpatrick Building
  188-194 York Way
  London N7 9AS
  Telephone: 020 7697 1520
  Website: [http://www.ncpc.org.uk/](http://www.ncpc.org.uk/)

- **All Ireland Institute of Hospice and Palliative Care**

  AllIHPc reflects a broad range of expertise in the service delivery, academic preparation for and management of hospice and palliative care across the island of Ireland. Consortium members and their organisations are experts in palliative care service planning and delivery, education and training, research and policy analysis. AllIHPc promotes strategic, evidence-based contributions to the policy/practice environment.

  Address: All Ireland Institute of Hospice and Palliative Care
  2nd Floor, Education and Research Centre
  Our Lady's Hospice and Care Services
  Harold's Cross, Dublin 6w
• **PCPLD (National Network for Palliative Care of People with Learning Disabilities)**

This network aims to:

- Enhance partnership working between services
- Promote best practice
- Contribute to policy and standards
- Support people with learning disabilities in making decisions and in using services through providing accessible information
- Compile information in relation to training and other resources

Area meetings and national study days are also facilitated.

Website: [http://www.pcpld.org/](http://www.pcpld.org/)

• **Occupational Health Department**

The Occupational Health Department in your Trust, or responsible for your organisation, can be contacted if you feel that you would like to talk to someone about any issue that is concerning you.

• **Marie Curie Support Line**

Marie Curie Support Line Advisors are there to help, support and advise people who have palliative care needs and their family carers.

Telephone: 0800 090 2309

Website: [www.mariecurie.org.uk/help](http://www.mariecurie.org.uk/help)

• **Cruse Bereavement Care**

Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support. It offers information, advice, education and training services. The main Cruse website has even more information for you and can be reached at: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk). Alternatively, you can always contact the Helpline which is a confidential service.

Day by Day Service: 0870 167 1677

*If you would like professional advice or personal support:*
• **Royal College of Nursing in Northern Ireland**

The RCN in Northern Ireland represents nurses and nursing, promotes excellence in practice and shapes health and social care policy. The RCN counselling service is part of RCN Member Support Services. The service provides free, confidential support and assistance to help RCN members deal with any challenging emotional issues they may face. This includes personal problems such as stress, depression, anxiety, bereavement, relationship breakdown, domestic violence, substance misuse, eating disorders and low self-esteem.

This service can also help with work-related difficulties such as bullying and harassment, managing your workload, manager/supervisor relationships and adjusting to new responsibilities.

Telephone: 0345 408 4391

Email: mss@rcn.org.uk

Referral form: [https://www.rcn.org.uk/support/services/referral](https://www.rcn.org.uk/support/services/referral)

(Select counselling from the drop down menu)

• **UNISON**

UNISON helps its members resolve work related problems. A number of professional support services are available to members such as legal services and employment relations.

Address: 4th Floor, Galway House
       165 York Street
       Belfast
       BT15 1AL

Telephone: 0800 0 857 857

Email: unisonnorthernireland@unison.co.uk

*If you wish to make a complaint about the research:*

**Complaints procedure**

Any complaints should be directed to the Chief Investigator (Kevin Brazil) in the first instance, followed by the Chair of the School Research Ethics Committee, Dr Oliver Perra. If you do not wish to make a complaint to the research team or they are the object of complaint and you wish to make a formal complaint, you can contact Dr Oliver Perra directly at the School of Nursing and Midwifery (details below).
Professor Kevin Brazil (Chief Investigator)
Telephone- (028) 90975782
Email- k.brazil@qub.ac.uk

Dr Oliver Perra (Chair of the School of Nursing and Midwifery Research Ethics Committee)
Telephone – (028) 9097 2313 Email –

o.perra@qub.ac.uk
Appendix 18 Terms of reference for expert reference group

Determining the information needs of family caregivers of people with learning disabilities who require palliative care: a qualitative study

Terms of Reference

Expert Reference Group

- To promote recruitment to the study by circulating information through advocacy groups and learning disability/palliative care services
- To assist in the development of a model, based on the findings of the study, which will reflect the information needs of family carers of people with learning disabilities who require palliative care
- To enable consultation on the recommendations from the study from a service user perspective and that of multi-professionals and policy makers
- To promote dissemination of findings from the study amongst networks and services

It is envisaged the expert advisory panel shall meet 3-4 times approximately between now and Oct/Nov 2017. This may be face to face or electronic.