EXPLORING PERSON-CENTREDNESS IN RESIDENTIAL SERVICES WITH OLDER PEOPLE WITH INTELLECTUAL DISABILITIES, THEIR FAMILY MEMBERS AND STAFF:

A MIXED METHODS STUDY

Volume 1 of 1

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ABSTRACT

Background: The importance of recognising the older person with an intellectual disability as a unique and valued citizen, living a connected and fulfilling life, is one of the foundations for this study. The principles of person-centred practice are strongly connected to intellectual disability services but are typically associated with person-centred planning. Key principles of person-centredness include choice, relationships and staff engagement. Policy changes in Ireland since 2011 has shifted the focus of care from large residential settings to living in a home environment within a community setting, created in partnership with staff. Previous research within intellectual disabilities services has focused on person-centred planning as a process. This study used an evidence-based person-centred framework as the theoretical lens to explore the concept of person-centeredness in practice.

Aim and objectives: This study explored how person-centredness is perceived and experienced within residential services. Older people with intellectual disabilities, their families and staff were research participants in the study.

The objectives were:

1. To examine staff practice and understanding of person-centredness within their day-to-day work.
2. To gain insight from older people with intellectual disabilities and their family members on person-centredness.
3. To synthesise the experiences of older people and family members with those of staff to expand the understanding of person-centred practice for older people with intellectual disabilities.

Methodology: A two-phase sequential mixed-methods approach was adopted for this research study. In phase one, a quantitative survey, the Person-Centred Practice Inventory-Staff, instrument was distributed to registered nurses and healthcare assistants working in residential services in one region of the Republic of Ireland. Phase two included 15 in-depth interviews with older people with intellectual disabilities and six in-depth interviews with their family members. Two focus groups and three semi-structured interviews were conducted with staff working in residential services.

Findings: The data from both quantitative and qualitative phases were analysed and integrated at the interpretative phase of the study. The 229 completed Person-Centred Practice Inventory-Staff questionnaires were analysed and the data revealed that staff reported they were person-centred in their practice and delivered person-centred care. In the qualitative data analysis with older people and the family members, they shared that they valued this time in their lives for comfort and enjoyment. They spoke of the importance of belonging and connection to home, family and community. The focus groups and interview data with staff revealed that they felt services were not always structured to realise person-centeredness in practice, despite this they reported a commitment to their role. The concept of 'othering' emerged from the data analysis finding that the attribution of negative characteristics impacted on how people with intellectual disabilities are perceived within communities and services.

Implications for practice: It should be a central aim within intellectual disability services to establish participatory processes in practice to create the foundation for the development of an in-depth understanding and implementation of person-centeredness. Future planning in collaboration with older people and their families is important to promote active ageing and belonging to their communities. The right to choose where to live and with whom should be recognised. The impact of 'othering' of people with intellectual disabilities needs to be meaningfully discussed in partnership with people with intellectual disabilities, their families and service providers at operational and strategic levels.

Key words

ABBREVIATIONS

CGH   Community Group Home

HCA   Healthcare assistant

HIQA   Health Information Quality Authority

MCAR   Missing Completely At Random

NIDD   National Intellectual Disability Database

PCPI-S   Person-Centred Practice Inventory-Staff

PCPF   Person-Centred Practice Framework

PPI   Public and Patient Involvement

QQI   Quality Qualifications Ireland

RNID   Registered Nurse Intellectual Disabilities

RoI   Republic of Ireland

UK   United Kingdom

X2   Chi square

Yrs   Years

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CHAPTER 1: INTRODUCTORY CHAPTER

1.1 Introduction

Person-centredness is consistently emphasised within national and international policy documents as a means of creating a meaningful and fulfilling life for people with intellectual disabilities, particularly as they age. Person-centred practices have long been advocated within the literature of intellectual disability services and are typically associated with person-centred planning and encompass many different principles including, choice, respect, relationships and staff engagement. These general principles provide a focus for care delivery in services but do not acknowledge the complexity of the concept, which is influenced by organisational cultures and interpretation, resulting in challenges to its implementation (DoH 2012a; Áras Attracta Swinford Review Group 2016).

Since 2011, the decongregation policy in the Republic of Ireland has shifted the focus of care away from large residential services to living in a home environment in a community setting. This will assist people with intellectual disabilities to become part of society and full citizens of the country, supported by staff using person-centred approaches (HSE 2011). The decongregation movement involves the relocation of people with intellectual disabilities who are living in residential services with ten or more people, often in conditions that lack privacy and dignity. These people are described as being older and live isolated lives away from their families and communities (HSE 2011). The current policy anticipates that moving from a congregated setting to community living will inevitably create person-centred cultures and safe and effective care (Áras Attracta Swinford Review Group 2016).

Staff engagement within residential services plays a key role in the implementation of person-centredness in partnership with people with intellectual disabilities (HSE 2011) but little attention has been given to how staff translate the concept into practice. As highlighted by previous researchers, for person-centred practice to become a reality, staff must be able to understand the complexities of the concept (Mansell and Beadle-Brown 2004; McCormack and McCance 2010). The prevailing emphasis on person-

centredness and the need for older people to live fulfilling lives within their communities encouraged the researcher to undertake this study. This opening chapter sets out the research context and will provide a brief history of philosophy of care and the development of residential services for older people with intellectual disabilities. It will also give an account of the development of person-centredness and associated approaches, such as person-centred planning. Finally, a definition of person-centredness used in the context of this study will be provided with the rationale for the study. It will conclude with an outline of the thesis, giving a brief overview of the content of each of the succeeding chapters.

1.2 What is an intellectual disability?

The World Health Organisation (WHO 2010) recognises intellectual disability as human experience which is positioned on a wide-ranging spectrum of human functioning with factors such as, family, environmental and health conditions impacting on the person's ability to fully participate in society. Intellectual disability is now the preferred terminology internationally, with the term learning disabilities widely used in the United Kingdom (UK) and Developmental Disabilities in Canada, and previously referred to as Mental Retardation in the United States (Haveman 2011). The American Association on Intellectual and Developmental Disabilities. (AAIDD 2014) diagnostic criteria attempts to move away from the previous Intelligence Quotient (IQ) classifications and offers a more comprehensive view of disability and the impact on the persons functionality regarding conceptual, social and practical abilities. The Diagnostic and Statistical Manual of Mental Disorders version 5 (DMS-5) describes how an intellectual disability may impact on the person's memory, reasoning abilities, literacy levels; also, their social skills, including empathy, social judgement, and interpersonal communication skills. Furthermore, an intellectual disability may also affect the person's ability to manage their daily living skills, personal care, finances and organisational skills. The definition states that intellectual disability is, *"…characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 22."*

(American Association of Intellectual and Developmental Disabilities 2014).

Northway and Jenkins (2003) highlighted the commonalities of definitions that generally refer to a group of people who have some level of cognitive impairment and challenges with social adaptation acquired in childhood.

1.3 The changing philosophy of care for people with intellectual disabilities

The lived history of people with intellectual disabilities has been impacted by historical care philosophies. Having a disability was often viewed with suspicion and fear with diagnostic terms such as '*idiot,' 'feebleminded'* or *'imbecile,'* labelling which continues to have pejorative meaning within modern discourse. In the early 20th century people with intellectual disabilities were perceived by society as defective and sick therefore their care was based on a medical model and their healthcare needs met within a specialist service. These services were based in large, long-stay hospital-style settings, known as asylums or institutions and were often located in rural isolated areas. Initially these establishments focused on education and occupational training, with staff such as intellectual disability nurses, playing a multi-faceted role delivering healthcare and education to people with intellectual disabilities (Sweeney and Mitchell 2009).

However, there were notable variations in the standards of care delivery within these environments and although it was acceptable practice at the time, they became synonymous with degrading and inhuman acts (WHO 2000). The work of Goffman (1961) critiqued life within asylums and described the depersonalisation of the individual. Care scandals such as Ely Hospital in Cardiff in 1967, exposed the abuse and ill-treatment of people with intellectual disabilities, leading to an inquiry and a national review of care (Drakeford 2012). As society's knowledge of disability widened the negative effects of institutionalisation gained greater recognition and was part of the civil rights movements of the 1960s and 1970s (Wiesel and Bigby 2014), creating a political and social justice movement which advocated for more humane patterns of care (Slevin 2004).

Subsequently, the development of a human rights mandate saw the promotion and acceptance of the concept of Normalisation which was first defined by Nirje (1994

[1969]) and later expanded upon by Wolfensberger (1972). As the principle of normalisation developed, Barr (1995) noted that its misapplication was causing some concern and confusion at the time. Therefore, Wolfensberger (1983) advocated that the principle should be renamed as 'Social Role Valorisation' (SRV), to develop valued social roles for 'devalued' people, so they can be positively recognised within society (Wolfensberger 2000). Normalisation and 'Social Role Valorisation' gave rise to an international social justice movement which influenced care philosophies and policy recognising that people with intellectual disabilities had the right to live an *'ordinary life'* that would be valued by other people in society.

There was a strong impetus for more humane services with the publication in the UK of '*Better Services for the Mentally Handicapped'* (Department of Health and Social Security 1971), followed in 1979 by the '*Report of the Committee of Enquiry into Mental Handicap Nursing and Care*' (known as the Jay Report) indicating that the long-stay hospital model could no longer be sustained or validated as providing adequate care for people with intellectual disabilities (Mitchell 2004; Taggart 2003). The Jay Report also recommended that 'Mental Handicap Nursing', as it was then known, should be replaced with a professional grouping based on the Certificate in Social Services (Mitchell 2003), signalling a shift away from the medical model to a social model of care. It was not until the 1980s that the decongregation agenda commenced internationally. The UK Community Care Act (1990) oversaw the implementation of the social model of care with people being supported to remain in their local communities (Gilbert *et al.* 1998). A decade later, the publication of the strategy *Valuing People* (DoH 2001) signalled the move from a standardised system-based approach to a person-centred approach (Kaehne and Beyer 2014).

In contrast, the development of services in the Republic of Ireland differed to other western countries. The growth of health and social services in 18th century Ireland was based on a charitable philosophy, funded by voluntary, religious organisations and philanthropic endeavours (Harvey 2007). Under the Irish Poor Law (1843-1948) entitlement to services fell into two categories, those who were perceived as deserving of support, known as the 'deserving poor', which included people with intellectual disabilities, while the 'undeserving poor' were held responsible for their own impoverished circumstances (Dukelow and Considine 2017). For those who needed

care or housing during this period, workhouses were at the core of service provision. According to Quin and Redmond (2003) specific residential provision for people with disabilities did not exist until the early twentieth century. Under the creation of the Irish Republic in 1922, funding for health services was not a priority due to restricted finances of the newly established state (Harvey 2007). There was continued reliance on religious orders and voluntary bodies for the provision of services for all disabled people through residential homes or special schools (Sweeney and Mitchell 2009), with state service provision eventual being established. In the 1960s it was common for people with intellectual disabilities to be admitted to psychiatric hospitals, either due to a lack of local service provision or the limited capacity of specialist services, but care practices within psychiatric hospitals at that time were described as inadequate and inhumane (Kilgannon 2020).

In absence of a cogent approach by the Irish government, voluntary organisations such as *Inclusion Ireland* and *Parents and Friends Associations* also emerged during the1960s and were influential in advancing care and shifting the focus to locally based services (Inclusion Ireland 2011). From the 1960s onwards the Republic of Ireland instigated changes in the reconfiguration of care but the pace of change to community-based services was not as rapid as witnessed within the UK or internationally. In 1990 the *Needs and Abilities Policy* (DoH 1990) outlined the imperative for the development of community-based services and the discontinuation of large residential services based in one location. The report advocated for a new residential style of provision of homes in small clusters of 3-4 houses over various locations. Several reports followed over the decades advocating for the mainstreaming of housing provision for people with intellectual disabilities. Sheerin and McConkey (2008) note that this involved a move away from segregated services based in isolated rural areas to a philosophy of integration in more urban settings via a community group home model. The *Needs and Abilities Policy* also recommended the relocation of people who were inappropriately placed in psychiatric hospitals to more suitable residential services and this relocation remains ongoing and is set to continue until 2022 (Hourigan *et al.* 2018).

Observers of the deinstitutionalisation movement have noted that the pace of change in the Irish Republic lags behind international standards (HSE 2011; NDA 2018).

However, as Linehan *et al.* (2014) contends the dearth of change is not due to a lack of policy in the area, with over sixteen key national disability policy reports published since the mid-1990s, all with the goal of assisting people with intellectual disabilities to live the life of their choice. More recently, several published reports have pressed for establishing a more person-centred based system, with choice and independence at the core of the reforms (Linehan *et al.* 2014). To contextualise the key influential policies a summary is outlined in Table 1.1.

Table 1.1 Significant disability policies influencing care approaches

1996	*A Strategy for Equality; the Report of the Commission on the Status of People with Disabilities* – A key strategy in proposing a rights-based approach to disability in Ireland.
1997	*Enhancing the Partnership: Report of the Working Group on the Implementation of the Health Strategy in Relation to Persons with a Mental Handicap*
2004	*The National Disability Strategy-* this strategy underpins the participation of people with disabilities in Irish society, education, allocated funding.
2011	*National Housing Strategy for people with a Disability 2011-2016.*
2011	*Time to Move on from Congregated Settings: A strategy for community inclusion.*

The Health Service Executive policy, *Time to Move on from Congregated Settings,* (HSE 2011), represents one of the central philosophies now underpinning Irish intellectual disability policy. This involves the decongregation of over 4,000 people to community living, who are described as being older with higher levels of complex needs. The report also states that people living in congregated settings are living isolated lives with little dignity or privacy afforded to them by their physical environment. Therefore, a model of community living is advocated with an assumption that this will create person-centred cultures of care. However, international researchers caution regarding this assumption as there is a risk of institutional practices being recreated within community group homes through attitudes and practices. Several researchers warn that some aspects of culture within community group homes are similar to those in congregated settings (Bigby *et al.* 2012; Linehan *et al.* 2014).

1.4 The development of person-centred approaches in intellectual disabilities

Traditionally, the area of disability policy and services were structured to meet the needs of collective groups and rarely referred to the person (Stainton 2002). As a result, people with intellectual disabilities had to adapt to the services that were available to them (Sanderson 2000) where they were often treated as passive recipients of care (Rose 2003). With the development of community living there was also a notable move away from focusing on people's deficiencies to their strengths. Many services adopted O'Brien's Five Essential Accomplishments (1992) which are closely linked to service activities to help focus and guide staff in their work. These interdependent accomplishments set out key principles which many services used to describe their values and philosophy of care as follows:

1. Community participation
2. Encouraging valued social roles
3. Promoting choice
4. Contribution community presence
5. Sharing ordinary places and activities

Approaches to care were also organised through tools such as Individual Programme Planning (IPP) to structure and deliver services to adults with intellectual disabilities. The IPP process aimed to identify and meet the needs of people while ensuring their involvement in decision-making and provided a forum for professionals and agencies to coordinate their roles and tailor service provision. However, Carberry (1999) outlines the criticism of this method as it focused on the person's social inadequacy rather than opportunities for development and the lack of involvement of family and others in the person's life.

Meanwhile, throughout the 1970 and 1980s the development of Person-Centred Planning began in North America. O'Brien and O'Brien (2000) chronicled the work of communities of practice which were active at that time and were applying the principles of normalisation with the aim of improving the quality of services to people with intellectual disabilities. There were notable workshops delivered by Karen Green-McGowan and Mary Kovaks on 24-hour planning for people with severe and profound

intellectual disabilities, with later work commencing on Personal Futures Planning (O'Brien and O'Brien 2000). These workshops and explorations shaped the earliest forms of person-centred planning with the approach then spreading to the UK providing an opportunity for international exchange of perspectives. Due to a growing dissatisfaction with previous service approaches, in 2000 the UK Department of Health, published the White Paper '*Valuing People'* which demanded a cultural change of power from staff and other stakeholders to individuals and their families and endorsed person-centred planning as the most effective approach to achieve this (O'Brien 2004). Similarly, reports were published in Scotland (Scottish Executive 2000), Northern Ireland (DHSSPS 2005) and Wales (Welsh Assembly Government 2007) advocating a focus on person-centred planning. Recent policy within the Republic of Ireland and internationally also places person-centred planning as the cornerstone of service delivery (HSE 2011; NICE 2018) with Australia and the USA also including person-centred planning in new policy guidelines (COAG 2011; CMS 2014).

Person-centred planning is described as an umbrella term, which comprises of a family of approaches. Sanderson (2000) explains that it requires a flexible and responsive approach to meeting the person's needs as opposed to a standard procedure utilised previously. One vital component of Person-Centred Planning is the role of families and the person's *'circle of support'* in planning to make improvements in the person's life, even in the absence of proactive policies or sufficient resources (O'Brien 2004). The process also focuses on the person's abilities and skills as opposed to the deficits and impairments (Sanderson 2000). However, studies undertaken to evaluate the impact of person-centred planning have highlighted that those with complex needs, such as mental and physical health problems, are less likely to receive a plan or benefit from a plan if they receive one (Holburn *et al.* 2004; Robertson *et al.* 2006). Previous studies illustrated that those with severe intellectual disabilities and communication deficits are often excluded from the planning process (Mansell and Beadle-Brown 2004; O'Brien 2004). What is clear from the published literature, is that person-centred planning alone does not guarantee positive outcomes for individuals, particularly for those with complex needs (Mansell and Beadle-Brown 2004; Michaels and Ferrara 2006). Research consistently observes the importance of prerequisites of a person-

centred culture prior to the implementation of person-centred planning, that is knowledgeable staff, management style and review of organisational structures (Holburn *et al.* 2004; Mansell and Beadle-Brown 2004; Dowling *et al.* 2006).

1.5 Ageing and people with intellectual disabilities

Older people are a growing demographic group in society. People are now living longer than previous generations and ageing populations are a testimony to the social and economic progress reflected in improved public health within society through better housing, sanitation, health, and nutrition, which have all contributed to people living longer (United Nations 2019). It is estimated that by 2050, 1 in 6 people worldwide will be over the age of 65 years old, which is an increase from 1 in 11 in 2019 (United Nations 2019). A similar demographic profile is reflected in 2016 Census Population in the Republic of Ireland, with a 19.1% increase in those over 65 years old (Central Statistics Office 2016). This increasing longevity has also been reflected in the lives of people with intellectual disabilities and has been well documented within the literature (WHO 2000; Haveman *et al.* 2011; Burke *et al.* 2014).

Although ageing is a life-long process, it is difficult to define exactly when a person becomes old, with most western societies have accepted the chronological age of 65 years as the definition of old age or 'elderly' (WHO 2000). As the WHO (2000) highlight, defining old age for people with intellectual disabilities is complicated due to premature ageing in some people, particularly those with Down's syndrome. The World Health Organisation's (2000) definition of older people with intellectual disabilities refers to populations from 50 years of age onwards, recognising that age-related changes occur when people are in their 50s. Within the Irish Republic, the National Intellectual Disability Database (NIDD) captures the national service needs of people with intellectual disabilities. The data is primarily used as a service planning tool to track service usage and future trends and the needs of people with intellectual disabilities. The NIDD identifies older people with intellectual disabilities as 55 years plus, and within this study the same definition has been adopted to aid the linkage of data regarding populations and services within the Republic of Ireland.

Reports from National Intellectual Disability Database (NIDD) provide a profile of the population within the Irish Republic, with 27,985 people with an intellectual disability registered on the database (Hourigan *et al.* 2017). Although the majority of people live at home with parents', siblings, or relatives (69%), there are 26.9% in receipt of full-time residential service. As services evolved a variety of residential provision has also emerged, with many services providing 24-hour support to people. The annual reports from the NIDD consistently reveal that there is an enduring high level of demand for residential services which are specifically designed to meet the needs of those who are aged 55 years and older (Kelly 2015; Hourigan *et al.* 2017). This trend is set to continue with McCarron *et al.* (2017) predicting that within the next 10-15 years the largest proportion of adults with intellectual disability will be aged 50 years and over. The IDS-TILDA longitudinal study, which studies ageing in Ireland among people with intellectual disabilities, found that most people living in residential services tended to be older with more severe and profound levels of intellectual disabilities (McCarron *et al.* 2017). Overall, it is estimated that about 40% of people with intellectual disabilities aged 55 years or over may be currently living in a congregated setting (HSE 2011).

Ageing for people with intellectual disabilities is recognised as being more challenging, as they are a socially neglected group who have not had the same opportunities for healthy ageing as the general population (WHO 2000). While the Department of Health (2013b) advocate strategies for positive ageing and highlight the importance of taking a psychosocial approach to ageing within society, rather than perceiving it merely as a health issue. However, as WHO (2000) highlights people with intellectual disabilities have experienced inadequate services and welfare provision during their lives and were given lower priority over the general population of older people.

1.6 The significance of a person-centred approach and rationale for the study

Health and social care organisations often articulate an intention to deliver services which are person-centred (McCance *et al.* 2011). While person-centredness is a central focus of strategy documents in both services for older people and for people with intellectual disabilities, such as *Future health a Strategic Framework for Reform of the Health Service'* (DoH 2012b); and '*Time to Move on from Congregated Settings'*

(HSE 2011); and furthermore, within professional guidance and reports such as '*Working with older people* (NMBI 2015) and '*Shaping the Future of Intellectual Disability Nursing in Ireland*' (McCarron *et al*. 2018), all of which identify the principles of person-centredness as key indicators of quality care. Much of the evidence to support the importance of person-centredness in the delivery of a quality healthcare service has emerging from the research literature in older person settings (McCormack 2004). The growth and development of person-centred practice has been shown to transform practices to improve care for people in a wide range of healthcare settings (McCormack and McCance 2017).

Person-centredness is not new terminology within the discourse of intellectual disability services but it is typical associated with person-centred planning. A systematic review on the effectiveness of person-centred planning by Ratti *et al.* (2016) found that studies are often characterised by small scale descriptive case studies or studies subject to significant bias. Further research studies have examined person-centredness through the tenets of person-centredness, such as choice, relationships, and inclusion (Dunn *et al*. 2010; McCausland *et al.* 2014; Ratti *et al*. 2018) but did not account for the wider organisational influences which may affect the implementation of person-centred practice. The emergence of models of person-centred care now provides an evidence-based framework to comprehensively examine the concept in practice, which previous studies have not addressed. The most widely reported model is the Person-Centred Practice Framework (PCPF) developed by McCormack and McCance (2010; 2017), who describe person-centred practice as being achieved through the development of healthful relationships and is underpinned by values of mutual respect and understanding for all persons (Parlour *et al.* 2014).

The PCPF was originally developed from empirical research and has its origins in a gerontological nursing context. The theoretical framework provides components for the realisation of person-centredness in practice and has been continuously developed since 2006 (McCormack and McCance 2017). The PCPF is particularly suitable for empirical studies that aim to explore person-centredness in practice settings. Additionally, the framework was chosen as the theoretical lens for this

research study as it encompasses the key philosophies such as inclusion, empowerment, and shared decision-making (Slater *et al.* 2017) which are central to the lives of people with intellectual disabilities. Consequently, the definition used in the context of this study draws on the work of McCormack and McCance (2010, 2017) where person-centredness is defined as:

> *"An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development".*
> *(McCormack and McCance 2017, p.3)*

1.6.1 Rationale for the study

The rationale for this study stems from the emphasis on person-centred practice and the challenges in providing person-centred services to older people with intellectual disabilities. It was an important prerequisite that the study be inclusive and guided by older people and this was achieved through Patient and Public Involvement (PPI). Therefore, before commencing the research I contacted a local residential service to assist in organising a face-to-face consultation with a small group of older people with intellectual disabilities, their family members and staff. It was an informal gathering where the aim and expectations of the study were presented. Together we discussed the topic and explored the potential focus, benefits and involvement opportunities. It also shaped the methods of data collection with older with intellectual disabilities and family members, with both stating that they would be more comfortable with individual interviews rather than a focus group interviews. The involvement of the three groups of people provided different perspectives and confirmed the value of the topic in the lives of older people with intellectual disabilities who clearly expressed their wish to participate. The PPI process benefitted the research study, filling gaps in the research proposal and facilitated mutual learning.

The importance of recognising the older person with an intellectual disability as a valued citizen is a key component of this study. Since 2011 policy in the Republic of

Ireland has clearly signalled the move away from living in large residential settings to a living in home environment within a community setting created in partnership with staff with a focus on person-centredness. However, person-centred practice is a complex concept which staff must be able to understand in order to translate its principles into practice (Mansell and Beadle-Brown 2004; McCormack and McCance 2010). An exploratory study which compares the options of the different persons involved in care, that is staff, older people with intellectual disabilities and their family members, will allow a comprehensive examination of the topic from different perspectives and is in-line with the philosophy of person-centredness. Furthermore, previous research within intellectual disabilities services has focused on person-centred planning as a process. This study will use an evidence-based person-centred framework as the theoretical lens to explore the concept of person-centeredness in practice.

1.7 Structure of the thesis

This section gives an overview of the structure of the thesis and includes a summary of each chapter.

Chapter 1: Introductory chapter has introduced the thesis and provides a background to the deinstitutionalisation movement for people intellectual disabilities and the development of person-centredness. It also outlines the justification for the study, followed by an overview of the thesis.

Chapter 2: Literature review details the search strategy used and the resulting number of articles retrieved and critiqued. The chapter is divided into two parts, the first part provides a review of the general literature in relation to person-centredness and examines the meaning and components of the concept, setting the context for the main literature review in part two. Part two then presents the published literature relating specifically to older people with intellectual disabilities providing an analysis of the components of person-centredness within the literature.

Chapter 3: *Methodology* outlines the aims and objectives of the study and presents the methodological and philosophical underpinnings of the study. It discusses the historical and current philosophy of pragmatism, and a rationale is provided for the use of the pragmatic approach for this mixed methods study. This chapter concludes with a personal account of my philosophical stance to reflect on and clarify my own beliefs and values and recognise their influences on my approach to this study.

Chapter 4: *Theoretical underpinnings and methods* details the theoretical underpinnings of the study and the data collection methods used within the mixed method research design. A rationale and justification for the use of the sequential explanatory design is provided and an outline of processes for both the quantitative and qualitative phases, including the data analysis procedures and integration of the two phases. The issue of validity and rigour within the study are addressed and how the credibility of the findings is ensured. Finally, the ethical considerations that relate to the study are identified, with reference to the inclusion of people with intellectual disabilities and the strategies implemented to ensure the study was conducted in an ethical manner.

Chapter 5: *Preliminary analysis of Person-Centred Practice Inventory-Staff* presents the findings from phase one of the quantitative data from the Person-Centred Practice Inventory (PCPI-S). The assessment of the normality of the data is given for each of the domains, Prerequisites, Care Environment and Care Processes.

Chapter 6: *Findings from the Person-Centred Practice Inventory-Staff* commences with the demographic profile of the participants of phase one of the study. The descriptive and inferential results are presented for each of the prerequisites, care environment and care processes domains. This is followed by the findings of the descriptive and inferential results and a summary of the key findings of phase one.

Chapter 7: *Qualitative Findings: Thematic analysis* presents the qualitative analysis from of the interviews from phase two of the study. The transcripts from the two focus groups and three in-depth interviews with staff; 15 in-depth interviews with older people with intellectual disabilities and six in-depth interviews with family members, were thematically analysed and are presented in this chapter under five core themes,

each with several sub-themes. Extracts from the transcripts are used to support the development of these themes to demonstrate the truthfulness and credibility of the findings throughout the chapter.

Chapter 8: *Discussion* presents the integration of findings from phase one and phase two data sets. The themes arising in the qualitative data, which are absent in quantitative data set, are identified and discussed in the context of the overall findings. The findings from both datasets are compiled under themes to provide a coherent understanding of person-centredness in residential services.

Chapter 9: *Recommendations and implications of the study* is the final chapter of the thesis and provides an account of the contributions to knowledge that this study makes. Recommendations are made for policy, practice and education to enhance person-centred practice within residential services for older people. The strengths and limitations of the study's findings are identified. Finally, a personal reflection on the experience of the research process within an intellectual disability context is provided.

1.8 Summary

This chapter has provided the background and context of the research study and provided the structure to the thesis. The next chapter will present and review the relevant literature to the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter is presented into two parts. The first part provides an overview of the historical foundations, terminology and components relating to person-centredness in the context of the theoretical framework which guides this research study. This leads to the second part of the literature review, which is also the main focus of the review, examining person-centredness and its related components within an intellectual disability context, with an emphasis on the literature relating to older people.

2.2 Search strategy

The initially review set out to explore the broad-spectrum of literature in the general context of person-centredness, its core components and how it relates to practice. The initial search of the literature explored what is meant by the term person-centredness and its associated terminology and included published literature in peer reviewed journals and published reports in the English language. The search included key terms outlined in Table 2.1 below and the key databases used were ProQuest, CINAHL Complete, Medline and Ovid. The retrieved literature was then reviewed by title, abstract and full text for inclusion.

Table 2.1: Keywords used in the initial literature search

• Person-centred	• Concept analysis
• Person-centred approaches	• Literature review
• Client-centred	
• Patient-centred	

A total of 40 articles were yielded from the first search, which helped to clarify the terminology and the components of person-centredness. Figure 2.1 of the Prisma flow chart outlines the process.

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│          │   │ Records identified through  │   │ Additional records          │
│ Identifi-│   │ database searching          │   │ identified through          │
│ cation   │   │ (n = 2192)                  │   │ other sources               │
│          │   │                             │   │ (n = 6)                     │
└──────────┘   └─────────────────────────────┘   └─────────────────────────────┘
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               │ Records after duplicates removed              │
               │ (n = 950)                                     │
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│          │   │ Articles, Records screened  │   │ Articles, screened by title │
│ Screening│   │ by title and abstract       │──▶│ and abstract and excluded   │
│          │   │ (n =950)                    │   │ (n = 853)                   │
└──────────┘   └─────────────────────────────┘   └─────────────────────────────┘
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┌──────────┐   ┌─────────────────────────────┐   ┌─────────────────────────────┐
│          │   │ Full-text articles assessed │   │ Full-text articles excluded,│
│ Eligibi- │   │ for eligibility             │──▶│ with reasons                │
│ lity     │   │ (n =97)                     │   │ (n =57)                     │
│          │   │                             │   │                             │
└──────────┘   └─────────────────────────────┘   │ Full-texts articles which   │
                            │                     │ were excluded were not      │
                            ▼                     │ eligible for criteria and   │
               ┌─────────────────────────────┐   │ did not provide clarity on  │
┌──────────┐   │ First search: Studies       │   │ the elements of             │
│          │   │ included in                 │   │ person-centredness          │
│ Included │   │ (n = 40)                    │   └─────────────────────────────┘
│          │   └─────────────────────────────┘
└──────────┘
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Figure 2.1: Prisma flow diagram of the literature selection process: part one

The second search of the literature was designed to source literature on person-centeredness an intellectual disabilities context. A variety of terms are used when referring to people with intellectual disabilities, such as learning disabilities and developmental disabilities.

These search terms were combined with other relevant terms such as older people, elderly, and ageing. The terms residential, congregated settings and community group home were used for the context of care delivery. When using the search term 'person-centred' within an intellectual disability context, the resulting search yields literature on person-centred planning. Owning to the exploratory nature of this study, person-centred planning is not the focus of the review as the literature needed to take a wider perspective of the concept. It was therefore necessary to diversify the search strategy to include related components of the Person-Centred Framework (McCormack and McCance 2010; 2017). Furthermore, terms such as, client-centred and relationship-centred care were explored but yielded few results. While family-centred care focused on parents and future planning, which was not the focus of this study.

Specific health related papers were excluded from the search. The rationale for this exclusion was to present an exploratory overview of the topic. For example, dementia and Down syndrome, is well documented and its inclusion may distort the overall findings. To help structure the search strategy and define the inclusion and exclusion criteria, the Irish Department of Health (2013a) guide was utilised. This helped define and outline the aims of the literature review and included the search question, key words, types of literature and potential sources and is outlined below in Table 2.2

Table 2.2: Literature review search planning (DoH 2013a)

Define your topic/research question	What are the core components of person-centredness for older people with intellectual disabilities in a residential context
Develop initial keywords to represent concepts in your search	Person-centred, person-centred practice, person-centred approaches, client-centred, intellectual disabilities, learning disabilities older people, aged care, residential and community group home
Identify what type of literature you are searching for	Published literature providing researched evidence-based findings connected to the subject
Identify sources to search	Databases such as Proquest, Cumulative Index to Nursing and Allied Health (CINAHL) and Medline Ovid • Thesis • Peer reviewed journals • Grey literature • Published reports
Identify scope / limits of search	Literature published in the English language that included the above search terms Search years between 2004 to 2016 **Exclusion criteria** • Person-Centred Planning literature which did not include core components of the PCPF (2010; 2017) • Quality of Life literature • Younger populations • Literature which focuses on community services • Specific healthcare related papers • Family-centred and future planning

Whilst the term 'person-centred practice' is customary within other care contexts, the term revealed a dearth of associated literature regarding the topic of practice development initiatives related to intellectual disability services. Therefore, there was a requirement to adapt the search strategy. A further search was conducted using keywords shown in Table 2.3 that are based on the core components of person-centredness within intellectual disability context and the definition of person-centredness that was used in this study.

Table 2.3: Revised keywords used in the further search

	AND	
• Choice • Shared decision-making • Culture • Active ageing • Values • Physical environment • Communication • Therapeutic relationships		• Intellectual disabilities/learning disabilities/developmental disabilities • Older people/aged/elderly • Residential • Community Group Homes

Using the above search strategies, the resulting literature was reviewed by title, abstract and then the full text to judge its suitability for inclusion. The broad range of search terms used in the second search yielded in a substantial increase in relevant articles being retrieved. The review found commonalities amongst the themes and findings with the most prevalent themes associated with the components of person-centredness identified and prioritised within this review.

This process of inclusion and elimination of the literature is illustrated in Figure 2.2. via the Prisma flow diagram (Page *et al.* 2021), with the main literature review search yielding 70 articles. The 70 articles which were included were initially screened by title and abstract, this followed on to using the Critical Appraisal Skills Programme (CASP) to guide the process and assess for quality. The identified studies relating to person-centredness in residential services and older people are summarised in Appendix 1. The literature varied in terms of the source of international studies, with a substantial amount of the relevant literature emanating from Australia and the Republic of Ireland. The selected studies were identified with themes that were pertinent to person-centredness.
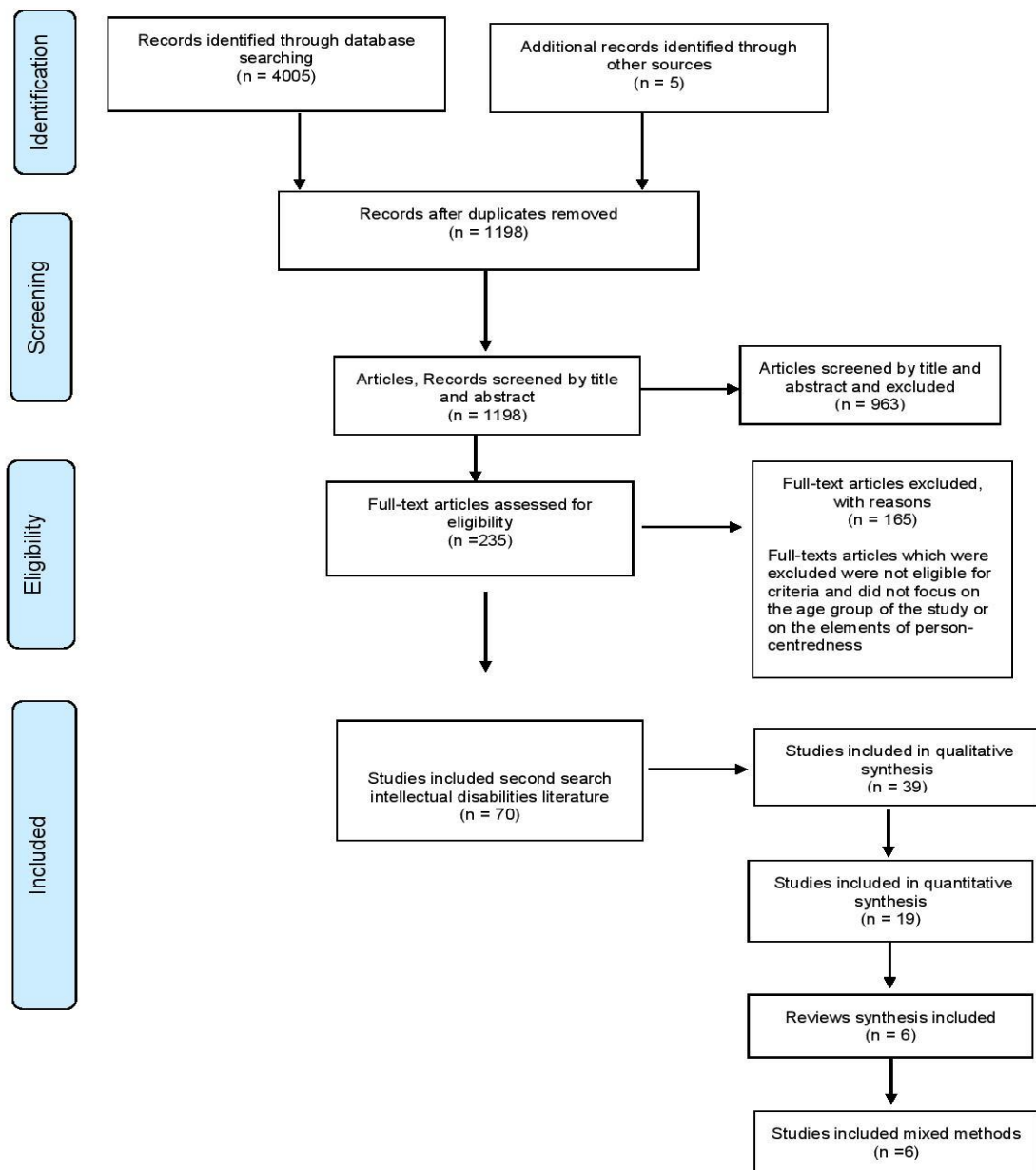
Figure 2.2: Prisma flow diagram of the literature selection process: part two

2.3 Person-centredness: historical development and terminology

The terminology and philosophy of person-centredness is now widely utilised within health and social care services and is internationally regarded as a standard of practice which demonstrates a respect for the person and the delivery of high-quality care (Binnie and Titchen 1999; Shaller 2007). The WHO has called for countries to make a fundamental shift in care strategy to align with its principles (WHO 2015). This signals a shift away from professionals holding the power of knowledge and expertise, while people in services remain a passive recipient in the delivery of care. Person-centredness stresses the requirement of services to respond to the needs of the individual, creating an equal partnership in decision-making and promotes a human rights approach to care (Wilberforce *et al.* 2016). The focus on person-centredness remains a priority in health and social care as it promotes accountability, service satisfaction and ultimately improves health outcomes of the person (Epstein *et al.* 2010).

Although the concept of person-centredness is considered to be a relatively new phenomenon within health and social care, the general concept of 'centreness' has been present within the literature for number of decades. Various authors, such as Hughes *et al.* (2008) and Morgan and Yoder (2012) recount the extensive history of the concept of 'centredness', tracing its origins to the work of Florence Nightingale, who advocated for a focus on the patient as opposed to the illness. More recently, its origins can be found in the field of humanistic psychology and the work of Carl Rogers which commenced in 1940s and had a significant impact in the field of psychotherapy. Through creating the concept of person-centred psychotherapy, sometimes referred to as client-centred therapy, he emphasised the importance of the therapeutic relationship between the client and the therapist, demonstrating empathy and positive regard to bring about change.

Meanwhile, the term patient-centred medicine was coined by Balint in1968 and began as patient-centred care within the nursing literature of North America in the late 1960 and 1970s (Morgan and Yoder 2012; McCance *et al.* 2011). Patient-centred care represented a change from the dominance of the medical model with a transference from paternalistic cultures of care to an equal partnership approach between the

healthcare professional and the patient/client (Docteur and Coulter 2012). Refocusing on individuality and the '*re-centring*' of patient care was also reflective of changes in societal attitudes towards medical care, with society expecting a more inclusive human approach and greater personal control and choice (McCance *et al.* 2011). This was also noted by Wilberforce *et al.* (2016) that around this time person-centredness was present in the conceptual theories and social movements of normalisation, citizenship and the social model of disability.

Multiple terms have now developed within the literature to reflect 'centredness' such as person-centred, client-centred, patient-centred and relationship-centred. These terms are often used interchangeably to express the concept of 'centredness' but frequently there is a lack of clarity on the difference of the terminology, which can create confusion (Schoot 2006; Slater 2006; Leplege *et al.* 2007). A literature review conducted by Hughes *et al.* (2008) examined the literature between the years 1987-2006 and set out to examine the usage of the variety of terminology of 'centredness'. They found no difference at a conceptual level and argue that types of 'centredness' are basically the same but rather the justification for the use of the different terms rests in their historical origins and the context in which care is delivered. While Schoot (2006) agrees with this assertion, in their thesis they choose to utilise the term client-centred care in place of patient-centred care to show equality between the patient and the care provider.

Conversely, other authors dispute that the terminologies are the same, for example Slater's (2006) concept analysis argues that the variances with the term client-centredness used in the field of psychotherapy, depicts a transactional element to the relationship between the client and the professional. However, the term client-centred is also frequently utilised within the field of occupational therapy, as Vessby and Kjellberg (2010) clarify, it represents participation and respect for the role of the client in their own care. Slater (2006) further suggests that the term patient-centredness and person-centredness, are different as the latter offers the opportunity to rebalance the power dynamic of the doctor-patient relationship. While more recent definitions by Manley *et al.* (2011) elaborates further on the difference, stating that patient-centredness is a narrower concept than person-centredness with the former focusing solely on the needs of the patient, while person-centred encompasses valuing all

persons, inclusive of staff. In contrast, the work of Kitwood (1997) cautions that terminologies such as patient/client can hinder recognising the person and that their care must be aligned to their personhood. Table 2.4 below outlines the definitions of the terminology.

Table 2.4: Definitions of related terms adapted from McCance *et al.* (2011 p.2)

Term	Description
Person-centred care	*"...an approach to practice established through the formation and fostering of therapeutic relationships between all care providers...patients and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development"* (McCormack et al. 2010, p.13)
Patient-centred care	*"...understanding the personal meaning of the illness for the patient by eliciting their concerns, ideas, expectations, needs, feelings and functioning; promoting the understanding of the patient within their unique psychosocial context; sharing power and responsibility and developing common therapeutic goals that are concordant with the patient's values"* (Drach-Zahavy, 2009, p.1465).
Client-centred care	*"…the client participates actively in negotiating goals, which are given priority…the therapist listens to and respects the client's values and adapts the intervention to meet the client's needs and enables the client to make informed decisions."* Sumsion (2005, p.14).
Relationship-centred care	*"… all parties involved in caring (the older person, family carers, and paid or voluntary carers) should experience relationships that promote a sense of: security–to feel safe within relationships; belonging–to feel 'part' of things; continuity–to experience links and consistency; purpose–to have a personally valuable goal or goals; achievement–to make progress towards a desired goal or goals; significance–to feel that 'you' matter"* (Nolan et al. 2004, p.49)

2.3.1 Person-centredness in intellectual disabilities

The above table of terms provides definitions that are frequently utilised in the literature and refer to the various strands of human service delivery in medical,

nursing, gerontology, mental health, and allied health professions. However, the development of person-centredness in intellectual disabilities and the associated terminology, is rarely referred to or included within the academic debate. Waters and Buchanan (2017) thematic analysis of the literature found that the use of the term person-centred has traditionally been siloed to the areas of practice and is presumed to be collectively understood regardless of the context.

Terminology within intellectual disabilities context does not utilise the term patient-centred as it denotes the connotation of an 'illness model,' but rather the terminology focuses on person-centred planning and person-centred approaches. As Waters and Buchanan (2017) analysis highlights these terms are used interchangeably without a clear or robust definition, often citing their historical origins as a means of differentiation. Person-centredness and person-centred planning have their roots within the theories of normalisation (Nirje 1994 [1969]) and Social Role Valorisation (Wolfensberger 1983) which emphasise valuing the person and the importance of placing them at the forefront of care through listening and respecting their choices, wishes and desires. The theory also included the service processes, that is, how the service delivers care through the provision of physical environment, the language used about the service and the people who use it, inclusive of those who provide the service (Cocks 2001).

Person-centred planning was developed from Social Role Valorisation (O'Brien and O'Brien 2000) and aimed to create social roles for devalued populations within society, that enhanced their image and personal capabilities. There is no one definition of person-centred planning as it is not a standardised approach and it is frequently referred to as an 'umbrella term' used to describe a specific family of approaches and techniques that have common characteristics (O'Brien and O'Brien 1998; Ratti *et al.* 2018). Person-centred planning tends to dominate the discussions on person-centredness within intellectual disability literature. It has been the focus of extensive analysis and research since its endorsement in policy in 2001 (DoH 2001). The early discussions on person-centred planning tended to describe its philosophical underpinnings (Sanderson 2003) and offered practical support towards its implementation (Sanderson 2003; Duffy 2004).

An additional term frequently found in the literature and service documents is, person-centred approaches. On occasions it is attributed to having its roots in the work of Carl Rodgers (1998) when referenced within reminiscence therapy work with older people with intellectual disabilities (Van Puyenbroeck and Maes 2008). Conversely, Ratti *et al.* (2018) thesis on person-centred approaches draws on the work of Suhonen *et al.* (2002) in the field of nursing for clarity on the term, asserting that no single or rigorous definition of the concept exists due to the diverse perceptions of what it involves. However, other authors take a different perspective and contextualise person-centred approaches in terms of the interventions it represents to support people with intellectual disabilities, that is, person-centred planning, person-centred active support and positive behavioural support (Beadle-Brown 2006; Ratti *et al.* 2018).

2.3.2 Social devaluation and personhood

The theory of Social Role Valorisation (SRV) was also utilised by Kitwood (1997) to develop his influential work on dementia and personhood (Stirling 2010). Kitwood drew on SRV to discuss the common experiences, or 'wounds', of devalued people in society, such as those with intellectual disabilities or dementia, as they experience the medicalisation of their person and a subsequent a loss of control, freedom, dignity and privacy. Social devaluation is strongly influenced by the perceptions of others through historical beliefs and societal actions towards the devalued group. Table 2.5 outlines the negative roles associated with this process as identified in SRV theory.

Table 2.5: Major common negative social roles associated with social devaluation (adapted from Cocks 2001 p. 14)

1. Less than fully human, e.g., pre-human, sub-human, non-human
2. Menace or object of fear
3. Object of ridicule
4. Object of pity
5. Burden of charity
6. Child, i.e., an eternal child or a child once again
7. Sick or diseased organism
8. Dead or dying

Kitwood's seminal work is cited as producing the original definition of personhood as it relates to dementia and gerontology (Dewing 2004) and is defined as:

> "*A status or standing that is bestowed upon one human being by others. It implies recognition, respect and trust.*"
>
> *(Kitwood 1997, p. 8).*

Kitwood endorses the use of personhood and person-centred care in the field of dementia, advocating that a medical approach does not allow for recognition of people with dementia as social beings (Kitwood 1997). Personhood discusses what it means to be human, and it is often defined in individualistic terms that emphasise independence, autonomy, self-reliance and success (Mehrotra and Vaidya 2008). Nonetheless, Post (2006) argues that other qualities such as humour, kindness and generosity are equally important within a collective concept of humanity which is not compromised by dementia or intellectual disability. In an intellectual disability context, personhood asserts that persons should not be reduced to their disability or a disease model but rather the focus should be on their needs, abilities, strengths and plans for the future within a rights-based model of care (Wilberforce *et al.* 2016).

The concept of personhood is also recognised and promoted within the work of McCormack and McCance (2010) who state that personhood is a prerequisite to person-centred care. They also acknowledge the complexity involved and in relating the concept to practice, as it includes concepts such as autonomy and individualised care. An individualised plan of care is also embedded in the philosophy of person-centred planning which endorses the mobilising of the family network of friends to assist in the delivery of the plan (Sanderson 2000). Disregarding the input of others, such as families, and to some degree staff, is a criticism of Kitwood's work (Adams 2001), while McCormack and McCance Framework (2010; 2017) highlighted the importance of the well-being for all persons involved, inclusive of staff. They assert that staff relationships have the potential to impact on the effectiveness of the team and ultimately on the creation of a therapeutic environment. Sanderson (2003) also stresses that teams are a key component of organisation effectiveness in the implementation of person-centred planning, but studies addressing team cultures and effectiveness are largely absent in the intellectual disability literature on person-centredness.

The significance of workplace cultures is also identified by McCormack and McCance and the Person-Centred Practice Framework (2010; 2017) with the inclusion of organisation structures, staff communication, shared decision-making and the physical environment, all playing a significate role in achieving person-centredness. A narrative analysis study of patient's hospital experience by Laird *et al.* (2015) found that culture of the care environment is the most influential factor to enhance person-centred practice. Within intellectual disabilities the literature regarding the implication of person-centred planning consistently observes the lack of prerequisites as an implementation barrier to person-centred culture, with particular reference to knowledgeable staff, management style and organisational culture (Mansell and Beadle-Brown 2004; Dowling *et al.* 2006; Robertson *et al.* 2006).

2.3.3 Person-centredness and the associated attributes

Defining the concept of person-centredness has caused some academic debate and confusion as it encompasses a diversity of views, theories, and conceptual models (McCormack *et al.* 2015). As the debate continues regarding definitions, a number of authors have conducted analysis of the attributes and commonalities to assist in clarifying the concept further. Several systematic reviews and concept analyses were examined to identify the key attributes of person-centredness. It appears to be commonly regarded a combined term which encompasses attributes of care which are also recognised individually as elements of quality of care (Wilberforce *et al.* 2016).

During the 1980s seminal advancements were published by the Picker Institute in the USA, who were instrumental in advancing the patient-centred care agenda (Morgan and Yoder 2012; Docteur and Coulter 2012). In 1987 they undertook qualitative research with patients and families to examine the salient elements of the concept through the patient experience. This resulted in the key attributes of the concept being identified as respect, physical comfort, integrated care journey, inclusion of family and friends, education and communication. Morgan and Yoder (2012) highlight that the work of the Picker Institute (1987) was first to advocate that 'patient-centredness' must not only be practised at the patient interaction level but also at an organisational level.

Several studies in the literature have examined and expanded upon these core elements identifying power-sharing relationships (Institute of Medicine 2001) health promotion (Stevenson 2002) and physical environment and strategic vision (Shaller 2007). The existing literature is consistent in agreeing the core elements of person-centredness and requires the formation of relationships between all parties involved with those relevant to the person and their care, relationships built on mutual trust and sharing of knowledge (Sanderson 2000; McCormack 2004). Håkansson *et al.* (2019) analysed previously synthesised literature and found nine common shared components between patient-centredness and person-centredness, with the analysis also revealing that the goal of patient-centred care is a '*functional life'*, while the goal of person-centred care is a '*meaningful life'*.

The concept of a meaningful life has long been present in the literature of intellectual disabilities with a focus on rights, independence, choice and social inclusion, achieved through a shift in power from professionals to empowering the voice of the person (DoH 2001). Person-centred planning is frequently the tool identified to deliver these principles (HSE 2011; DoH 2001). However, many authors revealed their concern that person-centred planning alone was unlikely to produce the changes needed in the lives of those with intellectual disabilities (Mansell and Beadle-Brown 2004). O'Brien and O'Brien (2000) highlighted that services often view person-centred planning as a toolbox of techniques which staff could be trained to use in workshops without taking into consideration the context in which the training is being delivered, that is the wider context of implementation such as, resource constraints, policy and implementation gaps and the lack of performance management (Mansell and Beadle-Brown 2004). To summarise the numerous discussions on person-centredness, Table 2.6 maps out the key components on the concept drawn from general and intellectual disability literature.

Table 2.6: Core components of 'centredness' identified in the literature

Shaller (2007) Patient-centred care	• Education and shared knowledge • Involvement of family and friends • Collaboration and team management • Sensitivity to nonmedical and spiritual dimensions of care • Respect for patient needs and preferences • Free flow and accessibility of information
Håkansson *et al.* (2019) Nine shared components identified in the literature between patient-centred and person-centred care	• Empathy • Respect • Engagement • Relationship • Communication • Shared-decision-making • Holistic focus • Individualised focus
Sanderson (2000) Intellectual disability and person-centred planning	• Person is at the centred (Individualised) • Shared partners with family and wider social network • 'Power with, not 'power over' • Aspirations and capacities • What is possible as opposed to available • Ongoing listening, learning and further action
Dowling *et al.* (2006) Intellectual disability scoping review of person-centred planning	• Personal empowerment • Rights • Choice • Respect • Equality • Inclusion • Independence • Community presence

However, the analysis of the concept of person-centredness in the context of intellectual disabilities literature is conducted through discussion on the philosophical underpinnings and the guiding principles, without reference to evidence-based models that can assist in the actualisation of the team dynamics of 'healthful' cultures in the context in which care is delivered. Having explored the definitions and the attributes of person-centredness, the definition of person-centredness adopted for this study is by McCormack and McCance (2017), as it encompasses the values aligned to the care of people with intellectual disabilities such as respect, relationships and having control over their own lives. The definition also includes that person-centredness can only happen in care settings if there is a person-centred culture in place, enabling staff

to experience person-centredness and carry out their role in a person-centred way. Therefore, the following definition of person-centredness was adopted:

> *"An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development".*
> *(McCormack and McCance 2017, p.3)*

The definition is supported by the evidence-based Person-Centred Practice Framework also developed by McCormack and McCance (2010; 2017) and it acts as the theoretical lens for this study. It was chosen for its comprehensive ability to deal with the wider components and attributes which the study aimed to explore, such as the cultural factors and the inclusion of staff attributes as components of the context of practice. The conceptual framework was first published in 2006 and originated from combined research focusing on person-centred practice within older person services and nurses and patient experiences of caring in nursing (McCormack and McCance 2017). The purpose of the framework was to act as a tool to operationalise person-centredness in practice and it continued to be tested through ongoing research both in the UK and internationally. Although the framework originally focused on nursing care, it grew in recognition and has been used in multi-disciplinary team settings across health and social care settings. As this study commenced in 2015, the framework has been revised and developed with the addition of the macro-context. The macro-context acknowledges the external impact of national policy, workforce development, strategy reports and strategic leadership has on the micro-system level in which person-centred practice is developed (McCormack and McCance 2017).

The Person-Centred Practice Framework highlights the complexity of person-centredness and comprises of four domains:

1. Prerequisites are the attributes of staff and includes professionally competent/developed interpersonal skills/commitment to the job/clarity of values and beliefs/knowing self.

2. Care Environment relates to the context in which care is delivered and encompasses-appropriate skill mix/shared decision-making systems/effective staff relationships/supportive organisational systems/power sharing/potential for innovation and risk taking.

3. Care Process describes the processes of how care is delivered and includes: working with patient's beliefs and values/engaging authentically/sharing decision-making/being sympathetically present and providing holistic care.

4. Person-Centred Outcomes are the results of person-centred care including satisfaction and involvement in care, a feeling of well-being and creating a therapeutic culture.

According to McCormack and McCance (2017) all four domains interlink and must be present and combine to achieve effective person-centred outcomes for all persons, that is the people being supported by the service and the staff working in the service. Through these elements people will feel involved in their care and have a positive care experience that is facilitated via a healthful culture of care.

2.4 Person-centredness and older people with intellectual disabilities

This second part of this literature review will focus on the main findings from the literature on person-centredness regarding older people with intellectual disabilities. The search terms were devised in consideration of the definition chosen for the study and the constructs within literature relating to person-centredness as outlined in Table 2.2 and Table 2.3. TILDA is one of the most influential studies on ageing in the Republic of Ireland, it commenced with the first wave of data collection in 2009. This nationally representative study aims to understand the health, social and financial situation of people aged 50 years and over. The Intellectual Disability Supplement (IDS-TILDA) is an addition to the TILDA study and allows comparisons with the general population and focuses on those aged 40 years and over. IDS-TILDA makes a significant contribution to the body of research regarding ageing in people with intellectual disabilities within the Republic of Ireland and many of the strands and different waves of data collection regarding health, social participation, friendships and

life in residential services are represented within this literature review (McCarron *et al.* 2011, 2017; McCausland *et al.* 2016; 2018).

This review also sought to include the views of older people with intellectual disabilities in-line with aims of the study. A summary table of the reviewed research literature is presented in Appendix 1. The analysis of the literature revealed the following five core themes, *living a meaningful life; what makes a home: needs and concerns; life in residential services; the role of staff: relationships, knowledge and training;* and finally*, choice and control, which* will now be discussed in more detail.

2.4.1 Living a meaningful life: growing older and keeping active

Influential key policy and research studies such as, the '*Positive Ageing Strategy'* (DoH 2013), *'Healthy and Positive Ageing for All Research Strategy'* (2015-2019) and the development of Positive Ageing National Indicators (Gibney *et al.* 2016) indicate the governments focus on promoting positive active ageing within Irish society. Although ageing is a lifelong process the WHO (2000) summary report highlights that there is no accepted age which defines exactly when someone becomes old. The report also draws attention to the complications of premature ageing and reduced life expectancy for those with Down Syndrome or with profound and multiple disabilities. Life expectancy may also be compromised by health inequalities and living conditions. Therefore, a challenge within the literature is the differing age criteria used to investigate old age, with longitudinal studies commencing at 40 years and other studies commencing in the 50th decade and investigating the 'younger old'. A systematic review conducted by Innes *et al.* (2012) on caring for older people, cautions against assuming that old people with intellectual disabilities are a homogenous group, and their experience of ageing will be different, as their experience of childhood, education, relationships and retirement will all differ.

Therefore, a reoccurring theme within the literature is perceptions of ageing from the viewpoint of older people with intellectual disabilities, staff, carers and family members. A common perception is that of premature ageing which Janicki *et al.* (2002) believe is unnecessary as many people with intellectual disabilities do not age prematurely

and this assumption may impact on the quality-of-service delivery. This idea is reinforced in a quantitative Dutch study by Evenhuis *et al.* (2012) who found that high proportions of older people who experienced frailty at an early age was in fact preventable with reversible factors, such as increasing physical activity, participation and social relationships, all increasing well-being.

Several studies utilised the framework of active ageing to research the lives of older people. *Active Ageing* is a global approach to older people achieving healthy, fulfilled lives and is defined by the WHO (2002) in terms of optimising opportunities for health and security to enhance quality of life. The framework has commonalities with intellectual disability policy with a focus on participation, choice and inclusion with access to meaningful pursuits that contribute to well-being. The following studies addressed what older people, the majority of whom lived in residential services, value and what gave them a sense of well-being as they age. Five studies from Australia, UK and the Republic of Ireland, address perceptions of ageing while also incorporating active ageing into their discussion (Buys *et al.* 2008; Bigby and Knox 2009; Buys *et al.* 2012; Judge *et al.* 2010; McCausland *et al.* 2010), with the studies also taking a user perspective and had relatively small sample sizes. Three of these qualitative studies found different levels of understanding regarding ageing by older people with intellectual disabilities ranging from no concept, to limited awareness, awareness of ageing effects, ageing requiring preparation and finally an overall understanding (Boulton-Lewis *et al.* 2008; Bury *et al.* 2008). These authors all had similar findings and reveal that some older people were "*blissfully*" unaware they were ageing and said they did not feel old. This contrasts with their carers who expressed concern regarding the health and future care of the person as they aged. Conversely, a longitudinal study by McCarron *et al.* (2017) reported older people expressed typical concerns that come with advancing age, such as the loss of family and loved ones and an increase in dependency.

Three studies also examined engagement with learning by older people and revealed that mental stimulation, companionship and staff support were all highly valued (Boulton-Lewis *et al.* 2008; Bury *et al.* 2008). It was also important for older people to continue to have opportunities to avail of new and interesting activities (Boulton-Lewis *et al.* 2008; Bury *et al.* 2008; McCarron *et al.* 2011). Additionally, a study by Bury *et al.*

(2008) highlighted the value of personal safety reported by older people, who talked about incidents of threatening behaviour, physical assaults and mental abuse, mainly from other people with intellectual disabilities which they had experienced within services, such as community group homes or day services.

Leading on from these studies, Bigby and Knox (2009) advocate for a different approach to care, one which is holistic and individualised. Again, their study clearly identified that older people with intellectual disabilities valued being active and staying connected with others. Although older people felt a sense of belonging, their lives were busy but *"directionless"*, which lacked continuity or planning regarding their future. Decisions about older people were made to suit the needs of the organisation and were not person-centred, with other people deciding their activities. Retirement was also found to reduced older people's access to activities they previously enjoyed, which concurs with the findings of a national longitudinal study conducted by McCarron *et al.* (2011) in the Republic of Ireland.

The concept of retirement was reported to be confusing and concerning for many older people who had no understanding of what it meant for them, as they had no previous opportunities for employment during their lifetime (Buys *et al.* 2012; McDermott and Edwards 2012). Two quantitative studies by McCausland *et al.* (2010; 2018) in the Republic of Ireland, report a range of unmet needs to support older people, such as lack of access to transport, education and access to services with low rates of employment. McCausland and colleagues advocate for life-long learning opportunities, while highlighting that occupational activity accessed through day services was associated with better emotional/mental health outcomes for older people.

The benefits of activity are discussed by several authors in the literature with six studies revealing the importance of a day service to older people, regardless of their living arrangements. Day services were described as a 'social hub' in facilitating activities and social connections, fostered friendships and socialisation (Bigby and Knox 2009; Judge *et al.* 2010; Buys *et al.* 2012). These studies reported a level of concern from older people that being 'retired' from their day service or supported employment (McDermott and Edwards 2012; Stancliffe *et al.* 2011) would limit their

access to participations in activities and socialising (Bigby *et al.* 2011; Judge *et al.* 2010; Buys *et al.* 2012). While Bigby and Knox (2009) found that staff and older people where frustrated at the lack of future planning by senior managers in both organisational and operational policies. An example of this is found in McDermott and Edwards (2012) study where an older person living in a community group home reporting that they could not retire and stay at home due to the lack of staffing.

An interpretive phenomenological study conducted in Scotland by Judge *et al.* (2010) reported similar concerns by 16 older people as they transition from day service towards retirement age. The study noted the potential loss of continuity and support was a source of anxiety, as older people were unclear about what 'retirement' meant and how it would affect their independence, which they valued. While McCarron *et al.* (2017) found that people did not want to retire if their health permitted, and they wanted to continue learning new skills. Finally, all the studies this section caution that there is an assumption that older people want to retire but they are wary of the proposition, as they may lose access to activities. These studies also bring awareness that decisions about activities are often made by others and older people require recognition of their ability to choose their own future paths (Bigby and Knox 2009; McDermott and Edwards 2012).

Participation in leisure activities has been found to be a strong contributor to satisfaction in retirement and old age. The positive contribution of physical and social activity to older people was noted in the literature, with a Dutch study by van Schijndel-Speet *et al.* (2014) on physical activity for older adults, found a range of a wide range of activities such as dancing, walking, gymnastics for older adults, cycling, and swimming, garden and household activities, were all enjoyable. Music appeared to be a motivating factor for older people to participate in physical activity through dancing. The study by van Schijndel-Speet and colleagues also identified three main barriers to participation as reported by older people as being, a lack of staff encouragement, a lack of transportation to activities and fear of falling. McCarron *et al.* (2017) found that older people engaged in regular activities such as eating out and shopping, but they had little involvement in various clubs in their local communities, except for Special Olympics, which was the most frequently reported. Although Tedrick's (2009) study on older athlete's participation in Special Olympics was limited to three case studies, it

revealed the benefits of sport participation which went beyond an increase in physical activity and included help with life skills, the social aspects of friendship, competing and winning, which in turn increased the person's self-esteem. In contrast to the value older people place on activity, the literature warns of the ill-effects of a sedentary lifestyle of on the physical and mental-health of people with intellectual disabilities, particularly for those living in residential services (Donoghue *et al.* 2016; van Schijndel-Speet *et al.* 2017).

2.4.2 What makes a home: needs and concerns

A consistent theme within the literature discussed the components of what makes a happy home environment for older people with intellectual disabilities. Since the early 1980s, the social policy of decongregation in many western countries sought to further social inclusion through community living (Clement and Bigby 2009) which is believed to have superior outcomes to congregated settings and assists with personalisation (Mansell and Beadle-Brown 2012; McCarron *et al.* 2017). In the Republic of Ireland, the transition to community living is ongoing in-line with international practice and is currently the preferred model of residential care delivery. The community group home model is not without its critics, who believe that it has the potential to be inflexible if a person's needs change over time (Mansell *et al.* 2013). As many people with intellectual disabilities are now living into older age there are increasing numbers of people ageing within all types of residential services (McCallion and McCarron 2004).

Several studies have focused on older people's preferences and choice of housing options. The literature highlights that for those already living in specialist services, limited housing options are available to them (Shaw *et al.* 2011; Buys *et al.* 2012). Both international and national studies consistently found that older people had little choice or flexibility regarding where they lived or with whom, despite being able to articulate their preferred choice (McGlaughlin *et al.* 2004; Shaw *et al.* 2011; Salmon *et al.* 2019; McCausland *et al.* 2018b). The choice of transition to residential care was a source of concern for older people and their families which usually stemmed from a crisis situation such as illness of death of their family member (Eley *et al.* 2009; Bigby

2008a). However, Bigby (2008a) found that people with intellectual disabilities were not included in the decision-making process about where to live, which left them feeling distressed by this many years later.

Ageing in Place

'Ageing in place' is seen as a human right for all older people and policies on ageing promote the maintenance of independence and retaining connections with social networks (WHO 2007). A mixed methods study by Eley *et al.* (2009) of accommodation needs for older people with intellectual disabilities in a region of Australia, stresses the concerns expressed by carers and older people about the services ability to continue caring for them, if they experienced increased care needs due to ageing. Bigby's (2008a) analysis of Australian policy on ageing in place for older people with intellectual disabilities, noted that services face barriers to facilitate this, as they do not receive extra government funding to support older people who develop extra care needs. While McCallion *et al.* (2012) found that staff working in intellectual disability services believe themselves to well-equipped to care for older people rather than nurses working acute hospitals or generic nursing homes facilitates.

Four Australian studies deemed that nursing homes were not an appropriate placement for older people with intellectual disabilities and there were noted fears that such establishments were ill-prepared to take on this role (Bigby *et al.* 2008; Eley *et al.* 2009; Shaw *et al.* 2011; Buys *et al.* 2012). Conversely, Webber *et al.* (2014) found that the physical health of older people improved when they moved into a nursing home from a social care facility. This was attributed to the comprehensive health assessment and treatment they received for underlying health conditions. However, Webber *et al.* (2014) revealed that the social isolation of the older person following the move had a negative effect and resulted in the persons disconnection from past relationships. The core philosophies of intellectual disability services involving social inclusion and participation were found to be neglected, with staff reporting that older people with intellectual disabilities missed their housemates and frequently spent time alone in their bedrooms (Webber *et al.* 2014). The social isolation of people with intellectual disabilities in nursing homes was also reported by Bigby *et al.* (2008), who highlights that they could be at a disadvantage and excluded from meaningful activities and relationships on moving into nursing homes. Similarly, a qualitative study (n=17)

by Strnadová (2019) relayed older people's fears about not being able to age in place and they expressed concerns about *"being locked away" and "unable to get out"* of a nursing home. Several of the studies presented here have small sample sizes drawn from local geographical areas although their findings may have transferability to other geographical locations.

The physical environment

The physical environment was the focus of the findings of several qualitative studies which asked people with intellectual disabilities what was important to them about their housing. A qualitative study conducted in Australia by Shaw *et al.* (2011) with older people and their carers, found that older people did not want to live alone due to fear of loneliness and lack of social connections. Contrary to international policy advocating for smaller community living environments, the participants and their families stated that larger living environments were preferable as they believed it offered enhanced opportunities for friendship, wider social networks and enhanced participation in recreational activities.

Several qualitative studies reported that the location of the physical environment played an important role in the happiness of older people with intellectual disabilities. Being close to town, shops and other amenities, offered a sense of independence and access to transport (Buys *et al.* 2012; Shaw *et al.* 2011; Garcia Iriarte *et al.* 2014) or being close to their day service which was a 'social hub' (McGlaughlin *et al.* 2004). Conversely, a study conducted in the Republic of Ireland by Sheerin *et al.* (2015) revealed that older people who relocated to a community group home lost the supportive function of the nearby campus and their new suburban location did not offer them the same sense of community. The limited availability of public transport and further distances to travel, resulted in staff having to accompany people to their daily activities. Sheerin *et al.* (2015) also found that staff felt that the ageing process and changes to health status may limit the person's ability use local amenities. Three studies from, the Republic of Ireland, UK and Australia, revealed that being close to family members was reported as important and community living assisted in maintaining closer contact (McConkey *et al.* 2004; McCausland *et al.* 2018; Shaw *et al.* 2011). Although analysis from the national longitudinal study IDS-TILDA in the

Republic of Ireland revealed there has been a decrease in the number of older people living in close proximity to their family members between 2013 and 2017 (McCarron *et al.* 2017).

A cross-sectional study conducted in the Republic of Ireland by O'Rourke *et al.* (2004) noted that the physical aspects of the environment were important to an overall sense of well-being for older people, that is good quality furniture and fittings, spaciousness, and quietness of their home, while having a garden and a pet was highlighted by McGlaughlin *et al.* (2004) in their UK study. Basic privacy and dignity issues such as, having your own bedroom was noted in four studies (McConkey *et al.* 2004; Buys *et al.* 2008; Garcia Iriarte *et al.* 2014; Sheerin *et al.* 2015) and the role of staff to support people were common cited attributes associated with accommodation needs (O'Rourke *et al.* 2004; Buys *et al.* 2012; Sheerin *et al.* 2015; McCarron *et al.* 2017).

2.4.3 Life in residential services

The reality of life in residential services has proven to be an evasive concept and can have different representations and meanings within the wider literature. It is often understood in terms of characteristics which translates into formal, informal, operational or organisational practices. Linehan *et al.* (2014) describe culture as the socialisation of staff into a specific mind-set of behaviours and unspoken rules which must not be broken, leading to a resistance to change from the usual practices. The characteristics of larger congregated settings have been well documented in the literature throughout the years as rigid task-orientated care, lacking in dignity and respect for the individual (Linehan *et al.* 2014). Similarly, a large body of literature exists supporting the move to smaller community group homes away from congregated settings as a superior model for people with intellectual disabilities to improve their lives (Mansell 2006).

A systematic review of services models and frameworks by Kozma *et al.* (2009) found further evidence of the benefits of the community living model, yet, their evaluation also revealed disparities in outcomes and implementation. It is often assumed that the move to living in community group homes will automatically change custom and

practices. However, authors such as Mansell (2006) have argued that that institutionalised cultures still prevail in community group homes. Although culture is often mentioned as a variable which influences positive outcomes for people with intellectual disabilities, authors state it has not been rigorously investigated (Walsh *et al.* 2010; Bigby *et al.* 2012). There are a small number of mainly qualitative studies exploring cultures and staff practices. For example, Kåhlin *et al.* (2016) Swedish study found that the formal culture in community group homes was absent or contradictory and unstructured with regards to the plan of care for older people with intellectual disabilities. These factors influenced staff's attitudes to the point that they did not openly discuss or address the issues of ageing which were perceived as irrelevant to care delivery. Meanwhile a study by Mansell *et al.* (2008) in UK residential services found that professional qualifications and knowledge were equally as important as staff attitudes and management style to help people with intellectual disabilities engage in meaningful activities. This also concurs with a cross-sectional survey conducted in the Netherlands by Nieboer *et al.* (2011) who found staff skills correlated with innovative culture, a clear strategy, a supportive management style with the successful implementation of community living.

A more in-depth examination of staff practices was conducted by Bigby *et al.* (2012) on life in five community group homes and identified three key characteristics of underperformance. Firstly, they found there was a misalignment of the organisation's formal values and the informal values of the staff which they referred to as "*the way things are done around here*" (p.456). This resulted in staff being resistant to change and external ideas and staff reported feeling distant from the larger organisation with senior management perceived as removed with no understanding of what their role entailed. The misalignment of values allowed other negative aspects of care to flourish, including an underlying assumption that people with intellectual disabilities were fundamentally different and "*not like us*".

Bigby *et al.* (2012) ascribe this attitude to the concept of 'othering', as staff perceived those residing in the group homes as childlike and held low aspirations for their potential as they were too disabled. Staff saw their role predominately as care takers, '*doing for*' as opposed to '*doing with*' which resulted in community presence but no community participation. Consequently, a task orientated culture existed with some

aspects resembling that of institutional care, providing group treatment as opposed to meeting individualised needs. Bigby *et al.* (2012) believes that it is important to examine the culture in other departments of the organisation that oversee the community group homes, and the authors speculate that there is no reason to believe they will be anymore aligned to the espoused values of the organisation than the community group homes.

A follow-on study by Bigby *et al.* (2014) identified the attributes of positive staff regard towards people with intellectual disabilities. Firstly, there was a notable difference in the shared areas with the community group home which contained the personal belongings of those who lived there, recognising their personal histories and reinforcing their 'personhood'. In contrast to the previous study, the authors found well-performing group home staff viewed people with intellectual disabilities as '*like us'* and perceived people with intellectual disabilities as having value and avoided imposing their own preferences and lifestyles. Similarly, a philosophical analysis by Reinders (2010) on personal relationships between staff and people with intellectual disabilities in community group homes, found that staff used empathy to guide their work and to develop positive interpersonal relationships.

Furthermore, Bigby *et al.* (2014) identified the organisational processes that allowed positive regard to flourish such as, the recruitment and induction of staff, rostering and practice leadership. New or agency staff were closely observed by more established staff members to ensure that standards were achieved, and expectations were clearly outlined, and poor practices were challenged. However, Bigby and colleagues caution that positive regard is not created by chance but rather it is planned and reinforced through organisational policies and procedures and the modelling of good practice which translates organisational values into actions.

The studies presented here offer an insight into the cultural characteristics which can emerge in residential services and impact on the lives of people with intellectual disabilities. The studies should however be treated with caution as methodological limitations regarding the instruments used, and the low response rate of the quantitative studies reviewed.

2.4.4 The role of staff: relationships, knowledge, and training

The literature reveals that cultural aspects of life in residential services are intrinsically linked to staff practices and positive outcomes for people with intellectual disabilities. Perry and Felce (2005) defined staff practices as attention and assistance which supports the person to increase their social engagement and community activities. Studies from the UK and Australia identified key staff attributes that affected outcomes both positively and negatively for people with intellectual disabilities were, low staff expectations of the person (Bigby *et al.* 2012); staff knowledge and motivation for the role (Mansell 2006) and positive interpersonal relationships with older people (O'Rourke *et al.* 2004; Bigby and Knox 2009). Positive staff relationships have been acknowledged as giving older people a sense of belonging, being valued and an acknowledgement of their individuality and helping achieve their goals (O'Rourke *et al.* 2004; Bigby and Knox 2009; Garcia *et al.* 2016). Within residential services congenial relationships with staff were reported as important by older people (Buys *et al.* 2012; McCausland *et al.* 2014; 2018a), while Stancliffe *et al.* (2011) found that when adults living in residential services reported the staff as being nice, it increased their levels of well-being. However, an inclusive research study by Salmon *et al.* (2019) in the Republic of Ireland noted incidents of staff being described as domineering by people with intellectual disabilities but overall, staff were reported to be a source of support. Furthermore, an Australian study by Strnadová (2019) also reported staff abusing their power in making decisions to suit their own needs as opposed to those of older people.

Wave One of IDS-TILDA longitudinal study in the Republic of Ireland, revealed that 75% of participants confided their worries or concerns to a staff member, such as their key worker or other support person McCarron *et al.* (2011), while further studies reported that older people considered staff to be their friends (Bigby 2008b; McCausland *et al.* 2016). Two studies conducted observations of staff interactions with people with intellectual disabilities in the context of community group homes and found that the brief interactions and moments of fun often provided insight into the level of personal relationships between staff and people with intellectual disabilities (Reinders 2010; Johnson *et al.* 2012). The attitude of the community group home leader was

also found to be a defining factor which promoted or hindered more inclusion and aspirations of the older person (Bigby *et al.* 2012; Craig and Bigby 2015).

Staff interpersonal relationships with family members and primarily siblings were also found to impact on care. Despite siblings no longer being the primary carer, many maintained close contact with their family member (McCarron *et al.* 2017). Two qualitative studies conducted in the USA and Australia revealed the continued supporting role of siblings as advocates, organiser and overseer of care. Siblings also contributed to the older person's identity as a brother, sister and family member, increasing their sense of belonging (Hall and Rossetti 2018; Bigby *et al.* 2015). A review conducted by Heller and Arnold (2010) revealed that one sibling usually takes on the lead role for the family and continues to have a high level of involvement and emotional connection with their sibling throughout their life. A longitudinal study by Bigby *et al.* (2015) found that relationships between siblings and community group home staff demonstrated levels of mutual respect but there can also be tension. Reported tensions were usually influenced by different personalities or the sibling's perception of the competency levels of staff. Siblings reported that they increased their monitoring activities when they had less confidence in the staff's ability to care for their family member.

Ageing with an intellectual disability is recognised as being more complex due to the 'premature ageing' and related health conditions (Haveman *et al.* 2010). Current systems are not designed to care for older people, and residential services are now finding difficulty to meet specific needs (Webber *at al.* 2010). A European wide quantitative study by Haveman *et al.* (2011) examined the health status of older people with intellectual disabilities and found that the majority of older people who live in residential services and have health related issues which frequently go undiagnosed and untreated due to lack of staff knowledge. In contrast, a quantitative Canadian study by Shooshtari *et al.* (2012) using logistic regression analysis, found higher levels of reporting of unmet health needs for older people with intellectual disabilities and furthermore, the authors reported that unmet health needs did not significantly affect the person's overall health status. Considering these findings further research studies have examined staff confidence and attitudes in dealing with meeting the changing health needs of older people.

Several qualitative studies originating from Australia and the UK both examined the role of staff in dealing with health-related issues of older people in community group homes. Webber *et al.* (2010) revealed that staff must balance two distinction philosophies of care, *active ageing* and *ageing in place*. Staff expressed concern about the impact of health conditions on fellow housemates while accommodating the person's right to age in their own home (Webber *et al.* 2010). However, the authors discuss the two concepts as separate competing issues, failing to acknowledge the impact that *active ageing* plays in maintaining health and avoiding frailty (WHO 2002), consequently supporting older people to remain in their own homes and *age in place*. While Bowers *et al.* (2014) used a dimensional analysis methodology to explore staff knowledge and found that the trained staff lacked the understanding to differentiate between age-related issues and serious health issues. Conversely, a UK study by 5Northway *et al.* (2017a) found that staff (n=14) both recognised and monitored health changes and advocated for older people who required health interventions. Furthermore, Kåhlin *et al.* (2016) advocates for clearer direction and working process to help staff improve the daily lives of older people.

Meanwhile Wark *et al.* (2014) examined the challenges of caring in rural areas of Australia and found staff were reliant on General Practitioners who were not necessarily up to date with complexities associated with ageing in people with intellectual disabilities. All the studies concurred that staff required clearer guidance and policy from their organisations to deal with the health needs of older people. It is important to highlight that the services reported in these studies were based in community group homes which predominately have social care staff while services in in the Republic of Ireland currently remain nurse lead by Registered Intellectual Disability Nurses (RNID) (Doody *et al.* 2013).

Compounding the lack of policy and practice guidance is the lack of appropriate training. Webber *et al.* (2016) surveyed seventy-six managers from community group homes regarding their training and confidence across several health conditions, combined with their attitudes towards relocating older people to nursing homes. Staff identified a lack of confidence in dealing with health issues but training in managing conditions increased their confidence and saw a reduction in older people being

transferred to nursing homes. Similar findings were reported by McCarron *et al.* (2017) in the Republic of Ireland, that a lack of staff training and knowledge in complex health conditions related to ageing, resulted in older people being moved into nursing homes. A UK study by Northway *et al.* (2017b) revealed that social care staff often have little or no previous training or experience for the role of monitoring health needs of older people and training should focus on healthy ageing. Furthermore, an explorative study by Alftberg *et al.* (2019) conducted in Sweden, revealed that staff were uncertain about the signs of ageing and the delivery of appropriate training would eliminate what the authors perceived as staff ambivalence towards ageing and it effects.

Although these studies strongly advocate for staff training, previous research reports mixed findings regarding the effectiveness of staff training on changing practice, particularly if the training is inappropriate or irrelevant (Wilkinson *et al.* 2005). A literature review by McGhee and Dorsett (2011) reviewed staff training programmes in relation to older people and their findings assert that there is insufficient peer-reviewed evidence to determine if training aided successful ageing for people with intellectual disabilities. The review highlighted the limitations of studies due to lack of comprehensive evaluation of training programmes which the authors believe should be measured against health outcomes.

A later study by Wark *et al.* (2014) utilised a multi-round Delphi project to identify training priorities with staff regarding the health needs of older people and identified generic training, medical issues, mental health changes and quality of life, inclusive of person-centred planning. The authors believe that several the topics included in the generic training were actual more aligned to 'mainstream' training such as staff attitude training regarding empathy, patience, consistency and record keeping monitoring changes over time. Wark *et al.* (2014a) conclude that staff training alone is insufficient to meet the needs of older people in residential services and should be combined with the appropriate policy and practice guidance to ensure positive outcomes.

2.4.5 Choice and control

The theme of choice and the associated opportunities to make choices, features frequently within the literature and policy and practice of intellectual disabilities. Making choices is an everyday occurrence and is associated with basic human rights and autonomy. Facilitating people with intellectual disabilities to make their own choices is frequently identified as prerequisite for self-determination, autonomy and empowerment (Hollomotz 2014; McCausland *et al.* 2018b; Salmon *et al.* 2019) and is central to the principles of normalisation and person-centredness (McCormack and McCance 2017). Research shows that older people with intellectual disabilities have lower levels of self-determination than those without disabilities (Wehmeyer and Abery 2011). Although Heller *et al.* (2011) asserts that older people may have had fewer opportunities to exercise choice throughout their lives, but they can learn choice-making skills and goal setting with support from staff and family to facilitate self-expression.

Ten of the studies included in this review focused on choice and control in residential settings in various forms with all the studies acknowledging that older people either lack or are excluded from opportunities to make choices in their lives. One central theme relates to opportunities provided to individuals to choose where and with whom they would like to live with. An in-depth statistical analysis in the United States completed by Stancliffe *et al.* (2011) reported that more than half of the 6,778 adults with intellectual disabilities across 26 states did not participate in decisions about where or with whom they would like to live. Similarly, IDS-TILDA reported on the participation of adults with intellectual disabilities (n =753), the majority of whom reported they had no control over their lives or major decisions about where to live (McCarron *et al.* 2017). Bigby (2008b) detailed that this exclusion from major life choices ultimately effects the mental well-being of older people and continues to affect them many years later. The findings in these studies do not indicate that older people lack capacity to make choices but rather they have less opportunities access to decision-making forums within services.

Studies in this area have found that people with intellectual disabilities had fewer choices if they lived in residential services and this did not differ significantly as they

aged (Stancliffe *et al.* 2011; McConkey *et al.* 2016). A study by O'Donovan *et al.* (2017) identified everyday choices, such as what to eat, what to watch on TV and what to do in their spare time, were found to be within the persons' control. Within congregated settings, studies reported lower levels of choice, with people such as staff and families, found to making the decisions on their behalf. (McConkey *et al.* 2016; O'Donovan *et al.* 2017; Sheth *et al.* 2019). In comparison, community group homes studies reported higher levels of choice and control across daily routines and activities but a USA study by Sheth *et al.* (2019) found people who had moved to community group homes still had less control over when to eat and what time go to bed. Equally, a large survey-based study conducted in Canada by Stainton *et al.* (2011) found similarly higher levels of choice and control for those living in community group homes than for those who lived in supported living accommodation. While Tichá *et al.* (2012) concurred with these findings, adding that the involvement of the person is significantly influenced by the structure of the disability support service in which they live and the range of choices available to them.

The environmental factor was also highlighted in a narrative analysis conducted by Wehmeyer and Abery (2013) who also found a lack of autonomy and empowerment for those living in congregated settings. Overall, these authors suggest that greater involvement in choice across all residential settings was influenced by the level of input and staff support received by people with intellectual disabilities. This conclusion echoes Stainton *et al.* (2011) earlier research in group homes regarding the importance of quality staff support as a predictor of positive outcomes for the individual. This also concurs with Strnadová (2019) findings who reported that staff make decisions on behalf of older people against their choices often limiting their social activities in the evenings.

Two studies caution that staff use their own attitudes, beliefs and values to inadvertently influence the choice and decision-making of people with intellectual disability and may base decisions on their own preferences and moral judgements (Smyth and Bell 2006; Dunn *et al.* 2010). Meanwhile, an ethnographic UK based study conducted by Antaki *et al.* (2009) found a policy practice gap regarding the facilitation of choice. They highlighted that aspirational policy recommendations were devised outside of the reality of competing and unpredictable demands within services.

Although staff had good intentions and tried to introduce choice to everyday activities, and they utilised the language of choice to meet service objectives. However, the authors question if addressing major decision-making within the context of residential service delivery is perhaps an unrealistic expectation.

Three qualitative studies identified what Hollomotz (2014) describes as the 'mundane' choices that people make in their daily lives. Although Hollomotz (2014) study found that there had been a shift away from the restrictive practices of the past, a pre-arranged menu of choices is often presented to people with intellectual disabilities. This results in a level of tokenism and lack of control over basic choices, resulting in the disempowerment of people living in residential services. However, Finlay *et al*. (2008) argued that it is these mundane choices that are an important aspect to facilitate choice and empowerment and should not be dismissed. Furthermore, Kåhlin *et al*. (2015) ethnographic study conducted in Sweden across four group homes for older people, found that choices were also impacted by environment factors within their community group homes. Choice and control were evident within their private space, such as their bedrooms, while shared spaces, such as sitting rooms, were controlled by staff. The study indicated that age and negative life experiences may reduce levels of interest and engagement in making their own choices.

Finally, Finlay *et al.* (2008) established links between low levels of choice and control and the cultural aspects of residential services. They revealed the challenges for staff who are often poorly paid and educated in this area, may lack the skills to realistically implement choice. The implementation of complex concepts such as empowerment and choice are challenging for staff and the authors call for recognition of the gap between policy and the realities of practice which are often dictated by inspection regimes. The study also found that staff face social, practical and philosophical challenges and were unsure how to balance these issues, with no support or recognition from senior managers cited as a source of staff disillusionment.

2.5 Person-centredness and older people with intellectual disabilities

Much of the literature presented in this review is predominately qualitative studies with small sample sizes and limited information on the age ranges, which is a commonly cited limitation of the reporting of user-focused studies. The analysis of the literature reveals the gaps and unmet needs in terms of current approaches to care of older people in residential services and the literature consistently demonstrates similar findings across national and international studies. Much of the research has identified elements of person-centredness but did not examine the concept in its entirety. The research studies presented here embrace the concepts and ideas of person-centredness but are not necessarily framed within the same discourse as the Person-Centred Practice Framework (PCPF). To contextualise the presented themes in this review, they are mapped to the PCPF (McCormack and McCance 2017) illustrated in Figure 2.2. below.

Prerequisites

- Staff knowledge and training
- Attitudes, values and motivation
- Quality of relationships with older people

Care Environment

- What makes a home-the physical environment and location
- Staff relationships with older people
- Policies and organisational guidance

Care Process

- Choice and control
- Building trust and confidence
- Level of staff support

Person-centred outcomes

- Meaningful life-positive outcomes
- Siblings experience of care
- Life in residential services: characteristics and practices
- Being Active
- Choice of where to live

Figure 2.3: Literature review themes mapped to the PCPF (McCormack and McCance 2017)

Firstly, the prerequisites within the PCPF focuses on the necessary staff attributes which are required to carry out the role. A significant proportion of the literature in this review related to staff competency, clarity of beliefs and values and commitment to the job. The literature revealed that interpersonal relationships developed by staff played an important role in building the self-esteem and happiness of people with intellectual disabilities within residential services. The themes emerging from the literature also included the professional competence of staff needed to care for those who are ageing. A lack of staff training, and confidence was identified as an issue within the literature. The attitudes and values and the motivation of staff were factors identified as impacting on the support levels offered to older people. Staff working from their own values as opposed to those of the organisation, can lead to a negative attitude towards people with intellectual disabilities, thus impacting negatively on person-centred outcomes. However, authors in this area also suggest that organisations and senior managers need to re-evaluate if their goals and values are aligned to those espoused by the organisation to ensure person-centred outcomes are achieved (Bigby *et al.* 2012).

Within the PCPF, the care environment refers to the context of the care delivery. Within this domain supportive organisational systems, the physical environment, organisational policy, and guidelines guide the staff to support of older people. The theme, '*what makes a home',* clearly outlined the requirements of the physical environment through the voice of the older person, that is, the location and the quality of the fixture and fittings of their home, privacy and dignity, staff support and friendships, were all highly valued. In contrast, studies also revealed that these requirements are not always met by organisations. Transition to residential services frequently occurred in a time of crisis, leaving the older person without choice of where or whom to live with (McCausland *et al.* 2018b) or being placed in a nursing home, which may not meet their specific needs (Bigby *et al.* 2008). The lack of formalised policy and guidance for staff to support training and staff confidence through recognition of the ageing process which can facilitate ageing in place, were also identified.

The care process was highlighted within the themes of the literature as impacting on how staff engage with older people and their families. McCormack and McCance

(2010) define the constructs of the care process as working with patients' values and beliefs, having sympathetic presence and shared decision-making. These core constructs emerged within the themes of the literature with a focus on choice and control in lives of older people, with staff assisting people with intellectual disabilities to make daily choices about food and activities but they were frequently excluded from major life choices. Sympathetic presence was an important component, with staff frequently reported as the key individual that a person with intellectual disability will confide in if they have a problem. The quality of staff support has also been identified as instrumental for older people successfully relocating to community living and achieving their goals.

Finally, the person-centred outcome domain within the PCPF brings together the prerequisites, the care environment and the care process domains to deliver quality outcomes for the person and staff. This inner domain looks at the person's care experience. The reviewed literature highlighted that many older people did not perceive themselves as growing older and had limited understanding of the concept. This was coupled with the idea of retirement which was viewed with anxiety as it removed the persons access to activities through their day service. Day services were described as 'social hubs' which had a positive effect on well-being outcomes. Although some older people with intellectual disabilities reported that they wanted to retire but were prevented from doing so due to organisational practices and low staffing levels in their community group homes. Living a meaningful life through being active, both physically and socially, was hugely important for older people. Although staff generally tried to facilitate activities, a lack of transport and staff motivation and control were prohibiting factors. Healthful cultures of care also featured within the literature and identified the quality of staff support and leadership as strongly effecting person-centred outcomes for older people with intellectual disabilities.

2.6 Summary

This chapter was presented into two parts. The first part of the literature review focused on the historical origins of the concept of person-centredness and the differing terminology which is often used interchangeably. It also explored the use of person-centred terminology within an intellectual disability context before moving on to the rationale for the use of the definition of person-centredness by McCormack and McCance (2010, 2017) in this study. The second part of the literature review focused on people with intellectual disabilities as they age. The findings of the literature review revealed aspects of their life and priorities which are of concern to them, and incorporated studies which utilised methodologies such as observations, questionnaires and in-depth interviews to evaluate care delivery. Although the term person-centredness is consistently used within intellectual disability literature the concept has not been previously investigated within an evidence-based framework. This exploratory study is therefore essential to providing a comprehensive overview of person-centredness currently within residential services and is design to meet this gap in the literature.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter will outline the aims and objectives of the study and provide a comprehensive discussion on the methodology employed, which is a mixed methods approach within a pragmatic paradigm. Initially a brief exploration of research paradigms will be provided and how these have influenced the choice of methodology for this study. This is followed by a comprehensive discussion on pragmatism and mixed methods and a rationale for their use will be presented. Finally, my personal history and philosophy in the context of this study will be presented.

3.2 Aim, research questions and objectives

The aim of this study is to explore how person-centredness is perceived and experienced within residential services. Older people with intellectual disabilities, their families and staff are the research participants in the study. The following three research questions were devised to meet the aims of the study:

1. How does staff understanding of the complexities of person-centred practice impact on their role?
2. What are the experiences of older people and family members of person-centredness?
3. What are the shared commonalties or differences regarding person-centred practice across the three participant groups?

These questions were then formulated into the following objectives to meet the aim of the study.

The objectives are:

1. To examine staff practice and understanding of person-centredness within their day-to-day work.
2. To gain insight from older people with intellectual disabilities and their family members on person-centredness.

3. To synthesise the experiences of older people and family members with those of staff to expand the understanding of person-centred practice for older people with intellectual disabilities.

3.3 Research paradigms ontology and epistemology

In order develop knowledge that can be translated into practice, it is important that researchers understand the paradigms involved within the research process (Weaver and Olson 2006). The term paradigm was first coined by the American philosopher, Thomas Kuhn, to describe a philosophical way of thinking or 'worldview' (Kuhn 2012). The term 'worldview' is a synonym for paradigm (Kaushik and Walsh 2019) and refers to the philosophical assumptions or conceptual lens the researcher uses to examine the methodological underpinning of a research study. Cohen *et al.* (2018) elaborate on this by saying that paradigms help define the research philosophy, providing a framework which assists the researcher to clarify their beliefs, theories and procedures to conduct a research study.

Kaushik and Walsh (2019) highlight that the paradigm functions as a conceptual but practical tool and provides the researcher with a philosophical underpinning which connects the aims and objectives with the methods employed within the study (Weaver and Olson 2006). Guba and Lincoln (2006) propose that paradigms are conceptual in essence and encompass of three elements of ontology, epistemology and methodology. While Heron and Reason (1997) argues that axiology is also an important philosophical element of inquiry paradigms and should be included as the fourth element. Each paradigm has its own different perspective on ontology, epistemology, axiology and research design which interconnect and illustrate the belief system in which the researcher is working.

Ontology is the study of being and reality, examining what is known through the human mind and is a socially constructed meaning (Crotty 1998). It is essential for researchers to be aware of ontology as they must take a stance concerning their own assumptions and perceptions of reality and how they believe reality functions (Tashakkori and Teddlie 2010). Another essential element of the paradigm is epistemology which refers to the nature and forms of knowledge (Cohen *et al.* 2018).

Epistemology relates to how we acquire knowledge, interpret, process and communicate the knowledge we obtain. Guba and Lincoln (2006) expand on this to say epistemology is about what it means to 'know' and the nature of the relationship between what they term as 'the knower', and what can potentially be known (p.108). It incorporates our internal judging process, how we decide whether the knowledge we acquire is valid or not (Scotland 2012). The epistemological stance forms the underlying philosophical outlook of a research study and embodies different 'worldviews' of how social research should best be conducted (Guba and Lincoln 2006).

While ontology and epistemological are concerned with knowledge and truth, axiology refers to values and ethics, primarily those of the researcher who needs to question the ultimate justification or value of the research inquiry (Heron and Reason 1997). It also values knowledge to inform or enable positive change (Guba and Lincoln 2006). Axiology creates equilibrium and a holistic approach to the questions of truth evident the first elements of the paradigm, it is posing the question of value to the researcher, questioning the value of knowledge itself (Heron and Reason 1997).

> *"...values of being, about what human states are to be valued simply because of what they are."*
>
> *(Heron and Reason 1997, p. 287).*

Tashakkori and Teddlie (2010) outline that research studies fall into the following theoretical paradigms:

- Positivism-Postpositive
- Constructivist-Interpretative
- Transformative- Emancipatory
- Pragmatic

Each paradigm has its own theoretical perspective with particular paradigms associated with certain methodologies which will now be explored in the following section.

3.3.1 Positivism and postpositivism

The positivism paradigm is associated with quantitative research which has been the most dominant social research methodology throughout the 19th century (Ryan 2006). A researcher that adopts a positivist stance believes in the principles of quantification, prediction, control and trusts that using the right techniques will provide the right answers (Ryan 2006). A positivist 'worldview' is therefore based on a single reality of one truth and uses rigid rules of logic and measurement based on absolute principles and prediction (Onwuegbuzie and Leech 2005). Positivists place great significance on empirical evidence, such as numerical data or data that can be transformed into numbers to measure reliably and validly and this is viewed as central to their scientific activity (Kaushik and Walsh 2019). Another feature of positivism is the use of deductive reasoning, which works from a '*top down*' method, postulating from theory to hypotheses to either add to, or contradict the theory which is being tested (Creswell and Plano Clark 2017).

Therefore, within this paradigm the researcher takes a philosophical stance that their work is carried out in an impartial objective manner, that is, impartial from their own values and cultural contexts (Tashakkori and Teddlie 2010). However, around the beginning of the 20th century these ridged values and beliefs were challenged and criticised. Ryan (2006) contextualises the criticisms of positivism as coinciding with the social change and social justice movements that were occurring. Research philosophies which concerned itself solely with the correct techniques of handling data were now deemed to be limited and unsatisfactory (Schratz and Walker 1995). This led to what is known as post-positivism which acknowledges that society is complex and cannot be studied with total detachment, this philosophical approach became known as '*critical realism*' (Onwuegbuzie and Leech 2005). A quantitative approach has relevance within this study as a cross-sectional staff survey was deemed necessary in phase one to gain a clearer comprehensive picture of the phenomenon being studied.

3.3.2 Constructivist/ Interpretivist

In contrast the constructivist paradigm uses an interpretative approach to examine a particular phenomenon and is associated with a qualitative research stance (Snape and Spencer 2003). Researchers who adopt a constructivists approach reject the idea of a single truth, as assumed in post-positivism. Their 'worldview' is that of subjectivity, as it stems from the individual perspectives whose life experiences may be multiple and varied (Wahyuni 2012). Researchers who are grounded in this paradigm believe that it is important to understand the world as it is experienced by others. Onwuegbuzie and Leech (2005) assert that new knowledge is generated from the different experiences, of different individual's and the interpretations of these meanings is dependent on the researcher's theoretical lens. Constructivists differ from positivists regarding the basic values and beliefs they hold and how they interpret the notion of reality. Those who are aligned to a constructivist approach are influenced by a variety of data sources and collection methods. Such data tends to be narrative in nature, which is informed by the 'lived experience' of participants. Denzin and Lincoln (2005) describe qualitative research as an activity that incorporates the following:

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

(Denzin and Lincoln, 2005, p. 3)

Researchers working within a constructive paradigm are cognisant of the relationship between the researcher and the participant as the researcher gains meaning through observations and interactions with participants in social and cultural contexts (Onwuegbuzie and Leech 2005). Such observations and interactions create theories and hypothesis at the end of the research process, and this is referred to as 'inductive reasoning' (Chilisa and Kawulich 2012). With no hypothesis applied at the beginning of the research study, the researcher has the flexibility to modify the direction of the study if required (Polit and Hungler 2013).

The credibility of qualitative research is often the subject of much debate within the literature, and it is often perceived as a substandard approach by those who are aligned to a quantitative research paradigm (Boeij 2010). The key criticisms focus on the perceived lack of rigour relating to researcher bias which has the potential to impact on the reliability and validity of the findings and conclusions drawn. Another frequently cited criticism is the tendency towards a small number of participants within a given study, creating a lack of generalisability across contexts (Kvale and Brinkmann 2009). Such criticism has been defended by researchers who identify with a qualitative paradigm, arguing that the established models of reliability and validity do not apply to this philosophical outlook (Wahyuni 2012). As Parker (2014) asserts, qualitative research functions in a different sphere of influence with a different focus and purpose. Qualitative research seeks to produce credible knowledge based on interpretations and understandings of the participants, with an emphasis on cultural perspectives.

3.3.3 Transformative: emancipatory

The transformative or emancipatory paradigm is an umbrella term that includes many strains of critical theory-based research such as disability, feminism, and race (Danieli and Woodham 2005). It emerged in the 1980s and 1990s due to dissatisfaction with the prevailing research paradigms and methodologies (Groat and Wang 2013). According to Mertens (2007) the paradigm emerged from the disability rights movement which also sought to move control of the research into the hands of the communities being researched. At that time constructivism/interpretivist paradigm was viewed as inadequate and could not address the issues of social justice and marginalised people (Creswell 2013). The principles of emancipatory paradigm are characterised as openness, participation, accountability, empowerment, and reciprocity (Danieli and Woodham 2007). Transformative researchers may use qualitative and quantitative data collection and analysis methods in much the same way as the interpretivist/constructivists (Mackenzie and Knipe 2006).

The focus of this research paradigm is to produce knowledge that is beneficial to disadvantaged groups, therefore it is closely intertwined with political agendas which aim to reform the lives of the participants and the institutions in which they live or work. This paradigm is closely aligned to participatory designs for social innovation, where

the researcher interacts and co-designs the research with and for people who have historically been marginalized for reasons of race, gender, sexual orientation, disability, economic background (Creswell 2013). Historically, research within disabilities has been criticized for excluding people with intellectual disabilities and being irrelevant to their needs (Northway 2000). According to Frankena *et al.* (2015) researchers realised that to overcome this disparity people with intellectual disabilities should be actively involved. Therefore, emancipatory and participatory approaches were advocated to empower people with intellectual disabilities throughout the research process (Bigby and Frawley 2010).

3.3.4 Pragmatic paradigm

The final paradigm as described by Tashakkori and Teddlie (2010) is pragmatism, the philosophical paradigm utilised within this study. A key feature of pragmatism is that it embraces varied and multiple methods of data collection to inform a study. It is a relatively new typology within social research, and it is strongly associated with mixed methods research (MMR) although not exclusively (Creswell and Plano Clarke 2017; Tashakkori and Teddlie 2010; Patton 2014). Pragmatism originated in the United States and emerged as a philosophical movement in the 1870s, with writers such as Charles Sanders Pierce (1878, 1905), William James (1907) and John Dewey (1917-1938) offering an alternative philosophical commitment that could lead to broader concepts (McKenna and Pratt 2015). The founders of this American philosophy focused on theory and the nature of '*truth',* and this is referred to as 'classic pragmatism.' These innovators tried to show the limitations of the prevailing positivists notions of the time which focused on one pure 'truth' that can only be reached through logical analysis (Onwuegbuzie and Leech 2005; McKenna and Pratt 2015). Indeed, pragmatists viewed pluralism as a central feature of their 'worldview' (Legg and Hookway 2019) and their beliefs are therefore free from the confines of models, theories and notions of truthfulness, normally associated with the established schools of philosophy (Danforth 2001). Kaushik and Walsh (2019) describe pragmatic philosophers as rejecting the prevailing concepts of knowledge, reality and methods

of inquiry and aimed to move philosophy away from abstract concerns towards an emphasis on the human experience.

As Albrecht (2002) explains pragmatism emerged as a philosophical movement as it facilitated theoretical thinking that was more attuned to the transformations occurring within contemporary society. Pragmatists were often found engaged in social reform and they were closely associated with education, politics, justice and feminism (Heron and Reason 1997). Consequently, the field of social science research turned to pragmatism due to its predisposition to producing socially useful knowledge (Danforth 2001) for practice and lived experience. Therefore, many pragmatists of this era were social activists, committed to social equality with the belief that society could be improved through human effort and philosophical study (Legg and Hookway 2019).

Notable pragmatists were often involved in social endeavours, such as the philosopher, John Dewey (1859–1952), and Jane Addams (1860–1935), who is credited with the development of modern-day social work, based on pragmatist philosophies (Legg and Hookway 2019). Pragmatism is also closely aligned to ethical and moral issues of a fairer society, stressing that these values shape who we are and how we behave (Morgan 2007). It is these values that closely align social justice and pragmatism together (Morgan 2014). A key significance for pragmatists is the practical implications of their beliefs and how their ideas are guided by moral and political action for individuals or their communities (Danforth 2001). Thus, knowledge or beliefs, are only viewed as worthwhile if they can advance and improve society.

The means to creating this new knowledge sought to move away from traditional paradigms and forms of inquiry which were categorised as either being objective or subjective (Goles and Hirschheim 2000). Pragmatism avoids positioning itself strongly with either stance, with the practice of seeking new knowledge perceived as a continuum rather than opposing positions (Onwuegbuzie and Leech 2005; Kaushik and Walsh 2019). For example, postpositivism utilises deductive reasoning to test a hypotheses or theory, while constructivism takes an inductive approach to create the theory. Meanwhile, pragmatism is used as the third approach of abductive reasoning (also referred to as an 'abductive approach') which alternates between deduction and induction (Kaushik and Walsh 2019). It is viewed as an alternative to the deficits associated with solely using a deductive and inductive approach (Mitchell 2017).

Abductive reasoning follows a pragmatist 'worldview', and the principal aim is to develop an understanding of a 'new' or surprising aspect of a phenomenon:

"…through the interpretation or re-contextual phenomena within a contextual framework and aims to understand something in a new perspective of a new conceptual framework."

(Kovács and Spens 2005, p 138).

Abduction therefore assists researchers to uncover new truths in a logical and methodologically ordered way with pragmatism reconciling and bridging the divide between the conflicting methodological issues and philosophical stances of qualitative and quantitative research (Morgan 2007). Embracing both positions provide the paradigm with a more adaptable approach to the research process (Morgan 2007; Feilzer 2010).

As a result of this flexibility, pragmatism offers an alternative to the historical debates between postpositivism and constructivism by breaking down the longstanding *'paradigm wars'* between both perspectives to look at what is meaningful from both (Tashakkori and Teddlie 2010). The need to clarify the ontology, epistemology and axiology as a starting point in the research process, is not viewed as vital for the pragmatic researcher; instead, the research question and objectives are central to determining the research framework (Wahyuni 2012). This typology is not concerned with taking an objective or subjective standpoint within the research process as they are not conflicting within this paradigm (Creswell and Plano Clarke 2017).

Rosiek (2013) charts the relatively recent renewal and interest in pragmatic philosophy as meaningful approach within social science research. The rationale for the use of pragmatism as a research paradigm is often referenced in the literature in simplistic terms as doing "what works". However, Morgan (2014) argues that all too often this diminishes the theoretical foundations of the philosophy and has caused an overly simplistic interpretation of the paradigm. Morgan's (2014) article uses the work of John Dewy to stress that research, and research design, concerns itself primarily with problem solving and that as a philosophy the key principles of pragmatism are a suitable tool for undertaking the analysis, and is an appropriate fit for research studies.

Pragmatism focuses on beliefs that are connected to actions as opposed to aligning a social science research study to an abstract set of philosophical beliefs (Morgan 2014). Pragmatic researchers are urged to be aware of the historical foundations of the philosophy and its association with bringing the voices of disempowered communities into the world of research. Albrecht (2002) contends that this should be done with a conscious effort to keep the life experiences of marginalised groups central to contemporary debate, as researchers have an ethical responsibility to change the world and to further social justice. Furthermore, Albrecht (2002) proposes that a moratorium to be declared on discussions of mixed methods designs and typologies in favour of pursuing a discussion of how researchers can contribute to the creation of social change:

> *"At the same time, the social sciences have always looked at pragmatism as a philosophy that offers useful critical tools for making sense of social, cultural and political practices and institutions."*

> *(Albrecht 2002, p.31)*

Table 3.1: Pragmatic alternative to the key issues in social science research methodology (Morgan 2007)

	Qualitative approach	Quantitative approach	Pragmatic approach
Connection of theory and data	Induction	Deduction	Abduction
Relationship to research process	Subjectivity	Objectivity	Inter-subjectivity
Inference from data	Context	Generality	Transferability

3.4 Mixed methodology

As a research paradigm, pragmatism facilitates the use of a blend of different research methods and modes of analysis while being guided by the researcher's aspiration to produce socially useful knowledge (Felizer 2010). Pragmatic researchers support the combined use of both quantitative and qualitative data as it enables them to better understand social reality (Creswell and Plano Clarke 2017). There are multiple terms

utilised for the combination and integration of qualitative and quantitative research methods, such as triangulation and multiple methods (Creswell 2013). The combination of both quantitative and qualitative research methods into one study is now commonly referred to as mixed methods research. This approach has often been described as the third methodology and the trend for mixed methods design has become more widespread in health and social care research in recent years. It is defined as a procedure for collecting, analysing and mixing or integrating both quantitative and qualitative data within a single study in order gain a better understanding of the research problem (Tashakkori and Teddlie 2010; Creswell and Plano Clarke 2017).

The early definitions of mixed methodology focused on the combination of qualitative and quantitative methods. According to Tashakkori and Teddlie (2010) mixed methods evolved from the published literature on triangulation which is concerned with the convergence of results. Although this brought about what has been referred to as the *'paradigm wars'* and reflected on the ongoing debate around bringing two opposing research perspectives and approaches together in one study (Lincoln and Guba 2006). As the methodology advanced it is now defined as a methodological positioning (Creswell and Plano Clarke 2017) with its own 'worldview', vocabulary and techniques (Tashakkori and Teddlie 2010). Following a review of the literature on mixed methods, Johnson *et al.* (2007) found many variations in the definitions of what constitutes mixed methods. The author integrated many of the different available perspectives into one comprehensive definition as follows:

> *"Mixed methods research is an intellectual and practical synthesis based on qualitative and quantitative research; it is the third methodological or research paradigm (along with qualitative and quantitative research). It recognizes the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative, complete, balanced, and useful research results."*

> *Johnson et al. (2007, p. 129)*

From the available definitions Johnson *et al.* (2007) summarises the commonalities of mixed methods highlighting the qualitative and quantitative viewpoints, a variety of data collection methods, analysis and inference techniques. While other authors, such

as Morgan (2007) suggest that pragmatism can bridge the divide between the two opposing methodological stances of qualitative and quantitative research. These definitions infer that mixed methods research paradigm offers a central approach for generating important research questions and provides a more complete overview of the subject matter, which using one method alone could not provide. Many researchers advocate that mixed methods research is likely to provide a superior and broader spectrum of research findings and outcomes to assist the understanding of the chosen phenomena (Johnson *et al.* 2007; Tashakkori and Teddlie 2010; Creswell and Plano Clarke 2017).

Table 3.2: Four worldviews summary (Creswell and Plano Clarke 2017, p.36)

Postpositivism	Constructivism
• Determination • Reductionism • Empirical observation and measurement • Theory verification	• Understanding • Multiple participant meanings • Social and historical construction • Theory generation
Transformative	Pragmatism
• Political • Power and justice oriented • Collaborative • Change-oriented	• Consequences of actions • Problem-centred • Pluralistic • Real-world practice oriented

3.5 Rationale for use of mixed methodology

Following a review of the main paradigms and associated methodological movements, this study adopted a pragmatic paradigm with a mixed methods research approach. Pragmatism is closely associated with mixed methodologies and is an appropriate paradigm as it allows flexibility within the research process. Pragmatism offered this study the freedom to use different methods and practical implementation within practice setting context. Pragmatists assess knowledge based on its usefulness and relevance to empowering and improving the lives of citizens within society, particularly those in marginalised groups (Danforth 2001). Therefore, this paradigm could be applied to examine the current emphasis on person-centredness with intellectual disability services, focusing on how these values and principles serve as a conceptual

precursor to practice while aiming to improving the lives of older people with disabilities.

Mixed methods are closely aligned to pragmatism, it is a philosophically underpinned model of inquiry facilitating the integration of both qualitative and quantitative models of research (Creswell and Plato Clarke 2017). According to Tashakorri and Teddlie (2010) choosing mixed methods is advantageous to researchers for several reasons, firstly, it facilitates the study of topics which are complex in nature, where one method alone may not be suffice, thus providing more comprehensive findings than using a single research design. Secondly, as a design method it can incorporate larger and more diverse viewpoints on a given topic. When used in combination, quantitative and qualitative methods complement each other and allow for a more robust analysis, taking advantage of the strengths of each method (Cohen *et al.* 2018). Other authors such as O'Cathain *et al.* (2010) see the integration component as key value of mixed methods as it provides readers with more assurance in the results and the deductions they draw from the data.

The six most frequently used mixed designs are categorised by Creswell (2013) include three concurrent designs and three sequential designs. One of the designs, the mixed-methods sequential explanatory design was identified as suitable for this research study to meet the objectives. This method involves two distinct phases of data collection and data analysis: quantitative followed by qualitative. The quantitative data is collected and analysed in phase one, with phase two involving the qualitative which helps explain or elaborate on the quantitative results, designed as two consecutive phases within one study. It is also important for researchers who conduct a mixed methods sequential explanatory study to consider certain methodological issues. Such issues include the priority or importance given to the quantitative data within the study the sequence of the data collection and analysis, and the stage in the research process at which the quantitative and qualitative data are connected and the results are integrated (Creswell 2013). The purpose of the mixed methods sequential explanatory study was to explore staff practices and beliefs on person-centredness by obtaining quantitative data from a survey and then further explore those results in more depth through qualitative analysis. Integrating the different categories of data allows

all persons involved in care to have their voice heard and provide comprehensive answer to the objectives of the study.

3.6 My personal history and philosophical assumptions

Pragmatism proposes that researchers must scrutinise *why* they conduct research in the way they do (Morgan 2014). The researcher can be influenced by many factors within society, cultural and political contexts and research communities which all shape the experiences and actions that we bring to the research context. There is a need for researchers to be cognisant of how these influences affect their values, attitudes, preconceptions and the choices they make, this in turn effects the ways in which we interpret and understand the results of those choices (Creswell and Plano Clarke 2017). However, Barusch *et al.* (2011) observed that researchers do not often divulge personal information about themselves within their published papers and surmised that this may be due to a fear of appearing unprofessional in their approach. These authors advocate that the researcher should reveal their personal traits and experiences as such disclosures can enhance the reflexivity of their work (Barusch *et al.* 2011). This is a similar philosophical view to the Person-Centred Practice Framework (2017) which contains a strong underlining theme relating to knowing-self and how this awareness shapes our professional practice. As a PhD researcher exploring person-centredness, I felt it was important to reflect on my own sense of self and examine how the cultures and experiences of my past working and personal life have shaped my philosophical assumptions and beliefs systems, and the potential of these experiences to impact on my approach to the research process. The following account is structured to address the issues of my own philosophy assumptions.

My career in nursing and working with people with intellectual disabilities was somewhat accidental. On leaving school I was unsure of which career pathway to follow, and I was offered a work experience programme in the local intellectual disability service. I had very little experience of the world of caring and I had not previously been interested in a nursing career, as my perception of nursing had been based on a medical model of care with a focus on illness. My work experience changed this idea and gave me a different perception on caring and the wider holistic aspect of

nursing. I found the work to be multi-dimensional, including skills teaching, communication skills, the impact of disability on families, and the empowerment, or often disempowerment of people with intellectual disabilities. Without realising it at the time, this experience also awakened my awareness to the concepts of social attitudes and justice and the ethical foundations of how marginalised people are treated by society.

Subsequently, I was accepted into a nurse training programme in the field of intellectual disabilities in the United Kingdom, during a time of huge change with the deinstitutionalisation movement having taken place and the realisation of an ordinary life for people with intellectual disabilities. The Community Care Act (1990) was a time of great potential and optimism within services with the real hope of transformation in the lives of people with intellectual disabilities for the better. Many of my placements were within community settings but in latter placements I was introduced to the remaining large hospital-style living for those people who were deemed more challenging to resettle. It was during this time that I realised that although the physical environment was not conducive to dignity and people's rights or living an ordinary life, the positive attitudes, beliefs and determinations of the staff had made the transition to community living possible for many people. A combination of these experiences instilled in me the importance of the promotion of justice and equality of opportunity for people with intellectual disabilities.

Following on from my training I worked in a variety of settings such as children's services and assessment and treatment before moving into respite services. I found the staff nurse role in assessment and treatment service had a clear process with a practical component which suited my personality. I felt that I was able to see real improvements in people's health and well-being and assisting them to get back to their daily lives. I enjoyed new challenges and moved from a junior staff nurse into a variety of managerial roles, quickly realising the impact of culture on care delivery and on the lives of people within services. My career moved into a community nursing role in central London, where I enjoyed the diverse workload with a wide variety of client groups from ethnic backgrounds, working in close partnership with families and the individual themselves.

The community nursing role also led me to reconnect with people living within residential services. It was evident that many community group homes had struggled to reach the potential of the philosophy of ordinary lives that had originally been envisaged. Despite the far-reaching changes in the physical environment, many institutionalised practices remained and people with intellectual disabilities still experience a continued struggle for equality and integration into a society and the wider health and social care service structures.

I feel my past experiences have certainly shaped my views and thinking. Much of my nursing career has been practice based utilising practical skills and concrete critical thinking skills with an emphasis on 'doing'. Therefore, I would consider myself a pragmatic person with my philosophical outlook based in social equality and I am motivated by issues relating to fairness. I feel that I relate to the pragmatic paradigm, as I believe that our realities are socially created through our life experiences and our own individual interactions with the world in which we exist. These interactions form our internal values and beliefs systems originating from our social and cultural histories. Previously, I would have said that I was more drawn to qualitative research and the lived experience of the person, however my PhD journey has led me to explore my own philosophical values in more detail and on a deeper level. Therefore, I agree with Barnett (2005) that the researcher should retain a level of humility that allows the acknowledgement of their standpoint, coupled with an openness that is prepared to have that standpoint changed.

It is important for researchers to recognise and declare their standpoints and philosophies in advance of the study to enhance the transparency and possible research bias (Smith and Noble 2014). This avoids researchers bringing their prejudices and personal philosophies with them to each study (Smith and Noble 2014). I was conscious that more recently I have been working closely with nurse managers and other staff members on continuing professional development education for staff working in intellectual disability services. Although I was not part of the official team and in many ways, I represented an objective 'outsider', I have developed professional and personal relationships with nurse managers. Although this assisted me in my current role, I felt conflicted about my new researcher status. I wanted to feel like an

'insider', as I empathised with many of my colleagues and particularly with nurse managers and the challenges they face within services.

However, Corbin and Buckle (2009) advise researchers that this personal connection to the participants has the potential to cloud the researcher's perceptions resulting in a struggle to separate themselves from the group. I was therefore aware of my susceptibility to framing the focus groups and individual interviews, particularly with staff participants, through my own experience and not through the participants. Furthermore, I was concerned that this could influence the analysis of the data, creating an emphasis on shared aspects between myself and the staff participants and perhaps detracting from other factors present within the data which may not truly reflect the participant's voices (Dwyer and Buckle 2009).

Attia and Edge (2017) offer advice on how to address insider/outsider researcher status. Rather than perceiving my connection with participants as a potential cause of bias that should be avoided, they call for '*prospective reflexivity'.* This assists the researcher to increase their ability to understand the importance of the knowledge, feelings and values that they have brought into the research study as each of these contributes to the analytical lenses that are chosen to employ to analyse the findings. As Borbasi *et al.* (2005) maintain, '*insider researchers'* tend to be more comfortable and confident in the research setting thus facilitating more effective interactions with the participants.

My personal belief is that the inclusion of people with intellectual disabilities was essential within the study. This is aligned not only to the underlying philosophies of person-centredness and pragmatism but also a rights-based model of care. Hearing the opinions and experiences of the person also adds authenticity to the study. I was concerned about the potential for an unequal power status between the researcher and the participant. Historically, research studies have discussed the issue of acquiescence as a potential challenge in interviewing people with intellectual disabilities. Previous concerns focused on the suggestible and eagerness to provide the correct answer, while also being susceptible to external cues (Henry and Gudjonsson 2003). However, in more recent studies researchers such as McDonald *et al.* (2016) discussed the importance of the inclusion of people with intellectual

disabilities and they did not recognise the power imbalance as an issue of concern. Instead, the focus is on the inclusion of their viewpoint as an essential element of the research process, particularly considering the persistent marginalisation of people with intellectual disabilities within society. Including older with intellectual disabilities in research validates that their opinion is worthwhile and allows them to experience equality by demonstrating their capabilities to speak on their own behalf and make a worthwhile contribution to the study. As previous researchers have demonstrated the opportunity for people to represent themselves in scientific work promotes the validity of the knowledge and ensures the production of research that is reflective of the views and experiences of people with intellectual disabilities, consequently offering greater insight into their lives (McDonald *et al.* 2016; Hollomotz 2018).

3.7 Summary

This chapter explored the main philosophical and methodological schools of thought of research. Through this exploration pragmatism was identified as the appropriate paradigm adopted for this study, due its foundations and affiliation to the social justice movements for marginalised groups such as, people with intellectual disabilities. The chosen design for the study is a sequential explanatory mixed methods research approach and the rationale for this choice has been provided. A mix methods approach facilitates the integration of both qualitative and quantitative datasets within the one study and ensures that the complementary aspects are combined to provide a comprehensive and shared meaning from both approaches and includes the voices of all persons involved in the care setting. The next chapter will outline and discuss the data collection methods and how the ethical issues were addressed within the study.

CHAPTER 4: THEORECTICAL UNDERPINNINGS AND METHODS

4.1 Introduction

The chapter will initially address the theoretical underpinnings of the study and outline the research methods and data analysis utilised. It and will also define the research plan, including the methods employed, the inclusion criteria for participants, analysis of quantitative and qualitative data, the data integration process involved in mixed methods and finally the ethical considerations for the study.

4.2 The theoretical underpinnings of the study

Developing knowledge and problem solving is an essential purpose of research inquiry. Leedy and Ormrod (2001) have described it as a systematic process which begins with a question relating to a phenomenon of interest. It is argued by Fawcett (2005) that to fully explore a research question a theoretical framework is an essential component to underpin the concepts of any study. A theoretical framework provides the research question with coherency and a methodological means to diagrammatically illustrate the theories and concepts involved (Parahoo 2014). Therefore, a framework clarifies the overall conceptual design of the study and contextualises the research. It also provides an organisational structure to guide the methods of data collection and functions to link the results of the study. Polit and Beck (2018) summaries this point by stating that the interpretation of findings flows from the conceptualisation represented by the framework. The theoretical model used within this study has been integrated within each stage of the research process, it has been utilised within the review of the literature and data collection and data analysis process.

A review of the literature identified a consistent reference to the importance of the role of staff support within intellectual disability services and within policy documents they are identified as the key personnel in implementing person-centredness within practice. There are several person-centred approaches or tools, available to staff to achieve this, such as active support or person-centred planning. However, the principles associated with these interventions do not address in any great depth, the

wide-ranging organisational and cultural issues that impact on practice. The absence of a robust evidence-based model within the intellectual disability literature led to the Person-Centred Practice Framework (McCormack and McCance, 2010, 2017) being identified as appropriate for several reasons. Firstly, the PCPF model has undergone systematic testing and its comprehensive structure offered an evidence-based theoretical underpinning for the study. Previous research studies have been guided by the framework which has acted as a lens to offer greater insights and understanding of person-centredness in practice settings (Parlour 2010; McCance *et al.* 2013; Laird *et al.* 2015; McConnell 2018). Additionally, the PCPF recognises and acknowledges the contextual layers of cultural aspects at play within the care environment that have had the greatest potential to limit or enhance the delivery of person-centredness (Laird *et al.* 2015; McCormack and McCance 2017)*.*

The Person-Centred Practice Framework (PCPF) was originally developed by McCormack and McCance (2006) to evaluate the effectiveness of the development of person-centred nursing in a hospital setting and originated in services for older people. The framework was originally devised for nursing professionals but was further updated in 2017 to include an interdisciplinary focus. The framework has been described as a mid-range theory (McCormack and McCance 2006) and offers teams within the health and social care arena a structure to understanding what is happening within their own practice settings. The framework is constructed into four domains which represent person-centred practice within the theoretical model. Slater *et al.* (2015) have described it as a means for staff to actualise person-centredness within their practice settings.

The PCPF is constructed in a manner which illustrates the inter-connecting relationship between the four domains, from the initial prerequisites which pertains to staff having the necessary identified attributes to managing the care environment. This creates an impact on the care environment which in turn impacts on the care process and the person-centred outcomes being achieved for both the person receiving care and the staff working within the care environment (Slater *et al.* 2017). The updated framework by McCormack and McCance (2017) includes the macro-context external influences that are acknowledged as impacting on the implementation of person-centredness, these are identified as strategic leadership, health and social care policy,

workforce development, and strategic framework were added to the reviewed PCPF in 2017 and is illustrated in Figure 4.1 below.
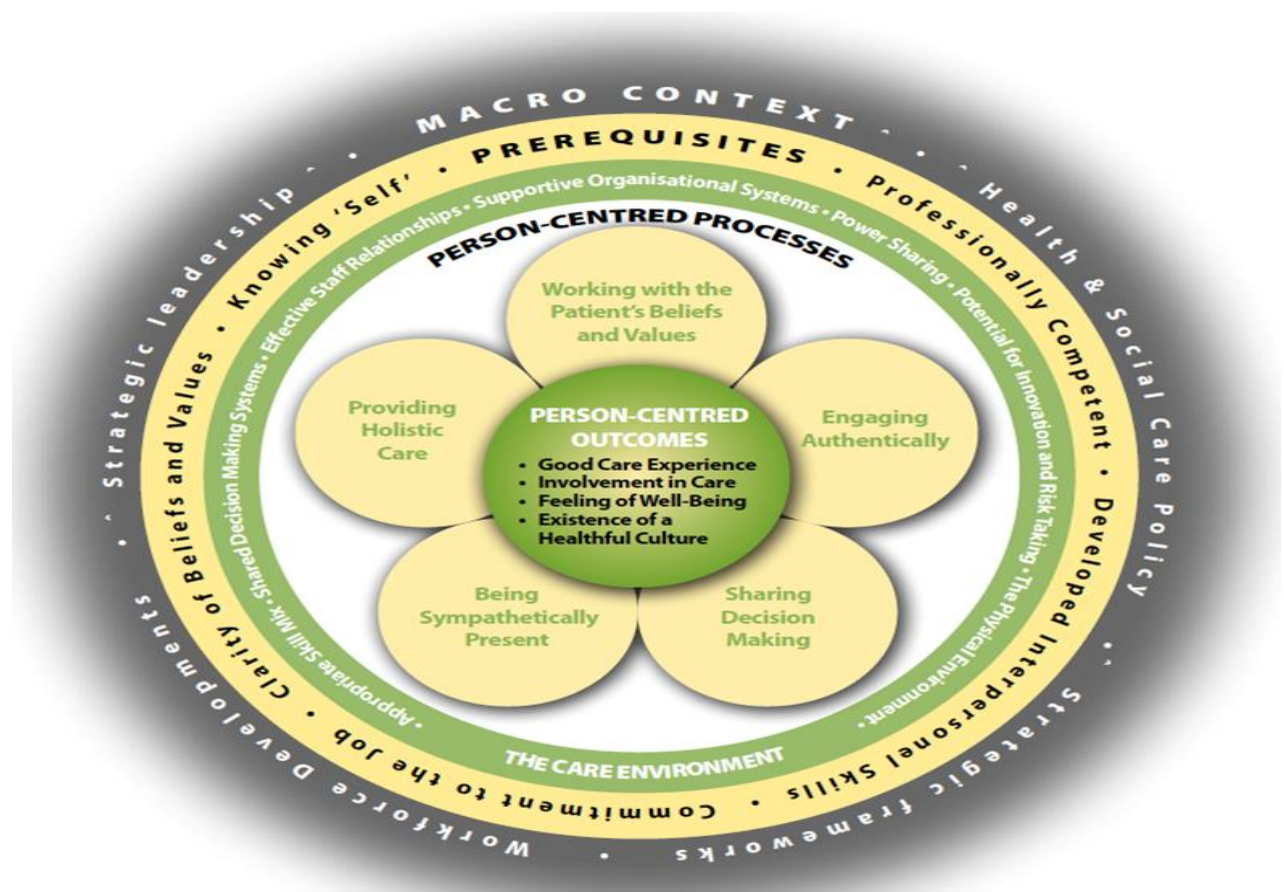
Figure 4:1: The Person-Centre Framework (McCormack and McCance 2017)

The Person-Centred practice Framework guides many of the components of data collection and data analysis within the study. The Person-Centred Practice Inventory-Staff is a questionnaire derived from the framework and is used in phase one to collect the quantitative data from staff participants. It has been designed specifically to test the interconnecting relationships between each of the domains within the framework; that is, staff prerequisites for the role, the care environment in which care is delivered and the care process which examines how staff engage in care (Slater *et al.* 2017). The statistical data analysis in the quantitative phase one of the study is mapped to the framework and involves the analysis of the questionnaire on a number of levels, variables, constructs and domains within the framework and the results of this analysis will be reported later in Chapter 6 *Findings from the Person-Centre Practice Inventory*.

The interview schedules employed in phase two of the study encompass questions derived from the data analysis in phase one and relate to the domains of the framework and the impact of these on all three participant groups and are documented in Chapter 7 *Qualitative Findings.* During the data integration and interpretation, the framework will be used to formulate the Chapter 8 *Discussion*, which will identify and explore the themes found emerging from both datasets.

4.3 Mixed methodology

This study utilises a sequential explanatory mixed methods design, a two-phase study which contains four procedural steps, with this choice of design influenced by several factors. Firstly, to fully examine person-centredness in residential services it required more than the use of one method, as the overall aim of the study involved two different but related objectives. The methods utilised were selected for their appropriateness to address each objective, while contributing to the overall aim of the research study. The first objective was to explore how staff of all grades within residential services perceive their attributes for their role, how they engage in the care environment and care process of the service. As the PCPF involves the relationship between variables, it was therefore decided that a quantitative approach would be the most appropriate method. Policy refers to frontline staff being responsible for implementing person-centredness (HSE 2011), but there is limited information or clarity regarding staff knowledge or attributes to carry out this role, or how staff deliver and organise care within services. An overview of staff perceptions on these related areas was therefore required initially. The Person-Centred Practice Inventory-Staff (Slater *et al.* 2015), was selected to measure the presence of these aspects and the relationships between these factors in practice, or rather in the care environment.

The second objective was to investigate how the factors identified within objective one, are actualised and experienced on a day-to-day basis by staff, older people with intellectual disabilities and their family members. A qualitative approach offered the most effective insight into the opinions and experiences of all the groups involved and would expand the findings from phase one. Focus group interviews with staff were deemed as the most effective method of bringing staff together to generate group

discussion and provide an opportunity for staff to explain and clarify the findings from phase one. This is the favoured approach advocated where mixed methods are the best approach to address the research question (Creswell and Plano Clarke 2017). Semi-structured interviews were selected for older people with intellectual disabilities and family members to facilitate in-depth discussion. The latter two groups had requested individual interviews as their preference during the PPI process at the outset of the research study.

The third objective was to synthesise the experiences of older people and family members with those of staff to expand the understanding of person-centred practice for older people with intellectual disabilities. The data integration within the mixed methods approach will provide the opportunity bring together both the quantitative and qualitative data from multiple sources and the analysis and comparison within each strand of the data collection and analysis to informing the other, expanding the understanding of the concept in practice.

4.3.1 Mixed methods as the chosen approach

The justification for the use of mixed methods within research studies has dated back to the 1980s with seminal work by Green *et al*. (1989) which is still frequently cited within the current literature (Bryman 2006; Onwuegbuzie and Combs 2010; Schoonenboom and Johnson 2017). The seminal work by Green *et al.* (1989) is the most widely recognised classification of purposes or justifications of mixed methods research and is still relevant today. The authors produced a scheme which distinguishes the following five justifications or purpose for combining quantitative and qualitative research and identifies them as triangulation, complementary, development, initiation and expansion, which are explained in Table 4.1.

Table 4.1: Greene *et al.* (1989) five purposes for combining quantitative qualitative research (adapted from Schoonenboom and Burke Johnson (2017, p. 110)

Purpose	Objective
Triangulation	Data is collected from different sources with the use of different methods and data collectors within the same study. The results are converged providing corroboration of one reality.
Complementarity	Using both qualitative and quantitative methods to elaborate, enhance, illustrate or clarify the results from one method with the results from the other method.
Development	One method is used to help develop or inform the other method (usually of equal importance). The results of one strand inform the next with development is broadly construed.
Initiation	Using both quantitative and qualitative methods within the same study, seeking to discover paradoxes and contradiction. This is to form new perspectives of frameworks, the recasting of questions or results from one method with questions or results from the other method.
Expansion	Seek to extend the scope, breadth and range of inquiry by using different methods for different inquiry.

Greene *et al.* (1989) classification has been augmented by several authors over the past number of decades, the most notable of which is Bryman (2006) who argued that there are six further rationales for implementing mixed methods research, thus developing further characteristics detailed in Table 4.2.

Table 4.2: Additional justification/purpose for combining quantitative and qualitative research (Bryman, 2006, p.106)

Purpose	Objective
Credibility	Proposes that employing both qualitative and quantitative approaches enhance the integrity of findings.
Context	Situations in which the combination of methods is justified in terms of qualitative research providing contextual understanding coupled with either generalizable, externally valid findings or broad relationships among variables uncovered through a survey.
Illustration	The use of qualitative data to illustrate quantitative findings, often referred to as putting "meat on the bones" of "dry" quantitative findings.
Utility	Improving the usefulness of findings refers to a suggestion, which is more likely to be prominent among articles with an applied focus, that combining the two approaches will be more useful to practitioners and others.
Confirm and discover	Using qualitative data to generate hypotheses and using quantitative research to test them within a single project.
Diversity of views	Two different rationales are included which combine the researchers' and participants' perspectives through both quantitative and qualitative research respectively and uncovering relationships between variables through quantitative research while also revealing meanings among research participants through qualitative research.

The purpose or justification for combining quantitative and qualitative methods within this study was to examine staff perceptions of their attributes for their specific role, the care environment in which care is delivered and the care processes which they use to facilitate care. The second objective corresponded somewhat with the first and aimed to elicit perspectives from different sources on the same phenomena, to assist in clarifying and expanding the findings from the first objective. Triangulation is cited frequently as a feature of mixed methods studies and is believed to provide certainty within the research process (Hammersley 2008). It focuses on bringing together different types of data for comparison to create one single reality (Greene *et al.* 1989). The term triangulation is acknowledged as complex and problematic by Greene *et al.* (1989). However, Fetters and Molina-Azorin (2017) highlight that the terminology of

triangulation was originally developed within a qualitative research paradigm and has a very broad range of meanings.

Subsequently, in recent times researchers have revisited the language used within the field of mixed methods and the terminology around triangulation has been of particular focus and debate. Triangulation has been described as complex, contradictory to purpose, confusing, with multiple meanings (Archibald 2016; Fetters and Molina-Azorin 2017). The current literature now advocates for language which articulates the work and procedures involved in mixed methods and the research process more clearly (Hammersley 2008; Teddlie & Tashakkori 2010; Fetters and Molina-Azorin 2017). While Richardson (2000) advocates for the term crystallisation over triangulation, acknowledging that there are more than '*three sides*' from which to approach a worldview, as opposed to the idea of a fixed point that can be triangulated (Richardson 2000, p.934). Fetters and Molina-Azorin (2017) support the use of the term 'integration', as opposed to triangulation, stating that it is a more accurate description of the work that mixed methods researchers undertake.

Whilst reflecting on these traits of mixed methods, the purpose of this study was not to create a single reality as described by Greene *et al.* (1989). Nor was it to take a fixed point or entity as described by Richardson (2000) but rather the purpose was to examine the same phenomenon from different viewpoints, thus hopefully yielding a more comprehensive understanding of the concept of person-centredness. Data integration is an aspect of the study as it facilitates the connecting and merging of data from different viewpoints. Similarly, traits of complimentary and development as described by Greene *et al.* (1989) are also features of this mixed method study. Quantitative findings from phase one would assist in connecting and formulating phase two interview schedules which would in turn further clarify the findings from phase one. When considering Bryman (2006) additional features, the purpose for mixing methods within the study were also related to credibility and illustration by using both quantitative and qualitative methods. This will add to the validity of the findings and to ultimately generating a more thought-provoking depiction of life in residential services for older with intellectual disabilities.

4.4 Research design

As stated previously mixed methods can be defined as a procedure for collecting, analysing and mixing or integrating both quantitative and qualitative data within a single study in order gain a better understanding of the research problem (Tashakkori and Teddlie 2010). As Tashakkori and Teddlie (2010) highlight, the argument for mixing both quantitative and qualitative methods is grounded in the rationale that one method is insufficient to understand the concepts and dynamics of a given situation. When used in combination, quantitative and qualitative methods complement each other and allow for a more robust analysis, taking advantage of the strengths of each method (Cohen *et al.* 2018).

Creswell and Plano Clarke (2017) recommend that once researchers identify the chosen method it is important to clarify the specific design, asserting that the design should be reflective of the research question and dictates how the datasets are merged and dealt with, that is, whether one data set builds upon another or merged into one analysis. Creswell and Plano Clarke (2017) categorised the six most frequently used mixed methods designs which include three concurrent designs and three sequential designs. There are two types of sequential design, exploratory and explanatory, with the former exploratory design characterised by the qualitative stage of data collection and analysis first, followed by a quantitative data collection and analysis. While the latter is the sequential explanatory design which is characterised by collecting the quantitative data and analysis in the first phase, to help explain or elaborate on the quantitative results (Creswell and Plano Clarke 2017).

Several research studies have demonstrated the effectiveness of the sequential explanatory approach and have cited that combining the approach with a pragmatic philosophical outlook allowed a greater level of flexibility for data integration, abduction and transferability of results (Arnon and Reichel 2009; Feilzer 2010; West *et al.* 2012). A study by Murphy *et al.* (2014) demonstrated that the mixed method research provided an additional added value by allowing researchers from different philosophical paradigms to learn from each other. This method of inquiry was deemed the most appropriate for addressing the research aims of this study. Firstly, pragmatism was an appropriate philosophical approach due to its origins within social

justice and work with marginalised groups, such as the elderly and disabled populations and the aspiration to make a difference within society (Albrecht 2002). This is reflected in its 'worldview' and that there is no defined line between daily life and research, with the value of research being judged by its practicality and social utility (Danforth 2001; Legg and Hookway 2019). Person-centred practice is rooted in daily practice which is aligned to the 'real world' pragmatic paradigm.

Currently staff teams in residential services primarily consist of registered nurses and healthcare assistants and although they individually and jointly deliver care to the same groups of people, preparation for their roles differ greatly (Cockayne *et al.* 2007). For person-centred practice to become a reality, staff must be able to understand the complexities of the concept (Mansell and Beadle-Brown 2004; McCormack and McCance 2010). There is also limited evidence regarding the level of staff knowledge on the concept of person-centredness within residential services, particularly how this relates to people ageing with intellectual disabilities. This supported the rationale for carrying out explorative quantitative work initially to looking at the various components of person-centred practice and identify any significant staff relationships within the constructs of the model.

A further rationale for this approach is that the quantitative data and the qualitative data and the subsequent analysis can be refined and elaborate on the statistical results by exploring participants view in more depth. This represents two consecutive phases within one study (Creswell and Plano Clarke 2017). It is also important for researchers who conduct a mixed methods sequential explanatory study to consider certain methodological issues, including the priority or importance given to the quantitative data within the study, the sequence of the data collection and analysis, and at what stage in the research process is the quantitative and qualitative data connected and the results are integrated (Creswell 2013). In the sequential explanatory design, the quantitative strand is traditionally weighted more heavily and informs procedures in the qualitative strand. The qualitative analysis is used to examine or clarify quantitative findings, the weight is therefore given primarily to the quantitative findings (Beaudry and Miller 2016). For this study it was felt that both should have equal weighting with importance of the qualitative data coming through for the voice of older people with intellectual disabilities. Several researchers agree

that both quantitative and qualitative data should have equal weighting if both sets of data contribute equally to address the research question (O'Cathain *et al.* 2010). Assessment of the configuration of the research design was based on Morse's (1991) taxonomy that provides emphasis to timing (e.g., using methods in sequence represented by a "QUANT→QUAL" symbol versus using them simultaneous. The stages involved in the sequential explanatory design are outlined below in Figure 4.2.
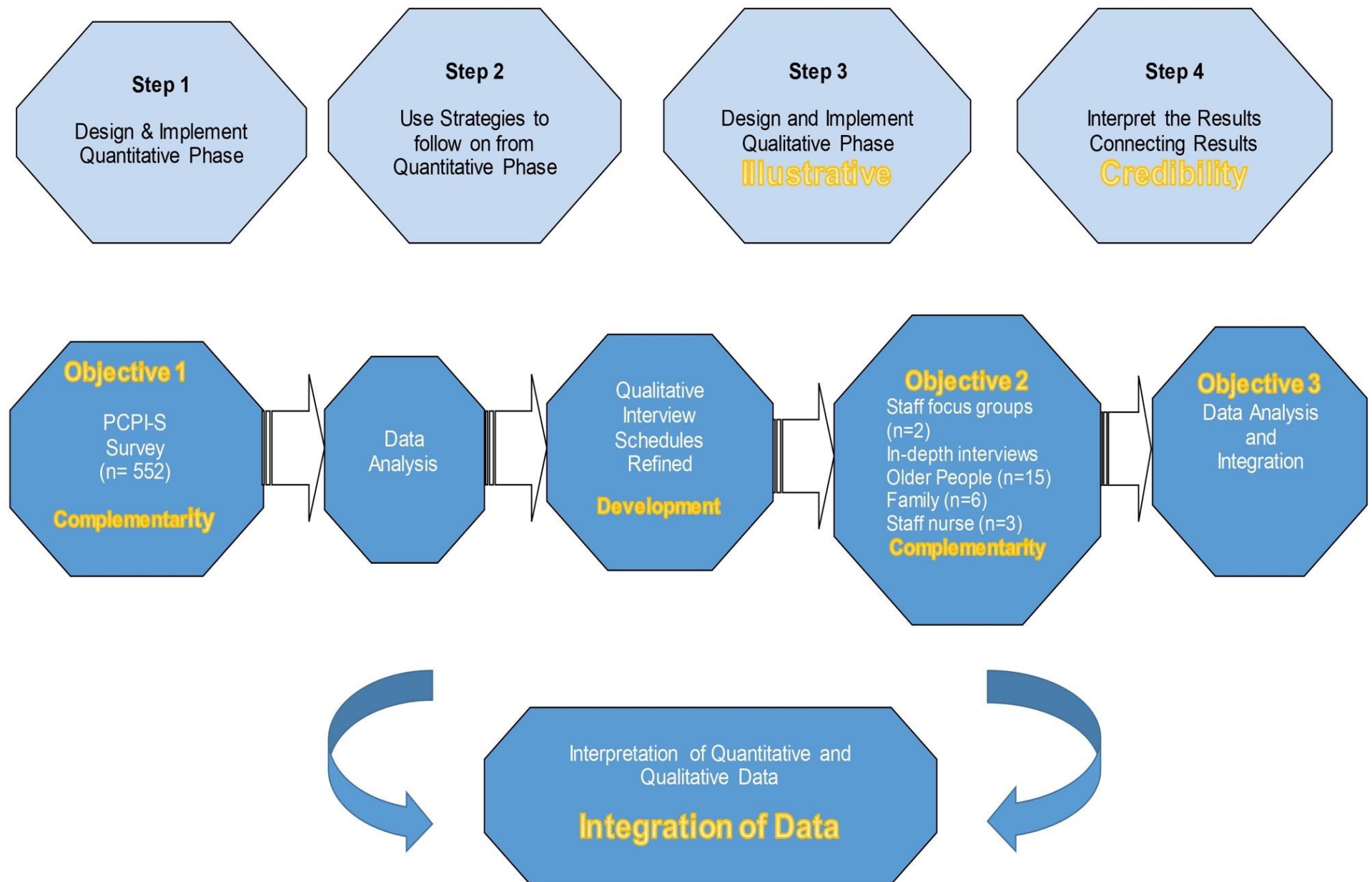
Figure 4.2: Sequential explanatory design phases of the research process (Creswell and Plano Clark 2011, p. 84)

4.5 The research setting

This study involved staff, older people with intellectual disabilities and family members from across selected sites in the Northwest of Ireland. The services are based in one Community Health Organisation (CHO) with specific sites chosen based on the numbers of older people (55 years and older), living within Health Service Executive Residential Services. The services were identified via an application to the National Intellectual Disability Database (NIDD) for a population profile on the age ranges and location of those living in residential services within this geographical area.

Table 4.3: Location of services

Site location	Large residential Congregated settings (and campus settings) >10 people	Small residential Community Group Homes <10 people
Co. Donegal	5	5
Co. Sligo	2	5

The term residential services will be used as an umbrella term to refer to large residential settings (i.e., congregated and campus style settings) and small residential settings (i.e., community group homes). During the PPI stage of the research, it was evident that staff were confused regarding the type of setting they worked in. For example, many staff interpreted their place of work as a community group home, but they were based in a campus setting, which is classified as congregated setting. Therefore, the simplified terminology of large residential and small residential was adopted with the research study and the definitions are clarified in Table 4.4.

Table 4.4: Definition of large and small residential services

A large residential service is where … "*ten or more people with a disability are accommodated in a single living unit or where people are placed in accommodation that is campus based.*" (HSE 2011, p. 25).
A small residential service is**... "***referred to in other countries as 'group homes', these are community-based services typically take the form of a house in a residential area that provides a service to people in a house-share arrangement. The service users are supported by staff which are present in the house on a 24-hour basis."* (HIQA, 2017, p.12).

4.6 Phase one: quantitative data collection

Phase one was designed to address objective one of the study by undertaking a quantitative questionnaire, the Person-Centred Practice Inventory-Staff (Slater *et al.* 2015) which will now be discussed in more detail below.

4.6.1 Sampling procedure

A purposive sampling technique was adopted for both phases of this research. Purposive sampling is a technique frequently used in research for the identification and selection of participants that are 'information-rich', assisting with the effective use of limited resources (Patton 2014). According to Morse and Niehaus (2009) whether the methodology employed is quantitative or qualitative, the sampling methods are anticipated to maximize efficiency and validity. The process of purposive sampling involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Creswell and Plano Clark 2011). This technique ensured that the sample targeted had the necessary experience of working in residential services and working with older people. Conversely, purposive sampling has been described as judgmental, as it involves the deliberate selection of individuals by the researcher on certain predefined criteria (Tuckett 2004) this ensures that the research participants are suitable and selected accord to the needs of the study (Palinkas *et al.* 2015). As well as knowledgeable and experienced, it is also important that participants are available and willing to participate and can communicate their experiences and opinions in an articulate and reflective manner (Bernard 2002). Table 4.5 outlines the inclusion and exclusion criteria for staff on phase one.
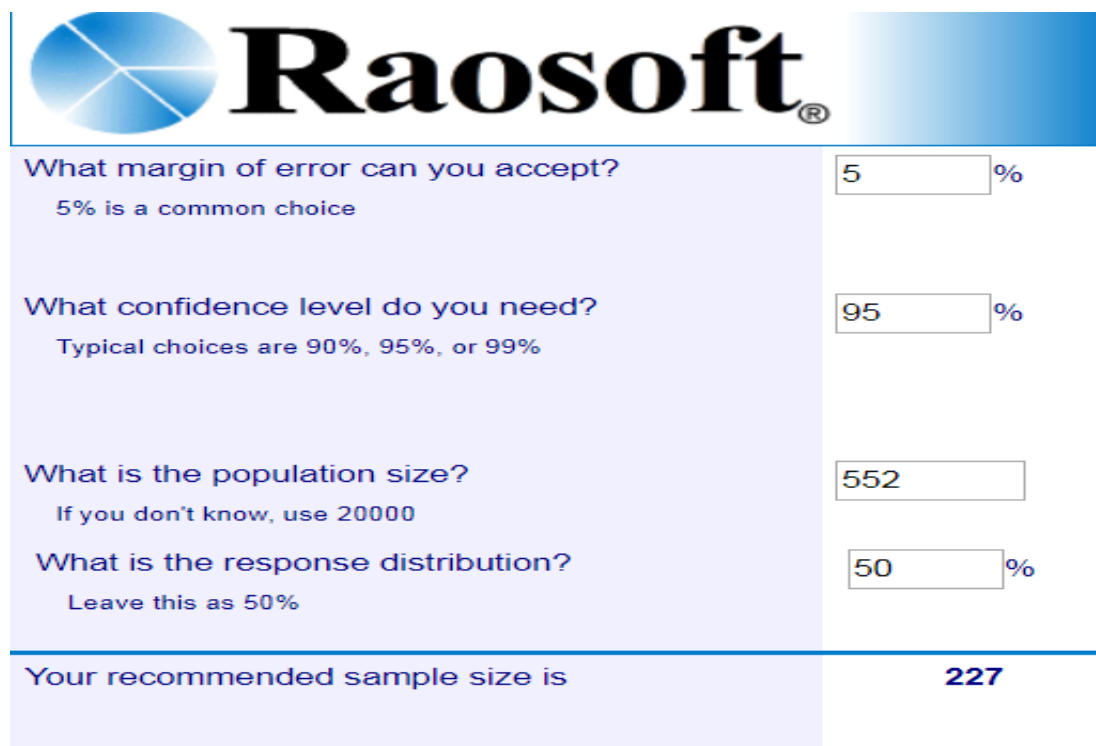
Table 4.5: Inclusion and exclusion criteria for staff phase one of research study

Inclusion Criteria	• Staff who are employed in a nursing or healthcare assistant role. • Staff who work partly or mainly, with people with intellectual disabilities who are 55 years or older in residential services in the Donegal or Sligo area.
Exclusion Criteria	• Student nurses

Student nurses are not included in the sample due to the temporary nature of their placements within residential services and they may not have sufficient experience of care processes involved. The number of eligible staff to participate in phase one was calculated by contacting the appropriate personnel departments who provided the numbers of staff for each identified site. The sample size was originally calculated as (n=652) and spanned across the geographical areas of the Northwest. A recalculation of the sample was required after the researcher visited one of the large residential campus style settings and discovered that 100 staff were employed in day service provision and were subsequently excluded from the sample size. Therefore, a total of (n=552) questionnaires were distributed across the two counties to seven large residential services and ten small residential services that were participating. The researcher visited each site to deliver the surveys in a hard copy format and to develop a relationship with each site with the aim of encouraging participation in both phases. The demographic profile of the participants is documented further in Chapter 6 *Findings from the Person-Centred-Practice Inventory-Staff.*

The calculation of sample size is based on a power calculation to determine the number of respondents to the questionnaire to ensure the validity of the findings (Burmeister and Aiken 2012). Factors that influence sample size include the effect size, the risk of error that researchers consider acceptable, and the rate of participant attrition anticipated during the study (Burmeister *et al.* 2012). The alpha error is linked to the P-value or probability value and is conventionally set at 5%, meaning that 95% of the results would be representative of the total population. Burmeister and Aitken (2012) recommends that researchers must make appropriate plans regarding these factors to maximise the probability of finding meaningful statistical results. The sample size return rate required for the study was calculated via Raosoft.com software,

demonstrated in Figure 4.3, indicating that from a population of (n=552) a return sample size of (n=227) was required. It was decided with the research team that hard copies only of the questionnaires was the most appropriate form of data collection, this decision was based on the experience of previous researchers in the area, who experienced low response rates to on-line surveys. Additionally, many of the identified services were in rural locations with limited or no Wi-Fi access and one computer on-site which was accessed by only the manager of the service.

Figure 4.3: Raosoft software calculation for sufficient sample power to ensure the validity of findings.

4.6.2 Quantitative data collection instrument

A frequently cited limitation of tools measuring person-centredness is that their conceptual underpinnings are rarely made clear (Edvardsson and Innes 2010). The Person-centred Practice Inventory-Staff (PCPI-S) addresses this issue as its theoretical development is clearly mapped to the PCPF (Slater *et al.* 2017). According

to Slater *et al.* (2017) the Person-Centred Practice Inventory-Staff (PCPI-S) is a theory driven measurement tool structured to directly measure the 17 person-centred constructs within three domains of the Person-Centred Practice Framework (PCPF). The domains are, *prerequisites*, represents the staff attributes, the *care environment* in which staff work, and *care process* in which they engage (Slater *et al.* 2015). The questionnaire contains 59-item Likert scale, which is measured on a five-point scoring scale that ranges from 1 (strongly disagree) to 5 (strongly agree). The questionnaire was used as it is theoretical aligned to the Person-Centred Practice Framework (McCormack and McCance 2017) and has been systematically tested for validity prior to its publication (Slater *et al.* 2015). Since its development, the PCPI-S has been validated in several settings such as, acute hospital setting (Parlour *et al.* 2014; Slater *et al.* 2017) and Emergency Departments (McConnell 2018). The questionnaire has been statistically tested using confirmatory factor analysis (CFA) to verify the measured variables represent the latent constructs (McConnell 2018). These studies found the PCPI-S to be a psychometrically sound instrument, with testing of validity and reliability conducted (Slater *et al.* 2015).

4.6.3 Data collection process

In this study the PCPI-S questionnaires were formulated and printed in hard copy booklet style format which contained the Participant Information Sheet (Appendix 3). The researcher delivered the questionnaire booklets to each site, apart from two, which were a substantial geographical distance away, and the survey was delivered and returned via post. The questionnaire contained a cover letter explaining the study and the issue of implied consent was clearly stated and explicit in the participant information sheet. A returned completed questionnaire indicated granting consent to the use of the information contained in the study. Prospective participants were asked to complete the questionnaire and return it in a supplied envelope either by post or for collection by the researcher. During the researcher's visits to the participating sites some staff were concerned that their completed questionnaire could be identified by their manager or others and were wary of participating. Staff were reassured that the questionnaires were anonymous and would only be analysed by the research team.

A persistent downward trend in response rates to questionnaires has been noted within the research literature (Harrison *et al.* 2019). To counteract this trend, Harrison *et al.* (2019) recommends a combination of approaches to encourage uptake of questionnaires and the following techniques were incorporated into the study:

- A pre-notification, explanation and purpose of the questionnaire was given via the manager or designated representatives to present to the staff team prior to commencement of the data collection.
- The questionnaire was converted into more personable style in the form of a booklet with user friendly artwork on the cover to make it more appealing. This was important for participants who were unaccustomed to taking part in a research study.

An additional reminder and the hard copy format provided easy access to the materials and led to an increase in the response rate. A deadline of three weeks was given for the return of questionnaires with weekly phone calls to each site which worked well with the majority of the sites. However, further follow-up visits were required with two of the larger congregated settings and a further two weeks was given to encourage uptake and retrieve the questionnaires. Although the overall uptake was modest, it was statistically significant and methodologically important and met the sample size response rate requirement.

4.6.4 Data analysis

The data analysis of phase one was carried out in several stages. It initially involved analysing the questionnaires for respondents who were not in the inclusion criteria and questionnaires that only had completed a few items. The overall total response rate was (n=236) staff, a response rate of 42.7%. Guidance was taken from Hair *et al.* (2010) and questionnaires which had less than 20% of the constructs completed were excluded from analysis, this amounts to a total of twelve constructs or less being completed. Therefore, questionnaires with a substantial amount of missing data (x 3), and responses from student nurses (x 4), who were not in the inclusion criteria, were

excluded from the sample, resulting in (n=229) questionnaires, which is an effective response rate of 41%.

The collected data was manually entered into SPSS® version 24. Following input, the dataset was screened for errors using descriptive statistics to check the data file for values falling outside possible range for each variable. This was to ensure the integrity of the data by checking the accuracy of the data coding and entry into SPSS (Pallant 2016). The dataset was then analysed for missing data, utilising the value 99 to represent missing data. The missing data was relatively small and consisted of single items or several items missing in the questionnaire. Current research recommends that statistical analyses of data sets with missing values requires researchers to make assumptions that cannot be assessed using the observed data alone (Bojinov *et al*. 2018). Therefore, missing values analysis was undertaken and revealed that less than 1% of the overall values were missing. Little's MCAR test indicated that the data were missing at random, χ_2 1156 = 1081, p =.054. As suggested by Tabachnick and Fidell (2013) the missing data was determined using Expectation-Maximisation algorithms to replace the missing data and allowed the analysis to be carried out with a full dataset. A significance level of p= 0.05 was used for all analyses.

Prior to any analysis being undertaken, the dataset was checked for data entry accuracy and screening for entry errors. An examination of outliers for each construct was then conducted with some discrepancies identified that mainly related to data entry errors. Data ranges were checked for each variable entered to ensure that all data was entered within the prescribed ranges. Of the (n=229) ranges examined, slightly over 3% of the cases (n=7) had at least one datum outside the delineated variable ranges. The original files for these cases were identified and examined for accuracy. In each case, the data had been entered incorrectly (i.e., entering a 6 instead of a 5 or entering 55 instead of 5). The data was subsequently corrected for each of the cases and all the data was found to lie within the necessary parameters.

During the data cleaning process, subsets in the predictor variables were analysed and required recoding. Recoding is a technique that allows the combining or grouping of two or more categories of a variable together to simplify the process of analysis (Pallant 2016). Three subsets in total were recoded due to there being <15 participants

in some of the categories, this would result in less meaningful analysis of the data. Therefore, predictor variable number four, '*Type of qualification', was* recoded from five subsets to three, variable five, '*Highest level of education'*, was recoded from five subsets to three, while finally variable six, '*Years' experience working with people with intellectual disabilities',* was recoded from four subsets to three. Recoding also assists with creating data tables which are easier to interpret and identify patterns in responses (Pallant 2016). It was at this stage of analysis that it was decided to use only subset number six '*Years' experience working with people with intellectual disabilities'* as it contained near identical results using subset number seven, '*Years' experience working with older people with intellectual disabilities.'*

Following this, tests for normality of distribution were required before conducting any statistical analysis. As Pallant (2016) advises, normally distributed data is an essential assumption in parametric testing. Field (2013) states that assessing normality should be carried out in two ways, either numerical or graphical, to analyse the degree of departure from normality. This ensures that the most appropriate statistical tests can be performed, therefore data distribution for each scale and subscale was assessed using histograms with a normal distribution curve overlaid to check whether data violated the assumptions of normality. Skewness and kurtosis values were computed at domain level. The skewness and kurtosis of the constructs are reported in more detail in Chapter 5 *Preliminary analysis of Person-Centred Practice Inventory-Staff.* In the domain *Prerequisites*, the kurtosis of the sub-scale for items No.1 and No.10 were high but did not present with a negative skew, while the domain *care environment,* kurtosis scores, for one item, No. 22 was high, but the skewness for the item was also within the normal range. Finally, the domain, *care process*, had a high kurtosis for items 45 and 56 but again the skewness was within an acceptable range of +/-2 (Pallant 2016), all others were within acceptable limits. The graphical results, such as boxplots and histograms revealed a normal distribution for the prerequisites and the care environment and non-normal for the care processes results. Based on the results from the analysis it was decided that parametric statistics would be used for the analysis of the scale across the three domains.

Finally, within this phase, descriptive and inferential data analysis were conducted to analyse the quantitative data. Initially descriptive analysis was carried out to examine

the frequency, mean and percentage scores with the standard deviation and skewness and kurtosis for each item within the questionnaire. Items were recalculated and summed with a mean score calculated for each factor. Demographic variables were examined such as, size of residential service, role, type of qualification, highest level of education and length of time working with people with intellectual disabilities. There was a variety of independent variables and each one could be a potential predictor of the dependent variable. Therefore, a variable selection method such as, the stepwise method, available in SPSS, automatic linear regression modelling was conducted and used to identify the significant independent variables (Yang 2013). One-way between group analyses of variance (ANOVA) was used to compare the means of two or more groups within a variable. Post-hoc comparison tests were used to identify which groups were significantly different from each other (Pallant 2016) and are reported in more detail in Chapter 6 *Findings from the Person-Centred Practice-Inventory-Staff.*

4.7 Phase two: qualitative phase

The qualitative phase aimed to address the second objective of the study which explored how staff and family members and older people with intellectual disabilities experience person-centredness on a day-to-day basis. This would also assist in examining the relationships identified in phase one and gain deeper insight and clarification on the results attained. Phase two involved the collection of qualitative data using:

- Semi-structured focus group interviews with staff (nurse mangers, staff nurses and healthcare assistants)
- Semi-structured individual interviews with family members
- Semi-structured individual interviews with older people with intellectual disabilities

4.7.1 Sampling and recruitment of participants

The sampling in phase two required inclusion and exclusion criteria for the three groups of participants involved. A purposive sampling technique was used to select potential participants. The researcher worked with the local nurse managers to identify potential participants for the focus groups and individual interviews. Participants were recruited from the previously identified residential services, with higher populations of people aged 55 years or older. The criteria for the initial group of staff participants, are outlined below in Table 4.6.

Table 4.6: Inclusion and exclusion criteria for staff phase two of the study

Inclusion criteria	Exclusion criteria
• Staff who are employed in a nursing or healthcare assistant role. • Staff who work partly or mainly, with people with intellectual disabilities who are 55 years or older in residential services across the Northwest region.	• Student nurses are not included in the sample due to the temporary nature of their work within residential services.

Due to 24-hour pattern of care within residential services, staff are rostered for 12-hour shifts, changeover of shifts were frequent, coupled with annual leave, sick leave and staff cover, meant it could be potentially challenging to track the population who participated in phase one. Therefore, participation in phase two was not dependent on having participated in phase one.

Access to potential participants was co-ordinated initially through liaison with nurse managers. The researcher worked with the relevant managers to identify potential participants and delivered individual envelopes to each manger to be distributed to all nurses and healthcare assistants who fulfilled the criteria. Each envelope contained a Participant Information Sheet (PIS) with an attached consent form for signing and included a stamped addressed envelope inviting them to participate (Appendix 4). There was also the option available to email the researcher directly, expressing their interest in participating. The PIS outlined the purpose of the study and what was involved if they agreed to participate, information on the complaints procedure, the

contact details of the researcher and the principal researcher were also provided. Once contact was made the researcher arranged a focus group in the area at a convenient time and date for the participants, with the venue organised by the researcher in a convenient location away from their place of work. Prior to commencing the focus group interview, written consent was sought from any of the participants who had not returned the form. Two focus groups were carried out, one with nurse managers, Clinical Nurse Manager II (n=7) and one with Healthcare Assistants (n=6).

The researcher made numerous attempts to arrange a focus group interview with staff nurses which resulted in cancellations on each occasion as they could not be released from their duties. On one occasion the researcher felt that it was unethical to carry out the focus group after discovering that one nurse would be attending after a night duty shift, and another had not expressed an interest in participating. The final attempt to arrange the focus group was also cancelled, when the researcher arrived at the site and the manager of the service stated that they could not release the staff to attend. Following this it was decided that interviews with staff nurses was the only possible option. Three staff nurses volunteered to participate, with two requesting to be interviewed in their workplace, while a third attended during their day off, away from their workplace.

Family members were also included in phase two of the study. Again, using purposive sampling, the researcher worked with local nurse managers to select eligible family members to participate in the semi-structured interviews. The nurse manager issued the PIS and the consent form (Appendix 6) enclosed with a stamped addressed envelope to family members. Family members then returned the consent form directly to the researcher if they wished to participate or emailed the researcher directly. The researcher then contacted the participants to arrange interviews in a location convenient to them. Table 4.7 below outlines the inclusion and exclusion criteria for family members.

Table 4.7: Family members' inclusion and exclusion criteria for phase two

Inclusion criteria	Exclusion criteria
• Family members who have a relative with intellectual disabilities aged 55 years or older, living in a HSE residential service in Northwest region. • Family members who have the most ongoing contact with the older person with intellectual disabilities (not necessarily the next of kin).	• Family members with little or no contact with the older person.

Older people with intellectual disabilities were also included in phase two. They were recruited using purposive sampling techniques. The researcher liaised with local nurse managers to suggest eligible older people who would like to participate in the study. Participants were selected across the previously identified services in the Northwest of Ireland. An invitation was provided to participates by the local nurse managers, who distributed the easy read PIS and consent form in advance (Appendix 5). The interview was also piloted with older people with intellectuals and their initial feedback suggested an inclusion of a photograph of the researcher on the easy read material so they could see in advance the person who would be visiting them, and this was added accordingly. Table 4.9 below outlines the inclusion and exclusion criteria for older with intellectual disabilities.

Table 4.8: Older people with intellectual disabilities inclusion and exclusion criteria for phase two

Inclusion criteria	Exclusion criteria
• People who are aged 55 years and older • People who have a mild to moderate intellectual disability • People who live full-time in HSE residential services • People who can communicate verbally • People who can provide consent, either by signing or making their mark on the consent form or can provide verbal consent	• Under 55 years of age • Any older person deemed by nursing staff to be unable to participate due to limited comprehension, illness or any state upset or distress

Initially nurse managers were requested to identify and approach older people that met the criteria. The number of participants increased via word of mouth amongst older people with intellectual disabilities who requested to participate with seven participants coming forward in this way. This method is referred to within the literature as self-selecting and is often cited as a possible bias within the research process as the decision to participate may be reflective of an inherent agenda in the traits of the participants (Smith and Nobel 2014). Conversely, Olsen (2008) disputes this assertion and states that self-selected participants are those who feel motivated and interested to participate any given study. On reflection the researcher felt that there was a palpable motivation by older people to tell their story and to be heard.

Older people who wished to participate were requested to contact a staff member or the researcher directly. The researcher then contacted the participant or the staff member to arrange a suitable time, date and location to conduct the interview. Over half of the older people requested to be interviewed at home while the others were interviewed at their day service. On-site data collection can increase positive bias results (Smith and Nobel 2014) but as many of the people were older, they felt more physically comfortable within their own homes.

Historically, people with intellectual disabilities were omitted from the research process as they were perceived as a vulnerable and lacked the capacity to consent and (Kitchin 2000; Northway *et al.* 2015). As researchers moved to a more inclusive era of engagement the challenges of interviewing people with intellectual disabilities focused on the effects of impairments. Hollomotz (2018) highlights that the use of proxies such as parents, carers or staff, were a common source of data collection with their opinions taken on important life issues and interpreted as those of the person with intellectual disabilities. However, the impartiality of proxies has been disputed, as Lloyd *et al.* (2006) highlights they may find it difficult to detach themselves from their own viewpoint with research studies providing the subjective opinions of the proxies as opposed to the people concerned (Hollomotz 2018).

Despite this, the use of proxies continues to be practiced within the current research arena, Cummins (2002) believe that this practice continues to avoid any methodological or ethical challenges that arise from talking to people with intellectual

disabilities directly. In comparison to the general population, the number of qualitative studies carried out with people with intellectual disabilities remains low (Irvine 2010; Coons and Watson 2013). Within the context of current legislation, policy, models of care and international human rights declarations, it is strongly advocated that research must be inclusive of all recipients of health-care services (McClimens and Allmark 2011; Taua *et al.* 2014). Northway *et al.* (2015) assert it is only people with intellectual disabilities that can answer questions regarding their lives and the exclusion of their voices from research raises questions regarding the validity of research findings, and the challenge is to find ways to support their inclusion.

This research study aimed to explore the experiences of older people with intellectual disabilities, informing us about their needs, opinions and experiences of living in a residential service as they age. The study therefore took the viewpoint that individuals with intellectual disabilities are experts in their own experiences and it is only through seeking their opinions directly that we will discover *their lived experiences* (Irvine 2010; McDonald *et al.* 2013). Current guidance for interviewing people with intellectual disabilities recommends that carers and staff members should not be present during the interview process to reduce 'gratitude responses' and eliminate the fear of repercussions due to critical answers (McDonald *et al.* 2013). An independent advocate was offered as an alternative, although an advocacy service is available, it is currently limited, therefore this need was reviewed on an individual basis.

4.7.2 Methodological considerations when interviewing older people with intellectual disabilities

The same principles are applied to conducting interviews with people with intellectual disabilities as with the general population (Perry 2004). Important issues to consider such as capacity to consent, confidentiality, ensuring the person can comprehend the questions being asked of them and to conduct the interviews in a relaxed non-hostile environment. The first concern within the interview process was that of informed consent. It was essential to ensure that any prospective participants were able to understand the information that was provided to them. Murphy (2006) outlined the importance of using a variety of supports to make language accessible, such as using

symbols, simple language, bullet points and repetition of information. Therefore, an easy read PIS and consent form was created (Appendix 5). The capacity of individuals with intellectual disabilities to provide full and informed consent has previously been described as problematic (Lloyd *et al.* 2006). This is attributed to the likelihood of individuals with intellectual disabilities feeling pressured or coerced into consenting by others, such as staff (Irvine 2010). To prevent this from occurring a two-method approach was taken to ensure that a robust approach to the consent process was in place.

Firstly, the PIS and consent form information was circulated well in advance so that potential participants had an opportunity to ask questions and consider whether they would like to participate (Coons and Watson 2013). This allowed all potential participants the opportunity to have the information in advance for discussion with family members, friends, staff or advocates. A framework to assess capacity to consent was also adopted within the process taking cognisant of the relatively new Assisted Decision-Making Act (2015) in the Republic of Ireland which represents a major cultural shift from a paternalistic viewpoint to a 'best interest' approach. Under the Act everyone is presumed to be able to make all decisions unless the contrary is proven. A framework was adapted from Dougall and Fiske (2008) which included guidelines from Inclusion Ireland (2015) on how capacity can be determined within the research process. A similar adapted framework was utilised in previous qualitative research study in Australian study involving people with intellectual disabilities who have mental health issues (Taua *et al.* 2014). After the consent form had been received, either via post or telephone, the researcher contacted the site and organised to visit the person at a date and time convenient to them. Many interviews were scheduled for the morning or early afternoon, with one participant requesting an evening visit. Before the interview commenced the researcher utilised the above framework to guide the capacity to consent process and ensure that informed consent was being given. Table 4.9 outlines the framework for obtaining consent with people with intellectual disabilities with this research study.

Table 4.9: Framework utilised when obtaining consent

Framework utilised when obtaining consent (Adapted from Taua *et al.* 2014, p. 5-6)
Understand the information relevant to the decision. ➢ Does the person have the relevant information they need to make the decision? ➢ Have they been given information about their right to participate or decline to participate in the study? ➢ Is the information presented in a way that is easier for them to understand, e.g., by using simple language or visual aids, presented in colour? ➢ Have different methods of communication been explored if required. ➢ Can another person help with communication, e.g., keyworker or advocate? ➢ Are there particular times of day when the person's understanding is better? ➢ Are there particular locations where the person feels more at ease? Is it quiet? **Retain that information long enough to make a voluntary choice** ➢ Ask for the instructions to be repeated back at regular intervals to confirm that the instruction has been understood correctly, and document using a digital recorder if necessary. ➢ Could the decision be put off to see whether the person can make the decision when circumstances are right for them? **Communicate their decision** ➢ The person must be able to relay their decision in whichever format they communicate, written or verbal. ➢ Allow sufficient time for this answer to be relayed.

Another reported methodological challenge when interviewing people with intellectual disabilities, is said to be that of acquiescence during the interview process (Finlay and Lyons 2002). Acquiescence bias is also referred to as '*yeah-saying'* which is the tendency to give affirmative responses to questions (Finlay and Lyons 2002). It has been argued that acquiescence is caused by a range of factors from the person's disability, a desire to please or a learnt submissiveness due to the person's life being largely controlled by others (Stalker 1998). However, alternative views on the subject have focused on the role that the researcher in acquiescence, research by Rapley and Anitka (1996) found that people with intellectual disability are capable of what they termed '*anti-acquiescence'* and the published research provided little evidence through the form of transcripts, to indicate if acquiescence or the structure of the interview questions was the issue.

To counteract the possibility of acquiesces, guidance was taken from work by Hollomotz (2018) who reviewed in detail the process of creating tangible conversations

that were concrete subject matter within the interview transcripts. Hollomotz (2018) cite the work of Finlay and Lyons (2002) who advocate that researchers' must be cognisant of the structure and type of questions they create if they want to avoid the phenomena of acquiescence. The interview questions should be conducted with questions that are not too long in structure or grammatical complex. According to Finlay and Lyons (2002) a question that is misunderstood can lead to a 'yes' answer. Therefore, the researcher was conscious that the interview schedule should avoid abstract references, metaphors or other vague forms of expression. The questions were focused on the relevant experiences of the older person and were directly related to their day-to-day lives. The interview schedules were also discussed and reviewed within the research supervision team. Guidance was taken on how to reword any questions that could lead the participant to give a positive or negative answer.

The process worked well with many of the participants, providing insight to the challenges and benefits of living in a residential service in older age. During the interviews the researcher asked the participants to provide examples of what they were discussing to increase reliability of the data (Patton 1999). During one interview assistance was sought for one participant as the researcher did not fully understand the points the participant was making. The participant's key worker at their day service joined the interview, with agreement from the participant, and the interview proceeded successfully. During another interview the researcher drew the interview to a close at an early stage, concerned that the participant did not fully comprehend the questions being asked of them. On reflection the individual interviews worked well with older people, as they were able to provide their own individual stories which may have been challenging in a focus group interview setting.

4.7.3 Establishing the required sample size

The required sample size in qualitative research often generates much debate and discussion. Data saturation is widely acknowledged as a methodological principle in qualitative research with the term used as a criterion to bring the data collection process to an end, that is when the researcher beings to hear the same observations continuously, it is timely to discontinue any further data collection (Guest *et al.* 2006).

Although researchers frequently acknowledge that there is uncertainty as to how saturation is conceptualised resulting in inconsistencies in its usage (Faulker and Trotter 2017). This was confirmed by Saunders *et al.* (2018) who found contradictions and uncertainties within published qualitative research papers highlighting that many researchers assert that the point of data saturation had been reached within their studies but continued to collect data regardless of theoretical concept.

Saunders *et al.* (2018) offer guidance on how data saturation should be approached highlighting the need to connect the research question, the theoretical position and analytic framework of the research study. When considering data saturation, the researcher also had to take into consideration other factors such as the timeframe for the study and the resources available (Guest *et al.* 2006). To ensure that data saturation was achieved for this study, direction was taken from seminal work by Bertaux (1981) guidelines for all qualitative research and identifying 15 interviews (n = 15) as the smallest acceptable sample size (adapted from Guest *et al.* 2006). The sample represented the grades of staff who currently work in residential services, older people who live in residential services and their family members.

4.7.4 Data collection methods

Semi-structured individual interviews were conducted with older people with intellectual disabilities and family members to allow the participants to recount their own lived experience of residential services (Schultze and Avital 2011) and also contribute to the findings from phase one. However, there were specific subjects which also needed to be addressed for clarification from the quantitative data phase of the study, such as the physical environment, team values and supportive organisation systems within the organisation to achieve person-centredness. Before commencing any data collection written consent was obtained from all participants. The interview schedules began with a broad open-ended question designed to build a rapport with the participants and to gain an overview of the subject (DeJonckheere and Vaughn 2019). The format chosen for the interviews was semi-structured, so the interview process could be flexible with the opportunity to explore issues that arise

spontaneously (Berg 2009). Semi-structured schedules prevent the researcher from rigidly following a pre-set guide and being open to new or unexpected themes (Holloway and Wheeler 2010). This approach also ensures that the researcher has the flexibility to change the wording, order or ask additional questions depending on how the interview is developing. The schedules contained a range of prompts to ensure specific aspects were addressed if they were not already included. The interview schedule for the staff focus groups is outlined in Tables 4.10; the interview schedule was developed based on the findings and gaps in data from phase one.

Table 4.10: Semi-structured focus group interview prompt for staff

- When you hear the term Person-centredness, what sort things come to mind?
- How is (mentioned topic) these would this put into practice within your area?
- What do you think life is like for people who live here?
- Do you or the team reflect on the team decisions made?
- What do you see as the three key challenges of putting person-centredness into practice?
- (Prompter: What is it like to work in residential services at the moment?)

Table 4.11 below outlines the semi-structured interviews for family members which were developed based on the findings from the relevant constructs in phase one of the study. The flexible interview schedule allowed for additional topics to be added if family members felt they should be included. One family member emailed their discussion points to the researcher in advance of the interview which allowed the emerging their own points of view to be included in the interview schedule.

Table 4.11: Semi-structured individual interviews prompt for family members

- Tell me about your (name of person)
- What do you think it is like living in residential services?
- Can you tell me about the staff team working residential services?
- Their relationship with the staff-expressing concerns?
- Level of involvement in their family members care?
- Is there anything that you would like to see developed or change?

Finally, Table 4.12 shows the interview schedule with older people with intellectual disabilities, which was guided by the findings in phase one and from the literature review. The questions were flexible and had an open structure to get a sense of what is important to older people and to facilitate the inclusion of aspects of their lives that they wanted to discuss with the researcher.

Table 4.12: Semi-structured individual interviews prompt for older people with intellectual disabilities

- Tell me about your day? What sorts of things do you do?
  - ❖ Prompter: When you wake up what do you do? Do you make your own breakfast? Do you need help? Who helps you?
- What sorts of things do you do in the evening?
  - ❖ Prompter: Do you cook dinner? Do you go out?
- Where did you live before moving to (name of place)?
- Who do you talk to if you are worried or unhappy about something?
- What makes your day happy?
- Is there anything you would like to change about where you live?

The staff were asked to expand on the findings from phase one, such as, celebrating success within teams, feeling valued as a team member and the impact of the physical environment on delivering person-centredness, with some participants reporting contrasting views from the findings reported in the phase one data. Any specific issues were explored in greater detail in subsequent interviews and focus groups. As Polit and Beck (2018) recommend the interview questions were asked and phrased in a manner which allowed the participants to respond in their own words and narrative which will in turn provided the full viewpoint of their experience.

4.7.5. Rationale for the use of focus group and individual interviews

Qualitative researchers must make decisions about how best to collect data using focus groups or individual interviews. Both methods are used to generate data and are often viewed as one and the same (Parker and Tritter 2006). The similarities between these two methods are often compared as they both aim to uncover people's perceptions and values (Nyumba *et al.* 2018). However, Smithson (2000) notes a key fundamental difference between these two methods is the role of the researcher and

the relationship they have with the participants. Individual interviews involve an in-depth discussion between a specific individual and the researcher, who according to (Nymba *et al.* 2018) controls the dynamics of the interview. While during a focus group interview, the researcher's role is that of a facilitator, who moderates a group discussion between participants (Nymba *et al.* 2018). To make informed decisions regarding the most appropriate method of data collection in phase two, the researcher had to examine the purpose and aims of the study and the key differences between both methods, and these are outlined in Table 4.13.

Table 4.13: Key differences in individual interviews and focus groups (adapted from Breen 2006, p. 465)

	Individual interview	**Focus group interview**
Purpose	Probe experience	Generate ideas
Researcher role	Interviewer	Moderator
Sample	Sample Aim to reach theoretical saturation (usually > 10–12). Homogenous or similar status groups of 4–6 participants in each	
Equipment	Tape recorder, lapel microphone, quiet room	Tape recorder, oval/round table/table microphone, props (flash cards, leaflets)

Focus group interviews are frequently used as a qualitative approach to obtain data from a purposely selected group of people to gain an in-depth understanding of social issues (Breen 2006). The published literature states that the use of focus group discussions is more appropriate if the purpose is to generate new ideas that are formulated within a social context (Breen 2006; Nyumba *et al.* 2018). In contrast, the purpose of individual interviews is to probe individual experiences, encouraging self-reflection on issues that could be distorted if social pressure, such as the focus group setting, were placed on the individual (Breen 2006).

The rationale for using both methods was based on the objectives of the study and the feedback from the PPI (Public and Patient Involvement) consultation, with family members and older people with intellectual disabilities, specifically stated that they would be more comfortable being interviewed individually as opposed to a group

setting, while staff expressed no preference. After reflecting on the objectives of the study, focus groups with staff members were chosen to develop new ideas and thinking on person-centredness. The purpose of employing the focus group interviews is that it gave the researcher the opportunity to observe group interactions (Joyce 2008) and to incorporate larger numbers of staff to elaborate on the understanding of the data from phase one (Joyce 2008). The staff were separated into homogenous groups as recommended within the literature (Nyome *et al.* 2018) and to ensure they were no power imbalances and they felt comfortable in groups where their shared experiences could be explored.

4.7.6 Conducting focus group interviews with participants

Organising the focus groups required detailed planning to access staff participants and negotiate their release. It was necessary to negotiate with several 'gatekeepers' (Clark *et al.* 1996), mainly line-managers or senior nurse managers. This detailed planning, organisation and moderation of the two focus group interviews was required and ensured rigor within the study (Nyome *et al.* 2018). Before commencing the focus group interviews, consideration was given to several factors, such as the number of participants, the recruitment process and a neutral venue for the focus group interview to be held (Breen 2006).

The recruitment involved purposive sampling to recruit potential participants, purposive sample allows for the identification and selection of information-rich cases related to the topic being researched (Palinkas *et al.* 2015). While Clark *et al.* (1996) recommends over recruiting for focus group interviews, particularly for nursing personnel, due to the difficulty in recruiting this population due to shift patterns. Recommendations on the size of the focus group varies within the published literature but generally four to eight participants are recommended (Morgan 1997), less than four participants are not considered a focus group (Clark *et al.* 1996).

As outlined previously, staff participants were approached and informed of the research study by their managers and the researcher. The researcher also asked for the assistance of nurse managers for their support to ensure the releasing staff who might wish to attend. This process worked well with two groups of staff, nurse managers and healthcare assistants. The recruitment of staff nurses proved more

challenging, with few staff nurses volunteering to participate, or unable to make the date or time due to workload, staff shortages and shift patterns. Following several failed attempts to hold a third focus group with staff nurses, it was decided with the research team that individual interviews was the most appropriate way to proceed and collect data with staff nurses. The decision to combine both focus groups and interviews methods for staff, was based on practical considerations. As Lambert and Loiselle (2008) suggest that offering a flexible combination of approach may lead to fewer refusals or withdrawals.

The focus group and one of the individual interviews with staff participants were held in nearby Centres of Nursing and Midwifery Education (CNME), as it was a central location, familiar and convenient for participants to access. The locations also represented a neutral territory so participants would feel more at ease away from their work environments and offered a level of anonymity if they did not want others to know they were attending. The focus group interviews utilised several recommended strategies to ensure that they ran smoothly, initially introductions and explanations were given and they were informed that recording and note taking would be used by the moderator (Joyce 2008).

A focus group moderator is usually defined as a facilitator who leads the discussion but does not participate, is respectful towards the participants, someone they feel comfortable with (Morgan 1997). To ensure the participants felt at ease, they were given the opportunity to establish the ground rules in conjunction with the researcher and ask any questions before commencing to create a relaxed environment (Turner 2010). The researcher reassured the participants that there were no right or wrong answers but rather a discussion to seek their experiences and views. Recording equipment was checked and members were asked to introduce themselves before commencing. The researcher was conscious to hear all the voices of those who wished to contribute, giving eye contact, nodding, looking at others and using active listening skills. At times there was nodding or nervous laughter and eye contact between the participants and as Joyce (2008) recommends they were encouraged to talk about these gestures in case the meaning was lost. Table 4.14 outlines the focus group attendance.

Table 4.14: Number of participants that attended focus group interviews phase two

Focus group semi-structured interviews	No. attended
Nurse managers	7
Healthcare assistants	6

4.7.6 Conducting semi-structured interviews with participants

The individual semi-structured interviews have several recognised advantages and limitations as a method of a data collection. In relation to the research objectives, this was a means of exploring the issues to obtain rich data individually from older people and their family members. According to Kvale (2006) interviews give a voice to the marginalised who do not usually participate in public discussions, but through interviews studies can have their experiences and viewpoints communicated to a larger audience. Therefore, interviews are frequently employed method which hears the story behind a participant's experience and the interviewer can pursue in-depth information around the topic (Polit and Beck 2018). The method is flexible and allows the researcher to clarify or prompt for more information (Holloway and Wheeler 2010).

The published literature has also demonstrated that interviewees have a positive experience of the interview process. Carter *et al.* (2008) examined participants' talk about qualitative research and found that participants have described the experience as empowering and an opportunity to share their stories with an empathetic listener in the hope that sharing their experiences may be helpful to others. Wolgemuth *et al.* (2015) outlined and identified the benefits of qualitative interviews for participants, with the most relevant to this study listed below:

1. Catharsis
2. Grants a sense of empowerment
3. Self-acknowledgement
4. Contributes to a sense of purpose
5. Gives a voice to the voiceless and disenfranchised

The main limitation of this method is the extended time frame required to carry out and conduct numerous interviews and additionally the time required to conduct the data analysis. Nevertheless, individual interviews allowed the participants more time and individual attention and it was judged the most appropriate way to proceed.

The PIS information and consent forms were circulated to services with the assistance from nurse managers. The participants contacted the researcher by returning the consent form in the stamped addressed envelope provided or via email. The interviews were arranged individually with participants, and they took place in a location comfortable for the participant. Again, strategies were used during the interview to help the participant feel relaxed and comfortable. They were informed of the recording devises being used and that notes would be taken during the interview. Open-ended questions were used, and the participant was encouraged to answer in their own words and describe their experiences (Holloway and Wheeler 2010). During the interview probing or prompter questions were utilised to encourage the participant to provide more information or elaborate on what was discussed. The researcher used active listening techniques such as, encouraging body language, leaning forward, eye contact and nodding to encourage discussion and demonstrate interest. If topics or information were unclear, clarification was sought from the participant. Overall sensitive questioning techniques were employed and on some occasions the researcher did not pursue topics as it was evident that the participant did not wish to elaborate any further. For older people with intellectual disability, clarification was required on occasions with the participant demonstrating or showing the researcher what they meant. The overall numbers of participants in the individual interviews are outlined in Table 4.15.

Table 4.15: Number of participants that attended individual interviews phase two

Individual semi-structured interviews	No. attended
Older People with Intellectual disabilities	15
Family members	6
Staff nurses	3

4.7.7 The process of data analysis

Maguire and Delahunt (2017) believe that the data analysis process is essential to ensuring the credibility of qualitative research. The purpose of qualitative data analysis is to organise the data into a logical structure and interpret meaning from participant's experiences and circumstances (Braun and Clarke 2013; Maguire and Delahunt 2017). The qualitative data obtained from the semi-structured focus group and individual interviews with staff, family members and older people, were transcribed verbatim and the analysis of the data was informed by a thematic analysis approach. Thematic analysis is a commonly used analytical strategy in qualitative research. It is often described as an umbrella term for several approaches used for analysis and focuses on identifying patterns of meaning or themes (Braun and Clark 2006).

The literature frequently refers to thematic analysis as an essential generic skill that is required for all qualitative data analysis as it involves identify thematic meanings (Holloway and Todres 2003). While Boyatzis (1998) describes thematic analysis as a tool which can be used with different methods as it offers a flexible approach and provides a unique benefit to mixed methods research. The technique can be adapted to compliment any qualitative methods and is not bound to a particular one theoretical approach and can be utilised across a range of epistemological approaches (Trahan and Stewart 2013; Braun and Clarke 2006). Thematic analysis was therefore identified as an appropriate analytical approach for this study, as it provided the study with a structured methodology for categorising key themes within the data and is not constrained by any specific epistemological position (Boyatzis 1998). The use of thematic analysis facilitated the analysis of large amounts of data from multiple participant groups to be analysed and synthesised into a structured and meaningful narrative (Boyatzis 1998).

Despite thematic analysis being widely used, Braun and Clarke (2006) innovative paper highlighted that there has been a lack of definition around thematic analysis and how to conduct the process. To provide clarity Braun and Clarke (2006; 2013) have developed a widely cited approach to thematic analysis, that is now referred to as reflexive thematic analysis, to distinguish it from other approaches. Braun and Clarke's (2013) offer thematic guidelines that present a six-phase process used for conducting

the analysis. The phases are described as sequential, with each phase building on the previous, while the actual analysis is a continually loop which can move backwards and forwards between the phases (Braun and Clarke 2013). These phases do not have to be rigidly adhered to and can be combined, depending on the data sets under analysis. The phases act as a guide for the data analysis to ensure a rigorous process of data interrogation (Braun and Clarke 2006; 2013). Using Braun and Clarkes (2006; 2013) reflexive approach, the following adapted version of the phases was used.

1. **Familiarisation with the data phase** initially involved reading the data so the researcher can become immersed in the content. This stage also involved checking the transcripts with the recording for accuracy and clarification on anything which was unclear.

2. **Coding phase** followed extensive reading and re-reading of the transcripts; the second phase involved generating the initial codes that identify key aspects of the data. NVivo 12 was used to aid the coding process and management of the data set. NVivo was a useful system for keeping track of the data and codes and being able to return to the source and context of the code. During this stage codes were revised and refined with new codes being created during the analysis process. Coding ceased once the complete dataset was coded and categorised with all associated data extracts identified and attached to the relevant codes.

3. **Generating the initial themes phase** was the third step in the analysis of the data which involved organizing the codes into potential themes. An inductive approach to the thematic analysis was used to develop 'bottom-up' themes. Braun and Clarke (2013) utilise an inductive approach and refers to coding and theme development that are derived from and directed by the content of the data. An inductive approach was deemed the most suitable as it assisted in answering the research question and objects of the study which was to explore how person-centredness is implemented and experienced within the day-to-day work by staff and those living within residential services. This approach allowed the analysis to reveal the participants' experiences and linked directly back to the data, as opposed seeking themes or topics informed and directed by pre-existing concepts and theoretical frameworks. It also avoids assumptions and

researcher biases by curtailing the researchers pre-existing beliefs influencing the analysis of the data (Braun and Clarke 2006). The inductive approach involved actively seeking out themes to ensure that a comprehensive portrayal of staff and older people and family members, was accurately captured and reported. The data was included into the relevant codes in NVivo and colour coded to identify which group the codes referred to and identify codes which had common threads and the initial themes were created.

4. **Reviewing themes, defining, naming themes phase** involved checking the identified themes for accuracy against the dataset and to assess if they tell the authentic story of the data. This involved returning to phase two on occasions to check that data extracts were accurate. Several themes were split, combined or changed and a detailed analysis of each theme was created. Themes were refined with titles of themes generated that accurately reflected the content of each theme to represent a more coherent story. Themes were grouped together to represent a shared meaning which was underpinned by an experience or central concept (Braun and Clarke 2013).

5. **Writing up phase** was the final phase of the analysis process involved telling the story of the data in an analytical coherent manner, corroborated with data extracts which supported the identified themes.

4.8 Integration of data sets

The integration of the analysis between the qualitative and quantitative elements can greatly enhance mixed methods research (Creswell and Plano Clarke 2011; Fetters *et al.* 2013). Conversely, Fetters *et al.* (2013) warn that a lack of integration between the methods will restrict the amount of knowledge that the study is able to produce. The published literature examining the implementation of integration highlights that the process is often limited and remains a challenge to researchers within mixed methods studies (Bryman 2006; Creswell and Plano Clarke 2011). Various authors advocate that there are a few approaches that be used to realise integration (O'Cathain *et al.* 2010; Bazeley and Kemp 2012). The use of metaphors is proposed by Bazeley and Kemp (2012) to achieve integration, however they acknowledge that this approach maybe challenging as it is an emerging complex field, and a shared understanding of

the metaphor may not exist. They recommend that integration is an interconnected process that should be evident throughout the entirety of the study and needs to commence before the analysis stage (Bazeley and Kemp 2012). Fetters *et al.* (2013) appear to concur with this analysis and describe integration as occurring at different levels throughout the study, namely the design, methods, interpretation and reporting levels. These levels will now be discussed in relation to this research study.

a) Integration at the design level

This occurs during the conceptualisation of a study and refers to the chosen mix method design. The research study employed an explanatory sequential design as described by Creswell and Plano Clarke (2017) which involved initially collecting and analysing quantitative data. These findings were used to inform qualitative data collection and analysis (Creswell and Plano Clarke 2017).

b) Integration at the methods level

Creswell and Plano Clark (2011) outline the theories of integration which occur through linking the methods of data collection and analysis. The linking can occur through connecting, building, merging and embedding, there maybe one or more of these approaches used (Fetters *et al.* 2013). Within this study, the first main instance of integration occurred through building, with preliminary analysis of the phase one questionnaire, the PCPI-S findings which then built upon and helped formulate the development of the semi-structured focus group and individual interview schedules for the qualitative data collection in phase two.

c) Integration at the interpretation and reporting level

The main integration of the quantitative and qualitative data sets took place at the interpretation and reporting level. O'Cathain *et al.* (2010) offered the clearest practical guidance on how to implement and achieve the integration of both data sets. They outline three techniques for conducting integration, the triangulation protocol, following a thread and finally mixed methods matrix. Of the three techniques, the triangulation protocol, was the most detailed and works well with a pragmatic paradigm (O'Cathain *et al.* 2010; McConnell 2018). Framer *et al.* (2006) applied this technique when integration multiple data sets in qualitative study, while more recently McConnell (2018) mixed methods study also successfully utilised this technique to achieve integration of quantitative and qualitative data sets.

In this instance the term triangulation is used to describe a process of examining a problem through different methods to achieve a more complete picture (O'Cathain *et al.* 2010). Following the separate analysis of both datasets, the researcher works towards producing a "convergence coding matrix" to display findings from each phase of the study on the same page (O'Cathain *et al.* 2010). This allows the identification of areas of agreement, disagreement in findings or silence between the datasets. Silences are described by Farmer *et al.* (2006) as when one set of data contains a theme which is absent from the other dataset. O'Cathain *et al.* (2010) point out that this is the only technique which addresses the issue of silences within the integration process. Identifying disagreements between findings is an essential part of this technique but as O'Cathain *et al.* (2010) highlights, this is not an indication of an error and may lead to a better understanding of the research topic. The next step involves a comparison between the converging data, which results in what Framer *et al.* (2006 p.383) refer to a "convergence of a coding matrix of themes". This 'coding matrix' essential traverses both data sets to identify the key findings (McConnell 2018). Finally, O'Cathain *et al.* (2010) advocates the use of an identified technique, such the triangulation protocol as it provides more credibility the integration of data and ultimately to the findings of the study.

4.9 Validity and rigour within the study

Creswell and Plano Clarke (2017) assert that researchers continue to face challenges when employing mixed methods research studies. One such frequently cited challenge ensuring validity and rigour within the research process. Quantitative and qualitative methods are employed within the same study, with each method having significant differences in the how validity and rigour are evaluated (Creswell and Plano Clarke 2017). The importance of validity and rigour cannot be understated as they refer to what Ivankova (2014) term the 'quality assurance' processes employed by the researcher to ensure the truthfulness of the findings and how they arrive at the stated conclusions (O'Cathain *et al.* 2010; Ivankova 2014). There is much debate presented in the literature on how best to ensure validity and rigour within mixed methods with no clear consensus reached (Ivankova 2014). However, much of the literature appears

to agree that validity and rigour are best achieved by using separate process within the quantitative and qualitative datasets which have a direct effect on the overall the quality of the study (Onwuegbuzie and Johnson 2006; Teddlie and Tashakkori 2010; Creswell and Plano Clark 2017). Several strategies were employed in the data collection and data analysis during the separate quantitative and qualitative phases and will now be discussed.

4.9.1 Rigour and validity in the quantitative phase

Within quantitative research rigour encompasses the concepts of validity and reliability of the research study. As quantitative research focuses on a positivist philosophical viewpoint of one truth, quantitative data is perceived to be more objective in nature and less open to researcher bias (Creswell and Plano Clarke 2017). One of the key issues in statistical terms is the reliability or the ability of an instrument to measure a topic repeatedly and consistently across different sample groups, contexts and time spans (Onwuegbuzie 2000). The reliability of an instrument refers to its content validity (Polit and Beck 2013), the Person-Centred Practice Inventory-Staff was the questionnaire instrument used during, quantitative phase one of the study.

Slater *et al*. (2015) reported the process involved in the testing for reliability and validity of the PSPI-S to ensured sound psychometric properties. Initially a Delphi consensus process was used, which included gathering the opinions of an expert panel on the area of person-centredness. This aimed to create a consensus and evidence in the development of acceptable definitions and item generation to confirm the validity of the survey as measurement tool (Slater *et al.* 2017). A Confirmatory Factor Analysis was utilised to develop and test the tool which Slater *et al.* (2017) state is a robust theory-driven process that enhances instrument development. The instrument was then piloted to test it is a psychometrically acceptable tool. The PCPI-S has been used nationally and internationally within studies which have tested and established the reliability of the PCPI-S as validated tool (Parlour *et al*. 2014; Slater *et al*. 2017; McConnell 2018).

Within this study reliability and validity of the questionnaire data was assessed using psychometric procedures. After the administration, Cronbach's alpha was calculated as a reliability check to estimate internal consistency of the of the survey scales. The scales and items in the survey were considered reliable as they met or exceeded alpha levels of 0.7 (Pallant 2016). Correlations between items were also carried out to assess the relationship between the variables within each of the three domains. These results are reported with all items found to be within acceptable limits and are reported in the next chapter.

4.9.2 Rigour and validity in the qualitative phase

The rigour of research studies is determined by how they been conducted and the processes by which the researcher arrived at the findings. As stated previously, rigour within research studies equates to the concepts of reliability and validity and are components of the quality assurance process (Ivankova 2014). However, within qualitative research there is continuous scrutiny about achieving rigor due to leading to questions regarding the trustworthiness and reliability of research findings (Cypress 2017). Therefore, careful attention to the reliability and validity holds particularly importance in qualitative work, due to the potential for researcher's subjectivity impacting on interpretation of the data (Cypress 2017). The work of Guba and Lincoln (1989) remains the most frequently cited within qualitative literature with their recommended strategies continued to be viewed as significant guide to ensuring rigour and trustworthiness within the research process. They identified four key strategies or criterion, which are credibility, transferability, dependability and confirmability to ensure rigour in qualitative research, how these were addressed in the study will now be briefly outlined.

Credibility refers to ensuring the truthfulness of the findings, this can be achieved by what Guba and Lincoln (1989) refer to as member checking which involves returning to the participants to check the interpretation that the researcher has made. Member checking was carried out with some participants to recheck content that was unclear or that the true meaning of their words had been interpreted corrected. Aspects of peer

review also took place within the supervision team by discussing the content of the transcripts and coding of the themes, the value of having experienced researchers discuss the process of coding and the creation of themes ensured accuracy. This also promoted objectivity and steered the researcher away from any preconceptions or interpretations that were not evident from the data (Holloway and Wheeler 2010). An independent moderator for focus groups was also used and reflections were carried out in conjunction with them following the focus group interviews regarding the overall content of the interviews.

Transferability refers to findings that are applicable from one context to another (Guba and Lincoln 1989). It is hoped that this study will have a level of transferability not only to services nationally but also within similar services in other countries. However, other researchers believe that transferability or relevance is up to the readers to make the judgement if the research is relevance to their own context (Murphy and Yielder 2010). To ensure transferability, Guba and Lincoln (1989) recommend providing a full description of the context to allow the reader to make judgements for themselves. Therefore, the researcher provided a wide range of information through the detailed and accurate descriptions of the experiences of the older people, family members, and the staff members, by continuously returning to the transcripts and providing data extracts to contextualise the experiences.

Dependability in qualitative research equates to the concept of reliability in quantitative research. Dependability was achieved by having an audit trail which comprised of field notes made during and after the focus groups and individual interviews, noting the location, context and observations regarding participant reactions and interactions. The audit trail also documented the decisions and rationale for decisions taken during the planning stages and the data analysis phases. Reflections were carried out at intervals during the different phases of the study and focused on issues which required further exploration both within the research supervisory team and with colleagues in the intellectual disability services.

Confirmability refers to the objectivity of the findings and that they remain faithful to participant's stories and are not influenced by researcher bias (Polit and Beck 2018). There are different means to demonstrating confirmability, one such method is the

audit trail which was described previously. Another method which assists in maintaining the objectivity of the research is that of reflexivity. Reflexivity involves the researcher analysing their role in the research process through self-reflection (Dowling 2006). The process of self-reflection is described by Parahoo (2014) as a continuous examination by the researcher of their own values and assumptions and their potential impact of these have on the research study. According to Lambert *et al.* (2010) this requires a level of consciousness by the researcher and promotes insight into how we influence and create meaning through our interpretation of the lived experiences of participants.

Within the study the researcher used reflexivity following each focus group or individual interview, particularly if emotional issues were raised by participants. The researcher found managing the emotional responses of participants one of the most challenging aspects of the research process. One individual interview with an older person with intellectual disabilities, stated they were very unhappy where they lived, and this impacted on the researcher. The researcher was questioning if the response was managed empathically and professionally, while avoiding appearing emotionless to their situation. The researcher reflected on these issues and discussed this with other PhD colleagues and through a reflective process within the field notes. Palaganas *et al.* (2017) cite van der Riet (2012) who reasons that complete detachment from research participants is unrealistic and may even hinder the research process. Reflexivity helped to examine how to deal the emotions of participants in future interviews and increased the level of self-awareness during the data analysis phase.

4.10 Ethical considerations

Multiple ethical issues can arise within health and social care research. Recognising and acknowledging these issues is an essential component of ensuring a rigorous approach is taken within any research study. To achieve this, the seminal work of Beauchamp and Childress (2013) medical ethics is frequently cited within the literature. First published in 1979, the authors set out four principles which researchers must take into consideration and address during the research process. These are

namely respect for autonomy, non-maleficence, beneficence and justice. These principles are closely associated with conducting clinical trials and have recently been open to criticism due to the lack of theory on what they term as "*moral action*" and responsibility of the researcher within the principles and the lack of clarity around the hierarchical importance of each principle (Roqué-Sánchez and Macpherson 2018). However, Roqué-Sánchez and Macpherson (2018) acknowledge that these oversights do not prevent the four principles from fulfilling their purpose when conducting research. Therefore, the research study used these principles to guide the ethical approval and governance process. Taking into consideration the critical appraisal of Roqué-Sánchez and Macpherson (2018) regarding the lack of hierarchy, the researcher found it was difficult to distinguish any principles as being more important than the other. The following outlines the key ethical considerations involved in this study.

Firstly, **respect for autonomy** within the research process is key to ensuring that participants feel empowered and in control of the decision-making process (Jahn 2011). There is a duty of care for researchers to respect the decision-making of all adults and this is particularly relevant for people with intellectual disabilities, who were invited to participate. As discussed previously, people with intellectual disabilities were excluded from participating in research due their perceived lack of capacity. The current legislation concerning consent within the Republic of Ireland is covered by the Assisted Decision (Capacity) Act (2015), which states that everyone is presumed to have capacity to make all decisions unless the contrary is shown. Therefore, if the person demonstrates their understanding of the information related to the decision and they can retain information long enough to make a voluntary choice and communicate that decision, then capacity is recognised. Within the research study the Participant Information Sheet (PIS) provided the participants with comprehensive information about taking part, clearly stating that they were free to participate if they so wished. The PIS and consent form also informed participants what the data would be used for and that they could withdraw from the study at any time. The PIS contained all the required information for staff, older people and family members and the language used remained simple, while adjustments were made for people with intellectual disabilities (Ennis and Wykes 2016). The PIS also communicated the following, aims of the

research, reason why participants were selected, the time commitment involved and what participation meant for the participant and the risks and benefits of taking part (Health Research Authority 2017). The PIS was circulated in sufficient time and the researcher did not approach the participants directly to avoid people feeling rushed or pressured, thus ensuring that free and informed consent was given.

Secondly, **non-maleficence** was considered, this refers to doing no harm to the participants and encompasses the concepts of causing no pain suffering or offense to and relates to issues of confidentiality (Jahn 2011). Numbers were assigned to each participant in the qualitative data so they would not be easily identified. It is important that researchers are responsible and have devised strategies to ensure that participants are not exposed to harm or distress from taking part in the study (Roqué-Sánchez and Macpherson 2018). Researchers must be cognisant of any potential for psychological harm during the interview process and ensure the reporting of any harmful or poor practice which may be disclosed during the data collection phases. To avoid harming participants who may become distressed during the interviews and focus groups, a distressed protocol was developed to safely manage anyone who became upset (Appendix 7).

This research study was carried out shortly after a major documentary within the Republic of Ireland which exposed the abuse of people with intellectual disability (mainly an older age group) within residential services (Áras Attracta Swinford Review Group 2016). Although the potential risks involved in the study were assessed as minor, there was the potential for participants to disclose harmful or poor practice, either currently or historically, during the interview process. To ensure that correct reporting procedures were followed, the researcher consulted a member of the local Safeguarding and Protection Team and Responding to Concerns or Allegations of Abuse protocol was devised (Appendix 8). The protocol was adapted from the Adult Safeguarding Policy (HSE 2014) and detailed how the researcher would respond to any issues of concern, disclosures of abuse, neglect, harm, or self-harm. In the event of a participant becoming distressed the researcher would either postpone or delay the interview. Such a situation did not arise during the interviews, but the protocol was in place for the protection of the participants and others who may be affected. The researcher was also conscious of the length of the individual interviews for people with

intellectual disabilities, in case the participant found it demanding or an excessive length of time (NDA 2009). In most cases the interview came to a natural close with the interviewer paying close attention to body language and physical prompts of the person.

The principle of non-maleficence also applies to the collection, storage and the correct reporting of the data collected. To ensure anonymity and confidentiality in phase one, several participants expressed concern about confidentiality and that completed questionnaires would be accessed by others. This was counteracted by providing stamped address envelopes so participants could return their questionnaires directly to the researcher and they were reassured that only the research team would have access to the data. During phase two, the individual and focus group interviews were held in a neutral and quiet location. All data collected was coded to avoid the participants being identified. The data was then stored on an encrypted password protected computer. Any hard copies of the data were stored in a locked filling cabinet in the researcher's office. Only the research team had access to the data relating to the study. No identifiable data was collected or reported, this included the age range of older people with intellectual disabilities, as they could be easily identified from their age, particularly those in 75 years and older age groups.

The term **beneficence** encompasses two moral obligations, to act for the benefit of others and balancing benefits and risks/harms (Jahn 2011). Demonstrating respect for the participants was paramount throughout the interview process, recognising when it was inappropriate to probe further as the risk to a person's emotional well-being may outweigh the possibility of gaining rich data (Townsend *et al.* 2010). For example, three older people with intellectual disabilities did not wish to discuss their experiences of living in a psychiatric hospital when they were younger, and this was not pursued as it could provoke and emotional response and was not essential to the research topic under study. Jahn (2011) states that beneficence supports and helps persons with disabilities and the research aims to generate data that informs future benefits to the lives of older people and identify barriers to implementation and raise awareness of what people with intellectual disabilities want from services as they age.

Finally, the principle of **justice** requires researchers to treat all participants equally and fairly. Equal treatment within a study refers to the quality of information each participant receives and equity of access to participant in the study (NDA 2009). People with intellectual disabilities were included within the research, with their voice and option holding equal importance to that of staff and family members. To exclude people with intellectual disabilities would have been unjust and contrary to the philosophy of citizenship, inclusion and empowerment (NDA 2009; Walmsley 2005). Therefore, the interview process was flexible, and adjustments were available for those who required assistance. They were given the opportunity to have an advocate or support person present if they wished, although a support person was required by only one participant. The opportunity to participate was also provided to four participants who heard about the study from others and requested to take part. Originally these participants had not come forward via their residential service but approached the researcher directly during visit to a day service. Anyone who came forward was given the opportunity to take part.

Furthermore, justice relates to the subject which can provide general benefit to a group, society as a whole or to the advancement of knowledge (Owonikoko 2013). This research may be of benefit to people with intellectual disabilities and seeking knowledge on their lived experiences of how society has treated them throughout their lifespan. Northway (2010) encourages promoting the inclusion of people with intellectual disability in research as the central means to structuring the development of more appropriate services.

Ethical approval applications for the study were made and structured upon the above outlined issues and principles. Ethical approval was granted from the Ulster University School of Nursing Research Filter Committee and two local Health Executive Service Ethical Committees (Appendix 2) where the research study was conducted.

4.11 Summary

This chapter has outlined the theoretical underpinnings of the study, the methods involved. Furthermore, the sampling techniques, data collection processes and how the data was analysed for both phase one and two of the study was also been discussed. The special considerations for the inclusion of people with intellectual disabilities within the research study was also provided. The key issues surrounding the data integration process within mixed methods were discussed. The issue of rigour within quantitative and qualitative data was outlined with a brief overview of rigour within a mixed methods approach. Finally, the ethical considerations and strategies employed within the study were outlined.

CHAPTER 5: PRELIMINARY ANALYSIS OF PERSON-CENTRED PRACTICE INVENTORY-STAFF

5.1 Introduction

The analysis of the quantitative data from the Person-Centred Practice Inventory-Staff (PCPI-S) is provided over the following two chapters. This was necessary in order to present the initial assessment of the normality of the data which is a prerequisite for the statistical testing presented in the succeeding chapter. This chapter will present the initial data testing and include the presentation of the item scores for skewness and kurtosis scores for each construct and domain within the PCPI-S. The correlation scores will also be examined to assess their relationship with other items within the same domains of the PCPI-S.

5.2. Test of normality

Testing of normality within data is important as the normality status indicates the selection of parametric or nonparametric statistical tests to be conducted (Field 2009). Tests for normality were performed for each construct. To ensure that the most appropriate statistical tests could be performed, data distribution for each scale and subscale was assessed using histograms with a normal distribution curve overlaid to check whether data violated the assumptions of normality. Skewness and kurtosis values and a Kolmogorov-Smirnov statistic were computed.

The following initial tests were carried out on the data:

1. Each item was examined for normality and skewness and kurtosis scores.
2. Correlation scores for each item were carried out and examined to assess their correlation with other items within the same domain.

The domains and constructs will now be examined for skewness and kurtosis scores and correlation scores will be presented.

5.2.1 Skewness and kurtosis correlation scores for the PCPI-S

Skewness and kurtosis scores were examined for the questionnaire at both domain and construct level of the PCPI-S. The results will firstly be reported at construct level for each of the 59 items which are measured on a five-point scoring range, from 1 (strongly disagree) to 5 (strongly agree). Item scores were aggregated to the level of the 17 constructs and the results present for ease of presentation.

A fundamental task in statistical analysis is to examine the location and variability of a dataset which includes skewness and kurtosis. Skewness is a measure of asymmetry or the lack of symmetry and the distribution of a variable (Kim 2013). A data set is described as symmetric when it looks the same to the left and right of the centre point. The skew value of a normal distribution is zero, usually implying a symmetric distribution. A positive skew value indicates that the tail on the right side of the distribution is longer than the left side and the bulk of the values lie to the left of the mean. In contrast, a negative skew value indicates that the tail on the left side of the distribution is longer than the right side and the bulk of the values lie to the right of the mean (Kim 2013). Kurtosis is a measure of whether the data are peaked or flat relative to a normal distribution and are determined by the extent of the responses clustered in the tails of the distribution. Data sets with a high kurtosis tend to have a distinct peak near the mean, decline rather rapidly and have heavy tails. Data sets with low kurtosis tend to have a flat top near the mean rather than a sharp peak. Both have a value of zero in a normal distribution, however, +/-2 is acceptable (Field 2009).

5.2.2 Prerequisites domain

The Prerequisites domain contains five constructs which encompass the initial 18 questions of the PCIP-S. For each item the skewness and kurtosis scores are presented. Both measurements have a value of zero in a normal distribution, however +/-2 is acceptable (Field 2013). Any significant deviation from the normal distribution in skewness and kurtosis determines later analysis and should be identified at an early stage. Tests of assumption of normality and distribution can be conducted via a combination of visual inspection of the skewness and kurtosis and demonstrate if data are drawn from a normally distributed population (Field 2013).

Table 5.1 presents the scores for the prerequisite domains. The kurtosis scores for items, No.1 and No.10 were high. A high kurtosis score in item 1 did not present with a negative skew and was within an acceptable range of skewness of +/-2. However, Kim (2013) asserts that the skewness and kurtosis will not impact significantly on larger samples > 200. As this sample is (n=229) and greater than 200 and is categorised as a large sample.

Table 5.1: Skewness and kurtosis prerequisites domain items

Item No.	Prerequisites Domain	Skewness	Kurtosis
Professionally Competent: Construct			
1	I have the necessary skills to negotiate care options.	-1.568	4.876
2	When I provide care, I pay attention to more than the immediate physical task.	-1.229	1.989
3	I actively seek opportunities to extend my professional competence.	-.411	-.633
Developed Interpersonal Skills: Construct			
4	I ensure I hear and acknowledge others perspectives.	-1.065	1.794
5	In my communication I demonstrate respect for others.	-1.212	.524
6	I use different communication techniques to find mutually agreed solutions.	-1.04	1.00
7	I pay attention to how my non-verbal cues impact on my engagement with others.	-.876	1.10
Being Committed to the Job: Construct			
8	I strive to deliver high quality care to people.	-1.538	.368
9	I seek opportunities to get to know people and their families in order to provide holistic care.	-.945	-.294
10	I go out of my way to spend time with people receiving care.	-1.183	2.489
11	I strive to deliver high quality care that is informed by evidence.	-.523	-.774
12	I continuously look for opportunities to improve the care experiences.	-.507	-.744
Knowing Self: Construct			

13	I take time to explore why I react as I do in certain situations.	-.655.	.728
14	I use reflection to check out if my actions are consistent with my ways of being.	-.749	1.108
15	I pay attention to how my life experiences influence my practice.	-.540	.129
Clarity of Beliefs and Values: Construct			
16	I actively seek feedback from others about my practice.	-.374	-.599
17	I challenge colleagues when their practice is inconsistent with our team's shared values and beliefs.	-.507	-.133
18	I support colleagues to develop their practice to reflect the team's shared values and beliefs.	.605	.804

5.2.3 Correlation scores prerequisite domain

Bivariate correlation is a statistical method used to assess the strength of the linear relationships between two variables (Muaka 2009). Latent constructs which are also referred to as latent variables, are described as '*research abstractions'* that cannot be measured directly; for example, items such as beliefs and perceptions (Gefen and Straub 2005). The variables with the PCIP-S would be described as such, as they relate to staff's beliefs and perceptions regarding their own practice. Each measurement item score should correlate strongly with its identified theoretical construct (Gefen and Straub 2005). Correlations can be either positive or negative. A negative correlation is present when the value of one variable increases and the other decreases. The strength of the correlation is based on the distance from +1 or -1, the closer the value, the stronger the correlation (Archambault 2002).

- -1 is a perfectly negative linear relationship.
- 0 is no relationship.
- +/-1 represents a perfectly positive linear relationship.

A value of 0.7-1 is considered to be a strong correlation and demonstrates factors with similarity, therefore values below 0.7 are desirable (Brace *et al.* 2013). As the Prerequisites variables are normally distributed, Pearson's correlation co-efficient was

used to analyse the domain. According to Pernet *et al.* (2012) Pearson's correlation test is overly sensitive to outliers, a single outlier can result in an inaccurate summary of the data. Table 5.2 presents the correlations within the domain, with no items noted to be highly correlated. Within the prerequisites a negative correlation was noted between three pairs of items; 17- 5, 17- 7, and 17-8 and are highlighted for ease of reference. The remainder are all positively correlated.

Table 5.2: Correlation between items in the prerequisite's domain

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
2	.427**																
3	.309**	.416**															
4	.336**	.484**	.471**														
5	.242**	.333**	.305**	.485**													
6	.297**	.354**	.336**	.434**	.501**												
7	.202**	.309**	.283**	.361**	.514**	.629**											
8	.237**	.410**	.279**	.323**	.434**	.339**	.459**										
9	.308**	.286**	.365**	.340**	.346**	.349**	.357**	.473**.									
10	.278**	.367**	.337**	.219**	.229**	.317**	.312**	.285**	.442**								
11	.290**	.384**	.358**	.316**	.275**	.330**	.368**	.363**	.374**	.465**							
12	.299**	.382**	.418**	.274**	.320**	.300**	.201**	.381**	.377**	.407**	.516**						
13	.190**	.218**	.264**	.196**	.233**	.297**	.197**	.206**	.205**	.227**	.298**	.374**					
14	.194**	.203**	.224**	.221**	.176**	.223**	.202**	.181**	.232**	.236**	.218**	.353**	.549**				
15	.120	.149*	.192**	.053	.179**	.192**	.144*	.221**	.317**	.233**	.117	.351**	.420**	.528**			
16	.152*	.197**	.236**	.237**	.172**	.204**	.112	.159*	.239**	.190**	.231**	.446**	.431**	.469**	.438**		
17	.140**	.284**	.117	.155	.053	.145*	.064	.084	.181**	.280**	.180**	.248**	.179**	.288**	.261**	.353**	
18	.186**	.303**	.265**	.216**	.263**	.339**	.282**	.296**	.185**	.339**	.279**	.402**	.303**	.321**	.249**	.369**	.393**

***Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed). Note, (N = 229), * p<.05, *p<.01**

5.2.4 Care environment domain

The scores were calculated for the care environment domain and are presented in Table 5.3 below. They indicate that skewness is within the acceptable range of +/- 2 with the majority falling below +/- 1. Kurtosis scores for one item, No. 22 was high, but the skewness for the item was within the normal range. The item scores will be aggregated to construct level and the skewness and kurtosis ranges will be re-examined later.

Table 5.3: Skewness and kurtosis of the care environment domain items

Item No.	Person-Centred Practice Inventory-Staff Care environment domain score	Skewness	Kurtosis
Skill Mix: Construct			
19	I recognise when there is a deficit in knowledge and skills in the team and its impact on care delivery.	-.232	.102
20	I am able to make the case when skill mix falls below acceptable levels.	-.536	-.093
21	I value the input from all team members and their contributions to care.	-1.022	.996
Shared Decision-Making: Constructs			
22	I actively participate in team meetings to inform my decision-making.	-1.331	2.816
23	I participate in organisation-wide decision-making forums that impact on practice.	-.329	-.482
24	I am able to access opportunities to actively participate in influencing decisions in my directorate/division.	-.298	-.408
25	My opinion is sought in clinical decision-making forums (e.g., support plans, case conferences, and annual reviews).	-.735	-.107
Effective Staff Relationships: Constructs			
26	I work in a team that values my contribution to person-centred care.	-.946	.495
27	I work in a team that encourages everyone's contribution to person-centred care.	-1.091	1.209
28	My colleagues positively role model the development of effective relationships.	-.715	.505
Power Sharing: Construct			
29	The contribution of colleagues is recognised and acknowledged.	-.956	.844
30	I actively contribute to the development of shared goals.	-.677	1.092

31	The leader facilitates participation.	-.866	.706
32	I am encouraged and supported to lead developments in practice.	-582	.121
Potential for Innovation and Risk Taking: Construct			
33	I am supported to do things differently to improve my practice.	-.488	-.009
34	I am able to balance the use of evidence with taking risks.	-.458	-.074
35	I am committed to enhancing care by challenging practice.	-.629	.595
The Physical Environment: Construct			
36	I pay attention to the impact of the physical environment on people's dignity.	-.862	.582
37	I challenge others to consider how different elements of the physical environment impact on person-centredness (e.g., noise, light, heat etc.).	-.665	.059
38	I seek out creative ways of improving the physical environment.	-.473	.043
Supportive Organisational Systems: Construct			
39	In my team we take time to celebrate our achievements.	.018	-.785
40	My organisation recognises and rewards success.	.189	-.684
41	I am recognised for the contribution that I make to people having a good experience of care.	-.329	-.630
42	I am supported to express concerns about an aspect of care.	-1.064	1.128
43	I have the opportunity to discuss my practice and professional development on a regular basis.	-.376	-.619

5.2.5 Correlation scores care environment domain

The correlation scores of the items contained within the c*are environment* domain were examined. A negative correlation was noted between 18 pairs of items: 29-23*, 32-19, 33-19 36-23, 36-25, 39-19, 39-36, 40-19, 40-20, 40-21, 40-22, 40-36, 41-19, 41-36, 42-36, 43-19, 43-36, 43-37. The remainder are all positively correlated. There were strong positive correlations above 0.7 between the following items 40-39 and 41-40. These are all highlighted in Table 5.4 for ease of reference.

Table 5.4: Correlation between items in the care environment domain

	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42
20	446**																							
21	361**	.398**																						
22	.251**	.300**	.462**																					
23	.192**	.305**	.181**	.338**																				
24	.263**	.357**	.249**	.271**	.633**																			
25	.155*	.243**	.166*	.358**	.442**	.479**																		
26	.172**	.335**	.319**	.307**	.305**	.525**	.528**																	
27	.128	.182**	.362**	.348**	.209**	.409**	.381**	.689**																
28	.179**	.140*	.303**	.285**	.228**	.421**	.323**	.510**	.649**															
29	.121	.190**	.264**	.132*	.091	.267**	.222**	.467**	.623*	.439**														
30	.297**	.230**	.347**	.353**	.251**	.395**	.335*	.468**	.556**	.447**	.523**													
31	.100	.320**	.328**	.311**	.256**	.315**	.400**	.453**	.476**	.413**	.560**	.467**												
32	.069	.162*	.233**	.271**	.366**	.389**	.415**	.414**	.443**	.474**	.458**	.411**	.668**											
33	.040	.204**	.227**	.209**	.185*	.293*	.280**	.418**	.446**	.426**	.542**	.392**	.590**	.638**										
34	.201**	.295**	.217**	.319**	.248**	.322**	.300**	.237**	.209**	.309**	.223**	.275**	.353**	.370**	.354**									
35	.304**	.244**	.327**	.227**	.261**	.449**	.270**	.432**	.422**	.378**	.296**	.441**	.318**	.296**	.399**	.380**								
36	.288**	.321**	.429**	.211**	.023	.112	.085	.339**	.303**	.217**	.244**	.372**	.206**	.153*	.209**	.257**	.370**							

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
37	290**	.341**	.332**	.298**	.214**	.227**	.215**	.287**	.244**	.129**	.172**	.311**	.184**	.128*	.192**	.192**	.235**	.423**						
38	.248**	.410**	.295**	.230**	.277**	.337**	.186**	.294**	.290**	.148*	.223**	.392**	.265**	.232**	.277**	.282**	.310**	.363**	.561**					
39	.072	.113	.060	.057	.314**	.484**	.329**	.379**	.363**	.356**	.391**	.348**	.350**	.454**	.402**	.248**	.244**	.031	.166**	.292**				
40	.034	.096	.093	.086	.312**	.415**	.347**	.375**	.424**	.452**	.448**	.338**	.391**	.499**	.497**	.247	.247**	-.029	.102	.199	.759**			
41	.093	.199**	.149*	.162*	.322**	.447**	.346**	.487**	.478**	.423**	.468**	.374**	.408**	.501**	.494**	.209**	.241**	.072	.193**	.175**	.652**	.700**		
42	.165*	.181**	.285**	.189**	.245**	.370**	.318**	.432**	.489**	.436**	.399**	.382**	.487**	.400**	.429**	.129	.292**	.068	.129	.197**	.501**	.505**	.582**	
43	.047*	.144*	.211**	.208**	.308**	.383**	.334**	.428**	.501**	.465**	.429**	.376**	.539**	.501**	.494**	.262**	.280**	.040	.088	.123	.537**	.633**	.618**	.615*

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed). Note, (N = 229). * p<.05, *p<.01*

5.2.6 Care process domain

The skewness and kurtosis scores were calculated for the remaining sixteen items which are within the care process domain. Table 5.5 below indicates a high kurtosis for items 45 and 56 but as the skewness is within an acceptable range no action was taken at this stage.

Table 5.5: Skewness and kurtosis of the care process

Item No.	Person-Centred Practice Inventory-Staff: Care process domain score	Skewness	Kurtosis
Working with Patients Beliefs and Values: Construct			
44	I integrate my knowledge of the person into care delivery.	-.800	-.944
45	I work with the person within the context of their family and carers.	-.1043	2.094
46	I seek feedback on how people make sense of their care experience.	-.314	.051
47	I encourage the people to discuss what is important to them.	-.795	1.267
Shared Decision-Making: Construct			
48	I include the family in care decisions where appropriate and/or in line with the person's wishes.	-.607	-.331
49	I work with the person to set health goals for their future.	-.958	1.878
50	I enable people receiving care to seek information about their care from other healthcare professionals.	-.648	.270
Engagement: Construct			
51	I try to understand the person's perspective.	-.629	.242
52	I seek to resolve issues when my goals for the person differ from their perspectives.	-.269	.070
53	I engage people in the care processes where appropriate.	-.276	.181
Having Sympathetic Presence: Construct			
54	I actively listen to people receiving care to identify unmet needs.	-.661	.273
55	I gather additional information to help me support the people receiving care.	-750	.445
56	I ensure my full attention is focused on the person when I am with them.	-1.427	2.306
Providing Holistic Care: Construct			
57	I strive to gain a sense of the whole person.	-.873	-.280

| 58 | I assess the needs of the person, taking account of all aspects of their lives. | -.877 | -.313 |
| 59 | I deliver care that takes account of the whole person. | -1.341 | 1.829 |

5.2.7 Correlation scores care process domain

The correlation scores of the items contained within the care process domain were examined. No negative correlations were identified. There were strong positive correlations above 0.7 between the following items 53-52, 57-56, 58-57, 59-57, and 59-58. These are all highlighted in Table 5.6 for ease of reference.

Table 5.6: Correlation between items for care process domain

	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58
45	.589**														
46	333**	.367**													
47	.479**	.388**	.501**												
48	.416**	.539**	.386**	.455**											
49	.389**	.411**	.369**	.465**	.570**										
50	.346**	.385**	.465**	.456**	.501**	.540**									
51	486**	.415**	.262**	.454**	.541**	.357**	.457**								
52	.444**	.442**	.388**	.438**	.409**	.412**	.455**	.477**							
53	474**	.451**	.371**	.432**	.494**	.438**	.469**	.554**	.733**						
54	.444**	.420**	.244**	.425**	.386**	.490**	.396**	.453**	.471**	.638**					
55	371**	.350**	.297**	.436**	.358**	.297**	.380**	.373**	.471**	.601**	.646**				
56	.272**	.260**	.262**	.399**	.252**	.169*	.258**	.330**	.385**	.398**	.486**	.526**			
57	.453**	.424**	.210**	.483**	.358**	.267**	.310**	.490**	.448**	.512**	.570**	.554**	.720**		
58	.439**	.434**	.265**	.435**	.400**	.321**	.303**	.550**	.422**	.538**	.589**	.553**	.635**	.789**	
59	.376**	.372**	.253**	.426**	.390**	.343**	.358**	.481**	.407**	.442**	.547**	.526**	.650**	.757**	.817**

*** Correlation is significant at the 0.01 level (2-tailed) * Correlation is significant at the 0.05 level (2-tailed) /(n=229), * p<.05, *p<.01*

5.3 Skewness and kurtosis scores at domain level

The skewness and kurtosis scores were reviewed for the PCIP-S at the construct and domain level. These are now reported at domain level for ease of presentation.

5.3.1 Skewness and kurtosis scores at prerequisite domain

The prerequisites items were aggregated to construct level for ease of presentation. The prerequisites domain is sub-divided into five constructs in total which in turn contain eighteen questions relating to the total PCPI-S items. At construct and domain level the skewness and kurtosis are at acceptable range.

Table 5.7: Construct and domain skewness and kurtosis scores for the prerequisite domain

Prerequisite Domaine Score	Skewness	Kurtosis
Professionally competent	-.345	-.689
Developed interpersonal skills	-.867	.675
Committed to the job	-..638	-.337
Knowing self	-.185	-.176
Clarity of beliefs and values	-.084	-.597
Prerequisite Domain: Score	-.061	-.358

5.3.2 Skewness and kurtosis scores at care environment domain

The care environment domain is made up of seven constructs which contain 25 questions in total relating to the total PCPI-S items. The constructs within this domain were found to be within normal range.

Table 5.8: Construct and domain skewness and kurtosis scores for the care environment domain

Care Environment Domain Score	Skewness	Kurtosis
Skill mix	-.388	.009
Shared decision-making systems	-.488	.365
Effective staff relationships	-.986	1.113
Power sharing	-.578	.392
Potential for innovation and risk	.035	-.437
Physical environment	-.515	.636
Supportive organisational systems	-.354	-.070
Care Environment Domain Score	**-.146**	**-.021**

5.3.3 Skewness and kurtosis scores at care process domain

The care process domain is made up of five constructs in total which contains 16 questions from the PCPI-S items which examine the caring process. All the constructs within this domain were found to be within an acceptable range.

Table 5.9: Construct and domain skewness and kurtosis scores for the care process domain

Care Process Domaine Score	Skewness	Kurtosis
Working with patients' beliefs and values	-.645	1.398
Shared decision-making	-.523	.210
Engagement	.013	-.757
Sympathetic presence	-.777	.425
Providing holistic care	-1.033	.421
Care Process Domain: Score	**-.328**	**-.215**

5.4 Reliability

Cronbach's alpha is a statistical method used to demonstrate that constructed tests and scales or those implemented in research projects are fit for purpose (Taber 2017). It is the most common measurement of internal consistency or 'reliability' used when

there are multiple Likert questions that form a scale within a survey such as PCIP-S and the researcher wishes to determine if the scale is reliable. Cronbach's alpha is deemed acceptable if the values between 0.7 or 0.6 are reached (van Griethuijsen *et al.* 2015; Taber 2017). The Cronbach's alpha values were computed for each of the data collection instruments in the sample are presented below in Table 5.10. Both total and subscale scores were calculated for each factor and the Cronbach's alpha was calculated based on the items. All the items reached the acceptable level of 0.6 and 0.7 and higher reliability levels of 0.8 and 0.9. The mean scores for each item will be examined more detail in the next chapter.

Table 5.10: Mean scores and Cronbach's Alpha of Person-Centred Practice Inventory-Staff constructs and domains

Construct	Mean	Cronbach's Alpha	Construct	Mean Score	Cronbach's Alpha
PREREQUISITES	4.30	0.85	**CARE PROCESS**	4.33	0.93
Professionally competent	4.36	0.64	Working with patients beliefs and values	4.18	0.77
Developed interpersonal skills	4.54	0.76	Shared decision-making	4.18	0.77
Being committed to the job	4.56	0.77	Engagement	4.31	0.81
Knowing self	4.10	0.75	Having sympathetic presence	4.44	0.78
Clarity of beliefs	3.93	0.62	Providing holistic care	4.60	0.91
CARE ENVIRHMENT	3.88	0.92			
Skill mix	4.25	0.65			
Shared decision-making systems	3.72	0.74			
Effective staff relationships	4.08	0.82			
Power sharing	3.98	0.80			
Potential for Innovation and Risk Taking	3.90	0.64			
The Physical Environment	4.29	0.71			
Supportive Organisational Systems	3.33	0.88			

5.5 Summary

This chapter has examined and presented the reliability and validity of the PCPI-S, using the concepts of the questionnaire as a measure of the framework. Evidence of the psychometric properties of the PCPI-S as a measurement tool of person-centredness, ensures that findings have a strong empirical base. The measurement of this PCPI-S with the responses of staff from residential services, revealed that the correlations were in acceptable range and the Cronbach's alpha examined at variable construct and domain level were all within acceptable limits, and therefore the current three domain model was accepted.

CHAPTER 6: FINDINGS FROM THE PERSON-CENTRED PRACTICE INVENTORY-STAFF

6.1 Introduction

This chapter covers the descriptive and inferential data obtained from the Person-Centred Practice Inventory-Staff (PCIP-S). The demographic profile of the participants will be examined in relation to the type of residential service, role and years working in intellectual disability residential services. Following on from this, the key results from the three main domains, *prerequisites, care environment and care process,* will be presented in relation to identified demographics that had a meaningful impact.

6.2 Demographic Profile of the Participants

The Person-Centre Practice Inventory-Staff (PCPI-S) was distributed in hard copy to residential services across two counties in the Northwest of Ireland. The staff sample (n=552) was representative across HSE Residential Services in both counties, with a combination of large residential (> 10 residents) and small residential services (community group homes) (<10 residents) participated. A total of 299 staff returned the survey. Firstly, the response rate from the two types of residential services was similar, with staff from large residential settings representing just over half the respondents, 56% (n=129) inclusive of campus settings, while 44% (n= 100) were based in a community group homes. Overall, the majority of those who completed the questionnaire were healthcare assistants (HCAs) 56% (n=128), with staff nurses represented 31% (n=72) and nurse manager respondents represented a smaller number of 13% (n=29). Table 6.1 below provides a summary of the demographic profile of the participants.

Table 6.1: Demographic profile of participants

Work Setting	Percentage				
Campus	56%				
CGH	44%				
Role		**Years' Experience**	1-5	6-10	Over 10
Nurse Manager	13%	Nurse Manager	2	1	26
Staff Nurse	31%	Staff Nurses	18	13	41
HCA	56%	HCAs	49	14	65
Type of Qualification		**Highest level of education**	Postgrad Dip	Degree (Hons)	Nursing Cert	QQI Level 5
RNID	38 %	Nurse manager	8	13	8	
RGN/RNP	7%	Staff Nurse	8	52	12	
QQI level 5	55%	HCA	3	17	N/A	108

Initially participants were surveyed on two questions, *'total years' experience working with people with intellectual disability'* and *'total years' experience working with older people with intellectual disability'*. As the two variables had similar scores, it was decided at this stage to analyse only one variable, *'total years' experience working with people with intellectual disability'.* This indicated that the majority of staff, 57.6% (n=132) who responded had over ten years' experience. While the next largest group represented those with 1-5 years' experience, 30% (n=69).

The overall assessment of the demographics revealed that many of the responses came from respondents working in larger residential services and were based in campus style settings. The registered nurses predominately held a RNID qualification and were educated to Degree (Hons) level, while HCAs mainly held a Quality and Qualifications Ireland (QQI) Level 5 qualification. Most of the respondents had over 10 years' experience working with people with intellectual disabilities, and the lowest number of responses came from nurses and HCAs in the 6-10 years' experience group. These demographics were used to make comparisons from the data and are reported later in this chapter.

6.3 Scales analyses

Frequencies, percentages and mean scores were examined for each of the three domains and the 17 constructs, and the 59 individual items within the PCIP-S. In addition, a number of inferential statistical tests will be presented.

6.3.1 Mean scores of constructs

The Person-Centred Practice Inventory-Staff contains 59 items measured on a 5-point Likert Scale ranging from 1-strongly disagree to 5-strongly agree. The items represent the 17 constructs of the Person-Centred Framework and three broader domains (prerequisites, care environment, and care process). Higher scores on items, constructs and domains represent higher level of agreement with the statement within the practice context. All three domains were positively scored, *care process* at x = 4.34 received the highest overall score, indicating a high level of agreement with the constructs, while *prerequisites* closely followed at x = 4.30. The care environment was scored at x= 3.86, which is positively scored, but less than the other two domains. On analysis of the individual constructs, the most positively scored was *'providing holistic care'* (x = 4.60), within the *care process* domain, and with *'being committed to the job'* (x=4.56) in the prerequisite domain, received similar scoring. The lowest scoring constructs were '*supportive organisational systems'* (x= 3.33) and 's*hared decision-making systems'* (x= 3.72) both within the *care environment* domain. Each of the 17 constructs of the PCPI-S that make up the three domains will be examined in the following section.

6.3.2 The prerequisites domain

The mean score for the *prerequisites* domain and the five constructs within the PCPI-S were examined and are shown below in Table 6.2. In order to interpret the mean scores, the value of the mid-point was selected between each point of the responses (Pearse 2011). The total mean score for the prerequisites was 4.30 (SD = .38), which indicated that staff agreed they possessed the necessary attributes to deliver person-centred care.

Table 6.2: Mean and standard deviation scores of prerequisites constructs

Prerequisites Items	Scale mean 4.30	Std. Dev .38
Constructs	Mean	Std. Dev
Professionally competent	4.36	.51
Developed interpersonal skills	4.54	.45
Being committed to the job	4.56	.39
Knowing self	4.09	.59
Clarity of beliefs	3.93	.62

Table 6.2 shows the highest scoring construct to be *'Being committed to the job'* at 4.56, indicating a high level of agreement. '*Being committed to the job'* represents an acknowledgement of the staff's commitment to individual care. On further analysis of the individual items frequency scores are presented in Appendix 9. It found that 80% of respondents felt that they '*strived to deliver high quality care*, whilst 65% of the sample strongly agreed that they '*seek opportunities to get to know people and their families in order to provide holistic care'.*

The construct '*Developed interpersonal skills'* had a mean score of 4.54, indicating a high level of agreement. This construct refers to the respondent's ability to communicate at a variety of levels with others and refers to verbal and non-verbal communication techniques. While 74% of the sample strongly agreed that their communication skills demonstrated respect for others.

'Knowing self' relates to the individuals' self-awareness and insight into their professional behaviour and reactions to situations through, self-awareness, reflection and how they engage with others. The mean score for the above construct was 4.09 indicating a strong level of agreement, with a lower percentage However, just 27% strongly agreed that they used reflection techniques as part of their day-to-day practice and to explore their reactions to challenging situations.

The lowest scoring construct within the domain was '*Clarity of beliefs and values'* and represents the impact of values and behaviours on the care provided. The mean score for the construct was 3.9, although indicating a level of agreement it is lesser than the

other constructs. This construct also contained the highest number of disagrees and neutral scores of the prerequisites domain, in particular, *'I actively seek feedback from others about my practice'* (mean 3.8, SD .89) and *'I challenge colleagues when their practice is inconsistent with our team's shared values and beliefs'* (mean 3.7 and SD .90). Over half the respondents reported sought feedback from others about practice activities and similar number stated they would challenge colleagues regarding their practice if necessary. Staff with the correct values and clarity of values was found to important to the provision of quality support to people with intellectual disabilities (Bigby *et al.* 2012).

6.3.3 The care environment domain

The '*care environment'* domain is made up of seven constructs and all the constructs were positively scored. The overall mean score of the domain was (x= 3.86) which was the lowest scoring of the three domains. Table 6.3 below demonstrates that staff were neutral about whether they work in a person-centred environment. Within the domain the highest scoring construct was the '*physical environment'* (x=4.28), while the lowest score belonged to the construct '*supportive organisational systems'* (x=3.33).

Table 6.3: Mean and standard deviation scores of care environment constructs

Care Environment Items	Scale Mean: 3.86	Std. Dev: 0.52
Constructs	Mean	Std. Dev
Skill Mix	4.24	.49
Shared decision-making systems	3.72	.73
Effective staff relationships	4.08	.74
Power sharing	3.99	.66
Potential for innovation and risk	3.90	.62
Physical environment	4.28	.54
Supportive organisational system	3.33	.90

To examine the above table in greater depth, the frequencies, percentages and mean scores are calculated for each construct within the domain (Appendix 10). The lowest scoring construct overall within the PCIP-S was *'supportive organisational systems'*,

with the mean score in the neutral range, indicating staff neither agreed nor disagreed with the statement. Most notable was the item, '*my organisation recognises and rewards success'* (mean 2.8, SD 1.1), with 72% of respondents disagreeing or remaining neutral on the item. Also *'In my team we take to celebrate our achievements'* (mean 3.1, SD 1.1) saw 62% of the respondents disagreeing or remaining neutral on the item. Approximately 52% agreed that they had the opportunity to discuss practice and professional development on a regular basis.

Shared decision-making construct emphasises the development of a positive workplace, relationships, communication systems and autonomy and accountability. It is one of the second lowest mean scores within the domain (mean 3.7, SD .73). Although the score indicates a high level of agreement, a notable number of the respondents remained neutral on two items, neither agreeing nor disagreeing on '*participating in organisation-wide decision-making forums that impact on practice'* (31%) and '*being able to access opportunities to actively participate in influencing decisions in my directorate/division'* (31%).

Skill mix involves the identification and creation of appropriate skill and staffing levels to ensure quality of care is delivered. The mean score of this construct was 4.2, indicating a strong level of agreement. Over 75% of the sample either agreed or strongly agreed that they were able to articulate a case for when skill mix falls below an acceptable level. While 61% of the sample strongly agreed that all team member's contributions were valued.

The '*potential for innovation and power sharing and risk taking'* encompasses professional accountability and its bearing in practice through evidence-based decision making. The mean score for the construct was 3.9 indicating a high level of agreement. Approximately 66% agreed and strongly agreed they were supported to improve practice, however, 34% reported that they disagreed or scored neutral on this statement. More than half (69%) felt that they were able to balance the use of evidence with risks. Yet 30% of the sample scored neutral or disagreed with the statement.

The '*physical environment'* plays an essential role in providing safe quality care to people with intellectual disabilities and it was the highest scoring construct with the domain (mean 4.2, SD .54). Almost all the respondents (97%) reported that they '*paid*

attention to the impact of the physical environment on people's dignity'. With many respondents (83%) reporting that they consider the impact of noise, light, heat on the person and 84% of respondents reporting that they '*seek out creative ways of improving the physical environment.'*

6.3.4 The Care Processes

Table 6.4 shows the mean score for the c*are process* domain which contains five constructs within it. The total mean score for the domain was the highest of the three constructs (mean 4.3, SD, .43), indicating that staff agreed that they engage the necessary practices required to deliver person-centredness. The scores were similar to p*rerequisites* domain and higher than the *care environment* domain. The mean scores of the five constructs were within a narrow range and there was little notable difference between the highest score '*providing holistic care'* (mean 4.6, SD .50) and the lowest score '*working with patient's beliefs and values'* (mean, 4.1; SD .52). Further analysis of the frequency, percentage and mean scores on items relating to the care environment domain was also conducted (Appendix 11).

Table 6.4: Mean and standard deviation scores of care process constructs

The Care Process Items	Scale Mean: 4.34	Std. Dev: .43
Constructs	**Mean**	**Std. Dev**
Working with patients' beliefs and values	4.16	.52
Shared decision-making	4.18	.61
Engagement	4.31	.50
Having sympathetic presence	4.44	.52
Providing holistic care	4.60	.50

A key element of Person-Centred Practice is the ability to work with the beliefs and values of the individual in a holistic manner, encompassing all aspects of the person's life and well-being. The mean score for this construct was 4.1, demonstrating a strong agreement with the construct concepts. The majority of the respondents felt that they integrate their knowledge of the person into the delivery of care. Over 70% of the

sample felt they that they seek feedback on how people make sense of their care experience, while 24% remained neutral on this question. Almost the entire sample reported a high level of agreement that they encourage the people they care for to discuss what is important to them.

Shared decision-making looks at the involvement of people in their therapeutic relationship and the establishment of agreed life goals for health and to improve independence. For staff working in intellectual disability residential services, this is a key component and requirement of their role. The construct is measured on three items with the mean score of 4.1 indicating a high level of agreement. However, this construct also received the highest number of neutral scores with the domain with '*I enable people to receive care to seek information about their care from other healthcare professionals',* with 18% either scoring they disagreed or were neutral on this item.

The *Engagement* construct had a mean score was 4.3, again indicating a high level of agreement. A significantly high number the respondents agreed they try to *understand the person's perspective* (97%), with over 90% felt that they '*engage people in the care process where appropriate'.*

Having sympathetic presence refers to acknowledgement of the uniqueness of the individual with the care process. Intellectual disability services often articulate their intention to maintain this uniqueness at the heart of their service delivery. The mean score for this construct was 4.4, indicating a strong level of agreement. Almost all the respondents reported that they actively listen to people receiving care to identify unmet needs and that they ensure their full attention is focused on the person.

Providing holistic care gave the highest mean score of all the constructs, (mean, 4.00; SD.50) indicating a high level of agreement with this construct. Many of the responds either, agreed or strongly agreed that '*they took into account the whole person* (96%)*, assessing all aspects of their lives'* (97%) and they *'strive to gain a sense of the whole person'* (97%).

6.4 Automatic linear regression model

This research study collected data with a significant number of independent variables, with each as a potential predictor of the dependent variables within the PCPI-S. Considering the number of subsets, researchers frequently test correlations between the outcome variables and theoretically relevant predictor variables (Cohen *et al*. 2013). According to Ratner (2011) it is important to assess the relationship between dependent and predictor variables to identify the significant subsets, as in some instances, one or more of the predictor variables can be uncorrelated with the outcome variable. This assists the researcher to accurately identify relevant predictors through the variable selection methods available (Field 2013).

Amongst these selection methods, SPSS offers the use of automatic linear regression model to identify the most significant predictor subsets. The variables within the PCPI-S were used as the target variables while the six independent variables were introduced as the predictor variables:

1. Size of Service   2.Campus Setting   3. Current Role

4. Type of Qualification   5. Highest level of education

6. Years' experience working with people with intellectual disabilities

The forward stepwise regression method and coefficient of determination (R^2) were calculated.

6.4.1 Automatic linear regression summary: prerequisites domains

Table 6.5 provides a summary of the predictor variables' effect on the dependent variables, within the *prerequisites* domain with a predictor figure representation also provided (Appendix 12a). It outlines the predictor importance which helps to identify the relative significance of each predictor and demonstrates the significance of each predictor within the domain. The three key variables identified as having the most impact was, '*highest level of education', 'type of qualification'; 'size of service',* while '*campus setting', 'current role', and 'years' experience working with people with*

intellectual disabilities', were the predictors with the least impact or no predictor impact within this domain. The model also shows if the predictor had a positive or negative effect on the variable within this domain, '*type of qualification'* had a negative impact on the variable *professional competence* and *'highest level of education'* on *clarity of beliefs and values*.

While the variable, '*highest level of education',* had a positive impact on the construct '*being committed to the job* and the *'size of service'* variable also had a positive impact on the construct '*knowing self'.* The Criterion Information (IC) and the Adjusted R squared (R^2) are outlined below in Table 6.5.

Table 6.5: Automatic linear regression-model summary for prerequisites domain-predictor importance summary

	Size of service		Current Role		Highest level of education		Type of Qualification		Years' experience working with people with Intellectual disability	
Prerequisites	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)
Professionally competent	-309.257	0.30	00	00	00	00	-307.910	0.30	00	00
Developed Interpersonal skills	00	00	00	00	00	00	00	00	00	00
Being committed to the job	00	00	00	00	00	00	00	00	00	00
Knowing self	-242.704	.020	00	00	00	00	00	00	00	00
Clarity of values and beliefs	00	00	00	00	-219.559	.040	00	00	00	00

A further breakdown of the results of the automatic linear regression according to predictor variable is provided with the significant results aligned to the domains. The predictors were significant at a confidence level of $p = 0.05$; if the confidence level was not confirmed the predictors were subsequently omitted (Appendix 12b).

6.4.2 Automatic linear regression summary: care environment domain

The same process was used to analyse the care environment domain with the results shown in Table 6.6. The three predictor variables identified to have the most impact were, *highest level of education, type of qualification and current role*, while *campus setting and years' experience working with people with intellectual disabilities*, had the least or no predictor impact within this domain, a figure summarising the predictor importance is also provided (Appendix 13a and Appendix 14b). A further breakdown of the results using this model shows if the predictor had a positive or negative effect on the variables within this domain: *type of qualification* and *highest level of education,* had a positive impact on s*kill mix, shared-decision making* and s*upportive organisations*, with c*urrent role* having a negative impact on the variable *physical environment.* The Criterion Information (IC) and the Adjusted R squared (R^2) are outlined below in Table 6.6.

Table 6.6: Automatic linear regression: model summary for care environment domain: predictor importance summary

	Size of service		Current Role		Highest level of Education		Type of Qualification		Years' experience working with people with Intellectual disability	
Care environment	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)
Skill mix	00	00	00	00	-312.495	0.46	00	00	-314.279	.046
Share decision Making	00	00	-148.710	.046	00	00	00	00	00	00
Effective staff relationship	00	00	00	00	00	00	00	00	00	00
Power sharing	00	00	00	00	00	00	00	00	00	00
Potential for innovation and risk taking	00	00	00	00	00	00	00	00	00	00
The physical environment	00	00	-289.944	0.57			-288.956	0.57	-289.572	0.57
Supportive organisation systems	00	00	00	00	-47.350	.020	00	00	00	00

6.4.3 Automatic linear regression summary: care process domain

The automatic linear regression model was repeated for the care process domain with the results shown below in Table 6.7. Within this domain the two key variables identified as having the most impact were, *highest level of education* and *type of qualification,* while *campus setting and years' experience working with people with intellectual disabilities* and *current role,* had the least or no predictor impact within this domain, a figure outlining the predictor importance is also provided (Appendix 14a and Appendix 14b). The model indicated predictors which had a positive or negative effect on the variable. Within this domain, *type of qualification* and *highest level of education* had a positive impact on *skill mix, shared decision making and supportive organisations, with current role* having a negative impact on the variable p*hysical environment.* The Criterion Information (IC) and the Adjusted R squared (R^2) are outlined below in Table 6.7.

Table 6.7: Automatic linear regression: model summary for care process domain: predictor importance summary

	Size of service		Current Role		Highest level of education		Type of Qualification		Years' experience working with people with Intellectual disability	
Care Process	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)	IC	R^2 (adj)
Working with patient's beliefs and values	00	00	00	00	-293.268	.020	00	00	00	00
Shared decision-making	00	00	00	00	00	00	-230.093	.034	00	00
Engagement	00	00	00	00	-317.803	.021	00	00	00	00
Having sympathetic presence	00	00	00	00	00	00	00	00	-293.327	.008
Providing holistic care	00	00	00	00	00	00	00	00	00	00

The automatic linear modelling was conducted on the 17 constructs, and it identified the potentially significant subsets within each of the constructs, which are, *type of qualification, highest level of education* and *current role*, identified as the potentially significant subsets. The coefficients of the independent variables are statistically significantly different to zero at the *p*<.05 level. There was independence (no correlation between) the other constructs at the *p*<.05 level. No Cook's distances were greater than 1, indicating there are no influential points of outliers.

6.5 Comparing the impact of type of qualification within residential services

The independent variable, *type of qualification,* was statistically significant, different to zero at the p<.05 level as identified through the automatic linear modelling analysis as a relevant predictor. A one-way analysis of variance (One-way ANOVA) between groups across the three domains, *prerequisites*, c*are environment* and *care processes*, was conducted to explore the impact of the variable *type of qualification* on the three constructs as measured by the PCPI-S. The impact of *type of qualification* was significant in the constructs, *professional competence, knowing self, physical environment,* and *shared decision-making.* The subset, *type of qualification,* refers to registered nursing and related qualifications (QQI Level 5) for healthcare assistants (HCAs), which are the qualifications currently required to work within residential settings.

6.5.1 Impact of type of qualification within professionally competent construct

Table 6.8 shows the scores for the *prerequisites* constructs. The only construct within this domain that reached statistical significance during the Automatic Linear Regression modelling was that of *'professional competence.'* A one-way analysis of variance between groups was conducted to explore the impact of *type of qualification* on *professional competence.* Participants were divided into three groups according to their type of qualification within residential services, Group 1: Registered Nurse Intellectual Disability (RNID), Group 2: Register General Nurse or Register Psychiatric Nurse (RGN/RPN) and Group 3: QQI Level 5 qualification for Healthcare Assistants (HCAs). There was no statistical significance at the *p* <.05 level in PCPI-S scores for the three qualification groups: $F_{(2, 226)} = 2.9$, *p* =.057. The actual difference in mean scores for the groups was relatively small. Post-hoc comparisons using Tukey HSD

test indicated that the mean score for Group 2 (*M* = 4.50, *SD* = *.528)* was significantly different from Group 3 (*M* =4.29, *SD* = .504). Group 1 (*M* = 4.43, *SD* =.511) did not differ significantly from Group 2, but it did differ from Group 3. This indicates that the staff currently feel that they have the necessary skills to deliver care that is person-centred, but that HCAs scored less confidence in this area than the other groups.

Table 6.8: One-way ANOVA comparing impact of type of qualification on professionally competent within prerequisites domain

	F	df between groups, within groups	Sig	Mean		SD
Prerequisites						
Professionally competent	2.909	2,226	.057	RNID	4.43	.51
				RGN/RPN	4.50	.52
				QQI Level 5 (HCA)	4.29	.50

6.5.2 Impact of type of qualification within care environment domain

Table 6.9 shows the results from the *Care Environment* domain, with the *physical environment* construct reaching statistical significance. A one-way analysis of variance between groups was conducted to explore the impact of the type of qualification on the *physical environment* construct. There was a statistical significance at the *p* < .05 level in PCPI-S for the three groups: *F* (2, 226) = 6.255, *p* =.003, as Levene's test was violated Welch and Brown-Forsythe were consulted. The effect size calculated using eta squared was .05, which is considered a small to medium effect size (Pallant 2016). Post-hoc comparisons using Tukey HSD test indicated that the mean score for each group, Group 1 (RNID) (*M* = 4.43, *SD* = .477*)* was significantly different from Group 3 (HCAs) (*M*= 4.18, *SD* = .544). Group 2 (*M* = 4.35, *SD*=.661) did not differ significantly from either Group 1 or Group 3.

Table 6.9: One-way ANOVA comparing impact type of qualification on the physical environment within care environment domain

	F	df between groups, within groups	Sig	Mean		SD
Care environment						
Physical environment *a*	6.255	2,226	.003*	RNID	4.43*	.47
				RGN/RPN	4.35	.66
				QQI Level 5 (HCA)	4.18*	.54

a Levene's test violated therefore the Welch statistical test was used *Scores which reached statistical significance.

6.5.3 Care process domain

Table 6.10 below shows the results from the care process domain. The automatic linear regression analysis identified '*shared decision-making'* as reaching statistical significance. A one-way analysis of variance between groups was conducted to explore the impact of the *type of qualification* on *shared decision-making.* However, this difference did not reach statistical significance (p = .15). The observed mean scores in each group were similar to each other. This indicates all staff agreed that they felt they facilitated the involvement of older people with intellectual disabilities and their significant others in decision-making in their care.

Table 6.10: One-way ANOVA comparing impact of type of qualification on shared-decision making within care process domain

	F	df between groups, within groups	Sig	Mean		SD
Care process						
Shared decision-making	1.903	2,226	.151	RNID	3.84	.48
				RGN/RPN	3.63	.59
				QQI Level 5 (HCA)	3.64	.67

6.6 The impact of highest level of education within residential services

The independent variable, *highest level of education,* was statistically significantly to zero at the *p*<.05 level, as identified through the automatic linear modelling analysis as a relevant predictor. A one-way between groups analysis of variance across the three domains, *prerequisites*, c*are environment* and *care processes* was conducted to explore the impact of *highest level of education* on the three domains as measured by the PCPI-S. The impact of *highest level of education* was significant in the constructs, *clarity of beliefs and values, skill mix, supportive organisational systems, working with patient's beliefs and values,* and *engagement*. The subset, *highest level of education,* refers to staff that have a Group 1: Postgraduate qualification: Group 2: Degree (Hons), Group 3: Nursing Certificate and Group 4: QQI Level 5 qualifications for HCAs.

6.6 The impact of highest level of education within prerequisites domain on clarity of beliefs and values

Table 6.11 shows the results from the prerequisites domain. Following the automatic linear regression modelling analysis, the only construct within this domain that reached statistical significance was that of '*clarity of beliefs and values.'* A one-way between groups analysis of variance was conducted to explore the impact of the *highest level of education* on *clarity of beliefs and values.* There was no statistical significance at the *p* <.05 level in PCPI-S scores for the four types of qualification groups: F (3, 225) =4.13, *p* =.007. The effect size, calculated using eta squared, was .05 which is considered small to medium effect (Pallat 2016). Post-hoc comparisons using Tukey HSD test showed that the mean scores for the groups indicated significant statistical significance between Group 1 (Postgrad Qualification) (*M* = 4.36, *SD* = .607), Group 2 (Degree) (*M* = 3.88, *SD* = .602) and Group 4 (QQI Level 5) (*M* = 3.86, *SD* = .639), Group 2 and Group 4 did not differ significantly. The mean score between Group 3 (Nursing Cert) (*M* = 4.10 *SD*=.552) and Group 1 (*M* = 4.36, *SD* = .607) was relatively small.

Clarity of beliefs and values allows practitioners to behave and communicate in an effective way in the care environment (McCormack and McCance 2017) values and

belief should be observable in the team and concerns arise if values do not match behaviours. These results indicated that those with a postgraduate qualification felt that they possessed greater *clarity of beliefs and values* within their practice than those with a degree qualification or QQI Level 5 qualifications. It also indicates that those with a nursing certificate were more closely aligned to those with a postgraduate qualification on this construct and agreed they had shared beliefs and values within their teams.

Table 6.11: One-way ANOVA comparing impact of type of qualification on clarity of beliefs and values within the prerequisites domain

	F	df between groups, within groups	Sig	Mean		SD
Prerequisites						
Clarity of beliefs and values [a]	4.134	3,225	.007*	Postgrad	4.36*	.60
				Degree	3.88*	.60
				Nursing Certificate	4.10	.55
				QQI Level 5 (HCA)	3.87*	.63

6.6.1 The impact of highest level of education within care environment domain

Table 6.12 shows the results from the *care environment* domain. The constructs within this domain that reached statistical significance in automatic linear regression were s*kill mix* and *supportive organisational systems.* A one-way analysis of variance on the impact of type of qualification was initially carried out on s*kill mix.* Although there was no statistical significance at the $p < .05$ level value ($p = .019$), post-hoc comparisons using Tukey HSD test indicated that the mean scores had statistical significance between Group 1 (Postgrad qual) (M = 4.57, SD = .428) and Group 4 (QQI Level 5) (M = 4.18, SD = .543). The effect size calculated using eta squared was .013, which is considered a large effect size (Pallant 2016). Group 2 (Degree) (M = 4.26, SD = .468) and Group 3 (Nursing cert) (M= 4.21, SD =.486) did not differ significantly. While the mean difference in score between Group 4 (M = 4.18 SD=.543) and Groups 2 and

3 was small. Skill mix is most often considered from a nursing context and means the ratio of Registered Nurses (RNs) and non-RN in a team (Slater *et al*. 2017). These results indicated that those with a postgraduate qualification agreed that the *skill mix* with their care environments was appropriate while those with QQI Level 5 qualifications (HCAs) did not. It also indicates that those with a degree qualification and nursing certificate were more closely aligned to staff with a QQI Level 5 qualifications on this construct.

Table 6.12: One-way ANOVA comparing impact of highest level of education on skill mix and supportive organisational systems within the care environment domain

	F	df between groups, within groups	Sig	Mean		SD
Care environment						
Skill mix	3.400	3, 225	.019*	Postgrad	4.57*	.42
				Degree	4.26	.46
				Nursing Certificate	4.21	.48
				QQI Level 5 (HCA)	4.18*	.54
Supportive organisational systems	1.912	3,225	.128	Postgrad	3.23	1.02
				Degree	3.15	.91
				Nursing Certificate	3.51	.66
				QQI Level 5 (HCA)	3.44	.90

The mean difference is significant at the 0.05 level**

A one-way between groups analysis of variance was conducted to explore the impact of highest level of education on the construct '*supportive organisational systems'*. This construct reported the lowest overall mean scores of all the constructs examined within the three domains. The *F (*3, 225) = 1.9*, p < .12* was not statistically significant, but the mean scores within groups showed potentially meaningful results regarding highest education level but were not statistically significant with this study size. Group 3 (nursing certificate) (M = 3.51: SD = .66) reported the highest mean score for all the groups while Group 2 (degree) (M = 3.15: SD =.91) reported the lowest mean score.

Group 4 (QQI Level 5) (M = 3.44, SD = .90), did not differ significantly to Group 2. While Group 1 (postgrad qualification) (M = 3.23: SD=1.02), difference in score was relatively small between Group 1 but significantly different between Groups 3 and 4. This indicates that staff who had a nursing certificate qualification felt that they worked in an organisational system that promoted initiative, creativity and safety of persons, underpinned by a culture that emphasised relationships, professional autonomy and accountability, while those with a degree qualification felt that they did not.

6.6.3 The impact of highest level of education care process domain

Table 6.13 shows the results from the *care process* domain with no clear pattern emerging. Differences between the scores in each group were small with neither construct reaching statistical significance.

Table 6.13: One-way ANOVA comparing impact of highest level of education on working with patient's beliefs and values and engagement within the care process domain

	F	df between groups, within groups	Sig	Mean		SD
Care Process						
Working with patient's beliefs and values [a]	1.972	3,225	.136	Postgrad	4.39	.41
				Degree	4.11	.53
				Nursing Cert	4.27	.39
				QQI Level 5	4.12	.55
Engagement	1.952	3,225	.122	Postgrad	4.57	.51
				Degree	4.30	.50
				Nursing Cert	4.26	.41
				QQI Level 5	4.28	.50

6.7 The impact of current role within residential services

Through automatic linear regression modelling analysis, the subset *current role,* was identified as statistically significant within one construct only, *shared decision-making*, within the domain, care environment. Participants were divided into three groups

according to their current role within residential services, Group 1: Nurse managers, Group 2: Staff nurses and Group 3: Healthcare assistants (HCAs). A one-way between groups analysis of variance was conducted to explore the impact of *current role* on the construct, *shared decision-making*. Table 6.14 shows the results from the analysis and as can be seen, no clear pattern emerged. Differences between the scores in each group were small with the construct not reaching statistical significance.

Table 6.14: One-way ANOVA comparing the impact of current role on shared decision-making within the care environment domain

	F	df between groups, within groups	Sig	Mean		SD
Care process						
Shared decision-making	3.201	2,226	.043	Nurse Manager	4.35	.44
				Staff Nurse	4.26	.52
				HCA	4.09	.61

6.8 The impact of size of service within residential services

Size of service refers to the number of people who live full-time within a residential service. Large residential refers to a service with more than 10 people living together or a campus setting, while a small residential service has less than 10 people living together, usually in a community group home. *Knowing self* was the only construct which reached significance with the independent variable, *size of service. Knowing self* refers to the way an individual makes sense of his/her knowing, being and becoming as a person-centred practitioner through reflection, self-awareness, and engagement with others. An independent sample t-test was conducted to compare the *knowing-self* scores for a large residential service and a small residential service. There was no significant difference in the mean scores for large residential (*M = 4.17, SD = .58*) and small residential (*M = 3.99, SD=.58); t* (227) 2.36, *p* = .019, (two-tailed).

The magnitude of the difference in the means (mean difference =.18. 95%, *CI:* .307-.337, with eta squared (eta squared = .024) was considered to be a small effect.

Table 6.15: Independent t-test comparing the impact of size of service of knowing self within the prerequisite domain

Prerequisite domain						
	Large Residential		Small Residential			
Constructs	Mean	SD	Mean	SD	T value	Sig. level
Knowing self	4.17	.58	3.99	.58	t = (434) 2.365	p =.019

6.9 Key Findings

The results showed that staff working in residential services felt that they possessed the necessary prerequisites skills to deliver person-centred care. They also agreed that they engaged in the required care processes to deliver person-centred care within the context of residential services. However, staff remained neutral, either agreeing or disagreeing, that they worked in a care environment that was favourable to person-centredness. Of the independent variables, *type of qualification* and *highest level of education* were found to be the two key independent variables that were statistically significant of the dependent variables across the largest numbers of constructs, with *current role* and *size of service* also found to have statistical importance but across a lesser number of constructs. While *campus setting and years' experience working with people with intellectual disabilities',* were found to have had no statistical impact across the three domains.

Registered nurses scored highly across all the constructs that were examined, while HCAs scored mainly lower across all constructs. This would indicate that nurses strongly perceive that they have the necessary prerequisites to fulfil their role and that they engage in the care process for the delivery of person-centred care within a residential setting, more so than HCAs. HCAs had a notably higher scoring, on the constructs '*supportive organisations'* and '*shared decision-making'*, and '*engagement,* which were similar to that of registered nurses with a Nursing Certificate qualification.

This indicates that they felt more supported by the organisation than some of their other nursing colleagues and that they felt they were involved in the decision-making processes within the team.

The impact of '*type of qualification*' on the constructs represented the nursing qualifications of the staff working within residential services. The constructs examined were *professional competence (prerequisites domain), physical environment (care environment domain)* and *shared decision-making systems (care process domain).* While there were some differences only one construct, '*physical environment*' within the care environment domain reached statistical difference. HCAs scored significantly lower than their colleagues with an RNID qualification, indicating that they did not feel that the physical environment in which they work is conducive to person-centredness (i.e., privacy, dignity, and choice/control). The s*hared decision-making* construct was also scored lower than the other constructs by both nurses and HCAs, while HCAs had a very similar score to RGN/RPNs, RNIDs were slightly higher, indicating that although the groups agreed that they actively participate in decision-making as team members, it was one of the lower scoring constructs.

The impact of *highest level of education,* was carried out on the five statistically significant constructs identified during the automatic linear regression modelling analysis. The constructs were spread across the three domains, with *clarity of beliefs and values* (prerequisites), *skill mix* and *supportive organisational systems* (care environment) and *working with patient's beliefs and values* and *engagement* (care process). However, just two of the five constructs reached statistical significances, *clarity of beliefs and values* and *skill mix.*

Within the *clarity of beliefs and values* construct, those with a postgraduate qualification scored significantly higher than those with a degree and QQI Level 5 qualifications, with both the latter groups having similar scoring. While those with a nursing certificate qualification, scores were statically closer to those with postgraduate qualification. This indicates that those with a degree qualification and QQI Level 5 qualification, were less confident on the impact of beliefs and values on the care provided.

Skill mix also reached statistical significance and this construct refers to the ratio of registered nurses to non-nurses, HCAs with a QQI Level 5 qualification score was significantly lower than those with postgraduate qualification, who were most in agreement with the construct. There was little difference between the other nursing groups with an honours' degree and those with a nursing certificate qualification.

6.10 Summary

This chapter presented the descriptive and inferential results from the PCPI-S. Initially the demographical profile of the respondents was presented, particularly in relation to the *size of the residential service, type of qualification,* and *highest level of education* The results from the three domains, prerequisites, care environment and care process have been presented in relation to these independent variables. The next chapter will now present the analysis of phase two data collection.

CHAPTER 7: QUALITATIVE FINDINGS: THEMATIC ANALYSIS

This is my now

I just had to go…

I wasn't happy with the change…
There were three beds in a row, not nice…

I go to my room for a bit of peace…

We live in a nice place now, beside the shops and everything…
They tell us about our rights and different things…

We love it, staying in the community home…
The staff are beautiful…

I wouldn't go telling you other things…
I like a glass of wine, I go dance…

You know me…

***Poem created from extracts from interviews with older people with intellectual
disabilities from this study (Conway et al. 2019: Poster Presentation)***

7.1 Introduction

This chapter presents the analysis of the qualitative data obtained through focus
groups and individual interviews with staff members, older people with intellectual
disabilities and family members. The chapter commences with an overview of the
biographical data, followed by the presentation of themes.

7.2 The profile of phase two participants

An overview of the key biographical details relating to participants who took part in this
study is provided in Table 7.1. The collection of data came from a number of sources,
two focus groups were conducted: one with nurse managers CNM II grade (n= 7), and
the other with healthcare assistants (HCAs) (n=6). The semi-structured interviews
were conducted with staff nurses (n=3), family members (n=6) and older people with
intellectual disabilities (n=15). A total of 16 staff of varying grades within differing types
of residential services, large residential (congregated settings) and small residential

Community Group Home (CGH) participated in the focus groups, and the semi-structured interviews. The older people with intellectual disabilities lived mainly in small residential services and had lived within services for most of their lives, with two of the older people moving into residential services in middle-age. The majority of the family members were siblings. Each focus group and individual interview lasted on average sixty minutes, with the interviews with family members and older people lasting 30 to 45 minutes.

Table 7.1: Profile of participants

Staff/Family Member/Older Person	No.	Type of Residential Service	0-5yrs in residential services	6-10 yrs. in residential services	>10 yrs. in residential services
Nurse managers (n=7)	3	Large residential		3	
	4	Small residential (CGH)			4
Healthcare Assistants (n=6)		Large residential			
	6	Small residential (CGH)	2		4
Staff Nurses (n=3)	1	Large residential	1		
	2	Small residential (CGH)	1	1	
			Male	**Female**	**Age Range**
Older person with intellectual disabilities (n=15)	**5**	**Large residential**	**2**	**3**	**55-80**
	10	**Small residential (CGH)**	**3**	**7**	**55-76**
			Male	**Female**	**Relationship**
Family Members (n=6)		**Large Residential**			
	6	**Small residential (CGH)**	**1**	**5**	**Sibling = 5** **Relative =1**

7.3 Themes and subthemes from the qualitative data

From the analysis of the transcripts (Appendix 15abc) five core themes emerged, underpinned by several subthemes. These core themes will be used as a structure to present the results of the data analysis and are presented in Figure 7.1. The five core themes identified are titled, '*to be treated as you would like to be treated yourself,'*

'*sainted or bottom of the barrel,*' '*the changing philosophy of services,*' '*given a life of their own*' and finally '*dealing with uncertainty.*' These themes will be explored and evidenced throughout the chapter by extracts from the data.

TO BE TREATED AS YOU WOULD LIKE TO BE TREATED YOURSELF	• It's about Individuality • Really knowing the person • Giving choice and respect
SAINTED OR BOTTOM OF THE BARRELL	• Social stigma of working with people with intellectual disabilities • Feeling valued • Leadership that is clued in and respectful
THE CHANGING PHILOSOPHY OF RESIDENTIAL SERVICES	• You put up with what you had to put up with/physical environment • The changing face of services • Emphasis on regulation
GIVEN A LIFE OF THEIR OWN	• The decision to move to residential services • Living in town • Being active • Fellow housemates as family
DEALING WITH UNCERTAINITY	• Facing retirement • Changing healthcare needs and ageing in place • Dealing with grief and loss

Figure 7.1: Themes and subthemes from qualitative data analysis

7.3.1 To be treated as you would like to be treated yourself

This theme relates to how staff perceive person-centredness within the context of residential services. Overall, the staff participants relayed theoretical knowledge of the principles of person-centredness, they also identified areas which they felt hindered its true implementation in practice. Three subthemes emerged that relate to this theme of *it's about the individual, really knowing the person, giving choice and respect*. The

following themes represent the staff participant's perspectives integrated with the views of older people and family member participants.

7.3.2 It's about the individual

All staff participants were familiar with the term person-centredness, and healthcare assistants in particular felt that it was a straightforward term for the work they do on a daily basis. They felt it was nothing more than new terminology for how they have always worked:

> *"Well, it's pretty self-explanatory, person-centred care, it's focused on each individual and what they need"* (HCA 11).

> *"It's just jargon for what we do."* (HCA 13).

> *"It's normal stuff really."* (HCA 8).

The majority of the staff participants stated that person-centredness was about focusing on the individual with a holistic view of their needs. They elaborated by saying that the uniqueness of the individual was recognised as opposed to a generic approach of service delivery:

> *"Every aspect of their needs, cultural, emotional, social, religious needs."* (HCA 10).

> *"Focus on their individual needs."* (Nurse Manager 9).

> *"Individual to that person alone and not... it's not one size fits all. It's completely the opposite."* (Nurse Manager 5).

When encouraged to elaborate on how individuality was actualised in practice, staff stated that it was facilitated daily by putting the person with intellectual disability first, or as one participant described it as the "*centre of care*" and the service then revolves around their wishes:

> *"I would automatically think that it's for the clients and for the person. It's individualised, it's what they wish: it's kind of client lead not service dictated."* (Staff Nurse 19).

> *"You are putting your service user first, their opinions, the service has to revolve around the service user and that staff have to practice what the service user's wishes are…"* (Nurse Manager 1).

> *"Well, you know you would be looking to be treated as you would like to be treated yourself."* (HCA 10).

The above extracts all represent the theoretical components associated with person-centredness, emphasising that care should be individualised and not service focused. However, in the final quotation staff spoke about how they would like to be treated themselves, thus providing valuable insight that person-centredness is viewed from a staff-centric viewpoint as opposed to the person's perspective.

When pressed to describe how the services revolved around the individual, several nurse managers acknowledged that this did not always happen, amidst busy routines, staff were often rushing the person from one activity to the next:

> *"It is definitely resources and its time as well because sometimes you are forcing somebody on to do something quickly to get it done, so instead of saying you don't have time to do this!"* (Nurse Manager 4).

The interface between the cited theories and actual practice was often compromised with the needs of the organisation taking priority over the person's wishes. Citing a lack of resources as a barrier to the implementation of the person's individual wishes, the following example illustrates how the organisational needs dictate how people's lives are structured within residential services. One nurse manager talked about a 70-year-old man with health issues, who still attends a day centre five-days per week and requested an extra lie-in during the week. She explains that this request is not straightforward to facilitate in a small residential setting:

> *"He is going to be 70 this year and he goes out to work every day. His choice is he would like to have a lie-in. Now that's a resource implication in that he has been allocated one lie-in, but at his review he has requested a second one. My line manager said I will have to look into resources because that will be three hours of an extra staff."* (Nurse Manager 3).

The nurse manager continued to explain that his request is still awaiting approval:

> *"He has only got one yet … don't get carried away!* (Laughing) *We are waiting for the white flag!"* (Nurse Manager 3).

When asked how person-centred practice is evident within their area, all staff grades felt that this was again achieved through individuality, which was expressed through the person's person-centred plan, and this is where person-centredness could be evidenced. All residential services had tools in place, such as a person-centred planning, to gather biographical and personal knowledge relevant to each individual. The plans were frequently alluded to by staff as a resource to record and demonstrate person-centredness in action. This collection of information is maintained to inform practice and staff appeared to place value on eliciting and utilising such knowledge in day-to-day staff interactions with older people:

> *"Well, it is reflected in their care plans like that they are all different, that they are not the same. Like not everyone likes going for a take-away."* (Nurse Manager 5).

> *"It's all in their care plans and it's all written in there. Over time there is a picture built up of the person, so if someone from the outside comes in, they get to know them as well ... they know what to do."* (HCA 11).

For one older person, they felt their person-centred plan was a means to talk about what they needed:

> *"Yeah, we do have PCP's we can talk about what we needed."* (Older Person 17).

Although some older people did not associate a direct link from their needs being met to their person-centred plan, making more frequent reference to the weekly house meetings, as a means of communicating their needs or resolving issues:

> *"They had a meeting every Tuesday what we were going to do for the week."* (Older person 25).

Conversely, one older person who lived in a community group home thought these meetings were held too frequently, with the same questions being posed repeatedly at each meeting.

> *"'We have the meetings twice a week, too often. Same things over and over again, asking you." (*Older Person 18).

Several staff cited that individuality was expressed through the personalisation of the older person's bedroom. Here their individuality was evident as opposed to the remainder of the house:

> *"Each client has to have their own bedroom. Going back years ago you have people sharing the room, but you can't have that anymore now, that's gone now which is only right. They have their own personal space."* (HCA 9).

> *"If you went into their bedroom, you would see that it is individual to that person, family photographs or whatever they are interested in...so it's the staff that would facilitate the service user to decorate their room whatever way they want to decorate it, bring out their own personalities in their bedrooms."* (Nurse Manager 4).

The importance of individual space was certainly evident from a comparative analysis of field notes across services. Many of the older people with intellectual disabilities who participated invited the researcher to view their bedrooms and personal photos of their family and friends during the interview, whereas others, invited the researcher to visit their home and view their bedroom later, if the interview had taken place at another location.

Participant's bedrooms were an important aspect of personal and private space containing their belongings and where they could relax and get time away if they wished:

> *"When we started off here, there was two to every room. Now we have our own privacy, and you can do what you want. I have my own TV and radio and if I want to go down there and listen to the radio or I can watch TV and it's better. The services have got a lot better but there is plenty room for improvement as you know."* (Older Person 17).

> *"I will show you all the rooms. I have a television in my room. I have my seat. If there is anything on, I go down to my room and I watch the television."* (Older Person 25).

> *"… I have a TV in my room, I watch it there, I must show it to you. Sometimes I watch in the sitting room…I have the photographs if you want see them?"* (Older Person 26).

Reference to the individual and individuality was frequently present within the data, but as the discussions progressed the healthcare assistants acknowledged this as a recent shift within community group home settings, away from '*group-thinking*' to an individualised approach, despite having worked in these settings for over 30 years. Previously they had been encouraged by '*the service*' to treat people as a homogenous group and not in an individualised manner, as the extracts below show:

> *"That's what I think the difference is now with person-centredness, it's changed now from where it started from years ago. We used to treat them as a homogeneous group, we used to make tea for everybody at the same time, we moved as group together….I think, we saw them as individuals, but the service didn't."* (HCA 3).

> *"Going back 30 years there was no such thing as person-centredness, but now each client has a goal, it could be a night away or whatever it might be. Years ago, there were no goals, you did the best you could, but you were catering to a group."* (HCA 9).

7.3.3 Really knowing the person

The majority of nurse managers outlined the attributes of the staff and what they believed contributed to achieving person-centredness. They referred to '*knowing the person*' as being crucial to the delivery of individualised care. However, this particular form of '*knowing*' the person went beyond the usual biographical knowledge of likes and dislikes and food preferences, facts that are generally documented with person-centred plans. This form of 'knowing' represented a more profound therapeutic knowing and was described as the '*core relationship*' that the staff should develop with the person. It involved staff members seeking to understand and respond to the person on a deeper level, both cognitively and emotionally, to facilitate greater life choices and personal development. '*Knowing*' the person involved taking the time and effort to develop a therapeutic relationship and was perceived to be a key requirement as detailed in the following quote by a nurse manager:

"... the key thing to me walking into a room would be the relationship the staff have with the resident/service user, …the more they learn about that person, and they learn and delve into, more than they like the colour green, but that they like different things, I think that's the core the relationship." (Nurse Manager 3).

The same nurse manager went on to elaborate on the essential components of staff relationships, which they felt went beyond the scope of the person-centred plans.

"...I think that is all person-centredness...and it's all very well that we have our plans, that Heather likes take-away but she doesn't like mushy peas, you know, but I think it is more than that, I think that true person-centredness is really knowing the person." (Nurse Manager 3).

However, the sense of *'knowing'* the person also had its detriments, as nurse managers felt that healthcare assistants who worked with the same people for many years, felt they knew the person best, resulting in a barrier or reluctance to try new approaches:

"I think for some staff in group homes... they think they know everything about that service user, so there is no change. They become institutionalised themselves." (Nurse Manager 4).

The same participant went on to say:

"I think its fear, they are fearful of change of what enhancement, impact it will have for them. How it is going to affect doing that sort of thing, more paperwork will I have to do? To keep things to a minimum." (Nurse Manager 4).

Three nurse managers associated this reluctance with fear of change and a consequence of a lack of role development and training other than mandatory training. There are now new higher expectations and responsibilities required of healthcare assistants, especially regarding maintaining documentation which they did not have previously:

"…but they weren't asked to keep report books or progress notes or whatever. Now we have got this big PCP and they feel daunted, they have been given no training. The only thing our staff get is mandatory training." (Nurse Manager 3).

Newly employed healthcare assistants who held a qualification in social care were familiar with and had the ability to complete the required paperwork. They also had innovative ideas and ways of working, all of which were reported as a source friction and resentment between the new and the established HCAs, some of whom were reluctant to take on board new approaches. Nurse managers were concerned on the impact of this opposition to change on older people:

> *"Now staff on the ground who have worked for years are feeling daunted because the 'newbies' are in, and the paperwork isn't a problem to them…"*
> (Nurse Manager 3)

> *"…who is this one coming in, she knows it all: "I have worked here for 20 odd years - I know." That's what happens."* (Nurse Manager 2)

> *"…some personalities will take it on board, other personalities will dig their heels in, and it will be confrontational and that reflects on the service users."* (Nurse Manager 4)

One staff nurse agreed that truly '*knowing'* the person went beyond the scope of the person-centred plan, with true *'knowing'* emerging from the experience of delivering the fundamentals of care, particular in relation to people with a severe and profound intellectual disability:

> *"I think it's quite hard calling in; you can't just: even by reading a person-centre care plan until you're working with them, you can put it down on paper, but I don't know…you know them, and you know when they're content with something or they're not or when they want something done."* (Staff Nurse 15).

'Calling in,' was a reference to staff consistency and continuity which nurse participants viewed as essential for *'knowing'* and the ability to work with people in a person-centred way. Several nurse managers questioned if it is possible to maintain person-centredness with staff shortages, referring to the frequent use of agency staff resulting in a lack of continuity of care. Although tools such as person-centred plans were in place, these were deemed to be limited or inadequate when maintaining continuity and safety in services:

"…last week I had a strange agency staff who arrived in. They all have huge personalities. Their PCPs are 4 inches thick…how can that person can even think about person-centredness...you want these people to be safe…" (Nurse Manager 3).

"…consistent staff and knowing and having that relationship, so even though it is not verbal, but you look for your non-verbal cues, the slightest change, do someone's eyes light up or is there a grimace when you offer something…but that's where it comes down to the regular consistent staff that want to build the relationship…" (Nurse Manager 2).

A healthcare assistant participant who had recently worked in the service as an agency staff shared her experience which reflected many of the concerns expressed by nurse managers regarding agency staffing:

"… prior to me coming in I was working as an agency, and I was thrown in the deep end… a lot ..." (HCA 11).

One older person did take note of when agency staff were replacing the permeant staff, stating that they didn't mind if they knew in advance who was coming in to replace the staff member:

"Yes, we don't mind it and its okay if someone has to go off." (Older Person 24).

A family member had experienced high numbers of agency staff working with their sibling in a small residential service, in the absence of permanent staff members. They expressed similar concerns to those of the nurse mangers regarding the frequent use of agency staff:

"…there was a lot of different people. So, in that it's not ideal really in any situation." (Family Member 31).

This family member was concerned about how this affected not only the fundamentals but also the continuity of care for the person and questioned how the health needs

and appointments of older people could be planned and monitored when staff changed frequently, as indicated by the following comment:

> "*… it's not the same as having people you know, with continuity, with planning for going to the chiropodist and other appointments and their clothes.*" (Family member 31).

However, staff consistency also referred to consistency of approach by permanent staff, indicating that staff do not always adhere to the principles of person-centredness within their role. Nurse managers attributed this to either a lack of understanding or the personality of the staff member, who either adopted a person-centred approach or simply decided not to, resulting in a negative impact on care delivery. There appeared to be a lack of clarity around acceptable standards of care that are delivered within teams, with staff randomly deciding how they work as opposed to an agreed approach:

> "*It is down to the way the staff actually feel and understand person-centredness and do they understand the concept of it and are they abiding by it. It doesn't take long to offer 'do you like Weetabix or Cornflakes?' It doesn't matter if you have asked that question every day but you still have offer it…*" (Nurse Manager 2).

> "*…some personalities will take it on board, other personalities will dig their heels in, and it will be confrontational and that reflects on the service users.*" (Nurse Manager 4).

Another nurse manager believed that person-centredness came from personal characteristics and the internal motivations of the staff member, regardless of training in the concept:

> "*Well, I think that the staff that I would work with at the moment, would never had any training in person centredness and I think it very much comes from the staff. I think that their instincts their personalities, the reason they are doing the job they are doing.*" (Nurse Manager 3)*.*

7.3.4 Giving choice and respect

The data further revealed that staff associated their roles with giving choice and respect to each person. These two factors seemed interconnected and were often mentioned in unison as one concept. When asked for examples on how choice is

currently facilitated, staff focused on food and menu plans and offering choice of outings and activities.

> *"Like meal plans or you know their different requirements or with their likes and dislikes something as simple as their meals."* (HCA 11).

> *"…it's high support. They need a lot of help, very poor communication; you're constantly asking them, offering them choices would actually be the best way to describe that, giving them choices every day …"* (Staff Nurse 16).

> *"… they have a menu choice. So then see what activities in the evening, if they like to watch TV, go downtown to get shopping, if they need to go to the Post Office. Attend to their personal hygiene as well, that all has to be done, so people would see us doing what we have always done, and they see all that. It's all very natural, very normal."* (HCA 9).

Offering choice of food via menu planning, outings and activities was also strongly associated with respecting the person and their wishes. Different grades of staff interpreted their role differently, with several healthcare assistants taking a parental view of choice and respect, comparing their role to that within their own family, and referring to the older person in terms of children.

> *"We treat them like we would treat our own children, with respect."* (HCA 9).

> *"They like to do that, to have the outing whenever, just have a staff to themselves, just like your kids would and get mollycoddled a bit, having their mummy-daughter day."* (HCA 10).

> *"All of their needs like our own family."* (HCA 8).

One staff nurse also referred to how older people were viewed as children by healthcare assistants, and this was attributed to the fact the people with intellectual disabilities had been in the service since childhood and the same staff members had known them since they were "*…like literally babies*" (Staff Nurse 15).

> *"Especially because a lot of clients are here since they were really young as well; you know they've grown up working with each other for so long."* (Staff Nurse 15).

Despite this, healthcare assistants demonstrated an awareness of the childlike perception of people with intellectual disabilities within society. One HCA relayed an account of an evening outing with older people when the organiser of the play advised the staff that there was 'adult content' in the storyline, and it was not appropriate for people with intellectual disabilities. It appeared that the older people with intellectual disabilities were not consulted or involved in the decision, but the healthcare assistant made the decision on their behalf and proceeded to see the play.

> *"... it was pointed out to them that they are adults…I tried to negate any upset that they might have. So, when I reflected on it at the time, I thought well they watch 'EastEnders' and they see all sorts of things on the telly, so would it be any different to the stage?"* (HCA 13).

One family member recognised that encouraging the person to make choices was now a prominent feature in their relative's daily life. However, they did question the number of choices the person was given and their capacity to cope with distinct options and they felt it may be causing the person to become stressed.

> *"…I feel with her capacity to deal with choice, make that decision. Sometimes it's causing more stress on her in some respects because she's now believing that she should, this should happen and this should happen…and if it doesn't happen it bothers her…"* (Family Member 31).

Several older people felt that the lack of staffing impacted on their choice and social outings. For example, one older person stated that he would like to stay overnight a hotel but was prevented from doing so due to staff shortages, his experience below is outlined:

> *"The staff seem to be the problem. We could arrange something if we were going away for a night or two maybe stay in a hotel but if they haven't the staff to go with them, because normally it would take about two staff now to look after things."* (Older Person 17).

Several staff noted that choice could be enabled to a certain point, but if someone wanted to be spontaneous with their activities this could not be accommodated due to lone working arrangements within small residential services in the community. Lone

working impacted upon individual choice and the person's freedom, as the needs of the group had to be considered. This nurse manager provides a scenario below:

"It is one staff member with 4 people, so 4 people have 4 completely different personalities. On a summer's evening if one of them says "I would love to go for a walk" but the risk assessment says that they have no road sense whatsoever. If the other 3 people don't want to go for a walk, well then, that person can't go for a walk. …we encourage them to speak, and we have weekly meetings, and they say what they like to do but really then they can't be impulsive." (Nurse Manager 3).

The data further revealed that important life choices for people with intellectual disabilities were being made without meaningful consultation or inclusion of the person, or their families. They purported that families are being presented with major life choices about their sibling, such as where to live and with whom, without proper consultation. They referred to the national decongregation policy with older people now moving from congregated settings to community living. In reality, these decisions had already been made at a higher management level within the organisation, rendering choice and family involvement meaningless and merely an illusion, as the decisions had already been made. As frontline staff, nurse managers reported that they were not included in the planning or decision-making process for the people they currently care for.

"… as an organisation we are inclined to give lip service to families… they have huge reservations about their family members moving into the community. Yes, they were met with by management, but really it was lip service because at the end of the day under de-congregation they were moving." (Nurse Manager 3).

"I walked into an office one day, there was a diagram of houses, and all the names were in it. It was the first I heard of it…so that person is going to come to live with strangers." (Nurse Manager 7).

This participant went on to talk about how choice is presented to families:

"They will have it presented in a lovely little package…but they don't have a say, maybe some do but others don't." (Nurse Manager 2).

Nurse managers felt that families did not complain or express their anxieties about changes for fear that it would impact on their family member and the service they receive.

"The families still have a fear factor…well it could impact their person, it could impact the service that is given, where it is not, maybe historically it might have been like that and if you say to them if something isn't right? It's a very kind of backward view." (Nurse Manager 1).

Fear of complaining was also echoed by one family member who felt that other families were not confident enough to complain, perhaps feeling intimated.

"I would be communicative whereas I know that some of the other families would not. And that could be a question of lack of confidence, of still an old relic of intimidation, being afraid to speak up…" (Family Member 35).

The lack of choice on important life decisions such as where to live, was also reflected in the accounts of two older people who reported that they had no choice other than to move into residential services. Both older people retold their experience where they had previously been living at home in their local community with their families until the death of their family member(s) resulting in an emergency admission into residential services, it was a difficult and emotional time for them.

"When my father passed away and then my mother, I moved... it's made it hard for me, I bottle it up." (Older Person 18).

"It was… terrible shock, I couldn't go home after that." (Older Person 23).

Both participants talked of being excluded from the decision-making process and they were not offered any alternative other than to move to a particular designated residential service. One participant said how they were told by staff to *'live there.'* Planning meetings took place, but the participants stated that they were not included or consulted during the process. Neither were happy about how the move to residential services had been dealt with and felt they were given no choice or input into the major life changing decision for them, as the excerpts below outline:

"Lots of meetings behind my back…Not to my face, behind my back meetings, not to my face…No, no choice." (Older Person 18).

"No, no I wasn't, nobody told me anything, I just stayed here, didn't go home." (Older Person 23).

This participant went on to say:

"No, nobody said anything… it's been going on too long, I don't know what's happening." (Older person 23).

Following this experience, the older people were left with troubled feelings about how the situation was handled and they expressed upset about their lack of control and their opinions not being taken into consideration, this situation remained unresolved for them both.

"I'd like to move back it's my hometown'…two times, staff didn't want to know, no-one wanted to know, all my friends there..." (Older Person 18).

"… what I would like too is move to it's a nice town…they're not doing anything for me here." (Older Person 23).

Respect for the person was closely connected with choice and perceived by staff as a central aspect of their role. Staff participants felt that they demonstrated respect for the older people through continual communication and listening to the person. This in-turn lead to shared decision-making and enabled the person's choices:

"*Respect, respect for them in every capacity, kindness."* (HCA 11).

"The respect that the staff have for the service user as well and they can demonstrate that in how they speak to them and how they acknowledge their choices…and fulfil those choices." (Nurse Manager 4).

The majority of older people agreed that they were respected and listened to by staff. However, one participant highlighted that when he asked to go out dancing at the weekends, certain staff refused to take him. Some staff were willing to go out while others were not, and this depended on which staff member was on duty. Eventually the older person required intervention from the day service staff to advocate on his behalf.

"Staff don't talk to you; they don't want to know…yeah more dancing… They didn't want to go, that's staff for you." (Older person 18).

Healthcare assistants appeared to carry out many of the social outings, they often provided feedback to the nurse on duty as to how the outing went and if the person enjoyed it. Their opinion appeared to maintain a level of control as to whether the person should engage in this activity again:

> *"… it's often care staff that will come back to nursing staff and tell the nurses what the client is interested in or if they've been out and undertook some activity and then feedback as to how much they enjoyed it and whether they should go again."* (Staff Nurse 14).

Older people talked about turning to staff if they had a problem or any worries. They felt that they could confide in staff and were confident that staff would resolve the issue for them and treat it in a confidential manner:

> *"Ohh the staff, we have too, you see, if we have a problem, we'll just go and say to the staff."* (Older Person 24).

> *"No one else hears it* (the problem) *only the staff, they keep it inside anything, it doesn't go outside the house. They keep it private."* (Older Person 25).

> *"I have been treated quite well indeed. I have been spoken to in all kinds of ways, but I can handle that, but no, they are not too bad that way."* (Older Person 17).

Two older people did not agree that they were listened to by staff. One older person, who lived in a small residential service used a powerful analogy when he described staff as being like "*ghosts"* who ignored his attempts to interact with them when he did have an issue he wished to resolve. It was evident from his disclosure that he felt staff attitudes were not reflective of a person-centred approach and they were not respectful towards him as a person:

> *"Every time I talk; they don't want to know'. Staff don't want to know what's going on, staff get away with too much...staff walk away, like ghosts, they just walk away."* (Older Person 18).

Another simply stated that he felt staff did not listen to him:

> *"No, they don't listen"* (Older Person 23).

7.4 Sainted or bottom of the barrel

This theme relates to how staff experienced their role from both the perspective of the society in which they live and the organisation in which they work. There are three subthemes within this core theme, *stigma of working with people with intellectual disabilities, feeling valued, and finally leadership that is clued in and respectful.*

7.4.1 Stigma of working with people with intellectual disabilities

Healthcare assistants spoke about their initial experiences of people with intellectual disabilities relocating from an isolated large residential service into smaller residential community group home settings some 30 years ago. Four healthcare assistants talked about the wary and hesitant reactions they received from the general public within the local community:

> *"…we would have been very much on our own and very much isolated, there was a lot of staring and looks and everything but gradually as we kept bringing them to things, going downtown into the pub, whether we were accepted or not, kept bringing them to mass…." (*HCA 8).

> *"…going back years ago they were probably afraid of them that was the perception."* (HCA 9).

Things had now improved and people with intellectual disabilities were now accepted as part of the community.

> *"…but it's totally different now, they got used to us, got used to the clients, it's more fair."* (HCA 8).

One healthcare assistant spoke about the reaction from people at that time when she talked about working with people with intellectual disabilities.

> *"I know before people would have said to me, are you not afraid to work with those people?"* (HCA 9).

Other participants then commented that they still receive similar reactions today and they found that many of their acquaintances considered that working with people with intellectual disabilities is something to be feared or is undesirable:

"Someone just said that to me recently." (HCA 10).

The interaction between the participants continued:

"I would say to them, I work with six gentlemen, and someone said to me, would you be there on your own with them?" (HCA 10).

"Are you not afraid of them? I was shocked the fear would be the last thing that would come into my brain." (HCA 11).

During the discussion it was suggested by one healthcare assistant that members of the general public who held this view were uneducated and ill-informed about people with intellectual disabilities:

"I suppose the lack of education on the part of these people." (HCA 9)

"But these people were not uneducated, and I was shocked, shocked." (HCA 11).

As can be seen from the above extract, the participant refuted that the level of education was the cause of these negative perceptions. Moreover, participants agreed that as paid carers for people with intellectual disabilities, they experienced two opposing views of the role by the general public. They were either elevated to the status of *'sainthood'* or someone who could find no other form of gainful employment.

"Some people would say things like well, sure it's a job, it's a job." (HCA 9).

One participant described her experience in the following manner:

"I find you are either completely sainted, or you are completely the bottom of the barrel, you can't find anything else to be doing only looking after these?" (HCA 13).

Healthcare assistants possibly experience public reaction more frequently as they carry out many of the social activities with older people within their local communities. One staff nurse highlighted that the healthcare assistant's role focuses on facilitating outings and enacting the person-centred planning goals as opposed to the registered nurses:

"…it is the care staff who then facilitate the outings and facilitate the actual activities that people want to do, …nursing staff are often left probably back on the floor doing the admin and the notes side of and you know doing medications." (Staff Nurse 14).

7.4.2 Feeling valued

The data revealed that staff had varied experiences of feeling valued in their role within the organisation. Some nurse managers described their interactions with their line-managers in terms of stressful and pressured encounters which left them feeling devalued and chastised:

> *"I feel I'm being hounded constantly, that's how I feel. I know that going in the door and I think she is going to kill me. What is she going to look for, I'm going to be held back and this is you going into work every day thinking that you are not up to scratch. You have not got the standards and you have not got your work done properly and you are going to be criticized about it. …"Why haven't you got this done, get me, get me, get me, where is it now?"* (Nurse Manager 4).

On examination of the field notes, the discussion brought about nervous laughter from nurse managers, who seemed uneasy and uncomfortable discussing the topic. In terms of their interactions with their line-managers, they portrayed them in a negative context, with the continual fault finding leaving them on edge:

> *"It's negative, they want to see it's not done."* (Nurse Manager 1).

> " *Yes, slap across the wrist for "Why isn't it done?"* (Nurse Manager 2).

> *"You are being told that they are disappointed in you and I'm there going I wouldn't say that to my child. You would say "You know you are not up to scratch you're not on the ball with that...!"* (Nurse Manager 4).

Nurse managers felt the attitudes from their line managers were unsupportive and lacked consideration regarding the difficulties they faced in managing small residential services which are sporadically place over a geographical area. They described the challenges of carrying out the administration work associated with their role, with scant resources:

> *"…I have got three houses, they are all over the place, I have no IT, they have no internet, I have no printing, I can't print anything off. I have to gather stuff in my car in one place and bring it to another place."* (Nurse Manager 3).

Staff nurses had varied experiences within their teams with most feeling supported and valued by their managerial structures. One staff nurse reported that they were being proactive in their role and tried to raising issues, concerns or even observations with their manager but it was perceived by managers as being negative and the issues was ignored:

> *"I don't think that, in general, the management support is that encouraging for you to actually bring issues. I think I've gone with various observations and issues that haven't been… that I've been told not to, you know, not kind of, not to be negative!"* (Staff Nurse 14).

While other staff nurses reported that they were supported within their role by their line-manager, more so than in previously places of employment:

> *"Yeah definitely…they'd always be there discussing, seeing what we think, any different opinions, definitely. It's not just one level I have to say, I've found managers really, really good ..."* (Staff Nurse 15).

In contrast to the nursing managers the healthcare assistants stated they felt valued in their roles and empowered to voice their opinions if they had concerns. They talked about how their teamwork and efforts were celebrated and given recognition their manager for a positive Health Information Quality Authority (HIQA) inspection report. They felt the recognition was appreciated but would not radically change the way they work:

> *"Well, our HIQA report is being celebrated I don't know if everybody knows or not, but our manager told me she is organising a night out for us all."* (HCA 13).

> *"We got a letter that said congratulations… my co-workers put in a serious amount of work into getting to achieve the HIQA improvement. She was slightly miffed you know that she really didn't get acknowledgment for work that you know that she would have done a massive amount and rightly so, some celebrate, some not."* (HCA 11).

> *"That's it, it's not going to change what you do anyway."* (HCA 8).

Various healthcare assistants highlighted as lone workers in small residential services they often work in isolation over extended periods of time and did not have regular

daily contact with their managers. As a result, they purported that their team support structures came mainly from other healthcare assistants. It emerged that some healthcare assistants did not really perceive their managers as part of the team structure, and this appeared to be either due to the lack of day-to-day contact or managers changing jobs regularly:

> *"Whereas my manager wouldn't be hands on at all, I wouldn't see her from week to week to week. Apart from rotas and practical things like that, or training, but no hands on at all, no 'how it's going?"* (HCA 11).

> *"Managers have come and gone over the years, and we continue our jobs."* (HCA 8).

The extract below describes the positive relationship that healthcare assistants had with their manager, but it was unclear from the data what prevents the manager being fully perceived as a team member or why limits were placed around belonging to the team:

> *"The other thing is our manager is very approachable, I mean she really is, so I would see her as just another member of the team, within reason"* (HCA 13).

Lone working was identified as impacting on healthcare assistant's morale and well-being, specifically over weekend periods that require sleepover shifts. They detailed the lack of sleep, dealing with stressful situations alone, with no official breaktime away from the service, which left them feeling socially isolated and psychologically stressed:

> *"…our jobs can be very stressful, we don't always sleep great at night the responsibility and all that, and sometimes you know breaks maybe at the weekends or stuff. …some of us are more stressed that others with stressful houses and it would be nice if you got half an hour off you know."* (HCA 8).

> *"We put up with a lot of isolation."* (HCA 9).

> *"…because our service users are mobile and we are out most of the time doing stuff, but there is one house …staff come in at 1 o'clock on Saturday and doesn't leave the house until Monday morning, with one staff on. That isn't easy."* (HCA 9).

Healthcare assistants articulated that they have experienced burnout in their roles. Whereas previously they would have given the extra time following their shifts to accommodate the needs of the older people, they no longer felt they had the energy to give more to their role:

> *"We would have started with a group back years ago; you would have done it. But now we are all burnt out, oh no I have to do again tomorrow I can't go for that walk."* (HCA 8).

Several family members spoke about how they valued the staff working in services and the positive relationships between the staff and their relatives, which reassured them that quality care being provided. They described the staff in terms of *'national treasures'* who ensured that the older person was happy in their home life:

> *"…she is very happy here and it's a great tribute and I say it as often as I can to the staff, it's a great tribute to them. I mean the housemothers are to me, are national treasures. But the whole team are fantastic…"* (Family Member 35).

The same participant spoke about how their family valued the residential services and the staff who worked there acknowledging the contribution they have made to the happiness of their sibling:

> *"It is wonderful. Absolutely wonderful….to me the carers, the house, everything…is just, we are absolutely as a family, we are just gobsmacked."* (Family Member 33*).

Family members also appreciated the significant level of input and communication they received from staff, saying they were happy with their current level of involvement in the care delivery. Staff contacted them regularly regarding the slightest change or incident which they found reassuring:

> *"So, they ring every single time if there's anything; if she's to see another doctor at all they'll ring you."* (Family Member 30).

> *"…I have enough…I suppose I know he's so well looked after and he's so involved in everything..."* (Family Member 32).

7.5.3 Leadership that is clued in and respectful

Leadership was specifically identified by family members as an influential factor in how services were managed and developed. It was evident from the data that the majority of the family members had a good rapport with the staff and although some of the family members did not use the word leadership, they acknowledged the leaders of the services and their personal commitment to their role and to their sibling. Family members described the effectiveness of new nurse manager in introducing change and consistency to the staffing within the service:

> *"...this made a difference in the houses."* (Family member 31).

Family members were conscious that nurse managers went beyond the of call of duty when an incident occurred, staying with them in hospital and visiting them on their day off to ensure the older person was okay and to support the family. The following two extracts reflect the positive impact and commitment of the new nurse manager:

> *"There seems to be more continuity... so rather than people coming and going because there would be a lot of locums coming as well."* (Family Member 31).

> *"…my brother went up to the hospital, but it was about eight o' clock in the evening. The nurse manager was supposed to have finished at four o' clock and was still there. Following morning she arrives up with a yogurt or whatever, she wasn't even on duty."* (Family Member 33).

One family member participant highlighted the importance of leadership beyond frontline staff as a key factor of how services are progressed and developed. They spoke about how people in positions of power should be monitored by robust governance structures to ensure they fulfil their remit and impart their role in an ethical and productive manner:

> *"It depends on who the individual is, who has the power in that position and how monitored they are and what their own personality is like."* (Family Member 35).

They went on to elaborate that those in leadership positions need to be respectful of the populations they serve and even more so if those populations that are vulnerable:

"…and people in decision power making positions; if those people are not clued in and respectful." (Family Member 35).

7.5 The changing philosophy of services

This theme relates to the philosophy of care and how services have changed and evolved over time to meet the needs of people with intellectual disabilities. This theme is comprised of three subthemes, *you put up with what you had to put up with, positive developments in services,* and *the emphasis on regulation*.

7.5.1 "You put up with what you had to put up with"

The data revealed the vast changes and improvements to the living conditions for older people with intellectual disabilities. It was clear that both older people and their family members felt that these changes had brought about major improvement in their lives. This theme reflects people's early life experiences, the move into residential services and the physical environments they encountered. The majority of the participants recounted their personal experiences and early years within residential services. Over half of the respondents entered residential services as children or young adults, while two of the residents entered residential services later in life following a family bereavement.

Some older people did not mind the move away from home, while others did not like the change, with many stating that nothing was explained to them about moving. Many of the older people spoke about the institutionalised nature of the services and the poor living conditions that they were faced with, such as, dormitories, damp living accommodation and isolated rural areas.

Many of the interviewees appeared resigned and conditioned to be accepting of these circumstances and one person felt the activities available to them out weighted the institutionalised nature of the service. They spoke about the poor-quality physical environment and the shared dormitories which were not easy to live with:

> *"When I was between six and seven when I went away first…it was all dormitories. There were three beds in a row. It was more institutionalised at that time, but you put up with what you had to put up*

with, but it was quite good actually. There was a lot of things to do there."
(Older Person 17).

He went on to describe how his parents travelled the long distance in 1970s from the Northwest to Southeast of Ireland each week to visit him:

"When I went away first in the beginning my parents God rest them, they used to come down every week to see me when I was about 6 or 7 years of age." (Older Person 17).

As he grew up, he described another residential service he was placed in, revealing that he had no choice but to tolerate the conditions:

"Oh no, it was ok. It was serious what you would put up with and that was it." (Older person 17).

Another older person described her experience of the first residential service she lived in as a young adult, she did not like the house as it was damp with a leaking roof and was in an isolated area in the countryside:

"No, I wasn't happy with the change...I just had to go there. No, I didn't like it at all, so I didn't. There was rain coming down through the roof..."
(Older Person 27).

Three family member participants also recounted these experiences from their perspective and the tough decisions their parents faced in wanting the best start in life for their child with intellectual disabilities. This often meant that the children had to leave home at an early age and move long distances from their families to attend a specialist residential school:

"...she had had to go to boarding school in Dublin from the age of eight. ...there was no Special Ed in those days. So, my parents had to make a very tough decision..." (Family member 35).

"But then she couldn't go to school, so she went up to that school for handicapped children in those days..." (Family member 34).

The reality of the move to specialist services did not always reflect the aspirations of the families, with some saying that they noticed their sibling had regressed on their return home or had adopted new behaviours they had not displayed previously:

"…her behaviour had gotten worse. I expect they copied the others, that's what they do." (Family member 33).

Another family member recounted how their sister had not improved from her time in the specialist school and attributed this to the attitudes of the time. This prompted them to provide an example of such attitudes, recalling a situation of cruel and unhuman treatment her sister was subjected to when a medical doctor sutured her sisters cut without an aesthetic or pain relief, under the belief that children with intellectual disabilities did not feel pain:

> *"….my parents were disappointed when she came back as to how little she seemed to have progressed…she fell off a swing one time…she had a whole gash on her chin that needed stiches and the doctor who was doing it, the nun said 'aren't you going to give her an anaesthetic?' and he said no, he said children like this don't feel anything hold her down."* (Family Member 35).

Following on from specialist schools, family members described their first experiences of the available residential services options at that time. They recounted the basic infrastructure of the accommodation with large numbers of people laid out in a dormitory style setting:

> *"… transferred her over into the HSE Residential and they were hostels, they were very basic, there were 20 of them in it. There were 5 in a dormitory style, no sitting room…"* (Family Member 35).

> *"…the poor wains* (children) *there were, you know like a day room. There were loads, maybe I don't know, 15-20 and they were all different, you know."* (Family Member 30).

Historically within the Republic of Ireland, many people with intellectual disabilities were placed in local psychiatric hospitals due to lack of specialist services. Family members talked about this experience as a negative time in the care of people with intellectual disabilities:

> *"I went over and took her home and it was the only place then at this stage… which was, it was awful….she was on a lot of drugs"* (Family Member 34).

Although these accounts were representative of the services throughout 1980s and 1990s, family members and older people spoke about their recent challenges in

accessing better quality housing, this experience has been within the last five years and for some is still ongoing:

> *"Yes, the house had deteriorated greatly because it was a private landlord who wasn't prepared to do repairs; they'd been in it a long time but also it wasn't suitable for them because you know they're older, even if they're not older they have mobility issues. They don't move very fast…and the stairs were quite narrow, and it wasn't suitable having an upstairs."* (Family Member 33).

One older person commented on the condition of the house they had been living in previously as being damp and in an unsafe area. They also described the challenges in finding a suitable property to move into:

> *"No not nice. The estate was terrible… it was leaking and everything. Damp, we had to move. It was an awful job to get a house anywhere. We got here."* (Older Person 25).

For one older person who currently shares a bedroom in a large residential service, talked about her previous experience of sharing a bedroom with another housemate, who would disturb her sleep during the night, by slapping her face, pulling her hair and pulling the bedclothes off her during the night but she had to continue sharing. She was resigned to this happening and did not complain but it was unclear if her complaints would have been recognised.

> *"…she would pull the clothes off me… but she wouldn't mean it, you know she wouldn't mean it."* (Older Person 28).

The accounts of older people and their families then moved into discussing their current homes. All the family members and the majority of the older people who were settled in small residential services within the community, expressing how happy they were with the vast improvement in their physical environments. This brought great peace of mind for the family members and older people alike:

> *"It's very nice, the people are very good to us here."*

> (Older Person 22).

"We love it, staying in the community home." (Older Person 24).

"Lovely, I like it. I wouldn't go telling you other things. The staff are beautiful; they are very, very good." (Older Person 25).

All the family members expressed their happiness that the living environments had changed beyond recognition from the early years of service provision:

"…only 4 you know residents and like a couple of carers and a nurse and it's amazing the difference you know; it's just like it's her home. You know underground heating, beautiful kitchen, lovely sitting room; lovely bed and everything." (Family member 30).

"Well, the physical house and the room and the setting is brilliant, and they'd been waiting for a number of years to get that. She has her own room and it's a fabulous house." (Family member 31).

"He has a house now, shares with four, bedroom en-suite and he could have went across to the apartments but ...he decided it was better in the house; he was better looked after you know." (Family member 32).

7.5.2 Noise levels

For those older people who remain living in larger residential services, noise levels emerged as a factor that had a negative impact on the physical living environment. One older person who had previously lived in his own home, was currently living in a large residential service, and complained about the level of noise he experienced daily. The noise was described as *"screaming"* and *"shouting"* and was due to other older people living there. The participant stated that he complained about the noise levels at the weekly house meetings but there had been no improvement. When it became too much for him to tolerate, the staff facilitated him to spend time in another small community group home, to get a break from the noise. On consulting the field notes, the researcher had noted the cramped environment with limited space for the number of residents, many of whom had mobility issues:

"I go to my room for a bit of peace, its wile (very) *noisy in the sitting room, lot of noise and screaming, I can't stand it'. Last Thursday there started a wile noise I couldn't stick it…"* (Older Person 23).

One family member whose sibling had previously lived in a large residential setting stated that they had concerns about the impact of living with high noise levels had on their sibling:

> *"…and some were really, really noisy …and I thought you know it must be really terrible for you and the noise, you know?"* (Family Member 30).

The family member also alluded that since their sibling moved to a small residential setting the one major improvement was that they could now live in a quieter more relaxed atmosphere:

> *"…it's just that she has more, more peace. I suppose relaxing you know what I mean?"* (Family member 30).

From the staff participants, only one staff nurse highlighted the noise levels within the environment as a factor which could impact on those who lived there. Although they felt it was noisy, they believed that people had the option to remove themselves from the environment into a quieter space if they wished. However, for those with restricted mobility this was not an option:

> *"… we've a big day room… so everybody is there. Is it noisy? Yes… if it's a small environment; if they don't want to be a part of it, they'll get up and walk out. So, although it may be a big group, they also have the choice to walk away whereas I suppose if it's a small house it's kind of hard to get away."* (Staff Nurse 15).

The staff nurse was also mindful of how these noise levels would be interpreted by others and indicated that managing the levels could be challenging:

> *"It is noisy...but then I suppose you have a full group of opinions. You can look at it different ways."* (Staff Nurse 15).

7.5.3 Positive developments in services

Family member participants celebrated the changes and advancements in the philosophy of care within the services and the overall improvements this has brought to the lives of their relative. One family member felt that the model of community living

could be an example to other service providers, such as services for older people, and they could learn from approach taken and the move towards smaller residential services:

> *"I think it was a major movement of taking them out into the community; that was huge shift, made a huge difference. That was back, was it in the 80s I think?"* (Family Member 31).

> *"I know that nursing homes are much too big for the elderly but by God I think if they were smaller that they could learn a few lessons from this project you know?"* (Family Member 34).

The move to the community care and the adoption of a rights-based approach within services, was evident in some excerpts of the data, with older people reporting that they were now informed of their rights by staff at the weekly house meetings:

> *"…they tell us about our rights and different things."* (Older Person 22).

One family member spoke about their sibling now being more assertive and able to express their feelings and wishes more clearly, through acquiring new vocabulary and ways of expressing themselves:

> *"…she put her hand up, she said…" He needs breathing space". …probably if they go for each other the housemothers are saying so and so needs breathing space."* (Family Member 35).

They felt this was something new and positive that their relative been taught to help build relationships between housemates:

> *"She is absorbing all the lingo and getting the language that she didn't have before."* (Family Member 35).

Another family member spoke about the improvements in staff training and knowledge, and this had led to improving the therapeutic interventions and approaches that are now used with people intellectual disabilities:

> *"There are brilliant younger better excellently trained staff that are looking after her and they have these great ideas, you know? They have group photographs, individual photographs, family photographs up everywhere. …it looks like a home…"* (Family Member 34).

The positive changes were also notable in day service provision which are often referred to as workshops. Family members described this change had a major improvement that helped their relative to flourish:

> "…it was a disused factory, it was very cold, the heating used to break down and they would be sitting there in their coats in the freezing cold doing this very boring thing like putting rubbers together … but the policy has changed…it's all about personal development…she is really blossomed there because they do stuff like assertiveness, communications, Special Olympics is the best thing that ever happened…" (Family Member 35).

Some of the improvements in services were attributed to the inspection process from HIQA. Both staff and family member participants felt that the inspection of services was positive and motivated the organisation to improve standards of care delivery.

> "Standards are rising all the time. HIQA are putting pressure on them to raise the standards all the time." (HCA 13).

> "But the care we delivered hasn't changed massively but with HIQA and everything there is more paperwork and transparency." (HCA 12).

One family member also mentioned the increased paperwork that HIQA now required which was communicated to them by staff, but they were still supportive of their inspection process and felt it was needed:

> "HIQA are requiring an awful lot of paperwork and I think HIQA are fantastic and I think they were very badly needed." (Family member 35)

Finally, a family member questioned what the future will hold for older people with intellectual disabilities. They expressed hope that the presence of HIQA would ensure that the organisation would meet the needs of older people as they age in services.

> "But their needs will change; … she's been doing the same routine but that's not going to continue…hopefully they'll have to with HIQA coming on-board; they may get things into place." (Family Member 31).

7.5.4 Emphasis on HIQA

Although it was consensus amongst participants that HIQA played a role in improving the quality-of-service delivery; the data revealed that meeting HIQA requirements were now a major factor that governed the daily work in residential services. The associated changes and paperwork that came with the HIQA inspection process had to be adhered too and appeared frequently within the data. All registered nurses spoke about the leadership within the organisation focusing solely on paperwork and documentation being correct and up to date to reflect an image to "*look good*" as opposed to a meaningful commitment to person-centredness.

Staff nurses felt it was left to the junior members of staff to advocate for the people with intellectual disabilities within services:

> *"Like the leadership side there's the pressure kind of to sign-off on policies that you've read them, that you've got all the PCPs up to date and that everything looks and reads good…I think it's more staff on the ground are fighting for, you know the clients, for them to actually have their person-centredness"* (Staff Nurse 14).

Nurse managers also echoed this experience, they felt the organisation became consumed by the HIQA inspection process. The focus of the organisation was no longer about meeting the needs of the person but about achieving compliance. Nurse managers talked about consulting with the older person and documenting their wishes and goals within their person-centred plan, only for these to be dismissed and changed to fit the organisation, as they would not, or could not, pay for the additional staff cover that would be incurred to fulfil the person's goals. The goals were altered as *"budgets have a lot to do with how care is provided"* (Nurse Manger 2) and nurse managers were told to change the goals to be more meaningful, if senior managers did not like them:

> *"…It's about making sure HIQA are happy and that we are not getting any non-compliance and I think where the person has been lost in that. …you are there with the person who is elderly, and their goal is… "I want to lie in 3 days a week or 5 days a week". Then they are like oh there are no staff for that …we don't have the cover',' That's not good enough.' …That's not meaningful enough."* (Nurse Manager 4).

Nurse managers attributed being consumed by HIQA, to senior leaders who had not been proactive and failed to make the appropriate preparations prior to the commencement of the inspection process. They highlighted that the organisational structures were inadequate to meet HIQA standards, so they were now caught in a chaotic process of trying to establish proper governance structures. They described the culture within residential services as "*madness*" (Nurse Manager 3) and *"the treadmill"* (Nurse Manager 4)*,* but ultimately, they felt the person had become lost within the organisation and paperwork, and they were no longer the focus of the service:

> *"…HIQA came on board, and we weren't ready, and we had huge anomalies with staffing, with structure…to us it's a tick box exercise…the service user has become lost in the madness of getting ready for HIQA. It's not our fault, it's the people above us who weren't ready."* (Nurse Manager 3).

Staff identified that recommendations from inspectors were often based on the physical environment, and they did not look at the wider implications for the older person. They spoke about an incident when a HIQA inspection report recommended that an older person move from their home due to ageing and the unsuitability of the building. Nurse managers felt this was unfair to the person, moving them away from their friend's in-services. The senior managers therefore took measures to ensure the person could remain in their home:

> *"I have one lady of 82 and HIQA have said she has to be moved out of her home of 60 years because the bungalow is not suitable…thankfully staff and management have fought HIQA…they are letting her move down to the main building and she will end her days down there. But she wants reassurance the whole time she will move with her friends…"* (Nurse Manager 7)

Several staff highlighted that the required procedures and paperwork stipulated by the inspection body for daily household tasks were at times excessive and time consuming and they questioned the rationale:

> *"… I think it is a bit extreme, …like having to lock cupboards if there is a dishwasher tablet being kept in it; …having to document when you*

open it and the time and what time you close it and lock it again..." (Staff Nurses 14)

Initially, under the inspectorate body HIQA, the nurse manger's role, Clinical Nurse Manager II, had now become a new role titled the Person-In-Charge (PIC). As a relatively new role, nurse managers reported that their work responsibilities within small residential services had extended beyond nursing duties. Their role now involved, building and maintenance issues, which meant it was difficult to fulfil the remit, leaving the nurse managers feeling unsupported and overwhelmed with the scope of the role:

> *"The PIC role…is a new role since HIQA came. It's like everything and anything is lobbed at the PIC, and we have no support structure."* (Nurse Manager 3).

> *"You have to be a plumber, a fire officer, a carpenter, maintenance, on top of your nursing duties. You are not a PIC you are a puppet."* (Nurse Manager 4).

> *"You're jack of all trades; everything lands with you."* (Nurse Manger 2).

7.6. Given a life of their own

The data revealed the theme *'given a life of their own'* which represented the impact and the contribution of residential services on the lives of the older person with intellectual disabilities. It also outlines the key factors which they identified that make a happy life for people as they age. The subthemes presented are, *the decision to move into residential services, living in town, being active, and fellow housemates as family.*

7.6.1 The decision to move into residential services

The first of these themes focused on the change in circumstances for families which brought about '*the decision to move into residential services'*. Family members cited various reasons for this decision, such as ill-health of their ageing parents, inability to manage the person's behaviour at home, or the person's needed to be independent from their family. They spoke about it being a major and difficult

decision for their family to make, but they discussed it in detail and included their relative in the decision.

Many of the families wanted their sibling to stay close to the area they were familiar with, even though many of the siblings had moved elsewhere in the country:

> *"…it was a big decision to take but I think her coming out and going into a house in a home situation was a huge difference…"* (Family Member 31).

> *"Over the couple of years before she passed away and we would have said about getting* (name of brother) *into respite at those times…we live all over the place and really* (name of brother) *would be very much a home person."* (Family Member 33).

> *"My father didn't want to come up with me. He wanted her* (sister) *to continue living at home, but all our family had emigrated, all my siblings and I was living in Dublin, and I knew I couldn't monitor that situation. So, I went up myself and she was very far sighted, and she said she should have her own life, be independent."* (Family Member 35).

Family members wanted their relative to be independent and they could achieve this by moving into a residential service:

> *"Now she said she should live independently, no two adults in family should live with each other."* (Family member 35).

Family members reinforced that they were no longer able to maintain the caring role, and they found it challenging to meet all the needs of the older person due to their own ageing process. They identified that they no longer had the energy or social outlets to meet the needs of the person. They also talked about the stresses associated with being a carer:

> *"I suppose you know I'm 77 years myself…he'd say to me in the morning where are we going today; I don't have the energy now to be away every day with him." (Family Member 32).*

> *"Even I find on a one-to-one with her for long periods can be wearing because she'll, she has this propensity to keep watching you; when I'm with her she keeps watching me for my next move as to where we're going next or what we're doing." (*Family Member 31).

Following the decision to move into residential services, three family members spoke about the loss of self-care skills and capabilities of their sibling due to the institutionalised nature of the larger residential services. However, as services

developed, they had to make another major decision years later to relocate their sibling to a small community residential service, which had a positive outcome:

> *"… she went backwards, her capacity to do things; she was more capable of doing things for herself because when she was at home, she was better at looking after her own hygiene, person hygiene and she'd various chores she used to do at home."* (Family Member 31)

All the family members agreed that making the moving into residential services was a positive experience and gave their relative a new lease of life, after living sheltered lives at home with parents. One participant described how their sibling initially accessed respite support services in preparation for a move to residential services. This was a happy time in their sibling's life as they could experience new opportunities and experiences:

> *"...he went into respite on a couple of occasions and was absolutely the happiest time of his life because mum would have been kind of very much in control…* (Family member 33).

They continued to describe the experience of eventually moving into residential services permanently and the positive difference it made on his life:

> "*He has been happier in that house than he ever was living at home."* (Family member 33).

Family members provided insight into how residential services had helped their sibling to become more independent and that facilitated the creation of their own adult identity outside of their family structure:

> *"She is now independent, and she has come into her own because she functions differently there, in the sense there she is an equal and she is her own person. When she is with us, she is back to being the baby of the family…"* (Family member 35).

> *"It's brilliant, she has really come on and come out of herself because she, in her own milieu she is her own person."* (Family member 35).

7.6.2 Living in town

The data revealed that older people much preferred to live in or close to towns. Being in town gave them a sense of independence where they could avail of the shops, cafes and activities. This theme emerged in the first interview when a participant was asked

if there was anything he would like to change about where he lived, and the participant replied:

> *"It's too far away, too far away from town."* (Older Person 18).

The participant continued to explain that walking on roads in the countryside was dangerous due to the lack of public footpaths, so he could not go for a walk independently despite this being one of his hobbies:

> "*No, too many cars, I'm too small, don't see me, I don't see them."*
> (Older Person 18).

Subsequently, other participants mentioned that they were happier close to town or that they spent a lot of time "downtown."

> *"I'm happier near the town because you have more liberty, more convenience in the town.*" (Older Person 25).

> *"We live in a nicer place now; we are beside the shops and everything. The other place was too far out so it was."* (Older Person 27).

The comments provided by the older people indicated that living in the countryside was viewed as having its disadvantages for several reasons. The lack of transport in rural areas meant that small residential services either had to have access to their own in-service transport or the person themselves had to pay for taxis which was financially expensive. As one older person commented:

> *"It's too far way, too far for taxis, it's costly."* (Older Person 18).

The participant went on to say that the lack of transportation limited their ability to attend activities in town at the weekends due to, *"No transport" (Older Person 18).* Public transport in rural areas, is limited or non-existent, one nurse manger also cited the lack of transport and the poor quality of the transport available to services as an obstacle to accessing activities:

> *"Just, lack of transport, they are all breaking down and they are not being replaced, that is our big problem at the minute."* (Nurse Manager 7).

One family member revealed the lack of transport as an issue for their relative and this had been highlighted at the last annual review as a priority need to facilitate social outings. The staff were now dependent on other services to access transportation:

> *"...they hadn't the transport. So, they were depending on another house maybe to come or whatever...and that was very much the priority at that time."* (Family member 33).

7.6.3 Being active

Living close to town and all its facilities was strongly associated with being active for older people. They mentioned activities such as getting their hair done, going for coffee, going to the shops, the library or going out to evening entertainment, all of which they talked about with enthusiasm. None of the participants reported going out by themselves, they were either accompanied by a staff member or other housemates or both, they felt they would either get lost by themselves or that they could not cross the road safely.

> *"I go out to the town; I have a coffee and a bottle of water. We can't go on our own, someone has to come with us, too many cars on the road. I can't cross the road you see."* (Older Person 20).

> *"Every Friday we go to the pub til half eleven..."* (Older Person 26).

> *"We go to the library to get books then."* (Older Person 22).

Being active was also connected to physical activity such as, dancing and sports, which many participants were involved in during the day or evenings. The sports were facilitated through the local Special Olympics branch and represented an attainable level of gentle exercise for older people. Special Olympics played a vital role in older people accessing sporting activities and it created a positive social outlet for this population group. It was unclear from the data exactly what the participants enjoyed the most about these activities, if it was the actual act of physical activity or the taking part and belonging in a social group that the sports facilitated. The contribution of Special Olympics organisation to health and well-being was notable from the comments from family members and older people:

> *"Special Olympics is the best thing that ever happened, best thing that ever happened...she loves watching golf on the tele, any sports, loves watching it."* (Family Member 35).

Special Olympics facilitated one older person's interest in sport from watching it on TV, to being an active participation resulting in finding new hobbies and experiences to build their self-esteem:

> *"…the sports she does badminton, her golf, there is something else, curling, I don't know what the heck that is…Absolutely loves it and loved the idea of in Belfast they paraded them all up you know?"* (Family Member 35).

The older person commented on the wide variety of sports they participated in and also the competitions:

> *"What we do, what I do is I play golf, badminton I play Bocce, we are playing Bocce later. What we do is sometimes take part in competitions."* (Older Person 24).

The same participant went to elaborate saying that she liked all physical activities and explains why:

> *"I do both, I don't mind it. There is a guy that comes in to-day and does exercises with us. It was one of these dancing to music... it helps my body to move."* (Older Person 24).

For another participant the enjoyment appeared to come from taking part in the competition and the social aspect of the group involvement:

> *"I do the Bocce as well, there's a Bocce competition in a fortnights time. … I got one last year, a small one..."* (Older Person 20).

Away from Special Olympics, one participant commented what they enjoyed going dancing at weekends and he added that it helped him to maintain his weight:

> *"I like a glass of wine, I go dance, you know me'. Keep the weight off me."* (Older Person 18).

A family member revealed that their relative had been reluctant to exercise but following encouragement from staff, who set up a walking group and put her in charge, she is now walking in the evenings:

> *"She didn't want to go walking here… she wants taxis…the walking group and she's in charge of it and that's given her a bit of motivation because it's her walking group, which is great."* (Family Member 31).

Being active also related to other activities taking place in day services, which many of the older people still attended well into their 60s and 70s and said they carried out a variety of activities there and it was also a social outlet for older people:

> *"I go to workshop, Monday, Tuesday, and Wednesday and the Day Centre Thursday and Friday. I have a lie in on Thursday and Friday."* (Older Person 22).

One participant in their late 50s was involved in what they called 'work experience', through their day service and they enjoyed this work:

> *"In the hotel…and the restaurant out in the hotel and I do the Leisure Centre. I fold the napkins and put them on the plates."* (Older Person 24).

The family member participants related being active to the person leading a fuller life and this gave them a feeling of confidence knowing that their family member was happy and leading a fulfilled life, particularly being present within their local communities as follow statements show:

> *"You could see her anywhere; you know go out shopping in the town and …out for dinner, to get her hair done."* (Family Member 30).

> *"He has a social outlet that he didn't have while he lived at home."* (Family Member 33).

Attending day services seemed to be the most prominent activity in the lives of older people living in rural areas. In contrast to older people living in urban areas, those in rural areas appeared to have restricted social activities and diversity to their routines, particularly in the evenings. All but one of the rural participants were attending a day service and purported that in the evening they mainly watched TV or spent time in their bedrooms and went to bed early as these accounts reveal:

> *"…and sometimes I go to bed, and I watch TV, Coronation Street, and the 'Late Late Show'."* (Older Person 28).

> *"I would watch TV or listen to the radio and if someone would chat to me, I would chat away to them."* (Older Person 17).

A different participant purported that they went to bed on their return from the day service, as they did not like where they were living:

> *"I'll have my tea, and something to eat, do you know what time I go to bed at? 6 o' clock… I just lie in bed… I can't stick it at all."* (Older Person 23).

Rural participants who reported that they would like to have more social outings identified a combination of barriers that prevented them from doing so. Two older people felt the lack of staffing was a barrier to them going out more and they mentioned this in the context of what they would like to change about where they live. They felt the lack of staff hindered their access to more activities and outings, and they use their own words below to describe this:

> "*More outings… and that kind of craic and I would say if we could go away for a day or two on buses. Get a bus for the day and go away for the whole day.*" (Older Person 17).

He further elaborated by saying:

> "*No because it is all to do with staffing but if the staff were there, we would get a chance to do all that but at the minute because of the staff we don't.*" (Older Person 17).

Another participant replied:

> "*More staff… Yeah more dancing." (Older Person 17).*

While one final participant identified her physical health status as a barrier to going out more:

> "*Well, I have had the flu…*" (Older Person 28).

Staff and family members observed that if older people had access to their own financial means, through a pension or other sources, they can self-fund activities and this financial independence allowed them bypass organisational obstacles such as lack of staffing:

> "*…they're out and they're socialising; they can go to the cinema and out for meals… sure he just pays…that's all he has to is look after himself and they're out and it's brilliant*" (Family Member 32).

One staff nurse also reiterated that access to personal funds allowed an older person the freedom to take part in activities of their choosing, thus being more socially active which otherwise they would be unable to do:

> "*…there's one lady here who was left a monetary estate, so she wanted to employ her own PA…a PA comes in 2 or 3 times a week and takes her to do wherever she needs …so it's great that way because like staff*

> *restrictions are huge…but if she didn't have the money…"* (Staff Nurse 15).

Being active in the home regarding household chores did not appear to have the same value or focus for older people. Participants reported that they did minimal housework and had limited independence skills with staff carrying out much of the housework for them. There was a mixed reaction from participants when asked if they would like to be more independent with daily household activities, such as shopping, cooking and cleaning. Several participants who lived in small residential services reported that they were cooking but mainly at their day service or with staff assistance in their home. Four of the older people participants said they enjoyed baking or cooking on occasions, and they had opportunities to do so if they wished. They also cleaned their own rooms or had staff support them to clean and tidy their bedrooms:

> *"I am going to learn how to cook here in the house now."* (Older Person 26).

The following participant explained the cooking experience in her own home and brought up the issue of risk management and the need to have staff present. Thus, adopting the language of the organisation and the regulation regarding carrying out her own cooking:

> *"I always cook in the house, but you have to have staff with you to cook because it seems you have too, to take the risk."* (Older Person 24).

The participant went on to mentioned that staff take photographs of her cooking in order to record it as an activity for her file, which she said with slight bemusement.

> *"Well, you have to have staff it seems, they have to take photography's and they have put them in our files."* (Older Person 24).

While another participant mentioned cleaning as part of an activity she enjoys, she mopped the floors in her home as part of her morning routine.

> *"Washing floors in the mornin'…"* (Older Person 20).

When asked about getting more involved in carrying out household tasks, the idea was not overly appealing to older people, particularly as they increased in age, stating

that they preferred if the staff carried out the domestic chores for them. One participant had previously lived independently in his own flat but had now moved into a small residential service, when asked if he wanted to continue to do household chores like shopping and cooking, he simply said he longer wished to do these things:

"No, not now." (Older Person 21).

While two older people said that although they enjoyed cooking and were able to cook when they were younger, the activity is no longer appealing to them, either because of general ageing or ill-health:

"We can do if we want… but I don't want to do that much now." (rain).

"I used to do the cooking but that stopped…we used to do dinners. We used to do everything. I used to peel potatoes…and they were paying me €5 a day." (Older Person 21).

He went on to explain that he no longer cooks due to ill-health:

"I had a stroke but I'm not too bad now. I was unwell." (Older Person 21).

A considerable number of the older people seemed unaccustomed and afraid to use common household appliances and when asked about this they replied they did not take part in cooking or washing their clothing, for fear of injury or they were nervous of breaking the appliances:

"No, I wouldn't know how, I prefer the staff to do it." (Older Person 22).

When the interviewer asked the participant if they could use a washing machine, the participant replied:

"No, I wouldn't go near them, they might get broken, the staff do it." (Older Person 22).

Another mentioned that they did not cook or make their own tea as they were afraid of being burnt.

"No, I can't touch kettles at all, so I can't, myself. They put the tea in the teapot, and they pour it out for me." (Older Person 20).

"I'm not allowed to cook, well in case I might burn myself." (Older Person 26).

It was unclear from the data if these fears were based in reality or had been perpetuated over the years of living in residential services and the person had come to believed that it was too dangerous for them to cook or operate the domestic appliances within their homes. None of the older people mentioned additional aids to help support them to use a kettle safely or easy read materials to use appliances. Although some older people mentioned participating in housework, the staff participants made few references to older people being involved in household chores or skills teaching within their role. One staff nurse talked about how an older person had been encouraged to be more assertive and communicate with staff to express their wishes, as opposed to resorting to behaviours of concern. They reported that this worked well within a smaller residential service coupled with a home-like environment:

> *"Having a more friendly, homely environment according to their own skills like making their own cup of tea instead of waiting for a staff to make it."* (Staff Nurse 16).

Two healthcare assistants felt that at times too much was being asked of some older people as they age, as the following quotes outline:

> *"Sometimes their capabilities are not there and sometimes you do feel the burden of it, as they are just not able for it."* (HCA 12).

> *"Some of them as they get older get more aggressive, they can't help it they are finding it harder, I suppose as they get older, like us all. We have to cater for that as well and be a bit more patient."* (HCA 11).

7.6.4 Fellow housemates as family

The subtheme emerged from the data, *fellow housemates as family*, which focused on older people having created their own close interpersonal relationships within their residential services, like a family. This theme emerged from the data early on with the participants referring to the strong bonds of friendship that older people had developed with their fellow housemates or a specific housemate, particularly as they lived together for many years. These bonds were recognised by staff and family members as crucial to the development of an emotional connection and a sense of belonging within their homes. The following extracts are from family members who provide their experiences of these friendships:

> *"She has got a particular friend, a male…they look after one another's needs…, for instance when they are at breakfast if he hasn't got the milk, she will make sure and the sugar and whatever else pass it on to him and vice versa."* (Family Member 34).

> *"He loved the house, he loved the people in it, the others that were in care ...he was part of a family they absolutely couldn't do enough for him."* (Family Member 33).

> *"…They get on very well; they're lovely girls and they're very closely knit as well. She loves coming out but she can't wait to get back to them."* (Family Member 31).

This participant went on to describe the group as being like a family:

> *"It's great, she runs back to her gang; like she sees them I suppose as her family."* (Family Member 31).

This description of being like a family was the similar to the staff participant's description of the relationships between the housemates. They observed that when older people were in the process of being relocated to community residential services, their established interpersonal relationships were not taken into consideration by senior managers or those responsible for the relocation. The following are samples of extracts from staff participants on the relationships between older people within residential services:

> *"They are their family."* (Nurse Manager 7).

> *"They are family to them, more family than relatives. I think that is what is not being considered in a lot of cases. They are not being considered as a family group..."* (Nurse Manager 4).

Another staff participant interjected with how 'the services' perceives people as:

> *"Individuals that are living together."* (Nurse Manager 7).

One older person described their fellow housemates as their friends and people who they enjoyed carrying out activities with:

> *"… they are my friends, I like them, go for a walk together, go to the pub with them."* (Older Person 18).

While another older person was asked what he liked most about where he lived, he replied that he liked the "company" of the others who lived there (Older person 21). This particular older person had recently moved back into a small residential service from his own flat and when asked if he liked living in his own flat, he responded by saying:

> *"…lonely, it was..."* (Older Person 21).

While one family member highlighted the lack of a wider circle of friendship for their sibling which had been challenging throughout their life and the pattern had continued into old age:

> *"…She doesn't have friends calling…to bring her for coffee the way the rest of us would... My parents tried it when she was younger but..."* (Family Member 35).

7.7 Dealing with uncertainty

The data revealed the final theme, '*dealing with uncertainty',* which represented the many aspects of change that older people may experience in the future as part of the ageing process. Within this theme three subthemes emerged regarding these various changes, and these were identified within the data as: c*hanging healthcare needs and ageing in place and experiencing grief and loss.*

7.7.1 Changing healthcare needs and ageing in place

The changing healthcare needs and ageing in place, are presented as one subtheme as they both interrelated. Age related healthcare needs and how they were addressed by services had an impact on all the participants. For the most part the older people and their family members reported that they were well and active but with some age-related health issues. Participants reported a variety of ever-changing healthcare issues from long-term conditions such as epilepsy, stroke, chest infections and influenza, which had an impact on their health and happiness:

> *"…he developed epilepsy about 10 years ago…I was really frightened, got the ambulance out and that was 25 minutes you know, long time for me… But I wouldn't be able to have him full-time now you know."* *(*Family Member 32).

> *"Some of them go to wheelchair aerobics which I am going to check out when I get back. I have been off sick for a while, but I am not too bad."* (Older Person 17).

> *"…once your health is good it's the big thing and that's looked after and checked up and she's to go for mammograms; we were always conscious of those given the cancer history…"* (Family Member 31).

This family member participant continued by saying that they receive regular updates on their relative's health status through the annual review process which kept them well informed:

> *"Which is great, and we get an update on her health…she'd have a bit of blood pressure, so they're watching that and what medication is she on…"* (Family Member 31).

The data revealed that residential services monitor older people's health and ensure that they are actively involved in health promotion and treated the person's health in a holistic manner:

> *"We are really impressed as a family with the way they give attention to each person. They have got a file on each person as to diet, as to physical needs, as to mental needs and they treat her like that."* (Family Member 34).

However, staff participants reported that if an older person's health deteriorates due to an acute illness, the service will provide resources until the person recovers. In the event that the illness becomes a long-term condition and worsens, then 'ageing in place', is not a reality in community group homes. Older people with long-term health conditions, such as dementia, that may require more than one staff member, were not supported to remain at home and were moved to a private nursing home.

> *"Three of our lads came out of the institution 30 years ago and they are still with us. One got sick and went into hospital and died, so they have spent their whole life with us and that was hugely important. But unfortunately, if some of clients gets dementia and has to leave early and go into a nursing home and that seem to be the only way now."* (HCA 8).

This practice was now a common occurrence and was attributed to a lack of resources and funding to support the person. Community group homes generally operate on a lone working model. Therefore, if the person requires more staffing input, then they are automatically transferred to a nursing home:

> *"...the moment when someone needs two staff, straight away they are sent to a nursing home."* (HCA 12).

> *"…people who have been transferred into nursing homes, it's because they haven't resources to put extra staffing in. Most of us have lone workers in our houses."* (Nurse Manager 3).

> *"…we do what is called 'sleepovers,' so we would have to get staff in to cover if someone needs to be cared for at night. The cover is there is something is acute but once the situation becomes chronic then they have to look to find another place for them."* (HCA 13).

The staff revealed that this practice was upsetting to them and unfair to the older person. They felt that moving someone from their home due to ageing was an unjust practice and was not reflective of the philosophical approach of rights-based model of care, which should ensure that the person's right to remain at home if they so wish. Staff felt that the organisation needs to reconsider the strategic approach to how ageing is managed within services:

> *"I find that quite upsetting because there really should be a service for them within the 'health-board,' so they can stay in their own environment."* (HCA 8).

> *"… if you look at people being regarded as having the same rights as anybody else…I mean we have to look at trying to facilitate these people who are getting older because it's **your home…** it's what they have known all their lives, and the group of people they are with… (*Nurse Manager 4).

Healthcare assistant participants also purported that frontline mangers had little or no control over these decisions and did their upmost to maintain people within their homes, but these decisions were made at a higher managerial level within the organisation:

"The management can only do so much and were very supportive of us when one of the lads was ill, they gave great support, but their hands are tied as well…and that is what they are being told that the nursing home is the only place." (HCA 9).

Family members conveyed that they were unsure of what happens if their relative develops a health condition that would impact on their current living arrangements. They hoped that their relative would stay within their current home environment as it would cause the older person great upset to be moved elsewhere:

"…she is hugely attached to the others in the house particularly one of them. I think to move her ...would cause great upset to be honest." (Family Member 31).

They went on to say that they hoped the person would continue to be looked after in their own home and that it would always remain her home:

"If something did happen her…I would hope that she would be looked after in the house or at least if she had to go somewhere else, she'd be back there; that that would always be her home." (Family Member 31).

Although family members recognised that transferring to a nursing home care might be a possibility, it was evident from the data that no discussions had occurred between services and the family members regarding future planning and annual reviews did not incorporate these discussions. There was a level of uncertainty amongst family members as to the care pathway if the person's health deteriorates. Family members would welcome this discussion in an open forum, as they reported that currently they had little or no information:

"…what sort of plans are there, what sort of communication is there between nursing homes and HSE? The need has never arisen but that doesn't mean that it mightn't and also there must be something because some people do end up going from that service into nursing home, so what's happening? We don't know." (Family Member 35).

"…and her age and what happens you know when she comes to; you know the whole thing of going every day, what's going to happen, what's her life going to look like in the ageing process? The next 10-20 years of life." (Family Member 31).

The situation was a sincere concern to family members, as older people with intellectual disabilities have no access to independent advocates and the responsibility falls to families. Over half the family members felt the organisation needed to urgently articulate its strategic plan of care, or at least provide a preliminary outline of their intentions and options available to reassure worried families:

> *"...I think that's an urgent need for HSE to begin to have information seminars and let people know this is what we do; just to reassure people and get the conversation going even if something isn't completely formalised…there's a timescale and certain structures..."* (Family Member 35).

Family members expressed several concerns and questions regarding the use of nursing homes. They wanted to know if the HSE services were making official links with nursing home providers to ensure that staff in were suitably qualified to work with people with intellectual disabilities, particularly with regards to communication skills and knowledge on their health needs:

> *"I don't know what planning, education, preparation, communication there is between the HSE and the local nursing homes where people do end up. So those staff in the nursing homes, would have the training and the understanding that these people have needs and need to be communicated with, possibly differently to other people that in the nursing home."* (Family Member 35).

Staff participants also questioned the knowledge base and quality of care that is being delivered to older people who are moved into nursing homes or acute hospital settings, stating they visited regularly or stayed with the person outside of work hours to ensure they receive the care they needed:

> *"… where a couple of the lads going into hospital…some of them are non-verbal and they were used to the consistency and familiar staff and suddenly they are going into this hospital environment or even the nursing homes, where staff don't really have the time, I'd say to deliver the individual care that we had been giving them."* (HCA 8).

This participant said that she and her colleagues knew the older people well and could therefore deliver care to a higher standard, particularly as the person has limited verbal skills and ability. They also felt that staff in acute settings or nursing homes were too busy to deliver individualised care and they felt the care deliver was not to a high standard:

"You know when you are looking after somebody for such a number of years, even the non-verbal…they don't have the time to deliver the individual care, its consistency as well, even if someone cannot verbalise, we know all their likes and dislikes especially when you have been looking after somebody for a number of years." (HCA 8).

"...we didn't feel the care was adequate enough and we had to go in..." (HCA 12).

Staff agreed that the lack of education was an issue in generic services, and they felt the care of older people with intellectual disabilities required more specialist knowledge which staff in nursing homes did not possess:

"A lot of the time in the nursing home they haven't the training." (HCA 9).

*"It needs to be specialised. You hear of people going to general nursing homes, and yes, the person is elderly, in need of care but they also have intellectual disabilities. Those people working in nursing homes don't have a clue about ID. And it's not being disrespectful to them, but they don't understand all the complexities of being older and having intellectual disability." (*Nurse Manager 2).

7.7.2 Experiencing grief and loss

The data revealed a subtheme which focused on older people with intellectual disabilities experiencing the grief and loss of their friends and fellow housemates. Older people mentioned their friends, whom they had previously lived with, who had died or became sick and were relocated to private nursing homes. They talked about missing them within the house they had once shared. It was evident from the data that they were close to the person and very fond of them.

"There is five of us here. There was six of us one time, but she died… she was a great knitter and great talker." (Older Person 25).

He went on to say:

"Oh, we loved her, we adored her. An old lass she was, lamb chops and plenty of salt on them and plenty of stout." (Older Person 25).

Another older person spoke quietly about two of the men who had previously lived in her house and had died and conveyed that the other housemates felt the loss following their deaths:

"Two boys died…it was sad, we missed them." (Older person 22).

The family members expressed concerns about the impact of loss and grief had on their sibling. They questioned how their siblings will deal with the loss of their housemates and friends as they age:

> *"…there was an incident in their previous house: one of the girls died. But she was new to them; she wasn't established and so that was a big shock to them. How they deal with death and loss; like that's going to be a big thing when she gets older."* (Family Member 31).

Another family member recounted an experience of a housemate who had to move to a nursing home due to early onset dementia, they described the impact the loss had on their sibling. The effect resulted in the person withdrawing completely from the things they used to enjoy. The staff contacted the family member to express their concern, not realising the impact the illness had on her:

> *"…unfortunately he developed early onset dementia…they were really really fond of him and then he had to be removed and eventually he went into a nursing home, but she went into herself big-time, and nobody could figure out what was wrong with her…" (Family Member 35).*

The manifestation of grief was not easily identifiable as many of the older people found it difficult to express their feelings but through discussion and a process of elimination it emerged that loss and grief was identified as the cause and root of the behaviour change. The older person had difficulty putting the feelings into words and could not communicate how she felt:

> *"I sat with one of the housemothers and herself and we teased out that it was sadness about this lad leaving the house and she said because we went through is it this? Is it that? Is it the other? And when we got to him, and I said how do you feel about that? She said I feel very sad, and I said why could you not say that to us? And she said I find it hard to talk about my feelings." (*Family member 35).

Although the staff maintained contact and continued to visit the person who had moved into the nursing home, his fellow housemates found it hard to cope with the deterioration and the change in their friend due to dementia:

> *"They were going up to see him very regularly. He was in hospital now and she was finding that upsetting because she still hadn't gotten her*

head around the deterioration that he wasn't the same person." (Family Member 35).

Grief and loss in residential services not only impacted upon people with intellectual disabilities but also those who worked closely with them for many years. When discussing other topics, healthcare assistants in particular recounted experiences of older people moving into nursing homes or acute hospitals due to ill-health. They spoke about how the relocation took an emotional toll on the staff, as they had created an emotional bond with the person. The staff spoke about feeling mixed emotions, a sense of responsibility and empathy towards to the person, particularly if they had no verbal communication skills and were used to having the same staff caring for them:

> *"I suppose because we come so attached to our clients we had a couple of incidents, where a couple of the lads going into hospital, and I suppose some of them are non-verbal and they were used to the consistency and familiar staff and suddenly they are going into this hospital environment or even the nursing homes…"* (HCA 8).

The staff expressed the feeling of loss as being difficult to see the person leave their home and moving to an environment that they eluded is not suitable or appropriate:

> *"It's hard for staff as well when you see them having to go into an environment like that."* (HCA 8).

Fellow participants recounted a time when one of the older people had been relocated to a nursing home and then in the acute hospital as their condition worsened over time. The staff team tried to ensure that he was not alone, as he a little verbal communication and few family members:

> *"We had one client who died…but had been in a nursing home for a few months previous to that. Now we tried to visit as much as possible. So, when he was in hospital, we took it upon ourselves to go in and sit up with him as much as possible until he died."* (HCA 9).

Another participant added that other staff in the service gave up their time to join them to spend time with him in rotation, so he was not alone during his end of life:

> *"And like people who didn't even work directly with him came in from the services and gave their time to be with him."* (HCA 9).

7.7.3 Facing retirement

As previously documented, being active was an important feature of the lives of older people, with their day service facilitating activities and acting a social hub. However, family members expressed concern about the lack of information on what the future held for their relative as they approach retirement age. Their main concern centred on maintaining activity levels and wanting meaningful activities and mental stimulation after retirement:

> *"…if retirement comes what will the HSE do to make sure that they are still stimulated and that they still have a quality of both physical and intellectual stimulation?"* (Family Member 35).

The same participant went on to express concerns about the available alternatives to day services. They indicated that a similar service is required in order to maintain the current level of activity, otherwise they feared the lack of activity would take a negative toll on their relative. Currently sports were provided by Special Olympics, which is accessed through the day service, without which family members feared their relative would lose access to their sporting activities:

> *"I would feel she would shrivel if she didn't have something equivalent and particularly as long as she's able…she adores her sports."* (Family Member 35).

There appeared to be a lack of clarity and information for family members if the person was to retire or if they could no longer continue to attend the day service past the age of retirement. Families felt that regular consultation and information from services would help keep them informed and up to date on what plans and developments were in place:

> *"And information…that we'd know the action plan, ongoing communication, regular consultation with the person and the family re their needs and the HSE plans and actions to address these. Nobody beyond yourself, has come to me and said…in two years' time she'll be 60; these are our plans as she gets older."* (Family Member 35).

> *"…as she gets older what facilities, what happens then...what happens with people at the moment who are elderly?* (Family Member 31).

The family member felt that they would like to enable their sibling to retire if they wished, the opportunity to slow down and relax more in older age without the pressure of having to attend a day service full-time:

> *"…it's nice to be able to sleep in some mornings till 9 or 10 o'clock, and go at your own pace, not to be dragged out of your home every day to be somewhere else five days a week…" (*Family Member 31).

They continued to say they were not concerned about this currently and felt it was something for the future:

> *"…I haven't thought about getting into this stage…heading in that direction."* (Family Member 31).

Conversely, one family member was clear on the retirement process within the associated service and was well informed. There appeared to be a clear structured approach to retirement, gradually reducing the hours and time spent at the day centre and this was communicated to the family member:

> *"…it was age related. At 65 yrs. they retire from the workshop. And do it gradually. The year before they went four days instead of five you know?"* (Family Member 34).

Other activities were now being provided by the residential service, in place of attending a buildings-based day service. The family member was happy with the therapeutic nature of the new alternative:

> *"…she wasn't doing horse-riding, but she was grooming the horses, she really enjoyed that … very therapeutic…"* (Family Member 34).

Retiring at 65 years' old was not for everyone and one family member spoke about how their relative did not wish to retire from his job and was quite unhappy at the prospect of giving up his employment which he enjoyed:

> *"He didn't like it, no… he worked in the butcher's shop there and he loved that, but he wasn't able; well, I don't think he'd be able maybe to work now with the chest and that…he missed his work…"* (Family Member 32).

While it did not appear directly in the data from older people, one family member mentioned that older people also had concerns about the future of their day service and they reported that older people discussed concerns amongst themselves that the

service could close and they would no longer be able to attend, as this family member provided an example:

> *"… the trainees are saying that the centre might close; we mightn't have a centre…but there would be certain things that are sort of negative or rumour mongering that they'll say among themselves"* (Family Member 35).

This perhaps reflects the lack of information sharing between the service and older people. It also identifies an important need for communication of future plans to everyone involved to avoid anxiety about the future and available options for them as they enter old age, even if people are living within services.

7.4 Summary

This chapter presented the thematic analysis of the qualitative interviews and focus groups conducted with staff, older people and family members about their experience of care in residential services. The vast improvement in the physical environment and the philosophical shift in services for people with intellectual disabilities was evident. Older people and families spoke about how these changes had a positive impact on their lives and well-being. Staff were able to articulate the theories of person-centredness, albeit from their own perspective as opposed to that of the person. Staff attitudes exerted a level of control over people's choices and activities as opposed to the rights of the person.

However, older people and their families reported positive relationships with staff, who displayed sincere empathy, compassion, and commitment to the older people they worked with for many years. Older people wanted to continue to be active into old age, socialising and being physical active through sports, with Special Olympics playing a pivotal role in their lives. Living in or near a town was important and negated the need and reliance on in-service transport or taxis which they had difficulty accessing or were expensive. Ultimately, the needs of the organisation were often prioritised over the principles of person-centredness, with organisational structures and practices impacted on staff ability to effectively meet the needs of older people as they age in services. The inspection process and the regulation of services was a welcomed development but resulted in the organisation becoming consumed by the associated

documentation to appear to be person-centred, effectively losing sight of the person within the process.

Nurse managers often felt devalued working to fulfil an undefined remit without supportive structures or administration resources in place and regularly undertook tasks outside of their nursing duties. Changes in the role of the healthcare assistants meant more responsibility and involvement with documentation, but these changes to expected without proper training and resulted in some healthcare assistants having difficulty adapting to new approaches thus impacting on older people and team dynamics. Family members felt uncertainty about what the future held for their relative as they aged in services, with communication on care pathways and options lacking in open discussion.

CHAPTER 8: DISCUSSION

8.1 Introduction

This chapter provides an integrated discussion on the findings from the quantitative and qualitative data. The chapter will initially outline the relationships between the macro-context and the constructs of the care environment and prerequisites and how these factors impact on practice. The discussion will then move on to illustrate how the relationship between the constructs and the care process interact to create the current culture within residential services. This chapter presents the integration of the data from both phases of the study, giving equal authority to the perspectives of older people with intellectual disabilities, their family members, combined with those of the staff, to reveal a disjuncture between the needs of the organisation and the needs of the older people living in residential services and the espoused values of person-centredness.

8.2 Person-Centred Practice Framework as a theoretical model within the context of intellectual disability residential services

Health and social care settings continue to emphasise person-centredness within policy and strategy documents (HSE 2011) and its implementation in practice has been proven to improve care (Laird *et al.* 2015). Published inspection reports (DoH 2012a; Áras Attracta Swinford Review Group 2016; The Muckamore Abbey Hospital Review Team 2020) reveal that intellectual disability residential services continue to experience challenges in the delivery of person-centredness. An editorial by Dewing and McCormack (2017) identified the key challenges to its actualisation in practice, such as the utilisation of ill-defined definitions that lack a robust theoretical foundation, thus resulting in an overly simplistic understanding of the concept. This could be argued as the case within the intellectual disability context, despite the concept being long-established within the philosophy of services, it has been based on a set of guiding principles as opposed to an evidence-based model of practice. Therefore, this study was underpinned the Person-Centred Practice Framework (McCormack and McCance 2017) an internationally recognised theoretical framework which

encompasses organisational and cultural dimensions which help staff to operationalise the concept in practice (Slater *et al.* 2017).

The Person-Centred Practice Inventory-Staff (Slater *et al.* 2015) is underpinned by the PCPF (McCormack and McCance 2010; 2017) and was able to provide an initial insight into person-centred practice in residential services. Overall staff perceived the delivery of care to be person-centred. In this chapter we will discuss the relevant findings within the domains, particularly the *care environment,* which staff either agreed nor disagreed was person-centred, followed by an analysis from the qualitative data which confirmed that the macro-influences from social stigma, strategic leadership, and workforce development all impacted on the role preparation, a lack of clarity of beliefs and values in staff teams and the life choices and outcomes for older people and staff. While staff scored the constructs and the domain c*are process* positively, the qualitative data was revealed a vagueness on how these processes functioned in practice.

The analysis of the qualitative data demonstrated one clear voice emerging, that of older people with intellectual disabilities. They talked about their personal histories with services, clearly articulating what they lost and gained throughout their lifetime. They had a desire to tell their story and wanted others to know the challenges they had faced. They demonstrated insight, resilience, and an ability to forge ahead within a society that did not always recognise their right to belong.

8.3 The impact of the macro-context on the care environment

The revised PCPF by McCormack and McCance (2017) identified the macro-context has having an impact on the delivery of person-centredness in practice. A recent mixed-methods study, set in the context of Emergency Departments (ED) of Acute Hospital settings, was conducted by McConnell (2018) and demonstrated a strong association between the macro-context and the impact on how care was delivered within ED departments. This resonates with the findings of this study, with the qualitative data revealing the impact of the macro-context on the ability of services to deliver person-centredness within residential services. These factors will now be

discussed in more details, commencing with the macro influence of societal stigma and the 'othering' of people with intellectual disabilities.

8.3.1 The 'othering' of people with intellectual disabilities

In the qualitative phase of the study the topic of stigma and people with intellectual disabilities emerged in the data. This topic was not addressed via the PCPI-S survey and was identified as a silence between the data sets (O'Cathain *et al.* 2010). According to O'Cathain *et al.* (2010) such silences can be expected within mixed methods research due to the strengths of different techniques employed to examine aspects of the phenomenon. Healthcare assistants spoke of the negative stereotyping they experienced by the public towards people with intellectual disabilities, who were reportedly perceived as aggressive, scary, or childlike. Healthcare assistants said they were frequently asked by friends and acquaintances if they *"were scared"* to be alone with people with intellectual disabilities during their work. A similar finding was reflected in a recent mixed-methods study by Pelleboer-Gunnink *et al.* (2019a) who reported the Dutch salient stereotypes of the general public towards people with intellectual disabilities included, *'being aggressive' and childlike.*

Furthermore, healthcare assistants spoke of how the negative stereotyping also extended to them as paid carers for people with intellectual disabilities. Their work was perceived as undesirable, receiving negative responses such as, they were "*a saint"* to do this kind of work or *"it's a job,"* taken only by people who could find no other form of gainful employment. This finding resonates with the work of Mitchell (2000) who argued that staff experience a phenomenon termed 'courtesy stigma', due to the nature of their work, which was often carried out in segregated settings. He identified RNIDs, as being stigmatised and marginalised by the wider nursing profession, due to their association and work with people with intellectual disabilities who were perceived as a '*deviant group.'*

Historically, the discourse surrounding people with intellectual disabilities has been negative and their segregation from society deemed them as, '*not belonging'* (Wolfensberger 1972; Sibley 1995; Grenon and Merrick 2014). Consequently, they were excluded from living within their local communities with no employment

opportunities and little control over their choices (Hall 2010). The legacy of these policies is still evident to-day, as people with intellectual disabilities continue to be one of the most marginalised groups in society (Ward 2011). The traits of social exclusion, overtly negative labelling, and stigmatisation of people with intellectual disability are all characteristics of the concept of 'othering.'

'Othering' or otherness, emerged from feminist theories in 1950s and as Johnson *et al.* (2004) highlight it has been used and developed by several authors to study issues of racism, identity, and difference of those in society (Powell and Menendian 2016; Roberts and Schiavenato 2017). The concept of Othering is defined as a social process by which dominant members of society attribute negative stereotypes onto others (Johnson *et al.* 2004). 'Others' are deemed different from mainstream society creating stigmatisation and marginalisation of that group. Pelleboer-Gunnink *et al.* (2019b) highlights that people with intellectual disabilities are of low priority in terms of policy and planning and this is evident within the Republic of Ireland with the Irish Governments delay in implementing the decongregation policy which lags behind that of international standards (HSE 2011; NDA 2018). Within the residential service context, 'othering' was evident in a study by Bigby *et al.* (2012), where staff failed to relate to people with intellectual disabilities as they categorised them negatively as being "*not like us".* This form of 'othering' is rooted in the removal of the person's human attributes and rights, a similar concept to the denial of an individual's personhood.

In terms of person-centred practice, the importance of personhood cannot be dismissed. The theories of Social Role Valorisation (SRV) advocated for meaningful social roles for devalued people within society and to create positive perceptions (O'Brien and O'Brien 1998). Similarly, Kitwood's (1997) work considers how 'devalued' people can be perceived as lesser and positioned as 'other', which Dewing (2008) highlights is still problematic in contemporary practice settings. However, Dewing (2008) reminds us that many human beings never attain the status of being a person within society and this has been historically true for people with intellectual disabilities. Although the concept of personhood and 'othering' are closely connected, the social process of 'othering' was clearly identified within the findings of this study, as it

encompasses the societal implications of stigma and marginalisation having a major impact on the life experiences and inclusion of people with intellectual disabilities.

Pelleboer-Gunnink *et al.* (2019b) argues that as members of the public, staff are also influenced by societal attitudes towards people with intellectual disabilities and can hold stigmatising views themselves which inadvertently impacts upon the care they deliver. Further scrutiny of the data revealed that healthcare assistants made recurrent references to caring for people as they would their "*own children*" or their *"own families,"* with one-to-one outings referred to as a "*mummy-daughter day."* This approach to care delivery appeared to come from a place of nurturing but there is a prominent level of paternalism within the statements. It is noteworthy that the organisation also promoted and endorsed a culture of paternalism through historically creating job titles for healthcare assistants such as, '*houseparent'* and *'housemother,'* titles which family members still utilise and were evident throughout the data when referring to staff members. As a result, healthcare assistants may have inadvertently taken on a parental approach to care delivery and perceived older people as 'childlike,' resulting in paternalistic approaches to care.

Cultures of paternalism may at first seem benevolent, but they are strongly linked to 'oppressive othering' and involve a superior group casting authority over a less powerful group due their supposed childlike inferiority (Taylor *et al.* 2018). The casting of this population as childlike, is not only evident within society but also within the organisation practices which are potentially influenced by societal stigma towards people with intellectual disabilities. Authors such as Powell and Menendian (2016) caution that the values of paternalism can permeate within the policy and practice of services, creating an invisible barrier to the life choices and social inclusion. This restricts a person's freedom, justified by the rationale that it is in the person's best interests (Garritson and Davis 1983). These barriers were evident within the data, as older people talked about their activities, day services, social clubs, living arrangements, predominately based in the community, but still segregated and 'protected.' This is also illustrated in the data by their preference for staff to carry out certain household task in case they injured themselves and the fact that they rarely ventured out alone for fear of getting lost. Furthermore, older people had little choice of where they lived, with these decisions being made in their best interest. The study also found that there was an established practice of '*doing for'* as opposed to '*doing*

with' (Bigby *et al.* 2012) which further demonstrating the presence of a paternalistic culture and 'oppressive othering' within service provision.

8.3.2 What makes a home: the needs and concerns

The analysis of the quantitative data revealed that the construct, c*are environment,* received the lowest overall scoring of the three domains with staff neither agreeing nor disagreeing that residential living environment supported person-centredness. Further in-depth analysis revealed the construct, *'physical environment'* reached statistical significance in relation to the independent variable '*type of qualification.'* HCAs scored significantly lower than RNIDs, indicating that they did not agree that the physical environment was conducive to person-centredness. A possible explanation for this is the higher response rate from HCAs working in large residential services where the environment presents more challenges to ensuring privacy and dignity (HSE 2011). Personal space and individual bedrooms have been previously highlighted in the literature as being highly valued by people with intellectual disabilities for their well-being (McConkey *et al.* 2004; Buys *et al.* 2008; Garcia Iriarte *et al.* 2014; Sheerin *et al.* 2015) but for older people who remain living in large residential settings, this is not yet a reality.

The qualitative findings of the study revealed varied results from all the participants, who depicted both the positive and prohibitive elements regarding the physical environment. Older people and family members focused their attention on the physical environment, both past and present. They spoke of the previously harsh conditions revealing that a quality home environment was an essential component to their happiness and well-being, that is, quality furniture, nicely decorated sitting rooms, houses free from damp in a safe location, and family like atmosphere (McGlaughlin *et al.* 2004; O'Rourke *et al.* 2004). In contrast, staff reported staff practices, leadership and organisational factors that created obstacles to the actualisation of person-centredness.

Older people living in large residential services talked of shared bedrooms and living accommodation with high levels of noise that felt overcrowded. Noise levels were reported as being difficult to tolerate and had an impact on their health and well-being.

These findings concur with O'Rourke *et al.* (2004) who reported the need for space and quietness for people with intellectual disabilities. However, the majority of staff did not refer to noise levels as a challenge within the physical environment, except for one staff nurse who felt that it was often unavoidable due to the structure of the building and the higher number of people living together. Consequently, having your own bedroom and personal space to escape to was considered essential by older people, particularly when the noise became intolerable. The importance of having individual bedrooms was also reported in previous studies (McConkey *et al.* 2004; Buys *et al.* 2008), but not from the perspective of a 'refuge' from the busyness of the environment.

For those who had their own bedrooms, they clearly cherished this individual space and spoke about how they valued it for peace and quiet and being able to spend time as they wished. This finding is also reflected in the literature, as shared bedrooms' impact upon dignity, privacy, and personal space (Garcia Iriarte *et al.* 2014). The concerns regarding the physical environment are reflected in the national policy for decongregation of intellectual disability services (HSE 2011), with community group homes cited as the preferred environment. However, the qualitative data revealed that community group homes were not immune to poor physical environments, with older people recounting that they had to relocate to a new house as their previous home was described as damp with water leaking in from the roof and was not located "*in a good area.*"

A notable factor of the physical environment within community group homes, was how staff referred to the shared and individual living areas within the group homes. They talked about the individuality of the older person being evident only in their bedroom, reflective of their personal belongings and interests. However, there was no mention of older people having influence over the decoration of the shared areas. Previous studies found that a feature of person-centred practices within community group homes was that shared spaces, such as living rooms areas, were also reflective of the personalities and personal histories for those who lived there and not solely controlled by staff (Bigby *et al.* 2014; Kåhlin *et al.* 2015)

The location of the physical environment is not addressed within the PCPI-S, but the qualitative data revealed that for older people with intellectual disabilities, the location of the physical environment is equally as important. They spoke of the challenges of

residential services being situated in isolated rural areas. They cited a lack transport as a barrier to accessing facilities and socialising within their communities. There is a limited or often non-existent, public transport network within rural areas with taxis being a *"costly"* form of transport. Internal services vehicles were shared amongst services and were reported to be in a poor and unreliable condition. The move from an isolated rural area to an urban residential setting was cited as a positive move by older people, giving them more *"liberty"* to access shops, cafes and libraries, and to socialise in the evening. These findings are similar to those reported by several studies (Buys *et al.* 2012; Shaw *et al.* 2011; Garcia Iriarte *et al.* 2014) were participants reported that they valued the freedom of urban areas and being within walking distance of amenities and shops which increased their social activity. The preferences stated here by older people are aligned to the national policy statement on housing for an ageing population within the Republic of Ireland (Government of Ireland 2020). It outlines six strategic principles of housing such as urban renewal which supports active ageing. The policy recommends the development of well-connected urban centres that offer a choice of housing which actively supports socially connected lives for people as they age. This policy statement strongly supports the findings of this study regarding the needs and wishes of older people with intellectual disabilities as they age.

The physical environment is an important aspect in the provision of effective care within the Person-Centred Framework (McCormack and McCance 2017). It is based on the perspective that staff should possess the necessary attributes to manage aspects of the physical environment and the care environment in its totality, to ensure the delivery of person-centredness. RNIDs scored higher overall in this construct, perhaps indicating that they are the main group of staff to manage the physical environment in residential settings. This was supported in the qualitative findings, as RNIDs talked about the challenges of managing the needs and choices of older people as they age within services. They referred to two-story housing with *"narrow staircases"* that were unsuitable for older people and often resulted the person having to move to a new house. Finally, this section reveals the quality and location of the physical environment continues to be a key factor in the lives of older people and their families and it contributes to their overall health and well-being.

8.3.3 The impact of contrasting skill levels

The results from the quantitative data confirmed that staff agreed that the *'skill mix'* within residential services supported person-centred practice. The skill mix construct within the PCPI-S measured the staff's ability to manage the skill mix within the c*are environment*. All registered nurses in phase one agreed that they recognised deficits in knowledge and skills within the team and its impact on care delivery and that they could argue for improved skill mix if it fell below acceptable levels. There was a significant statistical difference between registered nurses with a postgraduate level qualification and the healthcare assistants for this construct. The difference in findings could be attributed to their different role preparation, role requirements and perceptions of care. This is reflected in the writings of McCormack and McCance (2017) who caution that within this construct there is a risk that a greater value may be placed on observable physical tasks, as opposed to the less tangible ways of working, such as spending time and developing relationships with people in care.

The qualitative data expanded the above findings to reveal deficits within staff skill mix. Both nurse managers and family members voiced concerns regarding the frequent use of agency staff and the resulting impact on the continuity of care. Another contributing factor was the differing levels of knowledge and abilities between newly appointed healthcare assistants, versus that of the more established team. Nurse managers noted that many of the newly appointed healthcare assistants had a higher level of education and were competent in completing the required paperwork. Maintaining written records was not previously required by healthcare assistants and nurse managers highlighted that the contrasting skill levels had become a source of resentment and friction between team members.

Nurse managers also reported that implementing change and addressing ways of working was a source of confrontation with healthcare assistants, who they felt when reluctant to embrace change. This finding is reflective of a study by Bigby *et al.* (2012) which found the informal values of the staff dictated the practices with community group homes, resulted in staff being resistant to change. This allowed negative aspects of care to flourish and treating people with intellectual disabilities as 'lesser'. Nurse managers expressed similar concerns regarding the impact of the friction caused by the reluctance to change on older people within their community group

homes. Equally, they acknowledged that HCAs had limited role preparation for the new expectations that were placed upon them. Furthermore, many of the community group homes within this study function on a lone worker model which staff felt impacted on the care delivery and choices they could facilitate for the older person. They also talked about the restrictions that lone working places on simple spontaneous activities. The lone worker model within community group home structures may be a local macro-context which is not replicated in other geographical areas.

8.3.4 Unequal power dynamics

The quantitative data within this study found that '*supportive organisational systems'*, '*shared decision-making systems'* and '*potential for innovation and risk taking*' scored the lowest overall in the quantitative data and were the constructs that received the highest neutral scoring overall. The qualitative revealed a disparity between different roles of the residential services team, with nurse managers in middle management positions, experiences differing from those of healthcare assistants and staff nurses. The quantitative and qualitative findings were in agreement with the majority of the healthcare assistants revealing that they felt valued by their line-managers and used words such as, *"approachable"* and *"supportive"* to describe the relationship. They felt free to voice their opinions and to have their voices heard if they were unhappy with issues in practice. However, the qualitative data revealed that many healthcare assistants in the study were also lone workers and talked of having no interaction with their manager from week to week, with communication limited to rotas and training events. Healthcare assistants acknowledged that for the most part they received recognition and praise for their work and the support they received from nurse managers was valued to a point. Surprisingly, nurse managers were not perceived by healthcare assistants to be an integral part of the team but were viewed as being on the periphery, with their main source of support and advice emanating from their peers. Nurse managers referred to the service as being *'healthcare assistant led,'* which appeared to give them a high level of autonomy within their role but with no mention of mechanisms for guiding or monitoring practice.

In contrast, nurse managers talked about a senior leadership culture and communication style that was often negative and at times discordant. The leadership approach taken by some senior managers was depicted as critical and unapproachable as nurse managers talked of interactions that induced anxiety as senior managers seemed to lack trust in their level of competency. Within this study, nurse managers held middle management roles, and they carried the relatively new title of Person-In-Charge (PIC) (Health Act 2007) which involved high levels of diverse responsibility with their role including nursing and non-nursing duties, such as house maintenance. They talked about having duties '*thrown*' at them, with unsupportive organisational structures that failed to recognise the lack of necessary infrastructure required to carry out their peripatetic role in a community-based service.

An important finding of this study was the expressed feelings of exclusion by middle-managers from higher-level-decision making forums, exacerbated by a reported disillusionment in senior management's decision-making processes. Nurse managers talked of feeling wary regarding their freedom to express their opinions on such decisions openly to senior managers due to fear of an adverse reaction and effect on their working life. This finding relates to a lack of psychological safety in the workplace which is cited as a barrier to discussions and the creation of a learning organisation (Nembhard and Edmondson 2006). Despite having managerial responsibility, nurse managers talked of their exclusion from the decision-making process related directly to the people they cared for on a day-to-day basis. This scenario indicates a level of role ambiguity for nurses in middle management positions, while they bear the responsibility of service performance and outcomes, they did not have true autonomy in their role. The structure within the organisation appeared to become more hierarchical after the middle-management level, with senior managers having little reported contact with the people living in residential services. Person-centred organisations are inclined towards non-hierarchical structures with management systems that support staff and have contact with the people using the service (Sanderson 2003).

There is little evidence in the literature of decision-making processes within teams in intellectual disability services. The literature tends to focus on the staff facilitation of decision-making for people with intellectual disabilities, as opposed to the organisation decision-making forums that impact on practice. However, a few research articles refer

to the impact of organisational cultural and structures required to implement change within services (Bigby *et al.* 2012; Bigby *et al.* 2014). In the general literature, MacPhee *et al.* (2010) conducted a participatory action research study set in general nursing context, which suggests that strong leadership is required at all levels of the organisation for shared decision-making to become a reality. Their study also showed that effective team and team leader relationships were based on respect and trust, while failures or issues with communications often related to hierarchical difference and nursing power dynamics regarding roles and responsibilities.

In the quantitative data, '*shared decision-making systems'* was one of the lower scoring constructs but did not reach statistical difference*.* For this construct, McCormack and McCance (2010) identify a close association with autonomy and equality in professional relationships which in turn promotes accountability in decision-making. Within this study, nurse managers talked of restricted decision-making powers in aspects of their role, coupled with an ever-expanding remit. Although they expressed frustration at this situation, they seemed resigned or accustomed to accepting this without challenge. The quantitative data further reflects this through the scoring of constructs, *'professional competency,'* '*knowing self,'* with these constructs receiving positive scores overall by registered nurses. Within the PCPF-S McCormack and McCance (2010) advocate that staff should actively participate in decision-making which has a direct impact on their work environment with communications valuing all persons and conducted in a respectful manner. The findings of this study may suggest a complex interplay of unequal power dynamics between differencing grades of staff within the organisation.

8.4 Staff attributes and the impact on the care environment

McCormack and McCance's (2017) identified the key qualities in the *prerequisite* domain required by the practitioner for person-centred cultures to be realised. In the quantitative data participants reported a high level of agreement with the p*rerequisite* domain, indicating that they felt they had the necessary skills to deliver person-centredness. *Clarity of beliefs and values* is one construct that enables staff to facilitate person-centredness within the care environment. However, this construct received the

lowest level of agreement within the domain and was also one of the lowest scoring constructs across the three domains. The qualitative data indicated that the staff worked from a restricted view of the concept of person-centredness, similar to that of 'patient-centredness' as described by Manley *et al.* (2011), which focuses solely on valuing the individual receiving care and their needs. In contrast, 'person-centredness' is a wider concept and is inclusive of all persons, including staff (McCormack and McCance 2017). The importance of healthy interpersonal relationships at all levels of the organisation are emphasised by Clarke (2002) who stresses the need to listen, respect and value staff as persons, to achieve safe, person-centred cultures of care. It is well documented within the literature that healthful workplace cultures must first be supportive of staff before staff can support others (Manley *et al.* 2011).

The qualitative findings within this study also suggest that in day-to-day practice staff teams did not work with a shared vision and purpose. Nurse managers acknowledged that team members frequently approached the implementation of choice and other aspects of care in a perfunctory manner which they felt ultimately impacted on the quality-of-care delivery. Challenging practice, giving, and receiving feedback in a compassionate manner, were not part of the cultural fabric of residential services, with certain staff behaviours going unchallenged. As McCormack and McCance (2017) emphasise an effective workplace culture must aspire to having a shared explicit set of values that move from discussion to observable behaviours in practice. A key component of the shared values is that there is an individual and collective responsibility to uphold these principles (Manley *et al.* 2011), something which this study found was absent within teams in residential services. A lack of knowledge and training opportunities around the concept of person-centredness were cited as a reason for inconsistent approaches and attitudes. Nurse managers talked about the focus being on purely mandatory training as opposed to continuing professional development, coupled with a lack of lifelong learning opportunities, particularly for healthcare assistants.

Staff participants talked about how decisions were made to suit service needs or the financial restrictions of the organisation, as opposed to the needs of older people. This created an unsettling challenge to staff value systems when they witnessed contradictory decisions and behaviours, in contrast to the publicly stated values of the organisation, values which they were tasked with upholding. This caused them to

question the organisations commitment to person-centredness and left them with a sense of disillusionment. The qualitative data from study revealed an underlying ethical dilemma in the responses from residential staff who work within an ethical juxtaposition of meeting the collective demands and financial constraints of the organisation, while trying to balance this with the needs and wishes of the older person.

Currently within the Health Service Executive there is a focus on staff values and beliefs through the '*Values in Action'* programme, which aims to create a workplace culture where staff feel valued and empowered. More recently an article by a McCance *et al.* (2020) suggests that such programmes fail to acknowledge the complex factors that exist within workplace cultures. Translating values and behaviours into everyday cultural practice does not occur swiftly, but require the long-term commitment and implementation through transformation practice development work (McCormack 2015). The work of Manley *et al.* (2011) identified core values that influence and characterise a healthful workplace culture. Table 8.1 illustrates and contextualise how these core cultural values compare currently with the intellectual disability residential services context.

Table 8.1: Mapping the core values of effective workplace culture by Manley *et al.* (2011) to the findings from the datasets in residential services

	Core value	Current workplace values in residential services
1.	Person-centredness	A narrower concept of person-centredness exists within intellectual disability services 'patient-centredness', as opposed to 'person-centeredness'. In contrast 'person-centredness' is a wider concept and involves all individuals, inclusive of staff (McCormack and McCance 2017).
2.	Lifelong learning	A culture of lifelong learning was not evident in the qualitative data, where the focus was largely on mandatory training, particularly for healthcare assistants.
3.	High support and high challenge	The workplace culture lacked support structures for mid-level nurse manager positions. The process of challenging practice, giving and receiving of feedback are not part of the practice. Nurse managers felt unable to question practice within their teams and within the organisation.
4.	Leadership development	There was little evidence of supportive development of leadership skills. Nurse managers felt excluded from decision-making forums which had a direct impact on their

		service. They did not have the necessary infrastructure to carry out their role. Healthcare assistants however, felt supported in their role by their line managers.
5.	Involvement, participation and collaboration with all stakeholders including service users	Mid-level nurse managers talked about tense interactions with senior managers, while HCAs reported a more positive relationship with middle-managers. However, HCAs felt their contribution was not recognised. Nurse managers reported a lack of diversity of voices within higher decision-making forums and an illusion of choice for families. Families and older people with intellectual disability felt they were involved in decision-making to certain point but were excluded from major decision-making forums.
6.	Evidence: use and development	Rycroft-Malone (2004) states that role-modelling of evidence-based practice by clinical staff is valuable to team members. However, the healthcare assistants in this study worked in isolation with little or no contact with staff nurses or nurse managers on a day-to-day basis and had no role models to support or guide their practice. The services were reported as being 'led' by HCAs, but many HCAs have little or no role preparation for this level of autonomy, or ability to appraise evidence regarding the quality of care. There was no mention of mechanisms or forums to support HCAs reflect on their practice, role development or education.
7.	Positive attitude to change and commitment to continuous development	The research took place during a rapid time of change for services, due to the introduction of HIQA inspections. Staff reported an increase in paperwork, while healthcare assistants felt they had no need to change the way they worked. Nurse managers felt some staff were confrontational when encouraged to embrace change. Families and older people with intellectual disabilities welcomed change and perceived it as positive.
8.	Open communication	Communication was reported as strained within teams. HCAs felt empowered to speak up if they were unhappy about a decision or practice, but nurse managers felt unsafe to do so with senior managers.
9.	Teamwork and safety (holistic)	Teamwork was demonstrated through the commitment towards older people as they aged. HCAs were mainly lone workers and felt isolated. They did not perceive their line-managers as full members of the team. The physical, psychological and social safety of the older people was a priority. However, the psychological safety of the staff was not always considered.

8.4.1 The essence of core relationship and interpersonal skills

Although beliefs and values create a foundation for culture change, a complex interplay of factors affect the delivery of person-centred practice (McCance *et al.* 2020). A recent theoretical examination of the relationships between the constructs in the PCPF by McCance *et al.* (2020), found that the construct, '*interpersonal skills*', is one of the most influential attributes within the *prerequisites* domain. Person-centredness is fundamentally based upon interactive practice and is reliant on developed interpersonal skills that can be utilised regardless of the practice context (McCormack and McCance 2017).

Within this study, the quantitative data revealed that *'interpersonal skills,'* was one of the higher scoring constructs within the *prerequisite* domain, indicating that staff felt they had the necessary skills to communicate effectively. The importance of interpersonal skills was also emphasised within the qualitative phase of the study, with nurse manager's placing significant importance on the staff's ability to communicate at a deeper level with older people with intellectual disabilities. They identified interpersonal skills as really "*knowing the person,*" in order to develop what they perceived as the "*core relationship.*" They explained the core relationship as going beyond superficial knowledge of likes and dislikes often documented in person-centred plans. McCormack and McCance (2017) also refer to this in their writings, as the need to develop deeper relationships, and move to partnerships based on trust which will assist in identifying the holistic needs of the person, ultimately leading to shared decision-making.

Nurse managers associated interpersonal skills with being person-centred which they believed was an inherent trait, that you '*either have it or you don't.'* They felt that this way of being came from within, regardless of the training the staff member had received. They could identify certain staff who they felt personified a person-centred approach, through their behaviour and ability to develop meaningful interpersonal relationships with older people with intellectual disabilities. This idea is also discussed by McCance *et al.* (2020) who emphasise that person-centredness is more than the *'doing'* of certain practices but rather a way of *'being'* as a practitioner. Most of the

older people agreed that staff were nice, and they would confide their problems or worries to a staff member, indicating a deeper level of trust. This was also found in previous studies where staff interpersonal skills were acknowledged as essential to helping people achieve their goals (O'Rourke *et al.* 2004; Bigby and Knox 2009; Garcia Iriarte *et al.* 2016). However, not all older people agreed, describing staff as being *"like ghosts,"* who walked away from them and ignored them when they attempted to engage or express their needs, with staff controlling activities and prioritised their own needs over the needs of older person (Salmon *et al.* 2019; Strnadová 2019). It could be argued that this lack of regard for older people is also associated with 'othering' behaviours, when people with intellectual disabilities are devalued and not perceived as being deserving of equal treatment and respect.

8.4.2 A personal commitment is valued

The results from the quantitative data show that '*being committed to the job*' was the highest scoring constructs within the *prerequisite* domain, indicating a high level of staff agreement with the construct. The qualitative data supported these assertions to reveal a prominent level of commitment from staff to the older people living in residential services. The personal commitment of staff became evident through not only their own accounts but were also verified by family members. Many staff spoke of loving their job and they recounted how they felt strongly about caring for older people who lived all their lives in residential services. They talked about giving their free time to care for an older person with no surviving family members who was receiving end of life care in the acute hospital. Staff volunteered to carry out shifts when they were off duty to ensure the person was not alone or in distress during the final stages of their life.

Staff commitment to the job was also verified by family members who recalled examples of staff going beyond the requirements of their job. The staff in this study demonstrated their commitment through concrete acts (Watson 1997), such as visiting an older person who had been admitted to the acute hospital during their day off, checking their well-being and supporting the family members of those in the acute hospital during their free time; taking part in group activities with older people after their 12-hour shift had been completed, or staying behind after their shift to ensure

consistency of care. McCormack and McCance (2017) highlight individual commitment can be challenging to sustain if the staff feel disillusioned with care with the team or the organisation. Some nurses expressed disillusionment with the organisation, as they had worked hard to achieve higher standards of care within their teams but felt this went unacknowledged. This study found that there is a need for staff recognition of their commitment to the job at a team and organisational level (McCormack and McCance 2017).

8.5 The abstract nature of the care process

The *care process* was the highest scoring domain overall indicating that staff had a high level of agreement that they engaged in a range of activities and processes that operationalise person-centred practice, however, it was difficult to verify these results within the context of the qualitative data. The construct, 'w*orking with patient's beliefs and values,'* is an essential element of person-centredness, as it focuses on what the person values about their daily life. This construct encompasses the person's life history which has a direct influence on the choices they make and the lifestyle they want to live (McCormack and McCance 2017). The initial process is to integrate personal knowledge about the individual into the plan of care. Such assessments are referred to as key tools that transform the person's goals into reality. The tool for actualising person-centredness within intellectual disability services is person-centred planning (HSE 2011). It is based on a strengths-based approach and aims to respond to the person's key issues and aspirations for the future (Sanderson 2003). There were some significant differences noted in the responses from staff and older people towards the purpose of their person-centred plans. Firstly, within this study older people rarely mentioned their plans or related to them as a living document that reflects their hopes and goals. Instead, they talked about the weekly house meetings as the forum where they could exercise their choices and decision-making and where they were informed about their "*rights and things like that."*

In general staff referred to person-centred plans as documents which contained biographical details and information. Healthcare assistants referred to person-centred plans in an abstract manner, stating that the person's expression of individuality "*is all*

in their plan," thus appearing to confine plans to paper rather becoming reality. It is unclear from the data if healthcare assistants adapted their ways of working to reflect the goals of person-centred plans as they also stated, that despite changes in service philosophy over the years, they continued to deliver care as they always have done. Although each older person had an established plan, it was vague if they were continually updated and the level of involvement of the older person. A review by Doody *et al. (*2019) found there is a lack of published literature on the experiences of adults with intellectual disability in the involvement in planning their care, despite existing guidance. A previous qualitative study by Menchetti and Garcia (2003) in the United States examined 83 person-centred plans and found that if plans were not reviewed and updated annually, their relevance diminished. Although there were frequent references in the data to annual reviews being held, it remains unclear if the person-centred plan is part of that process and regularly reviewed with older people.

Nurse managers also mentioned person-centred plans, but they referred to them as documents that are "*four inches thick,"* implying that they were large, bulky items, that could be challenging for new or agency staff to decipher quickly if required. Staff talked about the focus of the plans as no longer being about the person but a paper exercise for "*looking person-centred"* for inspection purposes. They also referred to the limitations of person-centred planning, as demonstrating "*likes and dislikes,"* but did not represent "*truly knowing the person."* Nurse managers questioned the commitment to person-centred planning process, as enviably they would be requested to change the goals by senior managers to reflect what is available as opposed to what is possible (Sanderson 2000). A common challenge of person-centred planning cited in the literature is the implementation gap that is failure to carry plans into practice (Mansell and Beadle-Brown 2004). Overall, the findings in this study are in accordance with findings reported by Mansell and Beadle-Brown (2004) reaffirming that the practical reality of expenditure constraints within services prevent goals and needs from being achieved. However, documentation in general was a thorny issue amongst registered nurses, due to the sheer volume of paperwork they had to complete, stating that it restricted their interactions with older people. This finding concurs with a qualitative Australian study by Quillian *et al.* (2014), which examined staff attitudes towards paperwork in community group homes and found that staff felt that the organisation unnecessarily complicated practice with organisational paperwork,

creating wasted opportunities to engage with residents. These authors advocated that organisations' should review the use of tools and seek staff input into their use and value in practice.

The other components within the *care process* domain relate to the constructs 's*hared decision making'* and *'engaging authentically'* and *'being sympathetically present.'* Again, staff responded positively in the quantitative phase, agreeing that this occurred in practice. However, staff responses in the qualitative data indicated a discrepancy between these findings. One interesting view held by a healthcare assistant was that older people should be treated as "*you would like to be treated yourself."* Under certain assumptions this could be perceived as working from their own viewpoint, as opposed to that of the older person. This also accords with the earlier interpretations which showed that this belief portrays a paternalist approach to care delivery (Bigby *et al.* 2019) believing they know what is best for the person. Alternatively, it could be argued staff members may be trying to demonstrate empathy and seeing life from the other person's perspective (Bigby *et al.* 2014).

While the staff in this study did not mention supportive decision-making, there was evidence of practices that assisted older people to be involved in the process. Staff participants believed that knowing the person well was a requirement for providing support and they involved key people in the person's life, mainly family members who remained involved in their care. Bigby *et al.* (2019) argues that supportive decision making for people with intellectual disabilities can be a complex and demanding process for staff to negotiate, requiring them to incorporate a rights-based perspective, coupled with the practicalities and risk to the person. None of this complexity was mentioned by the staff within this study, perhaps indicating that meaningful supportive decision-making is not currently a reality within residential services or is not fully understood.

Finally, the results from *care process* domain revealed a high level of staff agreement with all the constructs, indicating that they engage in the person-centred care processes. However, the care processes within services were challenging to identify and articulate in the qualitative data, despite the high positive scoring from staff within the quantitative data. Healthcare assistants admitted to having their own way of being and caring but have not changed their ways of working for many years, while

registered nurses felt frustration as professionals, as they knew processes were not as they should be. The discrepancy between the data sets may be due to social desirability bias as described by van de Mortel (2008), which occurs in self-reporting questionnaires, such as the PCPI-S. This is when participants self-report to present a favourable image of themselves.

8.6 Life in residential services for older people with intellectual disabilities

The data revealed that residential services had a multi-faceted effect on the lives of older people with intellectual disabilities, staff, and family members. The discussion in this section aims to identify the contributing factors that make-up the care experience for those working and living in residential services within this study. The Person-Centred Framework places person-centred outcomes as the central aim of the person-centred practice, identifying outcomes as, the care experience, involvement in care, feeling of well-being and the existence of a 'healthful culture' (McCormack and McCance 2017). It was apparent from this study that the care experience in residential services was varied but overall older people portrayed a positive experience of residential services, despite many years of struggle to obtain a more humane service.

8.6.1 Relationships and loss

One of the central components of this study was to hear the experiences and expert opinions of older people living in residential services. This generation is one of the first to have lived through the hospital-style residential services and the subsequent transition to community living. This present study confirmed that many of the older people had mixed experiences of residential services but overall, they talked about the experience with positive regard. This study found that older people talked of enjoying this period of their life which gave them more freedom and opportunities than they had previously.

The majority of the older people who participated in this study lived in community group homes, they talked about being happy in their homes with friends and staff members

they liked. They also continued to enjoy close relationships with their family members. None of the participants talked of having intimate relationships, either past or present, and there was limited mention of friendships with non-disabled people (O'Brien 1992). They identified their friends as mainly the people they lived with or mixed with at their day service, they had little or no contact with their neighbours. This finding broadly supports those of previous studies in this area which examined the social networks of older people and found they had small social networks with a high percentage of their friendship circles consisted of fellow housemates (Bigby and Knox 2009; McCausland *et al.* 2014; 2016). Staff were identified as close confidantes of (McCausland *et al.* 2014) and being valued by staff was important to older people (Bigby and Knox 2009), but contrary to other research studies, staff were not perceived as friends. When describing their fellow housemates, older people used words such as, *'adored', 'great fun', 'company'*. Living with peers had many social benefits for older people namely companionship, friendship and a supportive family-like network. Living alone had not been a positive experience for one older person and they preferred the company of living with others. Respondents within the studies frequently described the relationships between housemates as being close, '*like a family.*'

The impact of losing a member of that family was notable in references to previous housemates who were now deceased or had moved into a nursing home, they noted that they *'miss them terribly'*. Family members expressed concern about the impact of loss and grief on their sibling at this stage of their lives and the difficulty they have in expressing their feelings. Secondary losses for older people can include the loss of their family and friends either through illness, the loss of their home or changes in roommate (MacHale and Carey 2002). Family members gave examples of how secondary losses went unidentified by staff but once the cause was realised, they took action to acknowledge the older person's feelings. Several authors refer to this as 'disenfranchised grief' (Doody 2014; McRitchie *et al.* 2014), which occurs when an individual experiences a loss, but their grief may not be understood by others. Within this study the impact of secondary loses appeared to go unrecognised by staff. For example, personality changes due to dementia, the transfer of friends to nursing homes or the fear of losing meaningful day activities, were not perceived as loss by staff and therefore went unrecognised.

expressed frustration that staff were not open to facilitating their chosen evening activities. This was coupled with lower staffing levels and lack of transport available to services which also restricted their range of choices. Therefore, these findings concur with Tichá *et al.* (2012) who found that the involvement of the person in choices is subjective to the type and structure of the service in which they live, and the variety of choices presented to them.

The older people in this study agreed that their choices were facilitated, however it is noteworthy that the majority of the older people had lived most of their lives within residential services and as a result they appeared to be more compliant and accepting of aspects of care. Those who articulated their dissatisfaction about how choice is facilitated were relatively new to living in residential services. Earlier research studies on choice indicate that the absence or lack of opportunity to make choices in early life can impact on how choice and decision-making is exercised in later life (Smyth and Bell 2006; Heller *et al.* 2011; Kåhlin *et al.* 2016). Several studies on choice for older people with intellectual disabilities have shown that people who live on their own or with family experience greater levels of choice compared to older people living in residential settings (O'Donovan *et al.* 2017; McCausland *et al.* 2018b). Contrary to the findings of these previous studies, this study found that both older people and family members reported having more freedom and variety of choices since moving into residential services, than they had previously living at home. The impacting factors on choice at home appeared to be for those living with ageing parents who could no longer facilitate activities or those who had moved from an isolated rural area to an urban area.

Conversely, macro-level choices were a key concern for several older people who expressed their upset about being excluded from major life choices such as where to live and with whom. They described that following the death of their family member, a series of meetings took place and decisions were made without their involvement. This resulted in them moving from their home and into residential services situated away from their local area. They talked about how the experience had upset them and they remained upset by this many years later. An essential part of healthy ageing is ensuring that people with an intellectual disability are supported to have their wishes heard (McGlinchey *et al.* 2019). The report on the Positive Ageing Indictors for people

with intellectual disability (McGlinchey *et al.* 2019) recommend that people should have access to an independent advocacy and professional advocacy service. However, in this geographical area very few older people had access to independent advocates who could offer support and ensure their rights were respected.

These results corroborate the findings of several previous studies, where older people had little choice or flexibility regarding the type of housing, location or who they lived with (Shaw *et al.* 2011; Stancliffe *et al.* 2011; Salmon *et al.* 2019; McCausland *et al.* 2018b). Conversely, McCormack and McCance (2010) emphasis, in order to make person-centredness a reality, the person receiving care should feel valued to create a feeling of well-being, thus ensuring person-centred practice is achieved. This study found that older people were excluded from major life choices did not feel valued.

Choice is a principal component of the concept of self-determination, which has been prominent theme within intellectual disability research for some time (Kåhlin *et al.* 2016; Salmon *et al.* 2019). Authors highlight that it is only when people are allowed the opportunity to make choices that self-determination can flourish (Wehmeyer and Abery 2013). This study found that there are three classification levels distinguishing choice within residential services. These are outlined in Figure 8.1 which also summaries the barriers to choice for older people with intellectual disabilities.
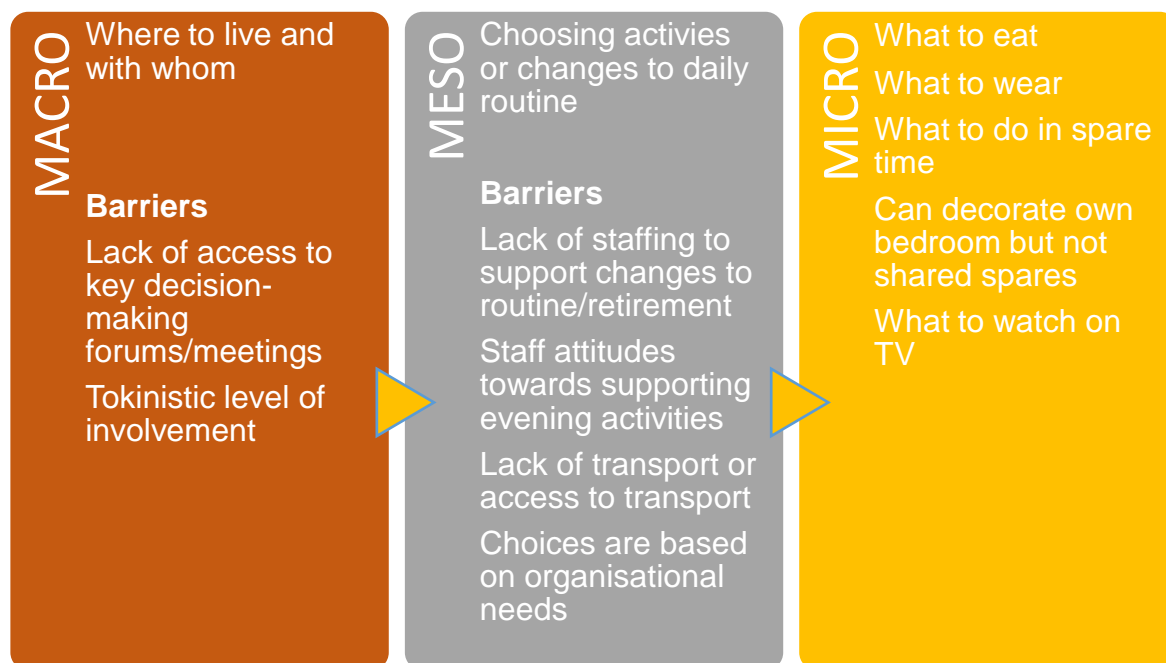
MACRO

Where to live and with whom

Barriers

Lack of access to key decision-making forums/meetings

Tokinistic level of involvement

MESO

Choosing activies or changes to daily routine

Barriers

Lack of staffing to support changes to routine/retirement

Staff attitudes towards supporting evening activities

Lack of transport or access to transport

Choices are based on organisational needs

MICRO

What to eat

What to wear

What to do in spare time

Can decorate own bedroom but not shared spares

What to watch on TV

Figure 8.1 Three levels of choice and barriers to choice within residential services

8.6.3. Living a meaningful life with a sense of belonging

Physical activity and participation are recognised as prerequisites for healthy ageing. A notable feature in the qualitative data revealed that older people place a high value on being active both physically and socially. The benefits of physical activity are frequently associated with improved physiological and psychological health (Bartlo and Klein 2011) with older people within this study recognised the benefits to their health and well-being. They valued physical activity such as dancing, music and sports, as important outlets (van Schijndel-Speet *et al.* 2014). Sport related activities were facilitated through the local Special Olympics branch and the benefits of participating in sports included, a sense of camaraderie, competing in larger national and international events, with sport also fostered a sense of achievement and celebration for the athletes.

These findings are substantiated by Tedrick's (2009) study on growing older in Special Olympics, with athletes testifying to the benefits of fitness, improving sporting skill

level, competition, and being part of a social group were major motivations for taking part. van Schijndel-Speet *et al.* (2014) work on physical activity demonstrated a wide range of activities for older people, in comparison this study found that older people had a limited number of physical activities, with a few participants mentioning swimming, dancing, and walking in their physical activities. Older people living in rural areas had a notable lack of physical activities compared to those living in towns, with their activities consisted of eating out and attending events.

The majority of the older people who participated in the study continued to attend a day service well into their 60s and 70s age range. Here they took part in other forms of activity, such as gentle physical exercise, stretching and dancing which they said, "*helped their body move.*" Those who had a form of work placement were working in hotels and talked about how they enjoyed their work which helped them feel more confident. However, a family member highlighted the challenge of retirement for their relative who was upset that they could no longer work. The qualitative data revealed that older people have noticeably clear views about remaining active as they age, which is similar to previous studies that have sought the opinions of older people (Buys *et al.* 2008; Bigby and Knox 2009; Judge *et al.* 2010; McCausland *et al.* 2010; Buys *et al.* 2012). The day service remained their 'social hub' and the centre for their physical activities to maintain their well-being, which is a key goal of the National Positive Ageing Strategy (DoH 2013b). However, there was a reported lack of future planning and organisational guidance in services to address ageing or processes to discuss this with older people and their families. For example, despite being in their seventies, older people could not stay at home in the mornings if they wished due to lack of staffing in community group homes (Bigby and Knox 2009; McDermott and Edwards 2012).

The quantitative data relieved that staff scored themselves highly within the *care process* domain, with the constructs *engagement* and *providing holistic care*, indicating high levels of agreement that they engaged older people in the care process. However, in practice older people living in community group homes, talked of being afraid to use household items, such as the washing machine or kettles and household tasks were carried out by the staff. There appeared to be a focus on *'doing for rather doing with'* (Bigby *et al.* 2012). Cooking their own evening meals was now more common and older people carried out household duties, such as mopping and tidying

of their bedrooms with assistance from staff. The ability to perform activities of daily living, for instance, shopping, preparing meals are thought to be a key component of successful ageing. Positive levels of staff support have been found by other studies to be a key factor in in helping people with intellectual disabilities achieve their goals (O'Rourke *et al.* 2004; Bigby and Knox 2009; Garcia Iriarte *et al.* 2014). Although older people were clear that at this stage of life, they did not want to carry out housework, nor were they interested household chores as a form of activity. This leads to questions regarding the strategies and types of activities which are suitable to engage and motivate older people.

The social activities for older people were also associated to a fundamental need to belong and feel part of their local community. When older people talked about their homelives, day service, local community and participating in sports clubs, there was clearly a desire to feel a sense of 'belongingness' and connection to others. For many older people a sense of belonging had been absent in their lives, and it has taken society decades to accept their presence. In the qualitative data, staff recounted the initial challenges and negative reactions to people with intellectual disabilities being physically present within the local community. The services were implementing the principles of normalisation and SRV which advocated the assimilation of people with intellectual disability into the community and to be seen as 'normal' to eliminate difference (Allan 1999).

Staff talked of people with intellectual disabilities now being welcomed in local areas and the community has accepted them, albeit with social barriers and isolation still evident. Several authors argue that public attitudes may have changed towards people with intellectual disabilities but there is still only a begrudging level of acceptance of their presence within communities. Culham and Nind (2003) attribute the continued barriers to social integration as a legacy issue of normalisation and SRV which advocates that people with intellectual disabilities need to assimilation into the general population. Interestingly they compare this approach to the empowerment strategies used by other devalued groups in society such as, the LGBT movement, Feminism, or the Anti-Racism Movement, which in contrast celebrated their differences and congregated together to demand their rights and acceptance by society. In contrast people with intellectual disability are continual expected to assimilate and attempt to

pass for 'normal' which Culham and Nind (2003) argue only leads to further isolation and exclusion.

In contrast this study found that older people were happy to be themselves and group together with their peers and participate in activities which foster a sense of well-being and fulfilled a fundamental human need to belong. This sense of belonging in society is again strongly associated with the concept of 'othering.' Powell and Menendian (2016) argue that the only solution to 'othering' is inclusion and allowing people 'membership' to society. These authors advocate for providing space for tolerance and acceptance of the difference of people who have marginalised from society. The social activities which the older people in this study discussed, frequently occurred in groups specifically designed for people with intellectual disabilities. These groups and activities were important in their lives and represented a place where they felt welcomed, wanted, and valued. This finding concurs with a recently published study by Adams *et al.* (2020) conducted in Greater Manchester in the UK, which aimed to reduce social isolation amongst older adults with intellectual disabilities. The study also identified a sense of belonging as a factor which can reduce social isolation amongst older people with intellectual disabilities. The authors suggest that even if people with intellectual disability do not feel part of their wider community, then they may feel part of an intellectual disability community which helps create a sense of belonging in their lives. Therefore, providing attainable opportunities to create attachments and belonging is important for older people and is a reminder of the human need behind the terminology of social inclusion (Hall 2004).

8.7 Family members: high hopes but future doubts

Family members within the study demonstrated a lifelong commitment and involvement with the care of their relative. Normally one family member acted as the communication link between services and the remainder of the family. At the outset of the interview many of family members recalled how the caregiving capacity within the family unit had depleted and they felt their sibling with an intellectual disability would benefit from residential services and a home of their own. They referred to this as a major decision which caused the family a lot of anxiety (McConkey *et al.* 2016). They

described the rudimentary physical environment they encountered on entering services. As a result, several the family members within this study had a history of being actively engaged with services to improve standards. These findings are similar to the literature on relationships between adult siblings when typically, one sibling takes on the role of family advocate and continues to have a high level of involvement and emotional connection with their family member with an intellectual disability throughout their lifespan (Heller and Arnold 2010; McCarron *et al.* 2011)

On the whole family members stated they had positive relationships with Service Managers and Directors of Nursing, who they worked collaboratively with to ensure better quality housing and service developments. However, several the participants felt that not all families were engaged with services, and they lacked the confidence to complain to management if they were unhappy about service delivery, for fear it may impact on the quality of care their relative would receive. Any discussion of strained relationships between staff and family members centred on the high numbers of agency staff which they felt caused a lack of attention to the fundamentals of care and the continuity of care. This finding is consistent with that of Bigby *et al.* (2015) who found that tensions between staff and families were often due to the perception of the competency levels of staff. Family members talked of the importance for partnership working and the necessity for progressive, inclusive leadership within all sectors of the HSE, as the key to improving the lives of people with intellectual disabilities.

Overall, residential services represented a relief from the responsibility of caring. Family members talked about the need for their relative to develop their own life and independence. As services have improved over the years, families felt reassured that their loved ones were settled and cared for in their own homes. They talked about residential services as giving their relative a new lease of life and developing their potential to participate in voluntary work, self-development, social outings and the opportunity to develop friendships. Sporting activities through Special Olympics were also viewed as invaluable to their loved one's health and well-being. Family members welcomed the development of the inspectorate body HIQA which they saw as essential to safeguarding the rights of people with intellectual disabilities. Although the older person was living permanently in residential services, families in this study remained actively involved in their care. They felt their current level of involvement

was sufficient as they no longer had the physical and mental energy to attend to the needs of their relative, due to their own ageing process and life commitments (Taggart *et al.* 2012).

While families in the study reported communication with residential services as positive, they shared concerns about the lack of collaboration on the anticipated changes to the lives of older people due to the ageing process. They felt apprehensive and concerned about the future care of their ageing family member, regarding retirement options, declining abilities, and ailing health needs. They expressed concern that any retirement plan must include physical, social, and intellectual stimulation for the older person, as they feared they would be left to "*wither.*"

Family members also expressed concerns about ageing in place and if their family member would remain in their community group home as their '*forever home,*' even in the event of deteriorating physical health. They reported that these topics were not openly discussed or addressed through the annual review process or any other discussion forums. Family members felt that there was a lack of orientation about the future by senior management (Bigby and Knox 2009) and they were unaware of any organisational policies or practices in place in the event of change in health-status. Hall and Rossetti (2018) advocate that professionals need to support families to be involved and share information to plan for the future. Service providers may assume that future planning discussions with families is not required for those already living within residential services. However, previous studies have highlighted similar issues and an indifference to ageing, but this was due to lack of staff knowledge (Alftberg *et al.* 2019) and clear policy and guidelines for staff when working with older people (Wark *et al.* 2014b). The overarching message from family members is that they would welcome the opportunity to discuss the options and future planning to put their mind at ease and to explore potential scenarios of what may lie ahead for their loved one.

8.8. Staff: personal commitment and distresses

Staff spoke about the stresses and challenges that came with their role. Nurse managers described the culture of working within residential service as being on a

'*treadmill*' and '*madness*' to describe their expanding and diverse workload which encompassed '*anything and everything.*' They used words to describe the delegation of tasks and initiatives as things being '*thrown*' at them, without their input or consultation. They had to be '*jack of all trades*' and were like a '*puppet,*' which left them feeling undervalued and unappreciated. The shift to person-centredness holds an important often overlooked element which is that the person who is delivering care is also central to implementing the philosophy (McCormack and McCance 2006). A key source of stress for staff came from the lack of infrastructure and organisational support to carry out their role. Similar findings were reported by Vassos and Nankervis (2012) who identified role ambiguity (unclear where role begins and ends and what tasks are expected) within intellectual disability services, as a variable in predicting staff burnout within organisations. A key component of person-centredness is feeling valued in a work role to foster a feeling of well-being (McCormack and McCance 2017).

Nurse managers and staff nurses expressed frustration at the lack of congruence in the espoused values of person-centredness by the organisation and the actual practices. They also talked about the conflicting priorities between themselves and senior management who they felt focused on paperwork for inspection processes rather than the person with intellectual disabilities. The nurse managers revealed discrepancies between their perspectives and that of senior managers regarding the goals of care delivery and the reality of practice within the organisation.

Staff participants also spoke of the personal toll their role had on their psychological well-being. They described strong feelings of loss and duty of care to older people who were moved to nursing homes when their health declined. Staff felt that registered general nurses (RGN) did not have the required knowledge to care for older people with intellectual disabilities. They also expressed a sense injustice, as they believed that intellectual disability service had a responsibility to create a tailor-made provision for the older people who became too ill to maintain them in their own homes. McCallion *et al.* (2012) found this was a common outlook amongst many staff working in intellectual disability services, as they believe they are more knowledgeable and sympathetic to people with intellectual disabilities than nurses working within nursing homes and that older people had the right to die in their own home. Previous studies

have shown that nursing homes were ill-prepared to take on this role (Bigby *et al.* 2008; Eley *et al.* 2009; Shaw *et al.* 2011) and a move to a nursing home resulted in older people being isolated from friends and their social networks (Webber *et al.* 2014). Staff also spoke of the difficulty of coping with the death of older people, many of whom they had worked with for over 30 years. Staff experience a disenfranchised grief and McCallion *et al.* (2012) argues that services need to be cognisant of this and provide support through policies and procedures.

Many of the healthcare assistants who participated in the study worked in community group homes and their shift patterns included sleepovers which proved problematic to getting a good night's sleep. They identified the lack of sleep, coupled with the isolation of lone working over extended periods of time, as the key variables that cause them physical and psychological stress. They described themselves as not being able to give more to the people they were working with, as they now felt exhausted by the thought of '*having to do it all again tomorrow.'* These findings indicate that the staff were reporting signs of emotional exhaustion, a recognised dimension of 'burn out.'

'Burn out' refers to the psychological state of those who experience prolonged interpersonal stressors in their work (Maslach and Leiter 2016). It is described by Maslach and Leiter (1997) as having three dimensions, emotional exhaustion, depersonalisation, and a lack of perceived personal accomplishment. These responses were noted in some of the staff who participated in the study which highlighted variables such as the lack of organisational support in a rapidly changing service, lone working for lengthy periods of time, role ambiguity, loss of idealism and lack of managerial support, as the factors that caused stress and burnout. Regrettably, these findings are not unique to this study but have been frequently documented within the disability literature, with considerable evidence identifying similar organisational factors, all of which create stress and burnout among staff and ultimately have a detrimental impact on people with intellectual disabilities (Mutkins *et al.* 2011; Gray and Muramatsu 2013; Ryan *et al.* 2021).

The presence of a 'healthful culture' for staff to work in has been emphasised by McCormack and McCance (2017), this is a culture in which staff feel valued in their role with shared decision-making and transformational leadership that is in line with their values. A healthful culture supports staff well-being and fulfilment within their role

and ultimately delivers person-centred outcomes. This study revealed that the residential services environment did not contain some of the key components of healthful cultures which are central to the delivery of person-centred services.

Finally, Figure 8.2 depicts the interconnecting relationship and impact between the macro context, the care environment, and the prerequisites on the delivery of person-centred practice. The relationship influences care both positively and negatively at all domain levels. At the macro level context, the impact of othering and belonging has been influential on the exclusion of people with intellectual disabilities from society and policy documents, location of their homes and paternalistic care patterns of care within residential services. The macro context of othering has also impacted on the quality of the care environment which older people with intellectual disabilities have experienced both historically and currently, with positive and negative experiences emerging from the data. The othering of staff as being less worthy due their association with people with intellectual disabilities, also impacted on the prerequisites, with the lack of recognition for the need for role preparation and staff development to work effectively with people with intellectual disabilities. Despite the barriers, improvements have been made by families, staff, and older people to create meaningful relationships and lifelong family-like connections, feelings of belonging and commitment in residential services.

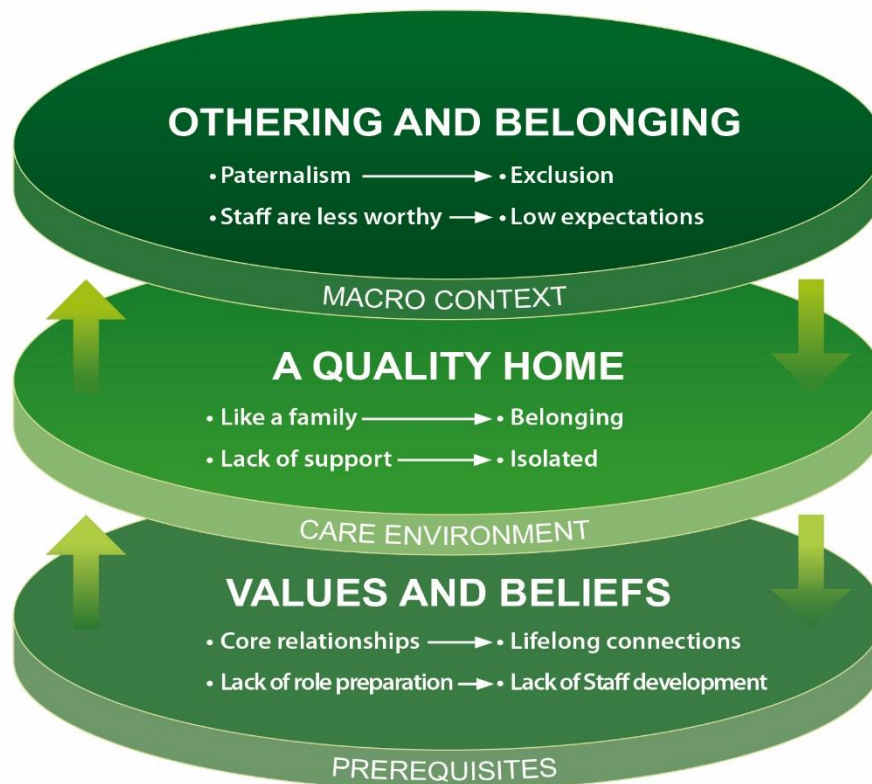**OTHERING AND BELONGING - A RELATIONSHIP**

OTHERING AND BELONGING
- Paternalism ⟶ • Exclusion
- Staff are less worthy ⟶ • Low expectations

MACRO CONTEXT

A QUALITY HOME
- Like a family ⟶ • Belonging
- Lack of support ⟶ • Isolated

CARE ENVIRONMENT

VALUES AND BELIEFS
- Core relationships ⟶ • Lifelong connections
- Lack of role preparation ⟶ • Lack of Staff development

PREREQUISITES

Figure 8.2: The influence of othering and belonging at the macro contest and domain level in residential services for older people

8.9 Summary of how the Person-Centred Practice Framework is experienced in residential services

This discussion chapter offered insight into the challenges associated with implementing person-centredness in the context of residential services for older people with intellectual disabilities. As demonstrated person-centred practice is not a linear process, but a complex interlinking of components that impact across all areas of practice. The quantitative data from the PCPI-S demonstrated that staff believed that they possess the necessary prerequisites to manage the care environment, relationships, and care processes to deliver person-centred practice. However, the results reported from the PCPI-S questionnaire may be subject to social desirability

bias and therefore is not truly reflective of reality, but there was some convergence between the findings of the two data phases. The qualitative data revealed a care environment in which person-centredness is not always realised due to a combination of interrelated factors. Firstly, at the macro context level, the 'othering' of people with intellectual disabilities within society had a powerful compromising influence on the way care is conceptualised, prioritised, funded, and implemented. Although this is not accounted for in the theory of the Person-Centred Practice Framework, the voices of the respondents revealed its impact across the domains.

Secondly, the theory and understanding of person-centredness within intellectual disability services contributes to how care is delivered. The focus on 'patient-centred' as opposed to 'person-centred' care for intellectual disabilities, has resulted in an emphasis on the administrative approach to person-centredness through documentation tools, such as person-centred planning, as opposed to a 'healthful' workplace culture, which has hindered the realisation of person-centred practice. The lack of clarity of beliefs and values and their translation into observable behaviours restricts daily choices for older people. Furthermore, giving and receiving feedback are not part of the current workplace culture, which allows certain staff behaviours to go unchallenged. The current practice of lone working has a negative effect on choice and control for older people, restricting their opportunities to fully engage in community living. Healthcare assistants also found lone working effected their well-being, with a reported lack of contact with line-managers. Nurse managers reported feeling disempowered with an ever-increasing remit of non-nursing duties and stressful interactions with senior managers. A lack of shared decision-making processes, role clarity and staff development hindered the ability of all persons to flourish within residential services. Both staff and older people spoke of the impact of loss of housemates who died, after working and living closely together for many years. Despite these factors, staff demonstrated a personal commitment to their role and developed positive interpersonal relationships which older people with intellectual disabilities acknowledged and valued.

Family members spoke about their happiness with the opportunities and lifestyle that residential services currently offered their relative, as they could no longer provide care for their family member due to their own ageing process. They expressed

concerns regarding the frequent use of agency staff on the continuity of care. They also had concerns regarding the lack of discussion around retirement options and ageing in place within services, and what the future held for their family member. Whilst older people spoke of this being a happy time in lives, with more freedom and access to social activities than they had previously experienced. They talked of being happy with their home life, which for those living in community group homes provided them with a quality physical environment. Although shared bedrooms, noise levels and living in isolated rural areas remained an issue for some older people. Lower staffing levels and staff attitudes restricted the control and choices for people living in all types of residential services. Older people clearly expressed that they wanted to be involved in decision-making regarding major life choices. Being physically and socially active and fostering a sense of belonging to groups and their communities was a fundamental need for people with intellectual disabilities as they age. Finally, the discussion chapter represents the complex interplay how of the macro context influences organisational and staff practice and ultimately determines person-centred outcomes for older people within residential services.

CHAPTER 9: CONCLUSIONS AND RECOMMENDATIONS

9.1 Introduction

This chapter will initially discuss the contribution to knowledge which the study makes. It will then outline the recommendations and implications for practice, policy and education which are drawn from the findings. Further research development is also suggested from the findings of this study. The limitations of the research are defined and finally, a personal reflection on the research journey concludes the chapter.

9.2 Contribution to knowledge

This study has contributed to the understanding of the theory of person-centredness within an intellectual disability context. This is the first study to investigate person-centred practice using an evidence-based framework that provides insight into the culture and barriers to the delivery of person-centredness in residential settings, inclusive of the macro-context level. Initially, the findings from the PCPI-S revealed that staff agreed that the constructs and components of person-centeredness are present within the residential practice area. Staff reported that they were person-centred in delivering care to older people in a person-centred way. The in-depth focus groups and individual interviews showed that staff have a long history of engagement with the concept of person-centredness through person-centred planning. However, this study found that staff work from a patient-centred model as opposed to a person-centred model of care, which should incorporate all persons within its worldview of person-centredness. As a result, person-centred cultures of care are not always understood or realised, and this serves as a barrier to implementation. Staff work from their own internal values and beliefs systems which were often misaligned to those of the organisation. Therefore, behaviours and actions that are contrary to person-centredness are rarely challenged. This takes place within a cultural context were giving and receiving feedback amongst staff and implementing feedback from older people is not common practice.

Furthermore, the study has contributed to the Person-Centred Practice Framework, and has shown that at the macro-context level the realisation of person-centredness for people with intellectual disabilities is also affected by societal attitudes through the phenomenon of 'othering.' The study found that 'othering' in society had a potential effect on the priority and pace with which government policy, strategies, staff education and quality services are implemented for people with intellectual disabilities. 'Paternalistic othering' was evident in patterns of service delivery and often acted as an invisible barrier to the realisation of person-centred practice and the accessing of opportunities and acceptance of people with intellectual disabilities.

9.3 Recommendations and implications from the study

The following three recommendations and implications for policy, practice, research and education can be drawn from the findings of the study and will now be outlined.

9.3.1 Recommendations and implications for policy

There are three key policy recommendations drawn from this study:

1. Clarity of language regarding person-centredness
2. Practice guidance document for staff working with older people with intellectual disabilities
3. The inclusion of people with intellectual disabilities in policy development

Clarity of language regarding person-centredness

Firstly, national policy and strategy documents should provide clarity regarding the language used around person-centredness. A lack of clarity of language, and or poorly applied definitions, which are not underpinned by empirical data, risk endorsing an over simplistic view of the concept. This creates a misunderstanding of the complexity of the practice context and promotes the view that person-centred practice is easily implemented and achieved (Dewing and McCormack 2017). Clarity of language will provide the organisation and staff with a clearer shared vision of the concept. Currently

terms such as, person-centred practice, person-centred approaches and person-centred planning are all used interchangeably and can result in misunderstand of what is being achieved. Furthermore, national policy documents currently place the responsibility for the implementation of person-centredness solely with staff working directly with people with intellectual disabilities (HSE 2011). Whereas an organisational wide commitment and approach to person-centredness needs to be adopted for all staff, inclusive of multi-disciplinary team members and those in senior management and strategic leadership positions to make person-centred practice a reality for older people with intellectual disabilities.

Practice guidance for staff working with older people with intellectual disabilities

The development of a practice guidance document for staff working with older people with intellectual disabilities is required assist staff with ways of working. The guidance document should be aligned to the national strategies for the general population and include clear direction on approaches to retirement, housing, healthcare, ageing in place, and being active as people age. As Bigby and Knox (2009) recommend, clearer direction for service providers can enhance continuity and planning regarding the future care of older people and would aid regional and local services to strategical plan and deliver services to meet the needs of older people. Several research studies agree on the importance of activities for older people, regardless of their living arrangements (Judge *et al.* 2010; Buys *et al.* 2012). Being active was consistently referred to by older people and family members as essential to their emotional and physical well-being and this needs to be acknowledged and developed to assist staff in implementing this priority need. Therefore, the importance of occupational activity must be emphasized within guidance documents, to support healthy ageing. Furthermore, the guidance document should provide direction for the development of person-centred practice within services and thus avoid further bureaucratic approaches to person-centred planning.

The inclusion of people with intellectual disabilities in policy

The perspective of older people with intellectual disabilities and their family members has enhanced the findings of this study. Their perspectives should be included to inform the priorities, planning and focus of national policy and strategy documents. This will influence the identification of priority areas and the implementation of quality-of-service delivery to meet their needs.

9.3.2 Recommendations and implications for practice

The following eight key recommendations and implications for practice are drawn from this study and will be discussed in more detail.

1. Implementing person-centred ways of working
2. Review of lone working in community group homes
3. Review of choice and decision-making for older people
4. Documenting and discussing future planning
5. Promoting physical and social activities
6. Creating person-centred home environments
7. Implementing person-centred clinical leadership
8. Support and self-care needs of staff

Implementing person-centred ways of working

Implementing a person-centred programme of work using participatory principles, would be beneficial to support staff engagement. Laird *et al.* (2015) highlights that the practice context is one of the key factors which influences the success or obstruction of creating person-centred cultures. It is vitally important that the methods and processes used to engaged staff create safe, trustworthy space and foster collaboration and staff empowerment. Manley *et al.* (2011) emphasise the importance of developing a shared vision for the service which reflects the needs and direction not only of the staff team but also of older people. This programme would assist staff to understand person-centredness, establish team values, communication, and shared-decision-making. Staff reported a strong commitment to the older people they worked

with but felt that this was not always celebrated or recognised. A participatory programme would provide an opportunity to celebrate their achievements whilst reflecting on what needs to improve within practice. This programme should aim to build and create psychological safety in the workplace for all levels of staff, assisting them to contribute, participate and facilitate person-centred practice within residential services.

Review of lone working in community group homes

The practice of lone working in community group homes should be evaluated considering the reported impact on staff and older people with intellectual disabilities. Lone working was shown to create a sense of social isolation for staff which they felt affected their well-being, this was coupled with limited contact with colleagues and their line-managers. Furthermore, lone working places restrictions on older people who wanted more flexibility, choice, and freedom to participate in activities within in their day-to-day lives. Lone working was identified as a barrier to the person's individual choice in community group homes.

Review of choice and decision-making for older people with intellectual disabilities

Services must review how choice and decision-making is considered within the service system. There should be a shared responsibility between all grades of staff to ensure that older people are consulted, listened to, and have their needs met. The findings from the data indicate that decisions were often taken by others on behalf of older people and staff reported that choice appeared to be service led rather than person-centred, with the operational service needs taking priority over the person's needs or interests. Several older people with intellectual disabilities talked of others having control over their choices and these decisions affected their happiness and how they lived their lives. Finlay *et al.* (2008) recommend that having a range of people from outside of services (such as independent advocates) supporting decision-making can ensure older people have control over their own lives.

Documenting and discussing future planning

A critical issue for practice is the need for open discussion and clarity with older people with intellectual disabilities and family members on the impact of ageing on their future support, relationships, and housing. Family members were concerned by the lack of future orientation and sharing of information by services. Previous research has also found this absence of a future planning for older people by senior management as an issue, with a lack of organisational policies and operating procedures being in place to guide staff and inform older people and their families (Bigby and Knox 2009). There is a need to develop future orientated plans informed by older people with intellectual disabilities. This will help identify and build sources of support to enable a planned implementation of flexible service delivery to meet the needs and wishes of people with intellectual disabilities as they age (Mansell and Beadle-Brown 2006).

Promoting physical and social activities

The promotion of physical and social activity for older people needs to have a priority focus within services. Social activities and exercise were reported by older people as being important to them. As recommended by van Schijndel-Speet *et al.* (2014) physical activities must be tailored to the interests of the older adults for them to have fun while participating. Sports and activities with music were popular and services in rural areas must review and expand the scope of activities available to older people. Quality support and pro-activeness by staff is important to encourage older people to try different activities and to encourage those who may lack confidence or the skill to participate. Tedrick (2009) also found the involvement in sports through Special Olympics was also an important consideration, as team sports contributed to a sense of achievement and belonging for older people with intellectual disabilities. Older people also need support and access to transport to attend activities.

Creating person-centred home environments

Identifying and implementing person-centred home environments is a key recommendation for practice, ensuring that the physical environment is a nice place for older people and staff to be. The physical environment included the location, a quality home with low noise levels and individual bedrooms. Staff need support and

guidance to give control of shared spaces in community group homes, such as living rooms, to older people with intellectual disabilities as opposed to their influence being restricted to their bedrooms (Kåhlin *et al.* 2015). The quality of the interpersonal relationships between staff and housemates is also an important consideration in creating positive homelike environments. The quality indicators for good groups homes by Bigby *et al.* (2014), is a starting reference point for staff to review current practices that can enhance the care environment.

Implementing person-centred clinical leadership

The implementation of a person-centred clinical leadership programme within services is central to the creation of a positive workplace culture. The person-centred practice framework highlights the interplay between leadership relationships and context of care (Cardiff *et al.* 2018). A person-centred approach to leadership that embraces transformational leadership should be implemented to help develop leaders at all levels of the organisation. 'Transformational leadership' would assist nurse managers to respond to the changing landscape of service development, with a more adaptive and flexible leadership approach. This also has the potential to positively influence respectful interpersonal communication relationships between staff and management grades in the organisation.

Support and self-care needs of staff

Staff well-being is an essential element of person-centred practice. This study found that staff felt that role ambiguity, isolated working patterns and the effects of loss, impacted on their well-being. Awareness and recognition of stresses and the effects of loss have been highlighted by previous studies, with McCallion *et al.* (2010) highlighting the need for service acknowledgement and provide staff support through policies and procedures. Mangers should be aware and recommend the free counselling services which staff can avail of through Occupational Health Departments. This may encourage staff to be open about the stress, loss, and bereavement issues they experience through working with older people.

9.3.3 Recommendations and implications for research

The following four key recommendations and implications for research are:

1. Exploring the constructs within the Person-Centred Practice Framework
2. The impact of 'othering' and belonging on the lives of people with intellectual disabilities
3. Life Story Work
4. Ageing in Place

Exploring the constructs within the Person-Centred Practice Framework

Further research is required to explore the constructs within the Person-Centred Practice Framework in more depth within an intellectual disability practice context. This will create a body of evidence regarding particular constructs of the framework in practice. The use of an evidence-based model would assist staff to understand and visualise how the concept is applied in practice, with a central focus on engagement with older people with intellectual disabilities to develop services that are responsive to their needs (McCormack and McCance 2017).

The impact of 'othering and belonging' on the lives of people with intellectual disabilities

The findings of this study revealed the influence of othering of people with intellectual disabilities in society and within services and this requires further exploration. Conducting research in this area should explore the attitudes of the public, health and social care professionals, staff in intellectual disability services and those in associated services (e.g., housing, welfare) towards people with intellectual disabilities and examine the implications of 'othering.' Previous researchers have commented on stigma and 'othering' as deeply entrenched attitudes in society which also effects care delivery within services (Bigby *et al.* 2012; Dorozenko *et al.* 2016). Othering is an antonym of belonging and whilst othering is associated with prejudice and exclusion, belonging implies acceptance and inclusion of all people in society (Powell and Menendian 2016). A sense of belonging was important in the lives of older people and

the lens of 'othering and belonging' can provide a useful framework to research how these concepts impact on the lives of people with intellectual disabilities.

Life story work

Older people were eager to have the opportunity to recount their personal histories, lived experience of services. It was their past life experiences which ultimately shaped their relationships and how they now wanted to live their lives. Life Story Work has been found to empower people with intellectual disabilities (Meininger 2006) and it is their individual stories that will make a valuable contribution to society, policy makers and service providers to enhance and improve the quality of support provided to people with intellectual disabilities. Further research in the form of Life Story Work (LSW) would be beneficial and contribute to previous work and the historical record of their experiences conducted within Ireland (Hamilton and Atkinson 2009) and internationally (Westergård 2016). This research approach would inform service providers on the long-term influences in people's lives and can enhance their sense of belonging.

Attitudes and barriers towards the involvement of people with intellectual disabilities in life choices

Further research is required to examine the attitudes towards shared decision-making and the involvement of older people with intellectual disabilities in major life decisions, such as where to live and with whom. This study and previous research have consistently found that older people are excluded from decision-making regarding their future despite having the ability to make their preferred choice (McGlaughlin *et al.* 2004; Shaw *et al.* 2011; Salmon *et al.* 2019; McCausland *et al.* 2018b). Furthermore, there is little evidence of older people being consulted in future decisions regarding ageing, for example asking where *'home'* would be if a dementia diagnosis progresses (Watchman *et al.* 2020). A research study in this area would focus on attitudes to the involvement of older people with intellectual disabilities and examine what stops services and professionals from listening and taking notice of what older people are saying and excluding them from shared-decision-making forums.

Ageing in Place

Further research is required to investigate the best living options to support older people if they develop a long-term condition, such as dementia. The data revealed that older people with intellectual disabilities are currently moved from their homes, usually a community group home, to live in a nursing home if they have a change in health needs that required higher staffing levels. This was also a common finding within the literature (Bigby 2008a) and several studies have shown that nursing homes are not appropriate placements for older people with intellectual disabilities (Eley *et al.* 2009; Shaw *et al.* 2011; Buys *et al.* 2012) as the move caused social isolation and disconnection from the person's previous life (Webber *et al.* 2014). Furthermore, the practice is inconsistent with the key principles of the National Irish Dementia Strategy (Department of Health 2014), which aims to facilitate the desires of people with dementia to remain in their own homes and communities for as long as possible. However, for older people with intellectual disabilities this is not the case and there was little evidence of the use of wider services or early interventions for people, with their return to a large, congregated setting seeming inevitable. Research in this area should explore if older people with intellectual disabilities are availing of specialist dementia services and supports that are available to the general population to address inequalities. The research study should also examine the experiences of older people, the impact of moving to a nursing home on the older person, their fellow housemates, family members and staff from intellectual disability services and nursing homes.

9.3.4 Recommendations and implications for education

The following four recommendations and implications for education have been identified:

1. Continuous professional development for healthcare assistants
2. Developing a person-centre curriculum for the undergraduate RNID programme
3. Education programmes to meet the specific needs of older people
4. Introducing social learning

Continuous professional development for healthcare assistants

Continuous professional development (CPD) for healthcare assistants supporting older people with intellectual disabilities needs to be developed. Currently the focus was reported to be on mandatory training which limits the knowledge and skill development for healthcare assistants who provide vital support to older people. The quality of the support provided to older people has been found to be an important predictor of positive outcomes (Mansell 2006; Stancliffe *et al.* 2011). The role of education needs to be acknowledged as a potential enabler to the achievement of person-centred cultures.

Developing a person-centre curriculum for the undergraduate RNID programme

The embedding of person-centredness throughout the undergraduate nursing curriculum for RNIDs is essential. This will underpin the concept within all teaching and learning and enable students to link person-centre cultures of care within practice. The active involvement of people with intellectual disabilities in curriculum design and delivery of education is crucial, as they can provide powerful insights for professionals, which combined with reflection and action plans could show transferability of learning to practice.

Staff education programmes to meet the needs of older people

Continuous professional development programmes for staff should be develop in the following key areas:

1. Coping with loss and bereavement and secondary bereavement.
2. Promoting physical, social, and cognitive activities for older people. Older people reported that they enjoyed being active and activity also helps to maintain or improve the person's well-being and avoids early frailty (Evenhuis *et al.* 2012).
3. The wider philosophy and discourse of person-centred cultures of care needs to be addressed to help staff understand and create 'healthful' cultures of care. Intellectual disability practice settings require clarity on the difference between patient-centredness and person-centredness.

Introducing social learning

The introduction of a social learning approach is recommended to promote shared learning in services. Staff in this study reported that they frequently worked in isolation with sources of support provided by an informal network of peers. Social learning brings staff, older people with intellectual disabilities and researchers together to promote shared experiential learning, in conjunction with service planners to shape services. Communities of practice, demonstrate social learning in action and have proven to be successful. For example, the Teaching Care Homes Programme established by the Foundation for Nursing Studies (FoNS) demonstrates how community homes for older people successfully came together to create centres for learning, practice development and research, supported by close relationships with academics and education providers (Sanders 2019). This approach would help the development of person-centred cultures by providing a forum to engage staff, students, older people with intellectual disabilities and the wider community to develop knowledge that is contextually based and relevant to their practice (Wenge 2008).

9.4 Limitations of the study

It is recognized that there are a number of limitations to this study. In phase one of the study the PCPI-S questionnaire was used; this is a self-reporting tool and there was the potential for staff participants to respond in a manner which presents a favourable image of themselves as opposed to the reality, this is commonly referred to as social desirability bias (van de Mortel 2008).

The use of staff to approach family members and older people with intellectual disabilities to participate in phase two of the data collection, meant that potentially staff would only approach families and older people they knew were happy with their care experience. This could be viewed as selection bias and is a potential limitation. The difficulty in the recruitment of family members resulted in a small number being interviewed, which is also a limitation of the study. The family members who participated in the study were connected to community group homes, there were no responses from families whose relatives were living in larger residential services. A greater insight may have been achieved with a larger more diverse sample. The

recruitment of older people with intellectual disabilities was also conducted through staff but as the interviews were held in several different day service locations, word of mouth spread amongst the older people and they came forward voluntarily without nomination from staff, thus lessening the possibility of selection bias.

The researcher had difficulty in accessing and securing the release of staff nurses to participate in the study. Despite encouragement to participate from various managers, low numbers of staff nurses volunteered to participate. Facilitating their release was challenging, and three scheduled focus group interviews had to be cancelled on separate occasions. This was either due to the researcher's concern regarding forced participation in the research study which would violate the consent process, the shift patterns of staff nurses or the line-manager's lack of commitment to release staff to attend the focus group interview. Within residential services staff nurses are pivotal to service delivery, as they have a quasi-managerial role delegating care and are often the only registered nurse on duty. To ensure that staff nurses were represented in the sample, individual interviews were deemed the most appropriate alternative for inclusion, although a larger representation would have been beneficial to the study. Finally, this research study was conducted in one geographical area where the majority of residential services are delivered by the Health Services Executive. Other voluntary services were not included in the sample, but it is hoped that the findings are transferrable from service to service and to other geographical areas.

9.4 The research journey: a personal reflection

I felt it was important at this point to reflect on my PhD journey as I feared that my experienced over the past six years could be forgotten and the learning lost. For this reflective piece I have adopted Gibbs (1988) Reflective Cycle as a guide to assist me in reflecting on the learning, feelings and thoughts that have emerged and evolved. Acknowledging older people with an intellectual disability as valued citizens of Irish society was one of my motivations for undertaking this study. At the outset of my PhD the key policies in the Republic of Ireland were focusing on the decongregation of many older people who still lived in large residential services. Having previously worked in the UK, I was disappointed that these settings were still a reality for people

with intellectual disabilities. Community living has been a success for many people with intellectual disabilities, but community group homes were also being referred to 'mini-institutions' and were not realising the potential to support people with intellectual disabilities to live full meaningful lives. The failure to create person-centred services was a topic that was receiving considerable media attention at the time, I knew the implementation of person-centredness could improve outcomes for older people, but it seemed challenging for staff to achieve this in practice.

Initially, the viability of a practice development project was considered; however, the context of the study was set during a period of rapid change for intellectual disability services. The introduction of the inspectorate body, HIQA, in the Republic of Ireland, resulted in services undergoing a period of rapid adjustment to the inspection process, placing even further prominence on person-centredness. With the supervision team, it was decided that services may not be receptive to this type of intervention and preliminary work would be beneficial to take stock and evaluate the knowledge base and perceptions of person-centredness within residential services. Much of the previous published research on the topic concentrated on person-centred planning but did not address the cultural issues which can promote or hinder the concept in practice. The concept of person-centredness had not previously been evaluated using an evidence-based model and I had limited knowledge on the many components of person-centredness and how they were interconnected. The inclusion of people with intellectual disabilities was also a crucial part of the study. However, I did not anticipate the response from local Research Ethical Committee, who took a paternalistic stance to the inclusion of people with intellectual disabilities as participants, questioning their ability to make informed choice regarding consent. I responded to this by reiterating the Assisted Decision Making (Capacity Act 2015) and the robust consent process within the study. Following some delay, ethical approval was granted.

The initial consultations with service managers regarding the study were positive. Prior to implementing the study, I attended a senior managers meeting to outline the aims and objectives of the study and the data collection process involved. On reflection, I was unprepared for the reaction of panic and resistance which the presentation caused by the nature of the topic and the age group of the participants. I also underestimated the stress levels and the climate in which managers were working under. Senior managers expressed their reluctance to participate, fearing the research

to be another form of inspection process, a criticism of the services and their performance. A culture of research within services was not common practice and it was evident that services were unaccustomed to participating in research studies, leading to a misunderstanding of the purpose and objectivity involved in the research process. Managers were nervous of the findings particularly from the perspective of older people, acknowledging that the services had not always been humane or adequate for this age group throughout their lives. Consequently, my request to access services to collect data was initially denied in one area. I recall feeling alarmed by this decision as I had not anticipated a refusal to access services. Yet, I realised that I had become so preoccupied by my own need to collect the data for the study that I had misjudged the levels of emotional stress and pressure experienced by senior managers.

I paused and re-evaluated how to deal with the reaction, and I had to admit to myself that I took the refusal personally and saw it as my own failing. I contacted my supervision team for support, trying to seek reassurance and disguise my sense of panic. We discussed how to best remedy the situation and we agreed it was best to wait for a few days to allow emotions to settle. I then contacted the senior managers via email outlining the benefits of the research for both staff and older people. Following the email, a meeting was arranged, and, on this occasion, the senior managers acknowledged the stress and challenges faced by staff to improve services notwithstanding the importance of the research topic. An open and frank discussion took place which set out the intention of the research process. Together we acknowledged the challenges and agreed to delay data collection until a planned service review had been completed. We also identified appropriate sites for data collection whilst excluded sites which were deemed to be inappropriate at that moment in time.

From that point onwards the research was supported by managers and with hindsight I can see that the initial refusal inadvertently brought about a partnership approach to the data collection process and broke down some of the barriers of fear and mistrust towards my role as a researcher. It also made me more cognisant that not all staff have same level of understanding of research, and from that point I ensured that I

explained the process in 'plain English' so not to alienate staff and potential participants.

On commencing data collection, I experienced an initial reaction of suspicion during my first visits to several services. Certain sites were difficult to engage with due to their isolated geographical locations, difficulty in accessing the building or a general atmosphere of segregation. It was evident that staff were not accustomed to a stranger visiting their space to discuss their opinions or work practices. Therefore, during phase one of the data collection I visited every site except one, that was involved in the research study. I worked hard to build relationships with key staff members to lessen any misgivings they had about participating. Although this was a costly and time-consuming process, the contacts, and connections I made during this period were invaluable. I developed 'insider contacts' within each area which were managers but often they were someone I had previously known professionally in a different role or a likeminded staff who had a passion to improve the service. These 'insider contacts' often took on a role of ensuring the questionnaires were distributed and collected, reminding colleagues about the study and/or recruiting family members and older people for participation. Without these key people I feel the response rate of the questionnaire and participation in phase two would have been much lower.

As a registered intellectual disability nurse who had worked in a variety of service settings including residential and community nursing, I had experiences which had the potential to affect my attitudes and opinions of service delivery. I acknowledge that I had some predetermined ideas regarding the findings of the study. I was surprised to discover that results from phase one showed that staff felt they were person-centred, despite inspection reports to the contrary. Having experience of residential services previously, the cultures and institutional practices had frustrated me, and I had not always considered them to be person-centred environments. I was also unaware of the social bias of participants completing questionnaires, I had believed that people would be objective due to the anonymity with the data collection process. Even those who clearly disagreed with the questions scored neutral, despite writing comments to the contrary in the margins of the questionnaires. Statistical analysis was not my strength and at times my fear of making mistakes often clouded my ability to objectively analyse the findings as I was so concerned with the process. Over time I learnt to recognise my preconceptions and acknowledge my own anxieties and abilities to be

able to complete the analysis successfully and to keep an open mind regarding the findings. Through discussions with my supervision team and the need to demonstrate rigour helped with this process. I have learned to interpret the data objectively and not fear unexpected outcomes and to acknowledge that it is human nature not to realise the influences that shape our behaviours.

As I moved into phase two of the data collection process, I began to experience a real connection with the participants. In contrast to the initial wariness of the staff towards participation in the study, older people with intellectual disabilities were open and keen to share their stories and the details of their lives. I felt this was the most enjoyable part of the study for me, yet I quickly learnt the demands of interviewing people can be exhausting. In my eagerness to capture participants experiences I had underestimated this completely. On one occasion there was an unexpected addition to the interview schedule at the end of the day and the staff informed me that an older person was waiting to be interviewed. Not wanting to disappoint the person, I went on to conduct the interview despite feeling tired. I expected the interview to follow the same pattern of the previous interviews and I was completely unprepared for how vocal and clear the person was from the outset about how unhappy they were in their residential service. Following the interview, I felt I had not entered the process fully engaged and alert, I worried that my fatigue may have affected the interview, not giving justice to this person's story. I still reflect on that interview even though I am approaching the end of the PhD journey. The experience has reaffirmed the importance of the inclusion of older people with intellectual disabilities and how their contribution has enhanced the research findings. Their enthusiasm and positivity about life in residential services has been encouraging and has changed my mind-set. I feel that the input from older people has made this study more meaningful and certainly more enjoyable for me as a researcher.

As with many PhD researchers I found the discussion chapter the most challenging to complete. The discussion chapter of a mixed-methods research study brings together the quantitative and qualitative findings. Having already conducted the analysis of both types of data separately, constructing the discussion involved a re-examination of both datasets and drawing further deductions while considering the previous findings. Presenting the staff in a fair an objective manner was important to me, while balancing

this with the representation of older people and their families. This involved a further analysis of the findings to reach a combined meaning for the previously analysed datasets. I found this process demanding, with the danger of repeating the same themes presented in the previous chapters. Due to personal life circumstances and a close family bereavement, I found it difficult to maintain focus and motivation, underestimating the time needed just to think and unravel the data into a meaningful discussion. With mixed methods a significant amount of time and effort is given to data analysis throughout the research process. I had originally thought that following the data analysis the discussion would materialise effortlessly. However, it requires a considerable amount of time, planning and thought which felt unachievable at times. Having used this research methodology I now appreciate the learning and knowledge I have gained but I would be mindful in the future of the challenges which the data integration stage entails.

Over the past number of years, I have had challenges but also opportunities to present at international conferences and contribute to publications with my supervision team, with a chapter included in the recent book 'Fundamentals of Person-Centred Healthcare Practice' (McCormack *et al.* 2021). Overall, the PhD experience has been empowering and enabled me to grow personally and professionally.

9.5 Conclusion

This two-phased sequential explanatory mixed methods study set out to explore how person-centredness is perceived and experienced within residential services by older people with intellectual disabilities, staff and family members. Phase one involved the PCPI-S questionnaire, with the quantitative data finding that staff believed that they are person-centred and deliver care in a person-centred manner. However, the qualitative data from phase two revealed a care environment where staff worked from a patient-centred model as opposed to a person-centred model of care, with the needs of the organisation taking priority over the needs of all persons. The macro level context of othering of people with intellectual disabilities was found to create an invisible barrier to the realisation of person-centredness and their belonging in society. Issues of choice and control were especially important to older people who said they

had control over micro-level choices but were excluded from the macro-level choices regarding their own lives. Such decisions are made by others as a matter of expediency or to fit with established service models. The practice of lone working in community group homes was also a barrier to choice and control over activities and created a sense of isolation for both staff and older people.

Despite these barriers older people revealed that they were happy and enjoying this period of their life, which gave them freedom, physical comfort, and more access to activities than they had experienced previously. A strong family-like bond between older people who live together in services was found to be fundamental to their happiness. Whilst this finding and the way it was articulated by older people, family members and staff was not anticipated, it does affirm that environments that emphasise more than technical tasks create a wider physiological benefit that generates a sense of belonging for older people. The importance of creating a sense of belonging to community, through groups and personal connections, with their disabled or non-disabled peers, was found to be essential factor in the human flourishing of older people with intellectual disabilities. It is hoped that the findings from this study will help to clarify and widen the debate around the concept of person-centred practice in an intellectual disability context. These are practical and important findings, as without the data informing us of what is hindering the actualisation of person-centredness, little can be done to lessen or manage their influence.

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Appendix 1: Literature, themes and main findings

Study and country and origin	Key themes	Study method and sample	Major findings
Alftberg *et al.* (2019) Sweden	Staff attitudes to ageing	Qualitative study • Content analysis • Sample (n=24) staff members in community group homes and day centres	• The study found staff were uncertain about the signs of ageing. • They also had an ambivalent attitude towards ageing of people with intellectual disabilities. • The findings of this study indicate the need to provide education about ageing to staff working in intellectual disability services.
Antaki *et al.* (2009) UK	Choice and control	Qualitative study • Ethnographic methodology • Sample = 2 community group homes that housed 15 adults with intellectual disabilities • Ages range of participants was 43 -65 yrs.	• The study found that staff were well-meaning and use the language of choice to promote organisational objectives but were not always able to offer choice due to the demands of everyday service delivery. • The study also found a gap between practice and the policy theory and recommendations.
Bigby (2008a) Australia	Ageing in place	Review paper • The paper explores the reasons for the slow development of ageing in place in practice	• Many people with intellectual disabilities have a mid-life disruption to where they live. They may continue to live in a group home as they age or may move prematurely to a nursing home for older people. • The review found that administrative and funding characteristics continue to hinder the development of implementation strategies to support ageing in place for older people with intellectual disabilities.

Study and country and origin	Key themes	Study method and sample	Major findings
Bigby (2008b) Australia	Social networks	Mixed methods research • In-depth interviews and survey • Four waves of data collection • Sample (n=24) residents of a large congregated setting moved to small group homes • Mean age of participants was 51.5 yrs.	• People did not form new relationships after moving from large residential settings. • Family contact decreased. • Ageing affected patterns of contact with family • 62% of people had no-one outside of the service to advocate for them.
Bigby *et al.* (2008) Australia	Accommodation needs	Quantitative study • Postal survey sent to generic residential services for older people • Sample of staff (n=286) Directors of Residential Care Facilities	• Service users were younger than general population. • 60.7% had higher care needs and came from family home to care home. • Reliance on care homes earlier in life cycle • Concerns with services offered, inability to fit in with older residents, lack of participation and meaningful relationships.
Bigby and Knox (2009) Australia	Ageing and retirement	Qualitative study • Social constructionism • Sample (n=16) older people with intellectual disabilities • Mean age of participants was 62 years	• The study found that older people have small social networks. • Being connected to others and being valued by peers and staff was important. • Importance of being active, although retirement had impacted on this for some people.

Study and country and origin	Key themes	Study method and sample	Major findings
Bigby *et al.* (2012) Australia	Life in community group homes	Qualitative study - Ethnographic methodology - Secondary analysis of large dataset - Community Group Homes	- The study found five cultural patterns in underperforming community group homes. - There was a misalignment of the staff values and that of the organisations espoused values. *'Doing for'* rather than '*doing with'* was present in how staff work. - Staff-centred approach - Resistance to change. - The differences from institutionalised cultures are discussed and those of high performing group homes.
Bigby *et al.* (2011) Australia	Ageing and retirement	Qualitative Study - In-depth interviews - Sample (n=35) older people with intellectual disabilities - Participants aged 45 years plus	- The study found that older people perceived retirement as a risk to their well-being and activities and were negative about support in retirement. - The use of inclusion strategies was not recognised with a focus on continued segregation through specialist programmes as the most commonly suggested retirement option by staff and family members.
Bigby *et al.* (2014) Australia	Life in community homes	Qualitative study - Case study approach using in-depth participant observation over 9-12 months for 21 people with severe and profound intellectual disabilities living in community group homes - Sample 1: (n=16) residents - Sample 2: (n=21) residents	The study identified quality indicators of good outcomes which can be used by auditors, community visitors, funders, advocates, or family members to guide observation and judgements about group homes.

Study and country and origin	Key themes	Study method and sample	Major findings
Bigby *et al.* (2015) Australia	Role of siblings in lives of older people	Qualitative study • Social constructionist research paradigm was used to explore how siblings and staff understand and experienced their roles and relationships • Sample (n=13) siblings (n=17) staff • Mean age of participant's siblings with an intellectual disability was 52-68 yrs.	• Siblings of older people are likely to take responsibility for their wellbeing and negotiation with formal support services. • Siblings valued the relationship with their brother or sister and played a key role in safeguarding their wellbeing. • Relationships between sibling and staff varied over time, sometimes becoming tense and difficult. • There was an absence of protocols to guide these relationships. The study recommended a principle-based framework could facilitate negotiation between staff and siblings about expectations of communication and decision making.
Boulton-Lewis *et al.* (2008) Australia	Ageing and activities	Qualitative study • Phenomenography methodology • Sample (n=16) older people with intellectual disabilities • Mean age of participants was 62 yrs.	• Study identified five semi-hierarchical conceptions of ageing: no conception, limited awareness, awareness of effects of ageing, ageing as requiring preparation and overall understanding. • No connection between older people's insight to their ageing and activity levels • Older people require variety of activities and interests regardless of their insight to their ageing.

Study and country and origin	Key themes	Study method and sample	Major findings
Bowers *et al.* (2014) Australia	Staff knowledge of health and ageing	Qualitative study • Analysis of longitudinal study using grounded theory methodology • Sample (n= 30) group home staff • Age of people with intellectual disabilities living in community groups was 45 yrs.	• Lack of knowledge regarding normal ageing and timely diagnosis • Staff could be more effective advocates for older people if they were more knowledgeable and this would improve health outcomes.
Buys *et al.* (2008) Australia	Perceptions of ageing by service providers	Qualitative study • In-depth semi-structured interviews • Sample (n= 48) support staff • Older people (50 years plus) • Key informal network members	• The study found that older people wanted to *"keep on keeping-on"* in areas of life that gave them pleasure rather than ceasing because of age. • The study identified themes regarding active ageing and what older people valued in their lives: ➢ More control over issues affecting their lives ➢ Meaningful roles ➢ Mental stimulation ➢ Companionship ➢ Reliable support ➢ Safety

Study and country and origin	Key themes	Study method and sample	Major findings
Buys *et al.* (2012) Australia	Meaningful life and active ageing	Qualitative study • Data was analysed against the six core World Health Organization active ageing outcomes for people with intellectual disabilities • Sample (n=16) care support staff	• The study found that services providers were promoting active ageing lifestyle. However active ageing principles need to be applied to consider both their individual and diverse needs as needs change. • The appropriateness of older people with intellectual disabilities being placed in nursing homes in old age was also questioned. • Staff of older adults with intellectual disabilities have a vital role to play in encouraging and facilitating active ageing.
Craig and Bigby (2015) Australia	A meaningful life and community participation	Qualitative study • Critical realist approach. Field notes taken over 2 years via participant observation over 5-10 months • Sample (n=5) people with a moderate intellectual were supported to actively participate in community social groups	• The study found that active participation was influenced by the interaction of 5 key social processes outlined below: • 1)Leadership response 2) characteristics of the participants with intellectual disability 3) access to expertise, 4) the presence of an integrating activity and 5) dealing with the difference dilemma • The study also identified interventions and ways of approaching community groups that have the potential to increase the activity levels of participants.
Ding Lin *et al.* (2011) Taiwan	Ageing in services	Quantitative study • Cross-sectional methodology using a self-administrative structured questionnaire • Sample (n=54) Managers of Community Group Homes	• The results indicated that 90% of the respondents agreed that there was earlier onset ageing characteristics of people with intellectual disabilities. • Government policies were inadequate, and the institution is not capable of caring for aging people with intellectual disabilities.

Study and country and origin	Key themes	Study method and sample	Major findings
Dunn *et al.* (2010) UK	Choice and control	Qualitative study • Grounded theory methodology • Sample (n=21) interviews with support workers working in residential and observations of care practice	• This study reports that care workers interpret choice and decision-making within a broad moral justification of their care role. Use their own values and life experiences to make the decisions on behalf of residents. • Implications for the implementation of legal aspects of care and for the role of support workers' values.
Eley *et al.* (2009) Australia	What makes a home and future needs	Mixed methods study • Cross-sectional design • Survey collected quantitative and qualitative data with in-depth semi structured interviews • Sample (n=146) carers (n=156) people with intellectual disabilities • Mean age 37.2 yrs. (18–79 yrs. age range)	• A family environment was important from a carer perspective. • Transition to residential living was difficult and competent staff was important. • Poor experience if there were low staffing levels • Staff training needs were highlighted.
Finlay *et al.* (2008) UK	Choice and control	Qualitative study • Ethnography- video recording of everyday practice and extended observations • Sample (n=3) residential services for people with intellectual disabilities	• Conflicting service values and agendas, inspection regimes. • Attention to bigger decisions could be promoted at everyday level of practice. • Staff are task oriented for fear inspection purposes or family visits. • Disempowerment happens in everyday practice and is rationalised with reference to other agendas-i.e. health and safety.

Study and country and origin	Key themes	Study method and sample	Major findings
García Iriarte *et al.* (2014) Island of Ireland	What makes a home Key concerns of people with intellectual disabilities in Ireland	Qualitative study • Thematic content analysis • Focus group interviews • Sample (n= 168) people with intellectual disabilities • Participants age = 18-50 yrs and over	• The study identified eight core themes of, living options, employment, relationships, citizenship, leisure time, money management, self-advocacy, and communication. • These themes have implications for transforming service policy.
García Iriarte *et al.* (2016) Republic of Ireland	Role of staff and staff practices on relocation to community residential	Qualitative study • In-depth interviews • Sample (n=16) key worker staff (n=46) people with intellectual disabilities aged 40 yrs. and over	• Staff support was important older people to settle into the community with support becoming more personalised towards community participation and developing social relationships.
Haverman *et al.* (2011) European wide	Ageing and health status	Quantitative study • Cross-sectional design • Sample (n= 1,253) across 14 European states • Older people with intellectual disabilities aged 55 years plus	• Older people were more likely to live in larger residential services. • More than half of older adults had a sedentary lifestyle. Evidence demonstrated that health disparities for older people in terms of underdiagnosed or inadequately managed preventable health conditions.
Hall and Rossetti (2018) USA	Role of siblings	Qualitative study • Sample (n=79) adult siblings. • Online survey with open-ended questions about their relationships with their brother or sister with an intellectual disability • Age range of people with intellectual disabilities was 19-72 yrs.	• The study identified several roles including caregiver, friend, advocate, legal representative, teacher/role model, leisure planner and informal service coordinator. • Siblings assume key roles in the lives of people with intellectual disabilities and need support from family and professionals to perform these roles.

Study and country and origin	Key themes	Study method and sample	Major findings
Heller *et al.* (2011) USA	Choice	Literature synthesis • Self-determination across the life span using a life-stages approach	• The review concludes that life span approach to choice and self-determination takes a holistic view of the person's life. Self-determination is also shaped by opportunities available through family and residential environments. • Practices and policies in support and training interventions that teach elements of goal planning and choice-making and self-regulation contribute to greater self-determination of individuals with intellectual disabilities.
Hollomotz (2014) UK	Choice and control	Qualitative study • Social model of disability used to guide theoretical framework • Semi-structured interviews • Sample = (n=29) people with intellectual disabilities aged 22 - 68 yrs. Old	• The study found that people with intellectual disabilities were presented with 'pre-arranged' menu of choices. • A lack of control and respect for mundane choices is disempowering and leads to learnt passivity.

Study and country and origin	Key themes	Study method and sample	Major findings
Innes *et al.* (2012) UK	Overview of caring for older people with intellectual disabilities	Systematic review • 42 research papers included in review	• The review found themes relating to concerns about accommodation; experiences of services; and perceptions of aging and unmet needs. • Carer specific findings relate to fear of the future; experiences of older carers; and planning for the future. • Services themes reflect the debate over specialist or generalist services as people age; accommodation; retirement from day services; and staff training. • The review reveals a lack of robust research evidence concerning the lives of older people.
Jingree *et al.* (2006) UK	Staff verbal interactions and power dynamics	Qualitative study • Recording audio footage of residents' meetings over two consecutive months • Sample (n= 5) staff and (n= 8) people with intellectual disabilities • People with intellectual disabilities aged between 49-70yrs	• Analysis of interactions between care staff and residents found that staff used a variety of techniques to influence discussions and produce certain kinds of statements and decisions. • This resulted in staff contributions patterns which were contrary to the goal of encouraging the people with intellectual disabilities to have more say in the management of their home.
Johnson *et al* (2012) Australia	Staff relationships and interactions	Qualitative study • Constructivist grounded theory approach • Sample (n=6) adults with intellectual disabilities as central participants and (n=29) staff • Aged 20-44yrs.	• Sharing time and fun during work with people with intellectual disabilities may enhance staff job satisfaction and increase social inclusion for people with severe intellectual disabilities.

Study and country and origin	Key themes	Study method and sample	Major findings
Judge *et al.* (2010) UK	Ageing, activity and retirement	Qualitative study • Interpretive phenomenology methodology with logical analysis (IPA) methodology • Sample (n=16) people with intellectual disabilities • Age 41-64 yrs.	• Day centre was main 'social hub'. • The concept of retirement is confusing for older people who have been employed. • Older people wanted to maintain their independence and they valued continuity in their care. • Desire to keep active after the age of 65 yrs. • What to do as retirees and how to plan for change in lifestyle.
Kåhlin *et al.* (2015) Sweden	Ageing and meaningful life	Qualitative study • Phenomenological methodology • Sample (n= 12) older people with intellectual disabilities • Mean age 64 yrs.	• The study found that ageing and later life as a multifaceted phenomenon, expressed through the two themes, 'age as a process of change' and 'existential aspects of ageing', each with three sub-themes. • The study also found social, cultural and historical factors of the world to be important in the informants' experience of ageing and later life.
Kåhlin *et al.* (2016) Sweden	Choice and control	Qualitative study • Ethnographic methodology • Sample (n=32) people with intellectual disabilities • Mean age 62 yrs.	• Older people with intellectual disabilities are vulnerable when trying to maintain choice and control. • Older people have control over private spaces but not over semi-private in their home. • Daily activities are on the whole controlled by staff with differing levels of input from older people.

Study and country and origin	Key themes	Study method and sample	Major findings
Lawrence and Roush (2008) Republic of Ireland	Ageing and retirement	Quantitative study • Survey • Sample (n=70) people with intellectual disabilities aged 60 years	• The findings of this survey indicate that there is a need for retirement options for older people, although little attention has been directed towards formalising these services through policy. • Lack of policy is limiting the implementation of comprehensive services to meet the changing needs of older people with intellectual disabilities.
Mansell *et al.* (2008) UK	Staff practices and organisational characteristics	Quantitative study • Group comparison design and multivariate analysis • Sample (n=354) managers from community group homes and (n=359) adults with intellectual disabilities	• The results suggest professional qualification, knowledge and experience appear to be important to improve outcomes. • Staff attitudes, clear management guidance, more frequent supervision and team meetings, training and support for staff to help people with intellectual disabilities engage in meaningful activities.
Maes and Van Puyenbroeck (2008) Belgium	Staff practices and ageing in place	Quantitative study • Questionnaire • Sample (n= 66) staff members working in residential services • Mean age of people with intellectual disabilities living in CGH was 46 yrs.	• The study revealed three different staff approaches: an activating/socializing, disengaging, and methodical. • Services have started to modify their accommodation and personnel to the needs of older people with intellectual disabilities. Staff training on specific working methods and in altering stereotypical staff attitudes needed to be addressed.

Study and country and origin	Key themes	Study method and sample	Major findings
McCarron *et al.* (2011) Republic of Ireland	Aspects of life and ageing	Mixed methods study Wave 1 • Survey and fieldwork • Sample (n=753) • Age range 40 yrs. and older	• The majority of adults had a level of contact with at least one family member and frequency of contact decreased with increasing age. • Older age, and people with more severe levels of intellectual disability, living in residential centres were at greater risk for social isolation.
McCarron *et al.* (2017) Republic of Ireland	Choice, health and well-being	Mixed methods study Wave 2 • Survey and fieldwork • Sample (n=753) • Age range 40 yrs. and older	• The study found that people with intellectual disabilities reported having a good level of choice with basic day-to-day items, such as the food, what to wear and how they spent free time. • While 75.4% reported having no choice in relation to where they lived and 85.5% reported that they had no choice in relation to whom they lived with
McCausland *et al.* (2010) Republic of Ireland	Meaningful life-Unmet needs	Quantitative study • Utilised CANDID-S to identify health needs of people with intellectual disabilities over 50 years. • Sample (n=75) people with intellectual disabilities	• The study identified various unmet needs: • Unmet needs were identified as basic education and monetary budgeting and access to transport for independence. • Wanted independence for privacy and to live near towns. • Met needs – food and daytime activities.

Study and country and origin	Key themes	Study method and sample	Major findings
McCausland *et al.* (2013) Republic of Ireland	Use of transport	Quantitative study • Sample (n=753) people with intellectual disability aged 40 yrs. plus	• Older people are most likely to never use public transport (75%) • People living in residential services were more likely to use transport by the intellectual disability service. • Younger age groups (40-49 yrs.) more like to complain of lack of transport in their area.
McCausland *et al.* (2016) Republic of Ireland	Meaningful life-social connections	Quantitative study • With analysis of data from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) compared to general population Wave One • Sample (n = 701) people with intellectual disability aged 40 yrs. Plus	• The study found that social connections are impacted by the type of residence. • People in congregated settings, older respondents and those with severe/profound intellectual disability had the lowest levels of contact. • People with intellectual disability living in the community have greater social contact than those living in congregated settings, but levels are below those for other adults in Ireland.
McCausland *et al.* (2018a) Republic of Ireland	Meaningful life-Interpersonal relationships for older people with intellectual disability	Quantitative study • Analysis of data from IDS-TILDA wave 2 • Sample (n=701) people with intellectual disability aged 40 yrs. plus	• Close proximity to family and community living are associated with improved social networks and contacts, • Older people with intellectual disability remain more isolated than the general older population. • Predictors of family contact and having non-resident friends were also explored. • While family proximity and community living are associated with better social networks

Study and country and origin	Key themes	Study method and sample	Major findings
McCausland *et al.* (2018b) Republic of Ireland	Choice and control-rights and citizenship	Quantitative study • Cross-sectional analysis of data from the IDS-TILDA wave 2 • Sample- (n=753) older people • Mean age 55.7 yrs.	• Found low rates of choice, decision-making and advocacy amongst this older people. • Two factors of choice were explored: key life choice and everyday choice. • Type of residence was the strongest predictor of key life choice yet not significant in everyday choice.
McConkey *et al.* (2004) UK	What makes a home: current and future needs	Qualitative study • Focus groups • Sample (n=180) people with intellectual disabilities • Age range 23-63 yrs.	• Four personal preference themes emerged reported by all participants: having their own bedroom, participating in household activities; having access to community activities, and maintaining contact with family and friends. • The findings indicate a need for greater consideration of personal preferences by people with intellectual disabilities in options for choice-making by housing and services providers.
McConkey *et al.* (2016) Republic of Ireland	What makes a home	Qualitative study • Contrasting three groups who moved to different types of accommodation, personalised, community group home, congregated setting. • Sample (n= 89) • Mean age 55 yrs.	• People who had moved to accommodation with personalized support tended to be younger and had fewer support needs than those in group homes. • They also had greater control and choice in their lives, more community engagement and increased personal relationships compared to residents in group homes. • Those who remained living in congregated settings had less community integration from the three groups.

Study and country and origin	Key themes	Study method and sample	Major findings
McDermott and Edwards (2012) Australia	Ageing and retirement	Qualitative study • In-depth semi-structured interviews with coding analysis used • Sample (n=33) people with intellectual disabilities (n=43) staff • Age group 65 yrs and under	• The study found that service providers supported the right of people to retire. • In contrast older did reported that they were empowered to make that decision • Barriers to self-determination included an association between retirement, poor health and meaningless activities. • The study recommends more flexible services, better information about retirement and assistance to express preferences and participate in problem-solving throughout the lifespan.
McGlaughlin *et al.* (2004) UK	What makes a home and choice	Mixed methods study • Multi-method collaborative study • Sample (n=72) people with intellectual disabilities • Age range of participants 31-44yrs	• The participants in the study reported that they preferred ordinary housing with small numbers and that staff support is highly valued People with intellectual disabilities were clearly able to verbalize their preferences as well as to think through potential options. • The study found clear evidence that people felt powerless in making choices, as decisions were often made by professionals and carers. The study recommends a cultural shift whereby the voices of adults with intellectual disabilities are heard and acted upon

Study and country and origin	Key themes	Study method and sample	Major findings
McGhee and Dorset (2011) Australia	Staff training	Literature review • Focusing on effective staff training programmes to improve care for older people with intellectual disabilities • Nine studies and reports identified and reviewed	• The review identifies and assesses programmes for frontline disability services staff working with older people. • It analyses if training programs contribute outcomes for older people and makes recommendations for future research and training measured against outcomes for older people.
Nieboer *et al.* (2011) Netherlands	Life in community group homes	Quantitative study • Cross-sectional survey • Sample (n=96) managers in seven care organizations for people with intellectual disabilities	• External influences on the implementation process of community living was government finance. • The results found that challenges to the implementation of community living are related to organizational characteristics. • An innovative management style was found to be associated with a more successful implementation of community living with a lack of possibilities to experiment were barriers in the implementation process.
Northway *et al.* (2017a) UK	Staff practices	Qualitative study • In-depth semi-structured interviews • Sample (n=14) managers of services	• Three of the emerging themes were found in this paper regarding meeting health needs, the consequences of ageing and relationships. • Findings indicate that residential care staff support older people with intellectual disabilities with complex and multiple health needs. • The importance of staff having a long-term relationship with those they support was identified as being important to identifying any health-related changes.

Study and country and origin	Key themes	Study method and sample	Major findings
Northway *et al.* (2017b) UK	Staff knowledge and training	Qualitative study • Exploratory design • In-depth semi-structured interviews • Sample (n=14) managers were interviewed using	• The study found that staff often have no prior experience of care work and that previous knowledge/experience of supporting people in relation to their health is not required for the post. • While health related training is provided, there is a lack of specific training regarding healthy ageing, with a focus on reactive training. • The study recommends that training is provided for residential social care staff in relation to health and include a focus on healthy ageing.
O'Donovan *et al.* (2017) Republic of Ireland	Examining choice and living arrangements	Quantitative study • Exploratory factor analysis • Sample (n=753) • Aged 40 years and older	• Two broad types of choice exist for people with intellectual disabilities-everyday decisions and key life choices.
O'Rourke *et al.* (2004) Ireland	What makes a home	Mixed methods • Cross-sectional design • Survey/Semi-structured interviews • Sample (n= 92) people with intellectual disabilities aged 40 yrs. and older: Mean age 58 yrs (n=103) staff and guardians	• Older people felt the physical features of living arrangements, the provision of activities, and staff as lead to their happiness and satisfaction with where they lived. • The main sources of dissatisfaction were issues related to staff, such as hindering personal independence, impatience and staff shortages. • Lower levels of loneliness reported by those in group homes.

Study and country and origin	Key themes	Study method and sample	Major findings
Reinders (2010) Netherlands	Staff support and relationships	Quantitative study • A philosophical analysis regarding the nature of professional knowledge • No age range provided • Analysis of other studies	• The paper argues that positive therapeutic relationship between professionals and people with intellectual disabilities is key for the delivery of quality care. Such relationships create the positive interaction that enables professionals to gain knowledge into the needs of their clients.
Salmon *et al.* (2019) Republic of Ireland	Choice, community living, relocation	Qualitative study • Thematic analysis • Sample (n=35) people with intellectual disabilities • Ages ranging from 22-77yrs	• The study identified four themes: "expressing choice" in the moving process; "feeling connected or isolated when moving"; "accessing supports during and after the move"; and finally, participants' reflections on "experiencing vulnerability and feeling safe" while resettling. • Benefits of engaging in choices regarding housing and supports, concerns remain about the extent of preferences of people with intellectual disabilities are respected when moving home.
Stancliffe *et al.* (2011) USA	Choice, community living, living arrangements	Quantitative study • Data analysis from the National Core Indicators programme. • Sample (n=6778) adults with intellectual disabilities • Mean age 46 yrs.	• Choice is limited, especially for those with severe intellectual disability. • Choice of where to live and with whom does not differ significantly with age.

Study and country and origin	Key themes	Study method and sample	Major findings
Stainton *et al.* (2011) Canada	Staff support, choice and control	Quantitative study • Sample (n=852) of family members and support staff of adults with intellectual disabilities • Mean age of people with intellectual disabilities was 56 years.	• Findings show that all measures other than choice and control, group homes showed better outcomes than either independent settings or family homes. • The findings may indicate that the move to more independent living settings is not being accompanied by appropriate staff supports.
Smyth and Bell (2006) UK	Choice and control	Review of literature on choice	• Study focuses on the choice of food and diet can cause major health problems for the decision-maker. • Choice is affected by past experience and opportunity to choose. • It reveals that the staff unconscious personal, beliefs and ideologies may impact on choices made by people with intellectual disabilities, and the 'choices' offered to them.
Shaw *et al.* (2011) Australia	Housing and support preferences	Qualitative study • Sample (n=15) people with intellectual disabilities: Mean age 46yrs • (n=10) family members	• Four major themes emerged from the data: living arrangements: housing preferences: ageing in place and transition from informal to formal housing and support. • Carers and older people wanted housing to enhance their social networks. • Participants preferred models of housing which allowed people to live in close proximity rather small dispersed community housing.

Study and country and origin	Key themes	Study method and sample	Major findings
Sheth *et al.* (2019) USA	Choice and control	Quantitative study • Surveys • Sample (n=150) adults with disabilities between 18-65 yrs.	• The study found significant differences between choice and control for those in institutional and community experiences. • Older people reported increased satisfaction, personal safety, but barriers to inclusion included transportation. • The study also highlights the experiences of people who previously lived in institutions and the improvements and understandings of community participation, integration for those who move to community living.
Shooshtari *et al.* (2012) Canada	Role of staff	Quantitative study • Secondary analysis of cross-sectional data from the 2001 and 2006 Participation and Activity Limitation Surveys (PALS). • Sample (n= 136,570). • Participants mean age 40yrs.	• The study reported unmet needs did not significantly affect respondents' overall health status. • The study states that compared to Canadians with other types of disability, those with intellectual disabilities were more likely to report unmet healthcare and social support service needs. • Further research is recommended to explore policies and programmes which support the healthy and active aging of this population.
Sheerin *et al.* (2015) Republic of Ireland	Meaningful life and resettlement in community	Qualitative study • Descriptive approach semi-structured interviews • Sample (n=9) older people with intellectual disabilities described as middle-aged	• The study found that ageing may have an impact on people's ability to utilise the community service fully. • This was a positive period in people's lives, however a number of issues such as transport, distance from services need to be addressed.

Study and country and origin	Key themes	Study method and sample	Major findings
Strnadová (2019) Australia	Choice and Control	Qualitative study • Semi-structured interviews • Sample (n=17) with older people aged 40 yrs. and older	• The study found the changes that older people faced are, life transitions, planning for the future, barriers. • Bullying cited as one of the main reasons for moving home with concerns about loss of independence, choices, especially for those living in CGHs. • Advocacy would help older people focus on planning for the future.
Tichá et al. (2012)	Choice and control	Quantitative study • Data taken from The National Core Indicators (NCI) Consumer Survey • Sample (n=11,569) People with intellectual disabilities • Age 18 yrs. plus • 41% aged 55 yrs. plus	• The study people with severe and profound disabilities had more control when living in community group homes with fewer residents. • Congregated setting of 16 or more people offered the lowest levels of everyday choice.
Tedrick (2009) USA	A meaningful life and physical activity	Qualitative study • Case studies • Sample (n= 3) • 30-55 yrs.	• Athletes confirmed the importance of the benefits such as physical fitness, sport skills, friendships, and competition.
van Schijndel-Speet et al. (2014) Netherlands	A meaningful life and physical activity	Qualitative study • In-depth Interviews and focus groups • Sample (n=40) people with intellectual disabilities aged 50 yrs. and older	• Older people with intellectual disability have low levels of physical activity (PA) • Facilitators to PA were enjoyment, *support from others, social contact, friendships and routine of activities.* • Barriers to PA were health and physiological factors, lack of self-confidence, lack of skills, lack of support, transportation problems, costs,

Study and country and origin	Key themes	Study method and sample	Major findings
Wark *et al.* (2014a)	Staff training on ageing	Qualitative study • Delphi method followed by thematic analysis. • Sample (n = 31) staff members	• The findings of this study have implications for the delivery of rural services and training of staff. • The results indicate that changes to initial training and professional development options to support staff to work successfully with people with intellectual disabilities who are ageing in rural areas.
Wark *et al.* (2014b) Australia	Needs of older people in rural areas	Qualitative study • Delphi method • Sample (n=31) staff members	• Challenges of delivering care in rural areas were identified as; community-based aged care, generic and specialist health services. • GPs had limited knowledge on needs of older people with intellectual disabilities
Webber *et al.* (2010)	Staff knowledge on ageing	Qualitative study • Grounded dimensional analysis • Sample (n=10) CGH supervisors and (n=17) people with intellectual disabilities aged 41-89 yrs.	• The ability of older people with an intellectual disability to 'age in place' is affected by staff knowledge about and confidence with age-related illnesses. • Staff skills at navigating formal services, staffing flexibility, and the philosophy of group home supervisors al had an effect.

Study and country and origin	Key themes	Study method and sample	Major findings
Webber *et al.* (2014) Australia	Ageing in Place Older people with intellectual disabilities moving to nursing home facility.	Qualitative methods - Dimensional analysis methodology - Interviews were conducted with staff and families - Sample (n=9) family members (n=10) staff from intellectual disability services (n=12) nursing or management staff	- Staff and families both acknowledged the importance of healthcare for the older people in the group home but were equally concerned about social isolation. - The findings highlight the importance of addressing health and social needs of older people with intellectual disabilities.
Webber *et al.* (2016) Australia	Staff confidence and training in supporting of healthcare needs of older people with intellectual disabilities.	Quantitative study - Survey data - Sample (n=76) staff from CGHs	- Staff training programme was conducted and was positively associated with increased confidence in supporting older people with health issues. - Targeted training of staff in age-related health issues may contribute to better health care and ageing in place and delay relocating to aged care facilities.
Wehmeyer and Abery (2013) USA	Choice and control	Literature review Narrative analysis of the literature	- The analysis highlights the gaps in the literature. - The authors advocate for professionals and services to forget the notion that one size fits all when thinking about strategies and for support choice and self-determination for people with intellectual disabilities.

Appendix 2: Ethical approval confirmations

The Mall, Sligo. F91 H684 Tel: 071 917 1111 Fax: 071 917 4648

Martina Conway
Centre for Nursing and Midwifery Education
St. Conals Hospital,
Letterkenny,
Co. Donegal

June 28th 2016

Re. Research Ethics Application

Dear Ms Conway,

The Research Ethics Committee (REC) at Sligo University Hospital has granted a **favourable ethical opinion** of the study "*An Exploration of Person-Centred Practice in Residential Services for Older People with Intellectual Disabilities*".

Documents reviewed:

- REC Application Form Version II June 2016
- Information Sheets and consent forms Version II
- Questionnaires
- PI CV

The REC requires that approved studies submit an annual report to the REC. The annual report for the above study is due on May 18th 2017.

Yours sincerely,

Dr. John Williams
REC Chairperson

Letterkenny University Hospital

General Manager's Office,
Letterkenny University Hospital, Letterkenny Co. Donegal
F92 AE81

Telephone: (074) 9123501   *Fax: (074) 9104651*

18.11.16

Ms. Martina Conway

Specialist Co-Ordinator/Nurse Tutor

Centre for Nursing & Midwifery

CNME – St. Conals

Re: An Exploration of Person-Centred Practice in Residential Services for Older People with Intellectual Disabilities

==

Dear Ms. Conway,

With reference to application listed above, your application has been considered by members of LUH Ethics Committee and I am happy on behalf of Letterkenny University Hospital Ethics Committee to grant Chairman's approval. However, please ensure you have approval from the Managers in the Residential Centres to carry out the study also.

Please do not hesitate to contact me if you require any further information.

Yours sincerely

_____

Mr. Seán Murphy

General Manager

Appendix 3: Person-Centred Practice Inventory-Staff and PIS form
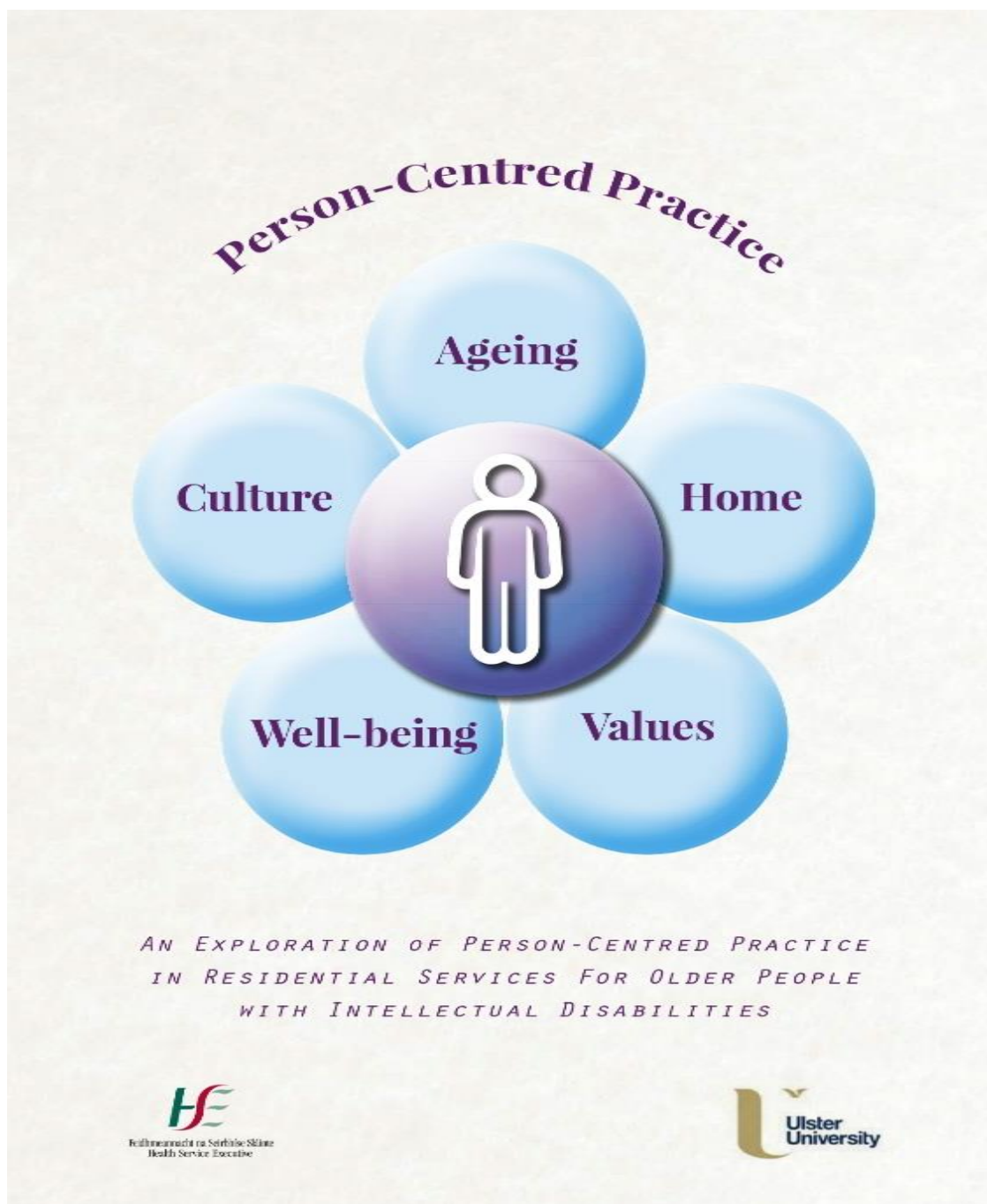
Dear Colleagues

My name is Martina Conway and I am a nurse for people with intellectual disabilities. I work for the HSE West in the Centre for Nursing and Midwifery Education, St. Conals Hospital, Letterkenny, Co. Donegal.

I am inviting you to take part in a research study to find out more about the lives of older people with intellectual disabilities who are living in residential services in the Donegal and Sligo area. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do. Please read the following information, and do not hesitate to ask any questions about anything that might not be clear to you. Your participation in this study is entirely voluntary. Thank you for taking the time to consider this invitation.

What is the purpose of this study?

The purpose of the study is to explore the needs of staff, older people with intellectual disabilities and their families, regarding how care is organised and delivered in residential services for people as they age. Through exploring your views and experiences it may help identify local and national supports needed to help staff improve care for older people living in residential services.

Why have I been chosen?

You have been chosen because you currently work with older people with intellectual disabilities (55 years or older) in a HSE Residential Service in the Donegal or Sligo area. The survey is being distributed to staff working in residential services in both these areas.

Do I have to take part?

No, it is up to you whether or not you wish to take part. Your participation in this research study is voluntary and consent is implied if you agree to complete the survey. If you choose to take part you can change your mind at any time, and withdraw from the study without giving a reason.

What is involved if I agree to take part?

I would appreciate if you would complete the attached survey which takes approximately 20 minutes to complete. The survey asks questions about how you deliver and organise care. It also includes questions about wider issues such as decision making processes and leadership within your organisation. Completed surveys should be placed in the designated box, labelled 'Completed Surveys', or returned directly to me in the stamped addressed envelope provided.

What happens to the information?

The information you provide will be treated as confidential and you will not be identifiable in any way. No residential service will be identifiable from the information you provide. The surveys will be destroyed once coded into the computer for analysis. The content of the surveys will then be carefully analysed. All data will be stored securely on a password protected and encrypted computer in a secure locked office and all information will be subsequently destroyed after ten years in accordance with the Ulster University's policy.

A summary report will be available and we will be willing to discuss the findings at future meetings you may consider appropriate. We will also inform participants should the study be published in the future.

Are there possible benefits from my taking part in the study?

You may find the study interesting and it is an opportunity for you to express your opinion about all aspects of the service where you work. Once the study is completed it may help to develop and influence policy and practices, enhancing the care systems.

What are the possible disadvantages and risks of taking part?

It is hoped that by careful attention to the questions, everyone will feel supported to complete the survey without any ill-effect.

If you have a complaint?

It is unlikely that anything will go wrong, but your well-being is of great importance to us, if you have a complaint about your participation in the study it will be taken seriously. It can be discussed in the first instance with myself and I will try to resolve your complaint to your satisfaction. If you continue to have concerns you may contact the senior researcher involved in the study Professor Owen Barr by email: o.barr@ulster.ac.uk or you can also contact the Senior Administrative Officer at the University, Mr Nick Curry via email: n.curry@ulster.ac.uk/tel: (0044) 289036 6629.

You can also direct your complaint to the HSE Complaints Officer and it will be addressed in accordance with the HSE Complaints Procedure. Indemnity for this study has been secured from the Ulster University's Research Governance Committee. A copy of the letter confirming indemnity is available from us on request.

Who is organising the funding for the study?

This study is being funded by the HSE West and is partial fulfilment of a PhD qualification being undertaken at Ulster University.

Has this study been reviewed by an Ethics Committee?

Yes, the study had been reviewed and approved by the Filter Committee at Ulster University, and by both local Research Ethics Committees in Letterkenny and Sligo University Hospitals.

What should you do now?

If you are happy to participate please complete the attached survey. Thank you for reading this information sheet and considering participating in this study. If you have any queries relating to the research study please contact me on the number or email address below.

Yours sincerely

Martina Conway
Tel: 0871351932/email: conway-M6@email.ulster.ac.uk

Prof. Owen Barr (Chief Investigator)
Tel: (0044) 287167 514/email: o.barr@ulster.ac.uk

2

Exploring Person-Centredness in Residential Services for Older People with Intellectual Disabilities

Thank you for agreeing to take part in this survey. Your participation is greatly appreciated. There are no "right" or "wrong" answers to these questions. Please tick the box that most closely matches your opinion.

Section 1

This section is about you. We are not asking any questions that will be able to identify you individually. Please tick one answer only to each of the following questions.

1. Please indicate the type of residential service you currently work in?

☐ A large residential service (more than 10 people)

☐ A small residential service (less than 10 people)

2. Where I work is part of a campus setting?   Yes ☐   No ☐

3. What is your current role in residential services?

Nurse Manager ☐   Staff Nurse ☐   Healthcare Assistant ☐

Other ☐   Please State _____

4. Please indicate your qualification:

RNID ☐   RGN ☐   RPN ☐   QQI (FETAC) Level 5 ☐

Other ☐   Please State _____

5. Please indicate your highest level of education?

MSc ☐   Postgraduate Diploma ☐   Degree (Hons) ☐   Nursing Certificate ☐

QQI (FETAC) Level 5 ☐   Other ☐   Please State _____

6. How many years' experience do you have working with people with intellectual disabilities?

<1 year ☐   1-5 years ☐   6-10 years ☐   Over 10 years ☐

7. How many years' experience do have you working in residential services with older people with intellectual disabilities?

<1 year ☐   1-5 years ☐   6-10 years ☐   Over 10 years ☐

Section 2

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I have the necessary skills to negotiate care options.	☐	☐	☐	☐	☐
2. When I provide care I pay attention to more than the immediate physical task.	☐	☐	☐	☐	☐
3. I actively seek opportunities to extend my professional competence.	☐	☐	☐	☐	☐
4. I ensure I hear and acknowledge others perspectives.	☐	☐	☐	☐	☐
5. In my communication I demonstrate respect for others.	☐	☐	☐	☐	☐
6. I use different communication techniques to find mutually agreed solutions.	☐	☐	☐	☐	☐
7. I pay attention to how my non-verbal cues impact on my engagement with others.	☐	☐	☐	☐	☐
8. I strive to deliver high quality care to people.	☐	☐	☐	☐	☐
9. I seek opportunities to get to know people and their families in order to provide holistic care.	☐	☐	☐	☐	☐

4

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
10. I go out of my way to spend time with people receiving care.	☐	☐	☐	☐	☐
11. I strive to deliver high quality care that is informed by evidence.	☐	☐	☐	☐	☐
12. I continuously look for opportunities to improve the care experiences.	☐	☐	☐	☐	☐
13. I take time to explore why I react as I do in certain situations.	☐	☐	☐	☐	☐
14. I use reflection to check out if my actions are consistent with my ways of being.	☐	☐	☐	☐	☐
15. I pay attention to how my life experiences influence my practice.	☐	☐	☐	☐	☐
16. I actively seek feedback from others about my practice.	☐	☐	☐	☐	☐
17. I challenge colleagues when their practice is inconsistent with our team's shared values and beliefs.	☐	☐	☐	☐	☐
18. I support colleagues to develop their practice to reflect the team's shared values and beliefs.	☐	☐	☐	☐	☐

5

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19. I recognise when there is a deficit in knowledge and skills in the team and its impact on care delivery.	☐	☐	☐	☐	☐
20. I am able to make the case when skill mix falls below acceptable levels.	☐	☐	☐	☐	☐
21. I value the input from all team members and their contributions to care.	☐	☐	☐	☐	☐
22. I actively participate in team meetings to inform my decision-making.	☐	☐	☐	☐	☐
23. I participate in organisation-wide decision-making forums that impact on practice.	☐	☐	☐	☐	☐
24. I am able to access opportunities to actively participate in influencing decisions in my directorate/division.	☐	☐	☐	☐	☐
25. My opinion is sought in clinical decision-making forums (e.g. support plans, case conferences, annual reviews).	☐	☐	☐	☐	☐
26. I work in a team that values my contribution to person-centred care.	☐	☐	☐	☐	☐

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
27. I work in a team that encourages everyone's contribution to person-centred care.	☐	☐	☐	☐	☐
28. My colleagues positively role model the development of effective relationships.	☐	☐	☐	☐	☐
29. The contribution of colleagues is recognised and acknowledged.	☐	☐	☐	☐	☐
30. I actively contribute to the development of shared goals.	☐	☐	☐	☐	☐
31. The leader facilitates participation.	☐	☐	☐	☐	☐
32. I am encouraged and supported to lead developments in practice.	☐	☐	☐	☐	☐
33. I am supported to do things differently to improve my practice.	☐	☐	☐	☐	☐
34. I am able to balance the use of evidence with taking risks.	☐	☐	☐	☐	☐
35. I am committed to enhancing care by challenging practice.	☐	☐	☐	☐	☐
36. I pay attention to the impact of the physical environment on people's dignity.	☐	☐	☐	☐	☐

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
37. I challenge others to consider how different elements of the physical environment impact on person-centredness (e.g. noise, light, heat etc.).	☐	☐	☐	☐	☐
38. I seek out creative ways of improving the physical environment.	☐	☐	☐	☐	☐
39. In my team we take time to celebrate our achievements.	☐	☐	☐	☐	☐
40. My organisation recognises and rewards success.	☐	☐	☐	☐	☐
41. I am recognised for the contribution that I make to people having a good experience of care.	☐	☐	☐	☐	☐
42. I am supported to express concerns about an aspect of care.	☐	☐	☐	☐	☐
43. I have the opportunity to discuss my practice and professional development on a regular basis.	☐	☐	☐	☐	☐
44. I integrate my knowledge of the person into care delivery.	☐	☐	☐	☐	☐
45. I work with the person within the context of their family and carers.	☐	☐	☐	☐	☐

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
46. I seek feedback on how people make sense of their care experience.	☐	☐	☐	☐	☐
47. I encourage the people to discuss what is important to them.	☐	☐	☐	☐	☐
48. I include the family in care decisions where appropriate and/or in line with the person's wishes.	☐	☐	☐	☐	☐
49. I work with the person to set health goals for their future.	☐	☐	☐	☐	☐
50. I enable people receiving care to seek information about their care from other healthcare professionals.	☐	☐	☐	☐	☐
51. I try to understand the person's perspective.	☐	☐	☐	☐	☐
52. I seek to resolve issues when my goals for the person differ from their perspectives.	☐	☐	☐	☐	☐
53. I engage people in care processes where appropriate.	☐	☐	☐	☐	☐
54. I actively listen to people receiving care to identify unmet needs.	☐	☐	☐	☐	☐

Please indicate how much you agree or disagree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
55. I gather additional information to help me support the people receiving care.	☐	☐	☐	☐	☐
56. I ensure my full attention is focused on the person when I am with them.	☐	☐	☐	☐	☐
57. I strive to gain a sense of the whole person.	☐	☐	☐	☐	☐
58. I assess the needs of the person, taking account of all aspects of their lives.	☐	☐	☐	☐	☐
59. I deliver care that takes account of the whole person.	☐	☐	☐	☐	☐

Thank you for taking the time to complete the survey.

Once you have responded to all of the above questions please place

in the box marked 'Completed Surveys', or return in the stamped

addressed envelope provided.

Appendix 4: Participate information sheet and consent form: Staff focus group interviews

Ulster University,
School of Nursing,
Magee Campus,
Northland Rd, Derry
BT48 7JL, Northern Ireland.
Work Tel: 0871351932
Email: conway-M6@email.ulster.ac.uk.

Title of the Study

**An Exploration of Person-Centred Practice in Residential Services
for Older People with Intellectual Disabilities**

Dear Colleagues

My name is Martina Conway and I am a nurse for people with intellectual disabilities. I work for HSE West and I am based in the Centre for Nursing and Midwifery Education in St. Conals Hospital, Letterkenny, Co. Donegal. I am inviting you to take part in a research study to find out more about the lives of older people with intellectual disabilities who are living in residential services in the Donegal and Sligo area. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that might not be clear to you. Make sure you are happy before you decide what to do. Your participation in this study is entirely voluntary. Thank you for taking the time to consider this invitation.

What is the purpose of this study?
The purpose of the study is to explore the needs of staff, older people with intellectual disabilities and their families, regarding how care is organised and delivered in residential services for people as they age. Through exploring your views and experiences it may help identify local and national supports needed to help staff improve care for people living in residential services.

Why have I been chosen?

You have been chosen because you currently work partly or mainly with older people with intellectual disabilities (55 years or older) in a HSE residential services in the Donegal or Sligo area.

Do I have to take part?

No, it is up to you whether or not you wish to take part. If you do decide to take part, you will be asked to sign a consent form. If you choose to take part you can change your mind at any time and withdraw from the study without giving a reason.

What is involved if I agree to take part?

If you are willing to participate, please complete the attached consent form and forward it to me in the stamped addressed envelope provided.

1. The one-off focus group interview will contain 6-8 other staff members who are the same grade as you. It will last one hour approximately.
2. We can arrange a convenient time, date and location of the focus-group for you to attend.
3. The focus group interview will also be recorded and transcribed; you will not be identified by name in the transcripts. I may wish to quote from the interview in the presentations resulting from this research, but you will not be identifiable from the information you provided.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable talking about work practices in front of other colleagues but it is hoped that through consideration and confidentiality, everyone will feel supported to have an open discussion. However, if you disclose anything that makes us concerned for your welfare or that of others, it is our duty to inform the appropriate person within the HSE who deals with these matters.

What happens to the information?

The information will be seen only by myself and the two other researchers involved. All the information provided will be anonymous and at no point will your name be identifiable in the transcripts from the tape recording. All data will be stored securely and subsequently destroyed after ten years in accordance with Ulster University's policy.

If you have a complaint?

It is unlikely that anything will go wrong, but your well-being is of great importance to us, if you have a complaint about your participation in the study it will be taken seriously. It can be discussed in the first instance with myself and I will try to resolve your complaint to your satisfaction. If you continue to have concerns you may also contact the other researchers involved in the study via their email address, Prof. Owen Barr: o.barr@ulster.ac.uk; and Dr. Vidar Melby: v.melby@ulster.ac.uk. You can also direct your complaint to the HSE complaints officer and it will be addressed in accordance with the HSE Complaints Procedure. You can also contact Mr. Nick Curry at Ulster University on his email address: n.curry@ulster.ac.uk. Indemnity for this study has been secured from the Ulster University's Research Governance Processes. A copy of the letter confirming indemnity is available from us on request.

Who is organising the funding for the study?

This study is being funded by the HSE West and is partial fulfilment of a PhD qualification being undertaken at Ulster University.

Has this study been reviewed by an ethics committee?

Yes, the study had been reviewed and approved by the Filter Committee at Ulster University, and by both local Research Ethics Committee in Letterkenny and Sligo.

What should you do now?

Thank you for reading this information sheet and considering participation in the study. If you are happy to procedure please sign the consent form and return in the stamped addressed envelope provided. If you have any queries relating to the research study please contact me on the telephone number or email below.

Yours Sincerely

Martina Conway (Researcher)
Work Tel: 0871351932

Exploration Person-Centered Practice in Residential Servicesfor Older People with Intellectual Disabilities.

STAFF MEMBER CONSENT FORM- FOCUS GROUP INTERVIEWS

Please initial each box

1. I confirm that I have read and understood the information leaflet for the above research study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.

3. I agree to the recording of the focus groups interview and that quotes from the interview may be used in presentations and written articles by the researcher.

4. I agree to take part in the above research study.

Name:…………………………………………………….…………………

Work Address:..

…………………………………………………………..

Contact Telephone Number:……………………………………………………….…..

I am employed as a Nurse/Healthcare Assistant (*please state***):**………………………

Signed:…………………………………………… **Date:**…………………………

Appendix 5: Participate information sheet and consent form: Older people interviews

Looking at Life in Residential Homes for Older Adults with Intellectual Disabilities

What is this Study About?

This study is about older people with intellectual disabilities who are living in a residential home in the Donegal or Sligo area.

The study will help us to learn about how you feel about your care, choices, and your activities and where you live as you get older.

How was I chosen?

Your name was suggested by the staff team where you live, as you are aged 55 years or older. They thought you might like to give us your thoughts and views.

Who will visit me?

Martina Conway will visit you, she is carrying out the study as part of a PhD at the Ulster University she also works for the Health Service Executive in Donegal. She can visit you at home, or in a place convenient to you.

Will anyone else know what you tell us?

No. We will keep all your personal information private. We may use some information you tell us in reports, but your name will not be mentioned in any reports.
But if we hear anything that makes us think you may be in danger we will have to tell the person in the Health Service Executive who deals with these matters.

Do I have to take part?
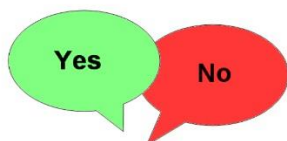
No. It is your choice to take part in the study. You can also change your mind and stop taking part at any time. Your decision will not affect the support you receive now or in the future.

Are there any risks involved?

You may feel a little uncomfortable talking about you life with Martina, but it is hoped that with careful attention you will feel supported in the interview. If you like Martina can arrange for someone to be with you for support. You can telephone or email her and she will talk to you about this.

If you have a complaint?

It is unlikely that anything will go wrong, but your well-being is important to us. If you have concerns you can discuss them firstly with Martina Conway. If you still have concerns you can contact the researchers supervising the study on email and ask to speak to them, they are;
Prof. Owen Barr: o.barr@ulster.ac.uk and
Dr. Vidar Melby: v.melby@ulster.ac.uk
You can also contact the local HSE Complaints Officer if you wish.

How long will it take?

The interview will take about 1 hour and will be recorded. If the interview is too long you can stop and take a break.

What should you do next if you decide to take part?
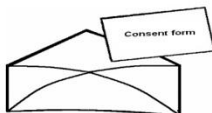
1. You will need to read and sign the consent form we have sent you.
2. Return the form in the envelope we gave you.
3. We will contact you to see when it suits for us to come and visit you.

If you need more information or if you have any questions, please contact:

Martina Conway
Work Telephone: **0871351932**
Email: **Conway-M6@email.ulster.ac.uk**

PIS for People with intellectual disability/ Version 3/ Jan 2017

Ulster University

Consent Form

If you want to take part in this study please tick the following questions, and give your name and how we can contact you below.

If you are unable to fill out this form but would like to take part, please ask someone to fill out **Sections 1 and 2** for you.

I agree with the following statements: Please tick
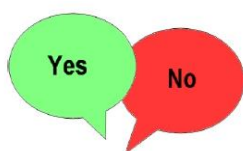
I know that it is my choice to take part in this study.

I understand that I can stop taking part in this study when I want to. I do not have to give a reason if I want to stop.

I understand that the interview will be recorded and all information I give will be kept safe and private. Things I say may be used as examples in reports, but my name or where I live will not be used in any reports.

Please give the following information:

Your name:

_____

Your address:

_____

_____

Phone number: _____

Please sign (or mark) your name here (selected participant only):

_____

Date:_____

Appendix 6: Participate information sheet and consent form: Family members interviews

Ulster University
School of Nursing, Magee Campus
Northland Rd, Derry
BT48 7JL, Northern Ireland
Work Tel: (00353)0871351932
Email: conway-M6@email.ulster.ac.uk.

Title of Study

**An Exploration of Person-Centred Practice in Residential Services
for Older People with Intellectual Disabilities.**

Dear Family Member

My name is Martina Conway and I am a nurse for people with intellectual disabilities. I work for HSE West and I am based in the Centre for Nursing and Midwifery Education in St. Conals Hospital, Letterkenny, Co. Donegal. I am contacting you to invite you to take part in a research study to find out more about the lives of older people with intellectual disabilities who are living in residential services in the Donegal and Sligo area. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do. Please read the following information, and do not hesitate to ask any questions about anything that might not be clear to you. Your participation in this study is entirely voluntary and will not in any way affect the services currently being provided for your family member or any future services. Thank you for taking the time to consider this invitation.

What is the purpose of this study?
The purpose of the study is to explore the needs of older people with intellectual disabilities their families, and staff, regarding how care is organised and delivered in residential services for people as they age. Through exploring your views and experiences it may help identify local and national supports needed to help staff improve care for people living in residential services and shape how care is provided in the future.

Why have I been chosen?
You have been chosen because you are a family member of a person with intellectual disability aged 55 years or older, and who lives full-time in a HSE residential service in the Donegal or Sligo area.

Do I have to take part?

No, it is up to you whether or not you wish to take part. If you do decide to take part, you will be asked to sign a consent form. If you choose to take part you can change your mind at any time and withdraw from the study without giving a reason.

What is involved if I agree to take part?

I would like you to take part in an interview which will be held in a location which is convenient for you. I will carry out the interview with you, it will last about 45-60 minutes. The interview will be tape recorded and transcribed by myself. All the information you provide is confidential, and your name and details will remain anonymous. I may wish to quote from the interview in the presentations resulting from this research but will not use any information that will identify you or your relative. If you are willing to participate, please complete the attached consent form and forward to myself in the stamped addressed envelope provided.

Are there possible benefits in taking part?

You may find the study interesting and enjoy the opportunity to give your thoughts and options on the care that your family member receives. This could be either positive or negative aspects or things that you feel need to improved. Once the study is completed it may help provide information on how to improve care and practice for older people with intellectual disabilities living in residential services.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable talking about your family member's life with us but it is hoped that through consideration and confidentiality, you will feel supported to have an open discussion. However, if you disclose anything that makes us concerned for the welfare of people with intellectual disability it is our duty to inform the appropriate person within the HSE who deals with these matters.

What happens to the information?

The information will be seen only by myself and the two other researchers involved. All the information provided will be anonymous and at no point will your name be identifiable in the transcripts from the tape recording. All data will be stored securely and subsequently destroyed after ten years in accordance with Ulster University's policy.

If you have a complaint?

It is unlikely that anything will go wrong, but your well-being is of great importance to us, if you have a complaint about your participation in the study it will be taken seriously. It can be discussed in the first instance with myself and I will try to resolve your complaint to your satisfaction. If you continue to have concerns you may also contact the other researchers involved in the study via their email address, Prof. Owen Barr: o.barr@ulster.ac.uk; and Dr. Vidar Melby: v.melby@ulster.ac.uk. You can also direct your complaint to the HSE complaints officer and it will be addressed in accordance with the HSE Complaints Procedure. You can also contact Mr. Nick Curry at Ulster University on his email address: n.curry@ulster.ac.uk. Indemnity for this study has been secured from the Ulster University's Research Governance Processes. A copy of the letter confirming indemnity is available from us on request.

Who is organising the funding for the study?

This study is being funded by the HSE West and is partial fulfilment of a PhD qualification being undertaken at Ulster University.

Has this study been reviewed by an ethics committee?

Yes, the study had been reviewed and approved by the Filter Committee at Ulster University, and by both local Research Ethics Committee in Letterkenny and Sligo.

What should you do now?

Thank you for reading this information sheet and considering participation in the study. If you are happy to procedure please sign the consent form and return in the stamped addressed envelope provided. If you have any queries relating to the research study please contact me on the telephone number or email below.

Yours Sincerely

Martina Conway (Researcher)
Work Tel: 0871351932

Ulster University,
School of Nursing, Magee
Campus, Northland Rd, Derry
BT48 7JL, Northern Ireland.
Work Tel: 0871351932
Email**:** conway-M6@email.ulster.ac.uk.

**An Exploration of Person-Centered Practice in Residential
Servicesfor Older People with Intellectual Disabilities.**

FAMILY MEMBER CONSENT FORM

Please initial each box

1. I confirm that I have read and understood the information leaflet for the above research study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.

3. I agree to the recording of the interview and that quotes from the interview may be used in presentations and written articles by the researcher.

4. I agree to take part in the above research study.

Name:……………………………………………………………………

Work Address:...

……………………………………………………………..

Contact Telephone Number:..

I am employed as a Nurse or Healthcare Assistant (*please state***):**………………………

Signed:……………………………………………… **Date:**…………………………

Appendix 7: Distress protocol

<div>

Distress Protocol

The following protocol is designed for managing distress within the research focus group and interviews with family members, staff and older people with intellectual disabilities

Distress

- If a participant indicates they are experiencing stress or emotional distress
  Or
- Showing behaviours that indicate the discussion is causing them distress, such as, nervousness, anxious or tearful

How to Respond

- Stop the discussion/interview
- The researcher will offer immediate support and reassurance
- If a participant feels able to carry on: Resume the interview
- If participant is unable to continue- facilitate them to discontinue
- Encourage the participant to contact a staff member, family member, or friend

How to Respond to issues of concern, disclosures of abuse, neglect, harm or self-harm

If the participant has disclosed an issue of concern, of abuse, neglect, or harm the researcher will:

- Express empathy with the participant for their experience

- Explain to the participant that confidentiality of the interview has to broken due to the nature of the disclosure, and that the researcher does not have the necessary skills to deal with the issue(s)

- Explain to the participant that the information needs to be conveyed verbally to the senior person on duty who will in turn inform the Designated Officer as required under Safeguarding and Protection Team (Vulnerable Persons) (HSE, 2014) policy which investigates such disclosures

- The nurse or relevant manager on duty will make the formal referral to the local designated officer.

</div>

Appendix 8: Responding to concerns or allegations of abuse flowchart

Appendix 8

Flowchart Responding to Concerns or Allegations of Abuse (HSE, 2014)

Concern/complaint arises or is raised (e.g. member of public/staff member)

Community Setting

Service Setting

DAY 1

Community Setting:
- Staff (HSE, Researcher, Line Manager of Service) immediately ensures safety of client
- Researcher informs Line Manager
- Line Manager assesses the need for support and/or intervention
- Contact An Garda Síochána as appropriate
- Staff outlines in writing all relevant information

Service Setting:
- Staff (HSE, Researcher, Line Manager of Service immediately ensure safety of client
- Staff informs Designated Officer and Line Manager
- Line Manager assesses the need for support and/or intervention
- Contact An Garda Síochána as appropriate
- Staff outlines in writing all

Community Setting (next):
- Line Manager/ Safeguarding and Protection Team will ensure that the preliminary screening is undertaken and all necessary actions are taken
- Researcher will follow up with Safeguarding and Protection Team to ensure a referral has been received

Service Setting (next):
- Line Manager, Director of Services and Designated Officer will meet to ensure that the preliminary screening is undertaken and all necessary actions are

- The Researcher will contact the Person in Charge of the designated centre and request a copy of the report forwarded to the Chief Inspector (HIQA) to ensure that notice in writing, of the concern/allegation has been made

- The Line Manager will notify the Safeguarding and Protection Team
- Researcher will follow up with Safeguarding and Protection Team to ensure referral has been received

WITHIN 3 WORKING DAYS

Appendix 9: Frequency, percentage and mean scores on items relating to the prerequisite constructs

Professionally Competent:	SD	D	N	A	SA	Mean	SD
I have the necessary skills to negotiate care options.	3 1%	3 1%	3.9 4%	123 53%	94 41%	4.3	.72
When I provide care I pay attention to more than the immediate physical task.	0 0%	2 0.9%	4 1.7%	85 37%	138 60%	4.5	.57
I actively seek opportunities to extend my competence.	0 0%	1 .4%	34 15%	108 47%	86 38%	4.2	.70
Developed Interpersonal Skills:	SD	D	N	A	SA	Mean	SD
I ensure I hear and acknowledge others perspectives.	0 0%	2 0.9%	2 .9%	94 41%	131 58%	4.5	.56
In my communication I demonstrate respect for others.	0 0%	0 0%	2 .9%	57 25%	170 74%	4.7	.46
I use different communication techniques to find mutually agreed solutions.	0 0%	3 1%	14 6%	92 40%	120 52%	4.4	.66
I pay attention to how my non-verbal cues impact on my engagement with others.	0 0%	1 .4%	7 3%	104 45%	117 51%	4.5	.58
Being Committed to the Job:	SD	D	N	A	SA	Mean	SD
I strive to deliver high quality care to people.	0 0%	0 0%	0 0%	45 20%	184 80%	4.8	.39
I seek opportunities to get to know people and their families in order to provide holistic care.	0 0%	0 0%	4 2%	75 33%	149 65%	4.6	.51
I go out of my way to spend time with people receiving care.	0 0%	1 0.4%	15 6.6%	97 42%	116 51%	4.43	.63
I strive to deliver high quality care that is informed by evidence.	0 0%	0 0%	7 3%	101 44%	121 53%	4.4	.55
I continuously look for opportunities to improve the care experiences.	0 0%	0 0%	8 3.5%	103 45%	118 51.5%	4.48	.56

Knowing Self:	SD	D	N	A	SA	Mean	SD
I take time to explore why I react as I do in certain situations.	0 0%	7 3%	27 12%	132 57%	63 28%	4.0	.71
I use reflection to check out if my actions are consistent with my ways of being.	0 0%	6 2.2%	42 18.3%	119 52%	63 27.5%	4.0	.73
I pay attention to how my life experiences influence my practice.	0 0%	4 2%	30 13%	120 52%	75 33%	4.1	.72
Clarity of beliefs and values: awareness of impact of belief and values on care provided.	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I actively seek feedback from others about my practice.	0 0%	20 9%	56 25%	96 42%	55 24%	3.8	.89
I challenge colleagues when their practice is inconsistent with our team's shared values and beliefs.	2 1%	18 8%	56 24%	101 44%	52 23%	3.7	.90
I support colleagues to develop their practice to reflect the team's shared values and beliefs.	0 0%	4 1.7%	20 8.7%	132 57.6%	73 32%	4.1	.66

** SD=Strongly Disagree, D=Disagree, N=Neutral, A=Agree, SA=Strongly Agree

Appendix 10: Frequency, percentage and mean scores on items relating to the care environment constructs

Skill Mix:	SD	D	N	A	SA	Mean	SD
I recognise when there is a deficit in knowledge and skills in the team and its impact on care delivery.	0 0%	1 0.4%	21 9%	141 61.6%	66 29%	4.1	.60
I am able to make the case when skill mix falls below acceptable levels.	0 0%	12 5%	43 19%	114 50%	60 26%	3.9	.81
I value the input from all team members and their contributions to care.	0 0%	1 0%	3 1%	85 37.6%	140 61%	4.5	.54
Shared Decision-Making:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I actively participate in team meetings to inform my decision-making.	2 0.9%	2 0.9%	19 8.3%	95 41.5%	111 48.5%	4.3	.74
I participate in organisation-wide decision-making forums that impact on practice.	10 4.4%	35 15.3%	69 31.1%	80 35.5%	35 15.3%	3.4	1.0
I am able to access opportunities to actively participate in influencing decisions in my directorate /division.	5 2.2%	33 14.4%	72 31.4%	88 38.4%	31 13.5%	3.4	.97
My opinion is sought in clinical decision-making forums (e.g., support plans, case conferences, and annual reviews).	12 5.2%	26 11.4%	43 18.8%	98 42.4%	50 21.8%	3.6	1.1
Effective Staff Relationships:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I work in a team that values my contribution to person-centred care.	2 0.9%	16 7%	30 13.1%	97 42.4%	84 36.7%	4.0	.92
I work in a team that encourages everyone's contribution to person-centred care.	2 0.9%	11 4.8%	25 10.9%	102 44.5%	89 38.9%	4.1	.86
My colleagues positively role model the development of effective relationships.	1 0.4%	10 4.4%	36 16.6%	115 50.2%	65 28.4%	4.0	.81
Power Sharing:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
The contribution of colleagues is recognised and acknowledged.	3 1.3%	15 6.6%	31 13.5%	111 48.5%	69 30.1%	3.9	.90

I actively contribute to the development of shared goals.	0 0%	4 1.7%	15 6.6%	131 57.2%	79 34.5%	4.2	.64
The leader facilitates participation.	2 0.9%	15 6.6%	33 14.4%	116 50.7%	63 27.5%	3.9	.87
I am encouraged and supported to lead developments in practice.	3 1.3%	19 8.3%	55 24%	108 47.2%	44 19.2%	3.7	.90
Potential for Innovation and Risk Taking:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I am supported to do things differently to improve my practice.	2 0.9%	17 7.4%	59 25.8%	106 46.3%	45 19.7%	3.7	.88
I am able to balance the use of evidence with taking risks.	1 0.4%	12 5.2%	56 24.5%	107 46.7%	53 23.1%	3.8	.84
I am committed to enhancing care by challenging practice.	0 0%	7 3.1%	29 12.7%	130 56.8%	63 27.5%	4.0	.72
The Physical Environment:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I pay attention to the impact of the physical environment on people's dignity.	0 0%	1 0.4%	5 2.2%	94 41%	129 56.3	4.5	.56
I challenge others to consider how different elements of the physical environment impact on person-centredness (e.g. noise, light, heat etc.).	0 0%	6 2.6%	32 14%	107 46.7%	84 36.7%	4.1	.76
I seek out creative ways of improving the physical environment.	0 0%	3 1.3%	31 13.5%	120 52.4%	75 32.8%	4.1	.69
Supportive Organisational Systems:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
In my team we take time to celebrate our achievements.	15 6.6%	57 24.9%	71 31%	58 24.3%	28 12.2%	3.1	1.1
My organisation recognises and rewards success.	24 10.5%	65 28.4%	74 32.3%	43 18.8%	23 10%	2.8	1.1
I am recognised for the contribution that I make to people having a good experience of care.	12 5.2%	40 17.5%	62 27.1%	80 34.9%	35 15.3%	3.3	1.0
I am supported to express concerns about an aspect of care.	9 3.9%	13 5.7%	37 16.2%	115 50.2%	55 24%	3.8	.98
I have the opportunity to discuss my practice and professional development on a regular basis.	13 5.7%	37 16.2	60 26.2%	79 34.5%	40 17.5%	3.4	1.1

** SD=strongly Disagree, D=Disagree, N=Neutral, A=Agree, SA=Strongly Agree

Appendix 11: Frequency, percentage and mean scores on items relating to the care process constructs

Working with Patients Belief and Values:	SD	D	N	A	SA	Mean	SD
I integrate my knowledge of the person into care delivery	0 0%	4 1.7%	15 6.6%	117 51.1%	93 40.6%	4.3	.67
I work with the person within the context of their family and carers	1 0.4%	5 2.2%	17 7.4%	120 52.4%	86 37.6%	4.24	.72
I seek feedback on how people make sense of their care experience.	0 0%	8 3.5%	57 24.9%	129 56.3%	35 15.3%	3.8	71
I encourage the people to discuss what is important to them.	0 0%	5 2.2%	14 6.1%	127 55.5%	83 36.2%	4.2	.66
Shared Decision-Making:	SD	D	N	A	SA	Mean	SD
I include the family in care decisions where appropriate and/or in line with the person's wishes.	0 0%	2 0.9%	30 13.1%	100 43.7%	97 42.4%	4.2	.71
I work with the person to set health goals for their future.	1 0.4%	5 2.2%	20 8.7%	124 54.1%	79 34.5%	4.2	.72
I enable people receiving care to seek information about their care from other healthcare professionals.	0 0%	9 3.9%	33 14.4%	119 52%	68 29.7%	4.0	.77
Engagement:	SD	D	N	A	SA	Mean	SD
I try to understand the person's perspective.	0 0%	1 0.4%	6 2.6%	108 47.2%	114 49.8%	4.4	.57
I seek to resolve issues when my goals for the person differ from their perspectives.	0 0%	1 0.4%	21 9.2%	137 59.8%	70 30.6%	4.2	.61
I engage people in the care processes where appropriate.	0 0%	1 0.4%	13 5.7%	136 59.4%	79 34.5%	4.2	.58
Having Sympathetic Presence:	SD	D	N	A	SA	Mean	SD
I actively listen to people receiving care to identify unmet needs.	0 0%	1 0.4%	6 2.6%	106 46.3%	116 50.7%	4.4	.57
I gather additional information to help me support the people receiving care.	0 0%	3 1.3%	19 8.3%	109 47.6%	98 42.8%	4.3	.68

I ensure my full attention is focused on the person when I am with them.	0 0%	3 1.3%	8 3.5%	77 33.6%	141 61.6%	4.5	.63
Providing Holistic Care:	**SD**	**D**	**N**	**A**	**SA**	**Mean**	**SD**
I strive to gain a sense of the whole person.	0 0	0 0	7 3.1%	82 35.8%	140 61.1%	4.5	.55
I assess the needs of the person, taking account of all aspects of their lives.	0 0	0 0	6 2.6%	81 35.4%	142 62%	4.5	.54
I deliver care that takes account of the whole person.	0 0	1 0.4%	4 1.7%	71 31%	153 68.8%	4.6	.54

** SD=Strongly Disagree, D=Disagree, N=Neutral, A=Agree, SA=Strongly Agree

Appendix 12a: Linear regression predictor importance prerequisites domain

Predictor Importance- Prerequisites
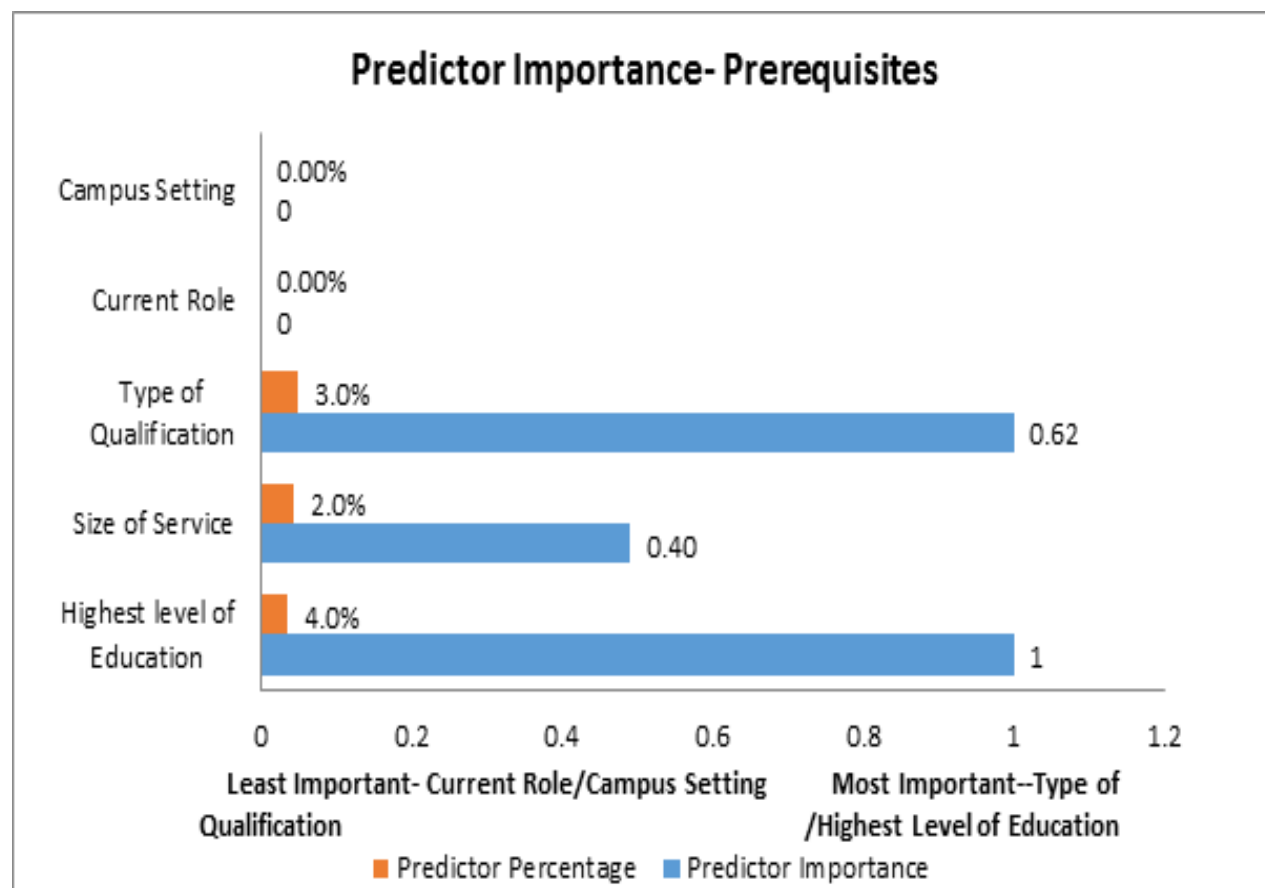
Appendix 12b: Perquisites co-efficiency summary (results of automatic linear modelling analysis)

Dependant Variable: Professionally Competent

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.518	0.062	72.666	.000	4.396	4.641
Type of Qualification	-0.159	0.067	-2.365	.0019	-0.291	-0.623

Dependant Variable: Knowing Self

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	3.992	0.058	68.790	.000	3.877	4.106
Size of Service	0.184	0.078	2.365	.019	0.031	0.338

Dependant variable: Clarity of Beliefs and Values

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.231	0.099	42.863	.000	4.036	4.425
Highest Level of Education	-0.352	0.078		.001	-0.565	-0.138

Appendix 13a: Linear regression predictor importance care environment domain

Predictor Importance- Care Environment

Predictor	Predictor Percentage	Predictor Importance
Years experience working in ID	0	0.32
Campus Setting	0.00%	
Current Role	4.60%	1
Type of Qualification	5.50%	0.76
Size of Service	0	
Highest level of Education	4.60%	1

Least Important-Size of Service/Campus Setting   Most Important Higest level of Education/Current Role
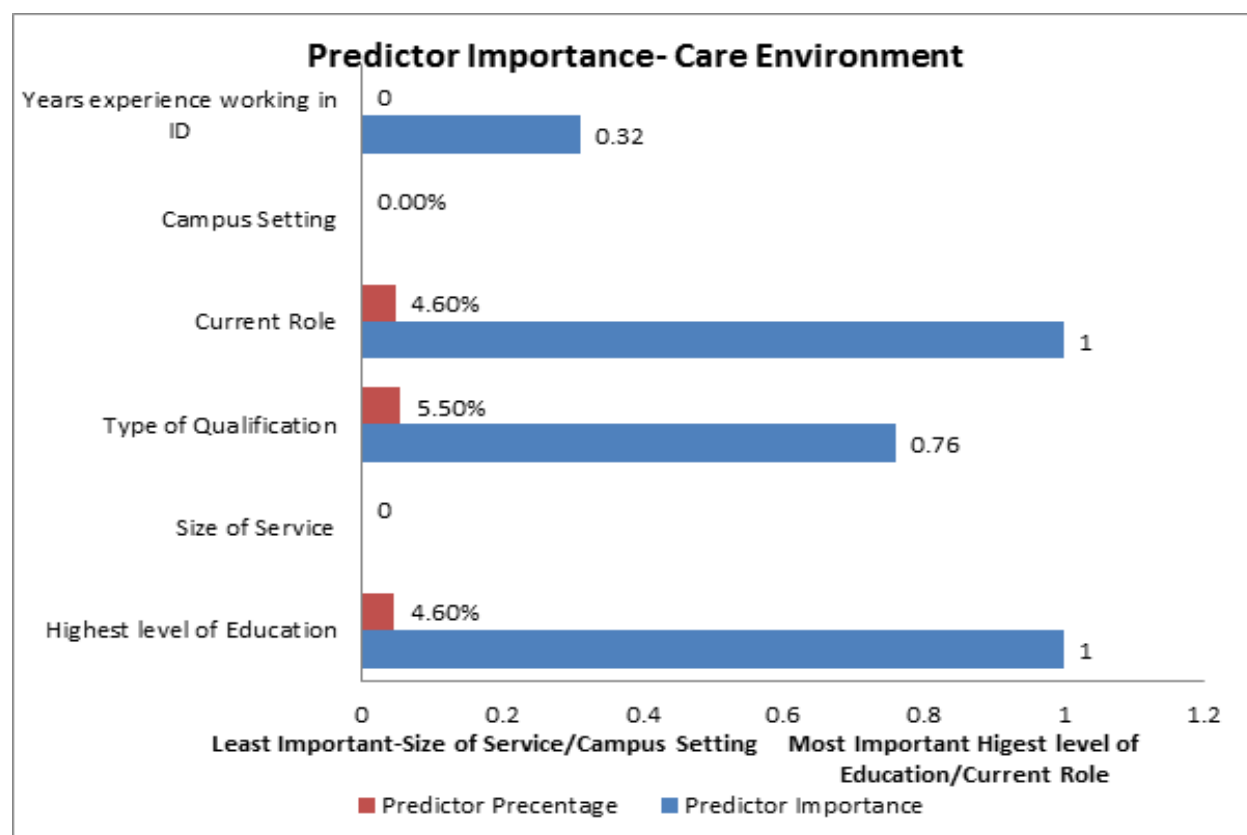
Appendix 13b: Care environment co-efficiency summary (results of automatic linear modelling analysis)

Dependant Variable: Skill Mix

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.262	0.041	103.125	.000	4.180	4.343
Highest Level of Education	0.339	0.120	2.820	.005	0.102	0.577

Dependant variable: Shared Decision-Making Systems

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	3.658	0.051	71.901	.000	3.558	3.758
Current Role	0.497	0.143	3.476	.001	0.215	0.779

Dependant Variable: Physical Environment

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.445	0.055	81.141	.000	4.337	4.553
Type of Qualification	-0.625	0.269	-2.324	.021	-1.155	-0.095

Dependant variable: Supportive Organisations

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	3.172	0.089	35.512	.000	2.996	3.348
Highest Level of Education	-0.283	0.119	2.365	.019	0.047	-0.518

Appendix 14a: Linear regression predictor importance care process domain

Predictor Importance- Care Process
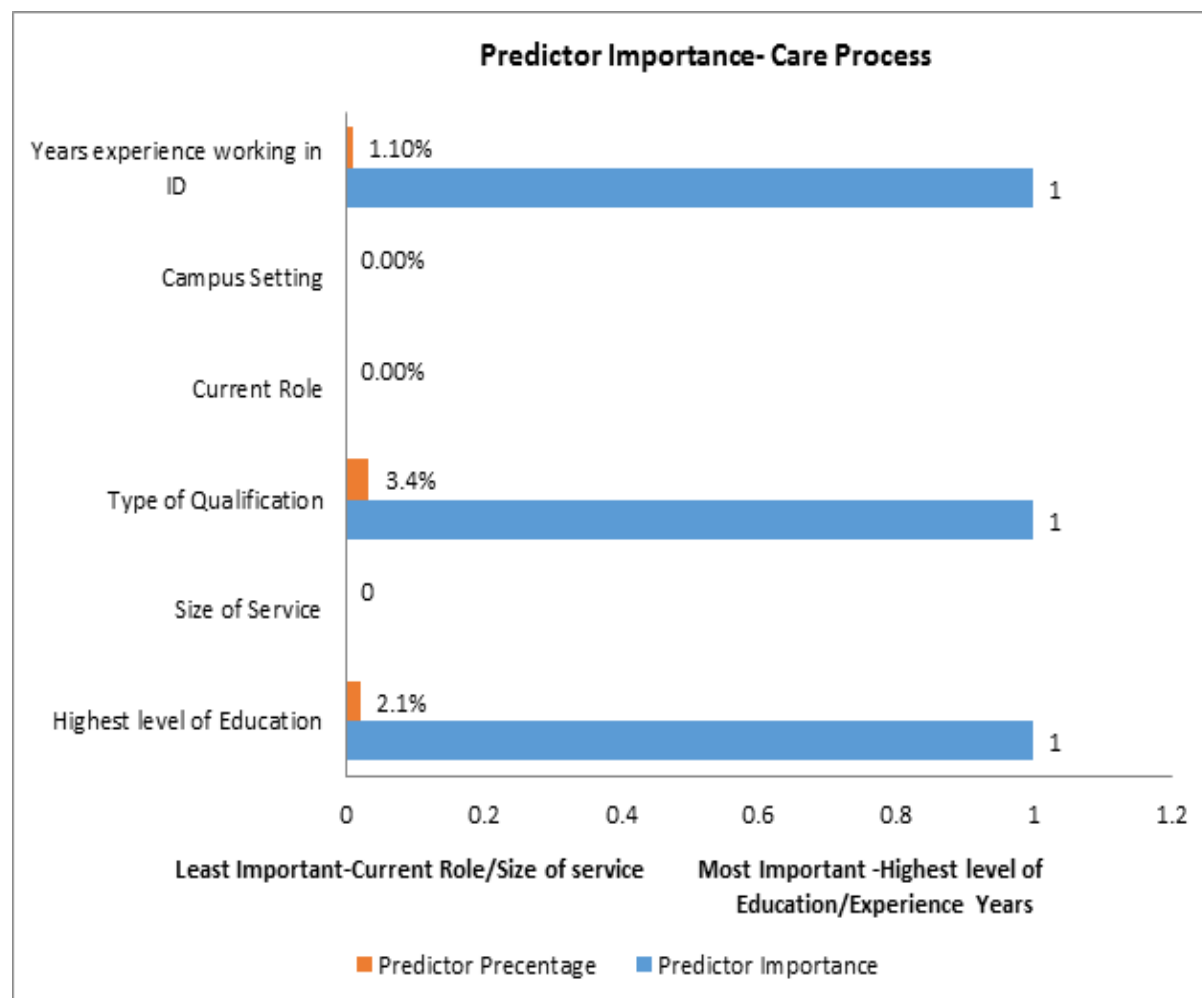
Appendix 14b: Care process co-efficiency summary (results of automatic linear modelling analysis)

Dependant variable: Working with Patients Beliefs and Values

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.333	0.084	51.568	.000	4.168	4.499
Highest Level of Education	-0.208	0.092	-2.259	.025	-0.390	-0.027

Dependant Variable: Shared Decision Making

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.091	0.050	81.210	.000	3.992	4.190
Type of Qualification	0.246	0.082	2.996.	.003	0.084	0.408

Dependant Variable: Engagement

Model Term	Co-eff	Std. Error	t	Sig	95% Confidence Level	
					Lower	Upper
Intercept	4.292	0.034	125.041	.000	4.224	4.360
Highest Level of Education	0.287	0.118	2.409	.017	0.052	0.522