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What are the Factors that Influence Person Centred Care in Public Residential Care Settings for Older People?

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Submitted for the
Degree of Doctor of Philosophy
at
National University of Ireland Galway

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February 2014
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This thesis is the work of Ann Campbell, and its contents have not been previously submitted in pursuit of a degree at National University, Galway or any other University.
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along the way. Most especially I would like to thank Tony for his constant emotional and practical support and unfailing patience throughout.

Most of all I would like to thank my mother. Her personal journey through dementia has privileged me with a prolonged insider view of the daily experience of living with dementia. She has been my constant teacher and inspiration and has caused me to challenge everything I have learned as a professional healthcare worker, as a daughter and as a member of a local community. Even in the most advanced stage of dementia she is still giving to those around her as she has always done.
Abstract

The term ‘Person centred care’ is used widely in health and social care discourse and is commonly employed in the articulation of policy, both at governmental and professional level. The concept, as it relates to older people in residential care, challenges traditional medical and task-orientated processes and promotes a shift in emphasis to holistic, collaborative, relationship-based care environments. While person centred care has become a watchword for good quality of care and quality of life, problems have been reported in relation to its implementation and sustainability.

There is a lack of research on the social relations that influence the experience of person centred care. Institutional ethnography was chosen to explore the everyday living routines of older people in residential care and the organisational practices that influence those routines in three public residential care facilities in the Republic of Ireland. The study was divided into two phases.

The first phase of the study explored the everyday life of these residential settings and the implementation of person centred care. This involved interviews with 12 residents, 10 relatives, 13 frontline staff and 11 managers. Observations of the daily routines in non-intimate settings were also undertaken.

The second phase connected the everyday life of the resident to the organisational structures of professional practice, human resource management and regulation. Mapping the social relations that influence the everyday lives of residents allowed the disjuncture between the espoused principles of person centred care and the organisational policies and practices to be explored.
The findings revealed that while some elements of person centred practice have been implemented, it is yet to be embedded in organisational practices in a way that would change the nature of relationships, shared decision-making or meaningful activity between residents, relatives and staff. These findings warrant the need for organisational and policy changes that give primacy to the implementation of person centred care, and rebalance of power in order to create a level playing field on which to develop interdependent communities within residential care.

**Relevant contributions/presentations**

*(in my married name of Ann Coyle)*


## Glossary

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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>ADON</td>
<td>Assistant Director of Nursing</td>
</tr>
<tr>
<td>C&amp;W Regs</td>
<td>Care and Welfare Regulations</td>
</tr>
<tr>
<td>DOH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DOHC</td>
<td>Department of Health and Children</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental activities of daily living</td>
</tr>
<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
</tr>
<tr>
<td>IE</td>
<td>Institutional ethnography</td>
</tr>
<tr>
<td>InterRAI/MDS</td>
<td>InterRAI Minimum Data Set</td>
</tr>
<tr>
<td>NCAOP</td>
<td>National Council for Ageing and Older People</td>
</tr>
<tr>
<td>NESC</td>
<td>National Economic and Social Council</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Cooperation and Development</td>
</tr>
<tr>
<td>PAL</td>
<td>Pool Activity Level</td>
</tr>
<tr>
<td>PCC</td>
<td>Person Centred Care</td>
</tr>
<tr>
<td>RLT</td>
<td>Roper Logan Tierney care plan model</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>WTE</td>
<td>Whole Time Equivalent</td>
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Chapter 1: Introduction and Policy Context

1.1 Introduction

The term ‘person centred care’ (PCC) is used widely in health and social care discourse and is commonly employed in the articulation of policy, both at governmental and professional level. The concept, as it relates to older people in residential care, challenges traditional medical and task-orientated processes and promotes a shift in emphasis to holistic, collaborative, relationship-based care environments.

While person centred care has become a watchword for good quality of care and quality of life, problems have been reported in relation to its implementation and sustainability. In its broadest sense, this thesis relates to the implementation of person centred care within residential care services for older people. However, in exploring the policy and professional discourse and the textual artefacts which shape and represent this system, it is necessary to look firstly at what happens in the everyday lives of older people who live in residential care and then make visible the social relations which order, coordinate and regulate their lives. Using the theoretical lens of Institutional ethnography and the theory of person centred care, and prompted by my own ‘bifurcated consciousness’ (Smith, 1987, p. 6), the thesis explores the interface between the principles of person centred care and the textually mediated institutional practices and power relations that influence professional accountability, human resource deployment and decision-making in residential care settings. The bifurcated consciousness relates to my own experience of being a healthcare manager immersed in the professional discourse of residential care while observing and feeling a very different way of being as the daughter of one such resident.

By using the methodology of Institutional ethnography, the study adopts a critical stance. However, as the focus is on institutional practices rather than
the motivations or competencies of individuals, its intention is to show how residents are drawn into social relations that are created externally to them.

As a means of locating this study in the wider context of residential care policy, this introductory chapter sets out an overview of its historical underpinnings. It then explores the social construction of residential care according to evolving beliefs and emerging professional knowledge and discusses the rationale for its continued presence in the light of alternatives. Following this, policy concerns and efforts to address these are described. The Irish context is then discussed, outlining the key policy and organisational events and processes that shaped its current construction. The chapter concludes by setting out the rationale and aims of the study and an outline of the thesis. Prior to this, the definition of the term residential care in an Irish context is explained.

1.1.1 Definition of residential care

In Ireland, the term residential care unit is used interchangeably with terms such as community nursing unit, geriatric hospital, nursing home or community hospital reflecting a range of services, some of which provide continuing care only, while others provide intermediate care services such as respite or rehabilitation alongside residential care (Murphy et al., 2006; O’Shea et al., 2008). As such, the term defines a structure akin to a Skilled Nursing Facility in the United States or a Nursing Home in the United Kingdom.

1.1.2 The Historical context of residential care

Residential care, as a social construct to manage dependency in old age, did not emerge as a carefully designed solution to age-related health care needs. Rather, it evolved historically from social institutions often designed for specific problems at particular times in history – often with very different intentions (Dobson, 2001; Kane, 2010). The institutions that we are familiar with today had their genesis in a separatist policy based on deviancy from accepted norms in the 17th century where the ‘mad, deformed, beggars,
witches and flagrantly immoral were housed in asylums’ (Baldwin and Capstick 2007, p. 306).

The Relief of the Poor Act in England in 1601 is regarded as the foundation of the poor law system in the United Kingdom, soon to be followed by Ireland, where children, the aged, infirm and destitute were consigned to ‘houses of correction’ (Burke, 1987; O’Connor, 1995). Townsend (1962) in his seminal work on residential care in the United Kingdom, The Last Resort, argues that this model was a necessary ingredient of emergent capitalism brought about by new definitions of the rights to private property and the need to establish compliant workforces. This house of correction or workhouse model was designed to make conditions so unpleasant that only the neediest would present themselves there, creating a residual or default position – a place of last resort. While workhouses were not originally intended as places for the ill, they attracted many whose illness or infirmity forced them into poverty to an extent that in time they developed ‘hospital wings’ (Means, 2007). Over time, as economic and social conditions improved, workhouses were stratified according to social groups such as children, the mentally ill, the old and infirm, and forms of patronage such as charitable institutions were replaced by state agencies (O’Connor, 1995). In recent years, many countries have moved away from direct provision of residential care to the adoption of a quasi-market model, funded through taxation or social insurance models. Populated by for-profit and not-for-profit agencies, a mixed economy of services is provided (Leichsenring, 2003; Le Grand, 2003; Pavolini and Ranci, 2008).

More recently, policy makers have considered more flexible forms of funding where residential care is increasingly considered as one element of a mix of long-term care strategies together with informal and formal homecare and alternative housing options. Combining monetary transfers to families with the provision of in-kind services, the establishment of competitive social care markets, empowerment of users through increased purchasing power and fostering care-giving through family networks, have all been developed as policy initiatives which impact on the provision of
care, including residential care (Pavolini and Ranci, 2008; OECD, 2011). The following section discusses the evolution of models of practice in line with prevailing beliefs and professional discourse, commencing with custodial models and culminating in the emergence of person centred care as a prevailing model.

1.1.3 Theories of practice in residential care

Residential care originally adopted a nihilistic and custodial care approach that focused on washing, dressing, feeding and elimination (Gubrium, 1997; Wilcocks, Peace and Kellaher, 1987). The following excerpt from interviews with geriatricians employed during the Second World War reveals the prevailing ideology at that time:

_They shoved me in charge of what they called the ‘chronic sick’ wards. These were mostly fairly elderly people, not always, because some had MS and were younger. But they were people about whom they said, ‘We can do no more for him or her, she’s just got to exist here until she dies’_ (Interviewee c.1940 in Ogg et al., 1998, p. 120).

As standards of physical care improved, the biomedical model became a more dominant theory of practice (Ogg et al., 1998). This model is said to have its origins in the philosophical concept of the mind-body split. Descartes presented this concept as the Cartesian duality which suggests that the body is comprised of independent parts portraying the body as a machine or container, the component parts of which can be inspected individually to determine the nature of their function (Koch and Webb, 1996). Continuing with this mechanistic metaphor, bodies can be entered and repaired and the individual as a person fades into the background as the component part becomes the focus for action. Koch and Webb (1996) argue that this mechanistic view of the body has contributed to the notion of ‘wear and tear’ in which, over time, the body wears out, prompting declinist attitudes amongst health professionals who may contribute pathology unnecessarily to the ageing process (Baltes and Baltes, 1993; Thomas, 2004; Ronch, 2004; Baltes et al., 2005).
Critics suggest that the biomedical approach creates a narrow pathological focus on parts of the body as opposed to the whole person leading to dehumanising and routinised care for those with health and personal care needs (Nolan, 1995; Koch and Webb, 1996; Binnie and Titchen, 1999; Flesner, 2009). Nolan et al. (2006) argue that this contributes to the low status of residential care within the healthcare arena and the creation of impoverished environments that have a negative effect on both residents and staff. The biomedical approach has also been criticised for pathologising conditions that were heretofore accepted as a normal part of ageing. The medicalisation of dementia is well documented in the literature where, it is argued, senility was an accepted part of life and absorbed within family routines (Kitwood, 1997). Following medical enquiry, it is argued, dementia became reconstructed as a ‘disease’ for which there was no cure but could be ‘managed’ through medical intervention and health-oriented regimes (Kitwood, 1997; Stirling, 2010).

While the biomedical model has had its critics it has also made significant contributions to healthcare and considerable advances in addressing the ‘geriatric giants’ of dementia, falls and incontinence, improving outcomes in these and other age-related health conditions (Ogg et al., 1998; Vincent, 2003; Kaufman, Shim and Russ, 2004; Phillips, 2010; O’Neill, 2013). Lack of attention to clinical aspects of care has led to malnutrition, high incidents of pressure sores and falls (O’Neill, 2006; Francis, 2013).

Getting the balance right between biomedical and more humanistic models has been seen to be a problem and an over-focus on health issues has been criticized for perpetuating what Ronch (2004) describes as a ‘chronicity model’ where the focus is on charting activities of daily living and measuring inevitable decline using rating scales devised to benchmark the functional capacity of older people against that of younger adults (Diamond, 1992; Ronch, 2004; Thomas, 2004).

In response to criticisms of the biomedical model in residential care, biopsychosocial models and a focus on more individualistic care emerged with
a focus on quality of life as well as quality of care (Murphy et al., 2006). Increasingly, a person centred or relationship centred approach that focuses on maintaining personhood, relationships, autonomy, and creating positive social environments as a means of improving quality of life in residential care settings has been promoted (Kitwood, 1997; Nolan et al., 2006; McCormack and McCance, 2010; Owens and Meyers, 2012; Rosvik et al., 2013). Such models are seen to represent a more humanistic approach to supporting older people and staff to create nurturing and mutually supportive environments (Ronch, 2004; Thomas, 2004; Edmonson and Von Kondratowitz, 2009).

1.1.4 Rationale for residential care

This section considers the rationale and continued presence of residential care as a social institution in the light of improving health technologies, emerging alternatives and funding structures (Pavolini and Ranci, 2008; Walsh and Callan, 2010; Shurgarman and Wittinhill, 2011; Bloom, Sulick and Hensen, 2011; Bowers et al., 2011) and the rejection of this communal living model by other social groups such as disabled younger people or those with mental health problems (Alakeson, 2010; Kane, 2010; Stirling, 2011). Much has been written about the negative aspects of residential care which is often depicted as inhumane and depersonalising both for staff and residents (Henry, 1972; Willcocks, Peace and Kellaher, 1987; Kayser Jones, 1990; Shavinsky, 1991; Diamond, 1992; Gubrium, 1997; Thomas, 2004). Many images are depictions of frailty and despair, loneliness and destitution and

> Above all else, a profound sense of loss, a loss not only of things but of who and what we are. (Agich, 2003, p. 2)

Inquiry into what older people want tells us that very few wish to be admitted to residential care and that they would rather be looked after by relatives or at least within their own homes (Wilson, 2000; Garavan et al., 2001; Tellis-Nayak, 2007). Loss of autonomy and choice, loss of home and disconnection from families and friends are cited as key reasons why older people do not wish to move to a residential care setting (NCR&DF, 2006).
Yet, others argue that for some older people the move to residential care, particularly if it was a self-selected choice, can be a positive one where unwanted responsibility, isolation or ill health have impacted on their quality of life (Wilson, 2000; Bowers et al., 2011). Some authors have argued that the fundamental problem is that residential care lacks a coherent rationale and therefore adopts a residual position of last resort when all other options are exhausted (Willcocks, Peace and Kellaher, 1987; Kane, 2010). This residual stance has been adopted as policy in Ireland where the aim is to support people to remain at home and:

*To provide a high quality of hospital and residential care for older people when they can no longer be maintained in dignity and independence at home.* (Ruddle et al., 1997, p. 3)

Kane (2006) suggests that in the light of higher expectations, changing environments and new health technologies, residential care requires more than a residual stance if it is to survive. Some of the proponents of person centred care ideology suggest that some forms of communal living have the potential to support people to remain socially included and to achieve self-actualisation through supporting mutually nurturing relationships and the provision of life-affirming and inclusive human habitats (Thomas, 2004; Ronch, 2004; Brownie and Horstmanshof, 2012). Others disagree with this, contending that such models represent a mere tinkering with a model that has an inauspicious genealogy and is fundamentally broken. These authors argue that until the totalising practices of providing combined health care and housing and services (described by Goffman (1961) as ‘total institutions’), are separated, the segregation of older people into a separate class of otherness cast to the margins of society will persist (Saraga, 1998; Kane, 2010; Stirling, 2010).

Kane (2005) also points to the dominance of the construction of residential care as taken for granted and notes that other constructions are depicted as ‘alternatives’, despite this inauspicious genealogy. He and others point to the fact that the burden of proof has been on these alternatives to ‘prove’ their effectiveness, while traditional models, i.e. task-orientated medically-
driven models, have no such requirement (Ronch, 2004; Edvardsson, Winblad and Sandman, 2008; Stirling, 2010; Love and Pinkowitz, 2013). Ronch (2004) suggests that the reason for this is that existing organisational structures such as funding and regulatory processes have followed this model making it much more difficult to change.

1.2 Policy concerns with residential care

There are ongoing concerns about quality, evidence of abuse of residents and impoverished environments in residential care (OECD, 2005; Nolan et al., 2006; Warters, 2011). Poor care practices and the low value placed on the predominantly female care workforce (Diamond, 1992; Foner, 1994; Harrington Meyer, 2000; OECD, 2011) are cited as causes of poor quality, as are a lack of investment in training and poor clinical leadership (Stone, 2001; Nolan et al., 2006). This on-going concern in respect of quality has been met by various policy responses ranging from greater regulation (LeGrand, 2003; Braithwaite, 2008; NESC, 2012) and quality improvement initiatives (Owens and Meyer, 2012). The following section outlines these responses in more detail.

1.2.1 Regulation

One policy response to increased concerns about quality in nursing homes has been an increase in regulation. The increase in quasi-markets in many developed countries has led to an associated increase in regulation (LeGrand, 2003; Braithwaite, 2008) where reimbursement and financial viability is connected to regulatory compliance (DOHC, 2009a; Colon-Emeric et al., 2010). Regulation as a tool of quality improvement is controversial, on the one hand praised for improving the quality of care while also criticized for an over-focus on structure and processes as opposed to outcomes (Braithwaite and Braithwaite, 1995; Du Moulin et al., 2010). Positive outcomes of regulation in residential care for older people include a reduction on the use of restraint and the inappropriate use of psychotropic drugs, and improvements in the management of incontinence and infection (Colon-Emeric et al., 2010). However, negative outcomes such as an over-
focus on protection and safety to the detriment of quality of life issues and reduced job satisfaction have been reported (Institute of Medicine, 2001; LeGrand, 2003; Colon-Emeric et al., 2010). Regulatory systems can rely on deterrence, quality Improvement, and forms of regulation based on outcomes (Angelelli et al., 2003). Deterrence models aim to remove amoral or incompetent operators from the system, through sanctions. This is generally mandated through legislation which allows the removal of individuals in leadership roles, revocation of registration, or closure of facilities (DOHC, 2009b). Alongside such sanctions, public reporting of quality information such as the publishing of inspection reports on the internet is seen to act as a deterrent to providers mindful and reliant on their reputation to stay in business. It is argued that the deterrence model has not improved quality and is seen to drive an adversarial relationship between providers and regulators (Angelelli et al., 2003). It has also been criticised in terms of the cost of regulation – in the absence of hard evidence of its efficacy – and for assuming that the public have a sufficient level of knowledge about what constitutes good quality care (Troyer and Thompson, 2004).

A quality improvement model on the other hand, suggests that regulators work with providers to improve quality. But again there have been criticisms that such a model may not be rigorous enough and can lead to collusion between inspectors and providers. Here in Ireland the regulatory process led by the Health Boards that was in place prior to the introduction of the Health Information and Quality Authority (HIQA) was criticised for a lack of independence and separation of commissioning and regulatory duties (O’Neill, 2006). Such a model also assumes a more intensive relationship between regulator and provider than currently exists (NESC, 2012).

An outcomes focus is considered essential in contemporary evidenced-based regulation. Here, it is argued, the focus of regulation is on the actual purpose of the service rather than the methods and processes that are used to achieve that purpose. Rather than producing a highly controlled regulatory system which has been criticized for reducing autonomy amongst professionals,
broader, less prescriptive standards that allow interpretation by professionals and inspectors are produced, which Braithwaite and Braithwaite (1995) suggest lead to a better regulatory process.

The term ‘responsive regulation’ has been used to describe a range of regulatory-focused options that create a more balanced system of enforcement and persuasion, self-regulation and continuous improvement strategies (Braithwaite, 2005: NESC, 2012). More recently, the concept of ‘smart’ regulation has been introduced whereby continuous quality improvement can be brought about by a broader coalition of actors such as advocacy groups and other non-governmental groups and increasing involvement of service users (NESC, 2012).

1.2.2 Quality initiatives

Large scale quality initiatives such as ‘My Home Life’ and the ‘Dignity in Care’ campaigns in the United Kingdom are examples of countrywide responses to the concerns relating to quality of care with significant investment in training and research aimed at improving practice. In the United States the concept of person centred care has emerged from the Culture Change movement which focuses on improving resident autonomy and choice, more homely environments, consistent staffing assignments and greater empowerment of staff (Koren, 2010; Hill et al., 2011). The Wellspring model, which aimed to improve the quality of clinical care and create better working environments, was one of the early models of culture change (Stone et al., 2000). Dr William Thomas created the ‘Eden Alternative’ based on the belief that older people’s quality of life could be enhanced through meaningful relationships, reciprocity and enhanced environments involving plants, animals and children. The associated Green House concept which advocates small scale and ‘normal’ living environments aims to counteract the medicalised environments of the traditional nursing home (Thomas, 2004).
Small-scale living has been a feature of residential care in some European countries for some time and has become stated national policy in some countries in terms of infrastructural development (Te Boekhorst, 2009; DeRooij, 2012; Morgan Brown, 2013). Studies tracking these models have shown improvements in quality of life and better engagement between staff and residents, but large-scale comparative evidence has as yet to be realised, largely due to the inconsistencies of models or resident populations (Kane et al., 2007; Rahman and Schnelle, 2008; Hill et al., 2011; Brownie and Nancarrow, 2013).

1.2.3 Section summary

The above section outlined the evolution of residential care from workhouses to its reconstruction as a response to the health and social care needs of older people. The changing models of care aligned to prevailing cultural beliefs and advancements in science have led to the development of biomedical models which are seen to have advantages and disadvantages. On the one hand, such models have greatly improved heretofore poor standards of physical care, and on the other, they have been criticised for reinforcing systems that have a narrow focus on the aged body. More recent models promote a person centred approach with associated attention on maintaining personhood and autonomy and creating positive relationships and environments.

The ambiguous rationale of residential care was discussed pointing to its residual position as a place of last resort highlighting the arguments of some authors who query its ongoing relevance in the light of alternatives. Ongoing concerns about the quality of residential care and policy responses were outlined along with an overview of the responses of regulation and quality improvement initiatives. The following section outlines the evolution of the public residential care system in Ireland through policy development and the legislative and organisational changes that have influenced its initial growth and subsequent decline.
1.3 Irish historical context

Adopting the United Kingdom workhouse model, the first ‘house of industry’ was erected in James St., Dublin, in the 1700s, followed by similar ones in Cork. Widespread building commenced in the 1830s and 1840s, with each county having its own workhouse. Severe overcrowding and inadequate resources led to poor conditions, harsh regimes and high mortality rates. In time, classification systems to separate the old and infirm from children and those described as deviants were proposed but implementation of legislation to drive this was slow (Burke, 1987; O’Connor, 1995).

A Poor Relief Act in 1862 saw the introduction of nurses to the system heralding a shift towards a care system, but, despite this, the shame and stigmatisation of individuals in need of support remained within Irish culture long after their reclassification as healthcare facilities (Hodgins and Greve, 2004).

Over time, as economic and social conditions improved, buildings were stratified into acute hospitals and ‘care’ facilities for social groups such as children, the mentally ill, and the old and infirm (O’Connor, 1995; Barrington, 1997). The workhouse system was gradually phased out and in the case of the elderly and infirm, was replaced by county homes as recommended by the Commission of Poor Relief in 1927. Thirty three of the existing workhouses were reclassified and upgraded to become county homes and were managed by local health committees within the local authority structure, chaired by the county physician. In time, the system evolved as the Hospitals Commission of 1933 recommended the development of welfare homes and district hospitals to cater for the more dependent elderly. In 1951 a white paper on the reconstruction and improvement of county homes, later to be known as geriatric hospitals, was published recommending their continuation and the building of additional facilities resulting in an additional 2000 beds being brought into the system (Warters, 2011).
Since then, the development and shape of residential care services has been recorded in various policy documents as discussed below where it is considered an accepted organisational reality and the focus has been on the provision of beds, the size of institutions, their role in local communities, funding mechanisms and quality standards (Ruddle, 1997; Murphy et al., 2006; Warters, 2011; O’Dywer, 2012).

1.3.1 Care of the Aged Report 1968

A major policy document on the needs of the elderly was published in 1968 focusing on the improvement and expansion of services, signalling a shift in emphasis to community care. The report also attempted to stratify various aspects of residential care based on dependency levels and marked a change in emphasis from custodial care to assessment and rehabilitation, and the development of two models of residential care, namely welfare homes and long-stay hospitals. The welfare home model proposed small and homely facilities where medical and nursing care was to be provided by the resident’s GP and Public Health Nurse. This model enjoyed a brief period of expansion before a decline as community services expanded and the demand for residential care for social reasons reduced (Ruddle et al., 1997). Long-stay hospitals were to be confined to patients who were mentally ill, confused or disturbed, were incontinent or were bedfast and in need of continuous nursing care. These long-stay hospitals were also to provide active rehabilitation and treatment over longer periods. For this reason, and concern about the ability to recruit nursing staff, it was recommended that they should be adjacent if possible to general hospitals and should have a high ratio of nurses (Care of the Aged Report 1968).

1.3.2 The years ahead – A policy for the elderly 1988

The 1968 report provided policy guidance for twenty years and its successor ‘The years ahead – A policy for the elderly’ (DOH, 1988) built on its key principles. Its overarching goal was to support older people to remain in their own homes. In relation to residential care the focus of the strategy was
on the structural and organisational elements such as improving assessment prior to admission, increasing throughput, reducing the size of facilities and increasing the range of services that the residential care unit provided for the wider community.

This document remained the key policy document in relation to ageing for over 25 years although implementation was slow and inconsistent across the country (Ruddle et al., 1997). Terms such as person centredness and participation were not in vogue at that time and there is little evidence of the resident as an individual or their voice in policy narrative of the time (Murphy et al., 2006). However, concern for quality was raised and recommendations were made in respect of inspection of residential care facilities.

### 1.3.3 National healthcare policies

Ireland’s first health strategy, ‘*Shaping a healthier future*’, introduced for the first time the concept of social gain and quality of life (DOH, 1994). The second health strategy *Quality and Fairness – a health system for you* (DOHC, 2001) identified specific objectives such as the expansion of the social services inspectorate to include long-stay facilities for older people and the disabled. It also proposed a financing framework for funding residential care and a standardised approach to dependency assessment and the payment of subventions. The concept of care planning was introduced with the notion of identified key workers, although the emphasis was on older people at risk of entering long-term care. The concept of involving consumers in their care was introduced and, as a result, regional forums for older people were established. Mangan (2002) notes that this system made no provision for representing the rights of older people who lived in residential care settings. In response to this, the Equality Authority (2002) made recommendations as to how policy makers should adjust their consultation processes to include the voice of residents, undertake age awareness training for policy makers, support networking between older persons’ organisations and develop advocacy services.
A more recent national framework – *Healthy Ireland: A Framework for Improved Health and Well Being 2013-2025* – has been published which provides an overarching framework to shape health services promoting goals of a) increasing the proportion of people who are healthy at all stages of life, b) reducing health inequalities, c) health protection and participation.

### 1.3.4 Positive ageing strategy

In 2013, the Government launched a new national *Positive Ageing Strategy* (Gov. of Ireland, 2013) that provides an overarching framework for future policy development. Underpinned by the World Health Organisation (*WHO*) *Active Ageing Policy framework* (2002), its mission statement is as follows:

> Ireland will be a society for all that celebrates and prepares properly for individual and population ageing. It will enable and support all ages and older people to enjoy physical and mental health and well-being to their full potential. It will promote and respect older people’s engagement in economic, social, cultural, community and family life and foster better solidarity between generations. It will be a society in which the equality, independence, participation, care, self-fulfilment and dignity of older people are pursued at all times. (p. 3)

The strategy sees a move away from a primary focus on health and social services as was the case of previous policy documents locating older people in the wider context of communities and intergenerational social relations. Participation and the language of needs and preferences are used liberally. There is little reference to residential care except to note the capacity for efficiency improvement given the number of residents who have been categorised as having medium and low dependency (p. 32) and a goal to make it more affordable.

### 1.3.5 National Dementia Strategy

The Department of Health is currently developing a National Dementia Strategy informed by a research review *Creating Excellence in Dementia Care* (Cahill, O’Shea and Pierce, 2012) and a public consultation process (DOHC, 2012).
1.3.6 Person centred care as a policy objective

The term ‘person centred care’ (PCC) is used frequently in Irish health and social care policy documents. Public bodies such as the Department of Health and Children, the Health Service Executive and the Health Information and Quality Authority use the term in policy statements, guidance documents and in descriptions of services (HIQA, 2009; DOHC, 2011). The Department of Health’s most recent strategic document; *Future Health; A Strategic Framework for Reform of the Health Services 2012-2015* (DOHC 2012, p. 38) outlines its direction stating that health services should:

- focus on the rights and dignity of the person concerned with care guided by the person’s own views and wishes
- have a strengths based approach to needs assessment
- have individual care plans with a focus on personal goals and outcomes and
- shift towards service provision in the community which includes natural supports.

Through the combination of the *Positive Ageing Strategy* (2013) and *Future Health* (2012) the policy underpinning for a person centred care approach has been stated. However, there are several other organisational factors which have impacted on the provision of person centred care in public residential care services which will now be discussed.

1.4 The impact of organisational changes on public residential care provision

The landscape of residential care services has been underpinned by some major organisational, legislative and regulatory changes which have had a marked impact on public sector provision including its location within a biomedical frame, changes in the distribution of services between the public and private sector, and the introduction of regulation.
1.4.1. The establishment of Health Boards

A major restructuring of Local Government in 1970 saw the separation of health and social services from local authorities and the development of regional Health Boards established through the Health Act (Government of Ireland 1970) (Carruthers, 2004). Hugman (1991) notes that how residential care services are organised varies in ideology and organisation from country to country with some countries adopting a ‘social’ model while others have a strong bio medical emphasis. The Irish residential care service became firmly ensconced within the health system located within the newly established Health Boards in a programme known as the Special Hospitals Programme alongside psychiatric institutions (Carruthers, 2004). The environmental design of geriatric hospitals mirrored the design of acute hospitals with nurses’ stations, wards with bays of 4, 6, or 8 beds with glass partitions for ease of surveillance and communal day rooms. Hospital practices also transferred with hierarchical management structures, handover reports between shifts and daily drug rounds. In 2001 this Health Board system was replaced with the Health Service Executive, a centralised system developed to streamline what was seen as an overly bureaucratic system influenced by local political systems (Brennan, 2003).

1.4.2 The emergence of the private sector

The history of the Private Nursing Home Sector can be traced from its initial cottage industry status through to its current dominance of the residential care sector. In the 1980s approximately 17% of residential care was provided by the private sector with 22% provided by voluntary providers who were in the main religious orders and 60% by the public sector. A combination of legislation and tax incentives played a significant part in the growth of the private sector. Firstly, the Health (1970) Act and the Health (Nursing Homes) Act 1990 made provision for the payment of means tested subventions. Secondly, the introduction of a tax relief scheme in 1998 for the construction of Private Nursing Homes (NCAOP, 2000) saw a rapid increase in the number of private sector places available. As a result the
overall percentage share of private residential care provision rose to over 60% (O’Shea, 2002).

1.4.3 The introduction of regulation to Irish residential care services.

The first piece of regulatory legislation; The Health Act (Homes for Incapacitated Persons) 1964 and its subsequent regulations targeted the developing private sector exempting public and voluntary sector facilities. The Health Act (Nursing Homes) 1990 brought the voluntary sector into the regulatory process but the public sector remained exempt (Warters, 2011). Concerns about the quality in nursing homes continued and a voluntary code of practice was published by the Department of Health and Children in an effort to improve quality (DOHC, 1995). However, concerns about quality continued (Ruddle et al., 1997; NCAOP, 2000; Murphy et al., 2006). The National Council on Ageing and Older People, amongst others, called for an independent inspectorate process, similar to that which already existed for children’s services through the social services inspectorate that would regulate all residential care settings, public, private and voluntary (Murphy et al., 2006).

1.4.4 The establishment of the Health Information and Quality Authority (HIQA)

The extension of the powers of the social services inspectorate to include all Residential Care Settings was influenced to a large degree by the media exposé of Leas Cross, a private nursing home where poor standards of care were revealed through an undercover investigation. The fallout from the subsequent television programme was a huge public outcry and questions about the impartiality of the Health Board inspection process, given that it was also the purchaser of beds in Leas Cross (O’Neill, 2006). Demands for a new independent inspectorate came from advocacy groups and professional bodies and the Health Board involved commissioned a geriatrician, Professor Des O’Neill, to undertake an investigation into the deaths of residents in the nursing home. The findings revealed many shortcomings in the standards of care despite a regulatory process being in
place. A further investigation established by the government under the *Commission of Investigations Act* (2004) highlighted poor standards in pressure wound prevention and management, poor management of continence, poor leadership and management of staff, poor assessment of residents’ care needs and gaps in service provision. The commission also criticised the Health Board response to complaints and concerns about poor care (O’Donovan, 2009).

A new regulatory framework was established by government and brought the public sector into the system of regulation for the first time. The *Health Act* (2007) provided the mandate for the permanent establishment of the Health Information and Quality Authority (HIQA), (an interim authority had been in place since 2005) and a transfer of the social services inspectorate to this authority. This authority now had the power to register, inspect and monitor all residential care settings, public, private and voluntary. A multi-agency working group was established to develop the national standards for Residential Care Settings (O’Dwyer, 2012). Extensive consultations were undertaken with subsequent publishing of the standards in March 2009. The 32 standards cover a broad range of quality of care and quality of life issues including citizenship rights, protection from abuse, health and social care needs, quality of life and governance described on the Department of Health Website as follows:

*The continued objective is to protect the vulnerable and weak and these standards are consistent with government policy, principles and legislation. The standards acknowledge the unique and complex needs of the individual person at the centre of care, and set a bar for service providers to deliver a person-centred and comprehensive service that promotes health, well-being and quality of life.* (DOHC, 2009d)

The HIQA standards were launched by the Minister for Health in March 2009. However, the governing legislation, the *Health Act 2007 (Registration of Designated Centres) Regulations* (2009b) and *The Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations* (2009c) did not come into law until June of that year. In legislative terms, the Health Act is considered the primary text from which
the secondary texts of the Health Act 2007 (*Registration of Designated Centres) Regulations 2009* and *The Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People)* are derived. The regulations underpin the HIQA standards but have legal dominance over them. In other words, the inspectors’ work is legally mandated by the regulations rather than the standards.

**Table 1.1 Hierarchy of regulatory texts**

When set side by side, there are differences in what is explicitly stated within the regulations and what is written in the more detailed standards. For example, there are a number of references to advocacy in the HIQA standards:

*The contact details of organisations providing advocacy services are included on the residents guide.* (Standard 1.1)

*The resident is facilitated to access and advocate/advocacy service when making decisions relating to consent to treatment or care if necessary and in accordance with his/her wishes.* (Standard 3.5, p. 16)

However, advocacy is not referred to within the Care and Welfare Regulations at all. As such, providers (in this case the HSE) are not legislatively required to provide or arrange access to such services. In terms of participation and decision-making, the HIQA standards explicitly advocate the participation of residents and as the second of all standards affords this a textual priority:
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Each resident’s rights to consultation and participation in the organisation of the residential care setting, and his/her life within it, are reflected in all policies and practices. (Standard 2, p. 15)

Below are several subsections which underpin this:

2.3 The resident contributes ideas to and participates in the day-to-day activities of the residential care setting

2.4 The person in charge facilitates the establishment of an in-house residents’ group for feedback, consultation and improvement on all matters affecting the residents. At least one nominated person acts as an advocate for people with dementia/cognitive impairment. Issues raised by the residents’ representative group are acknowledged, responded to and recorded, including the actions taken in response to issues raised.

2.5 Feedback is actively sought from the resident on an on-going basis on the services provided. The residential care setting clearly demonstrates how the impact of the resident’s feedback informs reviews and future planning. (p. 15)

Within the Care and Welfare regulations participatory rights are less defined. The provider is directed to make:

Arrangements to facilitate, in so far as is reasonably practicable, consultation and participation in the organisation of the designated centre. (DOHC 2009c, p. 6)

The regulations impose a duty on the provider to facilitate arrangements for participation in so far as is practicable but does not make explicit what those arrangements should be. In this way the absence of Residents’ Action Groups or other forms of participation do not constitute a breach of regulations. What the provider must comply with are the regulations and the sub articles which express the regulatory requirement in greater detail. The detailed criteria outlined in the standards proposing ways of meeting the standards are not mandatory. In this way, certain elements are enshrined in law and can be used as evidence in the removal of registration or other censure, while other elements are not. While the dominant texts – i.e. the Care and Welfare Regulations Acts – may not be expected to repeat verbatim the standards, drawing attention to what is omitted provides some clues as to what must be prioritised by the inspector when undertaking the
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legally defined inspection process and what constitutes ‘service improvement’ – a lesser construct in the legislative hierarchy. In 2012 HIQA produced a review of its findings from the first fifteen months of its operation (Pillinger, 2012). It noted that in this first cycle of inspections that it was focused on ensuring that basic structures and systems were in place in terms of safety and a good quality of life. The report concluded that the experience of the initial 705 inspections were generally positive while acknowledging challenges particularly in respect of the public sector engagement with this type of regulation for the first time. Physical environment, risk management, general welfare and protection, training and staff development, residents’ rights and assessment and care plans were identified as the key areas where breaches were found (Pillinger, 2012).

The introduction of regulation and standards was widely welcomed as a solution to improving the quality of residential care services (NESC, 2012). The model of regulation has itself been subject to consideration by the independent policy advisory agency, the National Economic and Social Council (NESC) which proposes a more flexible and responsive system of regulation based on a continuum whereby providers who have demonstrable quality services are subject to less stringent inspection processes while strengthening the processes of censure for those that do not meet acceptable standards.

1.4.5 The Nursing Homes Support Scheme

In 2009, a new funding scheme, called the Nursing Home Support Scheme (NHSS) for residential care, was produced by the Department of Health, removing a funding anomaly between public and private residential care settings, introducing more choice for consumers and securing the position of private operators as independent nursing home providers within a quasi-market system (DOHC, 2009a; Pierce, Fitzgerald and Timonen, 2010). The combination of tax incentives and the Nursing Homes Support Scheme has led to a reversal of the positions of public and private provision with the
private sector now providing approximately 75% of all residential care (HSE, 2013a).

1.4.6 The decline in public sector places

On the 31.12.2012 there were 129 public facilities in the HSE providing 7377 places, of which 5476 are designated for long term care for older people. The remaining 1901 places provide a range of supports, which include a combination of rehabilitation, rapid access, complex discharges and respite support for patients living in the community together with level 2 Palliative Care beds, and a small number of individuals under 65 described as ‘young chronically sick’. Between 2009 and 2012 the number of public sector places has reduced from 10142 to 7377. This decline illustrates the speed at which places are closing – somewhat similar to the rapid decline of public provision in the United Kingdom between 2000 and 2004 (Pavolini and Ranci, 2008).

Table 1.2 outlines the position between 2009 and 2012.

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of Long Stay Beds</th>
<th>No. of Short Stay Beds</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>31.12.2008</td>
<td>8111</td>
<td>2031</td>
<td>10142</td>
</tr>
<tr>
<td>31.12.2009</td>
<td>7850</td>
<td>2090</td>
<td>9940</td>
</tr>
<tr>
<td>31.12.2010</td>
<td>6681</td>
<td>1973</td>
<td>8654</td>
</tr>
<tr>
<td>31.12.2011</td>
<td>5916</td>
<td>2037</td>
<td>7953</td>
</tr>
<tr>
<td>31.12.2012</td>
<td>5476</td>
<td>1901</td>
<td>7377</td>
</tr>
</tbody>
</table>

In recent times there have been concerns about the future viability of public residential care (Cullen, 2013), in part due to the decline in overall numbers, as outlined above, but also due to an inability to meet regulatory standards
in terms of physical infrastructure and a higher cost of care than the private sector. These will now be discussed.

1.4.7 Physical infrastructure

Many of the existing public residential care buildings are unable to meet the standards required by the HIQA (Standard 25, p. 43) without major investment or replacement (HSE report 2007, unpublished). Facilities vary in age and type from those that were originally workhouses and fever hospitals through to county homes and geriatric hospitals built in mid-twentieth century to a small number of more recently-built community nursing units. The Health Service Executive was given a time frame by HIQA to upgrade its facilities to meet the standards. However, a national financial crisis severely curtailed a fast-track building programme to replace outdated facilities and create additional facilities (HSE, 2007).

1.4.8 Cost of care

The cost of care in public residential care is higher than that in the private sector (HSE, 2013a) largely due to a higher number of registered nurses when compared to the private sector. The skill mix ratio between nurses and care staff is approximately 45% nursing 55% care staff (HSE, 2012), in contrast to the private sector where ratios of 30% Nursing 70% care staff are the norm. The ratio of nurses to residents ranges from 1:2 to 1:2.5 in public facilities while in the private sector it ranges from 1:4.7 to 1:6.5 (Murphy et al., 2006). There is some dispute as to whether the higher level of nursing in public units is warranted. According to the HSE website, the public facilities have a proportionally higher share of residents who have been categorized as maximum dependency. However, others suggest that these categorisations do not entirely explain the differences in staffing levels (Murphy et al., 2006; Wren, 2009; HSE, 2013a).

1.4.9 Staff by category

There are approximately 7,553 nursing and care staff (nursing and other patient care), 374 allied health care staff and 119 medical staff in total. The
As in most countries, the workforce in public residential care in Ireland is overwhelmingly female (Foner, 1994; Stone, 2001). The current nursing staffing structure emerged from the Commission on Nursing (Carroll, 1998) which introduced a system of nurse management grades and proposed the up-skilling of care staff to undertake some nursing tasks under supervision. A review in 2006 revealed varied levels of implementation across the country (HSE, 2006)

### 1.4.10 Public sector moratorium

As a response to Ireland’s financial crisis, a public sector moratorium was put in place allowing for only limited replacement of staff in essential areas. A recent report shows a reduction of approximately 1000 staff in residential care from 2009, although no national data is available in relation to how many of these positions were replaced by agency staff (HSE, 2013a).
Table 1.4  Whole Time Equivalent Staff Reduction from December 2009 to June 2013

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical/dental</td>
<td>128</td>
<td>136</td>
<td>122</td>
<td>120</td>
<td>119</td>
</tr>
<tr>
<td>Nursing</td>
<td>4319</td>
<td>4120</td>
<td>3881</td>
<td>4061</td>
<td>3999</td>
</tr>
<tr>
<td>Health and social care professionals</td>
<td>373</td>
<td>356</td>
<td>351</td>
<td>390</td>
<td>374</td>
</tr>
<tr>
<td>Management/admin</td>
<td>578</td>
<td>580</td>
<td>527</td>
<td>532</td>
<td>524</td>
</tr>
<tr>
<td>General support staff</td>
<td>1378</td>
<td>1238</td>
<td>1121</td>
<td>1103</td>
<td>1077</td>
</tr>
<tr>
<td>Other patient care</td>
<td>1378</td>
<td>1238</td>
<td>1121</td>
<td>1103</td>
<td>3752</td>
</tr>
<tr>
<td>Total</td>
<td>10947</td>
<td>10464</td>
<td>9848</td>
<td>10001</td>
<td>9847</td>
</tr>
</tbody>
</table>

1.4.11 The introduction of Person Centred Care practice in public residential care services

In 2005, the National Council for the Professional Development of Nursing and Midwifery funded a two-year practice development pilot project to introduce the principles of person centred care to Irish Public Residential Care Units (Dewing et al., 2007). This study focused on practice development of staff and did not report on outcomes for residents. The participants reported better team working amongst nurses, being freer in their work, less rotation of staff, improved self-confidence and awareness, knowing the residents better, and better transitions into care. Barriers included issues of hierarchical power and lack of clarity of roles in team nursing. This was followed by a national two-year project on person centred care across seventeen sites, three of which participated in the field work for this study.
The outcome of the two-year project is discussed in more detail in chapter 2. However, its findings drew attention to a number of issues that warrant further attention. Staff reported low levels of stress or ‘intention to leave’ and the researchers reported statistically significant changes in staff behaviours towards person centred care. However, residents reported a sense of hopelessness, lack of connectedness and feelings of boredom, pointing to a disjuncture between these two experiences (McCormack et al., 2010a).

The project was underpinned by the McCormack and McCance’s (2006) Person Centred Practice Framework (Appendix 1) and employed a practice development and active learning approach. The authors identified several contextual issues that impacted on the implementation of person centred care cultures – such as poor physical environments, resistance to change and embedded task-oriented ways of working. Unequal power relations and a lack of power to change external organisational rules were also reported. While these contextual issues were raised, their direct influence on the implementation of person centred care was not explored.

1.4.12 Section summary

This section explored Irish residential care policy in general, noting how various policy documents have focused on expanding its role and capacity, and on funding and quality improvement strategies. The various organisational and legislative changes have been discussed in the context of their impact on public residential care services, specifically including the expansion of the private sector and the introduction of regulation. The financial and regulatory challenges and the introduction of person centred care practices were outlined by way of background for this study.

1.5 Summary

Historical and professional discourse has drawn attention to the challenges and negative perceptions of the residential care model as a means of
managing age-related health and social care issues. The dominance of biomedicine and chronicity has been criticised and other more positive approaches have been promoted. Several authors argue that the lack of a clear rationale for residential care has resulted in the adoption of a primarily residual position of last resort – as opposed to a positive lifestyle choice by older people. Responses to shortcomings have included greater investment in regulation and quality improvement strategies. The historical and policy contexts of Irish public residential care services have been outlined by way of background to this study.

1.6 Rationale for the study

The National Person Centred Care Practice Development Programme (McCormack et al., 2010a) provided details of the implementation of person centred care in public residential care units. However, it did not explore the coordinating influences of organisational structures that influence this implementation. While issues such as resistance to change and embedded task-oriented practices were identified the report but it did not go beyond these to examine how organisational processes impacted on the capacity of champions to implement and sustain new cultures of person centred care. Uncovering the social relations of this organisational process from the standpoint of the resident is the objective of this thesis. No studies were located that explored the social relations that coordinate the lives of residents in a way that makes visible the competing needs of the various social actors and the power relations that shape what actually happens – as opposed to what gets textually described in professional reports, and policy and pedagogic texts.

The account and analysis of the social relations of residential care is not just about older people and the people paid to care for them. Rather, it is about looking beyond this setting in the context of wider organisational priorities. Institutional ethnography provides an alternative way of looking and exploring ‘what actually happens’ in order to make visible the seemingly neutral organisational forces which underpin the ‘system’ of residential
care. By adopting the standpoint of residents, the study aims to provide further insight into the problem of implementing person centred care by connecting the everyday lives of real people to the wider social network of professional practice and organisational systems exploring the line of fault between espoused principles and the actualities of those everyday lives. The research process is exploratory rather than explanatory and aims to uncover and map the connections between the various elements of the system. Therefore the research objectives are:

- To explore the everyday living routines of older people in residential care and the social relations that influence those routines.
- To explicate the texts that coordinate the activities of care planning and reporting mechanisms.
- To explore the disjuncture between the theories of person centred care and the organisational policies and practices of Irish Public Residential Care Settings.

1.7 Outline of the thesis

The thesis is set out in 8 Chapters. Chapter 2 is an extensive literature review outlining the theory practice and research base of person centred care. Chapter 3 provides an overview of research methodologies and explains the rationale for choosing Institutional ethnography. As Institutional ethnography is considered both an alternative sociology and a methodology, its ontological underpinnings and its methodological steps are described. Chapter 4 describes the actual method used and discusses ethical considerations and issues of rigour. Chapter 5 describes the first of two key analytical tasks – the explication of a text that connects the theory of person centred care to the textual work of care planning. Chapter 6 then provides an analysis of the social relations of person centred care as it relates to the social engagement of residents in the everyday life of the facilities through their relationships with staff, how decisions get made and through meaningful activity. Chapter 7 discusses the findings in the context of the professional gerontological and person centred care literature and through
the lens of Institutional ethnography offering a ‘different way of looking’. Chapter 8 outlines the implications for policy and practice, reflections on the methodology, the limitations of the study, contributions to knowledge and contributions to practice, proposals for future research and concluding remarks.
Chapter 2: Literature Review

2.1 Introduction

In this chapter, the literature relating to person centred care is reviewed and presented in three sections.

The first section introduces the concept of person centred care and describes its historical and philosophical underpinnings, including its early focus in the field of dementia. The definitional challenges are explored and the commonly agreed principles of maintaining personhood, autonomy, relationships and creating positive social environments are discussed.

The second section discusses the research literature related to person centred care and in particular the organisational challenges of translating the concept into practice. Contemporary quantitative and qualitative studies as they relate to the principles outlined in section one are discussed.

Finally, the challenges and gaps in the literature are discussed and a rationale for this study provided. In advance of this, the search strategy used is outlined.

2.2 Search Strategy

The purpose of the search strategy was to locate and review theoretical and practice-related works dealing with the concept of person centred care and to identify research studies that have been carried out which inform the current professional discourse. The initial inclusion criteria used were:

1. Theoretical work, seminal books and literature reviews that defined and explained person centred care in residential care settings.
2. Commentaries and opinion pieces in peer reviewed journals.
3. Peer reviewed quantitative and qualitative research on person centred care between 2003 and 2013.
Exclusion criteria were:

1. Papers relating to non-residential care settings such as acute care, sheltered housing or day care.
2. Studies relating to associated concepts such as quality of life or quality of care.

I began the literature review by undertaking an electronic literature search focusing on the following databases; EBSCO CINAHL (Cumulative Index to Nursing and Allied Health Literature) Web of Science; Scopus; MedLine, AgeLine and Proquest. Initially, a broad search using the term ‘person centred care’ was entered into the EBSCO CINAHL database and resulted in 322 hits, all of which were screened for relevance. Papers which referred to settings other than residential care were omitted. An alternative (American) spelling, ‘person centered care’ was then entered into the search machine with 321 hits. These were compared with the previous search and 38 additional papers were retrieved. The search was then widened out to include other related terms such as relationship centred care, person directed care, individualised care, client centred care and resident centred care.

A similar process was undertaken with the other databases. Other search combinations using the Boolean operators were then employed, i.e. ‘person centred care’ AND Residential care/nursing home/aged care/skilled nursing facilities/care home/ long term care.
Table 2.1 Search Strategy

<table>
<thead>
<tr>
<th>Database</th>
<th>Search Terms</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cinahl</td>
<td>Person centred care</td>
<td>322 results: 51 retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centered care</td>
<td>321: 38 retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centred care AND residential care</td>
<td>no new articles retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centred care AND dementia</td>
<td>no new articles retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centred care AND care homes</td>
<td>no new articles retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centred care AND nursing homes</td>
<td>no new articles retrieved</td>
</tr>
<tr>
<td></td>
<td>Person centred care AND long term care</td>
<td>two new articles retrieved</td>
</tr>
<tr>
<td>Scopus</td>
<td>Person centred care AND long term care OR nursing home</td>
<td>24 new articles retrieved</td>
</tr>
<tr>
<td>Medline</td>
<td>Person centred care AND long term care OR Nursing home</td>
<td>20 new articles retrieved</td>
</tr>
<tr>
<td>Age info</td>
<td>Person centred care</td>
<td>no new articles retrieved</td>
</tr>
<tr>
<td>Proquest</td>
<td>1 study retrieved</td>
<td></td>
</tr>
<tr>
<td>Web of Science</td>
<td>Person centred care AND long term care OR nursing home</td>
<td>four new articles retrieved</td>
</tr>
</tbody>
</table>

From this search a total of 140 were retrieved and 109 full papers were reviewed. The papers were categorized according to theme.

2. Practice related information/frameworks/guidance documents.
3. Opinion pieces/essays/commentaries.
Empirical studies were further sub-divided into quantitative (RCT/Quasi experimental/Secondary data analysis) and qualitative (case studies/action research/practice development/ethnography).

The search process led on to the sourcing of other documents through a snowballing effect – which widened the search – incrementally identifying potentially useful references within these articles, which were also retrieved and entered into Endnote. These included seminal works and other books, government reports and grey literature. Additional searching by key authors was also undertaken.

2.3 Overview of person centred care

As indicated already, the term Person Centred Care (PCC) is used widely in health and social care services and is commonly employed in the articulation of policy both at governmental and professional level (WHO, 2007; An Bord Altranais, 2009; HIQA, 2009; DOHC, 2012). It is considered synonymous with quality of care and the quality of life of people who are availing of health and social services (Dow et al., 2006; Belchambers and Penning, 2007; Brownie and Nancarrow, 2013). As a concept it is difficult to define, with Brooker (2003) contending that this is because it means different things to different people in different contexts. Person centred care is considered multidimensional with many interrelated and overlapping attributes and components (Edvardsson, Fetherstonhaugh and Nay, 2010; Hill et al., 2011; Pol Grevelink, Jukema and Smits, 2012) including maintaining a focus on individuals, promoting autonomy, having a partnership or relational approach, and delivering flexible services based on individual needs and preferences (Innes and McCabe, 2006; Dow et al., 2006). When discussing person centred care in general, Koubel and Bungay (2009) have proposed that it is about respecting an individual’s right to autonomy in making decisions about their own health and social care. This, they propose, prompts a shift away from the position whereby practitioners are considered as experts with power and knowledge and individuals availing of services are seen as passive recipients of that service.
While a significant level of conceptual development has taken place within the nursing field, person centred care has a wider applicability within other disciplines such as medicine, occupational therapy and social work (Sumison, 2006; Finset, 2011; Rockwell, 2012), and within specific fields of health and social care services.

Each of these fields has tended to adopt a specific emphasis relevant to the types of individuals that avail of services. For example, within acute care settings, person centred care has been seen as the creation of a partnership approach to health care between the doctor and patient providing a counterbalance to medical power and ultimately leading to increased efficiencies, better satisfaction with the care experience and lower turnover of staff (Lutz and Bowers, 2000; Frampton and Guestello, 2010; Ekman et al., 2011; Olsson, 2013). Within the disability field there is considerable emphasis on the need to promote autonomy and a rights based approach and to create options for more individualised supports including shifting the way services are organised and funded (Powell, 2011; Barton, 2010). In gerontology an approach which acknowledges cognitive, physical and emotional frailty of older people is emphasised with attributes such as autonomy and independence being considered in that context (McCormack, 2001; Nolan, 2001). While these differences of emphasis exist within specific fields of health and social care, all have similar goals of challenging the traditional notions of professional power and paternalism and creating a more flexible approach to how services are delivered (McCormack, 2001; Dow et al., 2006; Koubel and Bungay, 2009).

### 2.3.1 Person centred care for older people in residential care settings.

Moving from the concept of person centred care within health and social care services in general, the following section explores the concept as it relates to older people and more specifically within residential care settings. It explores the general intention of person centred care to act as an antidote to adhering to rigid routines which have been seen to consistently depersonalise and objectify older people in the name of efficiency and order.
The concept of person centred care as it relates to older people was initially developed in the field of dementia, challenging traditional biomedical theories and custodial models of care (Kitwood, 1997). From there its applicability has been broadened out to gerontology generally (Brooker, 2003; McCormack, 2004). It has developed rapidly as a theory of practice for health professionals working in this area (Edvardsson, Fetherstonhaugh and Nay, 2011; McGilton et al., 2012) and now encompasses all areas of gerontological care including residential care (Hunter and Levitt-Jones, 2010; McCormack et al., 2010; Rosvik et al., 2011; Passquala and Harwood, 2012; Rosvik et al., 2013), day care (Brataas, 2010), respite (Kirkley, 2011), homecare (Masterson, 2007) and intermediate or sub-acute care (McCormack, 2001; Davis, 2008).

Several authors describe PCC as a standard of care that puts the person at the centre of the care delivery process supporting a shift away from a medical and task-orientated process to one which is holistic, collaborative and focused on relationships (Belchambers and Penning, 2007; McCormack and McCance, 2010; McGilton et al., 2012). This is particularly relevant in residential care for older people where the focus was seen to be on efficiency and quality of care rather than quality of life (Cooney et al., 2009; McGilton et al., 2012). Edvardsson, Fetherstonhaugh and Nay (2010) describe person centred care as a ‘multidimensional concept based on the subjective feelings of individuals’ (p. 2612).

Maintaining the identity of individuals who are vulnerable to a loss of personhood due to cognitive difficulties and/or institutionalisation is considered a key element of person centred care and it is suggested that by adopting this approach the life and value of the older person becomes central – therefore driving a change in how care is organised and delivered (Dewing, 2004; NCHR&RD, 2006; Buron, 2010). Promoting dignity, respect and autonomy of individuals as persons is seen to be central (Epp, 2003; McCormack, 2004; Wilkinson et al., 2009) as is incorporating knowledge of the values of the individual into the care process (McCormack...
and McCance, 2010). Creating positive social environments where individuals are valued and nurtured is considered fundamental to this approach (Kitwood, 1997; Brooker, 2003; Clayson, 2007; McCormack and McCance, 2010; Rosvek et al., 2013).

Person centred care is now commonly cited in policy documents, mission statements and promotional materials of service providers yet there remains a lack of clarity around its conceptual development, definition and translation into practice (Slater L, 2006; Edvardsson and Innes, 2010; McCance, McCormack and Dewing, 2011; Pol Grevelink, Jukema and Smits, 2012). The following section outlines the philosophical underpinnings, origins of the concept and its initial development in terms of gerontology in the field of dementia. Following this, the definition of PCC and its key principles are explored further.

### 2.3.2 Philosophical and historical context

The roots of PCC theory can be traced back to the philosophy of personhood which can be found within theological, ethical, and social-psychological discourse (Kitwood, 1997). Within the field of theology, most religions identify the sacredness of each human being. Within western philosophy, Kant espoused that each individual has an intrinsic worth, which obliges us to treat each person with respect and as an end in itself rather than a means to some other end.

> So act as to treat humanity whether in your own person or in that of any other in every case as an end and never as merely a means only. Each person by virtue of his or her reason has dignity and profound worth which entails that he or she must never be exploited or manipulated or merely used as a means to our idea of what is for the general good. (Kant in Kenny 1994, p. 192)

In order to understand about intrinsic worth we need to separate persons from ‘things’. Things have an extrinsic value – i.e. they only have a value if someone else wants them. If persons were only to be desired on the basis of extrinsic worth then a hierarchy of desirable attributes would emerge which
would militate against those unable to meet those desirable attributes. According to McCormack and McCane (2010) the moral law which guides our actions and exhorts us to value each human being intrinsically is what separates us from other species and defines us as persons. This type of thinking is the basis for much of the discourse on ethics and human rights (Kitwood, 1997).

McCormack (2004) considers the concept of ‘personhood’ in terms of what it is that makes humans different from other species and he sets out the arguments for defining personhood as a prerequisite to person centred care. If humans are considered unique based on physical and psychological characteristics, then it could be argued that other species such as animals also possess many of the characteristics of humans such as their senses, i.e. sight, hearing, taste and sexual desire and even higher order attributes such as thought and decision making. Therefore the traits that make a person human are defined as a capacity to engage in reflective evaluation of action (McCormack, 2004). Frankfurt (1989) propose that humans have ‘second order’ desires which are distinguished from ‘first order desires’, in that an individual can want to be different in their desires and preferences from what they actually are. These second order desires are considered fundamental to being autonomous and enable individuals to consciously develop a set of principles to guide what they do in certain situations, therefore making rational choices. Even if the ability to carry out the actions required to fulfil those decisions is curtailed (for example through disability) the will to make such decisions is retained, an important issue in respect of promoting autonomy within residential care (Collopy, 1988; McCormack, 2001; Welford, 2012).

These concepts of personhood and ‘second order’ desires become challenging when considered in the context of advanced dementia. Cognitive traits of rationality and self-consciousness were considered necessary ingredients of personhood by the philosophers of the enlightenment such as John Locke, who celebrated the capacity for reason and moral agency (McLean, 2007). However, Kitwood (1997) argues that
this focus on rationality has resulted in the criteria for personhood being reduced to just two – autonomy and rationality, thus endangering the claim to personhood of individuals who do not have this capacity due to having cognitive impairment.

2.3.3 The origins of Person Centred Care

The humanistic psychological approach to psychotherapy is seen as a precursor to person centred practice, emerging from the work of Carl Rogers (1951) amongst others, who acknowledges the subjective experience of all individuals (McCormack, 2004). Within the field of mental health Rogers developed the client centred approach to therapy which puts the therapist in the role of ‘helper’ as opposed to expert. With this approach the therapist seeks to understand the world of the individual from their perspective providing a safe environment to examine their own motives and behaviour (Rogers, 1951).

The term ‘person centred counselling’ replaced ‘client centred counselling’ over time in recognition of the expertise of the individual in terms of their own life and the role of the therapist in facilitating their search for self-actualisation (Brooker, 2003). The key elements of this facilitation were deemed to be openness, valuing the person and having an empathetic view of the person’s world, inspiring growth, maturity and positive change (Slater P., 2006). Belchambers and Penning (2007) note that this approach was a radical departure from the authoritarian approach of the professional as expert who could solve individuals’ problems for them to one that acknowledged that individuals were best placed to solve their own problems with professionals adopting a facilitative approach.

This approach, while having a major impact on the evolution on the theory of person centred care, has been criticised for being overly focused on the individual. The goal of self-actualisation, it is argued, may under-represent reciprocity or interdependency in relationships (McCormack et al., 2012; DuPuis, 2012). This is discussed further later on in the chapter.
The elements of person centredness as developed by Rogers (1951) have been adopted and incorporated into the theory of PCC most notably in terms of therapeutic relationships and communication approaches which in turn have been incorporated into frameworks to guide the practice of health care professionals (Kitwood, 1997; Binnie and Titchen, 1999; Nolan, 2001; Brooker, 2003; McCormack, 2004; McCormack and McCance, 2010).

2.3.4 Kitwood and dementia

Kitwood is considered by many to be the initiator of theory and discourse in respect of person centred care in gerontology and, more specifically, the field of dementia (Baldwin and Capstick, 2007). His prolific work in the 1980s and 1990s and book *Dementia Reconsidered* (1997) are considered seminal in describing its main concepts (Dewing, 2004). It is from him that the original definition of personhood as it relates to dementia and subsequently gerontology has evolved. Connected to the Kantian notion of intrinsic worth, as described above, he developed a definition of personhood as being:

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

Alongside Kantian thinking and Rogerian theory, Kitwood also drew on the work of Social Role Valorisation, Validation theory and Reminiscence. Social Role Valorisation theory draws attention to the dehumanisation and segregation of certain members of society, in this case people who are old with failing mental powers in a world which values youth and intellectual capacity (Race, 2003; Stirling, 2010). Validation theory proposes that previous negative experiences and unresolved feelings could influence behaviour and well-being in individuals with dementia. It suggests that by entering into the world of the person with dementia and acknowledging and validating these feelings, well-being can be maintained and deterioration slowed down (Feil and deKlerk-Rubin, 2003). Reminiscence theory acknowledges the capacity for long-term memory to remain intact. Not merely just a means of revisiting the past, it suggests that memories provide
metaphorical resources for people to talk about their present situation in a way which helps create meaning from their current situation (Kitwood, 1997; Agich, 2003).

Through his writing, Kitwood (1997) challenged the prevailing biomedical theory of dementia as being merely due to neuropathology, maintaining that it was rather a combination of this with social, psychological and environmental factors that could influence the acceleration or delay the trajectory of the dementia process. In setting out his arguments, he drew attention to the set of beliefs and attitudes which have shaped dementia care for many years including nihilistic attitudes, the exhausting and unrewarding nature of care giving, and the need to await medical breakthroughs before anything positive could happen. He argued that these beliefs have led to seeing the person with dementia as somehow different and apart, whose deficits and decline needed to be charted and whose behaviour needed to be managed. Routines of physical care together with this hopeless view of dementia, he argued, contribute to a form of care which actively accelerates the loss of personhood and well-being. He proposed that the overarching purpose of person centred care (in dementia) is to preserve a sense of self and personhood, stating that all human beings have a fundamental psychological need for comfort, attachment, inclusion, occupation and identity (Kitwood 1997, pp. 81-85) and that as cognitive capacity declines, attention to these needs become central to how people with dementia are supported. Therefore, he contended that by creating more positive social environments that addressed these fundamental needs focusing on feelings, emotions and being in relationships, the negative and depersonalising effects of dementia could be counteracted.

Using this theoretical position, Kitwood drew attention to the care practices commonly seen in residential care and developed the phrase ‘malignant social psychology’ to draw attention to the, often unintentional, way that health and social care staff disempowered and devalued people with dementia. The work of Kitwood is regularly cited in the literature on person centred care and has resonance with subsequent framework development by
others such as McCormack (2003) Brooker (2003) Nolan et al. (2006) and Edvardsson, Fetherstonhaugh and Nay (2010). Adams (1996) contends that Kitwood’s work has been instrumental in bringing the person with dementia back into the centre of care following their relegation to the sidelines while research and practice was focused on the needs of carers and what is perceived as the burden of care. While dementia care was the focus of this work, others have taken these ideas and adapted them within new settings such as non-dementia-specific residential care (Wright et al., 2006; McCormack et al., 2010) community and acute hospitals (McCormack, 2001; Davis, 2008; McCormack and McCance, 2010).

Despite this work, the concept of person centred care remains difficult to define and explain (Edvardsson and Innes, 2010). One of the difficulties that exists in relation to explaining its meaning relates to the fact that it is called different things, sometimes in different settings but also sometimes in similar settings or contexts (Brooker, 2003; Dow et al., 2006; McCance et al., 2011; Brownie and Nancarrow, 2013).

### 2.4 Definitions associated with Person Centred Care

Although now a commonly used term in professional discourse, a consensus among authors in the gerontological field as to the definition of person centred care has not as yet emerged (Brooker, 2007; Edvardsson Fetherstonhaugh and Nay, 2010; Edvardsson and Innes, 2010; Sjogren et al., 2011; McCormack, Dewing and McCance et al., 2011; Hill et al., 2011; Pol Grevelink, Jukema and Smits, 2012; Brownie and Nancarrow, 2013). A range of terms have been used to describe PCC and they are often used interchangeably. These include ‘patient centred care’ (Mead and Bowers, 2000) ‘client centred’ (Townsend et al., 2003; Sumison, 2006) ‘person directed care’ (White et al., 2008) and ‘relationship centred care’ (Nolan et al., 2006) all of which purport to focus on the subjective well-being of individuals. However, there is also a difference in emphasis between these terms which has relevance to how the concept is understood and put into practice in respect of older people who live in residential care settings.
2.4.1 Patient centred care

Patient centred care is a term often used interchangeably with person centred care and the two terms have much in common (McCance et al., 2011). Mead and Bowers (2000) in a review of the literature relating to patient centred care identified five dimensions which include; having a biopsychosocial perspective; the patient as a person; sharing power and responsibility; having a therapeutic alliance; and the doctor as a person; all of which point to the development of a more holistic and positive approach to care. However, Millburn and Walker (2008) suggest that the term patient implies illness and infirmity, incapacity and or incapability and, as such, presents negative stereotypes that are not consistent with the holistic concept of person centred care. Edvardsson, Winblad and Sandman (2008) suggests that the term ‘patient’ could be described as a ‘reductionist, stigmatic term’ (p. 363) that implies differences between the patient and health care professional. Brooker (2004) and Agich (2003) contend that the term patient centred, while clearly related to the term person centred has the potential to undermine the person as an individual as their identity is constructed in the context of a biomedical condition such as dementia or a stroke. This could imply that their needs only relate to those which come within the boundary of being a patient and other holistic needs of the person are external to this.

2.4.2 Client centred care or person directed care

The term client centred care is commonly used in place of person centred care in the social services literature particularly in relation to social work (Millburn and Walker, 2008) and occupational therapy (Townsend et al., 2003; Sumison, 2006; Hughes and Bamford, 2008). While the language and terminology could be considered different to that of person centred care so too could the meaning behind that language. According to Millburn and Walker (2008) the term ‘client’ (derived from the Latin word ‘cliens’ meaning ‘heeding’) denotes a person under the patronage of another, i.e. a passive recipient of professional expertise. They argue that clienthood represents an unequal power relationship between the client and worker.
Other authors adopt a different emphasis. According to Slater, L (2006) the term ‘client’ implies a contractual relationship, with a monetary transaction where in theory at least, the balance of power lies with the ‘payer’ or client pointing to a greater visibility of consumer rights. Continuing with this theme of consumer rights, the term ‘person directed’ as opposed to ‘person centred’ is more commonly used in the United States (White et al., 2008) and could be interpreted as placing the individual in a leading as opposed to central role. As such it could be interpreted as the health care workers adopting a role of being of service to residents and to be led by their wishes and requirements. This reflects a shift in power to the individual which Nolan et al. (2006) and McCormack et al. (2012) argue reflects a consumerist approach based on principles of independence and choice that fails to understand the interdependencies and reciprocal nature of relationships in residential care. The question is posed as to whether all older people can realistically direct their own care given the very real presence of cognitive incapacity and frailty.

The difficulty remains in the literature as to whether client centred or person directed care can be classified as consumerist as there are many overlapping and interrelated principles within each of the definitions. As such it is difficult to delineate elements or attributes that denote clear differences between them (Edvardsson and Innes, 2010; Hill et al., 2011; Brownie and Nancarrow, 2012).

2.4.3 Relationship centred care

Relationship centred care has emerged as a concept in health care generally (Tresolini, 1994; Beach and Inui, 2006) and gerontology specifically (Nolan et al., 2006; Faulkner et al., 2006; Brown Wilson, 2009; Brown Wilson et al., 2013). Promoting the centrality of relationships in all health care interactions, it challenges the traditional construction of care relationship between individuals and health care professionals suggesting a broader concept which also includes relationships between residents and family
members, family members and staff and relationships between staff. It is argued that this approach acknowledges the affective nature of healthcare incorporating attention to senses or feelings and promotes the presence of reciprocity and interdependencies between all stakeholders (Nolan et al., 2006). This definition promotes equality between stakeholders as opposed to placing the person receiving care at the centre, or as the director of care – important differences which, it is argued, promote the concept of interdependency (Dupuis, 2012). This definition also locates the person in a wider social context of their family and social network as opposed to the narrow context of a healthcare setting. Nolan developed ‘The Senses Framework’ to promote the well-being in each of the stakeholders: a sense of security, continuity, belonging, purpose, fulfilment and significance. While the senses are common to each stakeholder they may be experienced in different ways by each person (Nolan et al., 2006). For example, in the context of a ‘sense of security’, this may be experienced by the older person as attention to physical and psychological needs, feeling safe and free from harm, pain or discomfort. For staff this could include freedom from physical threat, rebuke or censure, having secure conditions of employment, having the emotional demand of work recognised and to work within a supportive culture.

2.5 Person Centred Care – key principles

Acknowledging the synergies with the terms of patient, relationship and client care and centredness as outlined above, the following section further explores the concept of person centred care drawing out common themes as described by various authors. This can be difficult to do as different authors use different language or define the core concepts in different ways. This resonates with the recurring theme of inconsistency and variations of terminology and language that cause difficulty in the articulation of a consistent definition (Edvardsson and Innes, 2010; Pol Grevelink, Jukema and Smits, 2012). McCormack (2004) building on the work of Kitwood (1997) and following a literature review on the subject of person centredness proposes four key elements to person centred care:
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- Being in relation – the idea that nurturing relationships between care provider and care recipient are central to the experience of caring and are based on moral integrity, reflective ability, are values based and involve flexibility.
- Being in a social world – knowing the person’s interests and being aware of their past and present biography as well as their goals for the future.
- Being in place – being aware of the environment and how it can enable or hinder person centred care.
- Being with self – knowing the person’s values and what is important to them while helping them to find meaning in their situation. It also refers to the health professional being aware of their own beliefs and values and how these can influence decision making. (p. 33)

More recently, McCormack et al. (2010a) proposed the following definition:

*Person-centredness is an approach to practice established through the formation and fostering of therapeutic relationships between all care providers, older people 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.* (p. 13)

This definition focuses on the relationship between the nurse, the person receiving care and others involved with them. It incorporates the core concepts previously described (McCormack 2004). However, it also explicitly draws attention to the right of autonomy, self-direction and empowerment.

Similar and related concepts to the ones captured in McCormack’s original four concepts (2004) and subsequent definition (McCormack et al., 2010a) have also been developed or written about by other authors. In a concept analysis of person centred care, Slater, L. (2006) identified the following attributes; recognition of personhood; evidence of a therapeutic relationship between the health care professional and individual; respect for
individuality; ethical care; maximising potential and strengths rather than focusing on weaknesses and problems and empowerment of the individual.

Edvardsson, Winblad and Sandman, (2008), in a review of the literature in respect of person centred care as it related to people with severe dementia, concluded that the concept person-centred care included: seeing the self of the person with Alzheimer’s disease (AD) as concealed and not lost; personalising care and the environment; making room for shared decision-making; interpreting behaviour from the person’s viewpoint; and integrating care tasks in relationships.

Other authors have identified similar attributes including: A focus on personhood and knowing the person (McCormack 2004; Slater, L. 2006; McKeown, Clarke and Repper, 2006; White, Newton-Curtis and Lyons, 2008; Cook, 2010; McKeown et al., 2010) Respect for individuality (Brooker, 2003; Epp, 2003; Edvarsson Winblad and Sandman, 2008) Autonomy, choice and control (McCormack 2001; Agich, 2003; Tutton 2005; Welford, 2012). Nurturing or therapeutic relationships between the carer and care recipient (McCormack 2001; Talerico 2003; McGilton et al., 2003; Slater, L. 2006; McGilton and Boscart, 2007) and creating positive social environments (Brooker 2003; White, Newton-Curtis and Lyons, 2008; McCormack and McCance, 2010; Koren, 2010; Passalaqua, 2012; Edvardsson et al., 2013).

The concept of normalisation has been added by Edvardsson et al. (2013) and others associated with the culture change movement in the United States (Grant 2008; Moloney et al., 2011). The following table outlines some of the common themes found in the literature and the associated authors who have written about, developed frameworks, or have undertaken research in this area.
Table 2.2 Common themes in the literature

<table>
<thead>
<tr>
<th>Themes</th>
<th>Authors</th>
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<tr>
<td>Maintaining personhood</td>
<td>Kitwood 1997; Nolan 2001; Epp 2003; Brooker 2003; McCormack 2004; Slater L 2006; McKeown, Clarke and Repper 2006; White, Newton-Curtis and Lyon 2008; Edvardsson 2008; McKeown et al., 2010; Cook 2010;</td>
</tr>
<tr>
<td>Autonomy</td>
<td>McCormack 2001; Brooker 2003; Agich 2003; Tutton 2005; Welford 2012</td>
</tr>
<tr>
<td>Relationships</td>
<td>McCormack 2001; McGilton et al., 2003; Talerico 2003; Slater L 2006; Nolan et al., 2006; McGilton and Boscart 2007; White 2008; Edvardsson, Winblad and Sandman 2008; Brown Wilson 2009.</td>
</tr>
<tr>
<td>Positive social environments</td>
<td>Brooker 2003; White, Newton-Curtis and Lyons 2008; Grant 2008; McCormack and McCance 2010; Moloney et al., 2011; Passalaqua 2012; Edvardsson et al., 2013</td>
</tr>
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In order to further explore PCC and how it relates to the context that is residential care, these themes which are common across authors will be discussed in more detail. Although there is significant interconnectedness and overlap between them, the following represent ones that are commonly discussed in the literature, i.e. a focus on personhood, autonomy, relationships, and creating positive social environments.

2.5.1 Maintaining Personhood

Maintaining personhood in old age is a key concept of person centred care and it can become increasingly difficult to do in the context of disability and illness and major life changes such as the move to residential care (NCHR&RD 2006). Acknowledging the unique personhood of the individual in old age is considered to be important, emphasising each person’s unique inherent value regardless of their social or healthcare status (Brooker, 2003; White, Newton-Curtis and Lyons, 2008; Edvardsson, 2008).
Winblad and Sandman, 2008). As an antidote to depersonalised routines in residential care settings (Townsend, 1962; Gubrium, 1975; Wilcocks, Peace and Kellaher, 1987; Diamond, 1992) maintaining personhood is considered a critical element of PCC (Brooker, 2003; Stokes, 2009). Building on the work of Kitwood, Brooker (2003) proposes the V.I.P.S. framework, built on four interconnected constructs for achieving person centred care for people with dementia:

- V – Valuing people with dementia and carers
- I – Treating people as individuals
- P – Using the perspective of the person with dementia
- S – A positive social environment

This framework has been widely used and connected to the observational process of dementia care mapping which records levels of engagement and occupation of people with dementia as well as practices of carers which promote or undermine their personhood (Martin and Younger, 2001; Ballard 2009; Argyle, 2012).

In order to support older people to maintain and reconstruct their identity within new settings it is suggested that staff must take time to know the person. According to Brooker (2003) this requires staff to see individuals as whole persons with all their strengths and vulnerabilities, and seeing dementia as just one part of a person’s identity. In this way the person is considered in the context of their unique set of circumstances including their family and social networks, their history and their personal coping resources. Looking at individuals in this way challenges some healthcare assessment processes which operate within a narrow biomedical frame and proposes that the wider context of a person’s life be considered. The construct underpins the idea of providing care that is tailored to an individual rather than categories in which a health care system might place people. This shift in emphasis, it is argued, happens through knowing each individual, who they are now and understanding the context of their lives in the past, present and future (McKeown, Clarke and Repper, 2006;
McKeown et al., 2011). By focusing on personhood, the health professional is exhorted to enter the person’s world, to see things from their perspective and, for example, in the context of dementia, to understand behavioural disturbances not merely as manifestations of the disease but rather a means of communicating unmet need (Feil and De Klerk-Rubin, 2003; Brooker, 2004; Stokes 2009; Stirling, 2010).

Agich (2003) contends that through the telling of their stories, older people actively rearrange and reconstitute memories as ways of establishing place and direction in their present world of experience and helping them to make meaning of their current lives. Listening to stories bestows a sense of value and respect of people as individuals. Not listening or providing opportunity to do so, he argues, can lead to withdrawal and isolation. Biographical approaches such as life stories, reminiscence, oral history and life reviews are seen to help the staff member to maintain personhood as well as improving cognition and mood in people with dementia. (Kitwood, 1997; Clark, Hanson and Ross, 2003; McKeown, Clarke and Repper, 2006; Thompson, 2011). Life story work is described as a process to elicit an account of a person’s life over and above that which is acquired in a routine health assessment to plan care and treatment. Usually there is an end product such as a life story book, recording or biography summary (McCormack et al., 2001; Agich, 2003; Tutton 2005; McKeown, Clarke and Repper, 2006; Welford, 2012).

McCormack (2001) proposes this as a key mechanism to support person centred care based on the persons’ values, their whole life experiences, desires and potential for growth and development. This requires practitioners to engage in a meaningful way with individuals to help them achieve their goal. He proposes the development of ‘life plans’ which require clarifying values and identifying goals that a person wants to achieve including what relationships the person wants to sustain or activities they want to pursue as a means of retaining control over their life.
2.5.2 Autonomy

To be autonomous is described as being a ‘free, self-governing agent’ (Sherwin and Winsby, 2010; Welford, 2012). As a concept, autonomy is underpinned by the values of independence, self-determination, self-rule and protection against oppression or power (even benevolent power) over vulnerable individuals (Collopy, 1988; McCormack, 2001; Agich, 2005; Welford, 2012).

Autonomy is also described as being centrally located within the professional discourse of person centred care where it is proposed that individuals should be actively included and involved in a partnership process with carers of ‘doing with’ as opposed to ‘doing to’ (Kitwood, 1997; Dewing, 2004; Belchambers and Penning, 2007; Zeisel, 2009). From an organisational perspective autonomy is interrelated with concepts of having choices, shared decision-making and user involvement (Tutton, 2005; McCormack and McCance, 2010; Dupuis 2012) and is embedded in professional ethics, human rights policy and regulatory texts (Beauchamp and Childress, 1994; United Nations Madrid Declaration on Ageing 2003; HIQA, 2009).

Autonomy is commonly framed within the context of liberal theory where the concepts of negative and positive freedom are explored (Collopy, 1988; Agich 2003). Negative freedom – i.e. the freedom to be left alone and to be protected from unwarranted intrusion – underpins certain rights that are important in all health care settings, i.e. the right to information or right to privacy. The opposite of negative freedom – positive liberty – is resisted by those who fear paternalism, a concept which has its roots in the parental care for children and making decisions on their behalf (McCormack 2001; Beauchamp and Childress (1994). Paternalism is described by Beauchamp and Childress (1994) as:

*The intentional overriding of one person’s known preference or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden.* (Beauchamp and Childress 1994, p. 274)
McCormack (2001) contends that the concept of autonomy, while it sits well in the context of healthy, independent and cognitively competent individuals, it may not relate as well to the older person who is dependent on others due to cognitive incapacity or illness. According to Nolan (2001) the popular conception of independence and self-reliance as frequently articulated in healthcare as instrumental activities of daily living (IADL) or activities of daily living (ADL) (OECD, 2005) can undermine the self-esteem of the older person who may consider themselves a burden or as less than a whole person when measured against these attributes. Conversely, making assumptions about individual’s physical or mental incapacity to be autonomous can lead to paternalism whereby the state and professionals step in to act in the best interests of individuals (Dewing 2004). This potentially coercive action, often unseen, can impose another’s vision on a group of individuals such as disabled older people, determining what happens to them (Sherwin and Winsby, 2010; Stirling, 2010).

A number of authors refer to decision-making in a way that addresses this issue in the context of disability and residential care (Collopy, 1988; McCormack, 2001; Bungay and Sandys, 2008). Two types of autonomy are proposed: decisional and executional. Decisional autonomy relates to the ability to make decisions while executional autonomy is the ability to act on those decisions. In residential care, executional autonomy can be limited by disability or the environment. However, McCormack suggests that even when this capacity is limited the will to make the decision is still present and should be present in care giving in a way that makes sense to the individual. This is reiterated by others (Boyle, 2008; Welford, 2012) who state that even when older people do not have the capacity to exercise autonomy, this does not mean that they do not wish to do so and may require assistance, rather than others assuming that role on their behalf. As such, respecting autonomy also recognises the right to defer or delegate decision-making to others (Boyle, 2008; Welford, 2012).
Agich (2003) suggests that the common conceptualisation of autonomy as is understood in the world of medicine and episodic health care is somewhat different to daily life in residential care where the application of autonomy relates to small day-to-day decisions rather than major life and death situations. While these conceptions provide guidance around issues such as consent and prevention of abuse, he contends that they are not of much help to health care workers struggling to balance the older person’s right to self-determination against professional issues such as duty of care and protection, and organisational demands for efficiency and accountability (Nelson, 2000; McCormack, 2001; Agich, 2003; Nolan et al., 2006). He and others (Collopy, 1988; Polivka and Moody, 2001) argue for a broader conceptualisation than autonomy as independence which, it is argued, can have little meaning for someone who cannot be independent in the common understanding of the word. In its place a more relational concept of ‘interdependence’ between staff and residents is proposed as a means of overcoming losses in cognition and rationality and promoting well-being through considering the specific context of the situation.

Several authors have discussed this concept of interdependence, as it relates to residential care – proposing negotiation strategies based on the values of the older person and other stakeholders such as family members and staff (Nolan, 2001; Brown Wilson, 2009; Dupuis, 2012). Adopting the concept of interdependency assumes an equal sharing of power between all parties and a capacity to reconcile competing values (McCormack, 2001). Power is a multidimensional concept which, like autonomy, means different things in different settings (Hewison, 1995). The flip side of power is powerlessness and several authors have explored the issue of the powerlessness of residents in nursing homes (Gubrium, 1997; Kayser Jones, 1990; Shavinsky, 1991; Diamond, 1992; Foner, 1994; Nelson, 2000; McLean, 2001).

Nelson (2000) suggests that an imbalance of power between residents and staff leads to learned helplessness, adopting passive behaviours as a means of reducing a sense of debt obligation, seeking staff approval and diminishing fear of alienation or abandonment. Thomas (2004) uses a
similar term ‘helplessness’ to describe the lack of autonomy that older people have in the traditional nursing home model where he suggests the ‘cult of adulthood’ – a term he has coined to represent the values of productivity and ‘doing’ that imbue society – has subordinated the wisdom and desires of older people to a world governed by performance targets, standards and budget sheets.

McCormack and McCance (2010) contend that in a context of low expectations and ill-health, supporting older people to make choices may require more than eliciting knowledge about likes and dislikes or providing superficial choices about care routines but rather requires skilled negotiation and actively seeking to understand the values of the individual. This, they suggest, requires a sharing of power and mutual respect as part of a partnership that goes beyond a more traditional professional/patient relationship.

The concept of interdependency also assumes that practitioners have an existing capacity to be autonomous in how they work with older people (McCormack and McCance 2010). The powerlessness of staff has also been reported and several studies refer to the hierarchical and command and control nature of residential care services which create conflict between what staff wish to do from a caring perspective and what they are obliged to do as an employee (Diamond, 1992; McLean, 2001; Dewing, 2004; McCormack et al., 2010; Brannon, 2010; Bowers, 2011).

2.5.3 Relationships

Relationships are considered central to the aspiration of person centred care as an antidote to routine and depersonalised care (Brooker, 2003; Brown Wilson, 2009; Zeisel, 2009; McCormack and McCance, 2010) This centrality is based on the view of the self being formed, at least in part, by relationships with others (Hill 2004; McCormack 2004). According to Harre (1998) and Kitwood (1997) the self has internal and external elements. The external or social self is that which is constructed and maintained by
relationships with others and feelings of being coherent and worthwhile come, at least in part, from the outside (McCormack and McCance, 2010).

Kitwood (1997) contends that by creating more positive social environments that address fundamental needs focusing on feelings, emotions and being in relationships, the negative and depersonalising effects of dementia can be counteracted. In theorising about relationships, Kitwood (1997) refers to the poetic work of Martin Buber (1937) *I and Thou*, where Buber makes the distinction between two types of relationship: *I-Thou* and *I-It* relationships. *I-Thou* relationships denote presence, reaching out, spontaneity, self-disclosure and awareness. On the other hand, *I-It* relationships denote coolness, detachment, maintaining a safe distance and avoiding risks (Kitwood, 1997; McCormack, 2004). The concept of *I-It* relationships connects to the idea of objectivising individuals and the creation of ‘the other’, creating conditions for marginalisation and depersonalisation.

Lack of relationships or connectedness to others can result in feelings of loneliness and associated feelings of isolation and depression in older people living in residential care settings (Thomas, 2004; Buckley and McCarthy, 2009; Cooney et al., 2013). Several authors have highlighted the importance of interpersonal relationships between residents and staff in the delivery of person centred care (Kitwood, 1997; Brooker, 2003; Cook, 2006; Heliker and Scholler-Jaquish, 2006; Nolan et al., 2006; McCormack and McCance, 2010; Heliker and Hoang Thanh, 2010; Pol-Grevelink, Jukema and Smits 2012). According to Slater, P. (2006) a therapeutic relationship between a health care worker and the older person who is receiving care needs to have a balance of power, be non-judgemental, caring and mutually trusting. This balance of power, according to McCormack and McCance (2011) is achieved through negotiation and a shared decision-making process between the resident and staff member. They also highlight the fact that all good relationships take time to develop, and that a key element of the organisation of person centred care is ensuring continuous staffing arrangements so that staff and residents get to know each other, and can negotiate the care that is required.
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Nolan et al. (2006) argue that definitions of person centred care do not adequately address the wider context of a person life such as their relationships with family members or those that are constructed between the triad of residents, family members and staff in residential care. He proposes a wider interpretation that recognises this broader construction. He described the experience of relationships in the context of older people as ‘a sense of belonging’ highlighting the need to maintain or create meaningful and reciprocal relationships and to feel part of a community.

This issue of reciprocal relationships – whereby residents can equally show feelings of care and reciprocity for staff – has been highlighted in the literature (Brown Wilson 2009; Heliker and Hoang Thanh 2010; Bowers et al., 2011; Rockwell 2012).

Bowers et al. (2011) describes mutuality and reciprocity as:

arrangements designed to enable those involved to give and receive support compared to those where one individual or group of people are intended to be the recipients of services provided by another person or organisation. (p. 4)

Emanating from social exchange theory, reciprocation subsumes the broad ideas of balance, equity and justice and directly influences all areas of human interaction (Nelson, 2000). Reciprocal relationships have been connected to better physical and emotional adjustments and closer care giving attachments (Diamond, 1992; Foner, 1994; Brown Wilson, 2009; Heliker and Hoang Thanh, 2010). Conversely, non-reciprocal relationships can incite feelings of injustice, apathy, and alienation (Nelson, 2000). Nelson (2000) also maintains that the challenge in maintaining a balance of power in relationships is connected to the capacity to have something to give, noting that friendships between residents rely on reciprocity, something they may be unable to do due to lack of health, strength and possessions. Thomas (2004), in the seminal book What Are Old People For? contends that as the knowledge, experience and wisdom that only come with age get subordinated to the goals of clinical care and safety, it removes opportunities for intergenerational social exchange and reciprocity.
Relationships between staff are also discussed in the literature. While on the one hand person centred care is seen to be about rebalancing power between older people and staff, equally it has been acknowledged that staff also need to feel supported and valued in the context of reciprocal relationships (Nolan et al., 2006; McCormack and McCance, 2010).

2.5.4 Creating a positive social environment

Positive social environments, connected to McCormack’s ‘a sense of place’ is a core concept of person centred care (Brooker, 2003; Slater, 2006a; McCormack and McCance, 2010). It can refer to both the physical infrastructure of residential care including whether the environment reflects normal or homelike characteristics (Te Boekhorst et al., 2009; Hill et al., 2011; Moloney et al., 2011) and to the way care is organised, how decisions get made and the ethos of care (McCormack and McCance, 2010; Brannon et al., 2010; Lynch, McCormack and McCance 2011).

‘Creating community’ has been identified as a way of shifting from environments where residents are seen as recipients of care to ones where people are engaged in mutually supporting each other (Brown Wilson, 2009). This vision, while imbued with positive ideals, has been challenged by McLean (2006) who suggests that this assumes voluntarily choosing with whom you will live, which she contends is at odds with the competing needs of providers to fill beds and the fact that many older people do not chose residential care from a range of options but concede to it when there are no other options. In this way she suggests that the concept of creating communities is unrealistic.

The ‘Culture Change Movement’ in the United States focuses on the creation of positive social environment through a range of strategies including environmental changes, staff education, the dismantling of hierarchical staffing structures and the promotion of autonomy and inclusion of older people and their families in the everyday life of facilities (Thomas
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2004; Kane et al., 2007; Grant, 2008; Koren, 2010; Hill, 2011). The Eden Alternative is one of a number of models of residential care provision that offers guidance for staff based on moral and ethical principles and promoting growth and development even in deep old age (Brownie and Nancarrow, 2013). The model was developed by William Thomas in 1991 who stated that:

*every creature has a habitat in which it thrives, and one in which it withers. Human beings wither in institutions.* (Edenalt. org. unknown)

His aim was to create a human habitat that would optimise growth of older people through the de-institutionalisation of residential care facilities. He proposed the introduction of children, animals and plants and the creation of home like facilities. The Eden Alternative is based on a set of 10 principles which have been described as a framework for reform (Appendix 2).

One of the key objectives of the culture change movement is to create ‘home’. Maloney et al. (2011) suggests that home provides a link to self-identity and is a reflection of ‘*personal, societal, and cultural values, beliefs, and norms*’ (p. 292). ‘Home’ conveys an attachment to both people and place and physical spaces become linked to people when individuals become familiar with, personalise and place a territorial claim over them. These places then become a part of the identity of the individual and provide emotional and physical security (Davis et al., 2009; Maloney, 2011). The connection to people who have shared experiences and culture, and retaining cherished objects is considered important in fostering ‘at – homeseness’ after relocation to new environments such as residential care settings (Moloney, 2011)

Greater involvement of residents and families in decision-making and having opportunities to engage in meaningful activity are seen to contribute to positive social environments (Brooker 2003; Gaugler 2005; Haesler, Bauer and Nay, 2007; Edvardsson et al., 2013). The Senses Framework describes the issue of meaningful activity as a sense of purpose where older
people have the opportunity to engage in purposeful activity and to be able to identify and pursue goals and challenges (Nolan et al., 2006). Incorporating such activity into everyday life is proposed (Edvardsson, Fetherstonhaugh and Nay, 2010; Edvardsson et al., 2013; Morgan Brown, 2013).

2.6 Section summary

The above section introduced the theory of person centred care locating it within healthcare policy and outlining it historical philosophical and gerontological context. The similarities and differences between related terms used to describe person centred care were outlined. Core principles which have emerged in the literature include maintaining personhood, promoting autonomy, developing and maintaining relationships and creating positive social environments. The potential of this theory of practice to improve the quality of older people’s lives has been explored. However, it is acknowledged that it is a complex issue with many contextual issues such as competing priorities and asymmetrical power relations.

The following section explores these issues further in the context of research literature in this field, focusing on these four key areas of maintaining personhood, autonomy, relationships and positive social environments as described above.

2.7 Person centred research overview

While there is a growing body of research on person centred care in residential care settings it is multi-faceted and diverse. Different definitions are used together with different types of interventions and no consensus on what to measure (Edvardsson and Innes, 2010; Hill et al., 2011; Brownie and Nancarrow, 2013). To date most outcome measures could be considered to be proxy measures in that they do not measure person centred care per se, rather they measure elements of mood or behaviour, the use of psychotropic drugs or perceptions of the various social actors (Hoeffer et al., 2006; Fossey et al., 2006; Chenoweth et al., 2009; Skaalvik, Normann and
Henriksen, 2010; Edvardsson and Innes, 2010; McCormack et al., 2010a; Sjorgen et al., 2012; DeRooij et al., 2012). The lack of consensus on definitions, outcome measures or methods have led to a heterogeneous body of literature which is difficult to compare or replicate such is the range of varying factors, environments, cultures and interventions.

While the volume of research literature increases there is no definitive set of outcomes, findings or conclusions to categorically guide practice and the experiences of older people in residential care settings. Overall there appears to be some evidence that person centred care practices can improve the experience of residential care for both residents and staff (Hoeffer et al., 2006; Chenoweth et al., 2007; McCormack et al., 2010b; Edvardsson and Innes 2010; DeRooijjs et al., 2012). Improved well-being, quality of life and quality of care are generally considered as outcomes of person centred care.

It can, however, be difficult to extract exactly what elements of PCC theory and practice contribute to these improvements (Edvardsson and Innes 2010; Brownie and Nancarrow, 2013). Outcomes for organisations, such as improved performance and satisfaction of staff and reduced turnover and absenteeism have also been measured and there are findings to support the view that adopting a person centred approach can impact positively on these (Nolan et al., 2006; Yeatts and Cready 2007; Pol Grevelink Jukema and Smits, 2012; Castle et al., 2013).

Much of the empirical work relating to person centred care relates to the field of dementia (Hoeffer et al., 2006; Fossey et al., 2006; Chenoweth et al., 2009; Rosvik et al., 2013; Sloane et al., 2013). Varying methodologies have been employed including on the one hand large-scale randomised control trials and quasi-experimental studies (Hoeffer et al., 2004; Nijs et al., 2006; Fossey et al., 2007; Chenoweth 2009) and, on the other, smaller-scale qualitative studies using exploratory designs, practice development, action research, ethnography and case studies (McLean 2007; Brown Wilson 2009; Wilkinson 2009; McCormack et al., 2010). Randomised Control Trials (RCT’s) are considered the gold standard of research when
measuring specific interventions such as drug trials. Some authors suggest that the application of rigorous controls and random selection to intervention or control groups is often not feasible in this type of research (Kane et al., 2007). Furthermore, their capacity to adequately capture multifactorial outcomes in terms of both the concept and context of person centred care and the nature of the population being researched has been questioned (Love and Pinkowitz, 2013).

There are many smaller-scale qualitative, practice development and action research studies which contribute knowledge and provide insight into contextual factors such as power relations that may be less visible in experimental studies. Such studies are generally context specific and are often associated with specific change interventions led by key champions or committed leaders (Fox 2007; Wilkinson 2009; McCormack et al., 2010a).

The following section provides an overview of the research literature pertaining to the principles of maintaining personhood through life story work and the associated challenges of translating this into practice.

2.7.1 Maintaining personhood

The erosion of personhood through institutional care has been well rehearsed in the literature with many instances of poor social connectedness, lack of meaningful activity and negative caring experiences (Nolan, 1995; Fiveash, 1998; Ice, 2002; Isola, 2008). Paying attention to actively maintaining personhood is seen to be an antidote to this erosion and is a core element of ‘entering into the person’s world’ (Kitwood, 1997; Brooker, 2003). The use of biography and life story work in care planning as a means of improving quality, maintaining personhood and supporting relationships has been growing in recent years (Clark, Hanson and Russ, 2003; McKeown, Clarke and Repper, 2006; McKeown et al., 2010; Thompson, 2012). It has been formally endorsed by the NICE dementia care guidelines (NICE, 2012, p. 42) and is recommended in the HIQA guidelines in terms of people with dementia (HIQA p. 66). Connected to McCormack’s (2004)
idea of being with self and being in a social world, this work is proposed as a means of seeing a person in the context of their past and current lives and by being aware of what their values are. Brooker and Wolley (2007) contend that such an approach can counteract the categorization of individuals within narrow biomedical frames while Nolan et al. (2006) contend that a ‘sense of continuity’ supports the idea of being known for who you are in the context of your whole life.

### 2.7.2 Life story work

Incorporating the personal biographies, known values and past and current preferences of residents into care practice is considered a key mechanism to translate this concept into practice. Studies have shown how care staff through the use of stories have changed their perceptions of residents from objects to be cared for and kept safe to that of real people with abilities, resources and futures (Hanesbo and Kilghren, 2000; Heliker and Scholler-Janquish, 2006; Heliker and Hoang Thanh, 2010). Heliker and Hoang Thanh (2010) suggest that through the respectful listening and bearing witness to others’ stories people enter into mutually positive relationships.

The translating of life story work into practice has been the subject of several exploratory studies (Clarke, Hanson and Russ, 2003; McKeown et al., 2006; Luyendyk 2007; McKeown et al., 2011). Researchers suggest that by seeing the narratives of people’s lives, particularly those most at risk of loss of identity such as those with dementia, staff will have a better understanding of, and pay more attention to, a person’s emotional and social needs helping them to make a link between a resident’s past and present and becoming aware of what matters to them (Hanesbo and Kihlgren, 2000; Bruce and Schweitzer 2008; Buron 2010; Thompson, 2011).

Hanesbo and Kihlgren (2000) compared how staff described the life story and current situation of residents before and after a one-year intervention that involved training in assessment using the InterRai/MDS and two hours of supervision monthly. The study was located in three wards of different
nursing homes in Sweden and involved 30 staff, 7 of whom were nurses and 23 nurses’ aides. The older people whose life stories were the subject of the process were 28% male, 72% female with an average age of 80 and an average length of stay of 1.2 years. The study coincided with a reorganisation of staffing to consistent assignments within small teams and allocating responsibility to each staff member for one or two specific residents within the limits of their qualifications. At baseline each participant was interviewed and asked to give an account of a resident that they were most familiar with describing their life story, and their assessed needs. This was repeated following the year-long intervention. In some cases the resident was not the same one discussed at both time points as some had died or were transferred to another ward. The interview question was ‘please tell me all you know about this person’s life story and current situation’. If certain topics were not raised, the interviewer used additional prompts to guide the process. 100 interviews were conducted and 60 were analysed using qualitative content analysis.

The main findings were that most staff gave a fuller and more detailed picture of the resident after the intervention, particularly where both narratives related to the same resident. Participant’s accounts moved from single facts to a greater emphasis on the person as a unique individual with abilities and resources despite cognitive or physical limitations.

Differences in outcome between the narratives of registered nurses and those of nurse’s aides were also considered. The study found that the registered nurses reported the least amount of change in their narratives between T1 and T2. The researchers point to the low participation of nurses as being problematic but also suggest that nurse has less time to engage in close relationships with residents. The findings of this study concur with other studies which have found that life story work has improved staff’s understanding and awareness of residents as unique individuals with abilities and resources (Clarke, Hanson and Russ, 2003; McKeown et al., 2006). There are, however, a number of methodological concerns.
Firstly, the authors do not provide information on how the staff participants were selected and as such it is not possible to ascertain if personality or intuitive capacity had more influence than the supervisory intervention.

Secondly, they do not adequately explain how they selected the 60 interviews for analysis leaving open the possibility of bias.

Thirdly, this intervention occurred at a time of reorganisation so it is not possible to establish if the improved narratives came about as a result of the assessment process and supervision intervention or from the continuous assignments and new team-based way of working.

Buron (2010) undertook a study of the effectiveness of life story collages on staff. The study involved an intervention and control group and included 5 people with dementia and 30 staff. The author worked with relatives to collate information based on the life history and current likes and dislikes of residents and a large collage representing their life was displayed in the rooms of the residents in the intervention group. A pre-test and post-test questionnaire was administered to both groups measuring their knowledge of the residents’ past history, likes and dislikes. A self-rated measurement of individualised care tool (Chapell, Reid and Gish, 2007) was then administered to staff to assess their perceptions of PCC practice following the intervention based on domains of: a) knowing the resident; b) communication between residents and staff; c) communications between staff. An additional domain looking at resident autonomy was excluded as it focused on organisational issues which the author felt was outside of the scope of the study.

The study concluded that there were many positive benefits to the use of life story collages and staff in the intervention group showed a statistically significant increase in knowledge about the residents’ past history than the control group. However, the control group demonstrated more knowledge of current likes and dislikes than the intervention group and in terms of individualised care no differences in practice were found. The author
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acknowledges that the two residents in the control group had higher MMSE scores that those in the intervention group which may have impacted on their capacity to express their likes and dislikes to staff. He also draws attention to the fact that the measurement instrument had not been previously tested for validity and reliability and that the small sample size may not have been sufficient to detect changes in perceptions of practice following the intervention. The measurement scale used was a subjective scale measuring the perceptions of staff about their knowledge of residents rather than their actual knowledge. A measurement tool which measured actual individualised practice may have yielded different results.

The study reports that life story work was viewed positively by staff and managers and draws attention to the need for further research to understand why staff awareness of a resident’s biography did not translate into more individualised practices. By excluding the domain of autonomy and associated organisational practices it does not explore the wider organisational barriers to translating the theory of life story work into practice.

2.7.3 Maintaining personhood summary

The incorporation of life story work into practice has been seen to be useful in raising awareness about the unique identities of residents and is viewed positively by staff and managers. There are several studies which explore this work, but there are few studies which report the translation of this work into sustained person centred practice. Supervision in life story work and the use of the InterRai/MDS assessment process was seen to have had an impact on the narratives of care staff. The same study identified a difference between the narratives of nurses and care staff in describing residents following the intervention. The sample size, however, was small. More research is required into the translation of this knowledge into more individualised or person centred practices.
2.7.4 Autonomy

A number of studies have been located that provide insight into some of the enablers and barriers to providing and sustaining choice, counteracting powerlessness or helplessness in residents and addressing power issues with staff – all issues that connect to the discourse of autonomy and person centred care.

2.7.5 Residents’ experience of autonomy

Increased choice has been identified as a core element of promoting autonomy in residential care but has been shown to be difficult to sustain in light of competing priorities (Barkay and Tabak, 2002; Tutton, 2005; Crandall et al., 2007; Burack et al., 2012). The issue of sustainability of choice over time was considered in a longitudinal quasi-experimental study (Burack et al., 2012).

The aim of the study was to examine the impact of a Culture Change intervention designed to promote person centred choice over everyday activities in a large unionised, not-for-profit long term care organisation in the United States over five years. Thirteen facilities participated, seven of which were involved in the first phase (the pilot phase) followed by five facilities who adopted the programme after three years (the comparative group). Data were collected at three time points over the five years. One (T1) at baseline, one (T2) after two years and one (T3) after five years. The researchers hypothesized that the pilot group would show a significant increase in choice between T1 and T2 and that this level of increase would be sustained between T2 and T3, and that the second comparative group would experience an increase between T2 and T3.

The Duncan Choice Scale was used to assess resident’s choice over everyday activities. Residents who had lived in the facility for more than three months were invited to participate following a determination by senior staff as to their capacity to consent and participate in a face-to-face interview. A total of 164 residents participated overall. Given that the study
was over five years there was a high attrition rate due to death, decrease in cognitive capacity or transfer, with 8 (5%) residents participating in all three time points. 25 (15%) participating at two time points and 131 (80%) participating at one time point. The study provides a good description of what the intervention was. A community coordinator was put in place in each facility to champion change from a traditional approach to a person centred care approach. This person was tasked with creating a sense of community and facilitating relationship building between residents, staff and family members. Training of staff was carried out including team building, problem solving, shared decision-making and more inclusive care planning. Organisational change included flattening hierarchical structures. All staff became involved in creating meaningful activity and residents had more input into determining their daily routines in relation to when they got up, when and what they would eat, how often they would bathe and arranging their medical appointments.

The researchers found that as expected, residents in the pilot group experienced a significant increase in choice between T1 and T2 and the comparative group experienced a similar increase between T2 and T3. However the expected sustained increase in choice for the pilot group between T2 and T3 was not realised. The most significant change related to ‘what leisure activities you do’. Less significant decreases of choice were found in ‘what you eat’ and ‘when you perform leisure activities’. The study highlights the challenges of undertaking longitudinal studies in this population given the high attrition rate, yet it is the very nature of this study spanning five years that highlights the sustainability challenges of organisational change. The experimental nature of the study, while offering a large sample, provides limited contextual data about the residents, what their values were and if these aligned with the survey instrument used. The lack of sustainability of choice across several sites, despite a programme of staff training and the presence of committed change agents, warrants further research of organisational practices that are trans-local, and which coordinate what people do, regardless of location.
A smaller qualitative study identified some of the contextual issues that impact on the autonomy of older people. McCormack (2001) undertook research in relation to this in a community hospital setting. The study produced 14 case studies on nurse-client’s interactions and involved thematic analysis supported by a group of expert nurses and patients as well as the nurses involved in the study. When interacting with older people around key decisions about their healthcare, he noted that the nurses involved often adopted a position of information-giving that served to reinforce decisions already made by professionals resulting in such information acting as another form of control. Equally, the external context of organisational issues (such as the need to have throughput through acute hospital beds or for institutional rules) impacted on the rights of older people to make decisions about their situations. In this context, the nurse had access to information that the older person did not have, reducing their right to exercise their autonomy. He concluded that facilitating the autonomy of older people in health care settings involved negotiation, being aware of the person’s values and the practitioner being transparent about their own values. He noted that for the older people in this study the important issue did not appear to be that of them being the decision maker but rather that their beliefs and values were incorporated into the decision making process, even if they were not the final arbiter of the decision. The study also found that advanced nurse practitioners were more likely to be mindful of an older person’s autonomy and incorporate their views into decisions than other staff.

Although it involved a small sample, this well-designed research provides a comprehensive overview of the many complex issues that influence the promotion of autonomy in older people. However, it was located in a community hospital where all of the research participants were transient thus providing a different context that a residential care setting. In this way the issues of power and control, while highly relevant to how staff and older people undertake shared decision-making, require further consideration in the context of residential care.
McLean (2001) drawing on an ethnographic study which explored person-centred care in dementia considered the influence of power and control on the lives of residents, relatives and staff. The study was undertaken with the researcher, an anthropologist, adopting a participant observer role. Selection of the residents to be studied followed a month of familiarisation and was undertaken in conjunction with staff in order to identify the most behaviourally-disturbed residents. The residents ranged in age from 66 to 95, with 86.5 being the average age.

Detailed observation of all aspects of daily life in the units was undertaken together with recording the views of staff and family members in relation to: a) The person with dementia and who they were, b) How the organisation was run, and c) What complaints and concerns existed. A detailed log of all observations pertaining to each participating resident was retained together with an additional log of all additional observations. Triangulation occurred through examination of several sources of data, in this case, medical records, interviews and observation of residents and staff behaviours. Data analysis was undertaken concurrently with ongoing cross-confirmation between data sources. Conclusions were confirmed through ongoing questioning of the data and discussions with key informants. In the main study, the researcher highlighted how one of the units took a person-centred approach while the other had a task-orientated way of working.

She concluded that two similarly staffed and physically similar units within the same facility held very different outcomes for residents. Nihilistic assumptions about people with dementia and their behaviours led to poor outcomes in one unit whereas when person-centred beliefs prevailed residents had a better experience.

Using data from the study, she provided an example of an event to illustrate the issues of power that she became aware of. She described the hierarchies within the unit, the levels of authority and noted that the less time certain professionals spent on the unit, the more power they wielded. The Doctors and the Assistant Director of Nursing (ADON) who visited weekly held the
most sway in decision-making. Families could yield power by bypassing the staff on the unit and going directly to the Doctor or ADON. While the Doctor yielded power over medication management, the ADON had the power to decide when and where people were moved to without recourse to relatives, the resident, or staff that worked closest to them. As staff moved up the hierarchy, the less contact they had with residents and the more paperwork they had to do, and in terms of hierarchical power the least powerful was the resident. The study provides a thick description of everyday life in one residential care setting. The prolonged engagement on the unit provides the potential for the study to be credible and believable (Denzin and Lincoln, 2003). The author suggests, however, that while this study contributes knowledge of the capacity of person centred care to improve outcomes for people with severe dementia, a wider social and political analysis is warranted to uncover the contextual issues which impact on its provision.

Bowers et al. (2011), in a study looking at choice and control of people with high support needs in the United Kingdom, found that older people had great difficulty imagining possibilities for improvement in the level of control they could exercise over their lives. The study involved a range of activities including an extensive literature review, field work in four sites which included discussions and interviews with 205 stakeholders, 84 of whom were older people who lived in care homes or housing with care. They also undertook a number of local and national sounding board events. The researchers used a common interview and discussion schedule and used a ‘realistic evaluation’ framework for data analyses. The study found that there was a significant gap in understanding about choice and control at all levels of organisation and by older people themselves, and a major absence of the voice of older people in policy, research and commissioning. A significant absence from the study was care home providers who did not attend any of the fieldwork meetings or local or national events despite invitations from the researchers.
Related to the issue of autonomy is its corollary: lack of autonomy. Thomas (2004) describes the opposite of autonomy as ‘helplessness’, which he contends, alongside loneliness and boredom, is a key scourge of residential care. Shura (2011) undertook a study which focused on addressing the sense of helplessness that older people in residential care experience. The study was part of a wider culture change intervention using the Eden Alternative model. Using a participatory action research methodology, its aims were two-fold. Firstly, it aimed to reduce helplessness, by promoting the competence and expertise of residents and relatives. Secondly, it aimed to contribute to the flattening of hierarchies and transformation of power structures that shape the relationship between care recipients and care providers. The residents were invited to become co-researchers and were asked to identify strengths and problems within the facility and to identify ways of overcoming these problems. The unique individual strengths, skills and knowledge of each participant based on previous vocational or family roles such as managerial, care-giving, parenting and grand-parenting roles were considered assets to be drawn on in the change programme. The intention was to identify issues that were important to residents and to engage them in collective problem-solving and implementation processes. Four units of a continuing care community were identified initially by researchers and administrators. Volunteer participants were recruited through a series of meetings and information leaflets for residents and relatives. Seven research groups of between four and seven members were established comprising of residents, relatives and staff which were supported by facilitators. The groups met weekly for one hour over a period of four months. A total of 49 residents, 37 of whom were from the nursing home (including dementia units) and 12 of whom were from the assisted-living unit, 19 staff and 6 relatives participated.

The study reported improved relationships and several ideas for organisational change that promoted relationship-building and shared decision-making processes which were implemented during the course of the research programme. The researchers contend that this approach was more effective than traditional resident councils in that it used the strengths
of residents as assets and involved them in providing solutions in collaboration with staff, rather than presenting problems for staff to solve. It provides interesting insights into potential strategies for shared decision-making and offers an innovative way to consider the shift in power that researchers say is required if residents are to experience competence and shared decision making. The programme provided innovative ideas as to how to engage residents, relatives and staff collectively. The researchers reported, however, that the participation of staff was low and irregular in contrast to residents. The reasons for this were cited as lack of time and competing needs and the groups were not sustained after the research period. This study’s findings challenges the view that older people are not interested in organisational decision making (Bowers et al., 2011) but also resonates with several other studies which show that sustaining person centred interventions in the light of competing organisational priorities can be difficult (Barkay and Tabak, 2002; Talerico, 2003; Tutton, 2005; Crandall, 2007). The study was participatory action research and did not use formal universal scales or measurements to measure the level of improved relationships or increased participation. Yet, it adequately explained some of the challenges and barriers to person centred care brought about through conflicting values and organisational priorities.

2.7.6 Staff experiences of autonomy

Staff can also experience a lack of autonomy due to organisational structures and processes (McCormack et al., 2004; Nolan et al., 2006; McCormack et al., 2010a; Rockwell, 2012; Brannon et al., 2010). McCormack et al. (2010a) highlight the issue of powerlessness of staff to change organisational structures and practices in a report of a two year practice development programme which aimed to develop and evaluate person-centred practice in residential settings for older people. The programme involved 17 residential care settings across Ireland. Two frameworks were used to guide the project, one the Person Centred Practice Framework (McCormack and McCance, 2010) and an emancipatory practice development framework. The programme adopted a broad range of
activities such as developing vision statements, critically observing work practices, and using creative approaches to foster reflection, wider collaboration and team work. Attention was paid to issues such as language, providing choice and meaningful activities and addressing environmental deficits. Contextual issues such as staff relationships were also addressed. A range of interventions and activities were developed during the programme. These included life story work (LSW) through the creation of memory boxes, and incorporating into care plans PCC texts called *My Day My Way, A Key to Me* and a *Calendar Of Important Events* aimed at collecting information about residents’ values, choices, likes and dislikes. Increased social activities and the development of volunteer services were also put in place as well as improved dining facilities and practices. Team meetings, reflective practice and environmental walkabouts were undertaken to support the development of a person centred culture. Collaborative vision statements were developed as were materials to improve communication such as newsletters and information booklets for residents and families.

Data was collected at three time points over the two years and a range of evaluation processes were used. Resident narratives from sixty individuals and 180 periods of observations of the environment were qualitatively analysed using a creative hermeneutic data analysis process. Four key themes were developed from this element of the programme: choice, connectedness and belonging, hope and hopelessness, and meaningful relationships. The analysis of these narratives was combined with the observations of staff participants. In this way it is not possible to separate out the actual voice of residents from staff in the findings. While there was some reported improvement in well-being between timelines this was not systematically measured and the interpretation of this improvement appears to be largely by staff participants as opposed to by residents or relatives themselves. No details were given of the attrition rate between the time points of the resident’s narratives.

Outcomes from the perspective of staff were measured using the Person Centred Nursing Index (PCNI) and Person Centred Caring Index (PCCI)
tool. These tools are not specific to residential care and have been used in other settings such as acute hospitals, where worker stress, intention to leave, satisfaction and commitment to the organisation are measured (Slater et al., 2009). An additional tool, the Caring Dimensions Index (CDI) evaluated staff’s perceptions of caring over time. The tool measured technical, intimate or relational and supportive aspects of nursing and included items considered supportive, unnecessary or inappropriate aspects of caring (McCance, Slater and McCormack, 2009).

The programme evaluation revealed improvements towards a more person centred environment with some statistically significant changes in nursing and care staff outcomes. Overall, the level of stress reported by staff was low at all time points. Statistically significant changes were found in relation to 12 of the 19 factors on the PCNI and PCCI tools including ‘satisfaction with pay and prospects’, ‘satisfaction with training’ and ‘intention to leave’. In terms of the CDI, a shift away from technical aspects of care towards more supportive and intimate elements was reported between T1 and T3 although there were fluctuations between scores at T2. The authors explain this as not uncommon as values change and new ideas emerges. While heavy workloads were identified as being a source of stress, improving team relationships and decision-making processes were seen to have had a positive impact on nurses’ experience over time. There was an overall decrease in response between T1 and T3 which the authors attribute at least in part to external management and supervisory constraints brought about by a financial crisis. As no information is given in relation to whether the same residents provided narratives over the three time points it is not possible to conclude whether there was a change in their experience.

In relation to the use of the PCNI and PCCI measurement tools the authors argue that these were appropriate, validated, tools that can determine the impact of change on creating a person centred environment. However, in commenting on the reported low levels of stress they also acknowledge that the context of care – i.e. that of residential care – may differ from that of an acute hospital and levels of stress may not be comparable therefore. As such
the use of this outcome measurement tool highlights the challenges that exist in measuring outcomes using tools designed for other contexts.

The evaluation report reveals many contextual factors that act as barriers to the successful implementation of person centred care cultures. The narratives of residents and observations describe a range of challenges including institutional buildings, a lack of meaningful activity to alleviate boredom, disconnection from previous family and social networks, loneliness culminating in feelings of hopelessness and loss, acceptance of circumstances and having no voice.

In relation to staff, resistance to change by both frontline staff and in some cases managers was highlighted, reiterating findings from a previous Irish study on quality of life in residential care settings (Murphy et al., 2006). The study reported that many of the (staff) participants felt powerless and bound by the rules of the organisation. A number of these issues warrant further investigation. While on the one hand there was a statistically significant increase in caring behaviours, there is insufficient data to suggest that residents experienced an improvement in their experience. The study draws attention to external organisational influences and the lack of power to change organisational rules in accordance with person centred principles but did not explore these as part of the programme.

### 2.7.7 Autonomy Summary

The literature on autonomy as it relates to the provision of person centred care reveals a complex mix of issues including asymmetrical power relations and challenges of sustainability. Providing choice over a sustained period in several locations has been seen to be problematic despite the presence of committed change agents and staff training, suggesting that these interventions on their own may be insufficient to bring about sustained change and pointing to possible external coordinating factors. Further research is required to explore other organisational factors which influence the provision of autonomy as an element of person centred care.
2.8 Relationships

A key element of person centred care is the issue of both therapeutic relationships between residents and staff (McCormack and McCance, 2010) and wider relationship triads between residents, family members and staff (Nolan et al., 2006; Buckley and McCarthy, 2009; DeRooij et al., 2012). There is a consistent view in the literature that the formation of relationships between residents, staff and families, built on trust, understanding and a collective sharing of knowledge are a core element of person centred care (Maas et al., 2004; McCormack, 2004; Nolan et al., 2006; Haesler, Bauer and May, 2007; Custers 2010; Helgesen, Larsson and Athlin, 2013).

2.8.1 Relationships and older people

The capacity of older people to continue to establish new relationships into advanced old age has been acknowledged and associated with psychological well-being and sustaining a sense of self identity and self-esteem in old age (Bond et al., 2007; Buckley and McCarthy, 2009; Cooney et al., 2013).

2.8.2 Relationships in residential care

Wilson Brown (2009), in a case study underpinned by a social constructivist approach, examined the nature of relationships in three care homes in the UK. She identified three types of relationships:

*Pragmatic* relationships focused primarily on instrumental aspects of care. Here the practical aspects of care-giving usually dominated conversations between staff and residents or family members, but staff actively sought knowledge of resident’s individual preferences which they tried to reflect in their care-giving. Residents and relatives cooperated with the routines of care and contributed by providing information to inform care plans.

The second type of relationship she described as *personal and responsive* relationships that engaged more fully with the wider needs of individual residents based on staff’s attention to personal biography which supported
them in making judgements about care. Relationships based on *reciprocity* emerged as a third type of relationship where, she argued, negotiation and compromise contributed to a shared understanding of what was happening in the home and where reciprocal activity took into account the needs of everyone leading to a sense of community.

She maintained that residential care facilities which are underpinned by principles of reciprocity and personal relationships can rebalance power relationships and increase well-being through shared decision-making in the daily life of the centre.

She also noted that key enablers to good relationships in residential care were leadership, continuity of staff, the personal philosophy of staff and contribution of residents and families leading to the development of a community of people as opposed to merely a care environment. This was a well-designed case study design which provided a good description of its theoretical basis and a comprehensive overview of the many contextual factors which were clearly outlined.

### 2.8.3 Relationships between relatives and staff

A number of studies focus on relationships between relatives and staff. In general, the literature would suggest that many relatives wish to remain involved with the care of their family members as a means of preserving the residents’ identity (Barkay and Tabak, 2002; Hertzberg, Ekman and Axelsson, 2003; Bauer and Nay, 2003; Robison *et al.*, 2007). According to Robison *et al.* (2007), families had better relationships with staff when they believed them to be caring and providing individualised emotional and cognitive support, and where they shared experiences of caring for the resident. However translating this into practice was seen to be problematic when staff were still focused on routines and everything else had to fit in around this (Bauer and Nay, 2003).
DeRooij et al. (2012) considered the perspectives of family members in relation to the social relationships between staff, residents and family as part of a reorganisation of facilities to smaller scale environments compared to traditional nursing homes. Similar to what Nolan et al. (2006) describe as the triad of care, this study aimed to provide insight into these relationships looking at the similarities and differences between these environments and traditional nursing homes and between The Netherlands and Belgium. The research was part of a larger study investigating the differences between the two models (small-scale and traditional) from the perspectives of residents and staff and family members. The study was quasi-experimental with data collected at baseline and again after twelve months. Because it was part of a wider study the family members of 179 residents were contacted and a final experimental group of 44 whose family member resided in a small-scale living environment participated with a control group of 20 family members in traditional homes. The participants were mostly adult children with an equal mix of male and females.

A questionnaire included questions about family members’ interactions with residents, staff’s interactions with residents, and family members’ interactions with staff. The research found that family members were more satisfied with the contact they had with staff in the small-scale living environments. They also felt that staff in these environments listened to residents more and were more likely to pay attention to the feelings of family members. The study highlights some of the challenges in reviewing research relating to person centred care as it is difficult to establish if the focus of this study is relationships between the various stakeholders or the introduction of smaller scale environments. The move to small scale facilities most likely involved staff training which may have accounted for the better listening skills of staff or it may have been as a result of consistent assignments of staff. The comparatively small control group raises an issue of potential bias.
2.8.4 Relationships between residents and staff

Relationships between residents and staff were the subject of a study by Heliker and Hoang Thang (2010). The study, which involved 84 nurses’ aides and 54 residents, was undertaken in 6 American nursing homes owned by three corporations. The study used a longitudinal mixed methods design and involved an intervention based on shared storytelling as a means of developing empathetic reciprocal relationships. A comparison group from the same corporations received an intervention based on communication skills. The outcomes measured for staff were: a) Mutuality; b) Caring relationships; c) Empathy; d) Self-efficacy of storytelling (for the intervention group only) and e) Job attitude. Participants were asked to complete pre- and post-interventions questionnaires. The outcome measures for residents were perceived caring behaviours and mutuality and residents were asked to complete two instruments measuring these. The study had an attrition rate of 50% due to death or cognitive decline in residents and staff moving jobs, or having personal problems. A mutuality scale measured feelings of connection and understanding and exchanges between individuals based on shared goals. Mutuality was said to be present when conversational language reflected give and take, shared understanding, exchange of ideas, respect for all possibilities, comfort, humour and humanness. The scale had four sub-sections; shared values, affective closeness, shared pleasurable activities and reciprocity. In relation to the nurses’ aides the findings showed no significant differences in mutuality or empathy between the two groups at baseline but a significant difference immediately after the intervention. These scores increased further at three months and six months. There was no significant difference in relation to the efficacy of story-telling in the intervention group and no significant difference relating to job attitude in either group. For residents, in relation to the caring behaviours there was some positive increase in one sub-scale which related to reciprocal caring and being cared for.
No significant difference was found in relation to mutuality. The researchers pointed out that the caring behaviours questionnaire was too long for residents and was eventually abandoned and replaced with interviews.

In relation to the job attitude scale, they noted that several of the questions related to pay and benefits which may have skewed the results and concluded that the research instruments proved to be a limitation in the study.

In the qualitative element of the study, individual interviews with residents and small group interviews with the nurses’ aides were conducted from which a number of themes emerged. The analysis was not undertaken until after the quantitative data was analysed in order to avoid bias. The findings complemented the quantitative findings describing increased feelings of connectedness and mutuality. Residents described identification of favourite nurses’ aides who checked in on them and knew them as persons, while nurses’ aides described visiting residents on their days off or slipping into their rooms on their breaks. Both spoke of reciprocal relationships based on give and take, being cared for and caring about, and feeling valued. In contrast, the nurses’ aides in the communication skills group spoke about behaviours that addressed resident deficits such as hearing loss. The researchers acknowledge the limitations due to the high attrition rate and difficulties with the measurement scale which had not been piloted first. They tried to use the scale as an interview guide but found that residents preferred to tell their own stories in their own way. The methodological design limitations and challenges in this study draw attention to the use of conventional research tools to elicit responses from very frail older people and to the construction of longitudinal studies due to the high attrition rate in this cohort of individuals. Several authors have pointed to the fact that there is a gap in the existing literature in relation to the involvement of residents in research into person centred care (Dow et al., 2006; Edvardsson and Innes, 2010).
A number of authors have highlighted the fact that educational programmes on their own are insufficient to ensure *I-Thou* relationships (Buber, 1937; Kitwood, 1997) between residents and staff (McGilton et al., 2003; Nolan et al., 2008; Viau-Guay et al., 2013; Venturato, 2013).

Nolan et al. (2008), following an extensive literature review, concluded that while education and training was an important element of changing practice other contextual factors such as societal attitudes towards older people and care homes in general needed to be considered.

McGilton et al. (2003) undertook a study of relationships in residential care in a quasi-experimental study with an educational intervention in two Canadian nursing homes. The study involved 35 staff 50 residents and data was collected at baseline and 10 months, which was 3 months after the programme had ended. The authors concluded that while there was a statistically significant improvement in the relational behaviour of staff, this did not result in the development of what they described as ‘close care relationships’, i.e. meaningful relationships between staff and residents. They also concluded that while educational programmes were important of themselves, they were insufficient to change the nature of close care relationships.

### 2.8.5 Relationships summary

Attention to relationships is a key principle in the person centred care literature. Three different types of relationships have been identified: pragmatic, responsive and reciprocal. The literature suggests that many relatives wish to remain involved with the care of their family members as a means of preserving their identity. Translating this into practice, however, was seen to be problematic, due to the nature of organisational structures and processes. Small-scale environments and consistent interactions with a small number of staff were found to improve relatives’ perceptions of relationship in residential care. Improvements in mutuality and reciprocity have been reported following an intervention based on storytelling.
However, the methodological challenges of undertaking longitudinal studies and employing conventional outcome measurement tools with frail older people have been highlighted. A number of studies have shown that education on its own is insufficient to improve person centred care and authors suggest that wider contextual factors need to be addressed.

2.9 Positive Social Environments

The issue of creating positive social environments has been the subject of several studies. One the one hand these relate to a sense of place (McCormack and McCance, 2010) as articulated in studies concerning physical environments and on the other contextual issues such as engaging meaningfully with that environment.

2.9.1 Normalisation

The concept of normalisation has existed within the disability literature for many years (Race, 2003). The idea connects residents to everyday activity through continuing with their previous routines and lifelong habits and has resulted in the development of domestic style environments and strategies to move from ‘care environments’ – where residents are passive recipients of services – to ones which promote the development of ‘home’ and ‘community’, based on mutually supportive relationships and more equitable decision making processes (Norton and Shields, 2006; Brown Wilson, 2009; Maloney et al., 2011; Edvardsson, Featherstonhaugh and Nay, 2012; Edvardsson et al., 2013).

2.9.2 Normalisation and the physical environment

There is a growing body of evidence supporting the development of domestic environments as a means of counteracting the dominance of biomedicine in residential care and as a means of improving social engagement (Kane et al., 2007; Van Beek et al., 2009; Te Boekhorst, 2009; Maloney et al., 2011; Morgan Brown, 2013). However, it has been acknowledged that environmental change on its own is insufficient to change decision-making systems and routines that prioritise organisational
goals of efficiency and clinical governance (Norton and Shields, 2006; Fox, 2007; Rosemond et al., 2012).

In a recent Irish study, Morgan Brown, Newton & Ormerod (2013) compared the social engagement and interactive occupation of residents with dementia in two Irish nursing homes before and after an intervention to create a household (domestic style) model of care. The intervention involved staff development, leadership support and the creation of a ‘homemaker role’ whereby one staff member incorporated cleaning and care duties in the communal area, which now had an open plan kitchen, encouraging residents to become involved in domestic roles and activities. Data was collected at two points: at baseline, before the intervention, and immediately after the intervention. The study reported that residents were more socially engaged to a statistically significant level following the intervention.

2.9.3 The Eden Alternative

The Eden Alternative is a model of residential care that combines changes in infrastructure, flattening organisational hierarchies, creating consistent and mutually supportive relationships and opportunities for meaningful engagement underpinned by values of growth development and intergenerational solidarity. The model has been the subject of several studies (Hill et al., 2011; Brownie and Nancarrow, 2012) and positive outcomes in relation to improved autonomy, reduced levels of helplessness and boredom and increased autonomy of nurses’ aides have been reported (Bergman-Evans, 2004; Kane et al., 2007; Yeatts and Cready, 2007; Bowers et al., 2011). Although this and other similar models have been enthusiastically adopted by committed leaders, widespread change has been slow, driven by concerns about time, economic viability associated with investment in restructuring buildings, clinical governance and regulatory compliance (Hoeffer et al., 2004; Grant, 2008; Chenoweth et al., 2009; Greene Burger et al., 2009).
2.9.4 Constraints to creating positive social environments

The issue of not enough time as being a barrier to implementing person centred care and its associated positive social environments has been identified by a number of authors (Hoeffer et al., 2006; Dow et al., 2006; Crandall, 2007; Argyle, 2012). This was a finding in a study by Hoeffer et al. (2006) which sought to investigate the efficacy of person centred showering and the use of towel bath techniques in residents with dementia in 15 nursing homes in the United States. The study involved 69 residents and 37 care assistants with an intervention and control group measuring levels of agitation using the Cohen Mansfield Agitation Inventory (CMAI). Purposefully selected care assistants were trained to focus less on the task in hand and more on the person who was being showered or receiving the towel bath. The care staff in the intervention group were taught to individualise and make more comfortable the experience by asking relatives which bathing products the person with dementia preferred, using warmth and comfort, distracting, and in some cases offering food. The researchers concluded that both person centred showering and towel baths were effective in reducing agitation and aggression and discomfort in residents by 53% and 60% respectively, when compared to the control group where there was no significant change. However, the person centred showering took an average of 3.3 minutes longer to achieve than the control method and the towel bath method 2.7 minutes longer. This increased amount of time required to employ a person centred approach concurs with other studies which have shown lack of time to be a perceived barrier to person centred approaches (Dow et al., 2006).

However, the study did not measure the increased amount of time and associated costs that are required to deal with the behavioural disturbances or agitation. One RCT examined costs of reduced agitation (Chenoweth et al., 2009). The study was located in Australia where fifteen sites were identified from a potential pool of thirty on the basis that their care practice was task-focused and not based on person centred care systems. A total of 240 residents were selected by senior managers in these sites as having
persistent needs-driven behaviour that made it difficult to provide care. The purpose of this study was to compare person centred care, dementia care-mapping and usual care and involved a wider range of outcome measures including agitation, neuropathology, quality of care, quality of interactions between residents and staff and costs. The economic evaluation connected improvements points on the agitation scale to an estimated cost per behaviour averted. The study found that there was a statistically significant reduction in agitation in both the person centred care and dementia care-mapping sites compared to the usual care sites and a modest reduction in costs. Other outcomes were less clear. No statistically significant findings were made in terms of neuropathology or psychiatric symptoms and no improvement in quality of life was reported. The researchers suggest that this may be because demonstration of more subtle elements of quality of life such as enjoyment of eating, touching and interacting may be more difficult to observe in a large scale study. This highlights one of the difficulties with randomised control trials in identifying and measuring outcomes of importance in PCC. The researchers suggested that the findings in relation to costs were tentative and as such recommended further study. Other studies that have addressed the issues of cost have connected person centred care practices to reduced turnover and absenteeism, both of which have associated economic implications (Castle, 2013).

### 2.9.5 Positive social environments summary

There are many interrelated factors associated with the creation of positive social environments including the creation of domestic style environments and improving the autonomy of staff. The idea of ‘normalisation’ and the creation of communities of people rather that care environments has been promoted. While large-scale culture change programmes have developed, the widespread adoption of these ideas is constrained by concerns about costs, clinical governance and regulation. There is some evidence of decreased costs due to the avoidance of adverse behavioural incidents and reduced turnover and absenteeism, but more research is required.
2.9.6 Section summary

The above section discussed the research literature as it relates to the person centred principles of maintaining personhood, autonomy, relationships and positive social environments and the organisational issues that impact on its implementation. Findings in studies in relation to life story work have pointed to its adoption as a mechanism to promote and maintain personhood. Translating this into more individualised care, however, has proven problematic. The autonomy of older people in residential care is considered an important element of person centred care. However, the competing needs of organisations have been seen to undermine this autonomy resulting in task-orientated practices and unequal power relations. Interventions to promote choice and prevent helplessness have shown difficulties with sustainability and the involvement of older people in their environments remains problematic.

The person centred care literature promotes the concept of mutually supportive and reciprocal relationships however studies have shown that this can be difficult to achieve. Studies which involve staff education have shown some improvements in the relational behaviour of staff but other contextual and organisational factors impact on the promotion of such relationships. There is a growing body of literature relating to positive social environments particularly in respect of creating new domestic style facilities and associated organisational changes such as flattened hierarchies and continuous assignments; however concerns regarding time, costs and clinical and regulatory governance remain.

Having thus far provided an overview of research in relation to person centred care and the contextual factors which influence its implementation, the following section will identify the contribution that this study can add to the literature.
2.10 Identified deficits in the literature

PCC as a theory of practice has been spreading rapidly but due to the multi-dimensional nature of the concept and the diversity of definitions, research goals and measurement tools, there is ambiguity about outcomes. Problems with sustainability have also been reported (Robinson and Rosher, 2006; Rockwell, 2012; Siegal et al., 2012). The body of research literature has increased in recent years and several large-scale RCT’s and quasi-experimental studies have been added to what was heretofore mainly smaller qualitative studies (McCormack, 2004; Dow et al., 2006; McKeown et al., 2006; Hoeffer et al., 2006; Edvardsson, 2008; Chenoweth, 2009; Edvardsson and Innes, 2010; Hill 2011; Brownie and Nancarrow, 2012).

The multiplicity of definitions, interpretations, measurement outcomes and tools has made it difficult to elicit conclusive findings about its translation into practice, yet overall it is considered a positive development (Edvardsson, 2010; Dewing, 2011; Hill 2011; Sjorgen, 2012).

2.10.1 An alternative view of the literature

Another way of looking at this body of literature is to notice how it privileges the voice of high status professionals and experts and is underpinned by assumptions of rationality, objectivity and universality (McNeil, 2005; Lirette, 2012).

According to Smith (2005), while this scientific knowledge may be valid, it is incomplete, as such research endeavours can silence embodied experiences through processes of objectification and categorisation through, for example, the use of universal rating scales to replace the everyday language and personal accounts of people.

Some authors point to the challenges of providing absolute proof of such a multi-dimensional concept that is person centred care and suggest that the burden of proof should shift in the other direction – i.e. why care shouldn’t be person centred (Edvardsson, 2008; Love and Pinkowitz, 2013).
alternative way of looking is raised by Peter Reed, CEO of the Pioneer Movement in the United States:

*I know this is a bit heretical coming from someone with a research background, but an over-reliance on research data and its categorized strength as meaningful evidence further medicalizes what is essentially a discussion about the way people live their life. If someone is agitated and expressing their agitation through behavior, it is not always a medical need. A music lover may be upset at being deprived of the music they love; a food lover may be upset at being unable to enjoy the foods that they love; a person may simply be thirsty. You could medicalize these and develop clinical interventions to address these needs, but I personally do not need to rely on the evidence developed in an ‘RCT’ to inform me that people find music soothing, food enjoyable, and water refreshing.*

Peter Reed, PhD, CEO/Pioneer Network

2.10.2 Including the voice of residents

Despite the conceptual underpinnings in person centred care of acknowledging individuals as experts in their own lives (Rogers, 1951; Brooker, 2003), including the voice of residents in research can be challenging due to physical and cognitive frailty and ageist assumptions (Bowers et al., 2011; Katz, 2011). Following an extensive literature review of person centred care, Dow et al. (2006) concluded that the absence of the voice of users was a major gap in the research literature. Edvardsson and Innes (2010), in a review of person centred measurement tools, noted that few adopted the perspective of the resident. Dementia Care Mapping (DCM) was the closest, as it adopted a subjective perspective of residents (Ballard, 2009; Ervin Kaye et al., 2012). However, the categorisation remains in the hands of the assessor.

There is a growing interest in gaining the perspective of residents of their lived experience particularly in relation to dementia (Aveyard and Davis, 2006; Shura et al., 2011, Brown Wilson and Clissett, 2011). The increasing recognition of residents as active participations in their social world points to a need for more research about how they live their everyday lives in residential care settings. However, given the reported experiences of loss of
autonomy and passivity it is necessary to extend beyond what older people say to better understand the social relations that govern their lives making what is often unseen and unknown visible. No study located has explored how the experience of residents is shaped, organised and linked to the professional discourse of person centred care and the actions of people both inside and outside residential care settings.

Using the methodology of Institutional ethnography and adopting the standpoint of those whose voice is not strong in the professional discourse the intention is to provide further insight into the organisational influences to person centred care. Given the acknowledged challenges of including frail older people in research and everyday decision making, attention is required to how older people tell their stories and express their views.

2.11 Chapter summary

This chapter provided an overview of the conceptual and empirical literature relating to person centred care. The philosophical, historical and gerontological underpinnings were described. Definitional problems were discussed and the key principles as defined by the various authors were synthesised. An overview of the research literature was presented drawing attention to the multi-dimensional nature of the research work, highlighted the research challenges relating to study designs, and lack of consensus about measurement tools. The challenges of translating the concept into everyday practice were discussed drawing attention to the need to explore organisational issues more fully. The absence of the voice of residents from both research and practice was highlighted, despite the promotion of collaboration in the conceptual literature.

The chapter concluded by providing a rationale for adopting the methodology of Institutional ethnography as an alternative way of looking, in order to gain further insight into the organisational barriers to person centred care that were identified in this review.
The following chapter provides an overview of research methodologies in general and Institutional ethnography specifically. Because Institutional ethnography is considered both an alternative sociology and a methodology, an overview of its ontological and conceptual development will be provided.
Chapter 3: Methodology

3.1 Introduction

This chapter describes the process of choosing the research strategy for this study. It explores briefly the various research paradigms that constitute sociological research discourse, outlining the philosophical assumptions or belief systems which underpin these approaches and the various methodologies that are available to the researcher (Guba and Lincoln, 1985; Crotty, 2003; Cresswell, 2003). As this study adopts a qualitative perspective, the various associated methodologies will be discussed briefly. Following this, the rationale for selecting Institutional ethnography will be presented. Because Institutional ethnography is considered both a sociology and methodology, its ontological and conceptual underpinnings are then described before outlining its methodological process of identifying the problematic, adopting a standpoint, data collection, data analysis and mapping.

3.2 Research Paradigms – Ontology and Epistemology

The term Ontology can be defined as ‘what we know’ or the ‘science of being’ (Crotty, 2003). Ontology is concerned with the nature of existence or knowledge and the assumptions that we make about the nature of reality. Thus ontological claims are about ‘what exists’ and address questions about ‘What is existence?’, ‘What is real?’, and ‘What is truth?’ Epistemology, which comes from the Greek word ‘episteme’ (knowledge), is the study by which we know what constitutes scientific knowledge. It refers to the assumptions regarding knowledge, how it can be obtained and how to assess whether knowledge is true or false (Cresswell, 2003). The epistemological stance that the researcher takes, i.e. whether the knowledge is something that can be discovered (positivism) or experienced (interpretivism), influences their theoretical perspective.
Chapter 3: Methodology

The underlying epistemological assumptions represent different worldviews of how social research can best be undertaken. Cresswell (2003) proposes four epistemological positions or knowledge claims in order to guide the researcher towards selecting the appropriate methodology to match the research question.

The four positions proposed are; post-positivism, constructivism, advocacy/participatory and pragmatism. Denzin and Lincoln (2003) point to similar paradigms – positivism, post-positivism, critical theory, constructivism and participatory. Each paradigm has its own ontology, epistemology and research design, articulating the belief system that the researcher is working within.

3.2.1 Positivism/Post-positivism

The positivist stance rejects metaphysics and contends that the goal of knowledge is simply to describe the phenomena we experience. Therefore the goal of any scientific enquiry is to consider only what can be observed and measured, and subjects such as emotions or thoughts (which cannot be measured), cannot be considered legitimate areas for enquiry. This view of the world is considered deterministic, i.e. that the world is governed by rules and theories and the role of research is to add to the understanding of the world by looking at cause and effect in order to predict and control it.

Post-positivism relates to the period of philosophical thinking that followed the positivist era and describes the period from the mid-twentieth century onwards whereby the central tenets of positivism, i.e. that there is a reality out there that can be studied, captured and understood, is rejected in favour of the idea that reality can never be fully understood, only approximated (Denzin and Lincoln, 2003). Post-positivism challenges the notion of absolute truth of knowledge acknowledging that we cannot be assured of absolute truth when studying humans and their behaviour. However, positivistic methods such as scientific methods, empirical observation and measurement, and theory verification are retained (Cresswell, 2003).
Quantitative research methodologies which measure cause and effect through the use of experiments can lie within the paradigm of post-positivism. This methodology is considered reductionist in format in that it aims to reduce the factors for enquiry to a small discreet set in order to test them. A theory or hypotheses is proposed and knowledge is acquired through numerical measurement of the objective reality. The theory or hypotheses is either verified or refuted and subsequently revised before further tests are carried out. Post-positivism relies on multiple methods to capture as much reality as possible including qualitative measures (for example, the use of participant observation in quasi-experiments). Emphasis is on discovery and verification of theories. Internal and external validity is emphasised in order to allow for generalisation of findings. (Denzin and Lincoln, 2003)

3.2.2 Constructivism

Within this paradigm, individuals seek understanding of the world in which they live and work (Cresswell, 2003; Crotty, 2003). The goal is understanding the complex world of lived experience from the point of view of those who live it. Constructivism examines wider society with its institutions and wider belief systems and how they contribute to the construction of self. Social constructivism is not a uniform school of thought but rather a broad movement which seeks to explore and question a whole range of taken for granted realities (Hacking, 1999; Gubrium and Holstien, 2002; Denzien and Lincoln, 2003). While positivists contend that the world stands independently of our representations, constructivists argue that objectivity is impossible and reality is both subjective and relative, based on temporal and historical influences, and by people’s situated shared views and meanings. This stance also implies that not only are social phenomena produced through social interaction but that they are in a constant state of revision.

Within research, the focus of constructivism is to view heretofore apparently self-evident and stable events or processes as being shaped by social,
historical and cultural forces in order to better understand social issues such as oppression of particular social groups by hierarchical institutional realities. Constructivism tends towards refusing to adopt any permanent or unvarying standard by which the truth can be known (Crotty, 2003). Denzin and Lincoln (2003) contend that truth arises from the relationship between the members of that social group, although this may be negotiated as to what will be accepted as truth or via a communal test of validity, i.e. what the group accepts as a valid construction. To this end, constructivists consider that the concept of validity is never fixed as it is subject to the temporal and historical conditions of that community. Guba and Lincoln (1985) describe the constructivist paradigm as having relativist ontology where truth, rather than being absolute, consists of multiple realities constructed by individuals in a specific time and place and a subjectivist epistemology in that the interaction between the researcher and participants shapes what emerges from the investigation. Knowledge is then created jointly through this interaction.

Within this paradigm, the researcher makes explicit their own background in order to acknowledge how their interpretation of data is influenced by their own personal, cultural and historical experiences, i.e. acknowledging that the researchers own interpretation of the social world is also a construction. Credibility, transferability, dependability and confirmability are deemed to be more important than the positivist criteria of internal and external validity, reliability and objectivity (Denzin and Lincoln, 2003).

3.2.3 Critical theory/ advocacy/participatory knowledge claims

The critical theory perspective assumes a material-realist ontology – that is, the real world makes material differences in terms of race, gender, class or age. Historically, this paradigm draws on the work or Marx, Habermas, Adorno and Freire (Cresswell, 2003). Subjectivist epistemologies and naturalistic methodologies are generally employed (Denzin and Lincoln, 2003). Empirical data and theoretical arguments are evaluated in terms of
their emancipatory implications. The purpose of critical theory is twofold: a) social critique linked to b) the possibility of social change.

In a research context, critical theory does not determine how the world is viewed but rather helps find questions and strategies for exploring it (Denzin and Lincoln, 2003). This advocacy/participatory paradigm is underpinned by the belief that the inquiry needs to be intertwined with politics and the political agenda. Building on critical theory, the research should contain an action agenda for reform that may change the lives of participants. Within this knowledge claim, specific issues are addressed such as empowerment, inequality and oppression and the advocacy researcher often begins with one of these issues as a focal point of the research (Cresswell, 2003). The researcher proceeds collaboratively and the voices of the participants become united. The aim of the research process is to empower the participants to transcend the constraints or structured dependency placed on them through language, relationships of power and the media and to help them help themselves. The focus is on specific issues or problems and the research questions are set by the participants rather than the researcher based on those issues or problems (Hart, 1998).

3.2.4 Pragmatic knowledge claims

Within this paradigm, knowledge claims arise out of actions, situations and consequences rather than antecedent conditions (Cresswell, 2003).

There is a concern with application and solutions, i.e. what actually works. Instead of methods being important, the problem is important and researchers use all approaches to understand the problem. Pragmatism is not committed to one system of philosophy and reality. Enquirers draw on both quantitative and qualitative methods and individual researchers have the freedom of choice. They are free to choose the methods that they feel best meet their needs. Therefore, pragmatists do not see the world as an absolute unity, but rather look to many approaches to collecting and analysing data (Cresswell, 2003). While pragmatist researchers look to the ‘what and how’
of research based on its intended consequences, they need to establish a purpose for mixing methods if that is what they do.

3.3 Approaches to research

In general, the main approaches to research in the social science arena fall into the categories of quantitative, qualitative and mixed methods design (Denzin and Lincoln, 2003; Cresswell, 2003). Quantitative strategies as associated with positivist and post-positivist thinking include experiments, quasi-experiments and surveys, structured observation and content analysis. Randomised control trials, often considered the ‘gold standard’ in terms of rigour come within this framework (Silverman, 2006). However, this type of methodology has been criticised in terms of ‘context stripping’ (Guba and Lincoln, 1985) – referring to the fact that by adopting a reductionist approach and removing variables through randomisation and controls, the research process, while ensuring theoretical rigour, reduces the applicability and generalizability of the results by reducing its relevance beyond similarly controlled environments.

Another perceived disadvantage of a quantitative approach is that it fails to provide meaning and purpose to the experience of participants. This acknowledges that humans cannot be understood without reference to the meaning and purpose that they afford to their activities and that reductionist and objectivistic approaches on their own do not provide a comprehensive picture (Guba and Lincoln, 1985).

Qualitative research has developed from the fields of anthropology and sociology (Holliday, 2002) and seeks to understand the complexity of human activity in a way that quantitative inquiry and statistics cannot. Equally, the concept of complete objectivity by the researcher has been challenged (Guba and Lincoln, 1985; Holliday, 2002). Within the qualitative field the values of the researcher are not only acknowledged but explicitly located within the process, reflecting the view that all research is value-laden. Therefore, the focus of validity moves from reliability as is the
case in quantitative research to trustworthiness, authenticity and credibility in the qualitative process (Guba and Lincoln, 1985). A qualitative approach seeks to observe actors in their own naturalistic setting and is concerned with understanding about the lived experience of the actors. Therefore, the focus is on interacting with the participants and giving them a voice while seeking to disrupt the study site as little as possible (Cresswell, 2003; Hammersley and Atkinson, 2007). The use of multiple methods of data collection such as open-ended observations, interviews and review of documents underpin this approach and support the use of emergent design – i.e. the questions or focus may change as issues emerge during the inquiry. According to Cresswell (2003) qualitative research is fundamentally interpretative, that is, the researcher interprets the data analysing it for themes or categories and ultimately drawing conclusions about its meaning.

The following section outlines the rationale for selecting a qualitative stance and the methodology of Institutional ethnography, outlining its paradigmatic positioning and describing how it draws on, but differs from, other qualitative methodologies.

### 3.3.1 Rationale for qualitative stance

Early on, I rejected a positivist stance in that this position adopts a view that the world is governed by rules and theories where the role of research is to add to the understanding of the world by looking at cause and effect (Cresswell, 2003). This approach seemed unaligned with a search for discovery relating to honouring the unique personhood of individual residents and the complex interplay of lived experience of residents within the hybrid model of healthcare and home that represents residential care settings. In this context, the need for standardisation and categorisation as would be required within a positivist construct seemed at odds with the complexity of the inquiry. Therefore, I looked to qualitative paradigms to shape the research process.
3.3.2 Research methodologies

Following on from research paradigms, and approaches to research, actual methodologies which follow these belief systems are employed. The most common methodologies used in qualitative research include phenomenological studies, ethnography, emancipatory action research, case studies and grounded theory although the field has expanded to include narrative studies, auto ethnography, institutional ethnography and other creative methodologies. (Gubrium and Holstien, 2002; Denzien and Lincoln, 2003). The following section summarizes these methodologies.

3.3.3 Phenomenological research

Phenomenology focuses on the subjectivity and relativity of reality seeking to understand how individuals view themselves and the world around them (Willis, 2007). It attempts to distinguish human perceptions of things from how things really are. While there are varying schools of thought, in general its focus is on understanding from the perspective of the person being studied. Its emphasis is on perceptions, consciousness, and subjective understanding (Willis, 2007).

3.3.4 Ethnography

Ethnography is a form of research in which the researcher is immersed in a social setting for an extended period of time, makes regular observations of the behaviours of the members and listens and engages in conversation with them. The Ethnographer develops an understanding of the group through this observation and listening and through interviewing and reviewing data in order to verify such understanding (Hammersley and Atkinson, 2007). An issue which is pertinent to this type of methodology is the cyclical nature of data collection and analysis. As one type of data provides new information, this may prompt the researcher to look at other types of data or to confirm this new data with someone such as a key informant who is part of that culture.
McLean (2007) notes that, despite using the same tools, no two ethnographic studies will ever be the same as each researcher brings to the study their own set of skills, beliefs, and values which will attune them towards some phenomena and away from others. Therefore, the study does not set out to create research which can be replicated but rather to give a greater understanding of the lived experience of those in the study site. Access to a social setting within which the researcher can immerse herself is critical to undertaking an ethnographic study as well as having the capacity to conduct the research over a sustained period of months or, in some cases, years (Gubrium, 1997; Kayser Jones, 1990; Schleper Hughes, 2001; McLean, 2007).

3.3.5 Case study

Case study is a generic term for the investigation of an individual, group or phenomenon, and is characterised by the use of multiple methods for data collection (Stake, 1995). As a research method, a case study can be used to contribute to knowledge about many situations including group or organisational behaviour, or social or political situations. As a methodology it seeks to understand a contemporary phenomenon and its context where the boundaries between both are not distinct (Yin, 2009). According to Creswell (2003), the researcher explores a single entity or phenomenon (‘the case’) bounded by time and activity and uses a number of data collection process over a period of time. A case study operates within a social, cultural, political and historical context (Stake, 1995) and the methodology can be used to study real life events within a contemporary context but where behaviour can’t be controlled, as for example, in an experiment (Yin, 2009).

3.3.6 Grounded theory

This approach to research seeks to describe and understand key social psychological and structural process in social settings (Polit and Beck, 2004). The focus of most grounded theory studies is the development and evolution of a social experience, i.e. the social and psychological stages and
phases that characterise a particular event or episode. The primary purpose of the grounded theory approach is to generate comprehensive explanations of phenomena that are grounded in reality. The approach usually involves in-depth interviews and observations as primary data sources. Other features of grounded theory are that it doesn’t start with a highly focused research problem and inquiry becomes increasingly focused as the research progresses. Data collection, analysis and sampling of participants are simultaneous and constant comparison techniques are used whereby categories are extracted from the data and constantly compared with earlier data so that commonalities and variables can be determined. (Charmez, 2006; Bryant and Charmez, 2007)

3.3.7 Emancipatory action research

The field of emancipatory research enquiry attempts to address the complexity of human behaviour within multidimensional contexts. The purpose of this type of enquiry is described as

helping a group help themselves through empowering the participants to research themselves and their situation. (Hart 1998, p. 46)

The focus is on specific issues or problems and the research questions are set by the participants rather than the researcher based on those issues or problems. This type of research attempts to address the issue of operationalizing good practice by helping practitioners take ownership of the process through becoming aware of what they do, why they do it, what context they work in, along with being able to act on that new understanding (Cresswell, 2003). As a methodology, the researcher engages with the participants and adopts a role of researcher and facilitator while continually reviewing the data and perhaps changing the ground rules as issues emerge (Binnie and Titchen, 1999). This type of research is often opportunistic and relies on a number of factors coming together in a timely fashion, i.e. an openness of change within a facility, and the presence of a supportive management structure. An advantage of this methodology is that it often provides practical accounts of how knowledge is translated into real settings (Froggatt et al., 2009).
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Emancipatory Action Research offers a form of research where empowerment of marginalised people is a goal. The idea of a collaborative research endeavour between residents, relatives, staff and researchers is attractive and aligned to concepts within the person centred discourse of creating community (Aveyard and Davis, 2006; Brown Wilson, 2009). However, it assumes an equality of power or at least a commitment to equality between the various groups that is unlikely to exist due to unequal access to knowledge and external organisational forces (McCormack, 2001; Shura et al., 2011). Democratising the relationship between researchers and participants and the development of interpersonal relationships between them may not make visible the conceptualisations of the power relations that create these asymmetrical power relations in the first place (Campbell and Gregor, 2004, p. 68).

3.3.8 Institutional ethnography

Institutional ethnography (IE) is a methodology, developed by a Canadian sociologist Dorothy Smith that allows a researcher to uncover how things work or how things happen (Benjamin, 2011).

The basic assumption is that people’s everyday experiences in local settings are organised, often unknowingly, by the actions of others located outside of that setting. Institutional ethnography is generally categorised within the qualitative framework as it looks to move away from the objectification of research participants while seeking to explore their everyday lives. It aims to create an entry point into discovery of the social setting without subordinating the participant and their embodied knowing about their everyday lives to the objectified forms of knowledge that come from professional discourse and the taken for granted views of particular social groups (Bell, 2008). Institutional ethnography examines how routine features of social life are established and maintained – based on people’s own knowledge and experience – and then moves outside of that ‘knowing’ to uncover the organisation structures and activities that shape that experience (Campbell and Gregor, 2004).
The above section outlines the research paradigms and methodologies that are commonly used in the advancement of social research. In selecting a methodology, I considered my research aims of interrogating the disjuncture between what is espoused about person centred care and what happens in reality. The voice of residents as articulated in the Quality of Life in Residential Care Settings in Ireland Study (Murphy et al., 2006), the narratives of older people in the McCormack et al. (2010a) study and from my own many conversations with residents who live alongside my mother, prompted me to consider the concept of person centred care from this perspective and how what actually happens in their daily lives connects to the wider discourse and external organisation that surround it. Therefore, I sought a methodology that would ground the inquiry in the actuality of their daily lives but also look beyond this. This led me to select the methodology of Institutional ethnography. The following section discusses further the process of selection through the consideration and rejection of other qualitative approaches namely phenomenology, ethnography, case study, grounded theory and emancipatory action research.

3.4. Selecting Institutional ethnography

Phenomenological research is based on the description of the lived experience of everyday life by individuals and as such provides a useful lens through which the lived experience of older people within residential care settings can be explored. As a methodology it acknowledges the unique personhood of individuals (a core attribute of person centred care) and their experiences which can provide insight into the actualities of their lives. However, as a research methodology it does not go beyond these experiences to address how they are socially organised externally to the immediate setting. In other words, while this approach will produce evidence of the lived experience of the resident it does not fully explicate the conditions that produce that experience. By focusing on how knowledge is socially organised, usually through texts, Institutional ethnography shows how this lived experience is replaced by textual representations which form
the basis of institutional action, transferring knowledge from people to organisations (Murray, 2011).

Ethnography provides an opportunity for an in-depth picture of residential care within its historical and cultural context. But, as its main methodological goal is to provide an account from within or from the perspective of insiders, an ethnography of residential care alone would not make visible the way in which residents’ lives are coordinated beyond this one particular setting into the world of governance and regulation that coordinates lives across many settings. Traditional ethnography attempts through the triangulation of data to provide an accurate account of a studied situation. In Institutional ethnography triangulation is not used. Rather, it relies on discovery and demonstration of how ruling relations coordinate people’s actions across many local settings (Bell, 2008).

Case study offers the opportunity to move from a micro experience of particular individuals to the wider macro arena of policy and social organisation and to make connections between them (Stake, 1995). In extending its reach beyond particular local settings into wider political and social environments it is framed by theory, building and adding to this theory. According to Smith (2005), however, this approach involves moving from actual embodied experiences to theorised forms of knowing without explicating how that form of knowing came into being. This is a key issue in Institutional ethnography where the dominance of theory is rejected as it is argued that the theory makers such as academics and professionals create objectified ways of knowing, to create new knowledge, in a way that may disconnect the actuality of people’s lives from the discourse that is built up around them. An example of this would be the use of secondary data sources such as minimum data sets in research studies. By adopting this approach, the researcher is acknowledging the privileged position of the knowledge which Smith argues is external to the individual, thus objectivising their internalised way of knowing.
In contrast, Institutional ethnography adopts a materialist stance of locating and returning to the embodied experience of the research participants. Smith is not dismissing this form of sociological knowing but argues that it is incomplete, the absent voice being that of the person whose embodied experience is not part of the professional discourse.

Grounded theorists strive to explore and explain the perspectives of individuals studied focusing upon explaining how the people studied live their everyday lives, at times identifying external causes and effects affecting those lives. It has a different methodological goal than Institutional ethnography, which emphasises discovery as opposed to the creation of theory. In contrast to the interpretivist stance of ground theory, Institutional ethnographers do not develop theory, develop concepts or create generalisable patterns. Rather they make empirical links between everyday life and specific social organisation creating a concrete link between the material circumstances of people living and the wider external influences of particular groups in society.

The following section provides an in-depth discussion of Institutional ethnography. It describes its background and ontological underpinnings including its core principle; the social organisation of knowledge. Because it is considered both a sociology and methodology, key concepts such as social relations, ruling relations, and how ideology is created are explored. Issues such as knowledge, objectification, the development of professional consciousness and the intersection of power and knowledge are discussed. Finally the use of texts in Institutional Ethnography is outlined.

3.4.1 Introduction to Institutional ethnography

Institutional ethnography, as a method of inquiry, interrogates the social organisation of everyday experience and provides a way of seeing from where people actually are, into the powers, processes and relations that organise and determine the everyday context of what we are seeing (Smith,
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1987). At its core is the belief that institutions organise and regulate society and people’s experiences, beliefs, values and ideas (Lirette, 2012).

The word Institutional (as used in institutional ethnography) directs the researcher’s attention towards the way people such as those who live in residential care are situated within ‘the system’. Unlike the concept of bureaucracy which is a strictly defined form of social organisation, institutional refers to the way different work processes and conceptual orders combine and intersect (Bell, 2008) such as the combination of academia with state governance regimes, actual locations of services such as residential care facilities and even the media.

The term ethnography in this context introduces a commitment to an exploration, description and analysis of social relations of a situation in a way that is different from conventional ethnography. Its purpose is to explore concretely the experience of people and uses this as an entry point into social organization which shape local settings but originate outside of them. The understanding of the local setting is not the methodological goal, rather it is actual practice – how things actually work – that is the focus of investigation. (Grahame, 1998)

3.4.2 Ontological underpinnings

Articulating the philosophical stance of Institutional ethnography can be challenging as Smith (1987), its primary theorist, does not locate her method of inquiry specifically within one established paradigm. Rather she draws on the various sociological schools of thought, including Feminism, Marxism, Constructivism and ethnomethodology (McCoy, 2008; Benjamin, 2011). Smith’s feminist consciousness began with her own experiences which brought her into the women’s movement of the 1970s. She describes how, influenced by her own experience of working as a sociologist within a university, she was puzzled by the distance there was between the forms of knowledge that she read, taught and wrote about in her professional life and her embodied experience of being a single mother trying to navigate the
social relations that organised her daily life. She describes this as a ‘bifurcated consciousness’ (Smith 1987, p. 6) that set up two modes of knowledge, experience and action, one which saw her negotiate the everyday world of being a mother to two small boys and one where she entered into a world of texts that created a world of administration, government and subject matter of sociological enterprise that was separate from the local and particular.

She describes how elements of Marxism influenced her thinking in relation to ideology, contending that people’s ideas arise from material activity and their beliefs and values are influenced by their material circumstances. Marx argued that as modes of production changed so too did peoples beliefs and values. By controlling the means of production, he contended, the ruling classes also controlled mental production. Therefore, the ideas of those who lack the means of material production, i.e. the working classes, were subject to the mental production of this ruling class. Using the term ‘ruling relation’, Smith (1987; 2001) draws on Marx and Engels’ work to evoke an image of a ruling class that is able to organise and control society because it is able to access the means of production at any time. In a contemporary context where social class may be less dominant as an issue, the emergence of ruling classes is more aligned to professional hierarchies, management and bureaucratic organisations than rich aristocracies.

Constructivism, as described earlier on, refers to the taken for granted beliefs, values, images and discourses that make up the concept that is, for example, person centred care in a way that helps discovery of how it is constructed. Smith explores how knowledge is created through the use of concepts and argues that taking a stance of understanding the world solely through such concepts does not take account of sensory reality. These concepts, she contends, never manage to capture our bodily experiences and sensations.

Drawing on both constructivism and Marxism and taking the example of the concept of ‘culture’ described as a set of images, ideas and symbols, Smith
argues that this is not something that exists in a neutral way but rather it is produced and defined by specialists who use communicative technologies to shape and influence it. By looking beyond the concept of ‘culture’ to the actual practical organisation of the production of these images, ideas, symbols, concepts and vocabularies, we can begin to see who produces them and for what purpose.

Deveau (2008) highlights the willingness of the non-ruling class to accept the ideas and concepts of the ruling class. This, he suggests, points to an invisibility of production of these ideas describing this as a process of detachment of the ideas from the ruling class itself by attributing them to an independent existence. These ideas take on a life of their own and become recognizable throughout society as being for the betterment of society and the ideas become abstract and seemingly neutral. At this point they become normalised, adopted once again by the ruling classes and are advocated as a righteous thing to do upholding what society has come to recognise as the highest proclaimed values and principles of that era. Examples from history include the portrayal of indigenous populations as being of lower intellect or requiring moral guidance being used to conceal the more materially driven objectives of colonisation for reasons of trade and wealth creation (Baldwin and Capstick, 2007).

Closer to home, we have seen how less than fifty years ago single mothers were portrayed as morally inferior, justifying their segregation and exploitation of their labour in the Magdalene laundries to meet the objectives of others (McCarthy, 2010). Several authors have contended that the marginalisation of certain sections of society such as the aged or disabled who do not meet societal expectations in terms of youth, beauty or material wealth continues to be justified in the context of concern for their well-being and protection despite evidence to the contrary (Diamond, 1992; Kitwood, 1997; Ronch, 2004; Sherwin and Winsby, 2011; Stirling, 2010).
3.4.3 The Social Organisation of Knowledge

A key principle underpinning Institutional ethnography (IE) is that of ‘the social organisation of knowledge’ (Smith 2005, p. 28), whereby some knowledge is dominant and authoritative, while other knowledge is subordinate (Campbell & Gregor, 2004).

In the seminal work The Everyday as Problematic, Smith (1987) explicates this social organisation of knowledge and identifies a number of key historical influences in the development of social relations as we know them. These influences include the evolution of thought in the enlightenment era, the development of capitalism and the emergence of printing and communication technologies. She argues that in the enlightenment era the middle classes became increasingly divided between public and private spheres with men increasingly involved within the public domains of politics, business and science with its associated knowledge-creation activities while women remained, relatively invisible, within the domestic realm. (Smith 1987, p. 18)

The rise of capitalism, with its associated focus on individual ownership and capitalistic enterprise, led to the development of large scale organisations (Smith, 1987; Deveau, 2008). What were once locally organised relations as demonstrated by family-owned enterprises became trans-local corporations and bureaucracies which in turn led to the development of management as a function in its own right in order to organise these large scale organisations. Written rules and administrative procedures were developed not only in order to manage but to evaluate the performance of managers (Wright, 2009).

The development of the print media enabled social organisation to be coordinated extra-locally, i.e. outside of a specific location and independent of particular individuals and particular sites. According to Smith (2005) this has created ‘objectified’ ways of knowing that are externally created rather than being located within the individual. Through these developments, she
argues, the world that is known, lived, and shared directly between people and expressed through images and ideas such as rituals and folklore has become subordinated by that which was made by others which comes from the outside and which does not arise from personal experience.

However, she also acknowledges that it would be naive to suggest that only formal and objectified ways of knowing shape experience. In many instances formal or authorised ways of knowing conflict with local knowledge and people can be seen to subvert or reconstruct formal ways of knowing. In an Institutional ethnography of physical activity in residential care, Benjamin (2011) noted how care workers subverted government standards of offering two baths per week to residents based on their local knowledge that showering was quicker and therefore adopted as local practice. In this context, competing needs come into play as certain groups have more power to resist or subvert than others (Taber, 2010). Smith (2005) argues that a different way of looking at how the world is organised requires an ontological shift away from taken for granted ideologies and forms of knowledge back to embodied forms of knowing. She contends that we need to ‘pull the mind back into the body’ (2005, p. 25) in order to reconnect with people’s actual lived experience as legitimate forms of knowledge.

To do this, IE seeks to interrogate the established ideology, which in this context relates to the ideas and images through which social relations are organised and how those ideas and images came into being (Smith, 1987). By looking at how forms of consciousness may originate outside personal experience and how this experience comes to be forced into categories of knowing, she points to the forms of knowledge created externally to the lived experience which is then used to populate the professional or managerial discourse that governs social relations (Smith, 1987). She also argues that in order to counter the discourses and social constructions that may render marginalised people invisible, knowledge recreation must go beyond adding the voice of the marginalised to the existing ideology and paradigms. Research must, she argues, shift these paradigms to take up the
standpoint of those who are marginalised, beginning from that experience and going beyond it to come to understand how this experience has come under the influence of specific ruling practices. The above section briefly outlined the ontology that underpins the development of Institutional ethnography as a sociological theory and a methodology. The following section outlines the key concepts of social relations, ruling relations and creating ideology and knowledge all of which underpin the analytical process. Other key conceptual tools such as objectification, the intersection of power and knowledge and the development of professional consciousness are also discussed.

3.4.4 Social relations

In the context of Institutional ethnography the term ‘social relations’ is not an abstract concept but rather the linking and coordinating of activities and work processes across different sites (Grahame, 1998). These extra-local forms of organisation shape the local and how people experience life without being immediately visible as such. The concept of social relations recognises that people’s activities are previously organised and project into those activities that follow (Smith, 1987; Bell, 2008).

In developing the concept of social relations Smith draws on the principles of Garfinkle’s ethnomethodology which maps what people do, such as, for example, how people queue for a bus or do their shopping. However, just being able to demonstrate how things actually work does not in itself explain how these actions are coordinated nor can people explain how they know how to do what they do as this knowledge is already organised before they talk about it. The study of the queue for the bus does not account for the social processes that lie behind the queue such as the scheduling processes, and employment practices of the bus company or the public transport policies and how these are constituted (Campbell and Gregor, 2004). Therefore, as people talk about what happens, what they do and what they understand is already shaped through organisational processes even though they may be unaware of them.
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An example of social relations in residential care is the work that a nurse undertakes when making an initial assessment of an older person with dementia who has transferred from an acute hospital. This work is connected to the work of the staff in the hospital and the multidisciplinary placement committees who made the assessment based on pre-determined criteria which are connected to rules about funding and levels of dependencies.

The process is shaped by the rules and goals of the hospital to maintain throughput and the concerns of local communities for the older person’s safety (Stirling, 2010). The nurse, prior to entering the residential care unit, organises her own family life through child care or connections with the school system in line with a shift system connected to rosters and skill mix. Her role as assessor is connected to her registration within a professional registration system that determines what she does and how she does it. By participating in social activity in this way, we may not be aware of the social relations that are influencing what we do and that are often invisible. By making visible those social relations and connections between them, the researcher is aiming to create a better understanding of puzzling issues or lines of fault in people’s experiences of the social (Campbell and Gregor, 2004). Ethnography in the context of Institutional ethnography commits the researcher to an exploration, description and analysis of the actual social relations of real people (Bell, 2008), in this case older people who live in residential care. Following this, there will be further exploration of how these social relations are tied into institutional processes that are coordinated by ideological concepts and categories that shape the relationship between what people actually do and the institutional functions of, for example, the ‘system’ of residential care.

3.4.5 The Ruling Relations

Ruling Relations is a key concept in Institutional ethnography and builds on the notion that people’s lives are shaped and coordinated by a dominant
form of knowing created by the management and professional classes. These forms of knowing are converted into texts which in turn are used to manage and regulate what happens to people. While influenced by Marx’s analyses of class oppression in the nineteenth century (Campbell and Gregor 2004, p. 39), Smith (1987) acknowledges that contemporary ruling relations are somewhat different from those of that era and suggests that:

*Taken together, management, the professions, government, the media, and the academy are seen as a complex of extended social relations that accomplish ‘ruling’ in the sense that they organize, coordinate, and regulate what happens in contemporary societies. This complex of ruling relations includes specialized scientific, technical, and cultural discourses which operate through a wide variety of textual formats as constituents of the process of ruling. (Smith 1987, p. 56)*

The ruling relations of contemporary society refer to the complex set of relations as described above that interconnect people across time and space and which organise daily lives through Institutions. In this sense the institution does not refer to the actual organisation, i.e. the heath authority or university, but rather the collective of organisations, bureaucracies, academic and professional discourses that collectively provide texts which coordinate behaviour and activity across, for example, residential care settings (Smith, 1987; McCoy and DeVault, 2006). Therefore, in respect of the ‘system’ of residential care for older people the intersecting processes includes the work within the Health Service Executive, the Department of Health and Children, regulatory bodies such as the Health Information and Quality Authority (HIQA) and the Nursing Board, advocacy bodies such as Age Action or the Alzheimer’s Society and academic institutions who undertake professional training and research activities.

The fact that these organisational units populate the ruling relations is not to suggest that these perspectives are malign or intentionally designed to deceive or oppress; rather, it is a set of positions designed to manage, administer and organise in order to get the work done and constitute a common perspective. However, according to Smith (1987), people who occupy these positions come to view the world in a certain way by virtue of their participation in the form of ruling. They are actively involved in the
production of knowledge producing ideologies that legitimise their dominance, giving social form to these and controlling the means of dissemination of its knowledge through academic texts and organisational forms of discourse such as policies procedures and regulations. In using the term ‘ruling relations’ Smith is not dismissing professional discourse but is arguing for its explication to make visible its origins and objectives in order to understand ‘who produces what for whom’ (Smith, 1987).

This aligns with Estes (1979) concept of the ‘Ageing Enterprise’ which points to the need for transparency of the agendas of the various stakeholders. Smith also argues that this professional discourse based on objectified as opposed to direct and embodied forms of knowledge is incomplete and it is here that possible disjunctures or points of tension can arise between what is commonly known and what is the actual experience of real people. A key feature of the ruling relations is its reliance on text based discourse and forms of knowledge. These texts are used to coordinate human activity across many locations and are organised around specific ruling functions such as health care or education. The use of texts is considered typical of late capitalist welfare state societies where texts have played a prominent role in defining the relationship between ‘professional’ and ‘client’ and creating categories of people such as the aged or disabled. Ruling occurs through the creation of knowledge that relies on multiple ways of reporting, categorising and accounting for particular aspects of people’s work and lives.

These recordings bring into being a specific framework of issues and tensions that organise and influence what happens in the everyday world. For example, the process of risk management relies on the reporting and accounting of the risk through textually-mediated plans and reporting sheets to specific formulae enshrined in legislation or policy. These remove the situated knower – i.e. the resident – in favour of objectified knowledge which is more readily administrable according to the priorities of the ruling relations (Smith, 1987). Thus, an elderly lady becomes known in an objectified way as, for example ‘highly dependent….at risk of falling’.
While the use of auditable objectified knowledge is not unreasonable for the purposes of governance, what makes it problematic is when this becomes a routine way of knowing in a way that subordinates other localised ways of knowing.

Smith (1987) argues that a non-dominant group’s standpoint is excluded from these textually-mediated discourses about the everyday world that is determined by a ruling apparatus and that, as a result, these objectified ways of knowing are adopted and normalised and absorbed into professional consciousness and that of the society in general.

3.4.6 Creating Ideology

Smith uses the term ideology, not as a system of thought or belief but as a way of explaining ways of thinking and representing. This concept of ideology brings into focus the conscious production of forms of thought which serves to organise and order the expression of local settings in accordance with the aims and perspectives of the ruling relations (Smith, 1987; deMontigny, 1995; Deveau, 2008).

Therefore, the experiences of people are expressed in ways that align them to the practices and social relations of these ruling relations. In a contemporary context, this would include ideas and social forms of consciousness that come from external sources such as education and law using generalised categories such as ‘care’ and ‘welfare’ as opposed to categories derived from individual experience. Smith suggests that ideas and concepts originating from outside experience, form a

\[\text{forced set of categories into which we stuff the awkward resistant actualities of our world.} \] (Smith 1987, p. 55).

A key dimension of the relation between individual experience and an institution lies in the use of institutional accounts of members’ practices. Institutional accounts are ‘ideological’ in the sense that local practices are made accountable in ways which express the functions of the institution
(deMontigny, 1995). Health professionals, he suggests, learn to account for residents’ actions within the organisational frames presented to them. For example, an embodied experience of fear, anxiety or confusion in a person with dementia may be reconstructed as ‘challenging behaviour’ (Stokes, 2009; Stirling, 2010). Previously determined care plan templates are examples of ideological practices whereby the feelings, actions and messy reality of a resident’s life are reordered to represent the expressed functions of the organisation (deMontigny, 1995). Such accounts narrow and transform what can be noticed and proposed about daily routine, making certain elements visible while others become unnoticed and invisible (Grahame, 1998).

One ideological concept in relation to residential care relates to the concept of ‘dependency’ and how this is used to categorise and replicate organisation of practice across multiple sites. Using this example of dependency, these codes are used to describe older people in terms of their physical and cognitive capacity in order to generate staffing structures, provide statistical data, and are the basis for calculations required to meet regulatory standards. By adopting and prioritising dependency as an ideological code, residents appear in an objectified way that defines their activities in a way that aligns with the organisations objectives, i.e. does this person need physical help with activities of daily living? ..... are they continent? .....can they walk unaided? These are all important pieces of information when determining the physical labour required but render invisible the subjective elements of, for example, ‘what support does this person need to have a good life?’ (Sherwin and Winsby, 2011; Stirling, 2010).

Smith proposes that ideological practice happens when actual relations and structures of everyday living are glossed over. The specific occasions of seeing, experiencing and talking which are rooted in concrete social settings are detached and taken up outside of people’s lives and social contexts and are reorganised as facts according to the theories, frames and models of an institutional discourse as determined by what is considered relevant by the
ruling relations (deMontigny, 1995). A key task of Institutional ethnography involves explicating the ideological practices which are used to make an institution’s processes accountable (Grahame, 1998).

3.4.7 Knowledge and knowing

Bell (2008) points to two forms of knowing. Knowing as it arises from our direct experience and knowing that arises from organisational facts. Adults working in organisations shift knowing to knowledge through socially organised and coordinated practices which in turn become practices that structure knowledge production. The theoretical aspects of ‘knowing’ and ‘knowledge’ apply within different contexts, i.e. real people as knowing subjects and texts such as policies and procedures analysed from the perspective of the knowledge they represent and what the relations of power are.

In institutional ethnography, the difference between ‘knowing’ and ‘knowledge’ is highlighted (Campbell and Gregor, 2004; Bell, 2008). Research participants are described as ‘knowing subjects’ who are experts in their own lives (Smith, 2005; Bell 2008; Lirette, 2012; Benjamin, 2012). In this context, the knowing arises from a person’s direct experience as opposed to accounts which arise from organisational facts constituted as objectified representations of events. Therefore, ‘knowing’ and ‘knowledge’ are different. On the one hand, you have the knowing subject – the resident or their family member – and on the other, the knowledge that is located within the professional, procedural and regulatory texts. Smith suggests that adults in organisational work settings shift ‘knowing’ to ‘knowledge’ through socially organised and coordinated practices which she describes as discourse. She defines discourse as sets of meaning expressed though beliefs, vocabularies, practices that together count as knowledge and succeed as power in any given culture. According to deMontigny (1995) people who work in large organisations or professional groups develop a discourse, i.e. a shared language, beliefs and values, and ways of working and protocols which create certain ways of knowing clients. This discourse
organises the professions via texts and language and students are trained to translate what they see and hear from the everyday world into, in the context of healthcare, this professional and often medicalised form of language (Diamond, 1992; Campbell and Gregor, 2004). These practices not only contribute to the language and authorised practices of that profession but frame how work is thought about and how it is undertaken.

According to deMontigny (1995), this type of framing becomes so common that workers begin to see them as natural and as the ‘way things are done’ to the extent that they are seen as the only way that things can be done rather than seeing them as rules and procedures developed by individuals with certain ideological views. Townsend (1998) in an Institutional ethnography of mental health services describes the taken for granted power of psychiatrists and their role as leader of mental health teams. She demonstrates how this medically-orientated way of knowing gets translated into therapy programmes, team meetings and mental health policies which espouse the empowerment of people with mental health issues but which in reality perpetuate systems of power and inequality.

3.4.8 Objectification

The translation of real people into ‘cases’, through objectification is a common Institutional ethnography theme where organisational practices are considered ‘generalisers of actual local experience’ (Smith 1987, p. 154). Statistical reports are an example of objectified accounts of everyday life as they extract pieces of information to form conceptual facts coordinating and taking on generalised organisational patterns (Diamond, 1992; Campbell, 1995; Townsend, 1998).

Objectified management refers to the management of textual objects using scientific methods that do not require face to face contact. The process requires real people to be firstly translated into ‘cases’ and categories. Then selected facts are used to make decisions that are difficult to attribute to
actual people yet it is real people who have created the facts in the first place (Townsend, 1998).

In a participant observation study of American nursing homes which adopted the standpoint of nurses’ aides, Diamond (1992, p. 210) describes a process of objectification whereby, through the textual processes of assessment and reporting, older people are converted into ‘cases’ in a way that often bears little resemblance to what is actually happening, providing ‘at best a partial (if not distorted) representation of those relations’.

3.4.9 The intersection of power and knowledge

Institutional ethnographers are interested in how power and knowledge intersect and how this intersection, often textually-mediated, organises the everyday lives of people. Standardised practices such as, for example, clinical pathways or care plans underpinned by theoretical frameworks generally define certain courses and sequences of action within a defined timeframe. This becomes the authoritative course of action introducing a ruling structure into local practice, establishing forms of knowing that are external and establish dominance over local ways of knowing. The use of these standardised practices draws staff into the relations of ruling as they come to know individuals within this discourse.

Campbell (1995) suggests that these practices build ‘an intellectual bridge between what people do and scientific knowledge’ (p. 222). She contends that they direct behaviour and assume a causal relationship between courses of action, how they are represented in the plan and how they are reported after the event. In a study involving nursing students and nurse tutors in Canada, she explored how students interacted with texts both in the course of their nursing work and when reporting on this work as part of their evidence of competency. The study traces their textual work showing how templates guide the nurse in one direction and away from others. She
contends that nurses learn to document their work to meet the goals of the model even if it is at odds with what is happening in reality. She notes that such practices are now taken for granted in health service management, often silencing the recipient of care and even the nurse from the health care discourse.

3.4.10 The development of professional consciousness

If the power and knowledge of the ruling relations is to remain dominant it must become part of professional consciousness. To deMontigny (1995), professional consciousness means that ways of thinking and ways of working are bound into the social relations required for building and sustaining an institutional model.

Within health care, information systems such as statistical reports or classification systems assume neutrality, according its information product scientific authority and overriding whatever else might be known (Rankin and Campbell, 2009). This in turn becomes a powerful form of socially organised knowledge which in turn influences health care workers who learn to reinterpret their own professional judgement and practice as a result. Rankin and Campbell (2009) note that this results in a form of circularity which creates knowledge about particular social groups that becomes the established ways of knowing although it may be different to the actual everyday experiences of the people within that social group.

Statistical knowledge, while an important part of health care and external forms of knowledge, is not the only form of knowledge as professional practice is evolving constantly in the light of research and practice development. deMontigny (1992) contends that when adopting new practices, staff try to make sense of new information that is emerging in the professional discourse. Over time through professional literature and professional development this new information is brought into the frame and eventually becomes the accepted way of knowing. Person centred care is emerging as one such discourse brought to staff through conferences,
workshops and professional literature. Staff are exhorted to ‘be person centred’ and over time the common sense about offering choice and more flexibility in their routines gradually replaces the old common sense of efficiency and regimented routines. Through discussion and debate following workshops, staff continually modify their old understanding and develop new sets of beliefs such as ‘it’s their choice’ which is a phrase that was commonly expressed by staff participants in this study. As part of this sense-making, new texts appear in an effort to standardise and reinforce this new common sense. As this new discourse intersects with other organisational structures, conflicting values may arise creating a sense of bifurcated consciousness or disjuncture between, for example, the external forms of knowledge required for management efficiency and that which is known locally through every day interactions.

Given that we can return again and again to discourse through the form of texts it as an essential part of the complexities of the relations that organise people lives. Building on this, the following section explores the centrality of texts to institutional organisations and their role in perpetuating the goals and priorities of the ruling relations.

3.4.11 The role of texts in institutional ethnography

Institutional ethnography assumes that texts have the power to shape and coordinate people activities obligating people to act in particular ways (Kinsman, 1995; Campbell, 1995; Jackson, 1995; Campbell and Gregor, 2004; Turner, 2001; Walby, 2013).

Texts come in a variety of configurations ranging from printed documents like standardized government forms, reports, drawings, photographs, computer images, visual and sound recordings (DeVault and McCoy, 2006). Regulatory texts, policies and procedures, assessment forms, care plans, and activity recording sheets are forms of texts within the healthcare sector.
Chapter 3: Methodology

Smith (2005) defines texts as:

*forms of writing, speaking or images that are replicable and therefore can be read, heard or watched by more than one individual in different places at different times.* (p. 165)

These replicable textual forms coordinate the actions of workers in different locations despite individual situations and needs and are created or shaped by powers removed from the location where the text is being enacted. In this context they organise social relations as people read them in their local sites (Smith, 2001). These textual conversations standardize the almost limitlessly various understandings of readers; that is, they bring a similar understanding of what is read about to all those, for example, health care professionals who read the same text (Bell and Campbell, 2003).

Assessment forms are one such text, commonly used in health care and other forms of public administration. The term is derived from the word ‘forma’ meaning to give form or mould. According to McLean and Hoskin (1998) the ‘form’ as a textual device came into being in medieval Europe well before the adoption of mass printing as a means of communication. In the 19th century it came to adopt its now familiar format of *impersonal writing, directives and questions with spaces waiting to be filled* (p. 521). In this way it has organising features that come into being through reading and writing, examining and grading. In undertaking the ‘work’ of assessment, professionals and service recipients are cast into specific and asymmetrical roles (DeMontigny, 1995). The professional becomes the examiner, grader and inquisitor while the individual being assessed becomes the object of examination, grading and clinical gaze (Foucault, 1963; DeMontigny, 1995; McLean and Hoskin, 1998; McLean, 2001).

A key feature of texts are their replicability therefore the ‘form’ is repeated over and over in many locations providing a similar representation of many people regardless of their heterogeneity or individual circumstances providing for standardisation (Smith, 2005). Knowledge and authority is
increasingly vested in textual procedures rather than individuals as institutional complexity increases (Rankin and Campbell, 2009). Texts provide for standardised recognisability of people’s doing as organisational or institutional as well as for their coordination across multiple locations and time (Smith, 2005).

Health Care workers generate texts on a daily basis as part of their practice. These texts are informed by policies and procedures and regulatory requirements and in turn provide information which drives future knowledge production (Rankin and Campbell, 2009). According to Smith, they create forms of consciousness that are properties of the organisation rather than individuals. She contends that the work of administration and management is to communicate those forms of consciousness and that they do this in a textually-mediated way. The stability of these texts is crucial to the organisation and is essential in ensuring standardisation of institutional processes across multiple sites. In this context they direct local actors towards institutional interests through their reading and activation of the texts coordinating and organising what happens. This creates a link between that textually driven local experience and the trans-local organising of the ruling relations (Smith, 2005).

deMontigny (1995) uses the IE technique of using a text to ‘burrow’ into an organisation as a means of explicating the social relations of professional social work (Turner, 2001). By using the ‘running record’ – similar to the narrative notes of nursing records – he explores how professional ways of knowing, shaped by policies and legislation, subordinate peoples own embodied experiences. deMontigny’s work draws attention to the hierarchy of texts and how the work of frontline staff becomes accountable and governed by law and the associated rules of the department. While client files are purported to represent their lives, he demonstrates how the client’s voice is silenced as even their ‘reported speech’, i.e. what they said happened is located inside ‘professionally determined schemata and documentary forms’. (p. 212)
In Institutional ethnography, analysis of texts is used to seek insight into social relations or as a way of uncovering ideological accounts rather than being used for factual information (McLean and Hoskins, 1998; Campbell and Gregor, 2004). In actual texts which progress actual work (such as rostering schedules) there may be contrasting stories between ideological beliefs of ‘person centredness’ and how care is organised. Text such as a facility’s ‘Statement of Purpose’ – its mission statement – may claim to be person centred but actual work recording texts such as activity records may drive work routines in a different direction. When a text is activated, its materiality offers the researcher an entry point into the social relations that the text organises (Campbell, 1995). The researcher must then show how the activator (e.g. the nurse undertaking a care plan) of the text is connected to other people who play a part in the organisational chain demonstrating how the nurse’s focus, whether she is aware of it or not, is textually organised (deMontigny, 1995).

3.4.12 Section summary

This section outlines the ontology and key concepts of Institutional ethnography. Its background and ontological underpinning are described as well as the key conceptual tools that shape the analytical process. It describes how the process of Institutional ethnography begins in the everyday experiences of real people and proceeds from there to explore the key Institutional ethnography concept – the social organisation of knowledge, examining how this knowledge is created and by whom. The concepts of social relations, ruling relations and the creation of ideology have been explored alongside the intersection of power and knowledge in creating institutional dominance. How professional consciousness is shaped by wider organisational goals and the critical role of texts in the social organisation of knowledge has been discussed.

3.5 The methodology process of Institutional ethnography

The following section outlines the defined steps that are required when following the methodology of Institutional ethnography. There are a number
of stages which guide its development such as identifying the problematic, adopting a standpoint and making explicit the researcher’s personal standpoint. The conventional qualitative research tools of interviews, observations and documentary analysis are then used. Following this, data analysis and a process of mapping is undertaken, connecting pieces of data to other pieces of data demonstrating how experiences are socially organised. In this way the process differs from other qualitative methodologies that employ thematic analysis or derive theory from the data. The findings are based on this mapping process and rigour is demonstrated through maintaining a materialist stance rather than seeking abstract explanations as to how things happen. The researcher is not seeking to claim that all experiences are similar but rather that the features of the ruling relations cut across many settings (DeVault and McCoy, 2006). Reflexivity is a key action and ethical considerations are no different than other methodologies.

3.5.1 Identifying the problematic

The idea of problematic relates to a disjuncture between the experience of individuals and how that experience is socially expressed by the ruling relations. Obviously, not all ruling relations activity has negative consequences and the need for social organisation is a necessary feature of contemporary living. However, when a disjuncture, or ‘line of fault’ arises between subjective experience and how the world is generally known, then this can be considered to be problematic (Townsend, 1998). This fault line makes visible an apparatus of social control which is partly ideological and presented as discourse in texts as, for example, the articulation of person centred care in policy documents. Smith describes this idea of disjuncture as follows:

*A disjuncture can arise between the world as it is known directly in experience and as it is shared with others and the ideas and images fabricated externally to that everyday world and provided as a means to think and image it.* (Smith 1987, p. 55)
Identifying the problematic sets out a project of research which focuses on how people’s everyday experience is coordinated by relations of ruling. A typical problematic starts with an exploration of the everyday lived experiences of participants. The inquiry then takes this experience and asks how it is organised, how it is determined and what are the social relations that generate it (Smith, 1987). The disjuncture therefore is between the experience and how the experience is socially expressed and made actionable.

All institutional ethnographers begin with this sense of disjuncture between how knowledge is socially organised and the actual experience of real people going about their everyday lives (Campbell and Gregor, 2004). However, this does not solely define the research direction. While they may set out with a sense of the gap between the espousal of, for example, person centred values in policy documents and the everyday experience of living in residential care, they cannot be constrained by this idea or make prejudgements. Rather than setting out a series of fixed questions or problems, the institutional ethnographer starts in the everyday world as it is actually lived proceeding from there to develop a description of that world. Here the problematic is not the problems that residents might experience or the research questions but rather a ‘territory’ to be explored and discovered which begins by talking to people and taking a lead from there (Bell, 2008). Therefore the research objectives must reflect that this is an exercise in exploration rather than explanation. While theory (such as the theory of person centred care) can guide the problematising of the research setting, the data collection and analysis process, when it comes to interpreting the data, Institutional ethnography relies on explicit linkages that are lived and brought into existence by people’s actual ‘doings’.

### 3.5.2 Adopting a standpoint

To learn about a problematic, the researcher takes the standpoint of the person or group with whom the research is being constructed (Bisallion and Rankin, 2013).
In taking this stance the researcher begins investigating the coordination of activities which affect the experiences of the research participants. In general, most institutional ethnographers adopt a standpoint of those who have been excluded from the institutional discourses and the investigation begins with the bifurcation between their everyday experience and institutional practice (Grahame, 1998). A standpoint is a place to begin and must be situated outside the standardised forms of knowing and inside the local world of the everyday experience (Bisallion and Rankin, 2013).

In Institutional ethnography the researcher must make explicit their standpoint in order to focus their attention in the right direction. This is not the same as gaining the perspective or ‘world view’ of the individual as Institutional ethnography is emphatically not a subjectivist enterprise (Grahame, 1998). Its goal is to explicate the forms of ruling that affect those life experiences and in doing so it is necessary to go beyond those everyday experiences to the social processes that are hidden and unseen and not necessarily obvious to those individuals (Smith, 2005).

As the researcher works on behalf of these expert insiders to learn how their practices are organised (Rankin and Campbell, 2009), the purpose of the data collection process is to gain understanding of what is involved in the ‘work’ of being a resident, and how that connects to the organisational practices of the facility. Creating a standpoint is not to privilege that standpoint but merely to use it as an entry point (Wright, 2009). One could, for example, also adopt the standpoint of the frontline staff who are also subject to ruling relations or of relatives who through prevailing social conditions are unable to provide on-going support for their family members. By beginning from this standpoint of real people we can begin to gain knowledge of how institutions function and how they are located within organisations such as the healthcare system.

Of course, all older people’s experience of residential care is not the same and therefore it is not appropriate to categorise all older people in the same
way. According to Smith (1987), however, the organisation of social relations is a common thread in the lives of people dealing with the extra local relations of ruling authority and knowledge. Therefore adopting a particular standpoint is a valuable way of challenging dominant perspectives and explicating marginalised people’s point of view exposing tensions between the everyday lives of people and the ideology advocated by the institutions.

3.5.3 The personal standpoint of the researcher

Smith (1987) asserts that the researcher must begin in the same world as those being studied. Each of us is situated within our own social relations which fundamentally shape how we experience and make meaning of our world. Smith contends that we could not and should not strive to be neutral observers, situated externally to the research and the practices of the ruling relations that constitute the research site. The institutional ethnographer is required to see herself as a knower located within everyday life and find meaning there.

My own personal standpoint relates to my experience of residential care as both a relative and a planning specialist for older people services. On the one hand I see and hear about the daily lives of residents when I visit one facility. Many of the residents I have come to know have advanced dementia and are unable to articulate their views or wishes in conventional verbal exchanges yet have distinct individual characteristics, personalities, agency and ways of communicating. As a planner of services, I notice how at odds this experience is from the objectified accounts of older people that I compile in management reports. I notice how the language of person centred care has entered into the professional discourse and how new ‘homely’ touches such as patterned wallpaper and carpets have replaced dull institutional walls and flooring. Yet, beyond this, I see little difference to the lives of residents who spend much of their time alone, in the company of others but not communicating. I see friendly but busy staff engaged in episodic conversations based around care interventions with little time to
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‘be in relation’ (McCormack, 2004). This is my personal standpoint and form of knowing that I bring to this study.

3.5.4 Data collection processes

The next Institutional ethnography step involves studying the work through which people are themselves involved in producing their world and conventional qualitative research methodologies such as interviewing and observing are employed. The context of ‘work’ may seem strange in the lives of non-active older people. Diamond (1992) notes Dorothy Smith’s ‘generous’ concept of work as not solely relating to occupational work but whatever actions (or non-actions) occur when interacting with social organisations. Therefore the act of ‘doing nothing’ so frequently related by the older people in this study can be considered as ‘work’ within the context of Institutional ethnography. A similar situation is described in Diamond’s Institutional ethnography of American nursing homes whereby the ‘work’ of residents involved a lot of waiting around for things such as mealtimes to happen (Diamond, 1992).

There are two types of data collection in Institutional ethnography, first or entry level data collection and second level data collection. (Campbell and Gregor, 2004; Deveau, 2008). First level data collection comes from the interactions and activities of participants in their own local settings through the process of interviews or observations. The second level looks at how these activities are coordinated by others.

3.5.5 Interviews

From an Institutional ethnography perspective interviewing has been described as ‘talking with people’ (DeVault and McCoy 2006, p. 756) who also liken the process to having ‘a ball of string, grabbing a thread and following it’. Questions can initially be based, at least in part, on the researcher’s accrued knowledge of the social relations (Deveau, 2008) but may change as participants describe activities which point to other previously unknown social relations. In this context, as the researcher learns
more and more they may seek out different information in different locations. The aim is to get a clear account of how things go together to make up standard practice without omitting things that are taken for granted. Interviewing in this way requires the researcher to continually analyse the sequence of connected activities and to constantly look for elements of social organisation in the everyday experiences as they are recounted. The process requires more than simply asking questions and listening to the answers provided. Rather, the process of analytical thinking begins in the interview (Deveau, 2008), followed up with immediate analytical writing (Benjamin, 2011) to identify social relations. The aim of this stance is to trace points of connection between different parts of the system or complexes of activity (DeVault and McCoy, 2006). Therefore, the goal is to elicit data that adequately illustrates the particular circumstances but also guides the researcher towards the next steps in tracing the organisational processes.

3.5.6 The use of observation in Institutional ethnography

Observation can enhance the goals of Institutional ethnography by incorporating place, time and motion and the presence of larger social organisation into a local setting (Diamond, 2006). The process adds additional depth and richness to the ethnographic description, in particular to record the physical environment, the tangible elements that assail the senses such as the noise, the business, the smell, and the rhythms of the institution. In addition, the purpose of observation is to look for coordinated or concerted activity that can be seen to be connected to social relations that are ruled externally to the location (Diamond, 2006). When undertaking observations, Stake (1995) contends that, while remaining open to what you are looking at, you do need some conceptual framework to bound what you can observe. In Institutional ethnography, this comes from the problematic for the inquiry in general. The researcher will bring this problematic into each observational site and will see what elements of what is happening touches on this problematic.
3.5.7 The use of field notes

Similar to conventional ethnography, field notes are an important part of an Institutional ethnography as the researcher continually looks for social relations in everyday life and through everyday conversations, connecting these to the process of reflection and analytical writing.

Diamond (1992) describes how as a participant observer he continuously wrote notes about everything he saw and heard in the three nursing homes he worked in as part of his study. In this study he adopted the standpoint of nurses’ aides and many of his field notes related to seemingly minor events that he then connected to wider social relations of residential care systems.

3.5.8 The analysis of texts

Texts are a key source of interest to institutional ethnographers underpinned by the belief that they drive social relations by replicating discourse and organisational rules across many locations in a standardised way (Smith, 2005). Beginning in the actual setting, watching and listening for how texts are used and following this through by attending to how the texts are activated, the quasi-legal or professional terminology and the textual transformation of an initial situation to its final outcome is a key analytical goal. From this point, specific strands are explored in order to make visible their points of connection with other sites and other courses of action. This process is underpinned by a number of key analytical concepts that are used in this explication and are outlined below.

3.5.9 Text – Reader conversations

Smith (2005) describes the process of ‘Text-Reader’ conversations, whereby the text guides actions directing the reader to consider specific issues and directing them away from others. In this text-reader conversation the reader of the text is engaged in both reading and activating the text. The actual text is inactive until it is read and remains the same after it is read. The act of reading does not change the text in any way. The text, however, has the power to stimulate the reaction of the reader. This reaction or response
activates the text and the reader becomes the agent of the text. An example of a Text-Reader conversation is the filling in of an assessment form or application for a public service. The activator or reader commences at the beginning of a pre-designed form and makes their way sequentially through the form conforming to its pre-determined subjects designed to elicit certain types of information while filtering out others. These pre-determined subjects become ‘shells’ which are nested within the texts and are filled in by the agent of the text. (Smith, 2005).

3.5.10 The hierarchy of texts

Some texts have dominance over others. Generally this is demonstrated in legal documents whereby various legal instruments have an ascending order of power. Acts of parliament have dominance over regulations which in turn have more authority than guidelines or standards. National policy documents in general have dominance over more localised ones particularly in centralised systems such as the Irish Health Service Executive. Intertextual hierarchies, (that is, where one text regulates another), are more likely to be present in highly regulated processes. In IE, the analysis process emphasises how such regulation subsumes the actualities of people’s lives as well as organising subordinate texts such as local policies or assessment and care planning processes. In this way the subordinate text aligns to the interpretative frame of the dominant text providing a clear line of sight to the goals of the ruling relations.

3.5.11 Intertextual circularity

This refers to a form of circularity which can be seen in the ongoing organisation of intertextual hierarchies. What is produced as a text under the regulatory authority, (for example, an assessment and care plan), must demonstrate that it is a proper instance of the higher regulatory categories and concepts. From the position of activating the regulatory text, for example as in the Care and Welfare regulations relating to care plans (Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2010; pp. 2-4), the question is
3.5.12 Data analysis

The analytical goal of Institutional ethnography is exploration and explication and making connections between the participants and social relations. Analysis proceeds by way of tracing the social relations people are drawn into through their ‘work’. The key aspect guiding the researcher is that these social relations are at the core of the research interest as is the need to create a ‘bigger picture’ beyond individual experience. The point is to show how people in one place are aligning their activities with relevancies produced elsewhere in order to illuminate the social forces that shape that activity (DeVault and McCoy, 2006).

During the analysis stage of the research, the researcher establishes connections between what participants say (and what is observed) and textual associations that the reader can see and understand (Campbell and Gregor, 2004). This is in contrast with other forms of analysis which seek to establish themes or theoretical positions. Therefore the data analysis process is also different. There is no attempt to create codes or categories or to engage in data reduction processes as would be the case in a thematic analysis (Miles and Huberman, 1994). The researcher does not engage in the counting of actions or seek evidence of replicable behaviours as a means of explaining behaviour (although evidence of coordinated actions across multiple settings is of interest). Rather, the goal is to reveal the social relations in the setting by illuminating the role that institutional texts play in coordinating people’s lives across many settings. There are two stages of data analysis. First level analysis considers the data that describes the everyday ‘work’ of participants, their activities and concerns focusing on the problematic. The researcher may draw up an initial descriptive account.
of everyday life or of these activities detailing the mundane everyday tasks in which participants engage. However, this is not the ultimate research goal as in a conventional ethnography. Rather, as stated above, the intention is to go beyond this into work of the ruling relations. This brings the researcher into the second level of analysis: investigating the antecedents of these activities and experiences. (Sinding, 2010). The analysis now moves from the work of the participants whose standpoint is adopted, in this case older people in residential care settings, to that of the work of professionals, regulators and management, focusing on the connections between them.

Campbell and Gregor (2004) propose a number of methodological steps in undertaking data analysis in Institutional ethnography. First, they propose that the analysis process begins during the data collection process rather than at a later stage as the researcher searches for these connections while ‘talking to people’ and advancing from there. Staying close to the problematic, they contend, helps the researcher to look in the right direction, helping them to filter out the many potential lines of inquiry that exist in any research site. Primary conceptual work as shaped by the problematic helps focus the researchers attention in a particular direction as does initial hunches or experiential knowing. Immersing themselves in the data and reading data analytically is a key next step. This involved asking questions of the data that will bring into being forms of social relations. McCoy (2006) proposes the following as the type of questions that should be asked of the data:
Table 3.1 Seeking Out Social Relations

- What is the work that these informants are describing or alluding to?
- What does it involve for them?
- How is their work connected with the work of other people?
- What particular skills or knowledge seem to be required?
- What does it feel like to do this work?
- What are the troubles or successes that arise for people doing this work?
- What evokes the work?
- How is the work geared into the system or institutional organization?

Keeping the Institution in view: Working with Interview Accounts of Everyday Experience McCoy (2006)

This process of analytical reading draws on the ontology of Institutional ethnography searching for instances of objectification, different forms of knowing, or the intersection of power and knowledge. Looking at, for example, text-reader–text sequences or seeking evidence of inter-textual circularity helps the researcher extract data in a way that is analytically relevant to the goals of the study.

The next stage is engaging in the action of analytical writing, as Campbell and Gregor (2004) contend that it is through this writing that the analysis is developed and deepened. The institutional ethnographer must write up their argument bringing in evidence from the texts as to how accounts, appearing in one or more texts, orientate what people do on a daily basis. Arguments have to adhere to what is found and actually happened in the situations studied. As the researcher begins to see the connections between pieces of the data, they draw them out in their writing inserting into the account
pieces of raw data that best reflect the social relations of this conceptual work (Campbell and Gregor, 2004).

The final task centres on mapping and involves illustrating the ways in which a local work practices operate as part of a broader set of social relations which link ‘*multiple sites of human activity*’ (Smith 1987, p. 166). This key methodological task connects the talk of participants to the taken for granted practices and texts that hook their experiences into the work of the ruling relations. In this way the process involves seeking connections between pieces of data and ‘joining the dots’ (Deveau, 2008). The objective is to create a map either written or diagrammatically of how things work showing how people’s lives are hooked into social relations that are outside their immediate experiences – often in ways that are unseen.

### 3.5.13 Ethical Considerations

Ethical issues in IE are the same as those in any other qualitative research endeavour. In the context of older people in residential care, there is some argument about the tendency toward paternalism as residents can be considered vulnerable on a number of levels (Cooney, 2008). Being aged can lead to vulnerability in itself, being aged with a number of disabilities, as is generally the case for residents (O’Neill, 2006), adds significantly to the risk of vulnerability, and older people residing in residential care could be considered to be ‘socio-culturally marginalised’ (Angrosino 2005, p. 734). Given that residents are partially or wholly dependent on others for the most basic levels of care increases the level of vulnerability even further. Focusing on a group who are not in a position to protect themselves could also be considered unethical, for example selecting participants who have no access to independent or familial advocacy who are in need of such support. Family members can also experience vulnerability, given that the reliance on professional carers to provide care for family members can place the non-resident family member in a position of disadvantage when expressing views or concerns.
3.6 Summary

This chapter outlined the various paradigms and research methodologies available to the researcher and provided a rationale for selecting Institutional ethnography. An overview of Institutional ethnography was then provided outlining its ontological underpinnings and key concepts. The methodological goals and steps were then described. The following chapter describes the method undertaken in this study as guided by the steps outlined above.
Chapter 4: Method

4.1 Introduction

The theoretical and methodological approach of Institutional ethnography informed the research design of this study and this chapter describes the methodological steps undertaken. The initial IE steps are outlined, i.e. identifying the ‘problematic’, defining the research objectives and describing the standpoint adopted and my own personal standpoint. I then describe the fieldwork sites, how access was gained and ethical considerations. The recruitment of participants, data collection and data analysis processes are outlined and the issues of rigour, reflexivity, bias and how I immersed myself in the methodology are addressed. The data analysis process is then described.

4.2 The problematic

The ‘territory’ that I wanted to explore (Smith 2005, p. 41) in this research is the social organization of work related to the implementation of person centred care in residential care settings. The challenge of implementation has been identified in the literature (Talerico, O’Brien and Swafford, 2003; Nolan et al., 2006; Skaalvik, Normann and Henricksen, 2010; McCormack et al., 2010a). In the evaluation of the person centred care project, McCormack et al. (2010a) identified contextual issues of unequal power, continued adherence to task-based, routinised care processes and a system bound by organisational rules. The findings of this evaluation align with my own personal forms of knowing as a manager and from prolonged engagement with one residential care facility as a family member.

Therefore the problematic I put forward in this thesis is that, despite numerous years of professional discourse in relation to person centred care, the organisational context of care continues to coordinate and shape peoples everyday lives in accordance with the priorities and goals of the organization.
The Person Centred Practice Framework which underpinned the McCormack et al (2010a) two year project identifies ‘context of care’ as a prerequisite for the implementation of person centred care and proposes the following as core elements; decision-making power, skill mix, relationships, organisational culture, risk and innovation. In institutional ethnography researchers are reminded to begin outside standardised ways of knowing therefore this framework was not used to structure the study however I did draw on it loosely as a means of ‘looking in the right direction’ (Campbell and Gregor, 2004).

4.3 The research aim and objectives

The overall aim is to explore the disjuncture between the discourse of person centred care and what actually happens. The objectives of the research are:

- To explore the everyday living routines of older people in residential care and the social relations that influence those routines.
- To explicate the texts that coordinate the activities of care planning and reporting mechanisms.
- To explore the disjuncture between the theories of person centred care and the organisational policies and practices of Irish Public Residential Care Settings.

4.4 Standpoint

The standpoint adopted was that of the residents, acknowledging that they are experts in their own lives but then moving beyond that to what they don’t know, that is, the social relations that coordinate their daily lives.

4.5 The fieldwork sites

As I was seeking to uncover social relations that are coordinated and concerted trans-locally, I undertook field work in three different public residential care units that were geographically distant within three different administrative areas of the Health Service Executive. The primary criteria
were that they had previously participated in the two-year national person centred care programme and had reported statistically significant outcomes identifying an awareness of person centred care (McCormack *et al.*, 2010a). The rationale for this was that these were self-selecting ‘early adopter’ sites with leaders who were deemed to be progressive and open to change. Staff had been exposed to the language and practices of person centred care and as such were aware of the prevailing professional discourse. None of the units selected was deemed by the regulator to have inadequate staffing or skill mix as was identified through the regulatory reports and all had received favourable inspection reports in terms of their technical competence in clinical care.

The three selected sites varied considerably in terms of infrastructure, representing the mix of buildings that provide public residential care services. The first was formally a private residence providing a small homely atmosphere; the second was an imposing old building that had many incarnations over the years ranging from workhouse to county home to its current role of community hospital. The third site was located in a relatively recently and purpose-built community nursing unit. Therefore, the purpose of this diverse selection was to uncover social relations that transcended geography, physical infrastructure, personal characteristics and competencies of staff. The study does not attempt to explain the contextual differences of specific sites or to draw conclusions about their individual performance, but rather seeks to uncover ways in which the lives of participants are socially organised often in unseen ways.
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### Table 4.1 Research sites

<table>
<thead>
<tr>
<th>Research sites</th>
<th>Number of places</th>
<th>Type of building</th>
<th>Residential care only</th>
<th>Residential care/intermediate care/day care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>26</td>
<td>Converted residence</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Site 2</td>
<td>120</td>
<td>Converted workhouse</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Site 3</td>
<td>80</td>
<td>Purpose built</td>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

#### 4.6 Gaining Access

A published list of the participating sites in the two year practice development programme on person centred care was used as a starting point for the selection of potential fieldwork sites (McCormack et al., 2010a). A geographical spread was then considered ensuring a distribution across different Health Service Executive administrative areas. Following this, a mix of infrastructure type and size was considered. Staffing levels and skill mix levels were checked in inspection reports. A list was then drawn up and contact was made by e-mail initially, followed up by a phone call to the Director of Nursing requesting permission to access the site for the research. (Appendix 3). Where this was not successful the next facility on the list was contacted. Only one site contacted declined to be involved. Where the Director of Nursing agreed to involvement, I forwarded on an information pack including the research protocol (Appendix 4), participant information sheets and proposed consent forms. I then made arrangements for an initial visit to provide further information and answer any questions about the proposed research process. Following this, ethical approval was sought from the relevant HSE ethics committee. Prior ethical approval had been sought and obtained from the University (Appendix 5). An information sheet on the research project was then forwarded to the Director of Nursing for
dissemination to staff and for public notice boards and dates agreed to commence the study (Appendix 6).

4.7 Ethical considerations

In considering the ethical implications of this research study, I focused on the needs of all participants including managers and staff but in particular residents and families. When defining selection criteria, I sought to be mindful of potential vulnerabilities of residents (O’Neill, 2006) but also of paternalistic decision-making on their behalf (Cooney, 2008). An ethical protocol was drawn up to guide the data collection process (Appendix 7). This included issues of consent, assent, and emotional distress during interview, disclosure of abuse and health and safety concerns. During the interviews two of the residents became tearful when describing their situation and recalling past events. In each of these cases I paused and asked if they wanted to end the interview. In both cases they said no, they wanted to continue. I also asked them at the end if they would like me to tell the staff that they had been upset and again they declined.

Confidentiality was maintained through the use of codes as identifiers. When writing up the narrative, I used pseudonyms alongside codes in order to locate the findings in real people’s lives. On reading through the narrative I made further changes to the text where it became clear to me that individuals may be identifiable by slightly amending excerpts from documents that could have identified people or facilities specifically.

4.8 The participants

A total of 46 individuals participated directly in the study through the interview process. However, the observation process involved a wider participation of participants across the three sites. Those interviewed are broken down by category as follows: 12 residents, 10 relatives, 13 frontline staff, 9 managers and 2 HIQA Inspectors. The notes of an additional 4 residents with dementia were reviewed. One copy of the names of
participants and their allocated codes was retained separately in a locked cabinet in my office.

### 4.8.1 Selection of residents as participants

The selection of residents to be invited to participate in the study was made in consultation with the Director of Nursing in each locality in that the director provided a list of all residents and identified residents who, in her professional opinion, would not be able to participate due to their cognitive status or illness.

I also sought their guidance to direct me towards individuals who were resident for less than three months and those who had lived there for more than a year. The purpose of this was to capture the observations of newly admitted residents who may more accurately recall the social relations surrounding their admission and care planning processes while wanting to understand the embedded social relations that residents who had lived there for a long time might elucidate.

After that, I spent some time located in day rooms and in wards chatting with residents where I told them the purpose of my presence. In doing so I also established whether individuals appeared to have a level of cognition that would allow them to participate meaningfully in the interview process. Mindful of the need to include residents who were bed-bound and those who appeared to have a range of disabilities which would require significant care input, I then invited interested residents to consider the participant information (Appendix 8), and stated that I would return within a few days to see if they wished to be involved. The participant information leaflet was designed to describe the research purpose and process as simply as possible and in large print. In a number of cases where residents stated that their eyesight was poor, I went through the form with them and explained what I was doing in layman’s language. I also suggested that they might, if they wished, discuss the information sheet with their relatives or a staff member.
Table 4.2  Participant Selection for Interview Protocol (Residents)

Obtain a list of residents in the facility from the Director of Nursing.

Include:

- Newly admitted residents (less than 3 months).
- Residents that have lived in the facility for over 6 months.
- Residents that can communicate independently.
- Residents that have some communication or cognitive impairment but who can understand and respond to questions.
- Residents that can respond through yes/no answers.
- Residents who are unable to communicate but who, in the opinion of the manager have relatives or close friends who may be willing to participate.

Exclude:

- Residents who do not live permanently in the facility.
- Any resident who has a history of serious mental or physical illness that participation could cause additional distress.

4.8.2 Selection of frontline staff as participants

The purpose of recruiting staff as participants was to gain insight into their everyday work and how it is organised and coordinated. Staff participants were randomly selected from personnel lists provided by the Director of Nursing and were forwarded letters of invitation to participate along with participant information sheets (Appendix 9) in advance of a follow-up telephone call. Only nursing and care staff were selected based on the rationale that these staff worked closely with residents on an everyday basis while other staff visited more intermittently and as such were not part of the all-day/everyday rhythms of the unit. The balance between nurses and care assistants reflected the skill mix within each facility. Agency staff and staff employed for less than three months were also excluded. The letter of invitation offered the opportunity to be interviewed at their work location or at another location of their choice. All opted to be interviewed at work. The majority of the interviews took place during the course of the work day.
However, three staff came in during their free time in order to coincide with my time in the facility. As staff opted to be interviewed during the working day it was not possible to be completely confidential about their participation as their managers were aware that they had absented themselves for the duration of the interview. However, confidentiality of the content of the interview was assured.

Twelve of the thirteen staff were interviewed using a semi-structured interview guide which allowed for further probing about what actually happened and how things worked. During these interviews nursing staff talked about their ‘textual work’ of compiling care plans and recording work activities in care flow sheets. In order to gain further insight into how this work was done, I conducted one additional interview with a nurse who described for me the ‘textual work’ of care planning. This identified nurse was suggested by the Director of Nursing, I sought her out, verbally outlined the purpose of the study and sought her participation to which she readily agreed.

Table 4.3 Participant Selection for Interview Protocol (Staff)

<table>
<thead>
<tr>
<th>Step</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Obtain personnel list from Director of Nursing</td>
</tr>
<tr>
<td>2.</td>
<td>Randomly select names (select every 3rd name)</td>
</tr>
<tr>
<td>3.</td>
<td>Select numbers of nursing staff and health care assistants in line with the skill mix of each facility</td>
</tr>
<tr>
<td>4.</td>
<td>Forward invitation to participate, and participant information sheet</td>
</tr>
<tr>
<td>5.</td>
<td>Follow up phone call</td>
</tr>
<tr>
<td>6.</td>
<td>Where potential participant refuses, exclude from list and repeat selection process as above</td>
</tr>
</tbody>
</table>

Include:
- Nursing Staff
- Health care assistants
- Permanent or long term temporary staff
4.8.3 Selection of relatives as participants

Relatives were selected through a combination of methods, including asking the resident if I could make contact with their family members, opportunistic requests to family members visiting, and as I also wanted to capture the experiences of relatives of residents who could not participate in the study due to their advanced stage of dementia, the manager suggested some relatives who in their opinion might be willing to participate. These contacts where all provided with a written invitation and participant information sheet which I followed up with a phone call (Appendix 10). Again all were offered an opportunity to be interviewed in their own home or an alternative location of their choice but all agreed to be interviewed in the residential care facility. No relatives declined to participate.
Table 4.4  Participant Selection for Interview Protocol
(Relatives)

- Seek advice of Director of Nursing
- Request introduction from Director of Nursing or Ward Manager
- Request permission of resident to approach family member
- Request participation from family members visiting
- Forward letter of invitation and participant information sheet, or provide participant information sheet in advance and follow up with phone call

Include:
- Family members of residents with dementia who cannot consent independently
- Family members of participating residents or other non-participating residents

Exclude:
- Family members of people availing of respite

4.8.4  Selection of managers as participants

The purpose of interviewing managers is to gain insight into how things are socially organised and how the everyday work of staff connected to the external ruling relations. Therefore, the selection process was somewhat different. In the first site, the Director of Nursing was identified by me as a key informant as the setting was small and she was close to the everyday forms of work such as rostering and human resource management. She also had been involved in the person centred care programme and through her work as ‘person in charge’ (HIQA, 2009) was involved in the regulatory process.

In the second site, I widened the selection process to include an Assistant Director of Nursing as well as the Director of Nursing. This was because as
a large facility the Assistant Director was involved more closely in the institutional work of rostering and human resource deployment and was also involved in the person centred care programme. The Director has a greater role in policy development and interfacing with the regulatory process. In the third site, I included an Assistant Director and a Ward Manager, both of whom had been involved in the person centred care programme and were involved in the day to day management work of the facility.

From this process, I sought participation of managers further up the chain of command in order to make further connections between what was happening in the sites and the wider social relations that shaped these. These included a manager of services for older people, a practice development specialist and a regional manager. In the case of the regulators the national manager was approached initially and agreed to circulate correspondence from me inviting participation from inspectors in the relevant HSE administrative areas. Five inspectors responded and two were selected based on their geographical location. The inspectors were not made aware of the specific residential care units that participated in the study. This process aligns with IE methodological goals of incrementally widening the pool of informants as social relations become visible and lines of inquiry are followed.
4.9 **Consent**

Each participant was asked to sign a consent form prior to being interviewed which I went through verbally, clearly articulating their right to withdraw at any stage of the proceedings (Appendices 11-13). Permission was sought and obtained to use a digital recorder to record the interview. I used the process of obtaining consent by proxy in order to observe individuals who could not consent and to have access to their care plans (Appendix 14). I did not attempt to interview them although I did converse with them in the course of my time in the units in line with normal social convention. My reason for doing so was to ensure that I did not exclude people with dementia from the study as this is a common condition within residential care and how the lives of people with dementia are organised is a critical element of this study.

---

**Table 4.5  Participant selection for Interview**

/Internal Managers/

<table>
<thead>
<tr>
<th>Discuss management roles with Informant (Director of Nursing)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include:</td>
</tr>
<tr>
<td>• Managers who are involved in everyday internal management</td>
</tr>
<tr>
<td>• Managers who are involved in policy development and</td>
</tr>
<tr>
<td>• Managers who interface with regulators</td>
</tr>
<tr>
<td>• Managers who were involved in person centred care</td>
</tr>
<tr>
<td>programme.</td>
</tr>
</tbody>
</table>

Exclude:  
• No exclusions
4.10 Consent for observation

In this study, I did not observe personal care routines. I did, however, locate myself within ward areas while care was being undertaken behind curtains and the conversations could be overheard. I sought verbal consent from those in a position to consent within these environments, i.e. residents who were cognitively intact, the ward manager, staff and relatives. At all times, when I introduced myself to people in the site, I made explicit my purpose of being there.

4.11 Data collection

Institutional ethnographers use conventional tools of qualitative research such as interviewing, observations, reflexivity and the analysis of texts, all of which were used in this study.

Interviews were semi-structured (Appendix 15) and the observational process was non-participant. (Appendix 16). Field notes recorded details of additional opportunistic conversations and general observations that occurred outside the formal observation periods, potential threads of inquiry, and connections between pieces of data and to flag issues which needed to be explored further (Appendix 17). A reflective journal was used to record my personal feelings to examine potential bias and to ask questions about what I was seeing (Appendix 18).

There were two levels of data collection. The first centred on the ‘work’ or activity that residents did as they went about their daily lives, what they intended to do, what activities they undertook that involved time, effort and skill and what their feelings were about this (Campbell and Gregor, 2004; McCoy, 2006; Sinding, 2010). Because many residents have advanced dementia and as such are not in a position to articulate their experiences, observation and interviews with relatives were also undertaken. This is not to consider that relatives are in a position to recount the experiences of their family members but rather to add to the knowledge of the social relations that exist within each facility.
The next stage involved gaining insight into how staff and internal managers undertook their daily work, what they did, how it is organised and what texts are involved in shaping this work. Because it was my intention to disrupt the research sites as little as possible and because the timing of interviews was controlled by residents and relatives and the availability of staff, these data collection processes did not happen sequentially. I moved forward and back between residents and staff interspersed with periods of observation. Rather than this being a limitation, the processes allowed me to see the intersection of the world of residents and staff, raising possible threads to be pursued. This aligns with a key analytical goal in IE whereby the researcher begins the process of data analysis in the field. (DeVault and McCoy, 2006; Deveau, 2008). The following section provides an account of the data collection strategies employed and the way they were used to meet the goal of explicating social relations.

4.12 Interviews with residents

The interview guides were shaped by the problematic and devised to elicit information about actual everyday activity – how things worked. Beginning with a request for concrete information about the work of being a resident, I asked each one to recall what they did at particular times of the day typically segmented into morning, afternoon, early evening or night time. Further topics included how they came to be living there, their first interactions with the system, their relationships with staff in general, whether they had ever made a compliant and their involvement in care planning and the running of the day. While the interview guide helped to maintain a focus on the issues of person centred care as identified in the problematic, I also listened for ‘threads’ which pointed to extra-local coordination to be pursued in order to understand how things worked.

The residents I interviewed all had physical or mild cognitive deficits but had the capacity to consent. In some cases I had to adapt my interviewing style to allow for sensory impairments such as deafness or difficulties in
speaking. As several of the participants were visibly frail I was mindful of, and observed, their body language for signs of fatigue. The issue of cognition is also a key issue in interviewing older people. Capacity to consent is one issue but so too is the reliability of the person with dementia’s response. People in the advanced stages of dementia cannot be interviewed except by proxy although others ways of communicating may be possible (Dewing, 2002). However, people with early or middle stages may present with socially intact behaviours which may conceal significant cognitive deficits. How therefore can the researcher be sure that the accounts related by the participant are accurate? Conversely, presumptions that what the older person is saying is not valid because of their cognitive difficulties can lead to a dismissal of valuable data. In this context where the objective is to gain an insight into institutional processes, the recollection of routines and embodied experiences are used merely as clues or hooks and as such I was not seeking meaning or interpretation by the resident. A number of individuals who had self-professed mild memory loss participated in the study and were able to recall institutional processes and routines similar to other informants with no memory loss.

The Interviews with residents therefore focused on getting a descriptive account of the work they undertake in their role as residents. As power is a key issue of interest, I was conscious of my power as a researcher and member of the ruling relations. I attempted to, as far as possible, create equitable relations and to conduct the interview as informally as possible. I suggested that the resident chose the time and location of the interview and stated that I considered them to be experts in their own lives and that I wanted to know about that. Diamond (1992) contends that in Institutional ethnography the text should not be privileged over the embodied experience. In this context I paid close attention to the body language and emotional responses of the participants. For example, there were several instances where residents who were, in the minutes before, passively describing their daily routines or relationships within the facility became animated when talking about family members or subjects that interested them. Interviewing in this way requires the researcher to continually analyse the sequence of
connected activities and to constantly look for elements of social organisation in the everyday experiences as they are recounted. In this context the process requires more than simply asking questions and listening to the answers provided. The process of analytical thinking begins in the interview (Deveau, 2008) and is followed up as soon as possible with written reflections, and field notes of connections and possible new lines of inquiry.

4.12.1 Profile of residents

Twelve residents were interviewed and their nursing notes reviewed, while an additional four who had advanced dementia were observed and their notes reviewed. The residents ranged in age from 72 to 94. Each of their interviews reflected different individuals with different life experiences although their descriptions of their current daily lives were remarkably similar. Ten were married or widowed and six were unmarried. The length of time in the facility ranged from 1 month to 5 years. Each resident had their own narrative (Gubrium and Holstein, 2002) but the focus of this process is not to understand meaning in their lives but rather to elicit common threads of the ‘work’ of being a resident in a public long-stay facility that could be tracked back to text-based ruling relations (Smith, 2005). Table 4.6 provides a summary of the demographical profile of residents who participated directly.
Table 4.6 Participant Resident Demographic Information

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Occupation</th>
<th>Length of time in facility</th>
<th>Dependency status</th>
</tr>
</thead>
<tbody>
<tr>
<td>S.1.RES.1</td>
<td>79</td>
<td>M</td>
<td>Single</td>
<td>Labourer</td>
<td>11 months</td>
<td>High</td>
</tr>
<tr>
<td>S.1.RES.1</td>
<td>82</td>
<td>F</td>
<td>Single</td>
<td>Nurse</td>
<td>18 Months</td>
<td>High</td>
</tr>
<tr>
<td>S.2.RES.1</td>
<td>90</td>
<td>F</td>
<td>Widowed</td>
<td>Housewife</td>
<td>5 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.2.RES.2</td>
<td>78</td>
<td>M</td>
<td>Widowed</td>
<td>Builder</td>
<td>3 Months</td>
<td>High</td>
</tr>
<tr>
<td>S.2.RES.3</td>
<td>80</td>
<td>M</td>
<td>Single</td>
<td>Labourer</td>
<td>3 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.2.RES.4</td>
<td>85</td>
<td>F</td>
<td>Single</td>
<td>Housekeeper</td>
<td>5 years</td>
<td>High</td>
</tr>
<tr>
<td>S.2.RES.5</td>
<td>83</td>
<td>F</td>
<td>Widowed</td>
<td>Housekeeper/Farmer</td>
<td>1 month</td>
<td>High</td>
</tr>
<tr>
<td>S.3.RES.1</td>
<td>84</td>
<td>M</td>
<td>Single</td>
<td>Farmer</td>
<td>2 years</td>
<td>High</td>
</tr>
<tr>
<td>S.3.RES.2</td>
<td>82</td>
<td>M</td>
<td>Single</td>
<td>Farmer</td>
<td>3 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.3.RES.3</td>
<td>94</td>
<td>F</td>
<td>Widowed</td>
<td>Housewife</td>
<td>1 year</td>
<td>High</td>
</tr>
<tr>
<td>S.3.RES.4</td>
<td>80</td>
<td>F</td>
<td>Widowed</td>
<td>Housewife</td>
<td>6 months</td>
<td>High</td>
</tr>
<tr>
<td>S.3.RES.5</td>
<td>72</td>
<td>F</td>
<td>Widowed</td>
<td>Housewife</td>
<td>1 year</td>
<td>High</td>
</tr>
</tbody>
</table>

An additional four residents who were unable to participate directly were represented by relatives.

Table 4.7 Residents represented by relatives

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Occupation</th>
<th>Length of time in facility</th>
<th>Dependency status</th>
</tr>
</thead>
<tbody>
<tr>
<td>S.2.REL. RES.1</td>
<td>81</td>
<td>F</td>
<td>Widowed</td>
<td>Housewife</td>
<td>3.3 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.2.REL. RES.2</td>
<td>79</td>
<td>F</td>
<td>Married</td>
<td>Housewife</td>
<td>2 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.2.REL. RES.3</td>
<td>85</td>
<td>F</td>
<td>Married</td>
<td>Housewife</td>
<td>4 years</td>
<td>Maximum</td>
</tr>
<tr>
<td>S.2.REL.</td>
<td>80</td>
<td>M</td>
<td>Married</td>
<td>Farmer</td>
<td>7 months</td>
<td>Maximum</td>
</tr>
</tbody>
</table>
4.12.2 Interviews with frontline staff

While the process of Institutional ethnography begins with the experience of those whose standpoint is adopted, it must go beyond that to gain insight into how these experiences are concerted and coordinated. There are many aspects of the work of facilities that are unseen and unknown by residents yet impact on their experience. Staff were interviewed to gain insight into how their work is organised and about the texts that they use which govern this work. Embedded in participants talk about their work is the tacit knowledge of how to do it, and how to concert their actions with others (Campbell and Gregor 2004, p. 79). Therefore the objective was to get to the actualities of the work by asking the participant to describe in detail what they actually did.

When interviewing staff I was conscious of the importance of getting beyond professional discourse to how things actually work. Regularly when asking staff about what they do, they would begin by describing what should or could be done in an abstract way and I needed to steer them back to what actually happened. Again the device I used for this was to ask them to describe what they did that morning or the last time they were on night duty. In this way I was looking at what frontline staff actually did as opposed to what their job description said they did. I was also alert to instances of ‘bifurcated consciousness’ (Townsend, 1998; Smith 1987, p. 41) where staff expressed tension between their values and beliefs and the social relations within which they worked.

<table>
<thead>
<tr>
<th>Role</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Nurse</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Health Care Assistant</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
4.12.3 Interviews with relatives

In addition to frontline staff as informants, relatives of residents who have dementia and relatives of some of the residents who were interviewed and three relatives who were not connected to any of the participants were also undertaken in order to seek further insight into the coordinated activities of the residential care units. The aim was to gain an understanding of their lives, likes and dislikes before they came to live in residential care and their involvement in care planning and with staff. This process was useful in gaining insight into the relationship ‘work’ between relatives and staff and in relation into the experience of transitions into care. The process yielded little useful information about the everyday lives of residents as relatives were unable to describe much about their lives as they were only present for specific periods of time and usually at the same time such as afternoons. Initially I considered this lack of knowledge in a negative way. However, my thinking on this changed through the process of reflection and analytical writing. I reflected on how little relatives seemed be involved in the care of their family members, not in a neglectful way but through the social relations of the work of residential care.
Table 4.9  Relatives interviewed

<table>
<thead>
<tr>
<th>Code</th>
<th>Gender</th>
<th>Relationship to resident</th>
<th>Resident participant</th>
<th>Resident by proxy</th>
<th>Non-participant residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>S.1 REL</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>S.2.REL.1</td>
<td>F</td>
<td>Daughter</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.2.REL.2</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.2.REL.3</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.2.REL.4</td>
<td>M</td>
<td>Son</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.3.REL.1</td>
<td>M</td>
<td>Son</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.3.REL.2</td>
<td>F</td>
<td>Daughter</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>S.3.REL.3</td>
<td>F</td>
<td>Daughter</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>S.3.REL.4</td>
<td>F</td>
<td>Daughter</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>S.3.REL.5</td>
<td>M</td>
<td>Son</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

4.12.4 Interviews with managers and external personnel

Finally, as part of the process of mapping the social relations, internal and external managers, specialists and regulators were interviewed in order to further explore some of the threads that were beginning to appear and to gain further information about the texts that governed work processes. These managers were also sensitised to the wider ruling relations stakeholders and the power relationships that existed between various social institutions such as staff representative groups, professional bodies and regulators providing useful signposting to externally coordinated social relations.
Table 4.10  Internal and External managers (including HIQA inspectors) interviewed

<table>
<thead>
<tr>
<th>Role</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director of Nursing</td>
<td>2</td>
</tr>
<tr>
<td>Assistant Director of Nursing</td>
<td>2</td>
</tr>
<tr>
<td>Ward Manager</td>
<td>1</td>
</tr>
<tr>
<td>Manager of Services for Older People</td>
<td>1</td>
</tr>
<tr>
<td>Regional Manager</td>
<td>1</td>
</tr>
<tr>
<td>Practice Development Specialist</td>
<td>1</td>
</tr>
<tr>
<td>Advocate</td>
<td>1</td>
</tr>
<tr>
<td>HIQA Inspector</td>
<td>2</td>
</tr>
</tbody>
</table>

4.13 Data Storage

The recorded interviews were transcribed by me and stored using an Nvivo software programme. The programme was used as a data management system to store interview transcripts, observation records, and field notes. As part of this data management process I developed a coding strategy following Miles and Huberman (1994). I allocated a code to each site and each participant group. After this each participant was allocated a number based on the chronology of the interview process. Observations and field notes were similarly coded.
Table 4.11  Identifier Codes

<table>
<thead>
<tr>
<th>Identifier Codes</th>
<th>Location</th>
<th>Participant group</th>
<th>Texts</th>
</tr>
</thead>
<tbody>
<tr>
<td>S.1. - Site 1</td>
<td>Res</td>
<td>Residents</td>
<td>Int - Interview</td>
</tr>
<tr>
<td>S.2. - Site 2</td>
<td>Rel</td>
<td>Relatives</td>
<td>Obs - Observations</td>
</tr>
<tr>
<td></td>
<td>SN</td>
<td>Staff Nurse</td>
<td>FN - Field note</td>
</tr>
<tr>
<td>S.3. - Site 3</td>
<td>HCA</td>
<td>Health Care Assistant</td>
<td>CP - Care Plans</td>
</tr>
<tr>
<td></td>
<td>IM</td>
<td>Internal Manager</td>
<td>SOP - Statement of Purpose</td>
</tr>
<tr>
<td></td>
<td>EM</td>
<td>External manager/HIQA Inspector/Advocate</td>
<td>Refl - Reflection</td>
</tr>
</tbody>
</table>

Therefore the first resident who participated became S1.RES.1.INT.

4.14  Field notes

During fieldwork, I kept detailed notes of conversations and comments – recording verbatim what people said, and observations that occurred outside of formal observation sessions. Initial thoughts, feelings and ideas about possible threads to follow were recorded intermittently throughout the day in a quiet location away from the communal areas during field work. This was followed by a more detailed account that evening. I wrote up notes about specific threads that I could see using this process to explore possible connections to other pieces of data such as policy documents or regulatory standards.

4.15  Observations

The intention of using observation in this study was to seek additional information and insights into the problematic. In this context, what I was looking for was evidence of activities that were aligned to the discourse of
person centred care (the problematic) and evidence of activities that did not. The guide was also influenced by the IE ontological assumptions that all activity is socially organised, therefore I was looking for evidence of coordinated activity (social relations). Because the assumption in IE is that this activity is coordinated across multiple sites, I used the same observation guide across the three settings.

4.15.1 Observation guide

The observation checklist had four columns, one which recorded date and time, one for a description of the activity or observation, one to record elements of person centred care (the problematic) and one to record social relations. I loosely used McCormack and McCance’s framework to guide my observations (see appendix 1). So, for example, when I observed the daily ritual of the handover meeting, I noted this as ‘staff relationships, shared decision making’ and ‘technical competence’. I then had a column for social relations, where I looked for threads between the PCC elements and other organisational practices. This helped me to consider the social relations that preceded specific activities and what came after them. For example, I observed the demarcation between physical spaces and artefacts that underpin the power differentials between staff and residents, such as different crockery and staff toilets leading me to seek out the associated rules and regulations. I also paid attention to the language of staff while observing the daily ritual of the handover meeting. I watched and listened to how staff interacted with one another and the language they used to convey information about residents and the daily routines of the facility.

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Observation</th>
<th>Problematic (PCC)</th>
<th>Social relations</th>
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</thead>
<tbody>
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</tbody>
</table>
4.15.2 Observation Method

I adopted the role of non-participant observer with mobile positioning which allowed me to move between locations through the facility (Casey, 2005). During the observation period I retained a stance of observer by using a clip board and taking notes in order to reinforce the reason for my presence there as a researcher. I used the observation guide to record observations and descriptions of physical environments, interactions between social actors and accounts of actual activities such as reminiscence groups or mealtimes. A process of time sampling was undertaken and the observations took place across 2 hour segments of time in order to capture the materiality of routines and activities at different times of the day starting with the start of the ‘shift’.

I undertook periods of observation, interspersed with interviews, to cover 12 hours of the day in each site. I did not observe night shifts but discussed these with informants during interviews or informal discussions.

**Table 4.13 Observation Schedule**

**Site 1**

<table>
<thead>
<tr>
<th>Date</th>
<th>8.00-10.00</th>
<th>10.00-12.00</th>
<th>12.00-2.00</th>
<th>2.00-4.00</th>
<th>4.00-6.00</th>
<th>6.00-8.00</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.12.2010</td>
<td></td>
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<tr>
<td>03.01.2011</td>
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<td></td>
</tr>
</tbody>
</table>

**Site 2**

<table>
<thead>
<tr>
<th>Date</th>
<th>8.00-10.00</th>
<th>10.00-12.00</th>
<th>12.00-2.00</th>
<th>2.00-4.00</th>
<th>4.00-6.00</th>
<th>6.00-8.00</th>
</tr>
</thead>
<tbody>
<tr>
<td>08.04.2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.04.2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>28.04.2011</td>
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</tr>
</tbody>
</table>
The observation notes were typed up and stored in Nvivo alongside the transcribed interviews, field notes, memos and personal reflections diary.

### 4.15.3 The Observation Process

Verbal consent was obtained in each location and I located myself in places that allowed me to observe and hear what was going on without observing intimate care routines. For example, I sat at the entrance to a communal ward or just outside it observing early morning routines such as breakfast, drug rounds and the daily work of staff as they moved between residents. I also observed activity and inactivity in day rooms and sat in general lobby areas observing the comings and goings of relatives and other health professionals. I also observed staff handover meetings. The experience of the observational periods was recorded in a reflective diary a few hours after the event in order to make explicit the personal positioning and to seek connections and hooks into social relations that are coordinated extra-locally. Field notes were written up based on the observations which were then used in analytical writing.

### 4.15.4 The embodied experience of observation

By far the most challenging aspect of this observational process was the long periods of inactivity that residents experience. This resonates with Diamond’s (1992) experience while working as a care worker in an American nursing home and the notion that the ‘work’ of the resident may be sitting around doing nothing. What I wasn’t prepared for was the intense feelings this process invoked in me, recorded in a reflexive diary, of
discomfort, embarrassment, boredom and stress as I struggled to describe this material world. Diamond (1992) described the embodied experiences of dealing with bodily fluids and intimate care routines that make up the daily work practices of staff. I did not undertake those work practices and as such my observation processes were more akin to the ‘work’ of the residents in that I wasn’t able to keep myself busy ‘doing things’.

I struggled to put words down on paper as I sat in communal areas – sometimes grateful for the television or the distraction of a staff member breezing through on their way to another task – and welcomed the noise of the food trolleys trundling down the corridor as a welcome distraction from this uncomfortable experience. I wrote copious notes about the physical environment detailing every aspect of the rooms and wondered if I should have undertaken a ‘molecular’ observation whereby I would have boxes to tick as a means of doing something.

4.16 The explication of texts

During the data collection phase I paid attention to what texts were used by staff in their work. I also listened during interviews for references to texts that shaped their practice. This led me to the assessment and care plan, the nursing notes and the care flow sheet as I observed nurses working on these texts in offices and at nurse’s stations. Permission was sought in general from the Director of Nursing and then specifically from participating residents and relatives to access and photocopy their written nursing notes. Each participant’s notes were photocopied and all identifying material was concealed. Each participating resident’s notes (sixteen residents in total) were placed in individual files with the same code as was used for interview transcription or in the case of residents who could not participate independently in a code connected to their relative (for example, S.1.Rel.Res.1) These records were stored securely in a locked cabinet in my office. Following on from this, I sought out other operational texts that connected what happened in the local settings to national policies,
regulatory and legislative texts in order to make visible the social relations that are textually mediated (Appendix 19).

Firstly, a systematic search of all policy manuals in each location was carried out and logged. I then searched for references to what Dorothy Smith (2005) describes as ‘boss texts’ which provide authority and direction to local policies. From here I obtained digital or paper copies of standards, regulations primarily legislation, national policy texts and guidance and directives from professional bodies which were also logged. Other context-specific texts that were clearly and publicly visible in the facilities such as the units ‘statement of purpose’, their information booklets and public notices, were then included.

4.17 Section summary

The above section outlined the methodological steps undertaken in establishing this study commencing with the articulation of the problematic and standpoint. A profile of the research settings and the participants was provided. I described how I gained access to the sites, the ethical considerations and the data collection processes that were used. The following section outlines the steps undertaken to ensure rigour in this study addressing reflexivity and issues of potential bias.

4.18 Maintaining rigour

Institutional Ethnography requires the researcher to identify concrete evidence of social relations which coordinate people’s lives. Therefore a key objective is discovery of the social and in this context mapping is used to identify the textually-mediated processes that drive social relations (Campbell and Gregor, 2004). Explication rather than explanation is the goal where a clear account of the textual processes and their sequence makes visible the interconnectivity between them and peoples actions as they engage in their everyday lives. Therefore rigour is demonstrated though accurate and truthful accounts, of what actually happened and how things actually work.
Chapter 4: Method

The research must produce accurate and faithful representations of how things actually work; it must be truthful. (Smith 2005, p. 42).

In this study I maintained rigour through a number of steps as recommended in the Institutional ethnography texts. I retained an audit log of each step of the analytical process outlining what I was doing and why. This included retaining a log of the mapping process and adopting a reflective questioning stance throughout the research process. I began from the standpoint of residents and from there moved outwards to frontline staff and from there to internal managers and, finally, to external managers, seeking out and making connections between the social relations of the identified threads and incorporating these into the analytical writing process.

The textual analysis involved mapping the hierarchy of texts moving from those closest to the resident and frontline staff through to local policies and management practices and then onto national standards and the legally binding Care and Welfare Regulations (DOHC, 2010). I retained a copy of each text in sequential order in the audit log.

I checked facts and my understanding of texts with staff and manager participants and sought their assistance in seeking out connecting texts. However, I did not attempt to triangulate the experiences of participants with written reports or care plans as to do so makes an assumption that those texts are factually correct, which may not be the case (Smith, 2005).

I adopted the approach a reflective questioning approach recommended by Rankin et al. (2009) of rendering everything as ‘fundamentally mysterious’ as a means of questioning taken for granted practices and seemingly neutral organisational practices. I adopted a critical stance towards heretofore taken for granted textually-mediated policy and legislative actions posing the questions ‘Who produces what and for whom?’ (Campbell and Gregor, 2004; Lirette, 2012).
I consistently made notes about what I was seeing and returning to the methodological goals to check if what I was thinking was consistent with these goals.

4.18.1 Reflexivity

Smith (1987) proposes that it is impossible to separate out the investigator from the investigation and in IE researchers are required by locate their own embodied knowing in the research process. My own embodied experience of working in the area as a health care professional, together with knowledge of how policies and professional discourses are formulated, my awareness of some of the disjunctures that exist within this sector, and the experience of the dynamics of power that exist between families and professionals all serve as ‘knowing’. This form of ‘knowing’ can be drawn on explicitly in the analysis process as it is not bracketed off or denied (Campbell and Gregor, 2004).

However, my position of being a researcher of white middle class and of working age, employed in health services management, locates me firmly within the ‘ruling relations’ where as part of my work I define and promulgate professional discourse through the development of policies, procedures and performance indicators. My location in what Thomas (2004) describes as ‘the cult of adulthood’ could also lead me to make assumptions about older peoples desired levels of activity based on my own levels of energy. I maintained a reflexive journal during fieldwork and through the data analysis process to capture my own embodied experiences, to process my thoughts and observations across the three sites, checking my motivations for pursuing particular lines of inquiry. This also helped me to stay focused on ‘what happens’ rather than seeking out theorised explanations as to how things happen.

For example, I noted how most staff participants used the terms ‘resident’ and ‘patient’ interchangeably. Rather than drawing conclusions about the inadequacy of training or personal competence, I sought evidence of how
these staff received constant reminders of a resident’s status as ‘patient’ through the texts they encountered on a daily basis in which biomedical terminology dominated.

4.18.2 Bias

In IE a very clear standpoint is adopted, in this case older people who live in residential care settings. Adopting the standpoint of one particular group could be considered as bias. The intention, however, is to serve the standpoint of those that are marginalised and the personal standpoint makes this explicit from the outset. However, another potential bias emerged during fieldwork.

As I engaged in conversations with willing staff participants, listened to their stories about the endless round of heavy physical work, observed their constant movements throughout the facilities as they cajoled, encouraged and negotiated with residents, I found myself sympathising with their situation and even understanding how their ‘busyness’ subordinated the needs of residents for social interaction and engagement. Maintaining the standpoint of the resident was helpful in keeping me orientated towards the social relations that coordinated their lives and returning again and again to their talk and actions helped me to stay grounded in their everyday lives. By attending to concrete actions and social relations of situations, as opposed to opinions and theories, I avoided drifting towards interpreting or drawing conclusions about the motivations or intentions of individuals as this is not the methodological goal.

So, for example, when staff complained about the onerous repetition of filling in the care work flow sheets, rather than seeking evidence to confirm or reject this I considered: what is the purpose of this activity, were did this text come from and where does it go to next?
4.18.3 Immersion in the methodology

Institutional ethnography is growing as a form of inquiry as evidenced by the increasing body of literature emerging in professional journals and on digital dissertation sites such as PROQUEST and ETHOS. However, it is still a relatively under-utilised methodology in healthcare when compared to other methodologies.

Therefore as a novice institutional ethnographer I undertook a number of steps to ensure I stayed faithful to the process.

Firstly, I immersed myself in the available literature seeking out seminal works that were quickly identifiable for journal articles located through entering the term ‘institutional ethnography’ in search engines Web of Science and Scopus. Using a snowballing approach I located further sociological and philosophical writings, studies and grey literature. While there is a small but detailed body of conceptual work relating to Institutional ethnography, and numerous journal articles, few of these provide concrete guidance or frameworks to guide data analysis. Retrieving a number of PhD dissertations theses proved helpful in this respect (Bell, 2008; Wright, 2009; Benjamin, 2011; Lirette, 2012).

Through this process, I located and joined an online organisation called the Society for the Study of Social Problems which had a sub-section for Institutional ethnography. From here I made contact with other institutional ethnographers and in November 2011, I attended a workshop ‘Mapping in Institutional ethnography’ in Toronto. The workshop also provided me with an opportunity to discuss my research with others and share experiences of methodological challenges. Finally, a key activity I undertook was discussing IE with my supervisor. Having to justify activities which stood outside conventional qualitative research activities required a constant attention to being faithful to the research methodology.
4.18.4 Record keeping

All recordings, transcripts, observation records, field notes and a log of analytical writing and reflections have been retained. All identifying texts from residents’ documentation have been concealed and the documents stored securely in a locked filing cabinet. The coding strategy has been retained separately to the other data. A log of all documents reviewed and either digital or hard copies of these documents have been recorded in the audit file.

4.19 Section summary

The above section outlined the data collection processes that were used in this study and the steps that were taken to ensure rigour. I have discussed the issues of reflexivity and bias and described how I have immersed myself within the methodology of IE. The following section provides an account of the data analysis process that was undertaken, outlining the sequence and actions that produced this institutional ethnography describing the three key analytical tasks of data analysis, analytical writing and the mapping of social relations.
4.20 Developing an analytical framework

There is no technical fix for finding meaning in Institutional ethnography. You have to read, think, puzzle, write and continue in that view for each piece of data. (Campbell and Gregor 2004, p. 93)

This section begins with an outline of the analytical framework I developed followed by a description of the actual steps of data analysis, how I engaged in the process of analytical writing and the mapping process undertaken. However, presenting the analysis in this sequential way belies the actual process which involved moving forwards and backwards between stages and levels of analysis.

4.20.1 Analytical framework

Table 4.14 below outlines graphically the analytical framework I developed to guide my analysis. As most institutional ethnographies aim to ‘tell a story’ (Bell, 2008), it can be difficult to extract from other works the exact and sequential steps taken in a way that would provide a road map for someone new to IE. I therefore developed my own guide based on the chapter on data analysis in Mapping Social Relations – A Primer in Doing Institutional ethnography (Campbell and Gregor 2004, pp. 83-101) and my knowledge of both the ontology of IE and the conceptual discourse on person centred care as outlined in previous chapters. I followed McCoy’s (2006) key questions related to keeping the institution in view and drew on notes from my workshop in Toronto in relation to the mapping of texts.
### Table 4.14 Analytical Framework

<table>
<thead>
<tr>
<th>Data sources</th>
<th>Key stakeholders</th>
<th>Analysis strategy</th>
<th>Foregrounding</th>
<th>Social relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>First level data analysis</td>
<td>Interview transcripts</td>
<td>Residents</td>
<td>Materiality</td>
<td>Describe what happens</td>
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<tr>
<td></td>
<td>Observations</td>
<td>Relatives</td>
<td>What actually happens?</td>
<td>Provide evidence of actual work undertaken</td>
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<td></td>
<td>Residents’ files</td>
<td>Frontline staff</td>
<td>The problematic standpoint</td>
<td>Provide evidence of texts that coordinate work</td>
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<td>Internal staff</td>
<td></td>
<td>Provide evidence of points of tensions</td>
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<td>Internal Managers</td>
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<td>Interview transcripts</td>
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<td>Residents’ files</td>
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<td></td>
<td>National policy documents</td>
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<tr>
<td>Second level of analysis</td>
<td>Interview transcripts</td>
<td>Frontline staff</td>
<td>The problematic.</td>
<td>Provide evidence of textually mediated coordination of actions</td>
</tr>
<tr>
<td></td>
<td>Observations</td>
<td>Internal managers</td>
<td>Standpoint.</td>
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<tr>
<td></td>
<td>Residents’ files</td>
<td>External Managers</td>
<td>Person centred care discourse.</td>
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<td>National policy documents</td>
<td>Maintaining personhood.</td>
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<td>Care plans</td>
<td>Relationships.</td>
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<td>Care flow sheets</td>
<td>Autonomy.</td>
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<td>National policy documents</td>
<td>Positive social environments.</td>
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<td>Regulations</td>
<td>Smith’s ontology of institutional ethnography</td>
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<td>Interview transcripts</td>
<td>Ruling relations</td>
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<td>Observations</td>
<td>Social relation</td>
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<td>Residents’ files</td>
<td>Creating ideology</td>
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<td>Policy documents</td>
<td>Objectification</td>
<td></td>
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<td></td>
<td></td>
<td>Care plans</td>
<td>The intersection of power and knowledge</td>
<td></td>
</tr>
</tbody>
</table>

McCoys questions (2006). Analytical writing

Materiality

What actually happens?

The problematic standpoint

Describe what happens

Provide evidence of actual work undertaken

Provide evidence of texts that coordinate work

Provide evidence of points of tensions.
4.20.2 First level data analysis

The first analytical task was to articulate the experience of residents as they participate in the daily life of the facilities and to identify potential lines of inquiry to be followed. I read and re-read the transcripts, observation notes and field notes drawing out descriptions of their activities, i.e. getting up in the morning, mealtimes, bathing routines, passing the time, retiring to bed in the evening and logged these as free nodes in Nvivo. Using McCoy’s key questions, described in Chapter 3, I interrogated each piece of data building up a picture of the everyday life of residents, their activities and feelings about their circumstances. I then wrote up an initial account of the everyday life of the residents.

Once this work of residents was articulated, I did the same with the frontline staff. From this I wrote up a descriptive account of everyday life in the residential care settings.

Table 4.15 outlines the descriptions used.

<table>
<thead>
<tr>
<th>Waking and getting up</th>
<th>Meals</th>
<th>Talking to people</th>
<th>Hopes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care routines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Passing the time</td>
<td>Going to bed</td>
<td>Values and Beliefs/ Concerns</td>
</tr>
</tbody>
</table>

I then re-read the transcripts, observation notes and field notes work drawing out data about how staff carried out their care work or in the case of internal managers their everyday work of administration, policy monitoring, human resource management and interfacing with the regulator.

I searched the transcripts, observation notes and field notes for data that would help me understand this daily work, (again using McCoy’s key
questions to interrogate the data), seeking out evidence of the texts that coordinate work and looking for points of tension based on the problematic.

Table 4.16 described the initial potential lines of inquiry that were logged.

**Table 4.16 Potential lines of inquiry**

<table>
<thead>
<tr>
<th>Physical environment</th>
<th>Transition</th>
<th>Task allocation</th>
<th>Spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skill Mix</td>
<td>Routines</td>
<td>Rosters</td>
<td>Risk</td>
</tr>
<tr>
<td>Resources and management</td>
<td>Relationships</td>
<td>Regulation</td>
<td>Purposefulness</td>
</tr>
<tr>
<td>Professional discourse</td>
<td>Power</td>
<td>Personal care routines</td>
<td>Patient activity sheets</td>
</tr>
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<td>passivity</td>
<td>participation</td>
<td>Meaningful activity</td>
<td>language</td>
</tr>
<tr>
<td>innovation</td>
<td>Individual personalities</td>
<td>Independence</td>
<td>Inactivity</td>
</tr>
<tr>
<td>Ideology</td>
<td>Home</td>
<td>Holistic care</td>
<td>Hierarchy</td>
</tr>
<tr>
<td>Grateful</td>
<td>Food and mealtimes</td>
<td>Empowerment</td>
<td>Complaints</td>
</tr>
<tr>
<td>Choice</td>
<td>Care Plans</td>
<td>Busyness</td>
<td></td>
</tr>
</tbody>
</table>

However, on reflection, I could see how some of these were abstract concepts such as ‘passivity’ or ‘empowerment’ rather than evidence of actual happenings. I then returned to the data and searched for concrete social relations that started with what people said happened and actually happenings that I observed for example the ritual of the daily handover or the long periods of silence in the day room. Through staying close to the problematic and analytical writing (which is described in more detail in section 4.20.5), I reduced this to three definite threads of inquiry – relationships, social engagement through decision making and social engagement through meaningful activity. (Maintaining identity was added later from the analysis of the care plans).
Table 4.17 outlines the steps taken in this first level data analysis process.

Table 4.17

First Level Data Analysis

- Interview schedules
- Observation Guides

The problematic
(Implementing Person Centred Care)
IE Theory

Ist Level Data
Transcripts from Participants
Interviews
Observation Notes
Field Notes
Reflective Notes

Data Analysis Guide
(McCoy's Key Questions)

- What is the work that these informants are describing or alluding to?
- What does it involve for them?
- How is their work connected with the work of other people?
- What particular skills or knowledge seem to be required?
- What does it feel like to do this work?
- What evokes the work?
- How is the work geared into the system or institutional organisation?

Identify potential threads to be pursued in Second level Data analysis

Descriptive account
4.20.3 Second level data analysis

The second level of analysis focused on the textually mediated practices of residential care work based on the assumptions of IE that people’s lives are coordinated by textually-mediated ruling relations external to their local settings.

As described earlier, I focused on the texts that staff talked about and that I observed them working on – namely the assessment and care plans, the nursing notes and daily activity record known as a care flow sheet. Sensitised by the discourse of person centred care, I focused specifically on one text within the care plan called *A Key to Me* as a starting point for the analysis. This follows a common IE practice of using a single document to ‘burrow into an organisation’ (Turner, 2001). Rather than taking a blank document and discussing what is meant to happen (an ideological account), I have taken the text that belongs to one resident, Mary, to explore what actually happened.

The selection of this one text was based on the fact that it had a comprehensive set of documents and there were interview transcripts available for both Mary and her Son Seamus. This is entirely consistent with the methodology of Institutional ethnography which does not undertake comparative analysis or use the data as a form of triangulation, but rather as an entry point into the social relations of a setting (Turner, 2001; deMontigny, 1995). As there were no previously defined data analysis frameworks published to guide this analysis, I developed my own based on the writings of Dorothy Smith’s chapter ‘Incorporating texts into Institutional ethnography’ in *Institutional ethnography as Practice* (2005, pp. 65-88). This guideline is outlined in Table 4.18 below.
Table 4.18  Guideline – Analysis of texts

- Text reader conversation
- Work-text-work sequences
- Person centred care principles: values, biography, relationships, well-being, autonomy, positive social environments
- Embodied feelings or experiences
- Evidence of compliance with regulations and standards
- Objectification
- Exercise of professional power
- Evidence of other social relations

Using the data analysis guide as described above, each section of this text as it relates to the person centred principles of maintaining personhood, autonomy, relationships and positive social environments was connected to pieces of data from the transcripts of Mary, her son Seamus, and frontline staff making connections between the two.

The analysis was widened out to include the rest of the care plan, care flow sheet, social activities reporting sheet and relevant HIQA standards and regulations. In this way, I began to ‘join the dots’ (Deveau, 2008) between what actually happens, the professional discourse of person centred care, what the ruling relations demand by way of accountability, and the points of tension between these.

4.20.4  Mapping the social relations

As part of the analysis process, I mapped experiential texts (what actually happened as described in the interview transcripts, observations and field notes) to the A Key to Me and then to the accountability texts of care
planning, reporting and regulation demonstrating how these texts connected to each other. I used my own existing knowledge of accountability practices and drew on the knowledge of participant managers to identify the coordinating texts both internally and externally. This led me to internal policy documents, mission statements, inspection reports, HIQA standards, the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009, the Registration and Inspection of Nursing Homes and Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2010, Ireland. Drawing on the notes of the workshop I attended in Toronto I developed a mapping guide to support this work seeking out examples of the following:

- Textual hierarchy – where there is evidence of overarching or ‘boss texts’
- Circularity of texts – connections between operational texts and what is required for accountability
- Use of quasi legal language – whether instructions are directive, e.g. the provider shall provide as opposed to the provider may provide.

This mapping guide is outlined in Table 4.19.

**Table 4.19  Mapping Guide**

<table>
<thead>
<tr>
<th>1. Hierarchy texts - Boss texts</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Circularity of texts - accountability circuits</td>
</tr>
<tr>
<td>3. Quasi-legal language</td>
</tr>
</tbody>
</table>

The process of mapping entailed analysing these documents, identifying the connecting pieces of text and following the lines of authority. So, for example, I explicating the differences between the HIQA standards and the textually superior Care and Welfare regulations, drawing out differences between what is aspired to in the standards and what providers were legally bound to do as described in Chapter 1.
Table 4.20 provides an example of the mapping of meaningful activity from ‘what actually happened’ through to the textually dominant Care and Welfare regulations. Despite Mary’s assertion that she ‘did nothing’, the mapping shows a textually-compliant care plan and accountability process.

### Table 4.20  Mapping The Texts

<table>
<thead>
<tr>
<th>M. Ah sure, nothing, I didn’t do anything</th>
<th>The IET care plan adapted to incorporate A Key To Me</th>
<th>Pool Activity checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pool activity profile</td>
<td>Goal identification sheet</td>
<td>Care Flow Sheet</td>
</tr>
<tr>
<td>Religion-mass, oratory, prayer beads,</td>
<td>That Mary is involved in everyday activities which reflects preferences and choices</td>
<td>Social activities chart</td>
</tr>
<tr>
<td>cookery, knitting, newspaper, chatting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>family/staff, art/craft, going out with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIQA standards</td>
<td>Care and Welfare Regulations</td>
<td></td>
</tr>
<tr>
<td>The resident is given opportunities for</td>
<td>The registered provider shall ensure that</td>
<td></td>
</tr>
<tr>
<td>participation in meaningful and</td>
<td>residents are provided with facilities for</td>
<td></td>
</tr>
<tr>
<td>purposeful activity, occupation or</td>
<td>the occupation and recreation of residents</td>
<td></td>
</tr>
<tr>
<td>leisure activities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.20.5 Analytical Writing

A key methodological step in IE is analytical writing (Campbell and Gregor, 2004; Benjamin, 2011). This process of writing and rewriting was used to move the account from ‘what actually happens’ to a demonstration of how this connects to the wider social relations both inside and outside of the residential care facilities. The analytical writing process involved moving from a descriptive account of daily life in residential care to one which provided evidence of the social relations both internal and external to the facilities. Several drafts outlining the work of residents and staff were written up. At this stage I returned to the discourse of person centred care to
align with what I was writing. This helped me pick and choose between lines of inquiry to follow as there were many possibilities. By remaining firmly focused on the standpoint of residents, reading from my own observational notes and the transcripts of what residents said about their lives the issue of ‘doing nothing’ became the most evident thread to be followed. The residents talk about who they related to in the course of the day became the second key thread as I read about how they described their relationships with staff and with other residents. These two threads – doing nothing and not really knowing anybody well – led me to the third thread, how people communicated and interacted with each other in the course of the day. Connecting these back to the PCC discourse I describe these threads as ‘having people to talk to’ (relationships), having a say in the running of the day (social engagement through shared decision-making) and ‘doing nothing’ (social engagement through meaningful activity).

Taking these three threads I began to write another version first seeking out pieces of data that represented what actually happens from the perspective of residents, then pieces of data from other sources such as the transcripts from staff and families that connected to the experience of the resident, either as clear evidence of social relations or as a point of tension to be explored further. Through this I began to build up a picture of the social relations that shape that experience, incorporating evidence obtained from other participants such as managers and regulators and from documents that coordinated work practices trans-locally. Finally, I returned to the literature on person centred care and Institutional ethnography and located my findings within this discourse.
Table 4.21 below summarises the second level data analysis process.

Table 4.21  Second level data analysis

- **Mapping the social relations**
  - Maintaining identity
  - Relationships
  - Social engagement through shared decision-making
  - Social engagement through meaningful activity.

- **Text Analysis Guide**
  - Text Reader Conversion
  - Work-Text-Work sequences
  - Person centred care principles: Values, Biography, Relationships, Well-being, Autonomy, Positive social environments
  - Embodied feelings or experiences
  - Evidence of compliance with regulations and standards
  - Objectification
  - Exercise of professional power
  - Evidence of other social relations
  - Analytical writing

- **Descriptive account of everyday activity in 3 centres (What happens)**
  - Care Plan analysis
  - Mapping Guide (Based on Turner 2001)

- **Write up account**
4.20.6 Methodological Challenges

There were a number of methodological challenges in this study some of which are discussed in more detail in chapter 8. The first of these related to the process of combining the theory of person centred care and Institutional ethnography.

As I moved forwards and back between the concrete accounts of what actually happens and the discourse of person centred care which relies on abstract concepts such as ‘autonomy’ or ‘personhood’, I struggled to connect the two in my written accounts. Connecting concrete happening to the abstract concepts of ‘relationships’, meaningful activity and ‘shared decision-making’ was a key methodological challenge in this study as I struggled throughout the analysis process to merge the concrete and the abstract. The temptation to move into thematic analysis or theory building was immense and at times my analysis showed evidence of what is described as ‘analytical drift’ (Lirette, 2012).

Through a process of analytical writing and retaining a focus on what actually happened, I returned to providing accounts of concrete social relations as was the analytical goal. By checking my drafts against those of other institutional ethnographies, I created new drafts which refocused on the social relations of the setting. Combining the discourse of person centred care with Institutional ethnography in the discussion chapter was challenging. This is because much of the person centred care discourse is positively framed within a language of morality and professional ethics while Institutional ethnography draws attention to marginalisation, and social relations of professional power and control.

Another key challenge was identifying who were the ruling relations. While regulators and external managers could be easily categorised as part of the ruling relations, within the facilities this was less clear-cut. At times the
frontline staff appeared to be just as objectified as the residents and on other occasions their competing needs won out over the needs of residents.

4.21 Summary

This chapter provides an account of the methodological steps I undertook in this study. I describe how the research questions were established using the IE analytical concept of identifying the problematic and standpoint. I outline the rationale for selecting study sites and describe the actions I took to gain access to these sites and to recruit participants. The methods used for data collection – namely, interviews, observations, the use of field notes reflection and textual analysis, are discussed and issues of rigour and bias are addressed. I present the analytical framework used to support the analysis, which draws on the ontology of IE and the conceptual and professional discourse of person centred care. The textual analysis guideline is outlined and the key steps of mapping and analytical writing are described. Finally, the methodological challenges are discussed. The following two chapters report on the findings of this study.

Chapter 5 provides and explication of a PCC text A Key to Me – in the context of its location within the care planning process, exposing a disjuncture between the aspirations of person centred care and the problem-orientated focus of care planning, and between what is written down and what actually happens.

Chapter 6 reports on the findings as they connect to the PCC goals of relationships and social engagement through decision-making and meaningful activity.
Chapter 5: The Analysis of a Person Centred Care Text

5.1 Introduction

In institutional ethnography, analyses of texts are used to seek insight into social relations or as a way of challenging ideological accounts rather than being used for factual information (Campbell and Gregor, 2004).

The assumption is that texts have a coordinating function connecting the work of people to organisational courses of action, which are themselves outlined step by step in documentary forms such as policy directives and legislation. Taking up the IE technique of using a text to ‘burrow’ into the organisation (Turner, 2001), I am using the text A Key to Me (Table 5.1) which connects to the PCC literature relating to maintaining personhood through life story work and being aware of a person’s values, likes and dislikes. The intention is to use this as an entry point into the social relations of the facility and its intersection with the discourse of person centred care. Rather than taking a blank document and discussing what is meant to happen (an ideological account), I have taken the text that belongs to one resident, Mary, to explore what actually happened. The key questions I asked were: what was the purpose of the A Key to Me text? What work did it involve? How did it connect to other texts? What was it intended to produce? What did it actually produce? The analytic focus is on the coordination of the work and activities of both the resident and staff. Sensitised by the person centred principles of maintaining personhood, autonomy, relationships and positive social environments, the site of analysis is the interface between the A Key to Me text, the operational texts of assessment, care planning and reporting and the experiential texts of transcripts, observations and field notes. Mapping is then undertaken to connect this data to regulatory texts.

The analysis shows a disjuncture between the espoused principles of person centred care and what actually happens. It also shows how this new person
centred way of knowing about the biography and ‘wants’ of the resident gets translated back into a problem-oriented frame that seeks to identify ‘needs’ in line with the organisational goals of a healthcare facility, despite the commonly heard mantra that the facility was a ‘home from home’. Prior to discussing the social relations revealed in this analysis, a profile of Mary is presented based on the experiential data obtained in the first stage data collection process. Background information about how the text came into being will then be outlined, together with how it is located in the textual work of assessment and care planning. As the issues which arise in this analysis are connected to those in the following chapter the implications for policy and practice will be outlined collectively following the discussion in that chapter alongside the limitations of the study and proposals for future research.

5.2 A profile of Mary

*Mary is a tiny and frail lady. From her care plan I know that she is 96 years old. I first saw her sitting in the corner of the room with her back to the door and the other residents. After I was introduced to her by a nurse, she invited me to sit down and we engaged in the general polite conversation of two strangers. Her voice was weak and I had to move in close to hear her. Using the paper as a cue, we engaged in some general discussions about the news of the day. After a while, and with some prompting from me, she told me a little about herself, how she was unable to do things for herself and how she came to be in this residential care unit. She talked about her family and how she didn’t want to ‘interfere’ in the lives of her children. She agreed to be interviewed by me and we set up a time. (S.3.FN)*

At the time of my fieldwork, Mary had been a resident for fourteen months. Her admission came about following a hospital stay and she came directly from there to the residential care unit. She described her life as a housewife and mother rearing three children and moving a number of times when her husband got promoted in his public service job. While Mary had been assessed as having the potential to engage in a range of activities when she was first admitted, she had physically declined to a point where she was now unable to engage in anything that required much strength or coordination. At times during our conversations she appeared confused and
at one stage talked about her husband as if he was still alive. She was unsure about the sequence of some events. She gave a spirited description of what was meaningful to her and what wasn’t as she disparagingly dismissed a painting event and talked about her new found enjoyment of the bingo sessions. Although very frail she retained an interest in current affairs and politics. She appeared to hold strong religious views and expressed an anxiety about not being able to get to Mass as often as she would like. In a discussion about the troubles of the Catholic Church she strongly defended it and contended that it was time the media moved on to something else.

During the course of my fieldwork I observed Mary on several occasions. For the most past she sat alone with the paper in front of her. She readily engaged with staff when they spoke to her and I did not observe her engaging with any other resident even at mealtimes. Her son Seamus described how, despite his hopes, Mary had not made friends with anyone and how she kept to herself. He described a personal connection she had to one staff member who was the daughter of a former neighbour whom she had known for many years.

In discussing her hopes for the future, Mary expressed resignation to her situation declaring herself lucky in that her husband’s pension paid for her care, and said that all she wanted now was ‘a happy death’. When the recorder was switched off she said she was afraid to say any more because she needed to be there because she couldn’t look after herself. She expressed no anger at the staff saying they were busy and doing their best. Nor did she express any anger towards her family who, in her words, ‘had their own lives to live’.

This short profile is based primarily on conversations with Mary and Seamus, connecting to their account of ‘what actually happens’. It describes a woman who has insight into her situation, who cares for her family and makes no demands on them, and appears to have few personal connections within the facility. She takes comfort in her spirituality and despite resignation retains some level of spiritedness and agency. This is in marked
contrast to how she comes to be known, textually, through the process of professional recording and goal setting.

5.3 **A Key to Me as part of the Care Plan**

The following section outlines the location of the *A Key to Me* text in the assessment and care planning process and its connections to other texts that are part of the organising system in residential care. The text is part of ‘the care plan’, a folder which contains a range of documents including biographical information, varying assessments relating to, for example, mobility, continence, and skin integrity, narrative notes, identified problems, goals of care and activity reports. Assessment and care plans have a long history in the field of health care and are generally underpinned by theory (Reed and Robbins, 1991; Moore, 2010).

In the field of nursing, models were introduced as a means of defining the profession separately from medicine and, in some cases, to move from task-oriented practice to a holistic model of care centred on activities of daily living (Roper, Logan and Tierney, 2000; Moore, 2010). The core objectives of care planning are considered to be the provision of individualised care, the promotion of continuity of care, and to ensure accountability (Dellafield, 2006; Worden and Challis, 2008; Moore, 2010). The overarching framework of the Nursing Process provides nurses with a systematic framework for assessing, planning, implementing and evaluating care (Campbell, 1995; Moore, 2010).

The facility where Mary lives has adopted an adapted version of the Roper Logan and Tierney (RLT) assessment and care plan (S.3.Statement of purpose) a model which is commonly used in residential care settings in Ireland (Power and Van Lente, 2012; Moore, 2010). Based on Henderson’s theory of human needs and the dependence/independence continuum, it focuses on actual and potential needs relating to twelve activities of living (ADLs) and combines preventative care with identifying and alleviating current problems (Roper *et al.*, 2000; Murphy *et al.*, 2000). According to
Moore (2010), the domains of the RLT model align with the guidelines for care plans provided as an appendix in the HIQA quality standards (Appendix 3 HIQA Standards).

The statement of purpose states that the care plan has been adapted to incorporate additional texts aligned to the contemporary discourse of person centred care. Here new knowledge derived from the practice development programme on person centred care resulted in the insertion of a number of new texts called *My Day My Way* and *A Key to Me* and a *Calendar of Important Events*. Within the same folder as the care plan, reporting texts are used to create accounts of the work that staff engage in. Three reporting templates are provided:

- A nursing observations sheet in which the nurse records vital signs such as temperature, pulse, blood pressure, etc. (Appendix 20).
- A Care Flow Chart which is filled in two or three times daily. It is set out as a grid that is completed according to the codes provided in the guidance document which is connected to the domains of care in the RLT assessment and care plan (Appendix 21 and 22).
- A social activities report, records the activities that the resident partakes in, providing 39 potential activities that a resident can partake in (Appendix 23). These reports are retained for each resident and located in their care plan folder. Periodically, when the file becomes too bulky, these reports are extracted and filed separately for accountability purposes. The textual work of care planning and reporting is primarily carried out by registered nurses (Power and Van Lente, 2012). Activity coordinators and allied health professionals contribute and colour coding or separate sections are used to differentiate the contributions of each. Healthcare assistants or care workers in this study did not undertake any of this textual work of care planning or reporting on an ongoing basis although some said that they had been involved in filling in the *A Key to Me* and other life story work. The *A Key to Me* text appears early on in the sequence of texts immediately following personal details such as name, age and next of kin. Its purpose is to gather and
record details about the resident’s childhood, adolescence and adulthood focusing on relationships, schooling and occupation, hobbies, likes and dislikes. Unlike the rest of the plan, this section is written in the narrative style of ‘I’ where we see, in as far as we know, Mary’s actual words. Table 5.1 outlines its contents.

Table 5.1  
*A Key to Me*

(Adapted from the Pool Activity Level (PAL) Personal History Profile) (Poole, 2008)

<table>
<thead>
<tr>
<th>Childhood</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Where were you born?</td>
<td></td>
</tr>
<tr>
<td>2 What are your family members’ names?</td>
<td></td>
</tr>
<tr>
<td>3 Where did you grow up?</td>
<td></td>
</tr>
<tr>
<td>4 Which schools did you attend?</td>
<td></td>
</tr>
<tr>
<td>5 What was your favourite subject?</td>
<td></td>
</tr>
<tr>
<td>6 Did you have any family pets?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What were their names?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adolescence and Adulthood</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7 When did you leave school?</td>
<td></td>
</tr>
<tr>
<td>8 Any special teenage memories</td>
<td></td>
</tr>
<tr>
<td>9 Did you have any special training?</td>
<td>(e.g. College, Apprenticeship)</td>
</tr>
<tr>
<td>10 What did you work at?</td>
<td></td>
</tr>
<tr>
<td>11 What special memories do you have of work days?</td>
<td></td>
</tr>
<tr>
<td>12 Did you have a partner?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partner’s name /occupation?</td>
</tr>
<tr>
<td>13 Where and when did you meet?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Question</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>14</td>
<td>Where and when did you marry?</td>
</tr>
<tr>
<td>15</td>
<td>What did you wear?</td>
</tr>
<tr>
<td></td>
<td>What flowers did you have?</td>
</tr>
<tr>
<td>16</td>
<td>Where did you go on honeymoon?</td>
</tr>
<tr>
<td>17</td>
<td>Where did you live?</td>
</tr>
<tr>
<td>18</td>
<td>Any children – what are their names?</td>
</tr>
</tbody>
</table>

**Adulthood**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>Any grandchildren – what are their names?</td>
</tr>
<tr>
<td>20</td>
<td>Did you have any special friends?</td>
</tr>
<tr>
<td></td>
<td>What are their names?</td>
</tr>
<tr>
<td>21</td>
<td>When and where did you meet?</td>
</tr>
<tr>
<td>22</td>
<td>Are they still in touch?</td>
</tr>
<tr>
<td>23</td>
<td>Did you have any pets? What were their names?</td>
</tr>
</tbody>
</table>

**Retirement**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>24</td>
<td>When did you retire?</td>
</tr>
<tr>
<td>25</td>
<td>What are your hobbies and interests?</td>
</tr>
<tr>
<td>26</td>
<td>What are the biggest changes for you?</td>
</tr>
</tbody>
</table>

**Likes and Dislikes**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>27</td>
<td>What do you enjoy doing now?</td>
</tr>
<tr>
<td>28</td>
<td>What do you like to read?</td>
</tr>
<tr>
<td>29</td>
<td>Do you celebrate your birthday?</td>
</tr>
<tr>
<td>30</td>
<td>What is your favourite time of year?</td>
</tr>
<tr>
<td>31</td>
<td>What is your favourite colour?</td>
</tr>
<tr>
<td>32</td>
<td>What kind of music do you like?</td>
</tr>
<tr>
<td>33</td>
<td>Is there anything you definitely do not like to do?</td>
</tr>
<tr>
<td>34</td>
<td>Do you have any special routines to your day?</td>
</tr>
</tbody>
</table>
Chapter 5: The Analysis of a Person Centred Care Text

<table>
<thead>
<tr>
<th>35</th>
<th>Do you want people to help you with anything?</th>
</tr>
</thead>
<tbody>
<tr>
<td>36</td>
<td>Do you want people to leave you to do anything on your own?</td>
</tr>
<tr>
<td>37</td>
<td>What are you good at?</td>
</tr>
<tr>
<td>38</td>
<td>Is there anything else you would like to tell us about?</td>
</tr>
</tbody>
</table>

The information in *A Key to Me* is considered useful for providing biographical information that staff can draw on when working with residents as well as helping to focus staff on meaningful activities. Siobhán, an external practice development specialist, describes one of the advantages of having such biographical information. We were talking about how several facilities had adopted the *A Key to Me* text:

**A:** *So has that made a difference now?*

**S:** *I would say it has, I would say that, you know, in some areas – you know, you get pockets – where care for – nursing care is fantastic, and the people know the residents, they know them very well. In some other areas you get a lot of agencies, a lot of turn-over stuff – or you did...so it was great that somebody was able to come in, and read this little, short biography of ‘A Key to Me’ and ‘My Day My Way’ and it puts that resident into context – and it’s there for using – if somebody had behavioural challenges, you know, that care staff or whatever would ask, you know, how do we do that? And have a read of ‘A Key to Me’ and get to know the resident as a person, you know? And it made it – I think it helped...that part.* (S.3.EM.1)

### 5.3.1 *A Key to Me* and person centred care

From the text we can learn about Mary’s background, who her family were, what schools she attended, and the names of family pets. We find out the names of her children and grandchildren and what she wore on her wedding day. We can see that she lost a lot of her friends to emigration. In the section relating to *Likes and Dislikes* outlined in Table 5.2, Mary gives a very clear account about what she likes: *‘Reading the newspaper, knitting, liking a*
“good chat”, and going outside’ (item 27). Liking a good chat appears twice (Item 38).

Table 5.2 Extract From A Key to Me – Likes And Dislikes (Residents)

<table>
<thead>
<tr>
<th>Likes and Dislikes</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you enjoy doing now?</td>
<td>Reading, newspaper, knitting, cycling, going outside.</td>
</tr>
<tr>
<td>What do you like to read?</td>
<td>花园, Independent, Non-fiction, Poetry.</td>
</tr>
<tr>
<td>Do you like to celebrate your birthday?</td>
<td>Not particularly.</td>
</tr>
<tr>
<td>What is your favourite time of year?</td>
<td>Spring or loved gardening.</td>
</tr>
<tr>
<td>What is your favourite colour?</td>
<td>Green.</td>
</tr>
<tr>
<td>What kind of music do you like?</td>
<td>Celli.</td>
</tr>
<tr>
<td>Is there anything that you definitely do not like to do?</td>
<td>No.</td>
</tr>
<tr>
<td>Do you have any special routines to your day?</td>
<td>Not really.</td>
</tr>
<tr>
<td>Do you want people to help you with anything?</td>
<td>More used to looking after everyone else.</td>
</tr>
<tr>
<td>Do you want people to leave you to do anything on your own?</td>
<td>Not really.</td>
</tr>
<tr>
<td>What are you good at?</td>
<td>N/A.</td>
</tr>
<tr>
<td>Is there anything else you would like to tell us about you?</td>
<td>I like a good chat.</td>
</tr>
</tbody>
</table>

The attribute of maintaining personhood connects to the HIQA standards relating to Standards 18 routines and expectations which promote a personalised approach to each individual:

Each resident has a lifestyle in the residential care setting that is consistent with his/her previous routines, expectations and preferences and satisfies her/her social, cultural, language, religious and recreational interests and needs. (HIQA Standard 18, p. 33)

In the Care and Welfare regulation, evidence of retaining a personalised profile on each resident is not required. Rather biographical details such as name, age, next of kin, and date of admission, a recent photograph and medical records are required. A care plan is also mandated but no specific model is required. In item 34 (Table 5.2 above), Mary says she has no particular routines or expectations. A Key to Me connects to the person centred discourse on autonomy by requesting information about what the resident wants to do for themselves and what they want help with. I asked
Mary about some of the choices she could make in the facility. Here we discuss her choices as they relate to her activities of daily living.

**A:** *Ok what did you have for breakfast?*

**M:** Well, I had a bit of porridge.

**A:** *And is that what you would have had at home?*

**M:** Yes.

**A:** *Ok, and if you wanted something different could you have it?*

**M:** Well, I could but I don’t like corn flakes.

In terms of bathing routines she fits in with the routines of the facility. However, she is not complaining about this, acknowledging that the staff are busy.

**A:** *Do you decide when you want to have a bath here or a shower or do you just wait until?*

**M:** Well, they decide.

**A:** *They decide, ok.*

**M:** *Whenever it suits the nurses, they’re busy, really it’s a back wash I get.*

This issue of the staff being busy arises again when she talks about getting to Mass. The importance of religion in her life was raised by her unprompted, and she expressed a wish to be assisted to attend Mass more often.

**M:** *See, we don’t have Mass at our church and I don’t get Mass every week but to pray is alright, when you have faith.*

**A:** *Yeah ok but you’d like to get to mass would you?*

**M:** *I would.*

**A:** *And why do you not have mass then?*

**M:** Well, you see, I have to be taken in a wheel chair and there’s no one to take me.

**A:** *Right, and did you ask for somebody to take you to mass?*

**M:** Well, I didn’t but who would I ask?

**A:** *Would you ask the nurse?*
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*M: But the nurses don’t have time.*

In contrast to her accommodating tone in terms of small everyday choices, when discussing her situation in a more generalised way, Mary appears to express resignation at her situation.

*A: Do you feel at home here?*

*M: Well I have to, where else do I go?*

*A: Is there anything that would make it more homely?*

*M: My husband’s pension is paying for me here. What more can I ask for?*

*A: Ok, well, can you think of anything that would make it more homely?*

*M: Huh?*

*A: Can you think of anything that would make it more homely?*

*M: Well, they’re doing their best.*

*A: They’re doing their best yeah, but is there anything you think would make it better?*

*M: I don’t.*

And later, when talking about the future:

*A: No ok, what kind of things are important to you now Mary?*

*M: Well, just to get looked after.*

*A: So, is there anything you would wish for now or anything that you would want?*

*M: A happy death. (S.3.RES.3)*

Within the HIQA standards the provider is directed to maintain a record of

*any limitations agreed with the resident as to the resident’s freedom of choice, liberty of movement and power to make decisions. (C&W Regs, 2009)*

This directive sits within the institutional frame of residential care and does not extend beyond this into freedom of choice, liberty of movement or power to make decisions that happens prior to admission. They fact that
Mary feels she has no choice but to accept the circumstances she now finds herself in is not reportable within this frame. Nor is she likely to articulate a complaint in the context of her liberty of movement to attend Mass or her freedom to express her religious beliefs as she considers the staff to be ‘doing their best’ (S.3.RES.3). In the *A Key to Me* text the issue of relationships is textually represented and Mary’s relationships within her family are recorded and we are told that she lost touch with many of her friends who emigrated. Mary confirms that she is in touch with her family but expresses no wish to ‘interfere’ in their lives:

*M:* *I have, and my own children have their own children.*

*A:* *Yeah, yeah and do they come and see you?*

*M:* *Oh they do.* (S.3.RES.3)

Later on she states:

*M:* *I don’t want to be interfering in my sons’ life, they have their own wives and children.*

*A:* *You’re a nice mother-in-law.*

*M:* *Yeah, well, I keep out of the way do you know because, well, I don’t want to be the nosey mother in law.*

Although she has family who visit when they can, Mary does not appear to have any close relationships within the facility. ‘Liking a good chat’ has been identified by Mary in the text yet, according to Seamus, she has not made any friends in the facility.

*S:* *It could have happened when she came in here, she made friends, eh, you know, with maybe three or four different people but she didn’t really make friends with anybody.* (S.3.REL.1)

While opportunities for engagement with others may happen sporadically during the bingo sessions she attends or during mealtimes, there are no obvious signs of friendships in Mary’s life. One potential source of ‘chatting’ with her room-mate, has been closed off:
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A: Would you like your own room?
M: Well, I more or less have my own room, you know.
A: Do you? Are you in a room on your own?
M: Well, there’d be a curtain between us.
A: How many of you are in the room?
M: Just the two ladies.
A: Two? Ok, so do you get on with your neighbour do you?
M: Well, she’s a bit deaf.
A: Is she? Ok so you’re not able to chat with her no?
M: Not much.

As we have seen, Mary lost many of her adult friends to emigration and hasn’t made any new friends since arriving fourteen months ago. Her opportunities to chat with her roommate are limited and she makes no great demands on her family to fill the gap. Yet this situation is virtually invisible to monitoring or evaluation. In’ A Key to Me ’ we learn something about her relationships. However, beyond that, no other information is written down about her lack of social connections. While a space is provided to record information about her social support network in the biographical section of her care plan, its purpose is to ascertain what supports there are in the community should she be returning home. There is no place to note the ongoing social network that Mary will require in order to maintain social connectedness within the facility. The issue of relationships connects to the HIQA standard 20 Social contacts (p. 36) which refers to ongoing connections with family, friends, representatives and local communities. However, friendships within the home or relationships with staff are not alluded to. In the Care and Welfare Regulations the person in charge is directed to ensure that:

a. Each resident is facilitated and encouraged to communicate.  
(C&W Regs 2009, p. 7)

There is no requirement to record or measure the absence of relationships or to assess loneliness as is the case with other domains of care such as falls or pressure sores. This does not exclude local knowledge or local staff working
to make social connections between people but in terms of visibility it is
vulnerable to subordination to other organisational priorities.

Mary describes her relationships with staff as being rather formal:

\[A:\text{Do you know the staff well here?}\]
\[M:\text{Well, I do.}\]
\[A:\text{Do you know any of their names?}\]
\[M:\text{Well, really I don’t become that familiar with … Pat Duffy’s daughter is here. That’s the only one, because I knew her father.}\]
\[A:\text{Alright, and why do you not feel you can’t become familiar with them?}\]
\[M:\text{Huh?}\]
\[A:\text{Why do you feel you can’t become familiar with them?}\]
\[M:\text{How do you mean?}\]
\[A:\text{I thought you said you don’t feel you can become familiar with them.}\]
\[M:\text{No, I don’t.}\]

Seamus also talked about this special connection between his mother and Pat Duffy’s daughter and how it helped her settle in.

\[A:\text{Can you tell me about what discussions you had with the nurses or the staff that day if you can remember? Or what did they ask you about or what did they want to know about her?}\]
\[S:\text{I can’t really remember anything. Like I mean, they were very nice and, well, I suppose the main thing that got her over the hump here was one of the caring staff, Marion Duffy is from, she knew, and she would not have stayed here. After she saw Marion Duffy, Pat Duffy’s daughter she was yeah, and Marion takes care of her, she takes care of everyone else like but, like I mean she’ll do personal things for her like buy her shampoo and that like and I’ll be there, you know, and she’d say no Marion, I’ll get Marion to get that for me, you know, and that but only for her, only for Marion was here, I don’t know if she would have turned a corner, you know.}\] (S.3.REL.1)
This relationship with Marion Duffy – the social connection based on a shared history and culture – does not appear in the *A Key to Me* even though for Seamus it was what made a critical difference to her emotional adjustment to the facility.

Here we are talking about knowing the staff:

**A:** *The staff that work with your mother most of the time, now do you think you know them or do you feel comfortable chatting to them?*

**S:** Yeah. There’s an awful lot of them you know.

**A:** *Do they change a lot?*

**S:** Yeah, they do, well, they change a lot and you know but there are people that I would have met here the first week and I meet them again every couple of weeks. Whatever time I happen to be here at, they’ll be on like, you know, like I mean ten times in a row I don’t meet the same person.

The issue of relationships as it appears in ‘*A Key to Me*’ connects to another text which is mandated by the regulations – the *Statement of Purpose*, which sets out the facility’s ethos and guiding principles. This mission statement contained within this text very clearly draws attention to relationships and was developed as part of the person centred practice development programme:

> We believe the purpose of our Unit is to develop relationships which enhance the delivery of Person Centred Care in a homely environment and where there is mutual respect and involvement for the residents, staff and family. (S.3.SOP)

This statement provides a guiding context for staff and provides information for residents and relatives but has no obvious connection to other organising texts or policies within the facility. It does not appear as something to be recorded in the care plan or daily care flow sheet for the purposes of regulatory compliance or as a means of organising rosters. In item 35 Mary is asked the following: ‘Do you want people to leave you to do anything on your own?’ Her response is ‘More used to looking after everyone else’
Chapter 5: The Analysis of a Person Centred Care Text

(S.3.RES.3.CP). Here we can assume that Mary is referring to her previous occupational role as a homemaker, mother and grandmother. There is no obvious connection between this statement and any other textual actions as offering reciprocity does not come within the frame of accountability or even quality improvement.

5.4 Meaningful activity

The information in *A Key to Me* has a direct connection to the assessment process for meaningful activities. Here a validated tool, the POOL activity level (PAL) profile and checklist is used to determine Mary’s capacity to partake in activity in order to maintain function (Appendices 24 & 25). According to its introduction, its aim is to

> Promote quality of life, self-esteem, pleasure, comfort, education, creativity and independence. Each registered nurse assessing the resident is accountable for designing, coordinating and implementing an individualised meaningful activity programme to meet resident’s psychological and social needs. (S.3.RES.CP.3)

Mary has been assessed as having the capacity to undertake a ‘planned level of activity’. In terms of communication she is ‘aware of appropriate interaction, can chat coherently and is able to use complex language skills’. The assessment notes that she is ‘aware of others and will seek interaction but may be concerned with her own needs’. She ‘engages with others in a group activity, can take turns with the activity/tools and can eat independently, needs help with washing, dressing, and needs assistance with most activities.

By having such an assessment, the nurse translates everyday living into a professionalised language that creates a textual record which meets the goals of having a comprehensive care plan recording both physical social and therapeutic needs (Moore, 2010; DeMontigny, 1995).

The following activities are recorded: Religion-mass, oratory, prayer beads, cookery, knitting, newspaper, chatting with family/staff, art/crafts, going out with family.
The texts create an impression of a busy, engaged woman. However, this textual representation contrasts with what Mary says actually happens, what staff say happens and what I observed. Here we are talking about what she did after breakfast:

**A:** What did you do then?
**M:** Ah sure, nothing, I didn’t do anything.

**A:** Alright, well did you stay in the bed or did you get up or?

**M:** Well, I sat by the bed.

**A:** Ok, you sat by the bed?

And later I asked her what she did in the afternoons:

**M:** Well, I play Bingo.

**A:** Ok, do you like that, yeah?

**M:** I’ve won a few pairs of socks. I’m not able to play cards now.

**A:** And what else would you do here?

**M:** Well, nothing else, what can you do?

**A:** Can you remember what you did yesterday?

**M:** Well, the same as the day before and I don’t know what and I suppose the same things I’ll do today.

**A:** Ok, alright so how do you feel about that?

**M:** Well, if you’re not able to do anything, if I was able wouldn’t I be at home?

**A:** Right, is it that you get tired very quickly?
Seamus also drew attention to the lack of activity.

S: Well, I sort of had that discussion with her, think it was some time during the winter and she was talking about going knitting again and that, now I don’t think she’d be able to knit because she’s not able to write properly with the shake in her hand, eh, but eh, just to keep her mind occupied, you know. That would be the biggest problem, really, would be lack of stimulation or, like, she would have never gone to bingo but she goes to bingo here, you know, and of course she wins a prize every week anyway. (S.3.REL.1)

As Mary has become frailer to the point where, in her own word she ‘can’t even write a Christmas card’ (S.3.RES.3) her capacity to engage in social activities such as knitting or arts and crafts or in self activities has decreased. She is no longer able to go out but her family still visit when they can. Therefore religion, newspaper and chatting with family or staff are her main source of meaningful activity that she has articulated as important to her. All work activity is recorded in reporting sheets. This reporting is a key part of the textual work of nurses. The care flow chart is one of these texts and is filled in two or three times daily and has a column for social activity (Appendix 20). One thing I noticed was that this column is left blank. I asked Laura why this is so. She explains that social activities are carried out and recorded separately by the activities coordinators, on a separate sheet. Her role is to maintain the record of the other domains of care.

L: That’s done by the activities, have you spoken to them?

A: Yeah
L: Yeah, so done by the activities generally, one of the crew from there.

A: What’s your own sense of that in terms of, you know, you’re doing the medical stuff? And the activities?

L: Well, I wouldn’t be looking there to see.

A: You wouldn’t look at that at all?

L: I’d know what they’d be doing or where they were gone, or whatever, but I wouldn’t really be looking at that to see, that’s for their own, well, it’s probably mentally but it’s their own. That’s their one that they are looking after. I think we just seem to have time to look after our own. (S.3.SN.3)

Here, Laura is describing the split between what is considered ‘nursing’ work and the work of the activities staff and was a feature of all of the residential care centres in this study. The textual representation of meaningful activity in the daily accountability process emerges as being separate to other daily records. The activity coordinator records social activities, the nurse records the other interventions which shape the daily schedules and routines. The connection between the work of the nurse and the work of the activities coordinator is something that comes together textually in the care plan folder but is recorded at separate times and to describe separate elements of Mary’s life.
Meaningful activity is textually visible in both the Care and Welfare Regulations (C&W, 2009) and the HIQA Standards (HIQA, 2009)

- The registered provider shall ensure that there is provided for residents maintained in a designated centre opportunities to participate in activities appropriate to his or her interests and capacities. (C&W Regs 2009, p. 5)

- The registered provider shall ensure that residents are provided with facilities for the occupation and recreation of residents (C&W Regs 2009, p. 6)

- The resident is given opportunities for participation in meaningful and purposeful activity, occupation or leisure activities both inside and outside the residential care setting that suit his/her needs, preferences and capacities (Standard 18.2, p. 33).

The professional literature has identified the intractable problems of inactivity in residential care settings over many years (Nolan, 1995; Isola, 2008; Ice, 2002; Ward et al., 2008) and the insertion of this standard and regulation is presumably intended to make this problem visible and subject
to regulation. However, it does not appear to have resolved the issue of inactivity as described by the residents in this study who almost all reported inactivity and feelings of boredom. Staff report that it has added additional textual layers to the existing levels of paperwork.

*D*: Well, like, HIQA ordered a lot of things, a lot of writing, we’ve got to do loads and loads and loads of writing, so we now write down the activities we do, even like when we put a DVD on. But we did that all the time, we just didn’t write it down, if we’d been for a walk in the garden. But I was on a long day the other day, and it was such a lovely day I couldn’t not bring these patients for a walk in the garden, but then I didn’t get my writing done and in the back of my mind I hadn’t done any of this writing. (S.2.SN.1)

Here Laura, when talking about another resident, is discussing the translation of everyday activity into categories that serve the reporting process.

*L*: Well, I suppose there’s a lot of things that are activities but we don’t seem to take them up as activities, like, whereas Sundays we should have probably put down that she listened to a match, I suppose that is an activity, but we don’t. That’s our fault that we don’t put it down as an activity and there was music and she was listening to a bit of that in the day room. I think she said she came up once but we still didn’t put it down.

*A*: Yeah, I’m just interested as is it that it feels stupid to write that stuff down or that’s just a way of life and why do you have to write it down or?

*L*: I think that it’s like that. It’s really life and it’s, sometimes you feel, I suppose, for an activity to be an activity you think they’re going off to see a concert maybe down in the day room or theatre and if it’s not, if it’s not, em, say, just say, for instance, this may have been done at twelve o’clock – well, it generally isn’t done till the afternoon – but if you missed out on the time that the activity then well that was done you may not have gone back to the [care flow sheet – my insertion]. (S.3.SN.3)
5.5 Connecting *A Key to Me* into the process of care planning

As stated above in this facility the *A Key to Me* text is now an integral part of the care planning process which is considered an important process in the provision of individualised care. The regulations do not mandate a specific model of assessment and care plan nor does it make recommendations about the domains. However, the standards provide a detailed guidance note on the domains that should be included in a care plan (*HIQA Standards Appendix A*). The concept of collaboration in the process of care planning is quite clear as the HIQA regulations direct:

8. (1) The person in charge shall ensure each resident’s needs are set out in an individual care plan developed and agreed with each resident.

(a) make the care plan available to the resident.

(b) Keep the resident’s plan under formal review as required by the resident’s changing needs or circumstances and no less frequent than every three monthly intervals.

(c) Revise the resident’s care plan after consultation with them unless it is impracticable to do so;

(d) Notify the residents of any review (C &W Regs 2009, p. 5).

I asked Mary about her role in developing her care plan.

*A:* Ok, do you know what care plan is?

*M:* Huh?

*A:* Ok, do you know what care plan is? When you came here first did the nurse sit down and talk to you about what you like and what you don’t like and what you were interested in?

*M:* Ah no, they didn’t. (S.3.RES.3)

I asked Seamus the same question.

*A:* Can you remember when they were doing an assessment on your mother, like whichever nurse was doing it, can you remember, like, what kind of things they were asking you about? Were they asking you about what she liked to do or what
she liked to eat, or what she did before she came in here, did they talk to you about anything like that? Can you remember?

S: No, no, not that I can’t remember, no.

A: Ok right, or later on? They might not have to had to because Mary is able to speak for herself.

S: Yeah, and you know, they would have had, well, I suppose there would have been the..., I suppose all the medical stuff would have all been on her charts and that. (S.3.REL.1)

Mary or Seamus might not be expected to remember what happened fourteen months ago. However, it does not seem familiar to them as an ongoing act of collaboration and there is no textual evidence of Mary’s signature on the plan. In contrast, the process of care planning is important professional work for the nurse as the assessment and care plan are afforded medico legal status and can be used as evidence in a court of law (Moore, 2010). In this adapted RLT care plan the opportunity for involvement is textually represented in three ways. Firstly, the nurse is requested to record the resident or relatives concerns as they relate to specific disaggregated elements of care, secondly, the care plan asks the nurse if she has involved the resident or relative in the process and requests a signature. Thirdly, the A Key to Me template provides an opportunity to articulates likes and dislikes alongside a number of shells within the care plan which provide an opportunity to record food choices or rest routines. All of these actions align with the regulatory requirement for consultation.

5.5.1 Creating goals of care

A key activity of the registered nurse is to assemble the various pieces of information, assessments, measurement tools and rating scales, including A Key to Me, that she gathers as part of the assessment and care planning process, and from these create a set of actionable goals which become a resident’s Care Plan. Following the Nursing process, the care plan directs the nurse to identify the problem/need, specify a goal and describe specific interventions and evidence of evaluation. Each problem has its own patient
needs identification chart (Appendix 26) and there is a summary sheet outlining the goals (Table 5.5 below).

### Table 5.5  Goals of care that were developed for Mary

<table>
<thead>
<tr>
<th>Problem/Need</th>
<th>Goal Specification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary is unable to carry out her own hygiene need</td>
<td>To maintain personal hygiene</td>
</tr>
<tr>
<td>Mary is incontinent of urine</td>
<td>To assist in maintaining Mary's comfort</td>
</tr>
<tr>
<td>Mary has been assessed as being at risk from falls from bed and requires the use of bedrails</td>
<td>Reduce the harm/risk to Mary from falling from bed</td>
</tr>
<tr>
<td>Mary has been assessed as being underweight</td>
<td>To maintain nutritional status</td>
</tr>
<tr>
<td>Risk of pressure sore</td>
<td>Maintain good skin integrity</td>
</tr>
<tr>
<td>Loose stools on an irregular basis</td>
<td>To alleviate discomfort</td>
</tr>
</tbody>
</table>

That *Mary* is involved in everyday activities which reflects preferences and choices

That *Mary* enjoys life within Hollywell and engages in activities available

The first six goals of care are created from the information collected through a combination of the various assessment processes and the nurse’s clinical judgement. The nurse is directed to identify the problem and provide a solution. As stated above, all of these goals of care correlate with the daily work on the care flow sheet. The final two goals of care relate to meaningful activity which as we have seen is connected to *A Key to Me*. However, it uses a different textual style whereby the statement is pre-printed and the nurse inserts the name of the resident (Appendix 27 and Table 5.5 above). Here the nurse is not required to exercise her clinical judgement but rather to follow the language as scripted elsewhere. Siobhán, the practice development specialist, speaking at a general level as opposed to this
S: So when we brought in meaningful activities, why we focused on it this is because what we’ve noticed among the units, and this was a common theme, was that the activity nurses were being employed in the units, and activities was seen as a separate part of caring, and nurses were giving up this area of caring because it no longer belonged to them, ‘because we have an activities nurse’ you know. So we looked at the whole area of activity and we wanted it to be meaningful but around activities of daily living, so Jackie Poole – we asked permission to use her tool, and she gave us permission to use it, and basically it has four levels of assessment or four levels of functioning and it’s to keep people at their highest functional level, and we just introduced a risk assessment, that’s all – we didn’t change the tool in any way, and we use the tool for assessment. And basically it was the only one where we used a pre-printed care plan, and because it was so new – this sounds so strange – but because it was a new idea, a new concept, a new tool, and the Staff weren’t familiar with it, we brought in a pre-printed care plan -

A: Yes, I think I saw that, and I wondered about that, about why this is …

L: Yeah, so...because this is the care plan that’s what the tool recommends for the different levels, but you individualize them, personalize them based on A Key to Me and your other assessments, that you would personalize those tools. And that was the only pre-printed care plan that we brought in. (S.3.EM.1)

Siobhán is explaining the introduction of the pre-printed plan as a means of orientating staff towards this new way of thinking in line with person centred discourse. It also helped them meet with their regulatory requirements, which she refers to at an earlier stage in the interview. The process of creating the proforma represents a professional attempt to translate this new way of knowing about Mary’s history, values and relationships into a set of goals that are actionable within the frame of an institution which provides ‘activities of daily living’ and ‘therapy’ as part of its menu of services. By re-inserting these within the existing care plan model designed to seeks out problems and solutions it identifies Mary’s
everyday life as something to be categorised, measured, monitored and evaluated for the purpose of accountability.

5.6 Connecting *A Key to Me* to the work of reporting

The daily flow chart is filled in twice or three times daily and the domains to be reported on connect to the RLT care plan template. I discussed the process of reporting with two of the nurses:

*P:* We do these, *em,* what we call them ticks at night because they are, little, you know what I mean, it’s about the dressing, what you did. You’re told, right, if you don’t write it you didn’t do it. So we tick the boxes that we washed her, we dressed her and we did everything. Now it’s a great I suppose, the only good I can see in that is legalities and purpose of looking back in years to come but like, what’s to stop me saying, me ticking that I washed her and I didn’t wash her? How do you prove like, fine, we’re doing all the ticks and we’re doing it, we are doing what we’re saying. I’m not saying we’re not but who is to say supposing I was, I said I’m very lazy and I went to the desk and I tick that.

*A:* Actually there’s a point now just say for example you had, you went to somebody and they were very distressed and you spent half an hour having a really good conversation with them and really talking to them or whatever. Are you able to record that?

*P:* No

*A:* No, ok, so that kind of stuff doesn’t get…?

*P:* No, no it’s all physical. Like washing and dressing and actually even some of them, some of them when you; number one could be; is she orientated, disorientated, standing up? And you suddenly look at them all and say ‘she’s none of them, what do I do now? Actually I better tick one of them’. You know, it’s so regimental, it’s so detailed. (S.3.SN.1)

Here, Pauline recognises that the boxes she has in front of her do not always fit with the reality of a situation. However, the accountability framework demands that she transpose the situation in hand into the warranted spaces in the activity record. Within this daily accountability framework, the person centred attributes of maintaining personhood, autonomy, or relationship are not visible at all. According to Pauline, even the work that is
connectable does not always fit with the reality of what is actually happening. One column offers an opportunity to record non-physical care. The column ‘Communication and pain’ has a sub-heading mental/emotional and tick boxes are provided to elicit whether someone is oriented or confused, anxious, restless, agitated or comatose. The nurse is asked to identify what time of the day these behaviours are exhibited. In twenty three pages of daily care flow charts representing six hundred and ninety entries, Mary’s emotional state is described as ‘orientated’ (1a) and occasionally ‘confused’ (2a) creating a textual reality that bears little resemblance to the everyday reality of her life in the facility.

Laura describes a similar situation.

A:  
Could you talk me through the tick, this one here. Is this the tick?

L:  
Yeah.

A:  
What, talk to me about that.

L:  
Yeah, em, not good, not good, well I don’t find it good personally but because right and I’m probably as much a person for doing it myself but it’s too automatic, it’s too automatic.

A:  
In what way?

L:  
Well, em, somebody might write here; 1 see 1 A and like, would you be orientated or, and they might be confused all the time but that 1 A because somebody has made a mistake in putting orientated or something it might follow the whole way down because it is automatic and then when you’re on night duty I think you are too tired to be looking at numbers and boggle eyed to be doing it, you know, and let me see. (S.3.SN.3)

The daily flow chart is a key accountability document that gets worked on at least twice daily. As a recorder of daily information its focus is on the work of the staff not the resident. Laura explained that it took her about thirty minutes each time (at least twice daily) to fill these in for the residents she was responsible for. She also explained that this responsibility for the resident related to textual work only, it wasn’t that she had a key worker role or had a special relationship with them.
In addition to this daily reporting the nurse also fills out a ‘narrative notes’ section where she can add additional information that cannot be inserted into the care flow sheet. Using free text, the nurse writes up additional notes on ‘what happened’, recording events or conversations of relevance. In Mary’s notes the first few pages following her admission report her distress and ‘settling in’ period and the nurse’s attempts to reassure her. After this the narrative notes tell an almost exclusively biomedical story (Appendix 28).

5.7 Mapping A Key to Me to other organisational texts

Table 5.6 provides an illustration of how the text A Key to Me connects to other texts in a way that highlights a disjuncture between the espoused goals of person centred care and the organisations forms of monitoring and evaluation. In general, there is a strong connection between the PCC attributes and the HIQA standards. The connection to the Care and Welfare Regulations is less explicit. The connection to the daily care flow sheet is weak and while the connection to the social activities sheet is evident, experiential texts, i.e. transcripts of what Mary and Seamus said, provide an alternative account.

Table 5.6 Connecting To External Texts

<table>
<thead>
<tr>
<th>PCC Goal</th>
<th>Textual evidence in A Key to Me</th>
<th>Experiential evidence</th>
<th>Monitoring</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining personhood</td>
<td>Biography Items 1-26, 34</td>
<td>‘it puts that resident into context if somebody had behavioural challenges’ (S.2.EM.1)</td>
<td>Daily Care Flow Sheet - No</td>
<td>Textual compliance through care plan - Yes</td>
</tr>
<tr>
<td>Life story</td>
<td></td>
<td>‘I’m interested in’</td>
<td>Social Activities Report - Yes</td>
<td>Social Activities monitoring form - Yes</td>
</tr>
<tr>
<td>Personal values</td>
<td>Like/Dislikes items 27-38 34;</td>
<td></td>
<td></td>
<td>Complaints - Unlikely</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Positive mention</td>
</tr>
<tr>
<td>Strengths</td>
<td>Any special routines? 36, 37, 38</td>
<td>polities. I have faith’ ‘not really’ More used to looking after everyone else I was good at housekeeping (S.1.RES.3)</td>
<td>Standard 18 Routines and expectations - Yes Care and Welfare Regulations - No</td>
<td>in inspection report - Yes</td>
</tr>
<tr>
<td>----------------</td>
<td>-------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>Relationships</td>
<td>Item 2, 12, 18,19,20,22,23</td>
<td>A: Do they (family) come and see you? M: oh they do (S.2.RES.3) She didn’t really make friends with anybody. (S.2.REL.1) Only for Marion was here, I don’t know if she would have turned a corner you know.(S.2.REL.1) More used to looking after everyone else (item 36 A Key to Me)</td>
<td>Daily care flow sheet - No Social Activities - partly Standard 20 - Yes Care and Welfare Regulations - No</td>
<td>No textual evidence required. Loneliness scale - No Evidence of interdependency - No Complaints - Unlikely</td>
</tr>
<tr>
<td>Interdependen cy and Reciprocity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>Items 33, 35, 36</td>
<td>Wouldn’t want to be poking my nose in Well I could but I don’t like cornflakes I don’t get mass every week but to pray is alright, when you have faith</td>
<td>Daily care flow sheet no Standards 2 yes Standard 5 yes Standard 19 yes Standards 17 yes Care and Welfare Regulation 4 yes</td>
<td>Record of menu choices - Yes Nutrition records - Yes Social activities - Yes Complaints - Unlikely</td>
</tr>
<tr>
<td>Positive social</td>
<td>Items 25, 27,</td>
<td>A: what did you do</td>
<td>Daily care PAL meaningful</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 5: The Analysis of a Person Centred Care Text

| environments | Meaningful activity | A sense of well being | 28, 32, Connect to PAL | Goal 7 in care plan | Goal 8 in care plan | then? | M: ah sure nothing I didn’t do anything | A: can you remember what you did yesterday? | M: well the same as the day before and I don’t know what and I suppose the same things I’ll do today | M: To get looks after | M: A happy death (S.1.RES.3) | assessment - Yes | Record of social activities - Yes | Flow sheet no | Standards appendix A.3 | Measurement of boredom - No |

5.8 Findings

The above analysis uses the IE technique of using a text to burrow into an organisation to gain insight into how the PCC goals of maintaining personhood, autonomy, relationships and creating positive social environment are translated into the everyday life of residential care settings. Using the text *A Key to Me* the goals were mapped against experiential texts (interview transcripts, observations and field notes) and internal and external monitoring texts (care plans, activity reports, HIQA standards and regulations) illustrating a disjuncture between the espoused goals of person centred care and the everyday work of residents, relatives and staff. What actually happens is that the information collected about Mary’s life, her family, and her values is taken up and translated into a professional frame in two ways. Firstly, it is taken up as a therapeutic endeavour and she is categorised as ‘exploratory level’, converting everyday ‘wants’ such as having a good chat, going outside and reading the newspaper into something to be worked on and reported on by activity coordinators. Secondly, by reinserting this ‘assessment’ into the existing professional frame of the adapted RLT template this information about her life, her relationships and her values become a problem to be addressed, reported on and evaluated. As such it becomes a professional way of knowing despite the fact that it is at odds with what Mary and Seamus says actually happened. Local forms of knowing such as her relationship with Marion Duffy or her capacity to ‘look
after everyone else’ becomes subordinated to the goals of care that are problem-orientated and based on the assumption that Mary is a service recipient rather than a possible contributor to community life. By reinserting it into the existing professional frame the focus is on Mary’s needs as opposed to her wants (Thomas 2004) thus taking the person centred principles of creating positive social environments and a ‘home from home’ – rendering it accountable to taken for granted systems that provides healthcare, therapy and recreation. The professional frames include an accountability process which has been shown to be unreliable at least, despite taking up a considerable amount of time. The analysis locates a point of tension between embodied ways of knowing and professionalised ways of knowing. When the two ways of knowing intersect, the organisations priorities take over. Because Mary evaluates the system based on taken for granted beliefs that there is no other choice and her interactions are with kind and respectful staff who are ‘doing their best’, she is unlikely to demand any special routines, seek redress through a complaints system or express dissatisfaction in a consumer survey. Yet her untapped potential to care for others and potential to look forward to something more than ‘a happy death’ is missed.

5.9 Summary

This chapter provided an analysis of one text relating to person centred care within the context of the care planning process. The text, while providing valuable information about who Mary is and what is important to her, gets taken up and reconstructed as ‘therapeutic’ and ‘recreational’ despite clues that Mary had the potential to maintain a socially valued role that would see her as more than a passive recipient of services. While such activity is an important part of counteracting nihilism and maintaining functional status, this categorisation and reporting of actionable goals made little difference to Mary’s life and added additional administrative burdens on already busy staff. By adopting a ‘different way of looking’ this analysis burrowed into the social relations of residential care in terms of maintaining personhood and creating meaningful activity. Despite the best intentions of staff and
managers to be innovative, the existing administrative tools drew the process back into a construction designed to address problems and *needs* rather than facilitate the promotion of values, hopes or mutuality.

The following chapter provides a further exploration of the issues raised here. This exploration focuses on the social relations that coordinate relationship building and social engagement between residents and staff. Following this, I will discuss the findings of both chapters collectively.
Chapter 6: The Social Relations of Person Centred Care

6.1 Introduction

The aim of this chapter is to provide a further analysis of the social relations of person centred care in the everyday lives of residents through mapping their ‘work’ to that of other people. The objective is to provide further insight into the work activities that support the person centred care principles of maintaining personhood, autonomy and relationships and creating positive social environments and those that work against these principles. While each resident had their own experience, there were several ‘threads’ or lines of inquiry that pointed to coordinated organisational practices that warranted further exploration. Although these threads are interrelated, for the purposes of discussion these have been defined as: how residents, relatives and staff relate to one another (relationships) and how residents are socially engaged through involvement in decision-making and meaningful activity (social engagement).

The chapter is divided into sections to reflect the above lines of inquiry. Each section begins by providing an account from residents and relatives of their everyday ‘work’ and then moves beyond this, connecting it to the work of frontline staff and managers. Following this, the analysis maps these experiences to internal and external texts created by the ruling relations such as standard operating policies, human resource practices, standards and regulation. As a means of staying faithful to the Institutional ethnography goal of returning to the material circumstances of those whose standpoint is adopted (Campbell and Gregor, 2004) an additional section provides an account of what the residents said about their hopes for the future. A final section will summarise the findings collectively.
6.2 Relationships – how staff, residents and relatives relate to one another

The section explores the issue of relationships between residents, relatives and staff. The experiential texts describe cordial relationships (similar to what Brown Wilson (2009) described as *pragmatic*) between residents, relatives and staff rather than the relational, collaborative or reciprocal relationships as defined in the person centred care discourse (Dewing, 2004; Nolan *et al.*, 2006; McCormack and McCance, 2010). In common with many other studies in residential care, residents described relationships that were primarily centred on care routines (Nolan, 1995; Ward *et al.*, 2008; Cooney, 2008). Staff described ways of working whereby they rotate between residents, based either on formal staff deployment strategies or negotiated arrangements between themselves.

6.2.1 The everyday work of residents

The morning routines start with helping people out of bed, to the toilet and assisting them to wash and dress. Residents who need full support waited to be assisted as staff made their way through each unit. Residents talked about these routines in a positive way as they interacted with staff. The routines provided opportunities for interaction between residents and staff and general banter and conversation was observed and heard during the observation process.

Tom describes his first interaction with staff that day:

*T:* The wee one said they had to get me up to wash me. They are always in a hurry. They are great girls. (S.3.RES.2)

My own observations included the following:

*One nurse is giving out the medication. She is chatting with residents. The catering staff come in with breakfast trolley. They greet residents, ‘good morning Kathleen, would you like some breakfast?’* (S.3.OBS)
Chapter 6: The Social Relations of Person Centred Care

Maureen talks about her morning routine:

**M:** Well I get taken out in a hoist. Put on me clothes and on the toilet. I have my breakfast in bed, everyone has breakfast in bed. You’re got ready, put on socks and shoes, got in the wheelchair. (S.2.RES.1)

Angela, a staff nurse, describes the opportunities for social engagement that happen around care routines:

**A:** Josie, now she has an only son that comes in and he’d be her pride and joy so…. we chat about that and his lady friend that comes in with him. And she likes to chat back. Today she mentioned Good Friday. Yesterday evening I happened to be on the late shift and she knew, sometimes now she mightn’t exactly know what date, even if she was reminded, she might forget but she mentioned Good Friday, so we talked about issues around that. She needed full help with her personal care as well and a change of incontinence wears. She is not continent due to the amount of CVAs she’s had. (S.2.SN.2)

I asked residents how well they knew the staff, did they know their names if they knew anything about their lives such as the names of their children or where they were from and if they had a favourite. In general residents describe limited knowledge of staff or other residents. Some residents knew the names of one or two of the staff but few claimed to know anything about them or their circumstances beyond their immediate role. Bridget describes her relationship with staff:

**A:** So, do you know the names of the staff here?

**B:** I don’t know their names, [inaudible] I never ask them their names.

**A:** Ok, so what would you talk to them about?

**B:** They don’t talk much to us, they leave us here.

**A:** Ok, right, would you like to talk more to them?

**B:** I wouldn’t mind. (S.2.RES.4)
Tony engages easily in conversation and observes the comings and goings within the ward. Here he describes his relationship with staff as being based on his health care needs and to him a superficial level of conversation is enough.

A:  Would you know them well?
T:  I do.
A:  Would you know who their children are, or who they are married to?
T:  Ah, I wouldn’t no. I wouldn’t want to know them things.
A:  Ok. And what would you talk about?
T:  I know all the nurses here.
A:  What would you talk about?
T:  Ah, if there was anything wrong with you, they’d see to you.
A:  Ok, would you chat about general things?
T:  [inaudible] Things to be talking about….
A:  Like what? Do you talk about the news or…?
T:  Talk about the good weather. (S.2.RES.3)

None of the residents in this study expressed dislike or fear of staff; rather the connection to staff could be described as cordial based on exchange of information about health care needs and acknowledged distance based on professional status. Most residents said they knew very few of the staff by name, citing poor memory as the reason for this. But residents also talked animatedly about staff with whom they had previous connections or where there was a social element to the relationship. Several of the residents, unprompted, mentioned by name, staff who came from their own parish or who they had some previous relationship to before they came to live in the facility. In these situations both first and surnames were recalled.

Maureen mentioned the connection she had with Angela a nurse on her ward as they both came from the same town:

A:  Do you have any friends here, someone to talk to?
M: No, no one to talk to.

A: What about the staff? Do they sit and talk to you?

M: Angela Ryan. She’s from Ballymore [her home town]. She sits and talks to you. (S.2.RES.1)

Jim, too, draws this connection to staff from his locality:

A: Do you know the staff here well, do you?

J: I do...

A: You do? Do you know all their names?

J: Ah God, I wouldn’t know all the names but I know some of them, you see it’s a shocking big place they all know me but I don’t know them...

A: Would you have a favourite?

J: They are all my favourites. I couldn’t pick one now.

A: Ok, but is there any of them that you know their names now?

J: Ah, there is, there’s a few, a few, the names from me own place in Drumintee...

A: Who’s here from Drumintee?

J: There’s, what do you call it? Oh, Caroline O’Neill...

A: She’s from the same part?

J: I went to school with her mother and father. (S.3.RES.1)

Relationships based on shared social interactions rather than care routines were mentioned by some residents such as Finbar who talked about the relationship he had with Cathy, a healthcare assistant, focusing on the social element of their interactions. One relative, Alan, contended that the staff that knew his mother best were the ones who shared the outdoor smoking space with her (S.3.REL.5). There appeared to be little expectation from residents about their relationships with staff. Most residents pointed out that staff are busy and as such do not have time to talk. This was stated not in a critical way but rather as just being the way things are.

A: And do you think the staff have enough time to sit and talk to you…?
Chapter 6: The Social Relations of Person Centred Care

J: Ah God, I wouldn’t, no, ah Jaysus, they wouldn’t have time, they’re on their feet morning to night...

A: And would you like if they had more time?
J: Ah no, sure they get on with their job and that’s that. (S.3.RES.1)

The cordial nature of relationships was reiterated by relatives who described friendly staff who kept them informed of their relative’s health care needs.

A: So, would the nurses talk to you very much about Annie?
J: Well, they always talk to me. I mean, if I wanted, or if I had a problem, if they didn’t talk to me, I would talk to them. (S.3.REL.4)

Beatrice describes a similar relationship:

A: Do you know the staff well?
B: Do I? Yes, I’d know, yes, because it seems to be the same ones that are on, I know their faces. I might not know their names, but I know their faces, you know, and I’d say it’s a small enough...
(S.3.REL.2)

This account of relationships as described by residents and relatives was in marked contrast to the contention by several staff that they knew the residents well, while conceding that the organisational processes militated against developing close relationships with residents and relatives. Assignments based on key workers or acknowledged connections between residents and staff were not a feature of any of the centres in this study, except for responsibility for maintaining the care plan (S.2.SN.3). Rather, the systems of staff deployment were based on locations such as wards or suites with sub-divisions based on geographical locations such as rooms or bays as I observed on one site:

At the end of the handover there was a discussion about how the work was to be allocated that day. This was based on areas of the ward. Staff self-selected where they wanted to go within these areas. (S.2. OBS)
One of the main reasons articulated for not developing relationships with residents is lack of time, yet staff report that reorienting themselves to new residents took time as they changed every few days. Working with the same residents helped to develop a rhythm where the staff knew what the resident liked and they, the staff, had set up their working tools of flannels, soaps etc. in a way that was familiar to them as Catriona describes:

\[ C: \text{Usually we decide ourselves, a lot of the time with the older ones that are here, seniority, the ones that are here longer, they pick their units. But, em, a lot of us, now we just kind of, a lot of us like to stay in the one unit for three or four days at a time. If you’re on the ward for four days, a lot of us are on it for four days at a time. If you’re in the one unit, it’s an added bonus because once you get the first morning, once you get into the routine and, you know, you have everything in your lockers and everything for the patient it’s so much easier because you go in the next morning and you know who has what, and what they’re wearing and all their creams and everything are in the locker, so you don’t have to go looking for them or replace, that you have already replaced them from the day before and their bowls and all are clean. It’s so much easier so we try and do that a lot of us...} \]

\[ A: \text{Right, ok. But the next time when you come back after you’ve been off?} \]

\[ C: \text{Yeah?} \]

\[ A: \text{You have to start all over again?} \]

\[ C: \text{We have to start all over again that’s why we like to stay in the one unit three or four days yeah. (S.2.HCA.1)} \]

Continually working with the same residents was seen to have advantages and disadvantages. While the advantage of knowing what each resident wanted or needed was seen to provide an advantage in terms of time, paradoxically most staff expressed a desire to move around so that they would have a better overall knowledge of the residents, especially for night duty when staffing levels drop significantly and where a more generalist knowledge is seen to be required. Tina reflects on the advantages and disadvantages continuous assignments could bring:
A: Ok, and which would you prefer? Would you like to be working with the same residents all the time or do you like to move about?

T: No, you like to move about. It’s nice for a bit of continuity that if your left in the one area for, we’ll say four or five days, because after a day or two you’re in your routine and you know the patient but then again because the ward is so big, 30 patients when you come on night duty we are left with the same patients all the time and you wouldn’t get to know the other ones that well or they wouldn’t get to know you which is more important…..

A: Right, ok, so you prefer it the way it is then?

T: Yeah, yeah, if you’re left there for four or five day… not one day here the next day there, which can happen.

A: You know this idea, say, to build up relationships with residents, you know that you would work with the same group all the time, how would you feel about that if you were? I take your point about night duty, that’s a good point, but other than that?

T: No, I feel that would be fine. Again you’d get to know the families, even you know, better than you do at the moment because you’d be dealing with one client all the time and their families, where when you’re moving around, you’re dealing with 30 clients and 30 families. You know it would build up better relationships to be left, say, for a period of a few months in one area. But, again, with the rosters and that, days and nights, early shifts and late shifts you know it doesn’t happen…

A: And could it happen?

T: It could, it could… because you do three weeks of day duty if you were left in the one area for those three weeks. (S.2.SN.3)

This dichotomy between knowing some residents well and the need to know all the residents is taken up by Paula in another centre.

A: But in terms of the people who are here all the time, would you work with the same people all the time?

P: No, we change around, we take roughly ten patients in the morning, em,…

A: What do you think about that? Would you prefer to work with the same people all the time or not?
Chapter 6: The Social Relations of Person Centred Care

**P:** Well, no, because if I find myself in charge, I need to know everybody, so there’s no point me knowing a few very well then not knowing somebody else. And, anyway, overall you will know the whole lot of them in your unit, you know… (S.3.SN.1)

Another reason given for not having continuous assignments is the need to create interesting working patterns.

**A:** Do you think it’s better? Would you prefer to be working with the same residents all the time?

**C:** Not all the time, no...

**A:** Not all the time? Why not?

**C:** Because then you’re in, I don’t know, you’re in a routine, you’re in a rut or whatever. I don’t know, I don’t think I’d like to be with working with them all the time.

**A:** There’s no right or wrong answers, so I mean, it’s fine, you know...

**C:** I mean, I’m trying to come up with an answer. I don’t think I’d like to be, it would be more like, to me, it would be more like a factory. You’d go in every morning, you get the same ones, the same thing, the same thing, you’d be doing the same thing every day. I think when you’re not with the same residents every day, things are different, you’re bringing in different. (S.2.HCA.1)

Some residents would be perceived as being difficult or particularly ‘heavy’ and, as such, the manager would try to ensure that no one staff member bore what might be seen as the ‘burden’ of caring for that resident on a continuous basis. Paradoxically, it is acknowledged that knowing a resident or having a connection with them can ease this perceived burden as the resident and staff member learn to communicate and trust each other. Brian describes a connection he has with one such resident:

**B:** There’s one man that’s a bit awkward, so he has to be got up before his breakfast every morning. It’s just the way it has to be done, so usually I do get him up when I’m here because he, he doesn’t get on with everyone but he gets on with me so I get him up. (S.2.HCA.2)
Despite the organisational structures, relationships and friendships do emerge as Lucy describes:

**L:** Well, there is some; again, it’s personality and things as well. Some patients you love, or residents, we still call them patients at times, there’s some you love and they love you back like and, you know, you don’t mind, there’s things you don’t mind doing for them ... (S.3.HCA.2)

The issue of reciprocity was discussed briefly in the previous chapter. Here Patricia describes a story which highlights the opportunity for intergenerational solidarity that can exist between residents and staff. She is describing an interaction with one resident who helped her over bereavement in her family:

**P:** They are probably more understanding than some of your colleagues can be at times. They probably are, because for me it was a resident here who said something to me. My sister-in-law died in February and she was only thirty five and she had small children and, you know, and I suppose it was not a bit of, I was on a huge downer. But I was coming into work and smiling and everything else, and one of the residents in here would have known her family and she just said to me one day: ‘How’s Joe and the girls?’ And I said, ‘Ah sure, they’re getting on grand’ and she said something... ‘You know, that girl lived more in thirty five years than I have done in my ninety and wasn’t she fantastic she had such a great life?’ and I just went ‘yeah....’ at the time and went home and thought about it and I think she did more for me than some of my colleagues did ... (S.3.HCA.1)

While the issue of staff turnover is often cited as a barrier to relationship-building in residential care, this was not a feature of any of the facilities in this study. Even where agency staff were in place, they tended to be the same people who provided this service.
6.3 Staff deployment system

From internal and external managers I learned that formal staff deployment systems are located in the management task of developing a roster. The practice of rostering requires the manager to bring together several forms of knowing including what the organisation says is possible in terms of budgets and skill mix, and what agreements are in place with unions regarding working conditions. This is combined with locally negotiated practices based on the need to ‘know’ residents from a clinical governance perspective and negotiated practices between staff. Personal connection between residents and staff are ruled in general, by rostering practices which are designed to be fair to staff and ensure an equitable distribution of workload. Within this institutional frame, the focus is on beds and locations rather than on an objective of:

*The formation and fostering of therapeutic relationships between all care providers, older people and others significant to them in their lives.* (McCormack et al., 2010, p. 13)

As identified in the previous chapter knowledge about the relationships between residents and staff is not collected as part of the data collection system of the care flow sheet rendering it invisible to daily or even occasional scrutiny. Instead, a combination of professional tools, intuitive and clinical judgement are used to calculate, categorise, and coordinate the deployment of staff. Within the public care system, decisions about skill mix, and the capacity to recruit agency and replacement staff are taken several levels above the actual site where residents and staff come together. However, the local manager has some capacity to move people within their allocated numbers of staff. Managers explained to me how they calculated skill mix based of the ‘criteria for care’ skill mix tool and rostering practices that were built around agreed shifts and staff numbers.
Table 6.1  Criteria for care tool

<table>
<thead>
<tr>
<th>Psychological Needs</th>
<th>Mobility</th>
<th>Hygien</th>
<th>Press Area Care</th>
<th>Hydration/Nutrition</th>
<th>Incontinence</th>
<th>Social Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal Reassurance</td>
<td>0</td>
<td>Independent</td>
<td>0</td>
<td>Self caring</td>
<td>1</td>
<td>Not at risk</td>
</tr>
<tr>
<td>Support Required</td>
<td>3</td>
<td>One Nurse Assistance</td>
<td>2</td>
<td>One Nurse Assistance</td>
<td>2</td>
<td>Air Risk</td>
</tr>
<tr>
<td>Disturbed/Distress Support Required</td>
<td>8</td>
<td>Two Nurse Assistance</td>
<td>4</td>
<td>Two Nurse Assistance</td>
<td>4</td>
<td>High Risk</td>
</tr>
<tr>
<td>Constant support required</td>
<td>10</td>
<td>Bedfast/Chairfast</td>
<td>8</td>
<td>Very High Risk</td>
<td>0</td>
<td>Total patient/ on hourly fluids</td>
</tr>
</tbody>
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Any resident who requires more nursing intervention should be separately listed and nurse hours recorded.

0 3 8 10 0 2 4 8 1 3 5 0 2 4 5 2 4 6 7 3 0 4 6 7 2 3 5

10 8 5 4 4 3 2 7 5

8 2 3 2 6 7 5

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Table 6.2 An Example of a Roster

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<th>Names</th>
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In the HIQA standards, the issue of relationships, while mentioned in respect of familial or lifelong neighbours and friends, has little to say about the everyday relationships between residents and staff or the development of new relationships. Relationships are not mentioned at all in the hierarchically superior Care and Welfare Regulations. What is required from a regulatory perspective is evidence that there is a sufficient number of suitably qualified staff available.
23.3 At any point in time, the number and skill mix of staff on duty is determined and provided according to a transparently applied, nationally validated, assessment tool, to plan for and meet the needs of the residents. This is subject to regular review.

23.4 The staffing numbers and skill mix of qualified/unqualified staff are at all times appropriate to the assessed needs of the residents and the size, layout and purpose of the residential care setting.

In this context each designated unit must provide evidence of using a validated tool. (p. 41)

The process of establishing skill mix and rostering removes the embodied presence of individual residents and replaces them with categories of dependencies, numbers of hours allocated and physical locations to be ‘covered’. Other forms of knowing, such as who gets on with whom, are not required within the institutional frame. While local knowledge may influence some local decision-making it is in the context of existing shifts and routines that have been established to meet organisational goals of human resource deployment rather than though the ‘fostering of therapeutic relationships’ (McCormack et al., 2010a p. 3).

6.4 Findings on relationships

Relationships are a key attribute in the literature and professional discourse in relation to person centred care. The findings from this study suggest that relationships between residents and staff were, in general, cordial and pragmatic and centred around care routines. While staff cited lack of time as a barrier to developing relationships, inconsistent staff scheduling was acknowledged as creating additional work. Residents spoke animatedly about staff with whom they had some historical or geographical link. Staff, however, expressed a need to ‘know’ residents in a generic way for the purposes of clinical governance. The textual practices of rostering and staff allocation involved a process of objectification which aligns staff to physical locations and categorises residents according to dependency levels as opposed to a goal of nurturing relationships. These findings reveal a tension between the espoused principal of person centred care and what
actually happens in the organisation of interpersonal relationships. While these ‘therapeutic relationships’ (McCormack et al., 2010) are part of the discourse in relation to person centred care, they are not part of the organisational activity of care planning, staff deployment or regulation.

6.5 Meaningful engagement in everyday life

The issue of resident engagement became a thread to be followed in this study as I observed residents spending long periods of time doing very little. I listened to their acceptance of the way things were while at the same time expressing feeling of inactivity and disconnection. Relatives expressed acceptance that the control of the facilities lay within the remit of staff and appeared happy to defer to them for most decisions. I did observe instances of negotiation between residents and staff, particularly in relation to care interventions which McCormack, Dewing and McCance (2011) describe as person centred care moments. However, I saw or heard little by way of negotiation about the ‘running of the day’. In contrast to the experience of residents, I observed many instances of decision-making and negotiation between staff that influenced what happened.

This section is divided into two sub-sections. The first explores choice-making and involvement in decision-making. I asked residents about their routines and the choices they have. Following this, I considered what staff say they do to provide choice and how organisational practices are negotiated between residents and staff and between staff. The second sub-section explores further the threads of involvement in meaningful activity that was raised in Chapter 5. I asked residents what they did outside of care routines and mealtimes – if and how they got involved in the running of the day. I then explored this with staff and managers and connected them to operational and regulatory texts.

6.5.1 The social engagement of residents in everyday life

I asked each of the residents to tell me what they did that day, providing prompts where necessary about the choices that they made.
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E: Well, I had breakfast in bed. I usually have breakfast in bed. I got up about 10.00. It takes me about an hour to get dressed. (S.1.RES.2)

Here Beatrice is talking about her weekly shower:

A: But do you decide when you have it or do the nurses decide?
B: They put me down for it.
A: They put you down for it? Ok. And do you have it at the same time every week?
B: Aye.
A: And if you didn’t want one, what would happen?
B: Ah, you need a bath don’t you?
A: You do [both laugh]. Do you like a bath?
B: I do.
A: Which do you have? A bath or a shower?
B: A shower.
A: Do you like the shower?
B: I do.
A: Ok. Would you like more than once a week?
B: Ah no… (S.2.RES.4)

Ursula describes what happened that morning:

U: The nurses came in and the helpers, and one of the helpers said to me was I going for a shower? And I said ‘yes’, so she took me out at nine o’clock. So, she came in then at nine o’clock and got me ready. I was back in then by ten past nine. (S.3.RES.5)

In these responses the residents describe a level of choice in that no one is coercing them to have a shower and they can refuse but only within the parameters established. It is not their decision to choose when or what type of bathing they undertake.
Food choices appeared to be available although these were generally ordered in advance the previous day and based on a cycle of menu planning.

A: Right, ok. And when they come around with the dinner, would they ask you what you like or do you know?

J: They ask you the day before ‘what will you have tomorrow?’ (S.3.RES.1)

Awareness by staff of providing opportunities for choice in relation to these activities of getting up, eating or bathing was evident in all of the facilities. ‘It’s their choice’ was a commonly cited mantra that I heard in all of the facilities. Staff commented on how the person centred care practice development programme had resulted in a less regimental approach to waking residents and getting residents ready for the day. Here Deirdre and Orla talk about how they incorporate this thinking into their practice:

D: Right, I know exactly. A lady that came in and you sit down with her and you just chat about what she likes, right, starting with what she likes to eat, how she likes to eat. (S.2.SN.1)

Orla, a health care assistant, points to the need to constantly check with residents the importance of not making assumptions. Here she is talking about checking with one resident about her breakfast choice:

O: Yes, but you’d still ask them. Like one woman last night, she wasn’t well, so she had only toast because she didn’t like the porridge because she didn’t feel well last night. So you really ask every day, ‘do you feel like having porridge or cornflakes or what would you like?’ (S.1.HCA.1)

Maria pointed out that while they had incorporated the principles of offering choice into their practice, at times it was difficult to do:

M: Ok. Well, straight away after you’ve had the handover and you’ve had a little chat with the girls, the bells are ringing so you’re going to cope with getting someone on and off the toilet or
whatever and also going round to each patient and asking them if they’d like to get up for their breakfast or how they’d like their breakfast, that kind of thing, em, what they want for breakfast as well because you can’t just assume they’re going to have the same thing every day. (S.1.SN.1)

In all of these facilities, staff described how the person centred care programme led to improvements in choices. However, when I explored this further with residents, it became clear that choices based on the residents’ previous routines that required organisational reconfiguration were more difficult to change. Here one resident called Mo is describing how her current routine contrasts with her life before she came to the facility, pointing to the taken-for-granted limits of choice in her current situation:

A: I suppose what I’m interested to find out, is your routine very different now from when you were at home?

M: Oh very, very different, it is, I don’t know if, you know you have to go with the, you know, when it’s meal time here it’s meal time, that’s it. And at home, I mean, if you felt like a cup of tea at any time or a cup of coffee you got it and the tea was, well, usually we’d have our tea between six and half six. Stephen [her son] would cook the tea and we had it together whatever but we were happy, you know, it was I suppose, more free and easy.

A: Ok, and do you think it could be more free and easy here?

M: How do you mean that way?

A: Well, would you like to be able to have a cup of tea when you feel like it or not have tea at the right time?

M: Yeah, I suppose, you know we, our tea is at half four and we have, well, I have a good dinner and then the cup of tea at three. I like that and half four is early for a tea. And I’m not really hungry for a tea then. I’d rather have it later but the staff have to, they have to go to where, they have their own time you know...

(S.3.RES.4)

This was reiterated by other residents who commented on how close the meals were together. Staff acknowledge that the tea is probably earlier than people would like but that it needs to fit in with the work schedules of both
the kitchen staff and those who work a short day. Brian describes how efforts to change the meal times in one unit never got very far.

**B:** Well, they were going to change one thing that was on about, they were going to change the meals, mealtimes and which. And that they were, sorry, I don’t know, there was some other residential care place like this anyway but that they’d move the meals back. And we’ll say the tea, that the meals is too near together but our meal in the morning, the breakfast we’ll say is at half eight, dinner is at half twelve, tea is half four, well, tea is actually four, because they place staff from half four on. So this plan was going to be brought in that they were going to change the evening meal and put it later but I couldn’t understand anyone even thinking about it because the first thing you’d have to come to and get is that now they changed the roster. Every one of them, because you’d have to have more staff at six o’clock. But whoever thought it up, there was never a thought about staff...

**A:** So what happened there? What happened in that situation?

**B:** Well, it went on and there was meetings and meetings it seems about it and I don’t exactly know what but it never came in, so I don’t know what, but I could never see... (S.2.HCA.2)

All of the managers in this study described complex decision-making processes around changing practices whereby committees were established that involved input from multidisciplinary teams or staff representatives.

**K:** In 2007 we went through a process of changing all the roles. They were all multi-task and that was done through partnership [National Partnership Process – my insertion], the unions, the multi-task attendants. They all got their roles, whether it was healthcare assistant, household or cleaning. And that went on for two years before we got it sorted out. (S.1.IM.1)

Fiona, another manager, describes a similar multidisciplinary process:

**F:** Well, you see, there was a, there is a meal times group, a group right and that’s comprising of different participants. We have somebody from the main kitchen, the kitchenettes, ward managers, health care assistants, speech and language therapist, dietician...
A: **But, has anybody’s work practice had to change because of this?**

F: Yeah, dinner breaks have to change, our staff dinner breaks have to change.

A: **So was there any difficulty around that?**

F: Well, initially our chef in the kitchen felt she couldn’t change at all, I mean there was a block....

A: **Talk to me about that. How did you manage to talk her round?**

F: Well, it was, well, this has been going on for our group is a good while in existence now, it’s well over two years so it, we had questionnaires, we had questionnaire to residents, again families and there was the HIQA standards where something had to happen, but I think with the standards coming on board and with the HIQA inspection. I think that sort of...

A: **That helped you, did it?**

F: Oh, that helped, that did help. I mean, if you were trying to do this on your own. I mean, ok, like I know HIQA and the standards and they ask for a lot sometimes, we say that, but the regulation of the standards are very, very good in another sense because things have to change. Practices that might never have changed have to change. (S.2.IM.2)

Kathleen, another manager, makes a similar comment about the power of regulation:

**K: I suppose that me, as a manager, it has given me the tools to say to staff, you have to do it, it’s legislation. You might have had some dispute about certain things that you would want to do or that needs to be done, so they’ll sit up and take notice now. So it’s not me, Kathleen Donnolly, saying it, it’s HIQA saying it. Yeah, HIQA has been good in that sense. And it has raised standards. I’ve seen how it has raised standards in other areas. Meeting them as well, definitely. (S.1.IM.1)**

While staff said they did not disagree with the principles of regulation, most of the nurses expressed frustration at the additional paperwork.
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T: No, not really, no, again it can tend to be very task-orientated you know, you have to get this done, that done. And, as I say, with HIQA coming at the moment, it’s ridiculous there’s so much emphasis on paperwork and if it’s not written it’s not done which we know isn’t true, the work is being done, we know the patients are being taken care of and their psychological needs and their families, never mind just their physical needs, but that it’s this paper work, this amount of time that has to be, and we’re told time is not an excuse. (S.2.SN.3)

The issue of what time residents went to bed at was raised by staff in each of the units primarily because it had been raised by the HIQA inspectors. This is a contentious issue which has been raised by HIQA as evidence of institutional practice and staff offered different perspectives as to whether this process is by choice or necessity.

C: Well, after the day staff are gone right, that’s 4:30, we finish picking up the dishes, bring them back up to the kitchen and the girl in the kitchen will sort them out. And then whatever patients are still up we start putting them back to bed, and once, it depends some of us have different ways of doing things but a lot of the time the nurses here are giving out drugs at that time so a lot of the time were on our own so we’ll put in, maybe one or two patients that we can do on our own. We’ll put them back into bed we’ll take off their day clothes and put on their pyjamas.

A: And why is that is it that there are less people rostered in the afternoon?

C: In the evening, yeah, see the staff are reduced in the evening. There’s half the staff in the evening, that’s why we try and get a lot of them back to bed before the evening, before the day staff are gone, because you have 28 patients then to turn around and change in the evening time and you could have someone very sick and you could have to spend a lot of time with them. So this is where it comes in and this is where you have to explain to the patient that doesn’t want to go to bed, well, I mean, we’ll leave them up as long as possible but a lot of them they have to, they have to go to bed before 9:00 before the night staff come on because the night staff certainly don’t have time to be putting them to bed. (S.2.HCA.1)
My own notes recorded the following:

*Place is quiet. It’s 5.15pm. Many of the residents are back in bed. Is it because they are tired or because it’s just easier for staff? (S.2.OBS)*

My observation in a different facility records:

*6.00p.m. This is a ward with one four-bedded ward and seven single rooms. The place is quiet as everyone appears to be in their rooms. I go down to the communal living/dining/kitchen.*

You can see most of the bedroom doors from here and there is nothing much happening. Everyone seems to have settled down for the night. The HCA is sorting out laundry and I haven’t seen the nurse in a while. (S.1.OBS)

### 6.5.2 Negotiation of choice

According to McCormack and McCance, negotiation is a key element of shared decision-making and several staff described how they tried to incorporate this into their daily work. Lucy recalled how she negotiated with residents as part of her early morning work:

*Then we finished breakfast, teamed up with the nurse because she was doing the medication while I was assisting the two people with breakfast and we went to one resident who was soiled and needed immediate attention and em then after that we just kind of go from one to the other and ask them if they’d like to get up, what time they’d like to get up? If they don’t want to get up that’s fine as well, it’s their choice, you know, if they don’t want to get up, they don’t want to get up. They might not want to get up until after dinner, that’s grand eh this morning everybody except two people wanted to get up and one of them was a gentleman that was unwell overnight. He just didn’t feel like getting up. The other lady just didn’t want to get up. (S.3.HCA.1)*

While Lucy was able to negotiate flexible care routines with residents within existing organisational frames this was seen to be more difficult when it came to moving outside the normal routine patterns. The balance of
power in these situations is seen to lie with staff, who readily admit that care
routines and other organisational priorities supersede any requests that a
resident might have. Orla recalls a recent request from one resident to take
her out shopping:

**O:** *Janet says to me this morning, ‘Is there any chance of getting
down the town? And I said ‘Janet, I just haven’t the time today’.*
(S.1.HCA.1)

In this vignette, Fiona is describing a situation where the balance of power
between a resident and a ward manager was played out:

**F:** *Well, staff’s decision could override the residents’ decisions,
yeah. I remember one gentleman about a year ago, wanting to go
to a horse show out the road there. And the ward was short
staffed that morning and of course the ward manager was on and
she said he wasn’t to go. The health care assistant would have
taken him if she was allowed but the ward manager wouldn’t
allow it because of the staff shortage and she just put her foot
down and said no way. Now, I mean, if she was flexible, the man
wanted to go, so who won out there? She did. Her views because
she’s the ward manager and she said this is my ward and I’m not
happy with the staffing of it and I mean if you were to just change
it around, this didn’t happen anyway. It was sad. I mean he got to
something else later, but it wasn’t what he wanted so that’s the
only thing I can think about at the moment, there’s lots of other
incidents. I mean the health care assistant was going to go.*
(S.2.IM.2)

The main organisational mechanism to decide what happens on a daily basis
is the morning handover meeting. In two of the facilities nurses and care
staff came together at the nurses’ station or in the office to discuss what
happened overnight and to plan the day ahead. In the other facility the
nurses had a handover meeting and someone was delegated to give a report
to the care staff. Details of doctor’s appointments, changes in health status
of residents and other medical details predominate. A Statement of Purpose
describes the process as follows:

*Reporting methods within each suite are standardised. A nursing
report takes place at the beginning and end of each shift & once*
One Observation of a handover meeting at the nurses’ station recorded the following:

*One nurse is feeding back to the whole day team. She went through each resident and made a comment on how they were during the night and if they needed any medical or nursing care. General comments about if they were in good form or not.* (S.3.OBS)

Paula, a Health Care Assistant, describes what happens at the Handover:

\[P: \text{ We get a rundown of all the clients, about the night they had or if something happened yesterday, if some of us weren’t on. If there is any care plans or if dressings have to be changed or anything like that, if they needed bloods, if blood samples are needed or urine, that would be given in the report. So we would do a plan of what we were going to do for the day.} \]

(S.3.HCA.1)

On the site where the non-registered staff do not attend the handover, one of the nurses is delegated to provide them with the information that is deemed necessary for them to be able to carry out their work:

*When we come out of the office, somebody’s allocated to go up and talk to the care attendants to give them a quick handover.* (S.2.SN.1)

The handover sets the tone and direction for the day ahead shaping the work of the nursing staff in terms of medical appointments, and medical and nursing tasks to be carried out. It is a common mechanism in healthcare facilities where it provides the clinical governance function of continuity of care. It is also the place where staff negotiate and make plans for what needs to be done. As it is at 8.00 am and 8.00 pm it includes mainly nursing staff and if it’s the practice, care staff. No other staff (such as activity coordinators or allied health care staff) are present and there is no evidence of resident input into these decision-making processes in a way that could be construed as shared decision-making.
6.5.3 Social engagement in the everyday life of the residential care facilities

As residents described their everyday lives, the most striking element was how little they appeared to do each day. Outside of mealtimes, care interventions and scheduled activities that at best filled an hour or two of the day a few days a week, residents described uneventful lives where one day was very similar to the next. In the previous chapter, I drew attention to the textual representation of activity in Mary’s care plan and the organisational separation of social activity from other clinical and physical care work. In this section I pursue this further, connecting meaningful activity to the work of frontline staff and the HIQA standards and regulations.

I begin this section with an observation from one of the sites:

12.30p.m. In the day room before lunch. Residents are sitting round the tables. Some are sleeping some are staring into space. Tom, whom I interviewed earlier, is sleeping. He doesn’t communicate with anyone and only wakes up when the dinner arrives. Mary, whom I also interviewed, is sitting on her own with the paper in front of her but she doesn’t read it. (S.3.OBS)

I asked residents to describe what they did in the day and hours prior to the interview.

A: Right ok, ok, so what did you do after that [shower]?
U: I came up and into bed, well, sat in the chair...
A: Sat in the chair, beside your bed was it?
U: For a while. Then I went out there to hear the news and obituaries and that was it.
A: Oh ok, so what did you do after that?
U: Nothing.
A: Ok right, did you sit there or did you come down?
U: I sat down.
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A: Alright, ok. Well, we’ll go back to yesterday then, em, what did you do say from, from about eleven or twelve o’clock till dinner time yesterday?

U: Not a whole lot, just sat down and that was it. (S.2.RES.4)

My own observations took a similar vein:

9.45a.m.  Very quiet. Two residents up and sitting in the lobby. One man is sleeping; the other is reading a book. I walk down the hall and can see into the various bedrooms. Some residents are in bed, other beds are empty as the people who occupy them are brought down to the dining room where they seem to just sit there quietly without communicating with anyone. (S.3.OBS)

Mo describes her ‘work’ as a resident that morning:

M: In a wheelchair, that’s what I do every day, sit in my chair all day every day. (S.3.RES.4)

Beatrice, who appeared quite passive when describing her morning routines, became quite animated as she described what she did that day:

B: I got dressed and came down to the sitting room, I sat there till dinner time. I went to my dinner. Then, I came back to me chair again.

A: So, when you got down to the dining room, what did you do then?

B: I sit there. I don’t do any work; I have bad feet so I don’t do any work.

A: So what do you do?

B: Sit there in me chair.

A: You sit in your chair... Do you chat with people or... watch television or...?

B: I watch television.

A: Ok, what do you like on television?

B: Ah I don’t mind, whatever comes on. (S.2.RES.4)
The following is an excerpt from my field notes:

However the more dependent residents, with high support needs, are taken to the day room where they sit in silence most of the time. There is a sense of very long days with lots of time when there is little to do. The people in the day rooms (who don’t seem to be able to move independently) seem to sit there staring into space or sleeping. Every so often a staff member breezes in to check on people, make a few comments and go out again. People look very bored. (S.3.FN)

When I asked Maureen what she liked to do, she replied:

\[ M: \text{ There’s nothing, nothing at all. Well, sometimes there’s music in the men’s ward.} (S.2.RES.1) \]

When talking about this music session she animatedly talks about her love of singing, rebel songs in particular and mentions how she would like to have more music and card playing. Later when talking about her daily routines, her eyes filled with tears and she said:

\[ M: \text{ I’m sad and I’m bored.} (S.2. RES.1) \]

Tony describes his experience succinctly saying:

\[ T: \text{ There’s nothing to do except eat and drink. Well, sometimes there’s music, down in the bottom lounge. We would go down to that the odd time.} (S.2.RES.3) \]

Planned activities such as art classes and Bingo do take place generally once a week, but how they are taken up depends on individual tastes and interest. Here Mary gives her opinion about an art activity:

\[ A: \text{ Are there music sessions or art or anything like that?} \]

\[ M: \text{ Well, I’d like to see them, I went to an art class, well now I thought it was a foolish thing.} \]

\[ A: \text{ It probably wasn’t that bad.} \]

\[ M: \text{ As far as I’m concerned, as the daughter of a small farmer, it was a waste of money.} (S.3.RES.3) \]
On the other hand, another participant, Ellen, proudly shows her framed paintings of her dogs which are displayed in her room. Ellen describes her love of painting and mentions the weekly session with an artist who visits the unit. In contrast to almost everyone else interviewed, Ellen says she is never bored:

*E:* No, never bored, the time passes quick enough. In the summer months, we had fantastic weather, we used to go out, Joan and I and we did the planters. The snow came and they all died. I sent away for bulbs, that’s them over there [points to a box in the corner] daffodils and narcissi. (S.1.RES.2)

Although quite disabled and ill with several cancers, Ellen has managed to hold onto her capacity to control this part of her life, she has a friendship with another resident and a dog which she brought with her to the facility. These seem to bring great pleasure to her life. Ellen is a former Director of Nursing and recalls how this common bond with staff has been useful in maintaining that sense of identity as staff draw on this previous role and ask her ‘advice’.

*E:* They know I’m a nurse and might ask me about a dressing on a wound. You know, what would you use, you know? (S.1.RES.2)

Here Ellen describes what she did that day:

*E:* Then I decided that today was a day for tidying. The girls do it alright but I wanted to get rid of the cards. The girls gave me a bag and I put them in that for the recycling bin. (S.1.RES.2)

In contrast to the views of all residents (except Ellen) that they had little to do, managers talked about the range of activities listing off interesting recreational pursuits and events:

*A:* Like, we would have people that are, you know, that read newspapers to the residents, em, there’d be art classes. They are
brought to Mass, you know, there’s all these different things.
(S.3.IM.1)

All of these facilities have activities coordinators or volunteers who plan and execute activities according to care plans or custom and practice. Textual representations of these activities appear on notice boards displayed in communal areas and in resident handbooks. The range of activities as represented is impressive. One handbook describes the activities on offer:

*Residents are encouraged to participate in a variety of activities including, art classes, shopping, gardening, arts and crafts, cooking, exercise classes, social afternoons, reading of newspapers, visits to theatre, bingo, board games & cards, rug making & knitting for example.* (S.3. Residents’ Handbook)

These textual representations give an impression of busyness. However, in the course of a full day they fill only small elements of time and only for some residents. All frontline staff conceded that physical care dominates the day and engagement in meaningful activity is either left to the activity coordinators or happens sporadically when everything else, i.e. physical care routines and paperwork is done, which is rare.

Here is what I wrote in my reflections diary soon after fieldwork in one facility:

*From a resident’s perspective, the sheer ‘nothingness’ of the day. They do very little and wait to be entertained or talked to whenever the staff have time. I understand that some older people (and some have expressed this) may not wish to engage in activity and are content to just ‘be’, but the issue here for me is structured dependency and forced lack of purpose, whereby residents cannot engage in meaningful activity due to the organisation or standardization of care.* (Reflection)

The dull passive lives recounted by participants and what I observed sits in stark contrast to the lives of staff who describe an endless round of toileting, washing and paperwork. Deidre described a typical morning routine when a resident has a shower:
D: So, em, on the day of the shower, you always totally strip the beds so while I was finishing off putting powder on her and getting her dressed, a care attendant went to the bed, totally stripped the bed, even if it had only been stripped the day before, it wouldn’t matter. Everything stripped, and she goes with a bucket of soapy water and it’s washed from head to toe. Underneath, you know, everything. And all new bed linen. So sometimes that has to be done because some patients are going straight from the shower into bed, well this lady wasn’t so we brought her to the day room. (S.2.SN.1)

Caitriona describes part of her morning routine:

C: We’d do the same we’d get the bowl and start, we’d take off their pyjamas we’d have another pyjamas ready for them, take off their pyjamas and wash them, shave them, put on a new pyjamas.

A: Every day?

C: Every day, yeah. Usually give them a new sheet every day because when they’re in bed all the time it’s nice for them to have a clean sheet. So I usually do that, sheets every day, new pyjamas every day and make them comfortable. That’s all you can do then and go on break, sometimes if we get a chance we go on break.

Deirdre talks about the constant bifurcation she feels as she struggles to balance the needs of several residents with her desire to provide holistic care:

D: Oh, I don’t know, like some patients would love you to sit and chat with them for a hour but it’s just not to be, you know, you don’t have an hour. You have some women and, they are very restless in the bed, shouting and I know, if you had the time to sit with them and maybe give them a hand massage, it does calm them down a bit, but you know that is, and we try to give them a quick moisturise when we are doing their care in the morning but it’s very hard to go back.

C: Activities, I mean we do try, we really try to do activities, to do things with them and for the ones that we can bring out to places out maybe for a coffee if we can but it’s not always possible. (S.2.HCA.1)
This sense of bifurcation was articulated by several staff who recognised the need for meaningful engagement but couldn’t see how this could come about without additional staff.

T: They try their best, em, it’s hard to tell, we would be big into social activities but the main barrier again is staffing levels you know, for days out and that. You’re trying to juggle the staff that there would be enough left on the ward and to be able to relieve somebody to go out with the clients for the day but again that’s the biggest barrier, do I think, no at the moment there isn’t. There’s more emphasis based on the physical care of the patients than there is on the social aspect. But they try and do, particularly going into the summer times, if the weather prevails, to have outings and that type of thing and we have them on the ward, but again everybody is so time conscious you know and it’s desperate that you can’t, you know you’d have musician’s in and that. And they do, the social activity group do try their best, but em again it’s trying to get a balance on the ward to be able to let the staff go and be there with the clients. (S.2.SN.3.)

One of the directors of nursing, Kathleen, talked about how as part of the person centred care programme they examined their routines. They invited in a retired nurse who had experience of changing a task-oriented system in another facility. She explained how this retired nurse was considered credible by the staff who felt she understood their experiences and that they listened to her:

K: Liz had been through the process herself. Her background was a nurse and she would say to them, ‘you know, ask yourself, why am I doing this?’ She kept giving them examples of how she worked and how she went about things and gave examples. She gave one very good example to staff. She said: ‘I asked staff one time, every morning every sheet was changed, the big, you know, ages changing beds, every bed was perfect’. And I went into the ward one day and said ‘I wonder if I went into the ward tomorrow and I said, don’t tell me what beds you are making, just tidy some beds up and see if I can tell the difference’. And she went in and she couldn’t tell the difference.
K: Then the clock, she would say ‘why have things to be done by a certain time?’ We were trying to get that through to them, the hamster wheel, and she gave us some good examples and I think they thought that was very good. (S.1.IM.1)

In the previous chapter, one nurse, Laura, described how the work of activities is separate to the everyday work of care giving and its associated physical and biomedical care tasks. This was something I also observed to be the case. Recorded as a field note I recall how I had been invited to join a reminiscence group in one facility which the activity coordinator was running:

One man did most of the talking. One other man joined in when he was asked a question but the others didn’t join in. The activity coordinator seemed to know the residents well and tried to engage with them. The engaged resident seemed to enjoy himself but the others looked bored. A Nurse came in. She told the activity coordinator that it was time to finish up as it was dinner time. (S.2.FN)

Sinead, a health care assistant described how the care staff tried to get involved in these activities whenever they can but commented that the nurses rarely did as they were too busy with clinical work and paperwork. Maria, a nurse, agreed that this is the case on an on-going basis despite her willingness to get involved:

M: Yeah, it is hard to do. Sometimes it’s hard to get an hour you know where that is your focus. Especially on a Monday when you also have the doctors rounds and two admissions coming in for respite, so that’s all going on as well. (S.1.SN.1)

6.5.4 The running of the day

There was little awareness on the part of residents that they could be involved in ‘the running of the day’ and all residents seemed puzzled by the question. Nor did any resident express dissatisfaction with this taken for granted arrangement citing lack of interest or not wanting to interfere.

A: Do you get involved in the running of things around here?
F: No, the staff run everything.
A: Would you like to be more involved?
F: No, the staff know the people. My memory wouldn’t let me.
A: I think there’s a residents’ committee here. Have you ever been?
F: No.
A: Would you go?
F: I would. (S.2.RES.2)

I asked Mary the same question.

A: Ok, would you get involved in the running of the day here? Would you make any suggestions?
M: Oh god, no.
A: No? Why not?
M: Well I don’t want, I don’t want to be interfering.
A: Ok, alright. You’d feel you’d be interfering, would you?
M: Well, if you’re sticking your nose in everything.
A: But sure it’s your home, you live here.
M: No I’m pleased with what I get. (S.3.RES.3)

Mo, who, although disabled, can communicate effectively and is involved in many of the scheduled activities, considers the notion of being involved in the running of the day to be an alien concept.

A: Ok. But you’d never decide yourself, you would never suggest something?
M: No, no I wouldn’t.
A: Ok.
M: No I don’t think I know of anybody that ever did. (S.3.RES.4)

I was struck by the lack of interest that I observed when talking to residents about their involvement in the daily life of the facilities. Residents expressed no real preference or dislikes.
**Chapter 6: The Social Relations of Person Centred Care**

**B:** I watch television.

**A:** **Ok, what do you like on television?**

**B:** **Ah I don’t mind, whatever comes on.**

**A:** **Would you ever get involved and say ‘let’s do this today’ or ‘let’s play cards today’ or…**

**B:** No.

**A:** **Why not?**

**B:** I don’t know, I don’t know. I don’t be interested. (S.2.RES.4)

Tom offers a similar sentiment.

**A:** **What do you like on the television?**

**T:** Well, I could say nothing in particular whatever comes up I’d be satisfied. (S.2.RES.3)

### 6.5.5 Resident and relatives groups input into the running of the day

The formal mechanism for residents and relatives to become involved in ‘the running of the day’ is the residents’ and relatives’ action groups. In terms of participation and decision-making the HIQA standards explicitly advocate the participation of residents.

*Standards 2: Each resident’s rights to consultation and participation in the organisation of the residential care setting, and his/her life within it, are reflected in all policies and practices. (HIQA, p. 15)*

Below this are several subsections which underpin this.

#### 2.3 The resident contributes ideas to and participates in the day-to-day activities of the residential care setting.

#### 2.4 The person in charge facilitates the establishment of an in-house residents’ representative group for feedback, consultation and improvement on all matters affecting the residents. At least one nominated person acts as an advocate for people with dementia/cognitive impairment. Issues raised by the residents’ representative group are acknowledged, responded to and recorded, including the actions taken in response to issues raised.

#### 2.5 Feedback is actively sought from the resident on an on-going basis on the services provided. The residential care setting clearly
demonstrates how the impact of the resident’s feedback informs reviews and future planning.

All of the facilities in this study had resident or relative committees with a stated commitment to such practices publicly stated in their publicity material. However, each of the managers described a process that was not organisationally strong.

A: But you know, to me they seem to be happy enough. We have RAG meetings (Residents’ Action Group) here as well every couple of months, em, and like, they voice their opinions, whatever and there’s an action plan put in place and there is a follow up on it, you know so at least they have their say (S.3.IM.1)

K: Well, we have a residents’ committee. Now, there isn’t great attendance at it, but they would be given a platform to make suggestions as to what they would like or whatever. They’ve done that in the past and it would be taken on board. (S.1.IM.1)

One relative, Pat, recalled being involved in occasional meetings:

A: Is there a residents’ committee?

P: Sometimes there might be meetings called but it mightn’t suit everyone.

A: Would you like to be more involved?

P: No

From the minutes of the meetings, I could see that ideas were put forward for activities and better food choices. However, there was little evidence of its impact beyond this. None of the residents or relatives I interviewed was aware of this mechanism except in a vague way and there was little evidence that it had a significant impact on their lives. In contrast to the vagueness around the resident and relatives councils, participants seemed well informed about the complaints process. While none of the residents or relatives in this study recalled making a serious complaint they all stated that they would have no difficulty doing so. In general, they expressed no
complaint against staff who they described as ‘great girls’ (S.2.RES.2) or as ‘doing their best’ (S.2.RES.3), sympathising with their busyness stating that they were ‘run off their feet’ (S.3.RES.2) or haven’t got a minute (S.2.RES.1). Joanne, the HIQA inspector, when talking about a recent inspection (not any of the study sites) described how the complaints process was a priority for them and something they checked verbally with residents.

A: Can you remember what you talked to them about?

J: Yeah, well, I would have talked to them about activities and the lack of activities. I would have asked them about that em, the health care there was issues around that. I would have asked them – the residents – if they felt they were being looked after in terms of their health specifically, complaint’s policy there was actions around that what they would do if they had a complaint who they’d speak to.

6.6 Complaints as a mechanism of involvement

The right of redress is as stated human rights and is provided for in the Care and Welfare Regulations (2009). The regulations require the provider to maintain

A record of all complaints made by residents or representatives or relatives of residents or by persons working at the designated centre about the operation of the designated centre, and the action taken by the registered provider in respect of any such complaint. (C&W Regs 2009, p. 22)

Providers are directed to provide visible information of these texts in their facilities as a demonstration of equity and right to complain as was publicly displayed in all of the facilities:

The hospital fully participates in the HSE Your Service, Your Say comments and complaints system. Service users and their families are advised that complaints may be made openly or anonymously and that complaints will be dealt with thoroughly and sensitively as per the HSE Complaints Procedure.

There are guidelines displayed throughout the hospital on the procedure involved in making a complaint, comments or compliments.
A box is provided in the Front Hall Entrance for completed forms. (S.1.POL)

Part 12 (39) of the care and welfare regulations relating to Complaints Procedures has twelve subsections outlining the formal process required in respect of complaints with clear directives in respect of textual policies required, processes, appeals, and recording of complaints. The process connects to the HSE’s advocacy unit which aggregates data from complaints, although not specifically for residential care, in order to inform the cycle of knowledge as is considered good governance practice. The complaints process connects to the wider growing network of patient advocacy systems and regulatory processes for rebalancing the power of professionals over patients and as material evidence of organisational goals of continuous quality improvement (Framework for Public Service User Participation 2011).

As such, complaints (as a mechanism of determining the rights of residents) are highly visible in the regulatory process. However, given that residents or relatives do not consider that their experiences warrant a complaint as a feedback mechanism, it is unlikely to drive changes or to destabilise existing organisational dynamics.

### 6.7 Hopes for the future

As part of the interview process I asked each resident what their hopes for the future were. Here I am not seeking threads to connect to organisational processes but rather staying faithful to the IE goal of returning to the lives of those whose standpoint is adopted following a mapping of the social relations of an institutional system (Campbell and Gregor, 2004).

**A:** Do you have hopes? Things you would like to do?

**M:** [pauses] I don’t think I have many hopes. I wish my family had more time [eyes fill with tears]. (S.2.RES.2)
Finbar’s response was as follows:

A:  What are your hopes now?
F:  That the man above would take me away. I’ve nothing to keep me here now. I’m ready to go. It’s not that I’d commit suicide or anything like that. They are wonderful here. (S.2. RES.2)

Waiting for death was expressed by two other residents when asked about their hopes or interests for the future.

A:  Ok. Alright. What kinds of things are you interested in now?
B:  Interested in?
A:  Is there anything that you want to do or you’d love to do?
B:  I’m a big age and I want to be let die.
A:  You want to be let die, yeah?
B:  Yeah.
A:  What age are you?
B:  I’m 85. That’s a big age isn’t it? (S.2. RES.4)

Ursula talks about the loss of her loved ones and wanting to join them:

A:  Ok, what kinds of things are important to you now?
U:  I’ll be honest with you, not a lot.
A:  What kinds of things, is there anything you would like to do or still like to do or?
U:  What I’d like to do now is lie down and die, to tell you the truth.
A:  Ok, right, and is that because you’re bored here or..?
U:  Ah, I don’t know. If me husband is gone and my son is gone and my father and mother are gone and me brothers are gone...
A:  What kinds of things make you happy?
U:  I don’t have anything that makes me happy now. (S.3. RES.5)
I recorded my feelings in a reflective diary following these conversations

Little hope or expectation of the future. I understand that being ready for death and accepting it is not a negative thing but if longing for death relates to the place that residents find themselves in, is this good care? (Reflection, 21.08.12)

In contrast, Ellen talks animatedly about her life and the things she is involved in:

**A:** What kinds of things are important to you now?

**E:** Well, the fact that we have the church again. We have mass every Saturday or Sunday. We have a priest, he’s a retired priest, you can discuss anything with him. An elderly retired man, he knows a lot of my relations.

**A:** So religion is important to you?

**E:** Yes. And my dog. (S.1. RES.2)

For Mo, retaining her independence was important to her:

**A:** What kinds of things are important to you now?

**M:** Being able to do as much as I can for myself, it’s not much, but I try to do as much as I can, you know, not to become really dependent on people all together, there’s an awful lot I can’t do but any little thing I can do I like to do it for myself, that is important to me. (S.3.RES.4)

Tony offered the following as a response:

**A:** Are there things you would like to be able to do now?

**T:** Sure, what am I able to do? I don’t know.

**A:** Like would you like to be able to go out, in the wheelchair? Is there any where you would like to visit?

**T:** After Easter, I must get out to me own place and have a look at it, you know. (S.2.RES.3)
Jim, Tom and Joe state that they are happy enough with what they have and with what they want to do:

**J:** Ah, I’m happy enough, good fine weather makes me happy, we’ve great weather next week, yeah.

**A:** Is there anything you want to do or things that you would like to do?

**J:** Ah no, there’s nothing there’s nothing I can do now anyway only sit down and talk I’m no good at that either. (S.3. RES.1)

**T:** What’s important to me in here?

**A:** Yeah, in your life now?

**T:** Ah sure, I don’t think anything could be changed, I have everything that I want, I go to bed when I’m tired the same as home and I get up when I like. (S.3. RES.2)

**A:** What do you want to do?

**J:** I don’t think there is ... probably a lot of things I’d like to do. I don’t know, I don’t think there is too much more. (S.1. RES.1)

### 6.8 Findings on social engagement

All of the residents commented on the fact that they had certain food choices and had some control over their personal care routines in that they could refuse to have a shower or stay on in bed if they wished. However, almost all said they did very little beyond occasional social events or scheduled activities which filled only a small amount of the week. Choices which moved beyond what could be accommodated within existing shift patterns were seen to be problematic. The organisational practice of the nursing handover meetings and negotiation between staff determine the routines and organisation of the day reinforcing a staff directed system.

Managers described the challenges of balancing the needs of residents and staff and all stated that regulatory power had helped them to overcome resistance to change. While the mechanisms of resident and relative councils exist, their influence over organisational practices appears to be minimal.
and involving residents in decision making about their everyday lives remains subordinated to organisational routines decided by staff who readily admit that this is the case.

The complaints process while textually dominant in all the facilities and in the regulations was not used by any of the participants as a means of expressing their views about their experiences. The majority of the residents expressed resignation at their circumstances and some expressed a longing for death. However, hope for the future and a desire to retain independence was also expressed.

### 6.8.1 Findings summary

This chapter mapped the social relations of two ‘threads’ of social organisation; how staff and residents related to one another and how residents got involved in the everyday life of the facilities. The analysis began in what residents said actually happened and what I observed and then proceeded to an analysis of the work of frontline staff, relatives and managers and through connecting these experiences to procedural and regulatory texts. The process highlighted some of the organisational barriers of translating the theory of person centred care into everyday practice.

Residents described their relationship with staff primarily in instrumental terms based around care routines and health issues and had no expectation of more personal or reciprocal relationships. Previous shared social connections with staff were raised by residents. Staff, however, claimed they needed to ‘know’ the residents in a more generic way for care and clinical governance reasons.

Managers and staff described staff deployment systems that connected them to locations and wards rather than to individual people. There is evidence that negotiation and choice in relation to some elements of activities of daily living have been incorporated into organisational routines. However, this has not translated into residents being involved in daily organisation of the facilities. Residents and relatives willingly cede power for this to the staff.
Biomedically-driven handover meetings drive daily organisation and resident involvement consists of ad hoc resident council meetings whose sphere of influence relates to food choices and proposing social activities. While the introduction of regulation has been seen as beneficial and has acted as an enabler to overcome resistance to change of work practices, staff have expressed frustration at the additional paperwork it has brought about.

Residents described uneventful days with little to do and most expressed resignation that this was just the way it was. No one considered that this was something that warranted a complaint. The following Chapter discusses these findings together with those of Chapter 5, drawing on the discourse of person centred care and Institutional ethnography.
Chapter 7: Discussion

7.1 Introduction

This chapter provides a discussion of the findings of Chapters 5 and 6 which concur with other studies which have found that translating the theory of person centred care into everyday practice is a multi-dimensional task and therefore difficult to sustain. Adopting the methodology of Institutional ethnography allows for the critical examination of taken for granted professional and management practices and attempts to show how these work practices create environments of care that prioritise professional ways of knowing over other local and personal forms of knowing. By adopting the standpoint of older people rather than professionals the study’s focus is on their lives, their concerns and their experiences. Opening up this line of inquiry gives voice to a group who are generally silent in the policy discourse and reveals a disjuncture between what is required by the organisation or ruling relations and the espoused goals of person centred care.

By mapping the work of residents to the work of staff the study provides insight into the complex set of social relations which organise and coordinate the work of the social actors – revealing how this work is coordinated in line with goals of professional accountability and perceived organisational efficiency which can actually work against the espoused goals of person centred care. The analysis revealed a privileging of professional and biomedical ways of knowing over local and embodied ways of knowing. It highlighted textually-mediated organisational processes of objectification and unequal power relations that subordinated opportunities for relationship-building between residents and staff and excluded residents and relatives from decision-making about, and participation in, the running of the day. The chapter is divided into three sections; care planning as discussed in Chapter 5, and relationships and social engagement as discussed in Chapter 6.
7.2 Discussion on *A Key to Me* in the context of care planning

The analysis in Chapter 5 connected the process of care planning to the theory of person centred care. However, by adopting an alternative way of looking, using an IE lens, the textual work of care planning is considered as a mechanism of the ruling relations that coordinate people's lives in line with organisational goals. Institutional ethnography assumes that texts have the power to shape and coordinate people activities, obligating people to act in particular ways (Jackson, 1995; Kinsman, 1995; Campbell, 1995; Campbell and Gregor, 2004; Turner, 2001; Walby, 2013).

Using the *A Key to Me* text as an entry point, the analysis showed that a textual representation of Mary – as a patient with fragile skin, who is incontinent and at risk of falling – was created. This representation also gave an impression of a busy, engaged woman which bore little resemblance to how she described her life. Both she and her son described a woman who had few social connections, little to do and no opportunities to contribute, despite some clues that she had skills that could be used in the facility. The analysis revealed how the *A Key to Me* document, which was intended to promote the maintenance of personhood, got taken up by the nurse and reinserted into a list of problems connected to what the organisation can provide – in this case, biomedical care, activities of daily living, group-based recreational activities and the creation of a regulatory compliant document. Through the process of care planning and in line with the intention of identifying ‘need’, the nurse was directed to identify problems and offer a realistic set of actions to remedy these problems. The process provided a disaggregated presentation of Mary and her ‘needs’ which got translated into a plan based on facts as established through the assessment process and as determined by her location in a healthcare facility. It represented problems to be solved and tasks to be done rather than personal goals to be fulfilled. As such, the work of care planning represented the actions of the nurse not the resident and therefore did not represent her ‘wants’ as might be defined within a ‘life plan’ which is promoted within the professional literature (McCormack, 2001; Agich,
From this textual representation, Mary’s capacity to read, knit, do arts/crafts, chat, and go to Mass were reconstructed into reportable categories aligned to therapy or social activities that happened when staff had time, which, by their own admission, wasn’t very often. Her voice was removed and replaced by that of the nurse and it is this work that was presented and reported on, not Mary’s. The incorporation of such ‘wants’ such as her desire to have a good chat or her capacity to perhaps ‘look after everyone else’ were not visible in any useful way and were subordinated to what the organisation is willing and mandated to provide.

This textual representation of Mary meets the professional and regulatory standards as required from a competent nurse working in gerontological care. Highly visible in both the everyday work of staff and professional and regulatory texts, it represents a dominance of professional ways of knowing and the professional practice of primarily prioritising the identification and addressing of ‘need’. This, I argue, perpetuates a system whereby frail older people are considered passive recipients of care rather than individuals with hopes and aspirations who, as espoused in the literature, are part of an interdependent community of people (Brown Wilson, 2009; Shura et al., 2011).

### 7.3 The textual act of daily reporting

Connected to the work of care planning and as part of the textually-mediated accountability process, a daily record of activity – the care flow sheet – is filled out two or three times daily (Appendix 23). In this study, staff described how on a daily basis they filled in these forms, sometimes guided by what went before, acknowledging that the boxes they ticked did not always represent the reality of what really happened. This recording work connected their actions to the routine practices of categorisation and accountability in a way that made certain ‘facts’ visible and rendered others invisible. The facts that are visible in the care flow sheet serve to categorise individual people as objects to be washed, dressed, provided with food,
entertained or receive biomedical care which, according to Diamond (1992), redefines the process of care-giving from one of subjective social relations to ‘acts performed on individuals’, transforming them into an ‘acontextualised object’ that is acted upon (p. 209). In relation to the domain of ‘social activity’, the staff described their bifurcated feelings of translating what they saw as just everyday life into a textual representation that complied with the regulations, rendering normal living into actionable and reportable goals. In Mary’s case, the reporting of social activity while physically located in the same care plan represented the work of different actors at different times, creating a disaggregation into separate silos or departments, where ‘nursing work’ was separate from ‘activities’.

Through this textual act of recording, the daily life of Mary, as experienced through her embodied feelings, relationships, activity and inactivity, was silenced and converted into a record that provided for textual representation and accountability. This process also objectified the staff who conformed to this professional act of inscription and categorisation even when it did not align with their local way of knowing. The textual work of individualised care planning, recording and reporting is considered important work from the perspective of continuity of care and accountability (Webster, 2004; Worden and Challis, 2008; Moore, 2010; Power and Van Lente, 2012).

However, Webster (2004) suggests that the adherence to rigid/unbending frameworks or tools for assessment contributes to the challenge of translating person centred care into practice. In a similar vein, McCormack and McCance (2010) note that the structured nature of the assessment criteria derived from models can direct the dialogue between nurse and older person rather than facilitating the gathering of information to build a picture of the person. According to Smith (2005) the process of assessment casts the nurse and recipient into asymmetrical power relations whereby, as discussed in Chapter 3, the nurse becomes the ‘inquisitor, examiner and grader’ (McLean and Hoskin, 1998). By using a predetermined template she is engaging in what Smith (2005) describes as a Text-Reader conversation, directing her attention towards certain elements of Mary’s life.
and away from others in line with the goals of the organisation. Because these templates are replicable and trans-local the process acts as a coordinator of social relations creating a professional form of knowing which reinforces the ideological goals of the organization – creating a circularity of knowledge that reinforces professional ways of knowing (Rankin and Campbell, 2009).

In this study, few residents and relatives recalled having input into the care planning process and willingly accepted the authority of health professionals to make decisions on their behalf based on their clinical expertise. None of the Health Care Assistants were involved in developing care plans or in updating them. The narrative notes in Mary’s care plan revealed ongoing discussions about her skin and her digestive problems and Laura acknowledged that she, as a nurse, ‘looked after her own piece’ while ‘activities’ were separate, both textually and in the everyday routines. I argue that the organisational process of care planning privileges professional knowing over other ways of knowing garnered through story-telling, local history and local rituals as these do not fit within the ‘rigid unbending frames of the care plan template’ (Webster, 2004).

Agich (2003) suggests that story-telling in residential care is important as a means of helping older people make sense of their current circumstances through the stories of their past lives and that listening to their stories bestows a sense of value and respect for people as individuals. Studies have shown how care staff, through the use of stories, have changed their perceptions of residents from objects to be cared for and kept safe to that of real people with abilities, resources and futures (Hanesbo and Kilghren, 2000; Heliker and Scholler-Janquish, 2007; Heliker and Hoang Thanh, 2010). Heliker and Hoang Thanh (2010) suggest that through the respectful listening and bearing witness to other’s stories, people enter into mutually positive relationships. The analysis draws attention to the intersection of professional power and knowledge, showing how the work of care planning draws staff into predetermined courses of action regardless of their knowledge and desire to be ‘person centred’. In this way, the nurse has
acted as an agent of the ruling relations, creating a representation of Mary that aligns with the current ideology of residential care.

7.4 Relationships

In Chapter 6, I described how residents defined their relationships with staff primarily in instrumental terms based around care routines and health issues and had no expectation of more personal or reciprocal relationships. Similar to what was described in other studies (Brown Wilson, 2009; Nakrem, 2011), residents said that they were getting well looked after from a health perspective and were grateful for what they got. During interviews, residents and relative participants claimed to have little knowledge of staff as persons except when they talked about those from their own locality. When this happened they talked enthusiastically about family or neighbourly connections and clearly recalled first and second names. In contrast, nursing staff claimed they needed to ‘know’ the residents in a more generic way for care and clinical governance reasons and to maintain interesting working conditions. Yet, at the same time, it was acknowledged that this way of working could waste time as they re-orientated themselves to a different resident’s personal requirements.

The analysis in Chapter 6 showed how staff were allocated to wards or units through a process of rostering, undertaken by managers, that involved calculating skill mix and numbers based on a process that measures dependency and decline and matches residents and staff based on needs associated with activities of daily living – washing, dressing, eating, going to the toilet, and moving. From an Institutional ethnography perspective, this rostering work draws managers into a process of objectification and categorisation of older people according to ‘dependencies’, rendering them objects to be cared for, primarily based on physical care and physical labour. According to Ronch, (2004) staff are also viewed as ‘interchangeable parts of a process churning out a quota of tasks per shift’ (p. 66) and as such are also objectified. Because the processes of staff calculation and rostering are trans-local, this system shapes and coordinates
the lives of staff and older people across many locations in a form of externally located social relations.

McGilton and Boscart (2007) suggest that the nature of relationships between residents and staff may vary depending on individual situations. Potential relationship types include therapeutic, personal, professional, friendly, and surrogate relationships. For example, in some cases a therapeutic relationship may be necessary if a resident is troubled or depressed, while in other instances where a resident has no other meaningful relationships or connections, what they may require is a more personal friendship. In this context, they suggest that staff need to be more aware of what is meaningful to residents. As a means of enhancing relationships between staff and residents, they propose that managers need to be aware of which residents and staff ‘click’ and be aware of their common interests. They also propose that residents who can should have at least some say in staff assignments.

Consistent assignments have been found to have a positive impact on person centred relationships from the perspective of both residents and staff (Yeats and Cready, 2007; Castle, 2013). In the United States, the Quality in Nursing Homes Campaign (www.nhqualitycampaign.org/files) advocate for an 85% consistent assignment rate suggesting that it is a key cornerstone for culture change. Defined as the same staff caring for the same residents every time they are on duty, this has been connected to the promotion of person centred care both in the context of improving relationships between residents and staff (Brown Wilson, 2009), improved staff satisfaction (Bowers, 2000; Yeats and Cready, 2007) and to reduced turnover of staff and absenteeism (Castle et al., 2013).

In contrast to the concept of relationship-based care as is espoused in the professional literature, I contend that the organisational process of rostering as it occurred in this study denied the subjectivity of both residents and staff, silencing the possibility of relationships based on shared interests, values or past associations. As such, this practice perpetuates a one-way
system of care-giving as opposed to the concept of reciprocal relationships that could benefit both residents and staff – reinforcing the status of residents as passive recipients of care. I argue that this represents a domination of organisational knowledge over other ways of knowing which, according to the person centred care literature, could deliver much more (Thomas, 2004; Ronch, 2004; Smith, 2005; Brannon et al., 2010; Rockwell, 2012).

7.5 Social engagement through shared decision-making

In the above study, residents were seen to experience choice in relation to some elements of the activities of daily living such as food choices, what time they got up at and if they wished to engage in social activities. However, these choices were determined by staff within existing institutional frames of working. Choices which impacted on rosters or working arrangements were seen to be problematic. Residents appeared to have low expectations of choice beyond what was available and expressed little interest or knowledge about the potential to have more choice or to be involved in decision-making.

Perceived lack of interest in making decisions has been cited as one reason why older people do not engage and a number of authors draw attention to the fact that some may welcome a release from anxiety provoking decisions and may be happy to cede autonomy for organisational routines within a climate of beneficence (O’Hanlon and Coleman, 2004; Mattiason and Andersson, 1997). Some authors contend that not everyone will want to be actively involved in every aspect of decision-making but may wish to have their views represented by somebody else (Katz et al., 2011; Welford, 2012). Welford (2012) suggests that, given the heterogeneity of older people, the level of decision-making they wish to engage in may be different for each individual. McCormack and McCance (2010) explain that, in order to be involved in decision-making, a person must have access to information and options to choose from and, if information-giving is to be meaningful, it needs to be at a pace that individuals can keep up with. Kitwood (1997)
coined the phrase ‘outpacing’ to convey this idea of care workers moving too fast for the person who had dementia, therefore running the risk of excluding them from decision-making. Perceptions of residents as patients, dependent and in need of protection have been connected to a lack of participation in decision-making leading to low expectations, a loss of self-esteem, passivity, depression and helplessness (Barkay and Tabak, 2002; Agich, 2003; Thomas, 2004; Tutton, 2005; Doble and Santha, 2008; Boyle, 2008; O’Dwyer and Timonen, 2010).

It has been revealed how the routines and work of the day were established at the daily handover meetings and how care routines revolved predominantly around drug rounds, doctor’s visits, bathing and toileting routines and mealtimes. This concurs with the literature that suggests biomedicine and activities of daily living tasks dominate the routines of both staff and residents (Barkay and Tabak, 2002; Tutton, 2005). While the process of rostering, as described above, connected staff to locations and wards rather than to individual people, staff participants also described informal decision-making processes between themselves at the start of shifts either at the handover meetings in the office or at the nurse’s station. The accounts of professional camaraderie, cooperation and flexibility, and my own observations of this, connect to the ‘context of care’ issue of staff relationships which McCormack and McCance (2010) suggest are an important prerequisite for person centred care. However, from my observations, I also noted that these decisions were made in physical locations that belong to the staff and are clearly demarcated as such through their design and artefacts such as signage, high counters, locked filing cabinets and designated offices. From what I could see, there was no obligation to enter into similar informal decision-making processes with residents, despite the rhetoric that this is their ‘home’.

Decisions about the running of the day were made primarily at the handover meeting which happened at eight o’clock in the morning and at eight o’clock in the evening, when residents were in bed and other ancillary staff such as activity coordinators or allied health professionals were not present.
As such, I argue that this rendered collaboration in the running of the day (as espoused in the HIQA standards) an idealised concept. I also argue that these taken for granted decision-making practices represent what Kitwood (1997) describes as ‘outpacing’ as they do not happen when residents or relatives could realistically participate. The privileging of the clinical governance goals of continuity of care over other forms of shared decision-making privilege professional ways of knowing over other forms of knowing in a way that I contend is exclusionary. While formal mechanisms of shared decision-making in the form of residents’ councils do exist, they appeared to have little meaning to the residents or relatives in this study and local managers stated that they were hard to sustain. As a decision-making mechanism, they appear to have little influence beyond extending food choices and proposing social activities.

Consultation through user groups is a key participatory concept connected to citizenship and democracy and has been incorporated into management and regulatory systems (Baur and Abma, 2011; Health and Social Care Regulatory Forum 2009). Yet in the context of residential care for older people, studies suggest that the effect of such forums is limited due to institutional constraints, the competing agenda of staff and residents and bureaucratic management systems (Meyers, 1991; Hunter & Tyne, 2001; Braithwaite, 2007; O’Dwyer and Timonen, 2010). As such, I contend that as a democratic mechanism for rebalancing power relationships between residents, relatives and staff, it is an idealised concept with limited applicability in the everyday lives of residents.

Equally, the democratic principle of redress through the visibly dominant complaint process, while providing an important protection against abuse or poor care standards, is unlikely to rebalance power or uncover meaningful information in relation to person centred care or its implementation. In this study, residents and relatives expressed low expectations about what the facility could deliver, in contrast to what the literature says is possible. Because residents considered the staff to be ‘doing their best’ and ‘run off
their feet’ satisfaction surveys were also unlikely to be instruments for change.

7.5.1 Social engagement through meaningful activity

The concept of social engagement connects the ideas of meaningful activity and participation together, as it is through the involvement in meaningful activity and occupation that people come together and get involved with other people (Townsend and Wilcocks, 2004).

We have seen how residents reported a lack of involvement in life situations, describing uneventful lives where one day was very similar to the next. The staff helped residents to wash and get dressed and took them to the day room where they mostly sat in silence or watched TV. Those that were able went to activities when they were on but reported that this represented only a small element of their daily lives. Despite being a regular visitor to a residential care facility, the observation sessions in the day rooms were particularly revealing as I struggled to find things to write down for two hours at a time while very little was happening. While residents conversed with and appeared to enjoy friendly banter with staff, there was little interaction when staff left the room. Despite managers and staff saying that social activity was important, it did not get prioritised over other routines, which is consistent with what the literature has repeatedly shown – that levels of social interaction and social activity in residential care settings are low (Nolan et al., 1995; Mattiasson and Andersson, 1997; Ice 2002; Tester et al., 2003; Ward et al., 2008).

It has been reported above how all of the staff acknowledged the dominance of ‘physical’ care over social elements of care and nurses in particular stated that they rarely had time to engage in anything other than this type of work. The sharp contrast between the lives of residents and the lives of staff was highlighted. Residents expressed feelings of boredom and passivity while staff expressed feelings of being rushed and overworked, reflecting occupational imbalances for both groups. Occupational balance is a concept
usually identified with the ‘all work and no play’ idea where the balance between productivity and leisure is out of kilter. There is a vast literature on the psychological aspects of occupational imbalance and associated patterns of ill-health such as burn-out or other stress-related illnesses. The corollary is where the need to be productive or to engage in self-care activity is curtailed through disability or frailty and the associated loss of occupations of choice can lead to emotional distress, depression, and loss of self-identity and self-efficacy (Polatajko et al., 2007; Lou et al., 2013).

Several authors have pointed to the social justice elements of meaningful activity, suggesting that the right to be occupational equates to participative inclusiveness, and its corollary constitutes occupational deprivation and social exclusion (Townsend and Wilcocks, 2004; Thibeault, 2007; Stadynk, 2010). While residents were encouraged to engage in self-care activities (such as washing, dressing and eating) when they could, opportunities for involving residents in a contributory role were not observed, despite the fact that the majority were women with a lifelong experience of homemaking and caring for others. While some were too physically frail, this was not the case for all.

All of these facilities provided activity coordinators and had, in their own view, worked hard to create interesting schedules of activity. The official accounts of daily life suggest that they are filled with interesting activity but the reality was very different. By connecting the work of residents to the work of others, I could see that textually visible standards and regulations relating to meaningful activity were not happening the way they were intended to happen. I contend that the provision of ‘activities’ and their construction as primarily recreational (as identified in the study), serves to distance residents from participating in the ‘running of the day’. This distancing sits within a model of care which espouses ‘home from home’ (Cooney, 2008) while in reality it follows a model more akin to a hospital.

Taken together with the physical distancing that takes place when staff retreat into ‘staff only’ locations (such as nurses stations, offices and kitchen
pantries) and the apparent incapacity of many residents to self-initiate occupation (Morgan Brown, 2012), an organisational model emerges that prioritises clinical activity and organisational efficiency over person centred care. The above section provided a discussion on the ‘threads’ of social relations as outlined in Chapters 5 and 6 highlighting issues of objectification and the privileging of professional and organisational ways of knowing. The following section provides a further discussion of these findings and associated organisational barriers in the context of power relations and the potential of the theory of person centred care to change the social relations of residential care.

7.6 The social relations of power

Smith (2005) contends that people are often situated in social relations that are unseen and hidden. In this way, one of the functions of an Institutional ethnography is to make visible the social relations so that people can become aware and change the prevailing social relations (Campbell and Gregor, 2004). This section explores the issues of power that emerged in this study, not in the form of coercive power or overt demonstrations of dominance but rather through taken for granted decision-making practices and textually-mediated organisational systems.

The literature contains many references to the power of professionals and the disciplinary and segregating power of residential care (Glouberman, 1990; Hugman, 1991; McLean, 2001; Ronch, 2004; Means, 2007). Unequal power relations and one-way dependent relationships have been connected to a lack of autonomy leading to powerlessness or helplessness passivity, and withdrawal (Kayser Jones, 1990; Diamond, 1992; Townsend, 1992; Duncan and Heubner, 2000; Thomas, 2004; Shura, 2011). Foucault, in the Birth of the Clinic (1963) and Madness and Civilisation (1965), describes the power of the able-bodied over the sick through processes of surveillance, the clinical gaze and disciplinary power. He theorises about how bio-power has becomes a means of controlling populations, regulating their lives and translating human beings into bodies to be examined, charted
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and managed in line with government and professional principles (Foucault, 1963; McNay, 1994). In ‘Asylums’, Goffman (1961) introduces the concept of ‘total institutions’ where ‘inmates enact all elements of their lives in one place under the surveillance of staff’. Several other authors have pointed to the dominance of prevailing models of care such as the ‘chronicity model’ (Ronch, 2004) or the declinism perspective of the medical model (Koch and Webb, 1996; Thomas, 2004) as models that have impacted on the power relations between older people and professionals, casting staff in the role of measuring decline and containing infection while residents are expected to conform to these organisational goals (Ronch, 2004).

In IE, different forms of knowing are explicated drawing attention to scientific knowledge and professional discourse and local ways of knowing informed by embodied feelings, local cultures, rituals and storytelling (Smith, 2005). Using an IE lens, I considered the intersection between professional knowledge and other forms of knowing. Technical expertise is an essential component of gerontology and technical competence considered an important prerequisite of person centred care (McCormack and McCance, 2010). According to Thomas (2004) the capacity to think beyond processes of activities of daily living and the geriatric giants of falls, incontinence and dementia is only possible due to the positive advances in healthcare in recent years. But in the current organisational construction of residential care as primarily biomedical and based on instrumental elements of care, the assumption that for all residents this is the most important aspects of their lives belies their heterogeneity and different life situations. For some, biomedical care will be to the forefront of their lives or may be so at different times depending on the trajectory of chronic or episodic illness, but at other times or for other individuals it may fade into the background as other goals such as a desire to contribute or be more socially connected become more important.

The privileging of professional and organisational knowledge as described above highlights a complex set of power relations that exist between the able-bodied and those that have age-related conditions that require ongoing
support. Nelson (2000) contends that a key problem in residential care is that frail older people lack power as they have no resources with which to bargain. He suggests that in order to counteract powerlessness one must have options, either in terms of physical or mental capacity, coercive power or strategic resources. He also suggests that inability to reciprocate through either inducements or harm is a major contributor to the powerlessness of residents and an obstacle to the development of intimate relationships. One mechanism designed to counteract this inequality of power is advocacy, which he explains involves the engagement of a third person as an ‘alternative exchange partner’ creating a triangle of conflict that destabilizes the patient/caregiver dyad and neutralises power asymmetries.

There is limited access to formal advocacy in Irish residential care settings. While independent advocacy is mentioned in the HIQA standards, it is not mandated in the textually superior Care and Welfare Regulations and therefore providers are not obliged to make formal provision for it. Independent advocacy as a formal (volunteer) system of support is only beginning to emerge in Ireland, supported primarily through philanthropic funding.

Another mechanism proposed to rebalance power is the creation of exit schemes which offer a choice to the user to go elsewhere. However, Nelson (2000) notes that taking a ‘money follows the user’ approach, that rewards successful providers while punishing the poor provider, can create a vicious cycle in that the poor provider now has less money. If the successful provider can cherry-pick, i.e. provide services to those who are easier and cheaper to care for, the gap widens with a resulting diminution in equity and decline in quality in the poor performing service. Some authors suggest that it is simply not possible for very frail older people to compete against other stakeholder groups whether those stakeholders are ‘younger’ older people (Vincent, 2003) or staff who belong to the powerful ‘cult of adulthood’ (Thomas, 2004). All of these authors propose that older people and the people who come to work with them primarily for altruistic reasons should form a coalition of reciprocity and interdependency, (Agich, 2003;
Thomas, 2004; Nolan, 2006; McCormack and McCance, 2010; Dupuis, 2012). Such a process assumes that the altruism of professionals will lead them to act in a way that puts the person first but this may depend on the degree of self-sacrifice involved (LeGrand, 2003). In theorising about public sector workers in the United Kingdom, LeGrand (2003) contends that many public sectors such as health professionals consider themselves to be first and foremost altruistic. However, if they feel they are not trusted by regulators or managers or their professionalism called into question, they can become de-motivated. He suggests that if they feel their professional goals are in conflict with those of the organisation this can move them in the direction of self-interest, or staff representative groups, to voice their interests.

Resistance to change has been identified as one reason why task-oriented care is so pervasive (Murphy et al., 2006; McCormack et al., 2010; O’Dwyer, 2012). Some authors suggest that the reason for this is that staff have been trained in an acute care model within which staff traditionally have higher levels of control over decision-making (Robinson and Rosher, 2006; Weiner, 2010; O’Dwyer, 2012). However, others contend that increased autonomy of staff can result in improved outcomes for residents (Ronch, 2004; Nolan et al., 2006; Yeatts and Cready, 2007; McCormack and McCance, 2010). In this study, managers described experiences of resistance from frontline staff and stated that the regulatory process had helped them overcome resistance to change. They also expressed their frustration at having to negotiate with unions and the centralised systems of the HSE which controlled their capacity to be flexible around shift patterns or skill mix in line with local knowledge. However, this regulatory power and the associated public exposure via media reports were also reported as having a de-motivating effect on staff. Most of the staff in the above exploration complained about the additional workload that had been thrust upon them by the regulatory process reporting that it took them away from spending time with residents.
7.7 Summary of findings

This thesis has explored the territory between the theory of person centred care and the organisational policies and practices of 3 Irish Public Residential Care Settings from the standpoint of residents. Despite introducing texts to promote the principles and practice of person centred care and increasing staff awareness of these principles through the practice development programme, organisational practices continued to shape what actually happened, based on taken for granted ways of knowing about frail older people constructed within a primarily biomedical frame. I have also described how residents and staff were caught up in social relations that coordinate what they do in line with existing institutional frames of care planning, professional accountability, human resource deployment and decision-making despite espousal of person centred principles that promote a different way of working and the presence of committed leaders and staff.

By using the methodology of Institutional ethnography, I demonstrated how organisational processes of objectification and the prioritisation of need as determined by the organisation, subordinated opportunities for ‘comfort, attachment, inclusion, occupation and identity’ (Kitwood, 1997 pp. 81-85). This had the effect of silencing real people, removing their embodied feelings and subordinating their ways of knowing to professional ways of knowing. The purpose of Institutional ethnography is to make visible hidden social relations in order to help change the situation of participants (Campbell and Gregor, 2004; Smith, 2005). In this context, in the following and final chapter, I outline the implications for policy and practice, provide a reflection on the methodological challenges and describe the limitations of the study. I also outline contributions to knowledge and proposals for future research. Concluding remarks are provided.
Chapter 8: Implications for Policy and Practice

This thesis has been guided by the professional discourse of person centred care and the ontology and methodology of Institutional ethnography, and has uncovered points of tension or disjuncture between what is espoused in policy and professional documents and what happens in reality. By adopting the lens of Institutional ethnography, the analysis went beyond this to reveal textually-mediated social relations of objectification and unequal power that located frail older people as passive recipients of care, despite the best intentions of committed champions and leaders. In this way what became evident was that, although the practice development programme raised awareness, created more flexibility and choice where it has previously been unavailable and created regulatory-compliant textual processes, it was not supported by the type of organisational change required to realise its full potential. In this section, I outline policy and practice implications of translating person centred care into organisational structures and actions.

8.1 Translating person centred care into organisational structures and actions

The privileging of professional ways of knowing has been highlighted in this study. The analysis in Chapter 5 found that the ‘care plan’ which in theory belongs to the resident in reality belongs to the organisation and is required as evidence of regulatory compliance and professional accountability.

The adoption of a ‘life plan’ as promoted in the PCC literature would assist in reorienting staff towards the wants and goals of individual residents rather than the goals of the organization. I propose that the ‘life plan’ become the key document that supports what happens to a resident, supported by other accompanying assessments or action plans as determined by their individual circumstances. In this way, I am proposing that the life plan becomes the superior text which then determines what actually
happens. In this context, Managers, as part of the ruling relations need to consider how these life plans can be used to reshape and reprioritise what actually happens in line with individual *wants* and goals. As we have seen, ‘boss texts’ shape other texts such as policies and protocols prioritising and organising what gets attended to. Therefore if the implementation of person centred care is to be supported, the concept of life plans need to be incorporated into the care and welfare regulations and standards in a similar way to what is mandated in the standards for adults with disabilities (HIQA, 2013).

I have demonstrated how the daily accountability practice of filling in the care flow sheet made certain elements of residential care visible while others became invisible reinforcing the textually mediated dominance of some activities over others. If person centred care is to be sustained it needs to be made visible within daily accountability practices. Evidence of maintaining identity, attention to relationship building, and involvement in the everyday life of the facility through collaborative decision making and normal activity need to be made part of the everyday accounting practices of staff. This will require a shift from ‘tick box’ systems to outcome focused accountability systems that demonstrate a clear connection between the *wants* and personal goals of individuals.

The development of a ‘*life plan*’ requires a specific set of skills that include facilitation, listening and finding alternative ways of eliciting information through story-telling, and involving relatives and advocates. It requires looking beyond expressions of passivity and resignation to seek out a person’s values and wants, without trying to make these fit what the organisation already provides. As existing assessment forms and universal rating scales require traditional practices of *inquiring, examining and grading*, (McClean and Hoskins, 1998) additional skills need to be incorporated into training and educational programmes. In this study the process of assessment and care planning was carried out almost solely by nurses, yet these nurses reported that the paperwork was onerous and interfered with their capacity to engage meaningfully with residents.
Therefore I propose that a programme of skills development should include health care assistants so that they can formally become active participants in life planning development and monitoring.

The practices of rostering should be reconstructed to reflect the different nature of relationships in residential care and the aspirations of the person centred care literature. Incorporating knowledge about what residents, relatives and staff ‘click’ and using additional forms of knowing such as community connections and shared interests and values to augment formal knowledge systems, could enhance the experience of all as a means of ‘fostering therapeutic relationships’ (McCormack et al., 2010a, p. 13), reciprocity and normalisation.

Adopting such practices could contribute to both a better quality of experience and greater efficiencies. Staff have acknowledged that the existing system of rotating between residents wastes time and several of them expressed frustration at not being able to align their new knowledge about person centred care with existing institutional routines. Stress and burn-out is cited as a common problem in residential care and recent studies have considered turnover and absenteeism both in terms of emotional and financial costs (Bowers, 2000; Slater P, 2006; Castle, 2013).

In contrast to the experience of several other countries, the rate of turnover in Irish public residential care units is low and McCormack et al. (2010) found that ‘intention to leave’ – a common indicator of occupational stress – was also low. However, the level of absenteeism in Irish residential care settings appears to be relatively high as identified in a snapshot of one local health area (Appendix 28). No composite absenteeism report of residential care is available nationally – with the associated replacement costs. Emerging evidence has pointed to a correlation between person centred care and staff satisfaction (Castle, 2013; Edvardsson et al., 2013). Castle’s (2013) study in the United States found that continuous assignment has a positive effect on absenteeism. While there are considerable cultural differences between the Ireland and the United States, a review of the
evidence and the associated models of person centred rostering including self-directed or delegated rosters (Yeatts and Cready, 2007) should be facilitated by the HSE Office of Nursing and Midwifery Development. Models that have potential in an Irish context should be piloted and implemented as service improvement initiatives. The regulatory process currently makes no reference to relationships in the context of rostering practices. In order to drive and reinforce a change in practice, evidence of person centred rostering should be incorporated into the regulatory assessment process.

I have shown how the formal handover system drove daily decision-making. Continuity of care and collaborative teamwork underpin such constructions but as identified the process can be exclusionary both physically and professionally. If the goals of PCC are to be realised, different forms of daily decision-making need to be incorporated with these professional ways of knowing. Continuous and small team working are common practices in other countries and could promote a more timely and collaborative decision-making process that involves all stakeholders in directing the pace and flow of the day. This should be piloted in a range of facilities supported by appropriate facilitation and training.

Pillinger (2012) noted that many providers of residential care had developed residents’ or relatives’ councils as a means of participation with varying degrees of success. The care and welfare regulations direct the provider to provide opportunities for participation in so far as is practicable leaving the way open for providers to develop alternative means of participation to formal residents’ councils. As such, more meaningful and immediate mechanisms to include residents in the ‘running of the day’ could be explored. Such mechanisms have been employed in other models of residential care and are described in the literature and on organisational websites (Norton and Shields, 2006; Fox, 2007; http://www.actionpact.org). Awareness raising of such models and training in person centred facilitation and communication skills as described above could promote the development of such processes. However, again adopting the principle that
‘boss texts’ shape what happens, the requirement for participation should be strengthened by adopting a similar directive language as relates to the complaints processes as opposed to ‘in so far as practicable’.

The dominance of rigid routines centred on shift systems and mealtimes has been identified as creating artificial deadlines in the rhythms of the day. I have argued that the artificial separation of ‘nursing work’ and ‘activities’ contributed to these rigid routines, excluding residents from contributing or being involved in the everyday life of the facility in a meaningful way.

To propose prescriptive structures to address these issues suggests replacing one ‘model’ of working with another, yet again subordinating the local knowledge of participants in creating their own community. Rather a facilitated collaborative problem-solving approach, using context specific means to include all social actors, including those with dementia, could be developed. This would involve establishing common priorities that could refocus the actual routines and deployment strategies and incorporate meaningful activity into everyday life.

It has been found above, in common with other studies, that residents and relatives have low expectations about what is possible in residential care. This suggests that the discourse of PCC has not extended beyond academia and professional practice into public discourse in a way that would raise expectations and demand for more person centred practices. Awareness-raising programmes that include residents, family, independent advocates and relevant external stakeholders should be developed. General awareness among members of the public and older people considering residential care as a future option should also be developed through the mainstream media.

By employing the theoretical lens of IE, I have drawn attention to the ruling relations and their capacity to shape what actually happens through textually mediated regulations, standards, policies, protocols and guidelines. The issue of regulatory power has been seen to have been effective in driving some level of organisational change. However, there have also been
disadvantages manifested in increased paperwork and accounts of less time to engage with residents. O’Dywer (2012) suggests that there is some ambiguity between the role and purpose of the HIQA standards and care and welfare regulations and as such the visionary elements of the standards are subordinated to the hierarchically superior regulations. In this case, the regulations act as a deterrent and a floor of minimum standards below which no provider may go. However, the quality improvement elements require a more intentional focus.

According to the NESC (2012), smart regulation provides a more responsive means of regulation, drawing providers and advocates into coalitions of self-audit and quality improvement. HIQA has begun to develop this concept through the development of thematic regulation in relation to End of Life Care, Elder Abuse and Nutrition and is currently piloting these across a range of public and private facilities. I propose that a similar process be established in relation to person centred care, addressing the key principles of maintaining identity, autonomy, relationships and creating positive social environments and should be accompanied by associated educational materials and self-audit tools as have been developed in other countries to support the development of person centred care (Degenholtz, 2013).

In summary, the above recommendations point to the need for a change in the organisational practices of residential care services if person centred care is to be implemented and sustained translocally. What is proposed is a change to the existing textually mediated practices of care planning and rostering as well as the incorporation of more inclusive decision making processes and more involvement of residents in everyday life. Attention to extended social relations is proposed through the inclusion of thematic inspections of person centred care practices by the regulator.

8.2 Reflections on the methodology

The methodology of institutional ethnography has been used to explore the organisational factors that influence the implementation of person centred
care practices. Staying faithful to the ontology and methodology while also attending to the theory and practice of person centred care proved challenging at times. This was particularly so when establishing the analytical framework and undertaking data collection and data analysis.

In establishing the analytical strategy I had to consider a core assumption of institutional ethnography – that knowledge is socially organised and that established forms of knowing can silence the embodied experiences of real people. For this reason Smith suggests that standardised forms of knowing (such as the use of standardised frameworks) should not be the starting point, rather the starting point should be in people’s everyday lives. Yet on the other hand the theory and practice of person centred care that has been developed over the past number years through these standardised frameworks has provided a language and discourse aimed at improving services that support older people with healthcare needs. Words such as interdependency, mutuality and reciprocity that had heretofore been absent have now entered the discourse sitting alongside the language of dependency and need. This resonates with Smith’s (1987) own discussions of early feminism whereby words and phrases -such as gender inequality or sexual harassment – which expressed the alienation felt by women at that time simply didn’t exist.

Therefore my first challenge related to how to connect the Person Centred Practice Framework which underpinned the 2 year person centred care project to my research which builds on that study. One the one hand I understood the need to stand outside standardised forms of knowing and remain located in everyday life, on the other I needed to stay focused on the implementation of person centred care. I overcame this by loosely incorporating the elements of PCC framework and the wider theory which underpins this framework into the development of data collection and data analysis tools.

The development of the analytical framework was challenging as I sought to incorporate IE theory with that of PCC. While this appeared to be
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deceptively easy as portrayed in the framework in reality the melding of these two in the analysis process was challenging. While identifying and recording the concrete social relations of everyday life such as getting up, having breakfast posed no significant problems, this on its own did not reflect the complexity of the field work sites that was emerging from the data. Early data analysis yielded 32 potential lines of inquiry, some of which reflected abstract rather than concrete social relations.

I struggled with these seemingly incompatible stances, for example in relation to the concept of ‘power’ as this was something I could see present in everyday acts. I read many texts that addressed the issues of power and inequality including the discussion of power in McCormack and McCance’s (2010) Person Centred Nursing Theory and Practice and then returned to Smith’s (2005) text ‘A Sociology for People’ to reconcile what I was seeing and what had been identified in both IE and PCC literature, but addressed in different ways.

What I found helpful was retaining an audit log where I wrote down what I did at each stage of the process. This and returning to the IE texts and work of other IE researchers helped me to stay faithful to the methodology of IE. While IE texts steer the researcher away from data reduction and the development of themes it is difficult to explain in scientific terms how the final threads are arrived at. The IE texts advise that staying close to the problematic helps the researcher to look in the right direction, helping them to filter out the many potential lines of inquiry that exist in any research site. These apparently simple explanations felt at odds with the data analysis processes I had read about in, for example, Miles and Huberman (1994) which used technical language and graphics to illustrate the analysis process and I worried that my presentations were not ‘scientific’ enough. In reality the development of ‘threads’ to follow felt rather similar to the development of themes, at least at the outset as I moved between the theory of PCC and what was happening in the research sites.
Overall, the combination of these two theoretical stances proved challenging. However, I believe that adopting this dual stance provided new insights into the factors which influence the implementation of person centred care in residential care settings.

8.3 Limitations of the study

The adoption of a standpoint of one group over another could be seen as a less than comprehensive inquiry approach as might be seen for example in a conventional ethnography or a participatory action research project. Nor can the standpoint of one group of residents, for example those that had the cognitive and physical strength to participate in this study, be seen as being the same as other older residents some of whom may be separated by a generation in terms of age or of those with advanced dementia or nearing death. However, IE is focused on ideology and organisational practices rather than individual lived experience. Therefore the standpoint knowledge is merely a tool and a point of entry into the social relations of situations (Grahame, 1998; Wright, 2009).

The adoption of the standpoint of only one resident in the care plan analysis could be seen as a limitation. Given that the accounts by Mary and Seamus as textually demonstrated in the interview transcripts provide for the account of ‘what actually happened’ it could be argued that this provides a limited view of ‘truth’ based on just two people’s experience. However, their accounts rather than being taken as ‘fact’ were taken as ‘threads to follow’ which were also explored in Chapter 6. As such, these accounts were merely used as an entry point into these social relations which broadened out beyond this care plan to wider organisational practices (Smith, 2005).

The account of the work of care planning was given retrospectively by Linda and Pauline using existing care plan and reporting texts. Although I signalled my desire to observe either a care planning meeting (with consent) following admission or an actual review of a participants care plan, neither
was planned during my time in each of the facilities. As it was my intention to disrupt the work of the facility as little as possible, I did not pursue this. In hindsight I should have made arrangements to return to the field to observe fully the actual process as opposed to relying solely on this retrospective account.

This study draws attention to the issue of objectification of residents through institutional practices such as rostering or skill mix development. Overall IE rejects objectification and tries, in so far as is possible, to retain the subjectivity of participants in its own research endeavours. However, by its very location within academia it must objectify individuals in order to advance knowledge-generation. Therefore, while endeavouring to acknowledge the unique and personal circumstances of each individual participant, the presentation of data from transcripts, observations and findings inevitably employs a degree of objectification in the final presentation of this thesis. Thus, the critique of institutional and professional forms of knowledge still intersects with these forms of knowing in order to advance both my own agenda (to obtain a PhD) and the service-improvement agenda that I am committed to.

IE also draws attention to unequal power relations. Located in the ruling relations as a health professional, a manager and a researcher, I could be described as having power on several levels. As a researcher, I have attempted to stay faithful to the materialist stance of mapping social relations. However, some level of interpretation is inevitable as I, rather than participants, made decisions to follow some ‘threads’ and discard others. As such the contention that the participants are research partners with equal power may be somewhat idealistic. However, by adopting an explicit standpoint of one particular group, staying faithful to the problematic and adopting a reflexive approach I have attempted to minimise this limitation.

Another limitation of this study was the voice of relatives. While all the relatives invited to participate did so, they appeared to have little knowledge
of the everyday lives of their family members. All could recall the transition process but appeared to have little engagement on an ongoing basis either in terms of care planning or through relatives’ councils. Proactively seeking relatives who do participate on the relatives’ forum may have provided an additional perspective on its influence. While this is a limitation in the study, it also highlighted the limited engagement in a relationship triad pointing to a need for further research.

Due to the scope of the study, I did not explore the social relations of shared decision-making that takes place in the context of transitions into residential care, the organisational demands on hospital beds and the existing funding structures that impact on the decision-making processes that older people and their relatives engage in. Although the work-text-work sequence identified that the work of care planning was connected to the work of others external to the facility, such as hospital discharge planners and local placement forums, the study was bounded by the initial research question and therefore did not explore this.

8.3.1 Contribution to Knowledge

There are no other studies that have investigated the intersection of the theory of person centred care and the organisation of residential care services for older people using Institutional ethnography as a methodology. As such this study provides ‘another way of looking’ at the acknowledged challenges of implementing and sustaining person centred care. To my knowledge there are no other IE studies that have considered residential care for older people from the standpoint of residents. While two other studies relating to residential care were located (Diamond, 1992; Benjamin, 2011) these studies adopted the standpoint of staff. Nor have I found any Irish studies which have used Institutional ethnography as a methodology to investigate any health or social care problems. Although this research related to residential care services for older people, this methodology could equally be used to address the issues of person centred care for younger people with a disability or older people living in community settings. An
analytical framework was developed which combined the theory of person centred care with the ontology of Institutional ethnography (p. 107). This framework could be adapted to support the investigation of other theories of practice in relation to other health or social care problems.

8.3.2 Contribution to practice

I have described how resident’s everyday lives are coordinated and controlled in line with goals of professional accountability and perceived organisational efficiency, despite the espoused goals of person centred care. By making visible previously unseen or unarticulated coordinating forces, the study reveals the need for wider reorganisation beyond what committed champions can achieve through practice development strategies. As such, this research prompts the need for organisational change. In this way the study may be of benefit to senior managers and regulators who develop and oversee organisational systems as it provides specific recommendations in relation to care planning, rostering, handover meetings and decision-making practices.

Important insight has been provided into the everyday worlds of participants, showing how participatory mechanisms currently have little meaning in residents’ lives. As such I would hope that the participants’ stories and other findings could provide an impetus for advocates and committed champions to seek alternative means of participation, rebalance power relations, and prompt a rethink of how this is evaluated by regulators.

This study also demonstrates the use of Institutional ethnography as a methodology that critically examines existing organisational and professional practice. By focusing on actual systems rather that the competencies or motivations of social actors, defensiveness is reduced and pathways to change are opened up.
I would also hope that regulators would adopt a proactive stance in supporting and acknowledging innovation and progress by providers in advancing this agenda.

8.4 Proposals for future research

There were several potential ‘threads’ that could have been explored in this study. The connection of risk management to the principles of person centred care was one such thread. The interface of residents with their physical environment was another. Institutional ethnography offers a methodology to further explore the social relations of both of these in the context of biomedical constructions designed for clinical safety and residual care. The issue of consistent assignments was raised as a means of improving relationships between residents and staff. While positive evidence is emerging from other countries, the specific context of Irish public residential care settings would warrant further study as to its applicability and implementation. The InterRai/Minimum Data Set is about to be introduced into Irish Residential Care Settings. In the light of the above findings, further work is required to explore how this standardised system connects with the theory and principles of person centred care, and how the personhood and life plans of individuals can be equally privileged in the light of dominant biomedical priorities.

8.5 Concluding remarks

Person centred care promotes the maintenance of identity, the promotion of autonomy, the presence of nurturing relationships, and the creation of positive social environments. The existing structures of residential care promote a primarily residual form of care based on biomedicine, activities of daily living and group-based social activities. Factors which influence the implementation of person centred care, as identified in this study, include:

1. Care planning systems that cast older people into passive recipient of care roles and privilege professional ways of knowing;
2. Human resource deployment systems that objectify both older people and staff;
3. Exclusionary decision-making systems that privilege professional ways of knowing over local ways of knowing.

By reorienting existing organisational processes to align with the principles of person centred care, the goal of implementing person centred care could be advanced. However, to do this organisational change is required and proposals for this are summarized as:

a. The development of life plans which supersede existing assessment and care planning processes with associated changes to regulations and standards
b. The development of accountability processes which make visible the principles of person centred care
c. Education and training to support the development of life plans
d. The development of person centred rostering systems
e. The incorporation of inclusive decision making processes into everyday life of facilities
f. Provide support to facilities to develop interdependent communities based on their own collaborative values and goals
g. Awareness raising programme targeted at residents, relatives, advocates and other relevant stakeholders and the general public
h. The development of thematic inspections for person centred care.
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Appendix 1: The Person Centred Practice Framework (PCP)

<table>
<thead>
<tr>
<th>Prerequisites</th>
<th>The attributes of the nurse</th>
<th>Technical competence</th>
<th>interpersonal skills</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>commitment to caring, clarity of beliefs and values</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>knowing self</td>
<td></td>
</tr>
<tr>
<td>The Care environment</td>
<td>The context of care</td>
<td>Decision-making power, skill mix, relationships, organisational culture, risk and innovation.</td>
<td></td>
</tr>
<tr>
<td>Person centred process</td>
<td>The delivery of care through a range of activities</td>
<td>Mutuality, transparency, negotiation, sympathetic presence, physical care</td>
<td></td>
</tr>
<tr>
<td>Expected outcomes</td>
<td>Results of person centred nursing</td>
<td>Feeling of well-being therapeutic environment shared decision-making relationships</td>
<td></td>
</tr>
</tbody>
</table>

(McCormack and McCance 2006)
Appendix 2: The Ten Principles of the Eden Alternative

1. The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering among our Elders.

2. An Elder-centered community commits to creating a human habitat where life revolves around close and continuing contact with plants, animals, and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.

3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.

4. An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.

5. An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.

6. Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.

7. Medical treatment should be the servant of genuine human caring, never its master.

8. An Elder-centered community honors its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.


10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.
Appendix 3: Introductory letter to Director of Nursing

Dear

I am a PHD student undertaking a research project on person centred care in residential care units for older people. I also work as a planning specialist for older people within the HSE. I am interested in exploring the factors which influence person centred care and how this relates to policy and organizational issues. I would hope that this study would contribute to the development of policy in this area.

The study will use Institutional ethnography study methodology and will involve semi structured interviews, observation of the daily life of the facility and an examination of documentation including care plans, policy documents and inspection reports.

I plan to include a range of stakeholders including residents, relatives, staff and senior managers and HIQA inspectors. The inspectors will be from the same regional area but will not necessarily have inspected this facility and will not be informed of its specific location.

I would like to include this facility in the research sample as it has demonstrated its commitment to person centred care through involvement in quality improvement initiatives in the last few years.

If you agree to participate I will be asking your assistance in accessing residents who have the capacity to participate, relatives including those who have family members who are residents that do not have independent capacity to participate, and staff.

I would also require access to residents’ care plans (following informed consent) and policy documents that are normally available publicly.

I attach participant information sheets for your information and would be happy to discuss this further with you at your convenience.

Yours sincerely
Appendices

Appendix 4: Research protocol

Research Title: What are the factors that influence person centred care in residential care settings for older people?

Researcher: Ann Campbell, PhD student in Health Sciences NUI Galway.

Introduction

The primary focus of this research is person centred care and its role in improving the organization and experience of residential care for older people. Its purpose is to examine the experience of person centred care in Irish residential care settings and the factors that help or hinder the delivery of this type of care.

In general terms, person centred care is considered a humanistic approach to care based on the biography, values and wishes of the individual receiving care (Kitwood, 1997; McCormack, 2004; Wilkinson, 2009). It is concerned with reaffirming the attributes of autonomy and respect, as an antidote to an increased results-orientated and economically-driven health and social care system (Nolan et al., 2006; McCormack and McCance, 2010).

While there is no universally agreed definition, Talerico, O’Brien and Swafford (2003) describe person centred care as ‘an evidenced based approach to care giving that uses care recipients unique personal preferences and needs to guide providers as they customize health care’ (p. 12).

Person centredness as an approach to care has been espoused at policy and practice levels within the healthcare arena for the past number of years, yet the literature would indicate that its implementation and sustainability is challenging (Epp, 2005; McCormack 2004; Dewing, 2004; Hill, 2004; McLean, 2007; Crandall et al., 2007).
Various authors have tried to unravel these challenges and a number of enablers and barriers have been proposed. Enablers identified to successfully implement person centred care have been identified as: an openness to change, the process being seen as an integral part of the facility life as opposed to being a ‘project’; documentation supporting the approach, and a committed management system (Crandall et al., 2007). Hindering factors include a lack of understanding of person centred principles, (person centredness not being a core value), the concept being seen as additional work and being set aside in times of stress such as budgetary difficulties (Crandall, 2007; Talerico, O’Brien and Swafford, 2003).

Some authors also point to a need for a wider historical, cultural and political analysis in order to understand the unseen and unarticulated issues which prevent us from acknowledging and valuing the unique personhood of those who are physically or cognitively dependent on others (McLean, 2007; Hill, 2004).

Within the Irish context, person centred care as a concept is embedded in policy documents (An Bord Altranais, 2009; HIQA, 2009) and has been the subject of a practice development programme in public residential care settings in the recent past (McCormack et al., 2010). Other recent studies in Irish residential care settings suggest that staff are aware of what person centred care is, at least in a general sense (Murphy, 2004; Murphy et al., 2006) and are frustrated with their inability to operationalise it in their practice. Perusal of inspection reports by the Health Information and Quality Authority would support the view that, in particular, residents with very high care needs or ‘dependencies’ have little choice or involvement in the daily activity of some residential care units (www.hiqa.ie).

**Justification for this research project**

An emancipatory action research programme to develop person centred care through practice development has been undertaken in Irish residential care settings with varying results across sites (McCormack et al., 2010). Initial
findings point to anomalies and context-specific issues which require a more in-depth analysis in order to support better understanding of the factors which support or hinder the provision of person centred care.

Other recent research studies in Ireland reveal an adherence to traditional task-orientated work practices and lack of choice and control for residents with high care needs (Murphy, 2004; Murphy et al., 2006).

The limitations of these studies are that they do not seek to uncover the interrelationships between policy, practice and organizational culture and their role in influencing the provision of person centred care. In addition, by undertaking an analysis of the social construction of residential care in Ireland, this study seeks to provide a wider understanding of the historical, social, political, and cultural context and how it relates to the provision of person centred care. No Irish study has undertaken such an analysis to date.

Research objectives of this study are:

- To explore the everyday living routines of older people in residential care and the social relations that influence those routines.
- To explicate the texts that coordinate the activities of care planning and reporting mechanisms.
- To explore the disjuncture between the theories of person centred care and the organisational policies and practices of Irish Public Residential Care Settings.

**Study Design**

The methodology of Institutional ethnography case study is proposed for this research project using a qualitative approach located within the constructivist paradigm. It is proposed that the sequential approach together with its use of different sources of evidence, i.e. direct observation of events, interviews and review of documentation, will help to determine the experience of person centred practice within the selected sites and help track
the text-based processes which contribute to, or hinder, the provision of person centred care for older people who live in residential care settings.

**Rationale for location of study**

The public residential care system is changing rapidly due to legislative and regulatory changes. Creating a better understanding of the public system in its own right can contribute to policy discussion in terms of its future viability or role in providing residential care for older people.

The purpose is to gain a better understanding of the factors which enable or hinder the provision of person centred care within the various contexts and identify which factors can directly be influenced by practice development and which factors are due to external contextual factors such as financial and organization constraints, regulatory requirements and wider social factors. The sites will be selected purposively to reflect the typicality of public residential care units in Ireland. Sites selected will provide a range of settings including purpose-built and converted facilities and will include an urban/rural mix.

As this type of study involves a holistic approach, a range of stakeholders will be asked to participate including residents, relatives, frontline staff, managers (internal and external to the facilities) and inspectors from the same region.

Access to the study sites will be through telephone contact to the Director of Nursing and Local Health Manager inviting participation in the research project. Following this, access to other stakeholders will be through a combination of methods including consultation with the director in respect of which residents would have the capacity to participate, and a purposive selection of individuals who best reflect the typicality of individuals who may reside within a residential care facility, including those recently admitted and those who have lived there for a number of years. Relatives or close friends will also be invited to participate following introduction by
manager. Staff who are rostered to be working at the time of the study will be invited to participate through a letter of invitation. All potential participants will be provided with a participant information sheet and will be asked to sign a consent form underpinned by the principles of informed consent. Next of kin or decision-makers will be asked to act as a proxy for individuals with dementia who are deemed incapable of independently consenting to participation. Verbal or non-verbal consent will be sought from all persons present during observation periods.

The data collection methods will include semi-structured interviews, observation of facility routines within communal areas and analysis of documents including care plans, and policies. Data collected will include personal histories of residents and the perceptions and experiences of all stakeholders, and data in respect of policy and organisational issues. The person centred framework (McCormack and McCance, 2009) and other concept analysis in the literature will provide theoretical guidance in shaping the data collection framework.

Audio tapes and field notes will be used to record data. A reflective diary will be maintained to make explicit the researchers stance and support transparency of interpretation.

All personal data will be made anonymous and coded. Any organizational or policy data will be on the public record. One key challenge will be preserving anonymity. For this reason, a range of stakeholders will be invited to participate across the whole facility as opposed to just one ward in order to minimize identification.

**Data Analysis**

The data from each location will be analysed within the framework of Institutional ethnography.
Appendices

Appendix 5: Ethical approval

Leas-Uachtarán um Thaighde
Vice President for Research

OÉ Gaillimh, NUI Galway, T +353 91 495 312
Bóthar na hOllscoile, University Road, F +353 91 494 591
Gaillimh, Éire Galway,
Ireland www.nuigalway.ie/research/vp_research

24th August 2010

Ms Ann Campbell
15 Faughart Terrace
St Marys Road
Dundalk
Co Louth

Dear Ms Campbell

Re. Ethics Application:
What are the factors that influence Person centred care in Residential Care Settings for Older People?

I write to you regarding the above proposal which was submitted for Ethical review.
Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted APPROVAL.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 31st June 2011. Please see section 7 of the REC’s Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

_________________
Allyn Fives
Chair, Research Ethics Committee
Appendix 6: Staff Notice re. Research Study

I am a PHD student undertaking a research study about Person centred care in Residential Care for Older People. I also work as a planning specialist for older people in the HSE. (Name of facility) has kindly agreed to facilitate me in the study which will involve interviews with residents, relatives and staff. It will also involve a number of day’s observation throughout the building and a review of documents such as policies, care plans of specific residents who have consented to this and other documents that are publicly available. Interviews with residents and relatives will be arranged through the Director of Nursing and I will be inviting staff through a random selection process to be interviewed also.

The observation process will involve me sitting and observing in relatively public places. This will include handover meetings, observing care planning and assessment processes and other activities on the wards and general activity areas. I will not be observing intimate care and I will try to be as unobtrusive as possible. The observation will be carried out in two hourly sessions throughout the day e.g. 8-10 am, 2-4pm etc. I will be seeking the verbal consent of all those in the observation area on the day.

The purpose of the research is to identify the things that make person centred care difficult to do, particularly from the perspective of those who know most about it, the residents and frontline staff. Therefore I am interested in seeing what is involved in the daily life of the residential unit. It is not in any way an evaluation of your work but rather looking at how policy would make it better.

Many thanks in advance for your cooperation. You can contact me on 087 2516960 if you would like any further information.
Appendices

Appendix 7: Ethical Protocol

Capacity to Consent
A number of strategies will be used to determine if a resident has the capacity to consent to be interviewed. This is to ensure that a balance is sought between protecting vulnerable older people without being overly paternalistic. Therefore a combination of proxy and process consent will be used. The opinion of the nurse manager or medical officer will be sought. In addition to this, the researcher will spend some time talking to the resident to ascertain if they are in a position to understand and respond appropriately to interview questions. If the participant seems able to listen and engage, make choices, to understand the information being given about the study and appears able to make a judgment about participating, then this information together with other elements of assessment will be used to make a decision about capacity to consent. In addition the researcher will re-evaluate participant’s consent immediately prior to the interview to ensure the participant is still able and willing to participate. All information about the study will be given verbally in language that is easy to understand and in written form.

Assent
Residents that do not have the capacity to consent independently but have some capacity to convey their assent to participate will be asked to do so. Verbal or non-verbal assent or no objection to participation will be sought. Where objection to participate is displayed, either through verbal or non-verbal or behavioural cues, this will be respected and the individual not included in the study, even where proxy consent has been obtained.

Emotional Distress during Interview
If, during the interview, the participant becomes upset or distressed, the researcher will halt the interview process to allow the participant to regain composure. In a supportive manner the researcher will remain with the participant. When they are calm the researcher will ask the participant if
they wish to continue. If they do not wish to continue the interview will be terminated in a sensitive manner and the researcher will stay with the participant and provide emotional support. If the participant wishes and provides consent to do so, the researcher may refer to a staff member of their choice to provide ongoing support.

**Disclosure re abuse or poor practice**
At the outset the researcher will reiterate the duty of care to report any disclosed experiences of abuse or poor practice.

**Health and Safety concerns**
The interview will be terminated if the participant becomes ill or is too fatigued to continue and assistance sought from unit staff.
Appendices

Appendix 8: Participant information sheet for residents

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, I will ask to ask you to sign a Consent Form. If there is anything that you are not clear about, I will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision.

Research title
What are the factors that influence person centred care in residential care settings for older people?

What is person centred care?
Person centred care is about ensuring that the staff know what is important to you, what your likes and dislikes are and how much choice you have in how you live your life here. It is about ensuring that you stay as independent as you can and want to be. It is about ensuring that you have an opportunity to stay connected to your family and friends, if that is what you want, and that you get to do the things that you enjoy doing and are able to do.

Purpose of the research
The purpose of this research project is to gain a better understanding of person centred care. You are being asked to participate in the study because you live in residential care and I am interested in hearing your views about your experience. I will also be asking other residents, family members, staff and managers for their views.
What will be involved?
I may want to undertake some short tests and interview you for a period of time, no longer than an hour at any one time or less if you feel that would be too tiring for you. You may have someone present if you wish.
I would also like permission to read and take notes from your case notes.
If you are in agreement the researcher may also talk to family members to get another point of view about your care.
I will also be in the unit observing what is going on in general. This will not involve observing your private personal care but rather a general observation of the routines and organization of the unit.

Are there any risks?
It is hoped that the experience would be a pleasant one and that the interview process would be an opportunity for you to tell me about yourself and your life here. However this could raise uncomfortable issues for you. All information provided by you will be confidential and you will not be identifiable by name in the final report. This is also the case for your family members. All information from your case notes will be kept confidential and secure and coded numbers used instead of your name in the final report. However I must point out that if in the course of this research project I observe or become aware of poor care or issues of abuse I am ethically obliged to report these to the Director of Nursing.

What are the benefits of taking part?
You will be contributing to a study which will try to better understand the reasons why it is hard to provide person centred care. It is hoped that the findings will contribute to improving person centred care for older people in residential care.
Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

What will happen if I take part?
I will agree to meet with you formally to interview you in a place and at a time that is convenient to you. I will be taking notes and I will read back to you what you have said in the interview to make sure I have understood you correctly and can give you a copy of the interview if you wish. You may wish to discuss whether to take part in this research with your family.

How long will my part in the study last?
I would hope to be in the unit over two or three days. While the formal interview should not take more than an hour (or a shorter length over two or more sessions if you feel that would be too tiring), I would hope that it would be a pleasant experience for you.

What will I have to do?
There are no specific things that you have to do other than tell me about your life before you came into residential care, what you liked to do, what was important to you and what your life is like now. I will give you a broad outline of the questions I have in mind in advance so you can have a chance to think about them.

You can have someone with you if you like or you can discuss the questions in advance with your family or someone else that you trust. It is entirely up to you. With your permission I would like to tape record the interview to help me record accurately what you have said.
**What are the possible disadvantages of taking part?**
I would hope that there are no disadvantages in taking part. You may be worried about being critical about staff members or worried that you might not seem appreciative of their efforts. The information will be presented in such a way as to minimize any possibility of quotes or findings being directly attributable to any one individual.

**What happens at the end of the study?**
If you wish you can receive a copy of the final study. All of the information collected will be analysed and written up in a final report. You will not be identifiable by name or characteristic which would make you identifiable to others in your location.

**What happens if I change my mind during the study?**
You can change your mind and withdraw from the study at any stage. This is entirely your prerogative and will not affect your position or your care in any way.

**What happens if you have a complaint during the study?**
If you are unhappy with any aspect of the research project you can make a complaint to the complaints officer in the unit. Any member of staff will assist you to do this. Alternatively, if you wish to contact someone independent and in confidence, you may contact the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.

**Who do I contact for further information or if I have further concerns about this study?**
You can contact me directly and I will be happy to discuss this project further with you at your convenience. I can be contacted by phone at 087 2516960 or by email at a.campbell4@nuigalway.ie
Appendix 9: Participant information sheet for frontline staff

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, I will ask to ask you to sign a Consent Form. If there is anything that you are not clear about, I will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision.

**Research title**
What are the factors that influence the provision of person centred care in residential care settings for older people?

**Purpose of the research**
The purpose of this research project is to gain a better understanding of person centred care as it relates to people living in this residential care facility and to what factors help or hinder it. Research studies have shown that staff want to be person centred but can be frustrated by a range of factors which prevent them from being so (Murphy, 2005, Murphy et al., 2006). I want to explore what those factors are. You are being asked to participate in the study because you work in residential care and I am interested in hearing your views about your experience of providing person centred care and what helps you and hinders you in doing so.

I will also be asking residents, relatives, other staff and managers for their views.
Appendices

What will be involved?
I may want to interview you for a period of time, no longer than an hour. That interview can take place wherever you wish, for example in a private room in the residential care unit, or in another public place such as a hotel. I will also be in the unit observing what is going on in general. This will not involve observing private personal care but rather a general observation of the routines and organization of the unit.

Are there any risks?
It is hoped that there will be no risks but I understand it may be difficult to talk about issues which may seem critical of other colleagues or family members or the organization that your work for. All interviews and information will be treated with confidence and I will ensure that quotes or information imparted is not identifiable to any one source. However I must point out that if in the course of this research project I observe or become aware of poor care or abusive practice I am ethically obliged to report these to the Director of Nursing.

The facilities involved will not be identifiable by geographical location or any other characteristics that would identify them to others outside of the unit.

What are the benefits of taking part?
You will be contributing to a study which will try to better understand the reasons why it is hard to provide person centred care. It is hoped that the findings will contribute to improving policy in terms of person centred care for older people in residential care.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any
time and without giving a reason. A decision to withdraw at any time, or a
decision not to take part, will not affect your rights in any way.

What will happen if I take part?
I will agree to meet with you formally to interview you in a place and at a
time that is convenient to you. I will take notes and I will read back to you
what you have said in the interview to make sure I have understood you
correctly and can give you a copy of the interview if you wish.

How long will my part in the study last?
I would hope to be in the unit over two or three days. However if that
timeframe is not convenient to you, I can arrange an alternative
appointment. While the formal interview should not take more than an hour
I may wish to chat with you generally during the times I am there. I will
also, with the consent of residents and the Director of Nursing, be looking at
care plans and other documents in the facility.

What will I have to do?
I will be asking you questions in respect to the provision of person centred
care and what makes that easy or difficult for you to undertake. I would like
you to speak as freely as possible about these issues. I am seeking to
understand the organizational issues that drive practice rather than
individuals practice. I am also interested in the ‘reality’ of person centred
care and how it relates or not to policy documents and overall goals of the
HSE.

What are the possible disadvantages of taking part?
I would hope that there are no disadvantages in taking part. As outlined
above, I will ensure that information is non attributable on any one person.
It may be helpful to get an opportunity to air some of the difficulties relating
to providing person centred care.
Appendices

What happens at the end of the study?
If you wish you can receive a copy of the final study. All of the information collected will be analyzed and written up in a final report. You will not be identifiable by name or characteristic which would make you identifiable to others in your location.

What happens if I change my mind during the study?
You can change your mind and withdraw from the study at any stage. This is entirely your prerogative and will not affect your position or the care of your relative in any way.

What happens if you have a complaint during the study?
If you are unhappy with any aspect of the research project you can make a complaint to the complaints officer in the unit. Any member of staff will assist you to do this. Alternatively, if you wish to contact someone independent and in confidence, you may contact the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Who do I contact for further information or if I have further concerns about this study?
You can contact me directly and I will be happy to discuss this project further with you at your convenience. I can be contacted by phone at 087 2516960 or by email at a.campbell4@nuigalway.ie.
Appendices

Appendix 10: Participant information sheet for relatives

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Participant Information Sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, I will ask to ask you to sign a Consent Form. If there is anything that you are not clear about, I will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision.

Research title
What are the factors that influence person centred care in residential care settings for older people?

What is person centred care?
Person centred care is about ensuring that the staff know what is important to your family member, what their likes and dislikes are and how much choice they have in how they live their life here. It is about ensuring that they stay as independent as they can and want to be. It is about ensuring that they have an opportunity to stay connected to their family and friends, if that is what they want, and that they get to do the things that they enjoy doing and are able to do.

It is also about ensuring that you as a relative are involved in decision making about care if that is what you and your relative want and that you get the opportunity to participate in that care in a way that you would like.
Purpose of the research

The purpose of this research project is to gain a better understanding of person centred care as it relates to people living in this residential care facility and to what factors help or hinder it. You are being asked to participate in the study because you have a relative who lives in residential care and I am interested in hearing your views about your experience of that. I will also be asking other relatives, residents, staff and managers for their views.

What will be involved?

I may want to interview you for a period of time, no longer than an hour. That interview can take place wherever you wish, for example in a private room in the residential care unit, in another public place such as a hotel or in your own home. I will only be talking to you if your relative agrees to be interviewed also or if you are the designated decision maker for a resident who does not have the capacity to consent for themselves.

I will also be in the unit observing what is going on in general. This will not involve observing private personal care but rather a general observation of the routines and organization of the unit.

Are there any risks?

It is hoped that the experience would be a pleasant one and that the interview process would be an opportunity for you to tell your story and that of your relative. However it may raise uncomfortable issues for you. All information provided by you will be confidential and you will not be identifiable in the final report. This is also the case for your family members. All information will be treated confidentially. However I must point out that if in the course of this research project I observe or become aware of poor care or abusive practice I am ethically obliged to report these to the Director of Nursing.

Appendices
What are the benefits of taking part?
You will be contributing to a study which will try to better understand the reasons why it is hard to provide person centred care. It is hoped that the findings will contribute to improving person centred care for older people in residential care.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

What will happen if I take part?
I will agree to meet with you formally to interview you in a place and at a time that is convenient to you. I will take notes and I will read back to you what you have said in the interview to make sure I have understood you correctly and can give you a copy of the interview if you wish.

How long will my part in the study last?
I would hope to be in the unit over a period of two or three days but I can meet you outside of the facility if that is your preference. The formal interview should not take more than an hour. I would hope that it would be a pleasant experience for you.

What will I have to do?
There are no specific things that you have to do other than tell me about your relative’s life before they came into residential care, what they liked to do, what was important to them, and what their life is like now. I will give you a broad outline of the questions I have in mind in advance so you can have a chance to think about them.
You can have someone with you if you like or you can discuss the questions in advance with your relative or other family members. It is entirely up to you. With your permission I would like to tape record the interview to help me record accurately what you have said.

**What are the possible disadvantages of taking part?**

I would hope that there are no disadvantages in taking part. You may be worried about being critical about staff members or worried that you might not seem appreciative of their efforts. The information will be presented in such a way as to ensure that quotes or findings are not directly attributable to any one individual.

**What happens at the end of the study?**

If you wish you can receive a copy of the final study. All of the information collected will be analyzed and written up in a final report. You will not be identifiable by name or characteristic which would make you identifiable to others in your location.

**What happens if I change my mind during the study?**

You can change your mind and withdraw from the study at any stage. This is entirely your prerogative and will not affect your position or the care of your relative in any way.

**What happens if you have a complaint during the study?**

If you are unhappy with any aspect of the research project you can make a complaint to the complaints officer in the unit. Any member of staff will assist you to do this. Alternatively, if you wish to contact someone independent and in confidence, you may contact the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.
Who do I contact for further information or if I have further concerns about this study?

You can contact me directly and I will be happy to discuss this project further with you at your convenience. I can be contacted by phone at 087 2516960 or by email at a.campbell4@nuigalway.ie.
Appendix 11: Consent Form (Residents)

Participant Identification code:

CONSENT FORM
Residents

Title of Project: What are the factors that influence the provision of person centred care in residential care settings for older people?

Name of Researcher: Ann Campbell

<table>
<thead>
<tr>
<th></th>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I confirm that I have read the information sheet dated ...................... for the above study and have had the opportunity to ask questions.</td>
</tr>
<tr>
<td>2.</td>
<td>I am satisfied that I understand the information provided and have had enough time to consider the information.</td>
</tr>
<tr>
<td>3.</td>
<td>I understand I will participate in an interview of no more than one hour.</td>
</tr>
<tr>
<td>4.</td>
<td>I understand that the researcher will review my care plan or case notes.</td>
</tr>
<tr>
<td>5.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.</td>
</tr>
<tr>
<td>6.</td>
<td>I agree to take part in the above study.</td>
</tr>
</tbody>
</table>

Name of Participant ........................................ Signature ........................................

Date.......................................................... Researcher Signature ..................................
Appendix 12: Consent Form (Relatives)

Participant Identification code:

CONSENT FORM

Relatives

Title of Project: What are the factors that influence the provision of person centred care in residential care settings for older people?

Name of Researcher: Ann Campbell

<table>
<thead>
<tr>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I confirm that I have read the information sheet dated ...................... for the above study and have had the opportunity to ask questions.</td>
</tr>
<tr>
<td>2. I am satisfied that I understand the information provided and have had enough time to consider the information.</td>
</tr>
<tr>
<td>3. I understand I will participate in an interview of no more than one hour.</td>
</tr>
<tr>
<td>4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.</td>
</tr>
</tbody>
</table>

Name of Participant .................................................................

Date ............... Signature .........................................................

Researcher Signature............................................ Date ...............
Appendix 13: Staff Consent Form

Participant Identification code:

CONSENT FORM

Staff

Title of Project: What are the factors that influence the provision of person centred care in residential care settings for older people?

Name of Researcher: Ann Campbell

<table>
<thead>
<tr>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I confirm that I have read the information sheet dated........................... for the above study and have had the opportunity to ask questions.</td>
</tr>
<tr>
<td>2. I am satisfied that I understand the information provided and have had enough time to consider the information.</td>
</tr>
<tr>
<td>3. I understand I will participate in an interview of no more than one hour.</td>
</tr>
<tr>
<td>4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.</td>
</tr>
<tr>
<td>5. I agree to take part in the above study.</td>
</tr>
</tbody>
</table>

Name of Participant..............................................  Researcher Signature...............................  
Date ........................................................................  Date .............................................................
Appendix 14: Proxy Consent Form

Participant Identification code:

PROXY CONSENT FORM

Title of Project: What are the factors that influence the provision of person centred care in residential care settings for older people?

Name of Researcher: Ann Campbell

<table>
<thead>
<tr>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I confirm that I have read the information sheet dated ................. for the above study and have had the opportunity to ask questions.</td>
</tr>
<tr>
<td>2. I am satisfied that I understand the information provided and have had enough time to consider the information.</td>
</tr>
<tr>
<td>3. I understand that my relative may be interviewed and that he/she may have someone present if they wish</td>
</tr>
<tr>
<td>4. I understand that my relatives care plan/case notes will be read and that notes may be taken.</td>
</tr>
<tr>
<td>5. I understand that my participation and the participation of my relative is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. I agree to take part in the above study.</td>
</tr>
</tbody>
</table>

Name of Participant ........................................................................................................................................

Name of decision maker ........................................ Signature ..........................................

Date................................. Researcher Signature ..........................................................

350
## Appendix 15: Interview schedules

### Residents

<table>
<thead>
<tr>
<th>Question/Problematic</th>
<th>Probe/ Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you describe your day for me from when you woke up this morning?</td>
<td>What is your favourite part of the day? Why?</td>
</tr>
<tr>
<td>What did you do yesterday afternoon?</td>
<td></td>
</tr>
<tr>
<td>What did you do yesterday evening?</td>
<td>Can you decide when to do things e.g. have a bath, or what activities to get involved in?</td>
</tr>
<tr>
<td>Do you have friends here?</td>
<td></td>
</tr>
<tr>
<td>Do you know the names of the staff here?</td>
<td>Do you have a favourite?</td>
</tr>
<tr>
<td>What do you talk about?</td>
<td>Why are they your favourite?</td>
</tr>
<tr>
<td>Do you know the names of their children/ where they’re from?</td>
<td></td>
</tr>
<tr>
<td>Do you feel at home here?</td>
<td>What makes it homely (or not)</td>
</tr>
<tr>
<td>Have you ever made a complaint?</td>
<td>If so can you tell me about it?</td>
</tr>
<tr>
<td>Do you get involved in the day to day running of things?</td>
<td>Who decides what happens here?</td>
</tr>
<tr>
<td>Can you tell me about how you came to be here?</td>
<td>What did you know about the place before you came?</td>
</tr>
<tr>
<td>Were you involved in deciding to come here?</td>
<td></td>
</tr>
<tr>
<td>What were you able to bring with you?</td>
<td></td>
</tr>
<tr>
<td>Do you know what a care plan is?</td>
<td></td>
</tr>
<tr>
<td>Were you /are you involved in your care plan. What did/do you have to do?</td>
<td>What are your hopes for the future What is important to you now?</td>
</tr>
<tr>
<td>Anything else you want to talk about?</td>
<td>Is there anything you would like to do?</td>
</tr>
</tbody>
</table>

351
## Relatives

<table>
<thead>
<tr>
<th>Question/Problematic</th>
<th>Probe/Values/concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell me about the day xx came here</td>
<td></td>
</tr>
<tr>
<td>Have you been involved in xx’s care plan?</td>
<td></td>
</tr>
<tr>
<td>Does xx have a key worker?</td>
<td>Do you discuss any concerns etc. that you might have with them?</td>
</tr>
<tr>
<td>Do you know the staff well?</td>
<td>Do you think the key worker knows xx well?</td>
</tr>
<tr>
<td>Who do you know?</td>
<td></td>
</tr>
<tr>
<td>What do you talk to them about?</td>
<td></td>
</tr>
<tr>
<td>Do they know much about xx’s life before they came here?</td>
<td></td>
</tr>
<tr>
<td>Do they know what xx likes and doesn’t like and what xx interests are?</td>
<td></td>
</tr>
<tr>
<td>Does xx have interests and are they able to get involved in them here? What was xx interested in before they came here</td>
<td>Do you feel involved in the running of this place? Would you like to be more involved? In what way?</td>
</tr>
<tr>
<td>Have you ever been involved in the relatives’ forum?</td>
<td>How do you feel about that?</td>
</tr>
<tr>
<td>Is xx able to do things for herself? Is there anything you feel she is discouraged from doing for safety reasons?</td>
<td></td>
</tr>
<tr>
<td>Would you call this place home for xx?</td>
<td>Does it feel like home? What makes it home? What takes away from it being home?</td>
</tr>
<tr>
<td>Have you ever made a complaint?</td>
<td></td>
</tr>
<tr>
<td>Any things else?</td>
<td></td>
</tr>
</tbody>
</table>
## Frontline staff

<table>
<thead>
<tr>
<th>Question/Problematic</th>
<th>Probe/Social Relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you describe what you did from when you came in the door today?</td>
<td>How were decisions made?</td>
</tr>
<tr>
<td></td>
<td>Who did you work with?</td>
</tr>
<tr>
<td>Describe yesterday afternoon/evening</td>
<td></td>
</tr>
<tr>
<td>Describe what you did the last time you were on night duty</td>
<td></td>
</tr>
<tr>
<td>Do you mostly work with the same residents?</td>
<td>Would you like to?</td>
</tr>
<tr>
<td>Can you tell me about the activities for residents?</td>
<td>Is there a balance between health care and social care/social life?</td>
</tr>
<tr>
<td></td>
<td>What difficulties are there in undertaking activities</td>
</tr>
<tr>
<td>Is there a balance right between risk and autonomy?</td>
<td>Can you tell me about the last incident that you have to report on/were involved in?</td>
</tr>
<tr>
<td>Are residents involved in decisions about care and life here?</td>
<td></td>
</tr>
<tr>
<td>What do you think of this place as a home for residents?</td>
<td>If money was no object what would you change?</td>
</tr>
<tr>
<td>Do you feel empowered to do your job?</td>
<td>What helps or hinders this?</td>
</tr>
<tr>
<td>Describe to me how you would do a care plan?</td>
<td></td>
</tr>
<tr>
<td>Can you give me an example of a new project you were involved in?</td>
<td></td>
</tr>
<tr>
<td>Anything else?</td>
<td></td>
</tr>
</tbody>
</table>
## Internal Managers

<table>
<thead>
<tr>
<th>Question/Problematic</th>
<th>Probe/Social Relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you describe what you did this morning</td>
<td>What organising work did you do?</td>
</tr>
<tr>
<td>Can you tell me what you discussed (in general) at your last internal management meeting?</td>
<td></td>
</tr>
<tr>
<td>What did you discuss at your last external management team meeting?</td>
<td></td>
</tr>
<tr>
<td>Do staff have the right skill set and competencies to do this job</td>
<td></td>
</tr>
<tr>
<td>Can you tell me about the vision statement?</td>
<td>Does it get translated into everyday work?</td>
</tr>
<tr>
<td></td>
<td>What helps? What hinders?</td>
</tr>
<tr>
<td>In there a good balance between health and social care?</td>
<td>What helps this? What hinders it?</td>
</tr>
<tr>
<td>Are residents included in decisions about care and life here?</td>
<td>What helps this? What hinders it?</td>
</tr>
<tr>
<td>Do you feel empowered to do your work here?</td>
<td>What helps this? What hinders it?</td>
</tr>
<tr>
<td>Has HIQA made a difference?</td>
<td></td>
</tr>
<tr>
<td>Is this a home for residents?</td>
<td>What makes it homely?</td>
</tr>
<tr>
<td></td>
<td>If money was no object what would you change?</td>
</tr>
<tr>
<td>Can you give me an example of an innovation you have led here? Is it still happening?</td>
<td></td>
</tr>
<tr>
<td>How do you balance risk and autonomy?</td>
<td>Can you give me a recent example of an adverse incident that you had to deal with?</td>
</tr>
<tr>
<td>Where do you see public residential care going in the next 5 years?</td>
<td></td>
</tr>
<tr>
<td>Are there any other issues which you feel impact on the provision of person centred care?</td>
<td></td>
</tr>
</tbody>
</table>
## External Managers

<table>
<thead>
<tr>
<th>Question/Problematic</th>
<th>Probe/Social relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me about the last meeting you had in relation to this facility. What did you discuss?</td>
<td></td>
</tr>
<tr>
<td>What do you think of the skill mix? Do you think we have the right skill set for this type of work?</td>
<td></td>
</tr>
<tr>
<td>Does the statement of purpose get translated into everyday work?</td>
<td>What helps this? What hinders it?</td>
</tr>
<tr>
<td>What are the barriers to innovation?</td>
<td></td>
</tr>
<tr>
<td>Is there a balance between risk and autonomy?</td>
<td>What helps this? What hinders it?</td>
</tr>
<tr>
<td>Has HIQA helped or hindered the provision of person centred care?</td>
<td></td>
</tr>
<tr>
<td>What do you think of this place as a home for residents?</td>
<td>If money was no object what would you change about it?</td>
</tr>
<tr>
<td>Do you think staff/management relationships help or hinder person centred care?</td>
<td></td>
</tr>
<tr>
<td>Do you feel empowered to do your job?</td>
<td></td>
</tr>
<tr>
<td>Where do you see public residential care going in the next 5 years?</td>
<td>What are the policy issues that impact on person centred care?</td>
</tr>
<tr>
<td>Are there any other issues which you feel impact on the provision of person centred care?</td>
<td></td>
</tr>
</tbody>
</table>
## HIQA Inspectors

<table>
<thead>
<tr>
<th>Question/problematic</th>
<th>Probe/Social relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you describe the last inspection you did in a public residential care facility?</td>
<td></td>
</tr>
<tr>
<td>Do you think staff are trained to provide person centred care?</td>
<td></td>
</tr>
<tr>
<td>Do the values of a facility as expressed in the mission statement or the statement of purpose gets translated down into the work facility in general?</td>
<td></td>
</tr>
<tr>
<td>What do you think of the skill mix in public units?</td>
<td></td>
</tr>
<tr>
<td>Do you think we have a good balance between health and social care in the public sector?</td>
<td></td>
</tr>
<tr>
<td>Management hierarchies in the public sector</td>
<td>What helps managers? What hinders them?</td>
</tr>
<tr>
<td>The balance between risk and autonomy</td>
<td>What helps this? What hinders this?</td>
</tr>
<tr>
<td>Are relatives and residents involved in the running of residential units?</td>
<td>What helps this? What hinders this?</td>
</tr>
<tr>
<td>Is there a balance between the needs and rights of residents and staff?</td>
<td>What helps this? What hinders this?</td>
</tr>
<tr>
<td>What are the barriers to innovation?</td>
<td></td>
</tr>
<tr>
<td>Are public residential care units a home for residents?</td>
<td>What helps this? What hinders this?</td>
</tr>
<tr>
<td>Where do you see public residential care going in the next 5 years?</td>
<td>What are the policy issues that impact on person centred care</td>
</tr>
<tr>
<td>Are there any other issues which you feel impact on the provision of person centred care?</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 16: Excerpts from observations

<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Observation</th>
<th>Problematic</th>
<th>Social relations</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.04.2011</td>
<td>8.00 Handover meeting</td>
<td>Technical competence</td>
<td>High visibility of biomedical care.</td>
</tr>
<tr>
<td>8.00am-10.00am</td>
<td>The reports were almost entirely about medical care and predominantly about the patients who were there for short stay.</td>
<td>Teamwork</td>
<td>Clinical governance</td>
</tr>
<tr>
<td>S.2.OBS</td>
<td>No care staff present</td>
<td>Shared decision making (between nurses)</td>
<td>Professional ways of knowing</td>
</tr>
<tr>
<td></td>
<td>Office door is closed</td>
<td></td>
<td>Hierarchical power</td>
</tr>
<tr>
<td>08.08.2011</td>
<td>Attended the handover meeting at the nurses’ station. One nurse is feeding back to the whole day team. She went through each resident and made a comment on how they were during the night and if they needed any medical or nursing care. General comments about if they were in good form or not. All staff on duty attended. Comments all relate to physical care. No discussion of social care. Rest of multi-disciplinary staff not present</td>
<td>Physical environment</td>
<td>Nurses station as a symbol of biomedical power and surveillance.</td>
</tr>
<tr>
<td>8.00-10.00</td>
<td>Team working (nurses and care staff)</td>
<td></td>
<td>Staff led decision making</td>
</tr>
<tr>
<td>S.3.OBS</td>
<td>Work based on locations rather than relationships. Negotiation of choice between staff</td>
<td>Decison making system</td>
<td>Rosters that determine shifts.</td>
</tr>
<tr>
<td></td>
<td>Shared values (between staff)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>At the end of the handover there was a discussion about how the work was to be allocated that day. ‘I’ll go to bay 3’, ‘I’ll go to the men’s unit’. Staff self-selected where they wanted to go. Amicable give and take.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Task allocation as opposed to relationship based care</td>
<td>Hierarchical decision making</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Then the work was allocated based on areas of the suite, ‘You go with Sarah, you go with Anne’.</td>
<td>Decisions based on</td>
<td></td>
</tr>
</tbody>
</table>
### Appendices

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Staff</th>
<th>Activity/Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>08.04.2011</td>
<td>12.00-2.00</td>
<td>S.2.OBS</td>
<td>Staff respond to allocation and move to respective ‘areas’. staffoman efficiently</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Some residents exchanged small talk with other residents. Then 20 minutes when no one is talking.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>I don’t see any staff around but I can hear one nurse on the phone in the office. Inactivity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Getting the work done efficiently</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Silence. Everyone stares into space. Radio has been turned off for communion so you notice the inactivity much more than when it is on. Inactivity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Getting the work done efficiently</td>
</tr>
<tr>
<td>09.08.2011</td>
<td>2.00-4.00</td>
<td>S.3.OBS</td>
<td>No interaction between residents. Residents only seem to interact with staff. Relationships.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HCA’s come round with the tea trolleys. I can hear them engaging with residents offering choice and chatting with residents. The conversations are two way and residents chat back Engagement Choice</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Getting the work done efficiently</td>
</tr>
<tr>
<td>08.08.2011</td>
<td></td>
<td>S.2.OBS</td>
<td>Nobody is talking. I can hear staff chatting in the adjacent pantry while preparing the meal trays. Engagement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Getting the work done efficiently</td>
</tr>
</tbody>
</table>
Appendices

Appendix 17: Excerpts from field notes

S.3. FN
One lady told me she was 96 and that she had to come here because she couldn’t manage on her own. When I told her my research was about the experience of living in residential care she said ‘what choice do you have? You have to just put up with it’. She declined to be interviewed formally. Another lady where I told her the same also grimaced and said ‘what can you do?’

S.2.FN
I was chatting to one of the HCA’S and she said that sometimes it’s hard to get people interested in going to activities. ‘They are institutionalised and set in their ways’.

S.3.FN
It is interesting that the concept of nurses’ station is that it provides a place of observation. When you are sitting down inside it you couldn’t possibly see anyone. Even if you were standing up the only people you could observe are those in the lobby area so what is the point of this station?

S.3. FN
I speak to the two ladies in the lobby. They both have family who they speak animatedly about. Willingness to discuss their family details, i.e. children’s and grandchildren’s names. One woman talks about how she spends the day. ‘There is nothing to do, I can’t wait to go to bed at half seven’.

S.1.FN
The staff member who was helping at breakfast this morning started talking to me about what she did. She explained that is a 'catering assistant'. She said she would much rather be a health care assistant and that was what she did when she was working in the Private Nursing Home in the Town. But there was no caring job here as the roles were clearly divided between catering/housekeeping and health care assistant. I asked her which she
preferred, the public or the private. She said she liked the private home, even though it was busier, she thought it was very good and that the manager was a very good boss. I asked her why she left and she said it was because the wages were better and there was more security although she was worried about that now as there was talk of closing the unit.
Appendices

Appendix 18: Excerpts from reflective journal

Reflection 08.04.2011
I think I have found my first thread. The work is very definitely task oriented. The Nurse Manager allocates the work by area and people head off to those sections. I will follow this up in the interviews but it seems to me like its work being allocated in a factory.

The points of tension that I think are emerging are:

- Tensions between physical and social care
- Tension between risk and autonomy
- Tension between being a respite patient and being a resident
- Tension between rhetoric of empowerment and disempowering practices
- Tension between rhetoric around relationships and actual reality of ‘them and us’ and non-reciprocity
- Tension between values and beliefs of staff and reality of this work
- Tension around the routinization of care and the rhetoric of choice
- Tension around participation and passivity
- Tension between goals of regulation and actual interpretation
- Tension between experience of care giving and paperwork, policies, risk assessments

Reflection 24.08.2011
There are a number of things that are striking me at this stage. When talking about relationships almost all of the residents have said that they don’t know the names of the staff, some using a lack of memory as the reason for this however, then they go on to mention one or two staff members who come from the same area as them or ones who they knew their parents. In all cases they do remember their names – both first and surnames.
Appendices

Is this something to do with kin and neighbours and the importance of older people being cared for within their own community? I am also noticing the language of ‘they’: ‘They are very nice, great girls’, but this does not translate into knowing their names or anything about them.

**Reflection 04.09.2011**

Power and empowerment is the next key social relation that I am seeing and it is very complex. It is not difficult to see how residents are disempowered often inadvertently and not in a malign way; however, their desire for relationships and engagement is consistently subordinated to the tasks in hand and everyone is aware of that. Staff have power over residents in terms of how it is decided who is to work with whom, in terms of deciding what is going to happen, yet staff in no way feel that they are powerful. There are power struggles between grades of staff and between staff and management or management and unions and probably between staff and relatives. It seems that people perceive others to be more powerful all the time. Is this something to do with self-determination, control over your environment? Does the fact that the current regime has a strong hierarchical focus have something to do with this? People are not self-directed at any level and yet there are examples throughout the data of negotiated work practices. Good examples of managers feeling they have to control things in order to ensure equity and fairness, but equity and fairness for whom?

The key issue running through all of this relates to the disjuncture between the ‘nothingness’ of the residents’ day compared to the busyness of the staff’s day. You can see if you were immersed in the routines that it would be hard to see how anything could be done to change it; after all, people have to be washed, dressed, brought to the toilet and fed. These are core basic elements and aligned to Maslow’s hierarchy of needs, i.e. need for food and shelter.

**Reflection 03.04.12**

I have deliberately picked what would be considered a very good care plan so I can look beyond issues of individualised practice to social relations.
What I see is a tidy, well balanced ‘representation’ or ideological view of the resident. Efforts have been made to balance the care plan by including social care stuff such as the KEY TO ME and activities work. But I know in reality these are not that integrated into the system. On paper they can look as if they are, i.e. the activities sheet is filled in and it matches the activity assessment, but it is filled in separately by the activities coordinator who ‘looks after that sort of thing’.
### Appendix 19: Documents Logged

<table>
<thead>
<tr>
<th>Hierarchy</th>
<th>Document Type</th>
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<th>National</th>
<th>Local</th>
<th>Purpose</th>
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<td>Legal</td>
<td>Human Rights Convention</td>
<td>Health Act</td>
<td>Resident contract</td>
<td>Legal mandate for action</td>
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<td>Health and Safety Act</td>
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<td>Food Safety Act</td>
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<td></td>
<td></td>
<td>Nursing Home Support Scheme</td>
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<td>Care and Welfare Regulations</td>
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<td>Working time Act</td>
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<td>Policy</td>
<td>HIQA Standards</td>
<td>Risk register</td>
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<td>HACCP guidelines</td>
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<td>Clinical governance</td>
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<td>HSE Quality and Risk Framework</td>
<td>Risk Management protocols</td>
<td></td>
<td>Quality of care</td>
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<td></td>
<td>Restraint Policy</td>
<td>Policy on;</td>
<td></td>
<td></td>
</tr>
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<td></td>
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<td>Elder Abuse Policy</td>
<td>Cognitive impairment</td>
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<td></td>
<td></td>
<td>‘Your Service Your Say’</td>
<td>Activities of daily living function</td>
<td></td>
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<td></td>
<td>Rehabilitation</td>
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<td>Communication</td>
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<td>Hydration/fluid maintenance</td>
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<td>Dysphasia</td>
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<td>Infection control and prevention</td>
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<td>Category 3</td>
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<td>Positive Ageing Strategy 2013</td>
<td>Overall mission, values and goals of Age related services</td>
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<td></td>
</tr>
<tr>
<td>------------</td>
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<td>------------------------------</td>
<td>----------------------------------------------------------</td>
<td></td>
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<tr>
<td>Professional</td>
<td>Board Altranais Guidelines</td>
<td>Care Plans</td>
<td>Legal mandate</td>
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<td>Action orientated</td>
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<td>HSE Annual Report</td>
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<td>Health Stat</td>
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<td>Performance reports</td>
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<td>Governance</td>
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</table>

Defines organisational priorities. Provision of standardised data.
<table>
<thead>
<tr>
<th>Appendices</th>
</tr>
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<tbody>
<tr>
<td>HR policies Practice Development strategy Trust in care Job Descriptions Education and training FETAC Guidelines</td>
</tr>
<tr>
<td>Standardises actions and behaviour. Matches educational action to organisation priorities. Adheres to legislative mandates regarding employment law</td>
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<tr>
<td>Resident information DOHC Website HSE website HSE Consumer information HSE Complaints Advocacy programme</td>
</tr>
<tr>
<td>Local resident information booklets Complaints policy Advocacy policy</td>
</tr>
<tr>
<td>Provides information to services. Mandate for redress</td>
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</table>
Appendices

Appendix 20: Nursing Observations

<table>
<thead>
<tr>
<th>Date</th>
<th>Temp</th>
<th>Pulse</th>
<th>Blood Pressure</th>
<th>Resp Rate</th>
<th>Blood Sugar</th>
<th>O2 Saturation</th>
<th>Urinalysis</th>
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<tbody>
<tr>
<td>2/16/16</td>
<td>36.7</td>
<td>70</td>
<td>125/74</td>
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<td>80%</td>
</tr>
<tr>
<td>3/1/16</td>
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<td>70</td>
<td>115/77</td>
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<td>96%</td>
<td>80%</td>
</tr>
<tr>
<td>7/23/16</td>
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<td>70</td>
<td>110/74</td>
<td>20</td>
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<td>95%</td>
<td>80%</td>
</tr>
<tr>
<td>8/3/16</td>
<td>36.1</td>
<td>82</td>
<td>98/56</td>
<td>20</td>
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<td>95%</td>
<td>80%</td>
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<td>8/5/16</td>
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<td>76</td>
<td>112/73</td>
<td>18</td>
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<td>8/7/16</td>
<td>36.0</td>
<td>79</td>
<td>120/74</td>
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<td>200</td>
<td>96%</td>
<td>80%</td>
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<tr>
<td>8/10/16</td>
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<td>8/13/16</td>
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<td>79</td>
<td>110/65</td>
<td>20</td>
<td>200</td>
<td>96%</td>
<td>80%</td>
</tr>
<tr>
<td>8/17/16</td>
<td>36.0</td>
<td>79</td>
<td>120/72</td>
<td>20</td>
<td>200</td>
<td>96%</td>
<td>80%</td>
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</table>
### Appendix 21: Care Flow Sheet

#### Daily Flow Chart

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Communication &amp; Pain</th>
<th>Mobility &amp; Safety</th>
<th>Personal Care Given</th>
<th>Skin Integrity Maintained</th>
<th>Nutrition</th>
<th>Continence</th>
<th>Sleep &amp; Rest</th>
<th>Spiritual Needs</th>
<th>Activities</th>
<th>Narrative Note</th>
</tr>
</thead>
</table>
# Appendix 22: Daily Flow Chart Guidelines

<table>
<thead>
<tr>
<th>CARE FLOW CHART</th>
<th>Mobility/Safety</th>
<th>Personal Care given</th>
<th>Skin Integrity</th>
<th>Nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Independent</td>
<td>Ability to sit</td>
<td>Independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Dependently</td>
<td>mobile using</td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. No change</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Personal Care given</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Wash</td>
<td></td>
<td>Independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Shower</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. No change</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Skin Integrity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Pressure area</td>
<td></td>
<td>Independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Repositioned</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. No change</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Nutrition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Able to eat</td>
<td></td>
<td>Independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Assisted with feeding</td>
<td></td>
<td>independence in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Bowsels passed</td>
<td></td>
<td>independence in</td>
<td></td>
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<tr>
<td>4. Defintion of bowel function</td>
<td></td>
<td>independence in</td>
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<tr>
<td>5. No change</td>
<td></td>
<td>independence in</td>
<td></td>
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</tbody>
</table>

## Insert NI when any change in the resident’s condition is noted

Inserting NI is the responsibility of the Primary Nurse on Duty.

**Insert NN when a narrative note is written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NE when an intervention was written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert N when a narrative note is written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NM when an intervention was written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert ND when a narrative note is written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NMD when an intervention was written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NMD when an intervention was written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NM when a narrative note is written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.

**Insert NMD when an intervention was written**

When there is no change in the resident’s condition, the Care plan needs to be reviewed and updated daily.
### Appendix 23: Social Activities Chart

<table>
<thead>
<tr>
<th>Number/Activity</th>
<th>Group Activity</th>
<th>Reminiscence/Exercises</th>
<th>Alternative Therapy</th>
<th>Orientation</th>
<th>Spiritual Care &amp; Communion</th>
<th>Recreation</th>
<th>Education Other</th>
<th>Date (mm/dd)</th>
<th>Initials/No</th>
</tr>
</thead>
</table>

*Note: CC indicates a comment or correction.*
### Appendix 24: Pool Activity Level (PAL) Profile

#### Meaningful Activities Programme - Residents Activity Level Profile

#### Exploratory Activity Level

<table>
<thead>
<tr>
<th>Likely Abilities</th>
<th>Likely Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can carry out very familiar tasks in familiar surroundings.</td>
<td>May not have an end result in mind when starts a task.</td>
</tr>
<tr>
<td>Enjoys the experience of doing a task more than the end result</td>
<td>May not recognise when the task is completed.</td>
</tr>
<tr>
<td>Can carry out more complex tasks if they are broken down into 2-3 step stages</td>
<td>Relies on cues such as diaries, newspapers, lists and labels</td>
</tr>
</tbody>
</table>

#### Method of Engagement

<table>
<thead>
<tr>
<th>Activity objectives</th>
<th>To enable [Activity] to experience the sensation of doing the activity rather than focusing on the end result.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position of tools</td>
<td>Ensure that equipment and materials are in the line of vision.</td>
</tr>
<tr>
<td>Verbal directions</td>
<td>Explain task using short simple sentences. Avoid using connecting phrases such as &quot;and&quot;, &quot;but&quot;, or &quot;therefore&quot;.</td>
</tr>
<tr>
<td>Demonstrated directions</td>
<td>Break the activity into 2-3 steps at a time.</td>
</tr>
<tr>
<td>Working with others</td>
<td>Others must approach [Activity] and make the first contact.</td>
</tr>
<tr>
<td>Activity characteristics</td>
<td>There is no pressure to perform to a set of rules, or to achieve an end result. There is an element of creativity and spontaneity.</td>
</tr>
</tbody>
</table>

#### Suitable Activities

<table>
<thead>
<tr>
<th>Tidying, weeding, planting</th>
<th>Hoarding, money, family, pets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knitting, cross-stitch, etc.</td>
<td>Going out, family, pets</td>
</tr>
<tr>
<td>Newspaper reading, crossword,</td>
<td>Cemetery, church, prayer beads</td>
</tr>
<tr>
<td>Reading, TV, CD, DVD, internet</td>
<td>Flowerpot, hobby, etc.</td>
</tr>
</tbody>
</table>
Appendix 25: Pool Activity Level (PAL) Checklist

The term meaningful activity includes activities of living & leisure activities that promote quality of life, self-esteem, pleasure, comfort, education, creativity & independence. Each registered nurse assessing a resident is accountable for designing, co-ordinating & implementing an individualised Meaningful Activity Programme to meet the residents' psychological and social needs.

Completing the checklist: For each activity, the statements refer to a different level of ability. Tick the statement that represents the person's ability in each activity. Assessment centres on 4 levels of ability & suitable meaningful activities: P: Planned, E: Exploratory, S: Sensory & R: Reflex. There should be only one tick for each activity. If in doubt about which statement to tick, choose the level of ability which represents their average performance over 5 days. Make sure you tick only on one statement for all of the activities.

| Risk Assessment for Meaningful Activities | Mobility Status: | □ Independent □ Supervised |
| Safety awareness: | □ Poor □ Intermittent □ Good |
| Falls risk: | □ Yes □ No |
| Risk of wandering: | □ Yes □ No |
| Mental Test Score: | |
| Alarm system: | □ Yes □ No, Specify: |
| On-site Activities: | 1:1 assistance needed: | □ Yes □ No |
| Requires assistance as part of a group: | □ Yes □ No |
| Off-site Activities: | 1:1 assistance needed: | □ Yes □ No |
| Requires assistance as part of a group: | □ Yes □ No |

1. Bathing/Washing
- Can bathe/wash independently, sometimes with a little help to start.
- Needs soap put on funnel & one-step at a time directions to wash.
- Mainly relies on others but will wipe own face & hands if encouraged.
- Totally dependent & needs full assistance to wash or bathe.

2. Getting Dressed
- Plans what to wear, selects own clothing from cupboards; dresses in correct order.
- Needs help to plan what to wear but recognises items & how to wear them; needs help with order of dressing.
- Needs help to plan and with order of dressing, but can carry out small tasks if someone directs each step.
- Totally dependent on someone to plan, sequence & complete dressing; may move limbs to assist

3. Eating
- Eats independently & appropriately using correct cutlery.
- Eats using a spoon &/or needs food to be cut up into small pieces.
- Only uses fingers to eat food.
- Relies on other to feed, needs feeding stool.

4. Contact with Others
- Initiates social contact & responds to needs of others.
- Aware of others & will seek interaction, but may be more concerned with own needs.
- Aware of others but waits for others to make the first contact.
- May not show an awareness of the presence of others, unless in direct physical contact.

5. Group work skills
- Engages with others in a group activity, can take turns with the activity/tools.
- Occasionally engages with others in a group, moving in and out of the group at whim.
- Aware of others in the group and will work alongside others although tends to focus on own activity.
- Does not show awareness of others in the group unless close 1:1 attention is experienced.

PP | E | S | R
---|---|---|---

Appendices
### Meaningful Activities

**Pool Activity Level (PAL) Checklist**

<table>
<thead>
<tr>
<th>6. Communication skills</th>
<th>8. Use of Objects</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Is aware of appropriate interaction, can chat coherently and is able to use complex language skills.</td>
<td>- Plans to use and looks for objects that are not visible may struggle if objects are not in usual/familiar places (toiletries in a cupboard below washbasin)</td>
</tr>
<tr>
<td>- Body language may be in appropriate and may not always be coherent, but can use simple language skills.</td>
<td>- Selects objects appropriately only if in view (i.e. toiletries on a shelf next to washbasin)</td>
</tr>
<tr>
<td>- Responses to verbal interaction may be mainly through body language: comprehension is limited.</td>
<td>- Randomly uses objects as chances upon them, may use inappropriately.</td>
</tr>
<tr>
<td>- Can only respond to direct physical contact from others through touch, eye contact or facial expression.</td>
<td>- May grip objects when placed in the hand, but will not attempt to use them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Practical Activities (craft, domestic chore, gardening)</th>
<th>Looking at a Newspaper/Magazine</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Can plan to carry out an activity, hold the goal in mind and work through a familiar sequence; may need help solving problems.</td>
<td>- Comprehends and shows interest in the content, turns the pages and looks at headlines and pictures.</td>
</tr>
<tr>
<td>- More interested in the making or doing than in the end result, needs prompting to remember purpose, can get distracted.</td>
<td>- Turns the pages randomly, only attending to items pointed out by others.</td>
</tr>
<tr>
<td>- Activities need to be broken down and presented one step at a time; multi-sensory stimulation can help to hold attention.</td>
<td>- Will hold and may feel the paper, but will not turn the pages unless directed and will not show interest in the content.</td>
</tr>
<tr>
<td>- Unable to &quot;do&quot; activities, but responds to the close contact of others &amp; experiencing physical sensations.</td>
<td>- May grip the paper if it is placed in the hand but may not be able to release grip or may not take hold of the paper.</td>
</tr>
</tbody>
</table>

**Total amount of ticks in each box below:**

<table>
<thead>
<tr>
<th>Planned</th>
<th>Exploratory</th>
<th>Sensory</th>
<th>Reflex</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

TOTAL: □  □  □  □

Now select the appropriate 'Meaningful Activities Programme - Residents Activity level Profile' to act as a general guide to engaging with the person in a variety of meaningful activities.

Then complete an individualised 'Meaningful Activities Programme' to act as a specific guide to facilitating personal activities.
Appendix 26: Patient Needs Identification Chart

<table>
<thead>
<tr>
<th>Date</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>11/31</td>
<td>Set up stool chart to check frequency, consistency, colour of stools. Give assistance in hygiene needs. Send stool samples for microscopy to rule out other infections e.g. C. diff. Teach antibacterial gel for severe episodes.</td>
</tr>
</tbody>
</table>

First Re-evaluation Date:
Appendices

Appendix 27: Need Identification chart – meaningful activities

<table>
<thead>
<tr>
<th>NEED IDENTIFICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>That P may be involved in everyday activities in a meaningful way which reflects preferences and choices</td>
</tr>
<tr>
<td>That P enjoys life within BCNU and engages in activities available</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GOAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>That P has a sense of well being from involvement in an activity programme</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SPECIFIC INTERVENTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ensure that P’s Key To Me Profile is completed and preferences for daily activity documented</td>
</tr>
<tr>
<td>2. That a PAL activity set has been carried out</td>
</tr>
<tr>
<td>3. The activity Nurse to assist in the development of planned activities for P as outlined below</td>
</tr>
<tr>
<td>4. See P’s profile exploratory activity level</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EVALUATION OF CARE (based on goals specified)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

Discontinued Date: .......... / .......... / 20...... Signature: .........................................................
### Appendix 28: Resident Narrative Notes

<table>
<thead>
<tr>
<th>Date &amp; Time</th>
<th>Information Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Use only to document one off incidents and other information not related to a specific goal</td>
</tr>
<tr>
<td>12/16/10</td>
<td>Assess &amp; noted no pain attacks or pain today.</td>
</tr>
<tr>
<td>28/16/10</td>
<td>Coton Exam applied &amp; securum applied.</td>
</tr>
<tr>
<td>7/5/10</td>
<td>Maintained wound with personal hygiene.</td>
</tr>
<tr>
<td>8/11/10</td>
<td>Assistance given with hygiene.</td>
</tr>
<tr>
<td>9/1/10</td>
<td>Pressure areas intact &amp; no small red area on upper spine remains.</td>
</tr>
<tr>
<td>9/5/11</td>
<td>Assistance with hygiene needs.</td>
</tr>
<tr>
<td>12/11/10</td>
<td>Assisted with hygiene needs.</td>
</tr>
<tr>
<td></td>
<td>.Notification for the aptronion form had not been filled out.</td>
</tr>
<tr>
<td>11/10</td>
<td>Nursing notes filled out.</td>
</tr>
</tbody>
</table>

- 12/10: *Did not sleep well last night. More rest.*
## Appendix 29: Staff Absenteeism in one Local Area January 2013

<table>
<thead>
<tr>
<th>Year to Date</th>
<th>Service Total Lost Hours &amp; %Abs</th>
<th>Management/Admin</th>
<th>Medical/Dental</th>
<th>Nursing</th>
<th>Allied Professionals</th>
<th>Health</th>
<th>Support Services</th>
<th>Other Patient &amp; Client Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Avail Hrs</td>
<td>Lost Hrs</td>
<td>% Abs</td>
<td>Avail Hrs</td>
<td>Lost Hrs</td>
<td>% Abs</td>
<td>Avail Hrs</td>
<td>Lost Hrs</td>
</tr>
<tr>
<td>Jan-13</td>
<td>291447.9</td>
<td>19252.6</td>
<td>6.6</td>
<td>34559.7</td>
<td>1429.0</td>
<td>4.1</td>
<td>19206.8</td>
<td>147.0</td>
</tr>
<tr>
<td>Feb-13</td>
<td>257905.6</td>
<td>14686.2</td>
<td>5.7</td>
<td>30854.4</td>
<td>1315.7</td>
<td>4.3</td>
<td>8969.9</td>
<td>21.0</td>
</tr>
<tr>
<td>Mar-13</td>
<td>244308.6</td>
<td>13975.6</td>
<td>5.7</td>
<td>25765.4</td>
<td>1089.9</td>
<td>4.2</td>
<td>8487.2</td>
<td>132.5</td>
</tr>
<tr>
<td>Apr-13</td>
<td>264105.9</td>
<td>13908.0</td>
<td>5.3</td>
<td>30993.2</td>
<td>1394.5</td>
<td>4.5</td>
<td>9179.1</td>
<td>155.5</td>
</tr>
<tr>
<td>May-13</td>
<td>275518.1</td>
<td>13731.6</td>
<td>5.0</td>
<td>32654.4</td>
<td>1022.3</td>
<td>3.1</td>
<td>10007.7</td>
<td>66.0</td>
</tr>
<tr>
<td>Jun-13</td>
<td>247209.9</td>
<td>13728.2</td>
<td>5.6</td>
<td>27945.6</td>
<td>851.5</td>
<td>3.0</td>
<td>7908.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Jan-Jun 2013</td>
<td>15800495.9</td>
<td>89282.2</td>
<td>5.6</td>
<td>182772.2</td>
<td>7102.8</td>
<td>3.9</td>
<td>54758.8</td>
<td>522.0</td>
</tr>
</tbody>
</table>

*Check 2013 Total*