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**Here Today Gone Tomorrow:**

an exploratory study of Housing with Care  
Development for People with Dementia in Ireland

by

Janet Brazier Convery BA, MA, MS, CQSW

Submitted for the Degree of Doctor of Philosophy

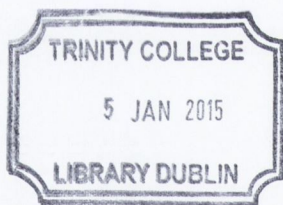
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University of Dublin, Trinity College

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Under the direction and supervision of

Professor Suzanne Cahill, Ph.D.

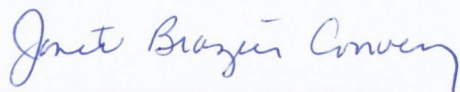


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Janet Brazier Convery

## Summary of the Research Findings

Housing with Care (HWC) for older people is unusual and HWC for people with dementia even more unusual in Ireland where long term care of older people is confined to nursing home care in almost all cases. This qualitative research focuses on HWC development for people with dementia in Ireland and the factors that impact on it. Case studies were used to capture the multiple perspectives of many stakeholders from different agencies about the complex issues involved in HWC development as manifested across several sites. Five HWC voluntary housing initiatives developed between 1989 and 2008 were selected to explore the factors that facilitated service development, the factors that created barriers, and the climate for further HWC service development in Ireland. Of the five schemes, three continue to operate, one closed within months of opening and plans for the fifth scheme never progressed to the building stage.

Data collection involved site visits, analysis of relevant documentation and in-depth qualitative interviews with 43 stakeholders; of these, 23 were administrative officers or health professionals from the health service, 8 were from voluntary housing associations, 4 from local authorities and 8 were experts with a stake or interest in HWC for people with dementia. Change theory provided a useful framework for the analysis of the forces that impact on the introduction of new ways of doing things in an organisational context.

The data show that common drivers for the development of the case study schemes were the desire to relieve pressure on housing and health services including acute hospital beds and dissatisfaction with existing nursing home models. Specific concern about the needs of people with dementia was a less prominent catalyst for service development. The availability of state capital funding and land, the intervention of individual champions and a favourable economic and/or political environment during the early planning stages were identified as the factors most critical to the development of the case study initiatives.

Lack of access to revenue funding was identified as the biggest barrier to HWC service implementation in all cases; as the Irish economy deteriorated in the late 2000's, this became more of a challenge. Although the Health Service Executive (HSE) was expected to provide revenue funding, there was no dedicated budget established for that purpose. A second major barrier was the resistance of community nurses and GPs who were reluctant to make referrals or provide services to HWC residents because they believed it was not in their professional self-interest and also because of concerns about the health and safety of older people in a care setting that was not nurse managed. Inter-agency tensions created by the different priorities and expectations of the housing and health agencies were identified as a further barrier across case

studies; Health Service Executive (HSE) structures and organisational culture presented particular challenges.

All except one of the 43 study participants acknowledged the need to further develop HWC services. However a number of stakeholders from the HSE in particular stopped short of fully endorsing the HWC model because of concerns about HWC capacity to provide more than just short term care to older people as their dependency level increases. For them, the possibility that some HWC residents might have to move a second time into a nursing home weakened the case for further development. Several HSE participants believed that a review of existing services was necessary before further HWC development is considered.

There was a consensus among study participants that the climate for HWC development is more unfavourable than it was when the case study schemes were planned and most put this in the context of the economic recession which has slowed down all public sector service development in Ireland in the last 4-5 years. The change from a capital funding system to a leasing system for the development of social housing was considered by voluntary housing participants to inflict an almost fatal blow to the development of all special needs housing in Ireland including HWC for older people. Other identified inhibiting factors included long term care funding mechanisms heavily biased in favour of nursing home care and the anticipated introduction of regulation which many feared would increase costs while restricting HWC access to people with low dependency needs. The absence of a strategic framework defining the role of the HSE, centralised HSE structures and an HSE organisational culture that discourages innovation were cited as additional reasons for pessimism.

The data shows a particular lack of optimism about the climate for the further development of dementia specific HWC services because of the higher costs involved and perceptions about the particular vulnerability of people with dementia. The findings suggests that revenue funding problems were already threatening service sustainability and there were fears that the introduction of regulation would ultimately lead to the screening out of people with dementia. Although there was some appreciation expressed about the particular benefits of HWC for people with dementia, doubts remain about its feasibility as a long term care alternative. The data suggests that the development of HWC for people with dementia in Ireland has at best stalled; the momentum that developed when the case study schemes were being planned had already been lost by the time that plans for the last two schemes were being implemented and few if any believed that further HWC was a realistic proposition in the short term.

## Acknowledgements

I had a huge amount of support since starting out on this PhD adventure. First I would like to acknowledge the assistance of Dr. Suzanne Cahill who gave me the opportunity to pursue this study and provided supervision and guidance throughout. She helped me to make sense of the huge volume of data involved in this study and her help during the writing up stage is particularly appreciated. I would also like to acknowledge the financial support I received from Atlantic Philanthropies to undertake this research which made the transition from paid employment to being a student much easier.

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I am enormously grateful to the 43 people who agreed to be interviewed for this study, many who also fielded follow up phone calls and emails and a few who agreed to be interviewed more than once. They include former colleagues in the HSE and the housing sector as well as people I was meeting for the first time; they were generous with their time and gave great encouragement and support. I very much appreciate the time given by officers in the Irish Council for Social Housing who educated me in the ways of the voluntary housing sector. Study participants from the housing associations involved in the case study initiatives were extremely helpful and always courteous. Their commitment and dedication to their residents is remarkable. I was very lucky to have such easy access to a whole range of stakeholders and I hope that the finished product does them justice.

Faith Gibson has been a mentor and friend over many years. She opened up a whole new world to me by putting me in contact with a network of social workers and other health professionals involved in work with older people in Northern Ireland at a time in the 1980's when attendance at conferences on older people's services in Ireland was confined largely of public sector

administrators, volunteers and nuns. I treasure her friendship and appreciate the support she has given to me over the years. I also value the friendship of Níav O'Daly, a retired social worker with exceptional commitment and heart who has always had confidence in whatever work I happened to be doing, including this research. They are two positive models for my retirement.

I want to thank all of my friends in Ireland who stuck with me during this journey, even those who asked me repeatedly, 'Are you done with that thing yet?' starting about 2 years ago. And thanks to those abroad, especially my sister Joan, Rona, Sile, Jim and Ralph who cheered me on from the sidelines. Rona's late mother Irene was a wonderful woman and a loyal friend; visits to Irene in the Independent Living facility where she lived up to the age of 100 convinced me of the value of this research.

Last but not least, I am grateful to my family who encouraged me and supported me and consoled me when things were not going well. I thank Claire for her friendship and support and I thank Niall for the occasional words of wisdom sent from afar that have helped to keep me going. I am proud of the way that both Claire and Niall have carved out new lives for themselves in recent years. Grace (who was born a few days before I began the PhD) has provided me with unconditional love, joy and light relief for the past four years and I look forward to spending more time with her when this work is finished.

Finally, it is Frank to whom I owe the most for his love, encouragement, support and loyalty for over 40 years. I really could not have done this without him.

### *Dedication*

This study is dedicated to the memory of my great grandmother Harriet Bonner and my mother Edith Martin Brazier, her granddaughter, who both lived to be 97. Grandma Bonner lived with my family until I was 16 and it was from her that I developed my interest in older people; as a child I was surrounded by older people who displayed wonderful wit. Funerals were a frequent topic of discussion but it was stories of horses and carriages and quilting that kept me interested.

Grandma Bonner was quite a force who, being a staunch Methodist, tried to impose the rule of no work and no play on Sundays, but fortunately my mother was cast in the same strong mould and we were spared that fate as children. In spite of very modest means, my mother was determined that all three of her children would go to college, something she never had the opportunity to do. And go to college we did and some of us are still at it. I am grateful to my mother for the sacrifices she made for us but also for giving me such a positive model of ageing and older people.



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## List of Abbreviations

DOH	Department of Health
DOHC	Department of Health and Children
DOE	Department of the Environment <sup>1</sup>
ICSH	Irish Council for Social Housing
HSE	Health Service Executive
NAHB	Northern Area Health Board
NCE	National Council for the Elderly
NCAOP	National Council for Ageing and Older People

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<sup>1</sup> DOE is used to refer to all name variations for the Department of Environment, including the Department of Environment, Heritage and Local Government and the Department of Environment, Community and Local Government.



## **Chapter 1: Introduction**

This thesis explores the development of Housing with Care (HWC) services for people with dementia in Ireland. It traces the development of five HWC schemes and identifies the factors that made service development possible, factors that presented barriers during the planning and implementation stages and factors critical to creating the environment for future HWC service development. The focus of the thesis is on the service development process and the factors that affect it; it is not an evaluation of HWC or a comparative analysis of long term care models. It did not measure HWC costs or outcomes for service users, although the issue of costs does feature in the discussion about barriers to HWC development. Finally the research was not aimed at capturing people's personal experience of working or residing in the HWC schemes used for the study. This dissertation was written mainly for stakeholders in the housing and health services whose job it is to plan and develop services for older people and it reflects their perspective rather than the perspective of older people or their carers. The focus was on the mechanics of service development in the housing and health sectors and the factors that impact on it, and the collection of data was undertaken from that perspective. This study is divided into seven chapters broken down as follows.

Chapter 1 of the thesis begins with a definition of terms in Section 1. Section 2 includes a discussion of the concept of HWC and Section 3 looks at the specific benefits of HWC for people with dementia. Chapter 2 includes a review of the international literature on HWC for people with dementia and the theoretical framework used for this study, and Chapter 3 presents the methodology chosen for the conduct of the research. Chapters 4-6 present the main research findings; Chapter 4 presents an analysis of the findings on the factors that made the case study scheme developments possible; Chapter 5 presents the data related to the factors that presented barriers to service development; and Chapter 6 presents the findings on the climate for future HWC development. Chapter 7 draws conclusions from the research. It includes a discussion of the strengths and limitations of the study and makes recommendations for research, policy and practice.

### **Section 1 Definition of terms**

Howe et al recently observed the confusion and ambiguity created by the lack of consistent terminology used to describe 'housing for older people that is combined with various support and care services' (2013:547). In their extensive search of the literature, they found over 70 terms in use; with some difficulty they reduced this number to 20 'generic terms' before choosing Service

Integrated Housing as the umbrella term for their study (2013:548). Literature reviews by Croucher et al (2006) and Dutton (2009) similarly observe the lack of a standard lexicon for housing services that also provide social care and support. Housing with care, enhanced sheltered housing, very sheltered housing, supported housing, integrated care, close care, flexi care and retirement communities are only some of the terms used in this context in the UK literature, and within each of these categories there is huge variation of services (Oldman 1990, Croucher 2006, Dutton 2009). To illustrate the difficulties involved in trying to categorise services in the UK, Oldman uses the example of 'very sheltered housing' provision which, at the extreme ends, '...ranges from only housing to something close to residential care' and she suggests a blurring of the boundaries between sheltered housing and residential care at the highest end of the scale(1990:23).

In the United States, assisted living and continuing care retirement communities are the terms used most frequently to describe services that provide housing and care for dependent older people, but again there is confusion about definition of terms and Hawes points out that for example '...there is tremendous variation among those facilities that call themselves assisted living' which makes it difficult to generalise about services or compare them (Hawes in Zimmerman et al 2001:2).

In Ireland, the term sheltered housing is commonly used to describe housing schemes for older people that at minimum provide individual dwellings, a warden and alarm systems (O'Connor et al 1989) and that is the way it is used in this study. But as in other countries, there is no standardised terminology in Ireland for housing schemes that provide more than this minimum level of services to older residents. O'Connor et al use the term 'extra care' to describe sheltered housing schemes with a mix of facilities to meet the increasing needs of tenants (1989:56-68). Cullen et al use 'supportive housing' to describe housing schemes for older people that include self-contained accommodation, tenancy arrangements between landlord and tenants, and an element of 'supportiveness' for residents. But under their definition, supportiveness can mean anything from 'the opportunity for social contact and collective security provisions... [to the provision of] communal facilities (living areas, dining rooms and meals, laundry, etc.), visiting support staff and on-site support staff' (2007:53-54). The Irish Council for Social Housing distinguish between 'low support group housing schemes...designed for active older people [with] visiting support services' and 'sheltered housing [which] have on-site support services...[and] provide a higher level of support than the group housing schemes described above but do not provide intensive care' (in Cullen et al 2007:55) In the absence of standardised terminology, 'supported housing' is used in this study to describe housing schemes for older people that

provide accommodation and a low level of support services to residents, for example meals, home help, social activities, laundry and alarm services. Housing with Care (HWC) is used as a generic term to describe services at the highest end of the housing and services scale, specifically those providing self-contained accommodation and 24/7 supervision and support either delivered by care staff or accessed from other agencies (Dutton 2009). HWC settings range from 1-2 bedroom apartments to single or double rooms in a congregate housing facility with meals, social activities and other services delivered in communal areas (Howe et al 2013). Nursing, medical and therapy services are typically accessed from outside HWC schemes as required. Housing with Care is used because it is simple and because it gives equal weight to housing and care, reflecting the nature and scope of the services being studied.

‘Nursing home’ is used in this study to describe all long stay residential care institutions that provide skilled nursing care because, according to Howe et al, it is ‘the most commonly used and least ambiguous term with common meaning’ in the literature in English (2013). It is used to describe public long stay units as well as private sector nursing homes in Ireland.

Hawes suggests that Housing with Care ‘represents a promising new model of long-term care that blurs the sharp and invidious distinction between nursing homes and community-based care and reduces the chasm between receiving long-term care in one’s own home and in an “institution”’ (2001:2). The perceived merits of HWC are discussed below.

## **Section 2 Why Housing with Care?**

Housing with Care (HWC) developed largely in reaction to medical model nursing home care and its perceived negative implications for older people which Lawton suggests include the ‘frequent provision of excess care and independence-undermining features of everyday life...’ (2001) Golant and Hyde observe that HWC is a social model that is less a set of specific services than a philosophy of long term care which ‘puts the person first, incorporating a person’s medical, psychological, social and personal needs, as well as strengths, abilities, interests and preferences...’ (2008:48).

Although the range and configuration of HWC services varies, HWC providers share an ethos that places value on the promotion of independence, empowerment and accessibility (Croucher et al 2006, Dutton 2009:22, Golant and Hyde 2008). The ability of older people to maximise their personal autonomy and to maintain some semblance of normal daily life is believed to be one of the biggest benefits of HWC (Tinker et al 2007, Oldman 2000, Wilson 2007, Golant and Hyde 2008). Greenwood and Smith observe that ‘The aspiration is to... [create an]...environment in which tenants feel much more powerfully in control of what is happening, largely because it takes

place in their own territory and to a degree on their own terms'(1999:8). Independence and control are a particularly important benefit of HWC '...especially when the inevitable comparisons [are] made with residential care which is carried out in a highly managed environment' (Heywood et al 2002:30).

HWC aims to provide some of the benefits of one's own home. Anthea Tinker wrote convincingly about the importance of home to older people and the value they place on having their 'own front door' (1999a:269) and Means observed that, for older people, 'home represents security, a refuge, a place where they could express their individuality...' (1997:416). Peace et al make the connection between environment and identity in later life, stating that '...people derive the security and confidence to use and enjoy their material and social surroundings only when they have a secure starting point (including their own room) from which to venture forth' (2006:111). Recent studies have found that what older people living in HWC schemes value most is: 'having their own front door, flexible on-site care and support, security, [and] accessible living arrangements and bathrooms...' (Tinker et al 2013). While it is the strong preference of older people to receive required long term care in their own homes and most would not wish to move anywhere (Tinker et al 2013:8) Housing with Care is promoted as the next best thing to home and its proponents argue that it supports continued participation in normal life activities which would be the choice of most older people but which is hard to achieve in traditional nursing home settings (Tinker et al 2007). Among the other perceived advantages of HWC over nursing home care are increased living space and personal privacy (Greenwood et al 1999, Cutler 2007, Tinker et al 2013). Cutler notes that in the US, where most assisted living residents pay the full cost of services, having one's own room or apartment is seen as a priority by those who choose assisted living (2007:80).

HWC is believed to offer personal benefits to individual older people in terms of quality of life, but it has also been promoted as a cost saving exercise for governments that believe it can prevent costly hospital admissions and serve as a cheaper alternative to other forms of institutional long term care (O'Connor et al 1989, Heywood et al 2002, Mercer Report 2002, Irish Council for Social Housing 2011, Mollica 2009, Howe et al 2013 Tinker et al 2013). Heywood et al note that not only governments but also housing associations interested in expanding their own services promote HWC as something that can enable older people to 'age in place' with 'only modest investment' (2002:65). Although some of the claims made may be exaggerated, recent research in the UK found that extra care can reduce the risk of initial hospital admission and also result in substantial cost savings (Tinker et al 2013:23).

### Section 3 HWC for people with dementia

HWC was not developed originally for people with dementia. People with dementia, who could no longer be cared for at home, were among those considered to be suitable only for hospital or nursing home care (O'Connor et al 1989, Cox 1999, Housing Learning and Improvement Network [Housing LIN] 2005, Zimmerman et al 2001). Even as the level of service provision increased in supported housing settings in response to an ageing population, people with cognitive impairment were not considered appropriate candidates for HWC until fairly recently. But in recent years, a more holistic understanding of dementia has developed and attitudes changed about the needs of people with dementia and how best to meet them (Kitwood 1997, O'Shea and O'Reilly 1999, Sloane 2001, Golant and Hyde 2008). Concern grew about the marginalisation of people with dementia who were considered to be most at risk of being placed in nursing homes in which services were developed and delivered through a 'sickness framework, the person with dementia being the patient for whom little can be done' (Gilliard et al 2005:574).

While traditional nursing home care had negative implications for older people in general, it was believed to be particularly inappropriate and even damaging to people with dementia. Kitwood was among the first to spell out the pernicious effects of traditional nursing home care that is 'medically based, deficit focused and therapeutically nihilistic' and he pioneered the concept of person-centred care as an antidote to the medical model approach to dementia care (in Capstick and Baldwin 2007:74). As 'person-centred care' gained currency so also did the idea of what was possible in terms of providing alternatives to what had been considered the only long term care alternative for people with dementia. Arguments developed around the advantage of viewing dementia as a disability and with it a new appreciation of the enabling and disabling impact of the physical and social environment on people with dementia (Marshall and Archibald 1998, Lawton 2001:viii, Dorenlot 2005)

Dissatisfaction with the medical model combined with the significant rise in the number of people with dementia requiring long term care and the high costs associated with it created pressure for the development of new dementia service alternatives (Tinker et al 2007). Nursing home providers who were already faced with the challenges involved in providing care to an increasing number of people with dementia, responded to the pressure by developing specialist dementia care units in which 'person-centred care' could be tailored to the individual needs of residents. (McCormack 2004, Dewing 2004, Cahill et al 2012) The development of specialist units prioritised staff training and the development of specialist nursing practice as well as the design of facilities sensitive to the particular needs of people with cognitive impairment (Cahill et al 2012:109). This

new culture of care was aimed at improving the nursing home experience of people with dementia and replacing old nursing care models with new ones.

Housing providers approached the development of dementia specific services from a different angle; they hoped to prevent the admission of people with dementia into nursing home care and if that was not possible, to at least prolong it. The aspiration was that HWC would provide an alternative to nursing home care and that it would allow people with dementia to 'age in place' in a secure home- like setting (Oldman 2000, Zimmerman et al 2001, Henwood et al 2009). HWC thus offered choice to older people with dementia where no choice had existed before (Poole 2006a). The HWC emphasis on private space and continued participation in normal life activities was considered to be particularly important to maintaining 'dignity and the feeling of competence, a particularly difficult challenge for people with dementia' (Heywood et al 2002:28). In recent years HWC has become more prominent in policy and practice in many western countries and the development of housing model alternatives to nursing home care for people with dementia has increased significantly.

#### **Section 4 Rationale for the Study**

O'Shea observes that '...there can... be no one solution to the provision of care for people with dementia and their families' (2007:6) and yet, nursing home care continues to be the only practical long term care 'solution' for older People with Dementia in Ireland who cannot be cared for at home (Cahill et al 2012). There is evidence of dissatisfaction with existing residential care services for people with dementia in Ireland (O'Shea and O'Reilly 1999, O'Shea 2007, Cahill et al 2012) but the response has been to prioritise home care services in order to avoid nursing home care altogether or to fine-tune existing nursing home models in order to make them more acceptable. There is little evidence of any concerted effort to develop housing service alternatives to nursing home care for older people as there have been for other service user groups including children and adults with disability for whom group housing services have long been the norm. This research was aimed at exploring the factors that explain this situation which marks Ireland out as being different from other western countries and which leaves older people as the only group left in Ireland for whom nursing home care is the only long term care option. A key question is why have the HWC models that have developed in other countries to cater for the special needs of people with dementia been so slow to develop in Ireland?

There were a number of reasons for choosing this topic for my PhD. First the research was driven by the belief that even with a huge increase in the provision of home care services, not all older people with dementia will be able to be cared for at home. And for these people, the exploration of new service models like HWC is imperative because of the need to provide *choice* of long term

care alternatives where little or no choice now exists. The research was also driven by the belief based both on personal experience and a reading of the literature that HWC may be particularly beneficial to people with dementia, especially when compared to nursing home care. It was hoped that the findings from this study would help to progress not just the HWC agenda for people with dementia in Ireland but also inform the planning and implementation of other new service initiatives aimed at filling service gaps and improving service quality particularly in older people's services.

HWC development was of particular interest to me a retired older people's services manager in the health services with a social work background and a long time belief in the unfulfilled potential of sheltered housing in Ireland and an appreciation for social models of care for older people. The research was approached with an appreciation of how difficult it can be to introduce new services in large organisations. I was a veteran of a number of campaigns to introduce new service models in the health board/HSE including the introduction of the Home Care Grant scheme and the creation of Case Managers posts in the former East Coast Health Board. Home Care Grants were subsequently eliminated and most of the Case Manager posts have also disappeared. The HWC initiatives identified in this study represent the fruits of other such campaigns to introduce a new service model, and I was interested to understand the particular set of circumstances that created the environment for their development and the practical realities for the stakeholders from the housing and health sectors who were involved in service development and implementation. I wanted to track the way that these initiatives were developed and explore the dynamic interaction of factors that influenced development in a way that has not been done up to now.

Finally, the study is aimed at enhancing understanding of what these HWC initiatives represent in terms of the potential for further HWC development in Ireland. Are they likely to survive and will they be replicated? Do they represent a shift in thinking away from the 'one size fits all' approach to long term care in Ireland (National and Economic Social Forum [NESF] 2004:41) or are they, like Home Care Grants and Case Managers for older people's services destined to disappear from the landscape?

The key research questions for this study were:

- 1) What factors made the case study initiatives possible?
- 2) What factors created barriers to the implementation of the case study initiatives?
- 3) What is the climate for further HWC development for people with dementia in Ireland?

Chapter 2 provides context to the study by outlining HWC developments for people with dementia in Europe, the US, the UK and Ireland as highlighted in the literature.



## **Chapter 2: A Review of HWC development for people with dementia**

The purpose of this chapter is twofold. First, it provides a critical review of the literature related to Housing with Care for people with dementia in Western Europe, the United States, the UK and Ireland and highlights issues relevant to the research topic. The second purpose is to identify the theoretical perspective used in this thesis to interpret the research findings. Section 1 opens with a brief description of how the literature search was conducted. This is followed by a review of the literature on HWC for people with dementia from northern Europe in Section 2. Section 3 includes a discussion of HWC development in the US and Section 4 tracks service development in the UK. Section 5 focuses on the development of HWC in Ireland which provides the background to the findings chapters that follow. Section 6 discusses the selection of the theoretical framework used for this study.

### **Section 1 Literature search**

The literature for the following review was identified from a number of sources. National Council for Ageing and Older People (NCAOP formerly National Council of the Aged) reports on housing, sheltered housing, dementia and related were used as starting points for identifying the relevant Irish social policy literature on HWC for people with dementia. The websites for the Department of the Environment, Community and Local Government (DOECLG) and the Irish Council for Social Housing (ICSH) were used to identify relevant Irish housing statutes, regulations and policy documents; the ICSH website and publications were particularly useful to tracking policy and practice developments and to capturing the voluntary housing perspective on Housing with Care. By scanning the bibliographies of NCAOP and ICSH reports, other sources were identified. The Department of Health (DOH) website was used to source relevant national social policy documents on services for older people.

Web of Science, Scopus and PsycInfo search engines were used to source literature from books and journals using the key words: sheltered housing Ireland, assisted living, extra care housing, housing with care, supported housing, housing and dementia, dementia care and variations on those themes. The following websites were helpful to identifying relevant literature on HWC in the UK; Housing Learning Improvement Network (Department of Health); Care Services Improvement Partnership and the Joseph Rountree Foundation. Grey literature accessed mainly via the websites of housing associations in the UK that provide Extra Care for people with

dementia (including Hanover, Anchor and Housing 21) presented the industry perspective on HWC. Proquest Dissertations and Theses (PQDT) was used to identify PhD dissertations of relevance. Two recent literature reviews on HWC by Croucher et al (2006) and on extra care for people with dementia by Dutton (2009) were the sources of many other references used in this review. Kotter's model of successful change implementation was identified initially by using the Google search engine to source information about change theory. Subsequently the *Journal of Change Management* search engine was particularly useful to sourcing relevant literature using the key words: change management, change implementation, public sector innovation, champions, resistance to change, obstacles to change, and related. References cited in *Journal of Change Management* articles were used to source further journal articles in other journals including *Public Administration Review*, *Harvard Business Review*, *Social Science Medicine*, *Leadership Quarterly*, and others. A brief consultation with an expert in change management from the Business School in Trinity College Dublin was helpful to identifying relevant literature that might have been otherwise missed.

Since this thesis explores the origins and development of HWC services in Ireland, it is helpful to first examine how HWC services have evolved in other countries.

## **Section 2 HWC for people with dementia in Northern Europe**

Although it is difficult to generalise because of the different welfare systems and structures involved, the European literature suggests a trend towards the development of small group housing models of long term care for people with dementia. In many Northern European countries there has been a strategic reduction in the use of nursing homes and long stay hospitals in recent years (Eurolink Age 1997, Verbeek et al 2008). Verbeek et al observe that dementia policy in many European countries is now aimed at delaying admission into 'an institution' and that increasingly small group living units are being developed for this purpose (2008:253). In the Netherlands, it is estimated that almost 20% (14,000) of all of the people with dementia who were living in residential care lived in small group living facilities in 2000 (Verbeek et al 2008). In Denmark, where the level of care provision for older people is generally very high, a major policy objective has been to convert existing residential care stock into self-contained accommodation with access to care services (Eurolink Age 1997). Cluster housing for older people with extensive care needs developed in Sweden in the 1960's; specially adapted apartments were grouped together and residents have 24/7 access to staff and services (Tinker et al 2013:24). In France in the late 1960's, 'cantou' which offer small group communal services in a homelike setting for people with dementia were developed as an alternative to medical model long term care with a

view to reducing the cost of care but also of increasing service user autonomy and functioning (Ritchie and Colvey 1992). The Salmon Group is a network of Housing with Care projects across Europe which include services for people with dementia; these projects were established on the 'life model', very similar to the person-centred or social models of disability which prioritise individual autonomy and the encouragement of participation in normal life activities (Curie et al in Heumann et al 2001).

### *2.1 Germany*

In Germany, the trend towards small group living for people with dementia is demonstrated by the development of Shared Housing Arrangements (SHA) which have grown significantly in recent years. In urban areas, SHA are often situated in apartments accommodating an average of 7 residents in buildings that are no different from other apartment buildings in the area (Graske et al 2012:205). Accommodation includes a kitchen, living room and individual bedrooms and life is organised around ordinary household tasks in a homelike environment aimed at fostering resident autonomy and choice (Wolf-Ostermann et al 2012). Family involvement is encouraged and the expectation is that residents will not have to move out of SHA even as their dependency increases (Wolf-Osterman et al 2012, Graske et al 2012:204). SHA are provided by both private companies and not-for-profit organisations and individual care costs are covered by a combination of statutory long term care insurance (LTCI), private long term care insurance and co-payments from residents depending on their means (Götze and Rothgang 2012, Lambert 2013). Residents undergo a standardised assessment of needs, and health services including nursing are provided by community services (Graske et al 2012). Wolf-Ostermann et al suggest that SHA development is important in terms of both the number of new developments but also in terms of user preference. Berlin is at the centre of much of the recent SHA activity 'aided by the state government through legal and financial provisions' with the number of SHA growing from 230 in 2006 to 331 in 2009 (2012:3048).

### *2.2 The Netherlands*

In the Netherlands the development of small scale living facilities (SSL) was originally driven by individual pioneers who were inspired by group living arrangements that had been organised for people with disability (Willemse et al 2011). Over time, nursing home scandals and growing disquiet about the quality of care in large nursing homes in the Netherlands created pressure to develop new long term care models for people with dementia (de Lange 2011). In 2009, €80m was allocated for the development of Small Scale Living units (SSL) and assistive technology in the Netherlands. The range of available SSL facilities includes: private rooms with adjacent kitchenettes, bathrooms and shared living rooms for an average of 13 people; small scale units

with single rooms, shared bathrooms and communal facilities within a large nursing home; 'clustered houses' with single bedrooms and shared facilities for up to 7 people; and group homes for 6 people that are part of a larger organisation (de Lange 2011). SSL facilities can be located in urban settings or in some cases on farms. 'Green care farms' are a very recent development in dementia care in the Netherlands and although they currently mainly provide day care, they are expected to expand further to include residential care in the near future (Verbeek 2013). A target set by the Dutch government that 25% of people with dementia requiring long-term care would be living in small-scale, homelike facilities by 2010 has been met and now the aim is that in 5 more years, that figure will rise to 33% (Verbeek 2013).

SSL costs in the Netherlands are funded from a combination of mandatory health insurance and co-payments by residents depending on their means as is the case for the funding of costs in traditional care homes. All residents undergo a standardised assessment of need before they are admitted. While traditionally it was not-for-profit organisations that provided long term care in the Netherlands, participation of the private sector has increased significantly in recent years (de Lange 2011).

The design of a small scale homelike environment is the defining characteristic of SSL but so also is the person-centred ethos that prioritises resident autonomy. The aim is not only to create smaller nursing home settings but rather to also change the way that care is delivered (Verbeek 2013). As in SHA in Germany, SSL is organised around normal household tasks, meaningful activity and routines dictated by resident preferences rather than nursing tasks. Care staff function as part of the household and carry out 'integrated tasks' required to support the welfare and independence of individual residents, whatever that may involve (Verbeek 2013). SSL staff typically have a low level nursing qualification (which may be roughly equivalent to Fetac Level 5 in Ireland) but they are managed by fully qualified nurses who may work off site and manage a number of small group homes (Verbeek 2013).

Verbeek et al liken SSL models to the Greenhouse model which developed within the private nursing home sector in the US (2009). Issues that have emerged from the Dutch research on SSL include the changed role for nursing staff which requires a shift in attitude about how care is delivered (Van Zadelhoff et al 2011). Considerable work has been undertaken in the Netherlands to measure SSL outcomes for residents, staff and family members compared to outcomes in larger institutional settings (Verbeek 2013, Groenewoud, H and de Lange, J 2009, de Rooij 2011). The research findings so far have been equivocal and interestingly have not yet shown better outcomes for SSL residents, although the views of residents with dementia themselves were not

sought or included. The research does suggest that SSL is the preference of families and it also confirms high levels of satisfaction with SSL services among staff (Verbeek et al 2008).

### **Section 3 HWC development in the United States**

Assisted Living (AL) for older people who need support and supervision but not skilled nursing care developed in the US as a response to consumer demand in the first instance (Zimmerman et al 2003, Calkins 2007, Wilson 2007, Mollica 2009). Wilson refers to the stimulus to AL development provided by 'baby boomers' seeking something better than nursing care facilities for their parents and Hyde et al suggest that AL is a social model that is 'less a set of specific services, building types or licensure categories than an approach to offering consumer-directed long term care in a congregate setting' (2008:46). Essential components of AL models include: normal homelike environments, enhanced capacity to provide scheduled and unscheduled health and social care services even as dependency increases, and priority on resident choice and normal lifestyle (Wilson 2007:10).

Wilson (2007) identifies four AL models that have developed in the US and these include the hospitality, housing, health and hybrid models which are to some extent self-explanatory. Hospitality models involve new build accommodation and concierge type services but little or no direct provision of personal care and health related services. Health models which Calkins and Keane refer to as 'nursing home lite' (in Golant and Hyde 2008:91) evolved out of nursing home services in response to market demand for services for older people who need support but not nursing home care. AL services developed on this model are usually situated on the same campus with independent living units and a skilled nursing facility (nursing home). Wilson observes that health models occupy a place between independent living units and nursing homes and were never intended as an alternative to nursing home but rather as 'a stop along the way or a feeder to them' (2007:16). Housing models of AL developed through the use of existing housing stock, service providers include non-profit organisations and unlike the other models which were developed to cater mainly for people with higher incomes, housing model services are aimed at people with lower incomes. They provide few health services. Hybrid models of AL are described as providing the full range of health and social care services to residents living in apartments with easy access to public space and shared services to encourage interaction with the community (Wilson 2007:15).

There has been rapid growth in the AL sector in the US in the last twenty years, and the percentage of people with dementia in AL is estimated to be between 25% – 68% or higher (Kopetz et al 2000, Zimmerman et al 2005, Smith 2008). The literature on dementia care in AL settings is dominated by large-scale scientific studies aimed at measuring the characteristics of AL

residents, service quality and service outcomes and the factors that impact on both including staffing, medication management and access to nursing and medical treatment (See for example Zimmerman et al 2003 and 2005, Hyde et al 2007, Sloan et al 2001). Many are comparative studies which identify the likenesses and differences between AL and 'skilled nursing facilities' and the research findings are at best equivocal regarding the capacity of AL to substitute for nursing home care. Zimmerman et al found that the dependency level of AL residents was lower than that of nursing home residents and that those AL facilities that did support residents with highest dependency (including those with dementia) tended to be newer, provided 'less privacy and less resident control-all areas seemingly consistent with the realities of a more impaired population' (Zimmerman et al 2003:8).

Because AL developed mainly in the private sector, access to AL is in many cases restricted to older people with high incomes who can afford to pay for the cost of their own care (Howe et al 2013). However since 1981, the situation with respect to access to AL has gradually improved, largely due to changes to the way that long term care funding is allocated under Medicaid, the national health insurance scheme which covers certain categories of the US population with low incomes and assets, including people over 65 (Mollica 2009). Medicaid funding for long term care was previously restricted to covering costs in licensed 'skilled nursing facilities' but in recent years, Medicaid 'waivers' have allowed funding to be diverted to cover the cost of other services 'that are required to prevent, delay, or substitute for admission to an institution' and these include AL (Mollica 2009:3). The change in regulations was stimulated by the concern of state governments (who administer Medicaid funding) about the high costs of nursing home care and the desire to cut long term care budgets. Thirty-seven states were using Medicaid waivers to cover AL costs in 2009 and several other states were in the process of doing so (Mollica 2009). Medicaid waiver programmes have enabled eligible older people to use Medicaid funding to offset AL costs, although not all AL providers are registered for Medicaid recipients and not all accept them even within the same state. Medicaid waivers originated in Oregon and marked a breakthrough in terms of giving AL access to people on lower incomes but their limited application raises issues of affordability for those who continue to have no choice other than to use Medicaid funding to cover costs in nursing homes because they cannot afford to pay for their own care in private Assisted Living facilities (Wilson 2007, Calkins and Keane 2008, Hyde et al 2008).

AL is in general is less regulated than nursing care facilities in the US and some states have no AL regulations and no minimum requirement with respect to access to nursing services or to staff qualifications for example (Wallace 2003, Wilson 2007, Calkins and Keane 2008). This has raised concerns about the adequacy of health monitoring and the timeliness of health professional

interventions in AL and about the ability of 'non-professional' staff in AL settings to provide safe and adequate health care to residents with high acuity including those with cognitive impairment (Wilson 2007, Calkins and Keane 2008:88, Smith 2008). However, regulation itself is also a concern because of its restrictive influence on the admission and retention of people with cognitive impairment (Golant and Hyde 2008, Wilson 2007). Other concerns about regulation include its effect on increasing service costs, on reducing service flexibility and making AL more institutional (Golant and Hyde 2008:66). In spite of such fears and reservations, Smith believes that the regulations regarding what services may be provided in AL facilities and to whom are changing rapidly in response to increasing resident acuity and health related needs, and she expects that the proportion of people with cognitive impairment living in AL may increase over time (2008). She observes that in the US, AL is increasingly the preferred long term care alternative for people with dementia (2008:817) although Calkins points out that AL development has been paralleled recently by the development of social model 'special care units' in nursing homes '...prompted by increasing recognition that nursing home residents with Alzheimer's disease and other forms of dementia often didn't have significant medical needs that required a medical model of care' and in an attempt to increase market share (Calkins 2007:263). A pioneer movement aimed at affecting 'deep system change' to the existing culture in nursing homes was spearheaded by nursing home innovators in the 1990's; the aim was to deliver required care in facilities that are small and homely. The Eden Alternative was one of the first models developed specifically to promote this new culture and later models include the Green House model, the Households and Neighbourhoods model and the Small House movement; all feature specially designed (if not purpose built) domestic settings that promote privacy, independence and participation in normal life activities (McLean 2011:27).

#### **Section 4 HWC development in the UK**

Because of the geographic proximity of the UK, a shared history and the similarity of some government structures and systems, HWC development in the UK deserves a more detailed discussion than service development in other countries. The extensive available literature from England is particularly useful to providing background to the discussion in the next section about Irish HWC development.

HWC is very much a housing phenomenon in the UK; it evolved incrementally from within the housing sector and it took place in stages over many years. The early origins of HWC development in the UK date back to 1909 when the Royal Commission in England singled out older people as being in need of specialised housing, but it was during the post-World War II period that sheltered housing for older people began to take on shape and direction. The Addison Act of 1919

established public subsidies for local authority housing in Britain and Ireland setting a pattern of '...direct provision of social housing being seen as part of the welfare state service rather than the province of private and voluntary action' (Mullins et al 2003:36). This led to the marginalisation of the non-profit housing movement '...that is in sharp contrast with the position in some other European countries where the non-profit sector occupies a major position in regard to the provision of social housing' (Mullins et al 2003:36).

A Government *Housing Manual* produced in England in 1949 gave remarkably detailed guidelines to local authorities for the development of housing for old people which included building specifications as well as the suggestion that such dwellings should be situated in *sheltered* sites, hence the derivation of the name 'sheltered housing' in use since that time (Silke 1994, Meghen 1963, Tinker et al 2007). Some of the recommendations in the Manual would be considered enlightened even by today's standards.

Special attention... should be paid to such points as the avoidance of draughts, the sheltering of front and back doors, good thermal insulation, easy access to the fuel store...a clear space on either side of the beds, and a handrail to the bath. Steps should be avoided wherever possible... A heated towel-rail in the bathroom [for warmth]... The living room should have a sunny aspect and, where possible a bay window or verandah should be provided (Meghen 1963:75).

A follow-up report, 'Housing of Special Groups' in England in 1951 proposed that, as well as ensuring that the physical facilities be built to a high standard as specified in the *Manual*, sheltered housing should also enable tenants to take part in community life and contribute to a '...full and happy life in healthy and congenial surroundings...' (in Meghen 1963:75). Tinker et al note the cosy connotation of the word 'sheltered'; the '...image of older relatives who are protected, cosy and, above all, safe from harm' (2007: 34). Concern for older people's welfare was an intrinsic part of the sheltered housing agenda from the beginning.

By the late 1970's it became obvious that ordinary sheltered housing was not appropriate to meeting the needs of many ageing tenants, including those whose dependency needs could not be met within existing sheltered housing services (Oldman 1990:42, McCafferty 1994). Some sheltered housing providers were already responding to the needs of this vulnerable group of tenants. But the nature and scope of these early service developments were undocumented until the late 1980's when Tinker was commissioned by the Departments of Environment and Health and Social Services to undertake an evaluation of 'Very Sheltered Housing' schemes which were then broadly defined as having '... greater facilities and care than [that] provided in ...conventional sheltered housing' (1989:9).



Tinker summarised the factors that influenced the development of VSH in England which had been undertaken largely by church organisations up to that time (Tinker 1989:14). The main drivers of VSH service development were predictions of a dramatic increase in the number of very elderly in the population coupled with concerns about the high cost and inappropriateness of institutional care which was still growing, in spite of its negative image as an outdated model of long term care. Concerns about low demand for 'hard to let' sheltered housing schemes, the under-occupation of local authority housing, delays in the discharge of older people from hospital and evidence that sheltered housing schemes were struggling to meet the needs of increasingly frail tenants were other factors that created an environment favourable to the development of Very Sheltered Housing services at this time (Tinker 1989:9). In addition there was a fall in demand for ordinary sheltered housing; sheltered housing providers were left with vacant units that were hard to let because of their location or because they were not appropriate to the needs of an ageing population (Tinker 1989:9, McCafferty 1994). Oldman observes that there was also concern about the negative effects of people having to move in order to access needed services (1990). While the concept of a 'continuum of care' had been popular up to this time, the belief that people should not have to physically move in order to access services was gaining momentum in tandem with the development of domiciliary and home care services (Heywood et al 2002:1).

VSH development was undertaken by local authorities as well as by voluntary housing associations and it was made possible through funding from a variety of sources. Capital funding for local authority service developments came from housing departments and/or social services departments, while voluntary sector housing associations relied much less on statutory bodies and much more on charitable trusts. Revenue funding similarly varied; voluntary bodies had to rely much more on rental income and fundraising than local authorities did (Tinker 1989:22). Tinker concluded in her evaluation that VSH was an acceptable and viable alternative to residential care for some older people but also cautioned that the costs of VSH were relatively high (1989).

By the early 1990's, VSH was the fastest growing form of special needs housing in England (McCafferty 1994) and service provision expanded to include a 24 hour warden service, a meals service and assistance with domiciliary and care tasks, thus extending the capacity of ordinary sheltered housing to support tenants. A national survey on sheltered housing undertaken by McCafferty in 1994 showed general satisfaction with sheltered housing and continued high demand for it but also revealed that many sheltered housing tenants could be maintained at home with home adaptations, health and social supports. However, the survey report also signalled the next stage in HWC development in the UK by presenting evidence that there was a

shortfall of sheltered housing schemes for a small but significant minority of older people who had what McCafferty called 'extra care' requirements because of their high dependency or disability (1994).

The Royal Commission on Long Term Care produced a Report, *With Respect to Old Age* in 1999 that was critical to airing issues of ageing and older people in the UK (Heywood et al 2002:15) and among these issues was the role of housing in meeting older people's long term care needs. Tinker's influential Appendix to the Royal Commission report on housing alternatives to residential care cited the findings of McCafferty's survey and supported his contention that there was a need for the development of sheltered housing schemes aimed specifically at people with high dependency needs; people with dementia were not specifically mentioned as a target group. Her recommendation for further service development was made in the context of an overall argument for the recognition of the preventive value of housing and its importance to the health and welfare of older people which had received little official recognition up to that time. Tinker saw benefits for older people but also for the state because service costs of VSH would be lower than the cost of residential care (Tinker 1999).

Tinker endorsed the continued development of VSH schemes but recommended that more work was required to clarify its role (1999:286) a theme that runs through the HWC literature. She had found evidence that services were not being targeted appropriately and also that some people in VSH were not receiving adequate care and recommended that further research be carried out to accurately cost and evaluate service effectiveness (Tinker 1999). The development of VSH continued but so did the concerns of policy makers and service providers that there was still a group of older people who fell between the two stools of VSH and residential care. The drivers for development of what came to be known as 'Extra Care', were the same as for VSH; the high costs of institutional care and the 'profoundly negative image of care homes in the UK' (Wright et al 2009).

Extra Care (EC) increasingly came to represent a specialist form of sheltered housing provision that went a step further than VSH as defined by Tinker in 1989, although the boundaries between the two remain ill-defined and somewhat confusing (Croucher et al 2006, Howe et al 2013). Although there is no consensus about exact definitions, there is general agreement that Extra Care should include the following; self-contained accommodation, provision of individualised care, provision of meals prepared on the premises, the availability of care and support staff 24/7 and communal facilities (Croucher et al 2006:11). The incorporation of special design features into the planning of Extra Care units and the use of assistive technology is also thought to be desirable (Care Services Improvement Partnership [CSIP] 2008a, Dutton 2009, Allardice 2005).

Tinker et al believe that the development of Extra Care marks a significant departure from sheltered housing and VSH development in that

[With Extra Care] The emphasis then, is less on 'bricks and mortar' and much more on lifestyle, individual need and independence. This then is above all the shift in conceptualisation that has occurred which frames the provision of extra care housing in the 21<sup>st</sup> century (2007:36).

Whereas historically the focus was on the provision of adequate housing, with care provision a secondary objective, now sheltered housing was seen as an appropriate setting *within which* to deliver care and support to vulnerable older people, and discussion and debate now focused on how best to do this. Both local authorities and voluntary not-for-profit housing organisations became involved in EC development as well as private sector for-profit housing and health providers.

The case for the development of Extra Care housing was strengthened by the introduction of new national policies and strategic frameworks which were underpinned by legislation from 1990. Fisk observes that HWC service development took place in the context of a general policy shift away from residential care to care in the community officially set out in the 1990 NHS and Community Care Act (1999:39) and Heywood et al suggest that the Government's belief in the potential of sheltered housing to provide a homely and cheap alternative to residential care explains how housing became more central to community care in the UK (2002). As suggested earlier, housing associations, in turn, capitalised on the perception that EC would reduce the number of people going into residential care and thus reduce government spending on long term care (Heywood et al 2002:66).

The Supporting People programme, introduced in the 1990's, was critical to EC development because it provided a revenue funding source with which to cover the costs of care of individual tenants with high dependency needs. Supporting People was established to help progress the community care agenda and its implementation involved changing the way that funding was allocated to housing associations in England (Office of the Deputy Prime Minister 2004). Instead of lump sum payments to housing associations for the general provision of services, payment was now made with respect to individual tenants following a formal assessment of their needs (Heywood et al 2002). This meant that, in theory at least, funding allocation became more responsive to the specific needs of tenants, and housing associations with high dependency tenants became better resourced to meet these needs although the plethora of personal allowances and benefits proved complex (Cox 1999, Heywood et al 2002). Supporting People payments are statutory payments with clear eligibility requirements and a formal assessment of need involved, and tenants of HWC schemes are considered eligible in the way that any other

older person living in the community is deemed eligible (Office of the Deputy Prime Minister 2004).

In 2003 the Extra Care Housing Fund gave another boost to EC development. The Fund was created to support and encourage the development of innovative schemes involving 'partnerships between the NHS, local housing authorities, social services authorities, care providers, housing associations and private sector and other developers of extra care housing in the interests of older people' (Darton and Bäumker 2008). A total of £227 million in capital funding was allocated for this purpose between 2004 and 2010 (Bäumker et al 2011). Significant in the context of this study is the fact that Extra Care housing was now being targeted at the group of older people with high dependency needs who were previously considered to be outside the scope of supported housing services, including people with dementia (Wright et al 2009). In a speech in 2005, the then Under Secretary of State for Community, observed that

Of course, Extra Care is not just for people who may need a little extra help. People with dementia, older people with learning disabilities and those needing intermediate care are also being included in mainstream planning and provision of extra care (Ladyman 2005:2).

Tinker et al note the political zeal with which EC housing was being embraced and the almost visionary rhetoric surrounding its promotion by politicians, housing providers and health and social care professionals who made extravagant claims about its potential to provide an alternative to residential care (2007:38).

EC development was supported by a number of national strategies. The publication of a strategic framework for older people's housing and the subsequent establishment of the Housing and Older People Development Group in 2001 (Heywood et al 2002) led eventually to the development of the *National Strategy on Housing* published in December 2008 which put EC firmly on the national agenda. The Strategy includes a commitment to increase funding for specialised housing with an emphasis on 'inspirational and innovative design' and partnership between the statutory, voluntary and private sectors. There is cross referencing to Extra Care in both housing and health policies for older people (Department of Communities and Local Government 2008:17, DOH: April 2008). Significantly, the Department of Health was given responsibility for overseeing EC development; the Housing Learning and Improvement Network (Housing LIN) set up within DOH to promote 'housing based models of care and support for adults' (Housing LIN 2005) was delegated to manage the EC Housing capital programme (DOH 2013). The *National Dementia Strategy* published in 2008 includes reference to the development of housing models for people with dementia and also of housing staff skills to support development of specialised housing (2008:55). A subsequent Housing LIN Policy Briefing on

delivering the National Dementia Strategy (Garwood 2008b) makes particular reference to the role of the housing sector in the implementation of the Strategy.

Dutton estimated that in 2009 there were 37,600 people in EC housing in England compared to 272,000 people in 'personal care places' (in residential care) and 177,000 in nursing home (Dutton 2009). Of those in Extra Care housing, approximately 25% of tenants had dementia. A large scale evaluation of Extra Care housing was undertaken by the Personal Social Services Research Unit at the University of Kent and the authors concluded that 'Although EC housing does not appear to provide a direct alternative to care home provision, it can support a proportion of older people who would otherwise be at risk of moving into a care home' with better outcomes and at the same or lower cost (Netten et al 2011). But the low level of EC provision is considered to be a problem and several related factors have been identified in the literature.

#### *4.1 Factors that have impacted on HWC development in the UK*

Revenue funding complexities are believed to have negatively impacted on EC development in the UK (Cox 1999, Fisk 1999, Henwood 2002, Vallely et al 2006, Darton et al 2011). Particular problems associated with the development of EC for people with dementia include: mixed and uncertain funding, the need to balance the requirements of a range of funding sources with the needs of individual tenants, and the difficulties associated with having to meet the requirements of inflexible funding structures while attempting to provide flexible, responsive services to individual tenants (Cox 1999). The continuing challenge for EC providers is how to recover the costs of care and support services (Housing LIN 2013). Affordability of EC for people with modest incomes and assets is another concern particularly in what's called the 'social sector' because of new restrictions on eligibility for state housing and care benefits (Housing LIN 2013:119). Capital funding is also a challenge because of recent reductions in Government subsidies and the need to develop new models which require little or no subsidy and 'draw from a more diverse range of funding arrangements' that involve private sector developers and investors (Housing LIN 2013:60). Tinker et al observe the progressive shift in long term care not only in the UK but in Europe generally from public provision to mixed models of care and with it a reduction in the State's contribution towards care costs (2013:9). With this shift has come the expectation that individuals should pay a proportion of the costs of their own care; in the UK, contributions are determined through needs assessment and means testing (2013:9-10).

The costs involved in delivering EC services to people with high dependency needs present another challenge for EC providers and funders. The achievement of Extra Care aims and objectives depends on the availability of resources with which to provide the staff time and additional community services required to address the unpredictable and changing needs of older

residents and this is a particular issue with respect to people with dementia (Henwood 2002, Poole 2006b, Garwood 2006). Service costs are determined by the number of care hours offered and this is a limiting factor in EC development as funders' may not be willing to increase resources above a certain threshold' (Henwood 2009:30) in spite of evidence suggesting that the higher costs associated with EC are associated with better social care outcomes and quality of life for residents (Netten et al 2011). Vallely et al observe that identified care costs and long term care funding complexities particularly impede the ability of EC schemes to support some people with dementia whose care is being funded from a number of sources as their dependency increases (2006).

Another barrier to EC development concerns the difficulties associated with establishing the framework necessary for the development and delivery of EC services (Dutton 2009). At local level, the division between housing and health departments, with their different traditions, separate priorities and interpretations of statutory duties and responsibilities is seen to make it particularly difficult to achieve the interagency collaboration necessary to develop and deliver EC services (Watson and Britain 1996, Tinker 1999, Cox 1999, Oldman 2000, Garwood 2004, Dutton 2009). Regulation is a concern for EC providers, specifically the issue of whether EC facilities must register as care homes under recently introduced social care regulations (DOH 2008b, DOH 2009) and the perceived negative implications of that for both tenants and EC providers in terms of restricted admission and discharge criteria and higher costs. The ability to demonstrate that EC is the home of residents is one of the main things that distinguishes EC from residential care and a critical issue for providers of EC for people with dementia is the validity of tenancy agreements signed by tenants who are cognitively impaired (Housing LIN 2010).

EC providers' ability to deliver on promises of independent living to residents with cognitive impairment is discussed in the UK literature (Fisk 1999 Greenwood and Smith 1999, Oldman 2000) and questions are raised about the limits of EC capacity, the boundary between EC and residential care and the factors that undermine EC 'home for life' aspirations (Cox 1999, Greenwood and Smith 1999, Fisk 1999, Heywood and Means 2002, Housing LIN 2004, Dutton 2009). The literature suggests that EC policies and objectives need clarification with respect to the admission and discharge of residents and that EC providers' ability to support older people with increasing dependency up to the end of their lives is contingent upon a number of factors including: staffing levels and staff training, access to specialist services, building design and use of assistive technology, and staff and resident attitudes (Greenwood and Smith 1999, Oldman 2000, Heywood and Means 2002, Housing LIN 2004, Housing Corporation 2007). There is consensus in the UK literature that while EC can provide support and quality of life to people with dementia, it

cannot provide a 'home for life' for everybody and that some residents will have to move to a care home as their dependency increases (Housing LIN 2005, Poole 2006a:12, Housing Corporation 2007, Dutton 2009).

There is agreement that Extra Care cannot directly *replace* all residential care (Housing LIN 2004, Poole 2006a, Croucher et al 2006, Dutton 2009, Darton and Callaghan 2009:291) but a recent evaluation of Extra Care services by the PSSRU at the University of Kent concludes that EC housing may be acting as a replacement for some care homes, specifically those providing personal care as opposed to nursing care (Netten et al 2011).

## **Section 5 Summary of Sections 2-4**

Housing with Care services for people with dementia were developed in Northern Europe, the US and the UK with the common aim of providing an alternative to institutional long term care models believed to undermine individual dignity, privacy and independence. Service development in these countries represents a growing recognition of the inappropriateness of traditional nursing home care for people with dementia whose main need is for support and supervision and not continuous nursing or medical care, and the literature supports the view that HWC can be beneficial for people with dementia. The development of small scale group housing has been more a feature of Northern European service development than in the US or the UK where services range from individual apartments in large complexes to large congregate living units with communal facilities. Unified systems to assess need, determine entitlement and allocate funding for long term care are a feature of all of the countries highlighted, although HWC in the US continues to be privately funded in many cases. The development of HWC for people with dementia has been further supported by national policy, housing and health care strategies and service development frameworks in the UK.

The European and UK literature suggests that integrated models of HWC for people with dementia can be created if there is the political will to change the funding systems necessary to support them and it reveals a number of service models that could act as a template for further development in this country. Research on HWC outcomes for people with dementia identifies improvements in quality of life and shorter hospital stays but it also suggests that at least some people with dementia will have to move on to another care setting as their dependency increases.

The Dutch literature identifies the challenges that the SSL model pose to nursing staff but also suggests high satisfaction on the part of families and staff. The US and UK literature identify funding complexities, service costs, and regulation as factors that can undermine HWC development for people with dementia; affordability is an issue for HWC applicants in the US and the UK. Tinker et al identify the general shift in Europe in the past 20 years away from publicly

financed long term care provision because of concerns about public budget spending (2013:9). All of the issues highlighted in Sections 1-3 are of relevance to this study on HWC development in Ireland. This review of the international literature on HWC development in Northern Europe, the US and the UK helps to put the development of HWC in Ireland into perspective. The next section presents a critical review of the literature related to the history of HWC development for people with dementia in Ireland which provides the background to this study.

## **Section 6 HWC development in Ireland**

Sheltered housing for older people provided the foundation for the development of HWC in Ireland as it had in the UK. Antecedents of sheltered housing in both the UK and Ireland date from much earlier. Almshouses and other small housing services were set up by voluntary organisations including the religious in the 19<sup>th</sup> century aimed at improving the housing situation of the urban poor and larger charitable housing societies were established by wealthy industrialists (including Sir Arthur Guinness) for the same purpose. Among the groups catered for were older people (Geoghegan 1983, Silke 1994, Williamson 2000). Tenant campaigns in rural areas of Ireland focused concern on the poor living conditions of rural people in the late 1800's and what Brooke refers to as 'semi philanthropists' provided rental housing for poor people in urban areas from the 1870's before the local authorities started providing social housing (Brooke 2001:5). O'Sullivan observes that the provision of large scale urban social rented housing took longer to develop (2004:330).

The Irish Housing Amendment Act 1948 introduced the notion of local authority housing for specified categories of people but in the first instance only urban housing authorities were given the power to provide 'reserved houses' and then only for newlyweds (Meghan 1963). In 1953 these powers were extended to rural housing authorities and also expanded to include the provision of housing for older people (Inter-departmental Committee 1968:36, Meghan 1963:78) although Norris and Winston report that the first local authority sheltered housing scheme was not actually developed until 1973 by Limerick City Council (2008).

O'Sullivan observes the very marginal role played by the non-profit housing agencies up to the 1990's in the Irish social housing sector that was predominantly state driven (2004:329).

According to the Norris and Winston the first voluntary (non-profit) sheltered housing scheme in Ireland was developed by the Dublin Central Mission in 1965 (2008:61). Section 65 of the Health Act 1953 was pivotal to early voluntary sector developments as it included provision for the first public subsidy that housing associations could apply for to assist with the running costs of 'similar or ancillary' services to those provided by the health authorities. The type of assistance that could be requested went beyond finance to cover running costs and also included the provision of food,



fuel and water and Mullins et al report that although take up was low, Section 65 grants were almost exclusively used by voluntary housing associations to develop sheltered housing schemes for older people (2003:37). Section 65 funding was discretionary and ‘...characterised by its uncertainty, ad hoc nature and late payments’ (ICSH 2005:38). Many of the housing organisations in receipt of Section 65 funding evolved out of local community organisations catering for the needs of vulnerable older people and developments were financed largely through donations and fund raising events (ICSH 2005:15).

The Housing Act 1966 formally acknowledged the potential role and contribution of sheltered housing by establishing a register of ‘approved housing bodies’ and it supported further service development by providing the legislative framework to enable local authorities to facilitate housing bodies by means of loans and grants, though not systematically until the 1980’s (Mullins et al 2003:37). This meant that in addition to the funding and services now available from the health boards under Section 65, it was now also possible for voluntary housing bodies to access capital funding from the local authorities. Voluntary housing associations were now to be encouraged and facilitated by the local authorities to be involved in the development of sheltered housing, although the expectation was that revenue funding would continue to be provided by private sponsorship (Inter-departmental Committee 1968:56).

The first suggestion that sheltered housing might fill more than a housing function came with *The Care of the Aged Report* in 1968 which defines sheltered housing as something ‘...for people in need of a little supervision and help...who may have difficulty with ordinary homes’ (Inter-departmental Committee 1968:55). The *Report* recommended that housing authorities provide accommodation in self-contained units complemented by some communal facilities and that voluntary organisations provide the services required to support tenants (1968); sheltered housing was seen as a way to promote independence and prevent admission to residential care, policy themes that have continued to feature in Irish social policy up to today (Acheson and Harvey 2008:45). However, in Ireland, residential care is defined almost exclusively as nursing home care while in the UK residential care includes both social model care homes *and* nursing homes. This is an important distinction especially in the context of discussion about the ability of HWC to replace residential care.

At the time that the *Care of the Aged Report* was published, the local authorities still had responsibility for older people’s services; this changed with the creation of the health boards in 1970 and this had the effect of separating housing services from older people’s services which were now the primary responsibility of the health boards (Acheson and Harvey 2008:46). A significant expansion of the voluntary sheltered housing sector in Ireland took place in the 1980’s

although still on a much smaller scale than in the UK. According to O'Sullivan, between 1971 and 2003, the number of local authority rental housing units that were provided was over 150,000 compared to only 14,000 units provided by non-profit housing associations (2004:332).

The expansion of sheltered housing was influenced by the setting up of the Task Force on Housing Conditions for the Elderly in 1982 which raised awareness of the poor housing conditions of many Irish older people and led to the setting up of grant schemes for home repairs and adaptations (Silke 1994:21, National Council for the Elderly [NCE] 1985). But it was the introduction of the 1984 Capital Assistance Scheme (CAS) which really stimulated voluntary sheltered housing activity in Ireland as it represented the first scheme to provide core capital funding to the voluntary housing sector for social housing development (Brooke 2001). The establishment of the CAS led to a big increase in the number of voluntary social housing units designated mainly for 'special needs' categories including older people (ICSH 2005:17) and the critical importance of the CAS scheme to the development of HWC is highlighted in the findings chapters.

Although little is known about the exact nature or number of sheltered housing developments for older people during this period, there are suggestions in the 1985 National Council for the Elderly (NCE) report, *Housing of the Elderly in Ireland* that at least some voluntary sheltered housing associations were already attempting to meet the social care needs as well as the accommodation needs of tenants and that the cost of doing so was putting financial pressure on them (NCE 1985). In 1988 an estimated 2,857 voluntary housing units were approved for CAS funding, a considerable increase since 1985 (Ruddle et al 1997:126). In the same year, twenty years after the publication of the *Care of the Aged Report* a second national policy document on services for older people was published. *The Years Ahead..a policy for the elderly* (1988) reiterates the *Care of the Aged* recommendation that sheltered housing be considered first choice in cases where it isn't possible to maintain older people in ordinary housing and further suggests that older people should have the choice between making adaptations to their home or moving into some place more suitable to their needs (Working Party 1988:74). *The Years Ahead* makes the direct correlation between the provision of support services to older people in sheltered housing and their continued independence (Working Party 1988:74).

Beaufort in Dun Laoghaire is cited in *The Years Ahead* as a good model of supported sheltered housing that was developed by a local authority in partnership with the health board and a voluntary organisation (the Lions Club) to provide a higher level of support to elderly tenants than was usually provided in Ireland at that time. Services were largely funded by the health board but also by modest service charges and voluntary contributions. A 24/7 warden service was provided by an order of nuns, daily meals were prepared on the premises, some para-medical services

were provided by the health board and community GP and Public Health Nursing services were available as needed (Working Party 1988:69). The point is made that if these services had not been available to tenants, they would have required institutional care.

The *Years Ahead* recommends that: the role of voluntary housing organisations should be expanded; service planning should be done in consultation with the health boards; the CAS scheme should increase the upper limit on capital funding; and financial assistance should be given to voluntary housing organisations to help cover management costs (Working Party 1988:78). The *Report* includes a section on dementia and notes the unsuitability of existing institutional care services in nursing homes as well as psychiatric and geriatric hospitals for many people with dementia, and this is of particular interest in the context of this research. Reference is made to facilities for 'elderly mentally infirm' in South Belfast as models of good dementia care practice that emphasise personalised care, good design, and key working. The Belfast model is very close to the HWC model that is the topic of discussion for this study although it is not identified as housing developments in the report.

The same year that *The Years Ahead* report was published, the Housing Act 1988 was introduced, updating the legislative framework for local authority housing programmes. The Act recognised specific categories of housing need; the homeless, the elderly and the disabled were all designated as 'special needs' categories, and the Act aimed to ensure that these groups be '... provided for in the planning, provision and allocation of local authority housing' (O'Connor et al 1989:29). As such, it formalised what was already happening.

Perhaps in response to Government recognition of the special housing needs of older people, the National Council for the Elderly (NCE) published *Sheltered Housing in Ireland* in 1989, the first Irish social policy document to focus exclusively on sheltered housing for older people. The Council observed that not all older people who cannot remain living in their own homes for social or medical reasons require institutional care, and they argued that sheltered housing could provide a 'home for life' that would function as an alternative to hospital or nursing home care for up to 75% of tenants, provided that adequate services (especially community nursing services) were made available to tenants (O'Connor et al 1989:9-10). Among the recommendations made were those for: an increase in sheltered housing capital funding to include funding for the building of communal facilities, the development of sheltered housing standards by the Departments of Environment and Health, and the development of guidelines, again by the Departments of Environment and Health, to coordinate the development of adequate and appropriate sheltered housing services in each area (O'Connor et al 1989:15-17). The Council saw the specific need to spell out the respective responsibilities between the 'cooperating voluntary and statutory bodies'

for sheltered housing development and delivery, and special reference is made to the need to apportion service costs 'between different Departments, health boards, local authorities and voluntary agencies' (O'Connor et al 1989:16-17). The authors of the report observed that the development of 'service rich' sheltered housing with on-site services was the most appropriate response to an ageing population and one that offers '...options from which to make the choice that best suits [individual] particular needs' (O'Connor et al 1989:60). They use much of the same language being used by Tinker who was arguing for the further development of Very Sheltered Housing in the UK at the time.

Acheson and Harvey suggest that the *The Plan for Social Housing 1991* 'effectively signalled that specialist housing need would become essentially a voluntary sector responsibility' (2008:56). *The Plan* acknowledged the contribution of voluntary housing associations, raised the funding limits for the Capital Subsidy Scheme from 80% to 90% of capital costs (the NCE had recommended 95%) and introduced the Loan Subsidy Scheme to further support the development of general needs low income housing. It also provided for the allocation of funding for the building of communal facilities in sheltered housing schemes as recommended by the NCE and specified that they were to be used for dining and kitchen areas, communal sitting rooms, activities rooms, laundries and therapy and treatment rooms (DOE:1991). This was a breakthrough of sorts because in spite of the expectation that sheltered housing tenants would be capable of independent living, there was now acknowledgment that some tenants needed more than basic accommodation and recognition of the role that sheltered housing had in addressing those needs. The 1995 Department of Environment report, *Social Housing: the Way Ahead* notes that there had been an increase in funding from £.5m in 1991 to £.75m in 1994 and that forty five 'communal facilities' projects had been funded, mostly for older people. There was also an increase in the management allowance for voluntary housing associations, another NCE recommendation. Guidelines were promised to assist local authorities in supervising the management of voluntary/non-profit housing bodies (DOE<sup>2</sup> 1995).

In 1996, the National Council for Ageing and Older People (NCAOP formerly the NCE) published a report on *Mental Disorders in Irish Older People* and the authors observe that the recommendations made in *The Years Ahead* had not been acted upon and that, as a result, many older people with mental disorders, including people with dementia, continued to be cared for in hospitals and other inappropriate residential care settings (NCAOP 1999:251). A further NCAOP report in 1997 on implementation of *The Years Ahead* recommendations reiterates the lack of

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<sup>2</sup> The Department of the Environment changed its name to the Department of the Environment, Heritage and Local Government and then to the Department of the Environment, Community and Local Government. For purposes of simplicity, DOE is used henceforth for all iterations.

progress achieved with respect to the development of 'hostels' for people with dementia as well as supported sheltered housing schemes for other vulnerable older people. The authors note an increase in sheltered housing capacity since 1988 but highlight problems with respect to: sheltered housing residents' restricted access to health board community services, the lack of a defined health board funding scheme to cover the running costs of care services provided by voluntary housing associations to tenants, and the lack of formal contact between housing associations and health board Coordinators of Services for the Elderly (Ruddle et al 1997:135-138.). The lack of legislation to underpin the development and delivery of older people's community services was considered to be a major obstacle to the implementation of recommendations (1997:319). Proceedings of a subsequent NCAOP conference concluded that there was a lack of real choice of long term care alternatives for older people in Ireland and that this undermines older people's ability to receive care that is most appropriate to their needs (O'Morain 1998)

Following a submission by the Irish Council for Social Housing (ICSH) in 1999 to the Minister for Housing and Urban Renewal, a dedicated unit for voluntary and co-operative housing was established in the Department of the Environment and a commitment given to establish a working group to facilitate the further development of the sector. Mullins et al interpret this as new recognition in Ireland of the important contribution of the voluntary and co-operative housing movement (2003:46). *The (2002) Memorandum on Capital Funding Schemes for the Provision of Rental Accommodation by Approved Housing Bodies* delivers on the promise made in 1995 to provide guidelines regarding the establishment, operation and funding of voluntary housing associations with a view to increasing the output of the voluntary sector and linking it more directly to local authority housing strategies (DOE 2002) <sup>3</sup>.

In *The Memorandum*, eligibility for communal facilities grants under the Capital Assistance Scheme is further defined and there is focus on creating better coordination between the local authorities and voluntary housing associations (and the health boards where appropriate) to ensure 'the optimum utilisation of... communal facilities and avoid duplication of services' (Section 6.7). The *Memorandum* spells out health board responsibility for providing services and revenue funding towards the running costs of sheltered housing schemes proposing to offer 'supportive accommodation with various levels of on-site and/or visiting support services' (2002:17). It directs voluntary housing associations to consult with the local health board 'at an

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<sup>3</sup> The Memorandum also provides details of the Capital Loan and Subsidy Scheme which was introduced in 1991 to give housing authorities the power to subsidise the loan repayments of approved housing bodies who have taken out mortgages in order to provide rental accommodation for low income households. The CLSS scheme did not figure in discussions with study participants about HWC.

early stage' and to make suitable arrangements with the health board before supported housing projects commence (2002:17, Mullins et al 2003:51). This instruction sends out a message about the distinct division of roles between housing and health that figures later is the discussion about the barriers to HWC development in Ireland.

Under new CAS regulations spelled out in the *Memorandum* (DOE 2002), capital grants increased to 95% of costs up to €5,800 per voluntary housing unit. They also stipulated that local authorities had the right to fill up to 75% of the housing units in voluntary sheltered housing schemes that had been built with CAS funding. There is reference to design guidelines which specify that dormitory style accommodation is not acceptable under CAS but that some forms of 'non-self contained accommodation' is acceptable. Of particular interest to this study is Section 4.9 of the *Memorandum* which stipulates that 'The Capital Assistance Scheme is not intended for the provision of nursing home or similar accommodation where residents would require extensive medical, nursing or institutional type care'. An exception is made for a small number of 'housing projects for persons with mental disabilities or handicaps [who] require a higher ratio of carers to residents' (2002:35-36). Although the *Memorandum* is not a statutory instrument and provides guidelines only, it does define a boundary beyond which housing authorities are advised not to venture and it reminds local authority housing officers that their primary responsibility is to provide housing and not care.

*The Study to Examine the Future Financing of Long-Term Care in Ireland*, also called the Mercer Report, was commissioned by the government of the day and published in 2002 (Mercer Ltd 2002). The Mercer Report acknowledged the potential of what the authors call 'assisted living facilities' to help to contain the rising costs of long term care for an ageing Irish population.

Sheltered housing – or 'assisted living facilities' – has the potential to bridge the gap between living independently at home and residential care. This is an area that requires further development in Ireland as does community care. (2002:4)

The authors suggest that a public initiative be undertaken to increase the provision of assisted living facilities using a public/private partnership approach involving a combination of private property developers, tax credits and either direct service provision or finance from the Department of Health and Children (DOHC) and the Department of Social and Family Affairs for required health and social services for tenants (Mercer Ltd 2002:12). This literature review has not identified any other references to the Department of Social and Family Affairs in the context of discussions about sheltered housing in the Irish literature.

In 2002 the Residential Relief Scheme was introduced to give 'tax relief for investment in the construction or refurbishment of residential units attached to private nursing homes' (Indecon 2007:i). The original conditions of the scheme included the requirement that: residents be certified by a medical doctor as requiring accommodation by virtue of 'old age or infirmity'; nursing home owners be registered and provide 'back up medical facilities (including nursing)... when required; a day care centre is provided on site; not less than 20% units be made available to the relevant health board, and rates charged to the health board be discounted at least 10% (Indecon 2007:9). Eligibility for tax relief was to be contingent on obtaining approval from the Health Service Executive, the Health Information and Quality Authority (HIQA) or the Social Service Inspectorate to ensure that they were fit for purpose. An evaluation commissioned by the Department of Finance in 2007 deemed the scheme effective in increasing supply of residential unit space over a short time and recommended its continuance (Indecon 2007).

In 2005 a small budget was established by the Government for the development and delivery of support services to residents in sheltered housing schemes. The budget was to be distributed by the health boards to voluntary housing associations in their area (ICSH 2005:58). This funding was allocated in the absence of any specific guidelines or regulations apart from a Department of Health circular that stipulated that funding should be allocated 'towards the provision of medical cover for sheltered housing schemes for older people' (ICSH 2005:58) which contradicts the stipulation in the 2002 DOE housing *Memorandum* that capital assistance should *not* be used for nursing or medical care as noted earlier (DOE 2002) and suggests that the two Departments were working at cross-purposes. Funding totalled £428,000 in 2005 and this was divided between health boards with the then Eastern Regional Health Authority getting €125,000, the largest share and the Midlands Health Board getting the smallest, €25,000 (ICSH 2005:58). Further HSE funding allocations for sheltered housing were made between 2006 and 2008 as follows; €928,000 in 2006, €1.5m in 2007 and €1.6m in 2008, again without guidelines about how it should be distributed or used (ICSH 2005:58). No information is available with respect to the disposition of funding allocated in each of the health boards or HSE regions up to 2007 but there is evidence to suggest that housing associations had difficulty in accessing the funding and there was the suspicion that not all of the funding was used for the purpose for which it was intended<sup>4</sup>. No new funding has been allocated since 2008.

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<sup>4</sup> Interview with study participant on 11 May 2011 and personal experience as a health board officer.

In a 2005 report entitled *An Overlooked Option in Caring for the Elderly: a report on sheltered and group housing* the Irish Council for Social Housing (ICSH) identified the potential of 'high support sheltered housing' to prevent the premature admission of tenants into institutional care'; no specific reference was made to people with dementia (ICSH 2005:20,37). The ICSH estimated that in 2001, 48% of the 300 approved housing associations on their register were actively providing housing and other services to older people (ICSH 2005:15), and under 'non-housing services' provided by voluntary housing associations, a very comprehensive list of services is offered that includes: social and recreational services, communal facilities and care services including meals on wheels, home help, assistance with hygiene and care, caretaking service, visiting public health nurses and doctors, chiropody, physiotherapy and other medical services, although the Council observe that the level, type and availability of services varies widely.

Using language from the Mercer Report, a National Economic and Social Council (NESC) report published in 2005 recommended that the on-going evaluation and assessment of housing schemes for older people be strengthened, that research be undertaken to assess older people's housing preferences and that the role of 'assisted and supported housing' be expanded 'particularly where it supports independent living and a continuum of care' (NESC 2005:XVII). NESC further acknowledged the need to develop a strategic framework for housing and care to address all aspects of service development and delivery including funding.

In 2005 a national working group was established by the HSE Older People's Services directorate to look at sheltered housing provision for older people in Ireland and there was heavy representation of the voluntary housing sector. Members of the sub-committee included representatives from FOLD and O'Connell Court, both HWC providers of services to people with dementia (HSE 2006 See Appendix 2). The sub-committee prioritised the need to put structure around the allocation of what was then the new HSE sheltered housing budget and the final report issued by the sub-committee recommended that the current HSE budget for sheltered housing be increased, that a standardised application process for HSE funding be adopted and that Service Level Agreements (SLA) be used to govern funding arrangements (See templates Appendix 2). Finally the sub-committee recommended that the HSE explore new models for the development of sheltered housing services for older people with special needs including those with dementia and a brief description of supported housing and HWC models were included in the Appendices of the final report (HSE 2006).



Although this sub-committee report was discussed at national level its recommendations were never officially adopted in practice<sup>5</sup>. However, it is interesting to note that a report produced by the Department of Health and Children in 2005 took a very similar position to that of the HSE sub-committee (Working Group on Long Term Care 2005). The report acknowledged the need to address the current ad hoc and discretionary nature of funding to sheltered housing providers and concluded that ‘the twin issues of accommodation and care’ in the context of services for older people should be tackled simultaneously. It recommends the establishment of greater clarity around the funding arrangements to ‘meet the agreed care costs associated with the provision of accommodation’ for older people (Working Group on Long Term Care 2005:37). A note appended to the original report states that although it was never formally endorsed by the Government, it did inform subsequent discussions about long term care.

*Building Sustainable Communities* was published in 2005 by DOE to provide a national housing policy framework; it acknowledged the important role of the voluntary housing sector in providing special needs housing and made a commitment to increase capital funding limits for voluntary housing associations but it does not provide the framework for the development of housing and care services for older people as recommended by NESC and others (DOEHLG 2005).

The national social partnership agreement *Towards 2016* picks up on the supported housing theme by giving a commitment to encourage ‘The continued development of sheltered housing options, with varying degrees of care support... within an infrastructure of long-term care services for older people’ (Department of the Taoiseach 2006:57). Future actions to be undertaken under the agreement include ‘Ensuring that future Housing Action Plans address special needs in a more strategic manner and specify, in particular, the role of the voluntary and co-operative housing sector in meeting the associated accommodation requirements’ (2006:59). Under ‘Governance Framework’ (Section 32.4) a commitment is given for the Department of Health and Children to ‘...establish a structured consultation with social partners on the development of policy in relation to long-term care issues for older people on the basis of principles outlined (2006:61).

In 2007, *The Role and Future Development of Supportive Housing for Older People in Ireland* was published by the NCAOP (Cullen et al 2007) eighteen years after the publication of the first NCE report on sheltered housing in 1989 which included the findings of a survey of supportive housing providers in Ireland. The authors found that only one local authority sheltered housing scheme in their sample were providing ‘supportive housing’. Among their sample of voluntary sheltered housing schemes providing supportive housing, only 16% were providing help with Activities of Daily Living at the time of the survey and only 14 % were providing both practical and personal

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<sup>5</sup> According to an HSE participant interviewed on 20 January 2011

care services. Only a tiny proportion, just 2.7% of schemes in the NCAOP survey, offered 24/7 care and thus could be described as HWC schemes as defined for purposes of this study (2007:102-103).

The authors of the 2007 report recommend that supportive housing development be prioritised nationally because of the important role it can play in addressing older people's needs, in providing needed choice and in preventing unnecessary admission to residential care. Much of the focus in the report is on increasing supply (not only in the voluntary sector but also in the private sector and the local authorities) and to this end, the authors make a number of recommendations including for: the standardisation of the terminology; the development of national supportive housing policy; the creation of a framework defining the respective responsibilities of stakeholders for supportive housing development and delivery; and the establishment of a secure revenue funding budget in the HSE(2007:24-27). The authors also suggest the need to 'amend' CAS funding criteria to allow for the allocation of funding to supportive housing schemes providing 'a higher level of care' in the same way that the regulations were 'amended' with respect to housing schemes for people with mental disability (2007:24-25). A service gap was identified for older people with high level support needs who are at risk of admission to long stay care, and it is suggested that there is a 'need to examine further the role that supportive housing might play in meeting the needs of people with dementia in Ireland' (2007:41). The need for further research was highlighted to assess: availability of services including in the private sector, demand for supportive housing, supportive housing costs, benefits and cost effectiveness (2007).

O'Sullivan observes that the commitment of successive Irish governments to finance, manage and support social housing 'through direct build acquisitions and other schemes' had by this time been abandoned by most EU states (2004:329). In contrast to what was happening elsewhere in Europe, CAS capital funding for special needs housing was actually increased in 2007 to 100% of the 'approved cost' of building if all tenants came from the housing waiting list (ICSH Annual Report 2008). However, the following year, the DOE issued a circular advising voluntary sector housing associations of 'Revised arrangements for the Appraisal, Approval and Implementation of Voluntary and Co-operative Housing Projects', which tightened up the requirements for accessing capital funding (DOEHLG VCH 2/08 19 May 2008). Approval now had to be secured at several stages including after planning permission is granted. Projects had to meet local authority 'strategic housing objectives... identified local need... [and] sustainable community proofing requirements' (2008). The requirement in the *2002 Memorandum* for voluntary housing associations to consult with the HSE at the planning stage if a project has revenue funding

requirements is re-iterated but the circular goes further by stating that capital funding approval will not be given unless revenue funding arrangements are already in place (2008:5).

A 'Cross Departmental Team' on sheltered housing was set up in 2008, chaired by DOE with committee members drawn from DOHC and the HSE as well as from the responsible Minister's office, housing authorities and the Office for Social Inclusion. Its aim was to 'develop the policy framework in respect of sheltered housing for older people' which had been recommended by the NCE twenty years previously. A sheltered housing protocols sub-group was established to 'set out arrangements for co-operation, understanding and joint working between agencies involved in the provision of sheltered housing and care services for older people' and to ensure 'the most effective use of care and housing resources, and value for money' (DOEHLG 2009a:2). No final report from either the cross departmental team or the sub-group was issued and it was suggested by one DOE official that the information generated by the cross departmental exercise would be used to inform the development of the Positive Ageing Strategy<sup>6</sup>. Protocols were subsequently issued by DOE to govern 'arrangements for inter-agency cooperation in relation to the delivery of services to people with disabilities' (but not older people). These protocols repeat directives to local authorities made in the *Memorandum* and subsequent Department documents designed to make sure that voluntary housing bodies provide full information regarding revenue funding requirements and secure HSE written approval to cover revenue costs before they are given approval by the local authorities for capital funding (DOECLG 2011 Circular 01/2011).

CAS funding of over €400m was allocated in 2008 for voluntary social housing but by 2009 the CAS budget was being threatened by the dramatic weakening of the Irish economy. In response to the deterioration in the public finances, DOE commissioned a *Strategic Review* of the funding 'mechanisms by which public investment in social housing can be achieved' in 2009 (Grant Thornton 2009:2) and the report that followed was influential to changing Government policy regarding state funding for social housing. Up to this time, successive Irish governments had been committed to financing the development of social housing 'through direct build, acquisitions and other schemes', a policy that other EU countries 'appear to have abandoned' according to O'Sullivan (2004:329). The authors of the *Strategic Review* acknowledge the role of voluntary bodies as 'providers of on-site support and care' to people with special needs but recommend that voluntary housing bodies 'seek to access a wider range of [capital] funding options to support the housing related activities' (2009:6) including loans from banks and other lending institutions, 'funding from investors such as pension funds... participation in commercial property ventures, participation ...in Public Private Partnerships and... the sale and lease back of existing assets'

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<sup>6</sup> Presentation by DOE participant at workshop 11 November 2011.

(2009:64). The authors suggest that current social housing rent restrictions be lifted and that consideration be given to allowing voluntary housing bodies to accept tenants not eligible for social housing but who can afford to pay higher charges. They suggest that by doing so, voluntary housing providers will be able to pay a greater proportion of total service costs, thus reducing the 'State commitment to particular schemes... [and] thereby provide better value for money for the tax payer' (2009:66).

In 2009, the introduction of the Social Housing Leasing (SHLI) Initiative marked the shift away from the capital funding model of social housing development (as recommended by Grant Thornton) towards a new leasing model (DOEHLG 2009). The SHLI, which was initially only offered to local authorities, introduces new arrangements whereby Approved Housing Bodies can lease housing units from private property owners/developers or can 'purchase (or where appropriate construct) units using private finance' in lieu of receiving capital grants to buy or construct housing schemes (DOEHLG 2009:2). A six stage approval process is involved and all tenants accommodated under the SHLI must be eligible for social housing which is something that the Grant Thornton report recommended against. In parallel with the introduction of the SHLI, the CAS budget was being reduced; by 2011 allocated CAS funding was reduced to €247m, a considerable reduction on the previous year (ICSH 2011:8). In response to concerns expressed by the voluntary housing sector, a Capital Advance Leasing Facility (CALF) was subsequently established in 2011 to provide 'a capital equity injection' to Approved Housing Bodies wishing to acquire or construct (as opposed to leasing) housing units under the SHLI (DOECLG 2011). The implications of this policy change from the perspective of voluntary housing providers are discussed in detail in the Chapter 5.

The results of a survey undertaken by the Irish Council for Social Housing to map voluntary sector 'housing and services provision' for older people were published in 2010 (ICSH 2010) and they are consistent with the findings of Cullen et al's 2007 study. The survey shows that the majority of housing associations that took part provide what the ICSH refer to as 'passive supports' defined as 'those that do not necessarily provide or demand direct interaction with tenants' including: alarms or security devices, laundry services, communal areas, activities and day centres which serve both tenants and older people from the community (2010:41). So-called 'active supports' or 'care intense services' are the least provided. The ICSH made a case for increased funding for supported housing development, suggesting that the voluntary housing sector bridged the gap between independent living and nursing home care thus delaying the unnecessary or premature placement of older people in nursing homes (2010).

In a submission to the Review of the Nursing Homes Support Scheme, the ICSH make the case for the further expansion of 'supported housing' on the basis that: it will increase older people's choice of long term care options; the infrastructure already exists; and that costs are only 1/3 of the costs of nursing home care (ICSH 2012:2) although no analysis of the method used to calculate costs is included in the submission. They suggest that the replacement of CAS with the SHLI undermines the ability of sheltered housing providers to support older people as their dependency needs increase, ultimately imposing higher costs on the state due to an increased demand for nursing home care (2011:42).

The ICSH recommend the development of pilot schemes to explore the development of supported housing schemes offering 'higher levels of care' although 'higher levels of care' are not defined in any meaningful way and there is no specific reference made to people with dementia (ICSH 2012:10).

### *6.1 Reference to HWC in the Irish dementia literature*

There has been only fleeting reference to the need for the development of supported housing or HWC specifically for people with dementia in the Irish social policy literature in general, but since 1999 there have been a number of reports and papers published on dementia policy and dementia practice in Ireland and these help to provide the context for this study. *The Action Plan for Dementia* (APD) published in 1999 is still considered to be the most important social policy document on dementia to date in Ireland (O'Shea and O'Reilly 1999). The authors promote the idea of dementia as a disability and propose a plan that goes beyond the traditional bio-medical approach to dementia care to embrace person-centred care. The central plank of the Action Plan is home care, with in-patient specialist treatment in an acute psychiatric unit to be reserved for those patients who have mental illness or are too unwell to be managed at home (O'Shea and O'Reilly 1999:89). Although there is a call for the development of a range of psycho-social model responses to the needs of people with dementia, the authors of the *Action Plan* found '...little support during the consultation process for group-living or sheltered accommodation for people with dementia' and the prevailing view was that

Group living arrangements were likely to be cumbersome and impractical, requiring high levels of supervision and a framework for coordination which is not evidence in existing Community Care structures in Ireland (1999:61).

The APD concludes that it would be more cost effective to use scarce resources to further develop home care for people with dementia rather than to develop '...group-living arrangements that were unproven in the Irish system' (1999:61). The APD consider HWC arrangements to be impractical but they do express dissatisfaction with existing residential long term care services

and recommend that 'small scale domestic oriented' units be developed for people with dementia who do not have 'significant behavioural problems' and suggest that these should be attached to 'conventional long stay facilities' (1999:31).

In a paper commissioned by the Alzheimer's Society of Ireland (ASI) in 2007, O'Shea notes that in the 2001 *Health Strategy: Quality and Fairness* (DOHC) the Government accepted recommendations made in the *Action Plan for Dementia* and committed to its implementation over 7 years but that progress had been slow largely due to 'reluctance to commit significant additional resources to dementia care [which is] at the heart of the matter' (2007:3). He observes that in spite of the call for the development of psychosocial approaches to dementia care, 'the medical model is still dominant' in Ireland (2007:2). While reference is made to the need for special consideration to be given to the design and scale of long stay facilities for people with dementia (2007:22), there is no specific call for the development of HWC alternatives.

The Dementia Manifesto produced by ASI (2008) emphasises the need for enhanced and flexible community based services to enable people with dementia to remain living at home. In a submission to the Review of the Nursing Homes Support Scheme in 2012, ASI suggest that 'For some people with dementia and their families, the most appropriate and realistic option is a move to a supported care environment' while noting that there are few such options available in Ireland (ASI 2012:4) They go on to argue for the development of 'supported housing models for people with dementia who can no longer remain at home but who do not need high dependency care' and this recommendation is made in tandem with a recommendation for the expansion of Specialist Care Units in nursing homes (ASI 2012:5)

*Creating Excellence in Dementia Care* draws together national and international literature and uses Irish data bases to inform the development of a National Dementia Strategy (Cahill et al 2012). The report notes the lack of alternatives to the nursing care model for people with dementia in Ireland in contrast to the situation in other countries (2012:106). In the context of dementia care best practice, reference is made to the recent development of the Teaghlach or household model in two HSE residential long term care facilities and to Special Care Units that have developed in private sector nursing homes (2012:112) in parallel with the case study HWC developments. Direct reference is also made to the need to prioritise the development of 'assisted living communities such as those provided by the FOLD Housing Association' in combination with the household model of care in nursing homes (2012:131).

## *6.2 Factors that have influenced Irish HWC development as identified in the literature.*

The limited development of HWC services in Ireland up to now may be seen as a reflection of a wider phenomenon, that is the relatively limited development of social services in general in Ireland especially compared to the UK and other European countries. Kelly argues that social services did not develop in Ireland in the same way that they did in the UK after the Beveridge Report of 1942 because of the influence of exponents of catholic action who found Christian charity more palatable than state intervention (1999). Kenna's research similarly finds a correlation between the subsidiarity principles of the Catholic Church in Ireland and the residual approach to welfare, including to the provision of social housing (2000:32). Kenna also suggests that the overwhelming social and political pressure in Ireland for the right to own one's own home and the high rate of home ownership especially among the older population has inhibited social housing service development over the years (Kenna 2001:25).

Never high on the list of national priorities, Acheson and Harvey suggest that the removal of older people's services from the local authorities in 1970 following the creation of the health boards had the subtle effect of putting housing even further down the list of priorities within older people's services than had been the case previously. They observe that this separation of services

...defined post 1970's services for older people within a medical institutional paradigm (and some say an unrestrained one), one in which considerations of planning, community and the physical environment diminished in importance and services became separated from important local authority roles such as housing, amenities and environmental services (2008:46)

Acheson and Harvey suggest that 'even where housing is built, there is the separation of housing from welfare needs, with little resourcing or coordination of the two' (2008:57). They also note the inability of community services 'to compete against much stronger institutional, hospital based big hitters' (2008:61) when resources are being allocated.

The domination of the voluntary housing sector by local community housing schemes with less than 10 units is offered as another factor that helps to explain the lack of supported housing development in Ireland (Mullins et al 2003, ICSH 2005, Cullen et al 2007). Brooke found that voluntary sector organisations are often perceived by statutory bodies as being inexperienced; the aspirations and ambitions of small voluntary sheltered housing providers are necessarily limited and those housing organisations that do wish to further expand services and compete for scarce state funding may not be taken seriously by statutory funding agencies (Brooke 2001).

The challenges involved in participating in voluntary/statutory interagency initiatives like supported housing are believed to be compounded by the lack of coordination and integration of services across agencies and this is a regular refrain in the social policy literature (Browne 1992,

O'Connor et al 1989, NCAOP 1997, Cullen et al 2007, Acheson and Harvey 2008). The varied and inconsistent support given by the local authorities to voluntary housing initiatives, due to the great differences in their interpretation of their function and role provides an illustration of the way that lack of coordination and integration can inhibit service development (Meghen 1963, Interdepartmental Committee 1968, Kenna 2000, Brooke 2001, Mullins 2003).

Brooke summarises the main factors which have limited the ability of voluntary housing organisations to reach their full potential including: a cumbersome service development process, funding limitations (both capital and revenue), and the cost of land (2001). Brooke's views mirror concerns highlighted by the NCAOP over the years (O'Connor et al 1989, Cullen et al 2007), and they are shared by the voluntary housing sector who consider funding problems to be the most serious barrier to the development of sheltered housing in Ireland (ICSH 2005, 2011, 2012). The ICSH have drawn attention to the inadequacy of available revenue funding for supported housing for a number of years and have more recently expressed concern about the negative implications of recent changes to the way that capital funding is organised for social housing (ICSH 2012). Cahill et al suggest that the existing funding mechanism for long term care in Ireland, specifically the Nursing Home Support Scheme (referred to as the Fair Deal), undermines the development of all community services for people with dementia because of its bias towards 'residential care' (Cahill et al 2012:12) and the ASI similarly point out the need to better balance the allocation of long term care funding between 'residential care and community based services' including supported housing (ASI 2012:).

Finally Ruddle et al cite the ambivalence of health board managers and Government officials as a factor that at least partly explains the failure over time to implement policy recommendations made in social policy documents like *The Years Ahead* (1997:319). Acheson and Harvey similarly refer to 'high level bureaucratic obstruction' and local managers who decide that recommendations would be too hard to manage and thus decide to do nothing (2008:61). They and NESF also make the link between the lack of consultation with consumers and the failure to implement policy recommendations (NESF 2009, Acheson and Harvey 2008). All of the factors identified in this section have relevance in the context of this study and their implications with respect to the development of HWC services for people with dementia will be discussed further in the findings chapters.

### *6.3 Summary of the Irish literature*

The Irish literature reveals acknowledgement of the need for supported housing if not HWC dating back to 1968 with the publication of the *Care of the Aged Report* followed by a number of reports that made policy recommendations for its further development. These recommendations



were made on the grounds that supported housing would improve the living situation of older people and prevent nursing home admissions; HWC has been promoted as a more appropriate and less expensive way to meet the needs of older people requiring care and support but not nursing care. In recent times the economic arguments for the development of HWC were put forward in *Towards 2016* and the *Mercer Report*. The rationale put forward for the development of HWC in Ireland is the same as the rationale reflected in the international literature, however the Irish literature demonstrates that in spite of this acknowledged need for HWC services there has been a notable lack of progress with respect to its development and many reasons are put forward by social policy analysts to explain this phenomenon. The fact that the case study schemes were developed at all is interesting in this context.

The statutory housing bodies have enabled HWC development through the allocation of capital funding but in repeated policy documents DOE are clear that their obligations do not extend much beyond the provision of accommodation, and recent shifts from a capital funding to a leasing model of social housing development suggest that the boundaries around DOE roles and responsibilities are becoming even more rigid. There is recognition in the literature of the critical role of the HSE in HWC development and delivery but a striking lack of evidence that the HSE has even acknowledged any role or responsibility for either funding HWC development or for providing services to residents. There remains no HWC policy or strategy in either the housing or health sector. An opportunity was lost when the Inter-departmental Committee on sheltered housing failed to complete its work and issue a final report which might have provided the framework for service development called for by successive housing policy analysts.

The international trend towards the development of HWC for people with dementia is a fairly recent phenomenon and the Irish literature suggests that it is something that has gone largely unnoticed so far in Ireland. The Irish dementia literature acknowledges the inappropriateness of current long term care services for many people and there are recent brief references to the potential benefits to people with dementia of small group supported housing arrangements, but there is little or no reference to people with dementia in the housing literature. It is not clear whether people with dementia are included in the group of frail, vulnerable older people believed to be suitable candidates for admission to supported housing or whether they are considered to be unsuitable for it. This lack of attention to the special needs of people with dementia or to the particular merits of HWC for people with dementia was also evident in the findings.

Change theory was used to guide the collection and analysis of the data collected for this thesis in order to better understand the development of HWC for people with dementia in Ireland. The

following section includes discussion about why change theory was selected as the theoretical framework for this study.

### **Section 7 Theoretical framework**

Theoretical frameworks give direction to the design of research studies and the collection and analysis of data (Finlay and Gough 2003). The identification of a theoretical framework for this study involved considerable searching. In the early stages of the research, social theories of ageing were explored because of preconceptions held by the researcher about the relationship between the limited development of HWC and the dominance of the bio-medical model in Irish older people's services. Bond, Coleman and Peace observe that the theoretical frameworks represented within social gerontology include biological, psychological and sociological perspectives that 'focus on the different aspects of the ageing process, make different assumptions, use concepts in different ways, pose different questions and arrive at different explanations of the ageing process' (1993) Of these, sociological perspectives seemed the most relevant to a study of HWC development because they address the relationship between social behaviour, attitudes and values and 'the organisation and structure of the society in which we live' (Bond, Coleman and Peace 1993:21-24). Foucault's theories on the influence of power relationships and the institutionalisation of discourses on the way that ageing is interpreted and managed were explored (Powell 2006, Saraga 1998) as were other social construction theories that give meaning to individual attitudes and behaviours and to the way that these are reflected in service developments (Saraga 1998). Social construction theory would have been very useful if the focus of the research was on stakeholder perceptions about the role of HWC as a long term alternative for people with dementia. But as the fieldwork progressed the research focus changed from stakeholder perceptions about the role of HWC to the actual development process and the many factors that interact to influence it at a practical level. It became less important to interpret why stakeholders held the views that they did and more important to look at the interrelatedness and interaction of these views with other forces and factors impacting on HWC service development. It became clear that a social construction framework could not be used to organise the type of data that was being collected in order to answer the research questions.

Public policy theories focus on the policy process; they can be used to understand 'government intention', that is how decisions are made about what *should be done* as well as to analyse the impact of policy and what *has been done* (Smith and Larimer 2009:155). Public policy theories offer a number of theoretical frameworks that might have been used for the analysis of data from this study. For example, Marxist, elitist or pluralistic theories that 'situate the location of power in policy making' might have been used to develop an explanation of why HWC development has

been so limited in Ireland (Adshead and Millar, 2003:xiv ). The lack of specific HWC policy in Ireland could have been interpreted as a policy in itself, a policy that upholds the power of the vested interests (the medical and nursing professions, the private nursing home sector) to retain control over older people's services. O'Sullivan's analysis of Irish homelessness policy (in Adshead and Millar 2003: 37-53) provides an illustration of the way that Marxist theory could be applied to explain the inconsistency between pronouncements in Irish public policy about health promotion, care in the community, and prevention of institutionalisation of older people and the continued dominance of and reliance on medical model services that works to undermine stated policy objectives and inhibit the development of alternative services like HWC. Clientelist theories highlight 'how resources are allocated within the parameters of much bigger systems' and again might have provided insight into why the case study schemes were resourced when in general there was little or no such development in Ireland (Collins and O'Shea in Adshead and Millar Chapter 6:88-107).

Institutionalism focuses on the context of 'rules, procedures, given constitutional arrangements, power relations, norms, values and behaviours' in which policies are formulated (Millar in Adshead and Millar 2003, Chapter 8:129-146). The principles central to historical and sociological institutionalism are relevant to this study which sought to understand the factors that influence HWC development in Ireland. Sociological institutionalism highlights the influence of the prevailing culture in every organisation and institution on policy formation and would have been an appropriate framework for analysis for this study if the focus was the implementation of policy from the different perspectives of the agencies involved in HWC development. Street level bureaucrat theories highlight the central role played by bureaucrats and managers in implementing policy and identify the constraints that influence the decisions they make (Lipsky 1980, Meyers and Vorsanger 2003, Bekkers, Tummers and Voorbeg 2013). The data for this study could have been structured and analysed using this perspective to explain why stakeholders involved in HWC development acted as they did and could also provide insight into the potential for further service development. Public policy theories would have been helpful to analysing HWC development in Ireland from the perspective of the formulation, implementation or impact of Irish social policy. But the emphasis in this study was not on policy but rather on the implementation of a change to the way that long term care services are traditionally delivered in Ireland, and policy theories were less appropriate to organising the data from that perspective.

### *7.1 The selection of change theory to provide the theoretical framework for this thesis*

This study involved baseline research conducted at micro level tracking the development of individual service initiatives and their outcomes; study objectives included the desire to find out how HWC schemes developed, what happened during the planning and development stages,

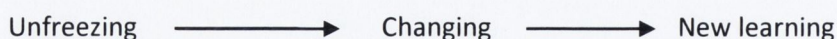
what impacted on service development and what lessons can be learned from these experiences. The focus is on about the planning and development *process* itself and especially about the challenges involved at local level in introducing a new service within or across organisations. A starting hypothesis for this study (based on long experience as a health services manager) was that the introduction of services that depart from traditional ways of doing things is more difficult than expanding existing services or tweaking existing service models. As the fieldwork progressed it became obvious that this was key to understanding HWC development in Ireland and change implementation theory was accordingly chosen as the theoretical framework for this dissertation. HWC development represents the introduction of a radical change to the way that long term care services are traditionally delivered to older people in Ireland. Change theory was developed specifically as a framework for the analysis of the process of implementing change in organisational settings; it starts with the assumption that change implementation is difficult and it flags the factors that need to be taken into account when any change implementation effort is contemplated. Change theory is routinely used for the retrospective analysis of innovative projects or programmes already undertaken to identify the factors that were critical to their failure or success but it perhaps used even more to guide leaders faced with the immediate challenge of introducing new practices that challenge old ways (Pasmore 2011). Change theory is prescriptive in that it assumes that although there may be powerful contextual variables that affect outcomes (including those highlighted in public policy theory), there are things that can be done to optimise the likelihood of successful change implementation. Both the analytic and prescriptive aspects of change theory are appropriate to this study that examines service initiatives that have already taken place but also is concerned with the potential for future HWC service development.

Although developed originally for use by business consultants and business leaders, change implementation theory is also used to analyse and guide the introduction of change in the public sector, especially in the context of budget constraints and the need for accountability and cost effectiveness and the desire to improve service outcomes and quality (See the brief discussion of New Public Management in Adshead and Millar 2003:174-75). Change theory has been used as a framework to analyse and guide the development of public sector initiatives aimed at broad organisational change but also at changing practices and procedures within organisations. It has been used to identify the factors associated with project success or failure as well as to guide the planning and development of change initiatives in the public sector (Fernandez and Rainey 2006, Zegans 1992, Cunningham and Kempling 2009) including in the health services (Dopson et al 2008, Hendy and Barlow 2010, Soo et al 2009, Coghlan and McAuliffe 2003, McAuliffe and Van Vaerenberg 2006). In Ireland, change theory provided the theoretical framework used to guide

the implementation of the HSE Transformation Programme 2007-2010 aimed at changing ‘not only what we do, but... how we do things and how we work together...’ (McAuliffe and Van Vaerenbergh 2006:ii); although a retroactive evaluation of that programme was never carried out, change theory would have also provided an appropriate framework within which to analyse the outcomes from that programme. Change implementation theory can similarly be applied to this study which looks at the development of services that represent a change to ‘what we do and how we do things’. It is useful to understanding the complex dynamics within and across organisations involved in change initiatives and it allows for the incorporation of the many contextual variables associated with implementing change.

Finally, change theory is very accessible; it is written in straight forward language that is easy to understand and apply and that was a big part of its appeal. It sets out the conditions necessary for the implementation of change and identifies the predictable obstacles that need to be negotiated during the change implementation process (in this case the implementation of plans to introduce a new service). It provided a useful framework for organising the data in such a way as to answer the research questions.

Kurt Lewin is widely acknowledged as having provided the foundation for the development of change theory. His three stage model of change was developed in the mid-1940’s and starts with the premise that human behaviour is based on an equilibrium that is held in place by forces that support it and restrain it. (Schein 1996:28) In Lewin’s model, the first stage in adopting change involves identifying the need for change and ‘unfreezing’ or unlearning old attitudes, behaviour, fears and anxieties that help to maintain that equilibrium. It also involves removing the restraints that act as a counterforce to attempts to upset established equilibrium (Schein 1996). The second stage in Lewin’s model involves changing or moving towards a new way of thinking and doing. The third stage involves ‘re-freezing’ or the consolidation of new learning in order to ensure the change works and can be sustained (Coghlan and McAuliffe 2003:12-13).



Change theorists built on Lewin’s model and refined it, and many change management models represent variations on these three concepts that he developed (Mento et al 2002). Within the large body of change theory used to manage change within or across organisations including public sector agencies, several models have been developed and among the most prominent have been the planned change model and the emergent change model although there is considerable overlap in the models identified in the literature and (as in the HWC literature) a lack of a

standardised lexicon of terms used to describe different models. In the planned change model, change is assumed to be deliberate and can be planned in advance (Wilson 1992, McAuliffe and Van Vaerenbergh 2006). Emergent change models assume that 'change emerges as a result of the interplay of multiple variables' (Wilson 1992:9) including some that are unanticipated. In emergent change models, change is not perceived as a series of linear events within a given period of time but as a continuous, open-ended process of adaptation to changing circumstances and conditions (Todnem 2005:375). McAuliffe and Van Vaerenbergh suggest that systems models of change management occupy a middle ground between planned and emergent change models; systems models are based on the assumption that 'while change may be planned in one part of the system, it may produce unplanned change in another part of the system' (2006:16).

Elements of two change theory models developed by Kotter and by Coghlan and McAuliffe were chosen to provide a broad framework for the collection and analysis of data for this study, although reference is made to other change theorists as appropriate. Kotter is considered to be an 'exemplar in the change management literature' (Mento et al 2002:45); his work is aimed primarily at teaching business leaders how to implement organisational change. Coghlan and McAuliffe are Irish change management theorists who developed a model aimed specifically at guiding change in large health care organisations.

Kotter outlined an 8 step model to be followed in order to produce successful change (Kotter 1996).

1. Establishing a sense of urgency
2. Creating a guiding coalition
3. Developing a vision and strategy
4. Communicating the change vision
5. Empowering broad based action
6. Generating short term wins
7. Consolidating gains and producing more change
8. Anchoring new approaches in the culture

Kotter proposed that the first step in introducing change in an organisation is to create dissatisfaction with the status quo and create a sense of urgency around the need to change. He suggests, for example, that the identification of market realities like a fall in market share is a good way to create urgency around the need to change the way business is currently being conducted (1996:35-49). The next step involves putting together a group with enough power to

lead the change. The third step is creating a vision with respect to the way in which the proposed change will improve the status quo and creating a strategy for achieving that vision which must be; imaginable, desirable, feasible, focused, flexible and communicable (1996:67-83). Kotter details the challenges involved in communicating a vision but emphasises that it is essential to motivating others in the organisation to engage in the change process.

Kotter's 5<sup>th</sup> step involves getting rid of obstacles including the 'dysfunctional granite walls found in so many organisations', the systems and structures that can undermine the change vision (1996:101). Step 6 is consolidating gains and this is necessary in order to counter the inevitable resistance that develops against any proposed change (1996:131-144). Kotter advises prospective change agents to anticipate resistance when any change is being introduced in an organisational setting and he colourfully describes change resisters who can be driven 'underground or into the tall grass. But instead of changing or leaving, they will often sit there waiting for an opportunity to make a comeback' (1996:133). He advises breaking the change implementation strategy into short term goals that can help to maintain critical momentum for change. Finally, anchoring change involves 'grafting new practices into the old culture' (1996:145-158).

Kotter's concept of a change vision was particularly useful to the analysis of data about what made HWC development possible as was the idea that before change can be successfully implemented, a sense of urgency must be developed around the need for it. Kotter's proposition that in order to consolidate and sustain change it must be anchored in the culture also resonated particularly well with the data.

Coghlan and McAuliffe propose a 5 stage change process that borrows heavily from Lewin and Kotter (2003). Coghlan and McAuliffe's model is similar to Kotter's but unlike Kotter, they do not assume that change is linear process that takes place within the confines of any one organisation and they acknowledge the influence of forces in the external environment on the implementation of change including political priorities, changing legislation and the economic climate (2003:55). This aspect of their model allowed for an understanding the dynamic interaction of internal and external factors that impact on service HWC development. Coghlan and McAuliffe's arguments about the powerful counterforce that organisational culture can be to change efforts was particularly useful to analysing the data related to what made HWC development difficult (2003:59). Their contentions about the particular problems created by the introduction of changes that challenge accepted practices and ways of thinking were extremely valuable as were their propositions relating to when and why resistance to change develops. Coghlan and McAuliffe's model, like Kotter's, is aimed at leaders involved in the introduction of large-scale

organisational change but the concepts in both models are also applicable to the analysis of small scale change including the introduction of a new service.

Kotter and Coghlan and McAuliffe's change management models provide an appropriate framework for the retrospective analysis of change implementation efforts that took place in the past and also a framework for looking at what needs to happen in future in order for further change to take place. As such they provide a good mechanism for organising the data in order to answer the research questions posed in this study; they help to make sense of the large volume of data collected and analysed. Reference is made to other change theorists where appropriate including Nadler (1998) and Pasmore (2011) whose arguments on the consolidation of change were especially valuable. The methodology employed for conducting the research is outlined in the next chapter.



## **Chapter 3: Study Methodology**

This chapter presents the methodological approach selected for this thesis that explores the development and implementation of HWC for people with dementia in Ireland and the climate for future service development. Section One discusses the rationale for the decision to use qualitative research methods to carry out the research. Section Two explains the reasons why the case studies approach was taken and Section Three discusses how the case studies were identified and briefly describes each of the five case study HWC schemes that are the focus of the research. Section Four outlines the process by which participants were selected for interview and Section Five presents the research design. Section Six presents a discussion of the ethical considerations related to this research and Section Seven provides details of the interview schedules. Section Eight includes a brief reflexive critique of the interview process and Section Nine concludes the chapter with a detailed discussion of the analysis of the data.

### **Section 1 Qualitative research.**

This study uses qualitative research to explore the development of Housing with Care (HWC) for people with dementia and the factors that are critical to it, including those that enable it and those that act as barriers. A qualitative research approach was used because it was considered the best way to develop an in-depth understanding of what is a very complicated topic from a range of different perspectives. Creswell observes that 'We conduct qualitative research because we need a complex, detailed understanding of the issue...that can only be established directly by talking to people...because we want to understand the contexts and settings in which participants in a study address a problem or issue...' (2007:40). Qualitative research is concerned with rich description and the natural context in which phenomena exist; quantitative research is not concerned with such detail (Denzin and Lincoln 2000).

In contrast, quantitative research involves a deductive approach in which theory drives data collection and the research tends to be about theory testing. This study was not interested in testing theory but instead sought to contribute to theory by using an inductive approach to identify patterns and themes in the data which might help to explain the phenomenon of HWC development (Bryman 2008). Whilst quantitative research 'emphasises quantification in the collection and analysis of data'; this study was aimed at understanding the HWC development process as interpreted by a large number of stakeholders and this could not be captured in quantitative form (Bryman 2008).

Interpretivist qualitative research assumes that there is no simple finite explanation for any social phenomenon but rather takes the position that there are 'multiple realities' (Lincoln and Guba 1985, Denzin and Lincoln 2000). This study was undertaken from that position. For example, it was assumed that the individuals involved in HWC development would all have their own perspective, their own 'reality' of the factors they believed to be critical to HWC development. It was assumed that a housing officer will have a different perspective from a Health Service Executive manager about HWC development and that the views of individuals within each group may also vary. In order to develop an understanding of how services developed it was necessary to capture the views of individuals from each group whose understanding of the relevant issues will have been shaped or constructed by their own experience in their own agencies or workplace, their own professions and personal lives (Crotty 1998). This study represents the first attempt to carry out such a complex mapping of such multiple perspectives and processes.

Stake observes that the most distinctive characteristic of qualitative inquiry is its emphasis on interpretation (1995:9). Qualitative studies involve interpretation on more than one level. Study participants' views of HWC development and how it works are already interpretations of 'reality' that are culturally and historically derived and specific to time and place; the analysis of information derived from interviews with study participants involves further interpretation through the researcher's worldview which informs the conduct of the study (Creswell 2007:15). The researcher's world view is also shaped by past experiences and beliefs that will necessarily influence the way that the research data is interpreted. Qualitative methods accommodate an ontological perspective that research is underpinned by certain values or principles that are a product of the researcher's knowledge and experience. It recognises that study participants' 'construction' of issues and events is influenced by individual values shaped by social and cultural norms (Lincoln and Guba 1985).

## **Section 2 Case study approach**

Although not a prominent feature of social policy research in Ireland, case studies are used routinely in business studies, education and social science disciplines (Yin 2009). Case studies were chosen for this research because of the belief that they would provide a methodology that would best answer the complex questions about HWC development being posed. To find out the factors critical to HWC service development since the late 1980's in Ireland, this study set out to look at the schemes that have been planned or developed in the past and engage the people directly involved in those plans or developments. A case study approach can provide a deep understanding of the issues relevant to HWC development because they can be studied within and across different settings. The case study method can help to explain the 'how' and 'what' of

HWC development and help to understand the factors that have impacted on it over time (Yin 2009:13). The case studies selected provide the opportunity to get the 'thick description' essential to finding answers to the research questions which apply in a particular case (Yin 2009:42) but which also may be used to draw broad conclusions and propositions for further inquiry (Stake 1995). Case studies also have the advantage that they make it easier to engage the reader in the research journey because of reference made to real life experiences and outcomes.

### *2.1 Intrinsic versus Instrumental case study research*

Stake distinguishes between intrinsic and instrumental case study research (1995). Intrinsic case study research focuses on one case that is of intrinsic interest to the researcher. Intrinsic case studies focus on what is particular about the case, its nature, background, physical setting and other contexts. In contrast, instrumental case studies are organised around issues rather than around the peculiarities of a single case and Stake argues that 'The issues are not simple and clean, but intricately wired to political, social, historical and especially personal contexts' (1995:17). Instrumental case studies create opportunities to illustrate the way that the issues that are the subject of inquiry are manifest in a number of individual cases (Stake in Denzin and Lincoln 2000:438).

For this study, instrumental case studies are used for the purpose of exploring the issues related to the development of HWC for people with dementia and the factors that facilitate and undermine service development. It is not the particular details of each case that are of interest in this study but rather the way in which they provide an illustration of issues across all of the case study schemes. For example, details about the way in which revenue funding was secured in any particular HWC scheme are only of interest in so far as they contribute to an understanding of the issues around the challenges of sourcing revenue funding for all HWC providers.

### **Section 3 Selection of Case Studies**

This study explores the development of Housing with Care which by definition provides 24/7 high support services to residents. As noted earlier, only 2.7% of Cullen et al's sample of 141 voluntary housing associations surveyed in 2006 were providing support services at the highest level of the scale broadly defined as 'round-the-clock care' (Cullen et al 2007:102). In the Irish Council for Social Housing's sample of 103 voluntary housing associations, only 4.8% reported that they were providing a 'higher level of care to tenants' although higher level was not defined (ICSH 2011:21). Neither of these two surveys made any reference to tenants with dementia or dementia specific service provision. The ICSH observe that the type and range of services normally available in sheltered housing schemes reflects the 'independent living ethos' (2011:24); that is, there is the

assumption that those older people who are admitted will require little or no assistance with activities of daily living.

The HWC schemes selected for this study represent a sub-section of the small group of supported housing providers identified by Cullen et al and the ICSH as providing a high level of support to residents. A total of five were identified through the process of purposive sampling (Stake in Denzin and Lincoln 2000).

### *3.1 Sampling of Case Study Schemes*

The main criterion for the selection of the five case study schemes was that they would be Irish HWC schemes that provide 24/7 support services to people with dementia. The case study schemes were selected using prior professional knowledge of HWC development in Ireland based on consultation with colleagues from the Irish housing and health sectors. The two FOLD schemes in North Dublin that met the criterion for inclusion in the study were already known to me in the context of my former employment as an HSE Director of Older People's Services. The FOLD schemes were unusual in my experience as an older people's manager; at the time that they developed there were few dedicated services available for people with dementia and little by way of high support sheltered housing. The development of Cherryfields and Anam Cara by the HSE in partnership with the FOLD housing association and the local authorities attracted attention in the health board where I worked at the time. I also had access to some of the HSE managers who had been directly involved in the FOLD developments.

I originally started the research with the idea of examining the development of only these two FOLD schemes. However, in the course of early discussions with colleagues from the Irish Council for Social Housing, I became aware of the fact that another HWC scheme, O'Connell Court in Cork, was also providing 24/7 support to people with dementia. The O'Connell Court housing association were represented on the HSE committee on sheltered housing which I chaired; again I had access to an O'Connell Court stakeholder who was intimately involved in the development of that service. In the course of interviewing people for those three case studies, I discovered the two other cases. Mount Bolus was identified by stakeholders from both the HSE and Department of the Environment, Heritage and Local Government as a HWC scheme that was planned and built to provide 24/7 support to people with high dependency including people with dementia. It had already closed before the fieldwork began but was added as a case study because I believed that its development and closure would give further insight into the research question about the factors that act as barriers to HWC service implementation. St. Bricin's was also mentioned in interviews with two HSE managers as well as two local authority stakeholders as a scheme that was planned to include dedicated services for people with dementia but had never been built.

Although never built, St. Bricin's was added to the list of case study schemes because, it was planned to include services for people with dementia. I believed that St. Bricin's would provide new insight into the threats to service implementation but also, because service plans were 'on hold' when the fieldwork was carried out, it might contribute to an understanding of the factors critical to future HWC development for people with dementia in Ireland.

A sixth potential case study scheme was already known to me from my work in the HSE: I had visited it and had spoken to the person who drove its development. Like the other identified HWC schemes, it was planned to provide accommodation and care services for older people with high dependency needs, including people with dementia. The outcome for this scheme is different again; after operating for a number of years as a HWC scheme, it was subsequently registered as a nursing home under the Irish nursing home regulations. (I would say *converted* into a nursing home except that there does not appear to have been any conversion of physical facilities involved.) It would have been extremely interesting to find out what led to the decision to turn this scheme into a registered nursing home, what particular set of circumstances were involved. Unfortunately, the key decision maker did not wish to be involved with this research and so this scheme could not be included in this study.

Yin suggests that clarification is required in order to distinguish the cases chosen for case studies from other 'external data' (2009:29). The distinguishing feature of all of the case study schemes selected was the fact that they included people with dementia in their target group. They were chosen because of the insight they could provide into the factors that influence the development of HWC for people with dementia which is the focus of the study. All of the identified case study schemes were developed within the Department of Environment framework for the development of social housing for people with special needs (See Chapter 2) which applies only to developments carried out by approved voluntary housing associations, and so this became another distinguishing feature of the case study schemes. Development of all of the case study schemes involved the participation of voluntary housing associations, the local authorities and the HSE (previously the health boards) at some level and this is a further defining characteristic.

Local authority sheltered housing schemes were not included in the study because there is little evidence to suggest the existence of high support services and none to suggest the existence of dementia specific services in local authority housing schemes in Ireland (Cullen et al 2007, ICSH 2011).

### *3.2 Brief description of the case study HWC schemes<sup>7</sup>*

Four of the HWC schemes selected for this study, O'Connell Court, Cherryfields, Anam Cara and Mount Bolus, can be described as 'shared housing' or 'congregate housing' units (Howe et al 2013). In each of these schemes, accommodation is provided in single en suite bedrooms as opposed to separate apartments, and residents share the use of communal areas used for dining, social activities and the provision of other services. From the outside, they could be mistaken for nursing homes.

O'Connell Court services have been situated in a hotel that was vacated by its previous owners since 2011; from 1989 to 2011 O'Connell Court was located in a former convent that is over one hundred years old. There are 50 en suite bedrooms and other facilities include a television room, an activity area, staff offices and storage rooms. Upstairs there are large function rooms and additional bedrooms that are not used because they cannot be accessed by lift. All residents are eligible for social housing, the majority would be classified as homeless and a large number receive out-patient services from the Psychiatry of Old Age services in Cork. There is a staff ratio of 1 to 17 residents. Only about 5-10% of current residents are people with dementia, although the percentage was at one time much higher.

The Cherryfields and Anam Cara Housing with Care units are purpose built, two storey facilities built to high specifications. Cherryfields opened in 2006 and Anam Cara in 2007. Both are run by the FOLD voluntary housing agency and they each accommodate 56 residents including 27 people with dementia on the ground floor and 29 'frail' older people on the first floor. Each unit has two day centres with adjacent activity rooms, disabled toilets and kitchen facilities; communal areas include sitting rooms on each floor, a library/computer room and a small bar only used on special occasions. Small dining areas for 8 people are provided for residents living on each corridor. Cherryfields and Anam Cara were designed to be disabled friendly and to promote a safe environment for the movement of people with dementia; assistive technology including bed sensors, 'wander alerts' and 'fall alarm pendants' are used to support individual residents with dementia. Three two bedroom bungalows were built on the periphery of the Cherryfields unit and the intention was to use them for couples where one person had dementia. These plans were never realised and the bungalows now house tenants who are the responsibility of the local authority and not FOLD. The staff ratio in the FOLD units is 1 to 8/10 residents upstairs and 1 to 5 downstairs where people with dementia live.

The Mount Bolus High Support Unit is a modern purpose built two storey building that is disabled friendly, but no specific design features or technology were incorporated in the plans specifically

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<sup>7</sup> See Appendix 1 for more detailed description of each of the case study schemes.

to address the needs of people with dementia. Although people with dementia were included in the target group for Mount Bolus, no beds were dedicated exclusively to people with dementia. It is spacious and was built and furnished to a high standard. There are 30 single en suite bedrooms, a lounge area for residents and guests, a large dining area, a library, activities room and treatment room. Other facilities include staff offices and a chapel. When the unit opened, staff included a manager, a small number of care assistants and volunteers from the community including housing association members. Mount Bolus opened in May 2009 and closed in September of the same year. Mount Bolus remained vacant until the Acquired Brain Injury organisation signed a lease to use the premises as their Midlands base of operations.

St. Bricin's is different from the other case study HWC schemes, first because as noted earlier it was never built and second because it was originally planned as a sheltered housing scheme; only later were the plans changed to include dementia services to be situated in a separate, purpose built facility adjacent to the sheltered housing scheme. There were to be 64 one bedroom apartments and 6 two bedroom apartments in the sheltered housing scheme targeted at older people capable of independent living. Central to the plans for St. Bricin's was a day care centre attached to the scheme to provide meals, assisted bathing, medical treatment, hairdressing and other services to sheltered housing tenants as well as to older people from the surrounding community. A 12 bed 'Respite Unit' for people with dementia was to be managed and staffed 24/7 by the Alheimers Society of Ireland (ASI) and would feature 'a secure sheltered environment with its own garden area, individual bedrooms and a shared kitchen, dining and living room' (Irish Times 5 June 2007:4). Planning permission was secured in 2008 but service development did not proceed beyond that point in spite of further protracted negotiations.

The case study schemes described above were all planned as inter-agency service development initiatives involving voluntary housing associations, the local authorities and at some level, the health boards or HSE. All of the voluntary housing associations involved in the case study schemes were eligible under CAS funding regulations to receive up to 90% of approved capital costs on condition that they take at least 75%<sup>8</sup> of their tenants from the local authority housing list (DOE 1995). All had developed social housing projects before, although FOLD's prior experience was limited to Northern Ireland. Dedicated dementia services were included in the plans for Cherryfields, Anam Cara and St. Bricin's. Mount Bolus services were targeted at frail older people including people with dementia and dementia services in O'Connell Court evolved out of already existing HWC services for homeless older people.

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<sup>8</sup> In November 2007 CAS funding limits were raised to cover 100% of costs provided all tenants are eligible for social housing. For those housing associations wishing to retain nominating rights for 25% of tenants, an upper limit of 95% of costs applies (ICSH 2008).

Case studies can be done on individuals, groups, institutions or, as in this case, on an innovation or service [Yin 2009]. Stake observes that cases should be chosen on the basis that they offer the best opportunity to learn about the research topic [in Denzin and Lincoln 2000:446]. The selection of the cases for this study was dictated by the research questions; they provided the best opportunity to pursue HWC development for people with dementia in Ireland.

Table 1 Case study schemes selected for the study

Case Study Scheme	Location	Date opened
O'Connell Court	Togher, Cork (previously Cork City)	1989
Cherryfields	Hartsdale, Co. Fingal	2006
Anam Cara <sup>9</sup>	Glasnevin, North Dublin	2007
Mount Bolus	Near Tullamore, Co. Offaly	2009
St. Bricin's	North Central Dublin	

### 3.3 Contact with participants from selected case study HWC schemes

Senior officers in the housing associations that hosted HWC development in Cherryfields, Anam Cara and O'Connell Court were approached for permission to use those three facilities as case studies for this dissertation. Telephone calls were made and documentation sent with information about the research and ethics committee protocols (See Appendix 3). Representatives from the housing associations involved in the Mount Bolus and St. Bricin's initiatives as well as participants from the HSE and local authorities were approached individually to obtain their agreement to participate in the study and the case studies were compiled from the information collected from individual interviews. Information letters and consent forms were sent to all participants prior to interviews.

### 3.4 Application for Ethical Approval

Approval was sought from the Research Ethics Committee, School of Social Work and Social Policy, Trinity College Dublin. Approval was granted on 11 October 2010 with minor modifications which were carried out before the fieldwork commenced.

## Section 4 Selection of participants to be interviewed

Stake recommends the purposeful sampling of participants 'through whom the case can be known' (in Denzin and Lincoln 2000:439). The focus of this study is on HWC service development

<sup>9</sup> Cherryfields and Anam Cara are operated by the same voluntary housing association (FOLD Ireland).



for people with dementia and the factors that influence it, and it aimed to capture the views of multiple stakeholders in order to shed light on the complexities involved in service development. In order to answer the research questions, it was necessary to talk to people who conceived of the idea to develop HWC for people with dementia, people who were involved in planning the case study schemes and those involved in the implementation of plans including HSE local managers, community nurses and consultant physicians in geriatrics and psychiatry. The agencies involved in the case study scheme developments included the local authorities, housing associations and the HSE (formerly the health boards). The process started with the identification of individuals known to me to have been directly involved in the development of HWC services in the FOLD and O'Connell Court schemes.

For the FOLD schemes, these individuals were HSE officers who had worked in older people's services in what was formerly the Northern Area Health Board (NAHB) and who I believed had the knowledge and experience necessary to answer questions about HWC service development that is the focus of this study (Stake 1995). For O'Connell Court, the person who represented O'Connell Court on the HSE sheltered housing committee (chaired by me) was selected for interview in the first instance. 'Snowballing' was then used for sampling study participants; during interviews for both the FOLD schemes and O'Connell Court, study participants were asked to recommend others who they believed should be interviewed, and a number of study participants were added to the list of interviewees through this 'snowball' effect (Robson 1993).

The HSE stakeholders initially selected for interview suggested others in the HSE who should be interviewed, and these included both local managers who had been charged with implementing development plans and department heads responsible for the provision of services to residents in the case study schemes, for example community nursing, geriatrician and out-patient psychiatric services. HSE participants also identified the names of both the FOLD agency manager and the local authority officers most closely involved in the FOLD developments. They in turn suggested others from their respective organisations. For the O'Connell Court case study, the method of selecting those for interview was the same; the first person interviewed was asked to suggest others who then had other suggestions. The local authority stakeholder who had been involved in developing O'Connell Court was retired and unavailable for interview.

Reference was made to Mount Bolus during interviews with both housing and health sector participants about the FOLD and O'Connell Court schemes and in the course of these interviews an HSE officer was identified as having been involved in the plans for Mount Bolus; this person was selected for interview. I already knew the local HSE administrative officer from the area who was working in the same position when Mount Bolus was built, and that person was also included

in the list of people to interview. She gave me the name of another HSE officer who had been involved in the Mount Bolus initiative. I did not have the name of anyone from the housing association and so I searched the internet and identified a telephone number for the housing association involved. I spoke with someone who referred my request for an interview to the housing association committee. In the meantime I sent information by email giving background to the research, the research methodology and ethical committee protocols. A consent form was included (See Appendices 4 and 5). Two committee members agreed to be interviewed, but ultimately only one came forward. No local authority officer was interviewed because the focus of my interest in Mount Bolus was on why it had closed and the local authority were not implicated in that decision.

The name of the housing association representative considered to be most involved in the St. Bricin's initiative was given to me by a local authority participant during an interview. The other St. Bricin's case study participants were interviewed in connection with the FOLD case study interviews; there was overlap because of Dublin City Council's involvement in both schemes and because St. Bricin's is situated in what was the NAHB where the FOLD schemes are also situated.

Hammer and Wildavsky recommend that retired people be interviewed because they are more likely to be available and because they have a wealth of experience from which to draw (1989). The seven study participants who were retired from the positions they held during the development of the case study schemes were generous with the time they gave for interviews.

In order to give a wider perspective to the issues relevant to HWC development for people with dementia, other experts or key informants (Yin 2009) were interviewed for this study. Key informants from DOE, the Department of Health and other government agencies were selected because they held positions that include national responsibility for older people's housing or health; experts from the special interest groups representing people with dementia were chosen because the thesis topic is HWC for people with dementia; a representative from the Irish Council for Social Housing was selected because all of the case study initiatives were developed by social housing associations, and others from academia and other agencies were selected because of their interest or stake in supported housing development for people with dementia from a policy or service planning perspective (Yin 2009). Ireland is a small country and because of the network that I built up over the years through my job in the HSE, my experience on the National Council of Ageing and Older People, committee work for the Alzheimer Society of Ireland and through teaching and research at TCD, it was not difficult to identify the people with a stake or interest in this narrow service area. For example, it was easy to identify the individuals with responsibility for

voluntary social housing within the DOE and the local authorities; the individuals leading special interest groups representing people with dementia were similarly easy to identify.

Consultation with former colleagues was also very helpful. Many of the study participants from the HSE in particular were already known to me and I was familiar enough with the structure of housing and health services to determine which other individuals would be of most help to the research (Hammer and Wildavsky 1989). This was particularly helpful to gaining access to key individuals at the outset of the study. Table 2 details the overall number of participants selected for interview. Table 3 provides a breakdown of all participants from the HSE.

Table 2 Total number of participants by agency/group N = 43

HSE	Local Authority	Housing Association	Experts	Total
23	4	8	8	43

Table 3 Breakdown of HSE study participants from all case studies N = 23

HSE Officers Admin Background	HSE Officers Nursing background	HSE Officers Other health professional background	Nurse manager	Consultant physicians	Other	Total
4	4	4	2	5	4	23

In the text the expression 'health professional' is used to refer to HSE participants (administrators, service managers and fieldworkers with a background in the health professions to distinguish them from HSE officers with mainly administrative responsibilities; the health professionals interviewed include nurse managers, consultant physicians as well as social workers and community workers who are not identified individually as such for purposes of anonymity.

Table 4 provides details about participants selected for the Cherryfields and Anam Cara case studies.

Table 4 Participants from the Cherryfields and Anam Cara case studies

Case study	HSE	Local authority	Housing Association	Experts	Total
Both FOLD schemes	13	4 (1retired)	5	4	26
Cherryfields only	4	1 - Fingal Co Council	1		6
Anam Cara only	3	3 - Dublin City Council			6

Cherryfields and Anam Cara are HWC schemes operated by the FOLD Ireland voluntary housing association. They were planned at the same time and developed by FOLD in partnership with the HSE (then Northern Area Health Board) and the local authorities. Many of the participants selected for interview were involved in both the Cherryfields and Anam Cara initiatives; for example, of the five FOLD officers interviewed for this study, four had been involved in the development of both schemes while one (a local manager) only had experience of Cherryfields.

Of the thirteen participants from the HSE interviewed for the FOLD case studies, four only had experience of Cherryfields and the experience of three HSE participants was limited to Anam Cara. Four local authority participants were interviewed including one from Fingal County Council (involved in the Cherryfields initiative) and three from Dublin City Council (involved in the development of Anam Cara and St. Bricin's). There was also some overlap with respect to expert participants who in some cases had direct knowledge of more than one of the case study schemes, for example the DOE participant had knowledge of all five case study schemes and one HSE officer had been directly involved in the FOLD initiatives but also had experience of Mount Bolus and St. Bricin's.

Table 5 Participants from the O'Connell Court, Mount Bolus and St. Bricin's case studies

Case study	HSE	Local authority	Housing association	Experts	Total
O'Connell Court	7		2	1	10
Mount Bolus	4		1	3	8
St Bricin's	2	2	1	1	6

#### 4.1 Sampling Frame

Of the forty-nine people approached for interview, two senior officials from the Department of Health and Children declined as did two senior administrative officers (one retired) and one consultant physician from the HSE. One local authority officer had moved jobs and did not wish to be interviewed. The other person who could not be reached for interview was an already mentioned retired local authority housing officer from Cork.

Although the original intention was to do so, older people resident in the case study schemes were not interviewed for this study. Time considerations necessitated that the scale of the study be reduced and also the focus of the study became more and more confined to an analysis of the factors that influence HWC service development and less on perceptions about the role of HWC

as a service model. Rather than capturing the experience of residents or their families, the research focused on the service development process and is written mainly from the perspective of administrative officers, service managers and others with knowledge and experience of housing and health service development in Ireland. While older people's views about HWC as a long term care alternative should be an important consideration when new services are being planned or evaluated, this was not the objective of this study and so older people were not included in the list of people to be interviewed.

The largest group represented in the sample of those selected for interview (See Table 2) are administrative officers and health professionals in the HSE (or former health boards). This reflects the easy access I had to former colleagues but also the high turnover of HSE managers during the period when the FOLD schemes in particular were being planned and developed; it was at this time that the health services were being restructured to form the HSE and there were new posts created and considerable movement of staff. It also reflects the critical role played by the HSE in HWC development, as it is the addition of intensive care and support services that defines the case study schemes and marks them out from other housing services for older people. The HSE is assumed to be responsible for either funding these additional services or providing them directly (See discussion in Chapter 5) and because of this, the participation of HSE stakeholders was particularly important to explaining how the case study HWC schemes developed when in most other places in Ireland, they did not.

The data on what made the early development of O'Connell Court possible was largely derived from interviews with two people who were part of the group who set up services in 1989. None of the other participants interviewed for the O'Connell Court case study (all from the HSE) played any role in planning or setting up the original scheme. The data on service implementation in Chapter 5 is heavily reliant on interviews with one individual from the housing association who has been directly involved with O'Connell since 1989. The other study participants in the O'Connell Court case study, all from the HSE, were involved either in providing HSE services to O'Connell Court over the years or in administering HSE funding to the scheme. Although HSE participants corroborated much of information provided by the central housing association participant, it needs to be kept in mind that the data for O'Connell Court lacks the depth of the data from the FOLD case studies in particular.

The data from Mount Bolus and St. Bricin's is similarly limited compared to the data from the FOLD case studies. Only one person from each of the housing associations involved were available for interview and no local authority representatives were interviewed for Mount Bolus. There were however four people from the HSE and three from the housing sector with enough

knowledge of the Mount Bolus project to be able to present different perspectives on its development. The limited number of participants consulted about the St. Bricin's initiative reflects the fact that the scheme never reached the implementation stage.

## Section 5 Research Design

Case study research involves the collection of data from multiple sources of information in order to show different perspectives on the issues being studied (Creswell 2007:74). The research design strategy developed for this study included the review of available documentation, site visits and in-depth face to face interviews with the people who were involved or had a stake or interest in the development of the case study schemes. The interviews provided most of the data for the research study.

### 5.1 Documentary Data

A request was made for any service development proposals or position papers that might have been written about the HWC schemes, minutes of meetings, correspondence or other documents that would contribute to an understanding of the factors that influenced service development. Table 6 lists the type of documents which were made available to me for each case study and also the date(s) of site visits.<sup>10</sup>

Table 6 Dates of site visits and list of documentation for each case study scheme.

Case study scheme	Date of site visits	Documentation available
FOLD: Cherryfields	02/03/2011 31/03/2011	FOLD annual reviews, correspondence relating to the construction of Cherryfields and Anam Cara, policy handbook, press releases, Service Level Agreement.
Anam Cara	14/02/2011 13/04/2011	NAHB minutes, position papers, reports, correspondence and newsletters, brochures, press releases
O'Connell Court	04/04/2011 09/02/2012 06/05/2013	Service Level Agreement, budget statement, strategy development proposal, application forms, brochure
Mount Bolus	19/7/2011	Press releases, local newspaper articles, Sisters of Mercy website
St. Bricin's	10 June 2013	Dublin City Council minutes, national newspaper articles, correspondence, position papers

<sup>10</sup> As St. Bricin's has yet to be built, a visit was made to see the existing local authority scheme and the neighbourhood in which it was situated.

Table 5 shows that the amount of documentation made available for each case study scheme varied considerably. However, even when documentation was sparse, what was reviewed was significant because it helped to create an understanding of the exact nature of the planned case study schemes, the rationale for their development and also of the ethos and culture of the housing associations involved in their development (Bryman 2008). In many cases the documentation that was made available later augmented and corroborated evidence from interviews with stakeholders (Yin 2003).

Much of the documentation made available by FOLD housing association managers was confined to details about the planning and construction of Cherryfields and Anam Cara facilities. For example it included correspondence relating to architectural plans and technical issues that arose during the early planning and construction stages. These documents contributed to an understanding of the role played by FOLD housing association at the early stages of the Cherryfields and Anam Cara projects. Other FOLD policy documents deepened understanding of the HWC model, its ethos and the practical implications for staff and residents.

NAHB documents include minutes of 'FOLD meetings' held prior to the opening of Cherryfields, correspondence, a draft Service Level Agreement (SLA) and also a number of position papers that were prepared for presentation to the NAHB Board at the early planning stages. The position papers were of particular interest because they were prepared by NAHB officers with the purpose of making the case for the development of the FOLD initiatives (Bryman 2008) and they support evidence presented by NAHB stakeholders in interviews (Yin 2009). Letters to legal advisors and others confirm the information offered in interviews regarding barriers that had to be overcome in order to implement FOLD plans. Additional press releases and NAHB journal articles helped to clarify the timelines for the FOLD developments.

As shown in Table 5, the documentary evidence pertaining to O'Connell Court included brochures, a Service Level Agreement with the HSE including a budget statement, and a 'Strategic Development' proposal to the HSE to cover the period 2008-2011. The O'Connell Court documentation confirms the commitment of the voluntary housing association to the provision of HWC services to vulnerable older people, outlines admissions criteria and also substantiates statements made in interview about O'Connell Court's financial situation. The 'Strategic Development' document was helpful to understanding the perceived potential for future service development.

Documentation available from Mount Bolus was limited to a small number of press releases and articles from local newspapers and this may be at least partly a function of the fact that formal negotiations never took place between the HSE and the housing association. However, the little

documentation that was available helped to put the Mount Bolus initiative into local context, and it later confirmed remarks made by participants especially about the aims and objectives of the scheme as originally planned (Bryman 2008).

In the case of St. Bricin's, documentation made available by Dublin City Council was most helpful to providing information about the sequence of events that transpired at all stages of the development of the HWC project and the issues that arose along the way. National newspaper articles and the minutes of meetings of the Central Area Committee of Dublin City Council which is charged with making motions with respect to planning applications were also useful to tracking events during the planning period often corroborating what was said in interviews with St. Bricin's participants.

### *5.2 Site visits*

Site visits are a part of the detailed, in-depth data collection associated with case study research (Creswell 2007). Visits to the FOLD, O'Connell Court and Mount Bolus case study sites were critical to creating the context for discussion with relevant stakeholders about HWC service development (Yin 2009). Visits involved 'descriptive observation' (Robson 1993:200) of the facilities and service operations in each scheme; notes were taken and all of the visits contributed to a better understanding of the HWC model. Site visits to the FOLD schemes and O'Connell Court were helpful to understanding how HWC services work to deliver services to people with dementia. Yin observes that in case study research focused on a contemporary phenomenon, 'contextual conditions are highly pertinent to the phenomenon of study' (2009:18). From this perspective there was a lot to be learned from visits to the case study sites in which the factors identified in the research were manifest (Stake in Denzin and Lincoln 2000:439). For example, the visits contributed to a better understanding of the relationship between location and service take-up, the practical implications of funding on service quality, and of the implications of situating a HWC scheme next to a nursing unit.

Detailed notes were taken during the site visits which provided background information necessary to understanding the complex set of factors involved in HWC development across different 'real-life' settings (Yin 2009). A visit to the St. Bricin's site was made at a late stage in the research in order to see the Dublin City Council sheltered housing scheme that St. Bricin's was meant to replace and to get a feel for the neighbourhood in which it is situate



### 5.3 Semi-structured interviews

Most of the data gathered for this study came from in-depth semi-structured interviews with the forty-three<sup>11</sup> people who participated in this study. Kvale and Brinkmann describe research interviews as professional conversations ‘where knowledge is constructed in the inter-action between the interviewer and the interview...an inter-change of views...’ (2009:1). Hammer and Wildavsky suggest that semi-structured interviews can be characterised by what they are *not* as well as what they are. ‘Closed interviews have fixed questions... while semi-structured interviews are open-ended and everything is provisional’ (1989:57). Semi-structured interviews allow the interviewer the freedom to ‘try out numerous questions’, change them and make ‘follow-up queries’ and the objective is always to develop questions best suited to the research project (Hammer and Wildavsky 1989). Yin more succinctly defines open-ended interviews as ‘guided conversations rather than structured queries’ (2009:106). He goes on to suggest that case study interviews require that the researcher operates at two levels ‘satisfying the needs of your line of inquiry’ while at the same time giving those being interviewed the chance to offer their own insights and opinions (2009:107).

In the context of this study, semi-structured interviews accommodated participants' different professional and occupational backgrounds and their work settings and allowed questions to be tailored to account for these differences. They facilitated the gathering of data of sufficient breadth and variety to answer the range of research questions posed by this study (Denzin and Lincoln 2000:652). Semi-structured interviews gave study participants the opportunity to elaborate on questions raised and also to introduce new issues or views into the discussion that might otherwise have been missed, and this was particularly important in the early stages of the fieldwork. Semi-structured interviews facilitated the use of a flexible ‘emergent’ approach to data collection (Charmaz and Belgrave 2012). Issues that emerged from interviews could be immediately pursued, and they could also be followed up in subsequent interviews with other participants. In fact in three cases, study participants were interviewed (face to face) more than once in an effort to dig deeper into the detail offered during the first interview (Charmaz and Belgrave 2012:682).

### 5.4 Arrangement of interviews

Telephone calls were made to the majority of study participants outlining the study’s aims and objectives and the reason their views were being sought; in all cases, they were told that a formal letter giving more information about the study and the study protocols would follow and that a

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<sup>11</sup> Data from interviews with a number of participants was used in more than one case study.

consent form would be included with this letter (See Appendix 5). No interviews took place until candidates received this information and signed consent. In cases where direct contact was not possible, the documentation was sent first by email with a request for a meeting, and interviews were sometimes arranged through an intermediary (usually an administrative assistant) or through subsequent emails. Once a date for the interview was arranged, study participants were asked to name a venue as well as a time that suited them. Most interviews took place in participants' offices; interviews with retirees took place in a range of places from former workplaces to hotels.

It was intended that interviews would last no more than one hour and be recorded using an Olympus Digital Voice Recorder. Interviews were transcribed by me as soon as possible after each interview. Italics or capital letters were used to indicate emphasis placed by participants on certain words or phrases during interviews and participants' names are anonymised although the organisation that each represents is noted in abbreviated form.

## **Section 6 Ethical considerations**

All interviews were carried out within the framework of conditions required for ethical approval in the School of Social Work and Social Policy, Trinity College Dublin. Initial contact was made either by telephone or email to give prospective candidates a general idea of the study that was being undertaken and to tell them that a formal information letter requesting their participation would follow. Information letters were sent to those who expressed an interest in the study containing a brief outline of the research, the interview protocols and study ethics (Appendix 3). Participants who then agreed to be interviewed were asked to sign a consent form (Appendix 5) before interviews took place, and each participant was assured that their participation was voluntary and that they could withdraw from the research study at any time. Participants were assured that the research would not harm them, that information collected would remain confidential and that every effort would be taken to protect the anonymity of those interviewed. No names would be used and nothing of a personal nature would be written about them in the research findings. Permission was requested and consent granted from each participant to use the voice recorder during interviews. Interview recordings and transcripts will continue to be subject to Data Protection guidelines on confidentiality and security following submission of the final PhD dissertation. In the meantime, all information from the study has been stored in password secure computer files and locked filing cabinets in my home office.

## 6.1 Anonymity

Yin notes that the issue of anonymity in case study research 'can be raised at two levels: that of the entire case (or cases) and that of an individual person within a case (or cases)' (2009:181). He considers that 'anonymity is not... a desirable choice' at either level in case study research.

Not only does [anonymity] eliminate some important background information about the case, but it also makes the mechanics of composing the case difficult. The case and its components must be systematically converted from their real identities to fictitious ones, and you must make a considerable effort to keep track of the conversions. The cost of undertaking such a procedure should not be underestimated. [2009:182]

Wiles et al found that issues of anonymity were particularly problematic for researchers conducting 'studies of organisations or communities, applied research and evaluations' (2008:423) and they even suggest that anonymisation can have a negative impact on the integrity of research data which has implications for both 'the transparency of research and for assessments of reliability and rigour' (2008:426).

One compromise is to protect the identity of individual case study participants while accurately identifying the case (Yin 2009:181) and that is the approach that was taken for this research. The decision was made to use the names of the case study schemes in the dissertation, although the identities of individual participants would be protected as much as possible. This decision was made with reference to the fact that Ireland is a small country and HWC development is extremely limited. It would have been extremely difficult to examine the factors that influenced the development of the case study schemes without giving away enough information for them to be identified. In interviews with participants from both the housing and health sectors, there was a considerable amount of cross referencing to the case study schemes which were already familiar to participants in the housing sector especially but also to many in the HSE. The case study schemes were well known as were the problems they experienced during the service development process.

Wiles recommends that if confidentiality cannot be guaranteed, individual participants should be alerted to this as part of the consent process (2012:2) and the same principle can be applied in the case of anonymity. From the outset of this research, participants were told that the names of the case study schemes would be used. FOLD referred the matter of participation in the study to their Board and formal agreement was given to use the FOLD scheme developments as case studies. The key stakeholder in O'Connell Court housing association gave consent for O'Connell

Court to be included in the study. Committee members from the housing association that developed Mount Bolus agreed to participate in the study and understood that Mount Bolus would be named in the dissertation. The key housing sector stakeholders involved in St. Bricin's similarly consented to participate on the basis that St. Bricin's would be identified as one of the case studies. Participants from the HSE were told at the outset of the study that the research would focus on specific identified HWC schemes and they consented to be interviewed in the full knowledge that the case study schemes that were the focus of the study would be identified by name. The individual from the sixth case study who declined to participate in the study may have been concerned that the HWC scheme in question would be named in the study but the issue of anonymity was not raised at the time.

Selected participants were asked to review drafts of sections of the dissertation at intervals during the writing up stage and these documents identified the case study schemes by name. The schemes were named in presentations given at the workshop in 2011 attended by many participants from housing and health and again at the annual conference of the ICSH in September 2013 prior to submission. Participants were never under the illusion that the case study schemes would be anonymised in the final report; they agreed to be interviewed in the knowledge that the case study schemes that were the focus of the study would be identified by name.

### **Section 7 Interview Schedules**

Two interview schedule templates were developed. The first interview schedule was developed for those individuals from housing associations, local authorities and the HSE who were involved in the case study initiatives and the second interview schedule was developed for the 'experts' selected for their wider perspective on the study topic (Appendices 7 and 8). Schedules were sometimes further tailored before interviews took place to reflect the particular situation of individual participants. All of the interview schedules included a set of general open-ended questions about broad issues (For example, What was your involvement in the development of the case study schemes? What factors facilitate HWC development? What challenges does HWC development present?) which provided consistency but also allowed participants to present their own unique perspective on the topic (Yin 2009). More structured questions were then used as probes to elicit information about issues of particular interest in the context of the study (Bryman 2008). Additional questions were asked about issues that emerged from participants' responses to questions on the interview schedule (Chamaz and Belgrave 2012).

Hammer and Wildavsky suggest that researchers begin their fieldwork by interviewing 'individuals most favourably disposed to being interviewed...who will provide a substantial base of knowledge to proceed' (1989:64). The first people interviewed were two former colleagues who were not directly involved in any of the case study schemes but who were health service managers with relevant experience and knowledge of older people's services in Ireland. Although the evidence from these interviews was incorporated into the general findings, they also functioned as pilot interviews at an initial stage when the research questions were still in the process of being clarified (Silverman 2011:197). These initial interviews helped me to gain confidence and they also pointed me in directions that I might not otherwise have taken in subsequent interviews.

In accordance with qualitative research approaches (Crotty 1998), interview schedules were changed somewhat as the research study advanced in response to new information that emerged from successive interviews. For example, broad questions asked at the early stages of the fieldwork about the perceived role of HWC were later replaced by more targeted questions about the service development process to reflect refinements made to the research questions over time. Questions became more focused as the interviews progressed and it became obvious which questions would best elicit data most relevant to the research questions.

### **Section 8 Reflexive critique of the interview process**

Creswell suggests that 'researchers bring their own worldviews, paradigms or sets of beliefs to the research project, and these inform the conduct and writing of the qualitative study... (2007:15). I came to this research with a bias towards the social model and the belief that HWC is more appropriate than nursing home care to meeting the needs of many vulnerable older people, including people with dementia. These beliefs are a product of my social work and social policy training and experience. I realised as the fieldwork progressed that I had approached the study hoping to find confirmation of my own beliefs and preconceptions. This 'personal dimension' that I brought to the research influenced the choice of topic, the questions posed to study participants and expectations with respect to the study findings (Gough 2003:23). This could have created bias in the data leading to 'predetermined conclusions' (Hammer and Wildavsky 1989:76, Chamaz and Belgrave 2012).

When I listened to the first few interviews that I conducted, I also became aware of a tendency on my part to seize on details that were of particular interest to me thus interrupting the natural flow of the interview. By essentially diverting the discussion away from the original question, I lost data that could have been very helpful to answering the research questions. Conscious of the danger of over influencing participants with my own views, (Finlay and Gough 2003). I later dropped some

questions from the interview schedule, worked to phrase my questions better and to improve my listening skills, and this helped to reduce any such bias.

Although I was not directly involved in any of the case study initiatives that are the subject of this study, the fact that many study participants were already known to me through my prior post as Director of Older People's Service needs to be acknowledged and the ramifications for the research in terms of potential bias need consideration. The advantages and disadvantages of qualitative researchers carrying out research on a group of which they are (or have been) a member are much documented (Hewitt-Taylor 2002, Asselin 2003, Rooney 2005, Dwyer and Buckle 2009, Costly et al 2010). It has been argued that insider status gives researchers legitimacy and acceptance by participants which can generate trust and openness and lead to 'greater depth to the data gathered' (Dwyer and Buckle 2009:58). Other advantages of being an insider-researcher include: 'greater understanding of the culture being studied..., an established intimacy which promotes both the telling and the judging of truth, [and knowledge of] the politics of the institution, not only the formal hierarchy, but also how it 'really works' (Bonner and Tolhurst 2002 in Unluer 2012:1). There is no doubt that understanding how the HSE 'works' made access to study participants easier in many cases. It gave me the advantage of being able to identify stakeholders who would either have the information I was seeking or be able to refer me to someone who did. It also made it easier to approach prospective participants and gain their consent to be interviewed. Only a small number of people known to me refused to participate in the study and it is possible that the number would have been larger if some participants had not felt under pressure to be a part of the study because they knew me. But this was not obvious from the alacrity and enthusiasm of the vast majority of those who agreed to participate.

Although there are advantages to being an insider research there are also disadvantages and the primary concern associated with insider research is that it can lead to loss of objectivity (Unluer 2012:1). It is argued that the conduct of insider research may

...result in an interview that is shaped and guided by the core aspects of the researcher's experience and not the participant's... Furthermore, its undue influence might affect the analysis, leading to an emphasis on shared factors between the researcher and the participants and a de-emphasis on factors that are discrepant, or vice versa.[Dwyer and Buckle 2009:58]

In the context of this study, because I was familiar with participants, there were times that I did not fully discuss issues with participants who were known to me because I assumed that I already understood their perspective. This resulted in the loss of data that might have provided balance

to the information that was collected. In other cases, participants' responses may have been influenced by what they believed I wanted to hear. For example, a careful reading of HSE participants' responses to the question 'Is there a role for HWC in the future long term care of people with dementia', reveals the inclination of most to give a positive response, even in cases where serious reservations are later expressed about HWC on further questioning. This may well have reflected participants' desire to please me which reinforced my own biases.

Dwyer and Buckle observe that the potential negative influence of the insider status of the researcher can be reduced with 'detailed reflection on the subjective research process, ...a close awareness of one's own personal biases and perspectives...an ability to be open, authentic, honest and deeply interested in the experience of one's participants, and committed to accurately and adequately representing their experience' (2009:59). As the fieldwork progressed, I became aware of the need to compensate for potential bias in the findings. The semi-structured nature of interviews allowed me to give participants more time to expand on their own perspective as distinct from my own. I self-consciously worked to make questions more open-ended, developed my listening skills and gave more time for response, and I became aware of the need to solicit opinions and views which at times were counter to my own (Yin 2009:107). In these ways, I worked to minimise the potential for bias in the study. As the fieldwork became more focused on the details of the service development process and less on participants' attitudes to HWC, my insider status became less of a problem; the data that emerged from the interviews sometimes took the research in directions that were not anticipated and this gave balance to any preconceptions or biases I held at the outset of the study.

I assumed that I already understood their perspective. I became acutely aware of this as the fieldwork progressed and tried to compensate by making the questions more open-ended and by being aware of the need to self-consciously solicit opinions and views which at times were counter to my own (Yin 2009:107).

This became less important as the fieldwork became more focused on the service development process and less on participants' attitudes to HWC. Over time a better understanding of the critical issues involved in HWC development was achieved as well as a better focus in the collection and organisation of the data (Kvale and Brinkmann 2009).

## **Section 9 Data analysis**

### *9.1 Analytic strategy*

Yin observes that 'the analysis of case study evidence is one of the least developed and most difficult aspects of doing case studies' and suggests that an analytic strategy is necessary in order to organise the large volume of data collected and decide what data should be highlighted and what data should be ignored (2009: 127-130). The most preferred strategy for the analysis of data generated by case study research is to use the theoretical propositions that provide a framework for the study to guide data analysis (Yin 2009:30). Guest et al note that 'theory, however implicit, gives direction to what we examine and how we examine it' (2012:8). Change theory was used to shape both the collection and analysis of data for this study which was undertaken on the assumption that the case study schemes represent a dramatic departure from the way that long term care services are normally delivered to older people in Ireland. Change theory influenced decisions about what data was to be collected and was also critical to the organisation and interpretation of the findings.

### *9.2 Thematic analysis*

Guest et al make the distinction between the analysis of words and data analysis using themes and codes, and they propose that the thematic approach is most appropriate to the analysis of data from studies such as this one in which the data is 'free-flowing' and typically elicited in 'unstructured or semi-structured interviewing or document analysis' (2012:9). Thematic analysis was thus chosen for this study; analysis involved the identification of themes or patterns that emerged from the data and the coding of data, defined by Creswell as 'reducing the data into meaningful segments and assigning names for the segments' (2007:148). He identifies the central steps of coding data as 'combining codes into broader categories or themes, and displaying and making comparisons in the data graphs, tables, and charts' (2007:148).

### *9.3 Overlap between data collection and data analysis*

The data analysis process employed in this study involved subjecting the data to a continuous process of organisation and management, reflection and interpretation (Yin 2009). There was some overlap between the collection of data and data analysis which is typical of case study research (Yin 2009). During site visits for example, the information being gathered was at the same time being processed (Robson 1993) and interpreted within the framework of the research questions and data from the other case studies. The interviews similarly involved both the collection and analysis of data; the responses of participants which were being recorded during interviews identified issues that inevitably invited comparison with the responses of other participants. This provided the context for the consolidation of data under different themes that



emerged from the interviews. Notes written after the interviews and the site visits and available documentation associated with the case study scheme developments provided the opportunity to put the data into better perspective; they helped to identify patterns or themes in the data but also identified gaps and questions that needed to be further pursued.

Data analysis became more refined when the interviews were transcribed. Listening to what was said during interviews allowed for further reflection on the information offered and provided the opportunity to hear things that might have been missed otherwise. In some cases, the transcriptions confirmed ideas remembered from the interviews; in other cases, they gave new insights. With the transcription of each successive interview, a general understanding developed of the many variables that influence HWC service development in Ireland.

#### *9.4 Organisation of the data using thematic analysis*

The data collected for this research included available documents, notes of observations made during and after site visits and transcripts from 46 interviews with 43 participants. The decision was made not to use computer assisted tools like NVivo for the analysis of this wealth of information. Yin observes that case studies pose particular challenges with respect to the use of such tools because they 'cannot readily handle' the diverse array of data collected (Yin 2009:129). Having taken an NVivo training course, I concluded that using NVivo would make the challenge of organising the case study data for analysis even harder than it would be otherwise and so the decision was made not to use it.

When the fieldwork concluded, data from all sources for each case study was first organised in tables under broad themes reflecting the research questions. So, for example, word tables (Yin 2009) were created for Cherryfields with the headings 'Factors that made service development possible', 'Factors that presented challenges', and 'Factors critical to future development', and relevant data from the Cherryfields case study was inserted under these headings. Tables using the same broad themes as headings were produced for each of the case study schemes.

The re-organisation of the data within each table was continuous throughout the data analysis process; data under broad themes was broken down and coded, and data was moved within and across tables. For example, under 'factors that created barriers to service development', revenue funding, resistance to the HWC model, location, access to community services and the challenges of working with the HSE were some of the sub-themes that were identified. Some data was discarded as the shape of the final study emerged.

The data in the tables produced for each of the case studies was then integrated with parallel data from the other case studies; for example, the information across case studies about the factors critical to HWC development was collated into a single table as was the data on barriers to

service development and on the factors critical to future HWC development. Data organised under each research question was then broken down into themes and sub-themes; for example under 'Factors critical to future development', the data pertaining to capital funding was grouped together as was the data on regulation. In some cases there was a further breakdown of the data as sub-themes emerged, for example under Attitudes to the HWC model, lack of understanding of the HWC model and resistance to the model were identified as sub-themes.

As the data analysis progressed, data from participants from each sector (voluntary housing sector, HSE, local authorities, special interest groups) was also in some cases grouped together to identify their different perspectives on particular issues. In this way, it was possible for example to develop an understanding of the housing perspective on future development as distinct from the perspective of stakeholders in the health sector. Using a technique referred to as 'cross-case synthesis', the findings across the five case study schemes were aggregated by themes but also by participant groups (Creswell 2007:156); cross case patterns were noted, some data was discarded and the data under some themes re-grouped and re-labelled. The process of making sense of the data involved continuous reading and re-reading of the transcripts alongside a reading of the notes from the site visits and also available documentation (Creswell 2007). The analysis of the data was necessarily influenced by my own knowledge and experience of HWC as well as by change theory which provided the framework for interpretation of the data and was critical to determining the way that the data was prioritised and organised (Yin 2009).

#### *9.5 Trustworthiness of the data analysis*

A very large amount of data was collected from a number of sources for this study. While this posed challenges at the data analysis stage, it also had the advantage of increasing the trustworthiness of the research by allowing for the triangulation of data (Denzin and Lincoln 2000) from many different sources in the voluntary and statutory housing and health sectors, from agencies providing services and those funding them as well as organisations representing the interests of people with dementia and their families. The use of multiple case studies, including one HWC scheme that had closed and another that was never built helped to enrich the findings by providing a range of service development scenarios. Multiple case studies were also critical to determining whether the issues that emerged in one case study could be generalised. This 'constant comparative method' helped to validate the findings (Silverman 2011). The incorporation of data from documentation, site visits and in-depth qualitative interviews with 43 participants contributed to what Silverman refers to as 'comprehensive data treatment' (Silverman 2011:280-281).

Lincoln and Guba suggest the importance of negotiating the meaning and interpretation of data with respondents who acted as sources of that data to confirm and verify working hypotheses (2000:41). Many iterations of the findings chapters were produced in the writing stage and sections of the findings chapters as well as the case study scheme descriptions were sent out to study participants who had already been interviewed for the purpose of 'member validation' (Silverman 2011:296). Factual changes were made to the text as appropriate. The workshop provided another opportunity to member check. 'Simple counts' of the number of study participants who expressed particular views and the sector they represent were also used in the text to enhance the credibility of the findings presented (Silverman 2011:296).

### *9.6 Summary of the data analysis*

The analytic strategy for this research involved using change implementation theory to guide the organisation and analysis of the findings. Thematic analysis was used to identify themes or patterns in the data and to code data into meaningful segments that could be combined and compared within and across case studies. The rigour of the data analysis was enhanced by the extensive volume of data collected from many different sources, by the 'multiple levels of data analysis' and by the use of member checking and triangulation to verify the accuracy of the findings (Crosswell 2007:45-47).

## **Section 10 Workshop**

At the end of the second year of this study, a workshop was organised with the objective of presenting preliminary research findings, getting feedback from stakeholders about the findings (Silverman 2010:388), raising awareness and generating discussion and debate about HWC for people with dementia. All participants interviewed for the study were invited to the workshop as well as others from the Health Service Executive, the voluntary sector and academia thought to have an interest in the topic. Study participants were told of plans for the workshop when they were interviewed and then formally invited subsequently by email.

A guest speaker from the Netherlands gave a presentation on Small Scale Housing for People with Dementia in the Netherlands and five study participants chosen because of the key role they play in older people's housing and health services planning and policy gave brief presentations giving their perspective on future HWC service development in Ireland. These included a senior officers from: the HSE, Dublin City Council, DOE, and representatives from the Irish Council for Social Housing and the Alzheimer Society of Ireland.

Although the workshop was planned to provide an opportunity to validate early research findings (Creswell 2007), this exercise was undermined by an over-ambitious programme that resulted in lack of time on the day for meaningful feedback or discussion. The presentation by the guest

speaker generated considerable discussion which took up time that might have been devoted to the preliminary findings. The fact that although over 70 people attended the workshop, many study participants did not or could not attend was another factor. However, the presentations confirmed early research findings from interviews and available documentation and also generated additional data concerning the priorities of the agencies represented with respect to future HWC development and the constraints on them that inhibited future development.

The workshop exercise cannot be described as participatory action research in the strict sense in that it was not aimed as diagnosing a problem and/or the development of a solution (Bryman 2008, Denzin and Lincoln 2000), but it does represent collective collaboration aimed at shaping the interpretation of the findings and at improving research reliability (Creswell 2007). The workshop also provided the opportunity to acknowledge the contribution of many of those present who had been responsible for HWC development in Ireland and it added to attendees' knowledge about alternative HWC models developed in the Netherlands.

### **Section 11 Summary of Methodology Chapter**

This chapter introduced the methodology which is employed in this thesis which aims to explore the factors that influence HWC development in Ireland. Qualitative research was chosen in order to address the complexities of HWC service development and the multiple perspectives of those involved. An instrumental case study approach was chosen because the focus of the research was aimed at exploring issues across case study schemes and not the particularities of any one single scheme. The use of case studies facilitated the collection and analysis of data from a number of sources about five separate HWC initiatives.

This chapter has provided a detailed explanation of the purposive approach to sampling used in this study to select both the case study schemes and the case study participants which was critical to answering the research questions. The ethical considerations that governed the study were discussed as were the limitations of the study including the potential for bias. The chapter concluded with a full discussion of the thematic analysis of the data including the workshop that was held at the end of the second year of the study. Although the study was not aimed at testing out change theory propositions, change theory was used to make sense of the findings by putting the events described in the data from individual case studies in a particular framework that could be applied across all of the case studies.

The next three chapters present the research findings. Chapter 4 analyses the data with respect to the factors that made the development of the case study schemes possible.

## Chapter 4 What factors made the case study schemes possible?

This chapter focuses on the combination of factors thought by study participants to have facilitated the planning of the case study developments. The findings from interviews with stakeholders, most of whom were directly involved in the planning and/or the development and commissioning of the five case study schemes, are presented. The findings from the two FOLD developments are combined because they were planned at the same time by the same people and FOLD Ireland manage and operate both schemes, using the same HWC service model. The data with respect to the FOLD schemes and St. Bricin's includes the views of housing association, local authority and HSE stakeholders. The data from O'Connell Court and Mount Bolus is limited to the HSE and housing association perspective. The FOLD schemes provide particularly rich detail because of the large number of relevant stakeholders available for interview.

In answer to the question, what factors made the development of the case study schemes possible, distinct themes emerged from the findings across all of the case studies. The first theme is the central role played by individuals in the housing and health sectors in the planning and development of the case study schemes and this is the focus of Section 1 of this chapter.

### Section 1 The Housing with Care Champions

Taylor et al define those leaders who are centrally involved in change implementation as 'champions' and observe that they are marked out by their commitment and motivation (2011:1). There was broad consensus among study participants that without the involvement of individual leaders who drove the case study schemes their development would not have been possible.

The 'champions' identified in the study included many study participants themselves, although they did not describe themselves in those terms. The champions were instrumental in marshalling the resources and enthusiasm necessary to the development of a new service model that did not fit easily into existing categories or frameworks (Kotter 1995, Heslin and Ryan 2008, Taylor et al 2011, Crosby and Bryson 2011). A FOLD participant observed that

[ LA2] ...quite often, if you ask the question, why some things haven't happened, it's because of the lack of somebody to drive it... A lot of it, believe it or not, is down to individuals, the behaviour of individuals.

The HWC champions identified from the data came from DOE, the local authorities and the HSE but also from the voluntary housing associations that hosted the new schemes. In the case of

Mount Bolus, individuals from the community also played key roles in promoting service development.

### *1.1 Cherryfields and Anam Cara champions*

The two FOLD schemes were driven by individuals from the ranks of senior management in both the NAHB (where both schemes are situated) and DOE and the fact that they held positions of authority in their respective agencies was considered to be particularly significant (HSE1, HSE8, HSE11, HSE13, F1, F2, LA1, LA2). One HSE participant observed that

[HSE 13] If it has the interest from the top of the organisation, it happens.

From the perspective of two local authority participants, early commitment from the NAHB to fund care services was the factor that was largely responsible for the realisation of the plans for the FOLD schemes. It was critical that the NAHB champions were able to make decisions to commit resources for service development.

[LA3] They were committed from the start, which is our biggest problem with any project we ever have – commitment from the HSE to provide necessary care packages, for the day to day running... What was different about it was that the HSE came in on top; they came in first.

An officer from FOLD was credited with having special powers of persuasion which helped to sell the concept of HWC in the Republic and inspire both the NAHB and in the local authorities to become active partners in the development of Cherryfields and Anam Cara.

[HSE9] What won it, I was there pushing and shoving, and then you had [name of FOLD housing association champion]. [She] is an energetic person full of life and could sell sand to the Arabs. That lady wears her heart on her sleeve, she was superb, believable, passionate.

[LA4] She's very forthright in her ethos and she's also very charismatic... If it's anybody who has spearheaded a whole different ethos by herself, she's done it and she's inspired loads of other people...

Not only did this FOLD senior manager provide the inspiration for the new service model, she also assumed the role of project manager during the planning and implementation stages, and this was crucial to keeping the project on track (LA3, F1, HSE9). She had previous direct experience of the HWC model in Northern Ireland and four participants spoke about her availability and willingness to show her counterparts in the Republic how it worked as well as the part she played in actually seeing the building projects through to completion (HSE9, HSE12, LA2, LA3). The fact that FOLD housing association had a service record and could point to already developed services was an advantage.

A former NAHB senior manager was cited by nine participants as the main driving force in the FOLD projects from the NAHB side (F1, HSE1, HSE3, HSE8, HSE9, HSE12, LA1, LA2, N4).

[N4] FOLD were lucky. [Senior manager] hit upon it and he liked the idea. And that's all. It was personal.

This person was in a very influential position in the NAHB and his energy and enthusiasm was infectious; one participant was able to describe the vision he communicated eight or so years previously in great detail.

[HSE 6] [His] idea was, look at an older housing estate, look at the residents, many are single, living alone in a row. All vulnerable but they all want to stay living there. There are security issues; they are afraid of being on their own. Wouldn't it be a good idea, when building a housing estate, to include a FOLD type accommodation in which people could still be independent. The old warden system with sheltered housing units but extended to include care and support. Politically, we should be looking at sites, possibilities... [In Ireland] their only exit strategy is into an institution.

Three other participants noted the same senior manager's commitment and ability to communicate a vision of the FOLD service model to others involved in the partnership venture.

[F2] [NAHB champion] was a great advocate of housing with care. He had visited a number of our schemes in the North of Ireland, had seen them in operation, had spoken to the residents, had spoken to members of the residents' families, was extremely impressed with the balance we struck. [He] was one of a number of advocates from within the HSE who had passion to see the model developed.

HSE participants identified health board local service managers and geriatricians who also played a critical role in making the FOLD schemes possible, especially at project implementation stage (HSE11, HSE13, F2, F5). NAHB local managers were particularly crucial to the integration of the new services into existing health services systems and structures (F2, HSE11) which proved to be very problematic and are discussed in the next chapter. The geriatricians were generous in their support to FOLD managers and staff by providing assessment and treatment services to FOLD residents (HSE 6, HSE7, HSE13, F2, F4).

According to eight of those interviewed, NAHB and local authority champions were very much influenced by visits to Northern Ireland where they could see the FOLD model in operation.

[HSE 13] You do a lot of selling initially but I think the fact that you could actually go and see what FOLD were operating [made the difference]

[LA 1] We were very impressed with the FOLD facility in Derry because it ticked a lot of boxes that nothing had ticked before.

[LA 4] We would have brought [housing officer] up to FOLD in the North of Ireland and he would have been very impressed, and he said, yes we'll work with them... People have to see to understand.

[HSE8] What had sold it to the Director of Nursing, myself and other people in NW Dublin in the early stages was the visit to Derry. So I suppose, it's almost like the doubting Thomas, when you see it in action.

Direct observation of the Northern Ireland FOLD schemes in operation helped to convince a number of key stakeholders in the NAHB and the local authorities that the FOLD model was worth replicating. But in order to progress the initial plans to implementation stage, many other people within the NAHB in particular had to be persuaded of its efficacy, especially those who would be expected to provide services to residents in the planned new units. Their cooperation was necessary to actually open and run the new units, but as one former senior manager observed, it was not to be taken for granted.

[HSE13] But you have to do the groundwork. It's not an easy thing, but I find that, once you put out the proposal to people, you get them to buy in, you get their interest, you get their commitment and you get all the bits and pieces, their time, their enthusiasm and it runs along.

The same person noted that every angle possible was used to promote the proposed HWC initiatives so that they would be prioritised for development within the NAHB.

[HSE13] [When we had decided to go for the FOLD model]... it also fitted in with, there was a lot of talk about North/South initiatives so it fitted in under that too. We had quite a number of axes. And anything else we could get to hook it on to, we did.

A number of stakeholders suggested that the champions from both the health board and the local authority were willing to take chances in order to progress development plans and this sometimes involved taking a liberal interpretation of existing rules and regulations (LA1, LA2, LA3, HSE13, F1).

[HSE 13] I suppose I had been in the system long enough to know that you have to be a little bit wily about how you get your innovative models up and running...We did push out the boundaries. The rest of it involved how to get around the system.



[LA 2] [Principal Officer in DOE] exercised flexibility with respect to the land, to allow us to take into account that there was a land price...All you need is a little bit of inflexibility and everybody drops tools and the opportunity gets lost...So we managed to push our way through it.

[F1] The local authority boundaries changed because the agreement was that if there was not enough applicants [for Cherryfields] in the Fingal area, that because Dublin City Council bordered that area, that there could be that flexibility. That's what makes these schemes work.

Rules and regulations that had been developed in a different context without reference to HWC were bent in order to circumvent the system in the short term in order to overcome obstacles and facilitate the development of a new hybrid service.

The individual champions identified from the FOLD case studies were instrumental in driving the new initiatives within their respective agencies, but they also needed the close cooperation of their counterparts in the other agencies involved in this partnership venture, particularly at the planning stage. The fact that it was forthcoming was noted by four participants as a factor that was critical to bringing development plans to fruition (F1, HSE9, HSE13, LA1). Particular importance was placed on the role that formal and informal partnerships played in the development of close personal relationships across agencies.

[HSE9] ...we had a strong relationship with Fingal Co. Council ...It doesn't happen like this in all areas. ...you'll hit roadblocks but you deal with it... The reason it worked in the end with all the minefields was mutual trust.

[LA1] Now around the same time we established regular meetings with the health board ...we began to know people. The establishment of relationships became a very important function because you were not dealing with an anonymous person in an anonymous authority. You could discuss their problems around the table. Also both sides were getting a greater understanding of the problems on both sides.

The strong coalition that developed between the individual champions from the NAHB, the local authorities and FOLD housing association was unique in the context of the case study HWC schemes. This was seen as a factor critical to the progression of the FOLD projects.

### *1.2 O'Connell Court champions*

One champion who was identified by 5 HSE participants emerged very prominently from the O'Connell Court case study findings (HSE01, HSE02, HSE04, HSE05, HSE06). She was a member of the small group of altruistic individuals who established the O'Connell Court voluntary housing

association, having already set up a number of community services for older people in Cork in the 1970's.

[OC1] There was a group of us, there's still three of us from the 1972 group that are still together on this... It's a core group of about 8 people. People who saw a need for services for older people, people who had a life experience of caring for an older person. Personal commitment and we had done our research...

The group were motivated by compassion for the vulnerable older people whom they had encountered as volunteers delivering community services in Cork City. But this person is marked out by her extraordinary commitment, leadership and drive to promote the human rights of older people, not only in the early service planning stages but throughout the history of O'Connell Court (HSEO1, HSEO4, HSEO6).

[HSEO1] And in the meantime there are people like \_\_\_\_\_ who, through the kindness of their heart as it were said, god almighty we have to do something here and they get on and do it.

[HSEO4] ... the ethos of O'Connell Court was very much generated by the individual who led it...

The evidence shows that this champion had strong beliefs and values that deeply influenced her desire to introduce a new approach to the long term care of vulnerable older people (OC1, HSEO4, HSEO5).

[OC1] ...the divinity in the person. The belief in the need for equality. Dignity of the individual. You're managing the place to facilitate their living rather than managing an institution to comply with legislation and your staffing levels. That's the vast difference. They have rights, they're the tenants and we are here to serve them.

The sheer determination and persistence of this one individual was believed to be critical to overcoming the problems that presented at every stage in the development and operation of O'Connell Court (HSEO1, HSEO4, HSEO6, HSEO8). She was willing to take risks and demonstrated extreme resourcefulness in trying to achieve her vision of HWC, particularly with respect to sourcing needed funding and implementing a person centred service model for what was seen as a very difficult client group. HSE participants in the O'Connell Court case study believed that that without this person, HWC services would not have developed in O'Connell Court and indeed would not still be in operation (HSEO1, HSEO2, HSEO4, HSEO5, HSEO6).

Three other groups were identified as having been influential to helping to progressing O'Connell Court development plans and they were the geriatricians and psycho-geriatricians who were willing to make referrals and provide follow up services after the scheme opened and housing officials in Cork City Council who facilitated access to CAS funding for the acquisition of the original premises (OC1, OC2). There was no mention of the health board in discussions with the nine O'Connell Court case study participants about the people who played an instrumental role during the planning stages of the development of O'Connell Court.

### *1.3 Mount Bolus champions*

In Mount Bolus, the HWC champions came from the housing association and from others in the community. As was the case in O'Connell Court, it was the volunteers involved in an already established service (in this case a sheltered housing scheme) who took the lead in driving this development. According to one HSE participant, this group of volunteers had a good track record of developing other services in the community (MB3).

[MB3] First of all, they're a very good group, a very good organisation. They had provided housing, just 10 houses for older people, individual housing units, sheltered houses. And they have managed that project, probably over 20 years at this stage. They also provide social houses for young families as well in the same area. Very good track record... In fairness, they're a very strong group.

Among them was a local politician who provided leadership that was critical to gaining approval for the project from the local authority; a Mount Bolus participant observed that this politician who was a member of the local authority was in a position to directly influence decision making and did so by 'hammer[ing] away at Council meetings' about the benefits of the project to the community (MB1). National politicians who came from the area were also credited with having a role in progressing plans for Mount Bolus. As one person put it

[M4]Everybody was involved at the time and they were all mad for it. And all had praise for it, especially the Government at the time. We had [Minister of State in DOH] at the time who was a key advocate of mental health and carers issues. [National political figure], this is his constituency. We got a lot of support from them.

The Mount Bolus project had the full support of the community including the local priest in this very small Midlands town (MB1, MB4). One participant noted that earlier successes with respect to raising funds for other smaller projects gave the community confidence to go further with plans that they saw to be in their own interest.

[M1] So when they came to the housing scheme, it didn't daunt them. And they believed they were doing it for themselves. You know what I was saying about the vision and the community need; the whole community bought into it.

Members of the Mount Bolus housing association took inspiration from other supported housing schemes that had been developed in other parts of the country, specifically in Counties Mayo and Limerick. Services in Limerick were of particular interest; they evolved out of an already existing sheltered housing scheme and the service delivery model was one that committee members believed could be achieved in Mount Bolus (MB1, MB4).

[MB4] And we were also put in touch with a nun in Limerick... who had taken over some kind of a structure in the town. And it kind of developed on an informal/formal basis where she was getting this grant from the Health Board at the time and converting it through the Home Care Packages and through the Home Help, and along with the rent allowances she was able to get from people, into kind of an informal development like this...She was the person who inspired the model.

The idea to provide accommodation to people who had emigrated from the area came from County Mayo where services had been similarly targeted at older people who wished to return to their home place, mainly from the UK (M1, M4).

Mount Bolus is unique among the case study schemes in having widespread support of the local population and this is perhaps a function of its location in a very small but close knit rural community. It generated considerable attention in the region and many people came forward to promote its development including local people who expected that they or members of their own families might one day become service users (MB1, MB4). This groundswell of community support was not a factor in the other case studies.

Although no one health board/HSE officer was identified as having assumed the role of champion of Mount Bolus, one health board manager who retired before Mount Bolus was built did play a supportive role at the early planning stages (MB1, MB2, N1). No champions from the local authority were identified during interviews with Mount Bolus participants, although the local authority obviously did play an important role by approving the allocation of CAS funding for the project.

#### 1.4 St. Bricin's champions

Champions of the St. Bricin's proposal came from Dublin City Council and the housing association involved, with the later involvement of the Alzheimer Society of Ireland (ASI)<sup>12</sup>. They had direct positive experience of HWC through their involvement in the FOLD developments and were keen to replicate the FOLD service model or something like it in St. Bricin's. However, once the local authority agreed to support plans for the scheme, most of the responsibility for progressing the plans for St. Bricin's fell to the housing association and to one person in particular who was committed to the project and persisted with it in spite of barriers that materialised along the way. This person had a belief in HWC which developed out of past education and professional experience with other client groups, including people who were homeless (SB1).

[SB1]I would have developed or pioneered [voluntary agency] transitional housing for homeless families and single people. And it was really using housing provision with a social care programme that was particular to the client group. And a lot of that model was successful working... And I suppose it was going back to the old social work model of the 19<sup>th</sup> century where you had housing with social care provided together.

A stakeholder from ASI became another champion of the St. Bricin's project and his enthusiasm for HWC reflects personal values and knowledge gleaned from long experience in dementia services. This person made the point very well that HWC could be used to avoid the premature and unnecessary admission of people with dementia to institutional care.

[N6]Working with people with dementia I've recognised that HWC is I think a viable option as a real alternative to staying in the community that you belong to. As opposed to moving out of your own environment into institutional care whenever there's a social or a health crisis, often far too early. And there's no turning back.

ASI were interested in expanding services to the St. Bricin's area where they had already identified a need for dementia specific day care (N6, SB1).

No one individual from the HSE was identified as central to plans for St. Bricin's although three housing participants spoke about the fact that a plethora of HSE officers attended planning meetings at every stage (SB1, LA2, LA3).

Study findings presented in Section 1 provide compelling evidence that a number of highly motivated and committed individuals played a big role in creating the direction, alignment and

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<sup>12</sup> The Dublin City Council housing managers who were involved in plans for St. Bricin's were also involved in the FOLD scheme initiatives, suggesting a commitment to HWC that transcended interest in any one individual project (LA2, LA3, LA4)

commitment necessary to introduce change (Pasmore 2011). While it will be shown in Sections 2 and 3 that the influence of champions was only one factor that made the development of the case study schemes possible, the evidence does strongly suggest that without the involvement of the individuals cited above, these projects would not have been developed. As one FOLD case study participant from the HSE succinctly put it, 'Why didn't we build ten of them in Dublin, including the Southside? Why didn't we build them in Cork and Galway? It goes back to people again' (HSE9).

The champions who drove the case study initiatives were motivated by the identification of the need for new services and that is the focus of the discussion in Section 2.

## **Section 2 Identification of a need for HWC services**

The findings in this section are divided as follows; in Section 1, the views of participants from the housing sector are presented and these findings are further divided into two sub-sections, findings from the local authorities and those from voluntary housing association stakeholders. Section 2 presents the findings from interviews with participants from the health sector. The division of the findings was done in order to reflect the fact that each group was approaching the case study scheme initiatives from a slightly different perspective which was shaped by the circumstances in which they found themselves at the time.

The findings show that all of the study participants from both the housing and health sectors who were directly involved in planning the case study schemes did so in the belief that the new HWC service initiatives would help to address certain challenges facing their respective agencies and would also address the identified unmet needs of vulnerable older people. They suggest that the pressure that these challenges put on their respective agencies helped to create the urgency necessary to progress these projects.

### *2.1. Housing perspective*

The crux of the arguments from both local authority and voluntary housing sector participants about the need for the case study schemes was that there was a group of older people whose needs could not be met in existing social housing settings and that this situation was causing problems for housing providers as well as for the tenants concerned (LA1, LA2, LA3, LA4, F1, F2, OC1, OC2, MB4, SB1).

### 2.1.1 Local authority perspective

Two local authorities were involved in the FOLD scheme initiatives, Fingal County Council were involved with Cherryfields, and Dublin City Council with Anam Cara (and subsequently St. Bricin's). Dublin City Council had a much larger proportion of older people in their population than Fingal and had a long tradition of providing sheltered housing, services which Fingal had not yet developed. In spite of this difference, their perspectives on the need for the FOLD schemes was very similar and housing officers from both local authorities spoke of the unmet needs of a significant minority of older local authority tenants (LA1, LA2, LA3, LA4).

[LA 2] ...the big issue that was constantly coming back to me ... was that many people needed much more than [what we could provide], they needed care. And the HSE weren't able to come in and provide the care... So what was really needed was the FOLD type experiment.

The situation in Fingal was perhaps more serious due to the complete absence of sheltered housing at the time, although the proportion of older people was still much smaller than in the Dublin City Council catchment area.

[LA1] ...people were living longer so the health problems they were beginning to experience were also causing problems. As things began to move on, we began to experience more problems with elderly, ill health etc. We didn't do sheltered housing; we didn't do warden services... People who became higher dependent had to move out of the housing.

A Dublin City Council stakeholder spoke of the unsatisfactory living conditions in the existing St. Bricin's sheltered housing scheme and the security risks posed to residents as a reason to progress the development of a HWC model.

[LA2] It was an old complex that needed something done to it. There were issues of security. I remember being up there for some man was murdered, in fact, up there. It was very open, old style complex, very little safety so the idea was, let's demolish this and start afresh or let's re-vamp it or refurbish it. But if we're going to do it, do it properly and get care in because we were conscious that many of the people in the complex were very very old and were getting older.

Concern about the health and safety of tenants figured in the thinking of local authority housing officers but so also did concern about the management problems created by some older tenants who exhibited anti-social behavior (LA1, LA2, LA3). Housing officers were getting complaints from neighbours about the eccentric or intrusive behavior of some older tenants and this put pressure on them to do something about it (LA1, LA2, LA3). They were also under pressure from local politicians who were receiving similar complaints from constituents living in local authority

housing schemes. The FOLD schemes were seen as a way of alleviating this pressure on both housing officers and politicians whose approval was required in order to progress development plans.

[LA 1] ... the politicians were open to accepting these new initiatives [because] They were seen as methods of solving problems that they were being faced within their clinics...[and they] did see it as providing a solution to problems that were manifesting.

Although it is likely that at least some of the troublesome tenants described had dementia, the need for dementia services did not figure specifically in the thinking of Fingal County Council housing officers when plans were being developed for Cherryfields (LA1). But the data shows that Dublin City Council participants had identified the particular unmet needs of tenants with dementia when they agreed to participate in the Anam Cara and St. Bricin's initiatives.

[LA2] [There was] a subset of those tenants who couldn't manage independent living. People with dementia and other health problems. So we came under big pressure then to find some way of re-housing those people and trying to get the health services to take responsibility for them was a big factor, and in many cases there was no place for them to go.

[LA4] ...it was very prominent in my thinking. You'd see it happening...and every time you looked at somebody who perhaps had a mental health issue you had to look beyond that issue and say, is this actually a dementia... there were people falling through all the cracks and ending up in sheltered housing, some of them with dementia...

The situation of some tenants with dementia was considered to be highly unsatisfactory and that provided another incentive to support the development of Anam Cara and subsequently St. Bricin's.

The fact that older people were having to move out of their council houses or flats in order to access needed health and social care services led to other problems for the local authorities associated with the difficulties involved in re-securing the possession of the houses of some of these people because of family opposition or legal reasons.

[LA1] And...they're not able to move back to their flat and we end up with a flat we can't take back because technically it belongs to the tenant that is in the hospital bed...

[LA3] For a local authority, that causes problems; you have vacant premises subject to vandalism but also you've nowhere to move the next person on the list. ...it could take a couple of years to surrender the tenancy.



Under-occupation was perceived by the Fingal participant as another problem that the FOLD schemes would help to resolve.

[LA 1]...at this stage we were talking about one person occupying a three bed house...they weren't able to manage the house themselves because they had become quite elderly, so we were trying to encourage them to downsize.

There were many young families on the waiting list for council housing with no place to go while individual older people were living in houses judged to be unnecessarily big for them (LA1). A related problem was that some council houses were being run-down because ageing tenants were no longer able to maintain them and this was a problem for both Fingal and Dublin local authorities (LA1, LA2 ). A Dublin County Council stakeholder observed that if these older people could be moved to someplace more appropriate, savings could be achieved.

[LA2] ...if residents are not getting the care they need, they allow their flat to get totally in bad order and it's up then to the local authority every now and then to do a major clean up. It's all the hassle that goes with that. For instances if care services are being delivered, that won't happen. It's caught much earlier, much earlier. Even with regard to costs, it's the human costs.

The Fingal participant who championed the development of Cherryfields also saw financial advantages to the scheme which presented an opportunity to acquire additional state funding for Fingal County Council with the added benefit that there would be no requirement for on-going revenue funding by the Council.

[LA1] When the Government would allocate money for social housing, so much would be allocated for voluntary and so much for the local authorities themselves. So in order to grab more of the kitty for Fingal, we got involved with the voluntary bodies...it was another way of increasing the housing stock for people in need... It was effectively what we'd call a 'self-financing' model. It didn't require any support from the Council in terms of a long term financial drain.

The Cherryfields initiative offered an opportunity for Fingal County Council to attract additional DOE capital funding with which to increase social housing stock in Fingal. As such it was a very attractive proposition.

Local authority participants had mixed motives for engaging in the FOLD and St. Bricin's projects. There was genuine concern about the vulnerable older people in social housing schemes but at least equal concern about the management problems created by them. The case study schemes

were seen as a way to relieve them of responsibility for older people whose needs they could not meet.

### *2.1.2 Voluntary sector housing perspective*

Participants from the voluntary housing associations involved approached the development of the case study schemes from a different perspective. Although they shared the concerns of their local authority counterparts about the limitations of existing housing services for vulnerable older people, as prospective HWC providers, they put more emphasis on the benefits of the HWC care model itself.

For the O'Connell Court champions, awareness of the need for HWC services arose out of direct experience of the terrible living conditions in which some older people were living (OC1, OC2).

[OC1] ...you had tenements, you had absolutely no kind of services, you just had the basics. I do remember in the late 70's, one of the doss houses burning down in \_\_\_\_ Street and people being burned to death. Nobody cared, that's my own personal opinion, nobody really cared...

They were determined to fill an identified service gap and accommodate the homeless older people whose needs were not being met by any other agencies (HSEO1, HSEO6, OC1, OC2) but also determined that they do so in a way that would allow this vulnerable group 'to remain in the community for as long as possible [and] to live their lives with dignity the same as anyone else' (OC1). The champions were on a very personal journey to protect what they saw as the right of vulnerable older people to participate in at least the semblance of normal daily life.

[OC1]They have freedom here. They can come and go out. They can get up when they want, they can go to bed when they want. They can refuse to have a shower, have their meals... supports to keep their independence for as long as possible and to be involved in the community.

Awareness of the specific need to develop dementia services within O'Connell Court came later when some residents began to display signs of cognitive impairment and there was the realisation that these people had no place else to go because of the general dearth of services for people with dementia, particularly those without family or money. The champions recognised 'a particular niche with regard to people with dementia'. New referrals came to O'Connell Court once it became known that people with dementia would be accepted for admission served to reinforce the idea that there was a need for dementia specific HWC services.

[OC2] We accepted persons with Alzheimer/Dementia as they were recommended by the Clinical Consultants and there was a great demand...every hospital in Cork and other un-supported sheltered housing groups were referring tenants to us.

The champions believed that the HWC approach represented a more humane and therapeutic approach to the long term care of people with dementia than traditional institutional care.

[OC1] We always thought people with dementia should be allowed in the main stream because I think when you take them out of circulation and they're with other people with just memory loss, they deteriorate quite quickly...So I'm holding on to my social skills longer. ... It is memory loss. It's not cancer... And what's required is emotional supports, supervision from the point of view depending on what level they're at...

They argued that HWC can provide dignity and respect to which people with dementia are entitled and also assist them in maintaining a higher level of functioning than would be possible in an institutional setting.

Mount Bolus housing association champions were motivated in the first instance by the desire to prevent their own sheltered housing tenants from having to move into a nursing home in order to access needed care and support as they aged (MB1, MB2, MB3, MB4).

[MB3] But then they began to see the need, as people were no longer able to live totally independent in the sheltered houses... it became extremely difficult...there was no option but to go to a nursing home somewhere because they couldn't live totally independently in the houses that were provided... So that's where they set about putting up the unit; that was the vision. Meeting a need that was there.

Among the people who could not be managed in the existing sheltered housing scheme were people with dementia (MB4). The fact that there were no nursing homes in the immediate area and older people thus had to move away (sometimes a considerable distance) in order to access nursing home care was a big bone of contention for the Mount Bolus champions (MB3, MB4). They believed that older people would be better off if they could remain living in their own community and the proposed Mount Bolus facility would enable them to do that. The champions also believed that older people who had emigrated from the area would benefit from being cared for in the place where they were born and plans for Mount Bolus proceeded on the assumption that these emigrants too would welcome the chance to avail of the new HWC services located in their home place (MB1, MB3, MB4).

The strong belief in the need to keep older people in their own community near family and friends was a big motivating factor for the Mount Bolus champions. So also was their dissatisfaction with the nature and quality of nursing home care.

[MB4] And we were losing people who had grown with the association and they were going out to nursing homes and families were kind of stopping visiting them, and there were all the things that were happening to people in nursing homes in a bad way unfortunately that were being reported back to us...relatives were coming to pick up their belongings and stuff and the situation for the older person wasn't getting better in the nursing home.

The Mount Bolus champions believed that the new facility would allow vulnerable older people to stay living in the local community and like their O'Connell Court counterparts they believed that HWC would support older people to have a better quality of life than they would have if they had to move to a nursing home setting. People with dementia were not singled out as being in need of separate specialist services but were included in the wider target group.

The principal champion from the housing association involved in plans for St. Bricin's was very articulate on the subject of why HWC was needed. The belief was that there would always be people (from all age groups) who needed more than what was generally on offer from the housing services and that services needed to be developed for this group of vulnerable people who included the homeless, people with mental illness and some older people (SB1). HWC would fill a service gap in a way that is more responsive to the special needs of certain categories of vulnerable people than either existing sheltered housing or nursing care alternatives. The housing association involved in the St. Bricin's proposal were also interested in developing a new service model; the proposed new scheme would expand the housing association's repertoire and raise its profile in the voluntary housing sector, and this was another reason to be involved (SB1). Plans to build the dementia unit were added on to the original plans for conventional sheltered housing at the suggestion of ASI with initial support from the HSE (SB1, N6).

FOLD was different from the other case study housing associations in that FOLD had considerable experience of developing and delivering HWC services including HWC for people with dementia, although they had never developed housing services in Ireland before. Their perception of the need for HWC was based on their experience in Northern Ireland; FOLD managers were confident that HWC worked well as an alternative to nursing home care for at least some older people with high dependency needs (F1, F2). Like the other housing association participants, FOLD housing

association participants believed that HWC was more responsive to the needs of many older people and provided a better quality of life than nursing home care settings could do (F1, F2, F3, F4).

FOLD managers brought with them from Northern Ireland a HWC template for the development of the proposed new units in North Dublin and it included the provision of dedicated beds for people with dementia. FOLD had prior experience of providing dementia specific HWC services and promoted the idea with champions in the local authorities and the HSE during the early planning stages of Cherryfields and Anam Cara.

FOLD as an organisation were eager to pioneer a new service model and also motivated by the desire to expand services south of the border.

[LA2] Probably the main reason why the FOLD one developed was FOLD themselves. They were very very keen.

[HSE1] FOLD were very keen at the time because they were setting up down here and they wanted to establish FOLD Ireland...So they worked very closely with Fingal County Council and ourselves to progress the whole idea around Hartstown...It was they who brought that to our attention and their ethos and how they actually operate.

FOLD managers who were working on the north Dublin initiatives were supported by senior FOLD managers in Northern Ireland who believed that participation in the new service initiatives was in the interests of the organisation (F1).

## *2.2 Health sector perspective*

This section focuses on the reasons why the health board/HSE champions became involved in the FOLD schemes and to a lesser extent in Mount Bolus, and the findings suggest that, like their housing counterparts, it was a combination of factors that motivated them to participate in the case study scheme developments (Pasmore 2011).

There were a number of pressures on the NAHB that the champions believed the FOLD schemes would help to alleviate. According to four HSE managers, the biggest pressure came from the general lack of long term care beds in north Dublin which made it difficult to discharge older people from acute hospitals (HSE 1, HSE8, HSE12, HSE13).

[HSE8] There was a lack of long stay beds in the Dublin NE area and particularly the North city area compared to the ratio around the country...

few private or public beds relatively speaking. It was a way of bringing beds into the system... very linked towards the bed pressures in Beaumont, the Mater and Connolly.

It became a political priority for the Department of Health at the time to address the gridlock that had developed in the Dublin acute teaching hospitals (known as DATH's in health board parlance) that was attracting much negative publicity for the Department (HSE1, HSE8, HSE13, N2). An HSE senior officer noted that the acute hospitals in North Dublin were 'chock a block with people who needed residential care and were no longer able to go home. The Government were looking for solutions to the acute beds crisis and the hospitals were very exercised because their waiting lists were getting longer...' (HSE13). Pressure on the health boards to solve the problem of so-called 'bed blockers' became a major stimulus to the development of the FOLD schemes.

One HSE participant observed the way that this political crisis worked to the advantage of the FOLD initiative champions.

[HSE2] ...what they did have to their advantage was... all the political pressure around A&E's. That was a big lever for them...I really do believe it was to do with political pressure in relation to A&E as opposed to any ideological drive or shift. It was political pressure in many ways.

The gridlock in beds in the DATHs put the FOLD schemes higher on the NAHB priority list than they would have been otherwise and freed up resources for their development. That said, the findings show that there was also recognition among most of the study participants working in the NAHB at the time that there was a gap in services for older people as well as the need for a model of care that was different from available nursing home services.

A population needs analysis had been carried out by the NAHB in conjunction with Trinity College and the evidence from this analysis was also used to build the case for the new initiatives (HSE13). There was particular concern about the lack of adequate services for older people living alone in the community and the belief that they were being inappropriately placed in residential care. An intermediate service that offered something in between home care and residential care was thought to be needed.

[HSE12] But I think there was also a cohort of older people who were not totally medically unfit but who were going to nursing homes and they didn't really have a medical need. All they had was a social need, people on their own really.

[HSE8] At the same time...There were quite a lot of vulnerable people and we thought that they probably could stay living in their sheltered housing but were moving to residential care because they needed to have this level of support. So this ticked all those boxes, that you would have something else.

Apart from wanting to expand the range of available services, HSE champions were also dissatisfied with existing long stay services for older people at the time and believed that the FOLD schemes offered a better quality of life to residents including people with dementia.

[HSE13] And I also knew that the only kind of services that were available at that particular time were long-stay nursing care in very out of date and outmoded institutions of the Health Board and residential nursing homes...the care of people with dementia in nursing homes wasn't being met. I suppose they were being restrained in ways that we weren't happy with...

[HSE1] I had a poor sense of residential care and the fact that it needed to be done differently. Very negative, particularly given the age profile going into long stay care. ...the institutional model of long-stay care, which it very much was then, because it was pre-standards, pre-HIQA...

Disquiet about existing long term care services led to a desire to develop service alternatives that were new and different according to three HSE participants who were involved in both of the FOLD schemes.

[HSE8] There was certainly a sense and a feeling that there was a need for something different from the other types of services that we provided. ...the need to do other things rather than just create more residential units, which we'd no money to do anyway.

[HSE13] We researched a number of models in terms of innovative approaches particularly to housing or providing care for older people... and we wanted to look at maybe starting from a particular ethos and working from the needs of the individual, rather than providing something and trying to get the individual to fit in to what we were providing....

[HSE1] I suppose where it generated from my perspective at the time was looking at an alternative rather than what we had usually developed, which was the traditional long stay residential or nursing home care...

A former Midlands HSE manager had similarly identified the need to provide something in between sheltered housing and nursing home (MB1). For this manager, the fact that there was widespread participation of people from the local community made the Mount Bolus project particularly appealing; the housing approach to long term care that the proposed service characterised also represented 'new ground', something different and better than what was currently available (MB1).

The evidence is inconsistent with respect to whether the HSE champions were motivated by the specific desire to improve services for people with dementia when plans for the FOLD schemes

were developed. Two HSE participants believed that concern about dementia was not a factor, and both suggested that it was FOLD themselves who introduced the idea of including dementia specific beds in the proposed schemes.

[HSE1] [Dementia was] Not a particular issue. More frail elderly, a choice element for frail elderly...It was they [FOLD] who brought that to our attention and their ethos and how they actually operate.

[HSE8] I'm not so sure that was the strongest part really. I think it was probably an added bonus, the fact that these were dementia specific type of facilities... I think when we went looking at it [FOLD services in Northern Ireland], we were impressed by that part of it.

They believed that dedicated services for people with dementia might not have been included in the plans for Cherryfields and Anam Cara if FOLD had not introduced the idea. However, four other NAHB participants who were directly involved in the planning and commissioning of the FOLD schemes suggested that awareness of the need for services for people with dementia was a motivating factor for at least some of the NAHB champions.

[HSE13] ... we also had a backlog of need in that particular area, where people were reasonably healthy but suffered from dementia. ...Oh, there was, absolutely, I mean all the GPs in our area whom we met regularly had lists of people who suffered from dementia. And there would also have been some resident in the local authority housing and they would have been known by the PHNs.

[HSE12] It was part of the agenda from the start... we had people with dementia all over the place, I'd get calls at 5 o'clock Friday evening, this man is missing and we had nothing for them. And what you always had, you had Psychiatry of Old Age refusing to take them on, and the Consultant Geriatricians saying they weren't theirs and you had this constant row with people and families in acute distress...

Although it is not absolutely clear when or why dementia specific units were incorporated into plans for Cherryfields and Anam Cara, from the data there appears to have been recognition on the part of at least some of the NAHB/HSE champions of the special needs of people with dementia and that this contributed to their enthusiasm for the proposed new schemes.

The final issue that figured in the thinking of a number of NAHB/HSE stakeholders was the problem of rising nursing home costs and the health board's need to reduce expenditure on long term care. We have seen above that cost savings also figured in the thinking of stakeholders from the local authorities.



[HSE13] Also the cost of nursing home care was beginning to become very expensive and we had various different levels of subventions for people in nursing homes. And we felt we weren't really getting much value for money out of the nursing home sector...

There was widespread belief among NAHB participants at the early planning stages of the FOLD schemes that HWC was less costly than nursing home care (HSE1 , HSE2, HSE8, HSE9) and it was indeed promoted as such. This perception that it was cheaper and would result in cost savings to the NAHB made it an attractive service alternative for health board champions.

### **Section 3 Availability of resources**

The findings from data collected from both housing and health sectors are combined in this section that focuses on the availability of resources that helped to create a positive environment for the development of the new service initiatives. These included the availability of capital funding in the form of Capital Assistance Scheme funding.

#### *3.1 Capital funding*

There was a consensus among all of the study participants that the availability of CAS scheme funding was critical to the progression of all of the case study development plans from the point of their conception. Only voluntary housing associations (Approved Housing Bodies) can apply for CAS funding under the regulations; local authorities and government agencies like the HSE could not. Although the CAS scheme was not specifically aimed at the development of HWC services, it was possible to use it to access the capital funding required to build/purchase/renovate all of the case study scheme facilities and without it, it is doubtful whether proposals to develop the new schemes would have progressed at all.

A Mount Bolus participant spoke of the alacrity with which CAS funding was approved for the building of a purpose built HWC facility which provided early momentum for the progression of plans.

[MB4] ...money was no object. So I mean 3.3m to the DOE was like, what a great idea, what fantastic plans, here's your money. Bring it to tender. That's literally what happened. Once the plans were finished and we moved into the tender stage, once they had allocated their builder, the sky was the limit.

Four participants who were working for the NAHB at the time noted that CAS funding was particularly opportune because there was no comparable funding available to the health boards to build residential care units at the time.

[HSE13] ...what else was the driver and the 'what else' was finance... Now as a statutory body like the NAHB, we couldn't avail of [the CAS scheme] but FOLD could. So we saw an opportunity where FOLD would establish themselves in the Republic of Ireland... And once that had been done, that would satisfy [DOE] criteria for funding and we were able to tap into that.

[HSE8] ...there was no [Department of Health] funding [available] but what was attractive about this was you could draw down DOE funds for it. ... The DOE funding covered the building of the whole complex. It was all good really.

The FOLD schemes would cost the NAHB little in terms of capital costs and for one health board stakeholder, the opportunity to develop them seemed too good a chance to pass up.

[HSE9] That was one of the things that pushed the FOLD developments; the capital outlay by the health service was going to be reduced by 90%. It's a no-brainer. In building the two FOLD units, instead of having to spend 10 million, we spent 500,000.

Two participants noted that the availability of capital funding for the FOLD schemes also made it easier to sell the new service model to board members, managers and staff in the NAHB.

[HSE1] The funding came from DOE to build it. It was the cost factor from our perspective, it was very little. It was a very easy thing to drive...So from that perspective it was a very easy sell and a very easy thing to move on

[HSE6] ...the health service were delighted with it because they didn't have to pay for it.

The data suggests that CAS funding provided an opportunity that was seized upon by stakeholders from both the housing and health sectors who each had their own reasons for engaging in HWC service development. It provided the momentum necessary to drive the case study initiatives.

### *3.2 Availability of land*

The ready availability of sites made it easier to progress plans for the FOLD schemes, Mount Bolus and St. Bricin's and again the champions played a role in recognising the opportunity that it presented. The NAHB carried out an audit of health board assets in order 'to create some leverage in funding' that would facilitate the development of new services, and the potential to build the FOLD units on sites already owned by the NAHB in Hartstown and Glasnevin was identified from the audit (HSE13). The availability of these sites meant that plans for the FOLD

schemes could progress without having to find sites and negotiate either their purchase or acquisition and according to four study participants, this made a big positive difference to the FOLD developments (F1, LA1, LA2, HSE13).

[F1] The health board had some land [which is] usually the biggest prohibiter of developing any service. Land and revenue funding... but they had a couple of small plots of land near their own facilities... [and the] sale of that land helped to offset some of the capital costs.

[LA1] One of the difficulties in producing social housing was the acquisition of serviced sites...one of the difficulties was, certain authorities had land on which certain elements of social housing could be provided, but it wasn't serviced.

Following the audit, other NAHB sites were sold and some of the profits were then used to offset some of the 'top up' capital costs not covered by CAS and this was only possible because of the fact that the Department of Health allowed the NAHB to retain the profits from the sale of the land and use them for local service development (HSE13). This involved making an exception to the rules as set down in legislation.

[HSE13]...under the legislation that money [realised from the sale of health board land] would have had to be returned to the Department, but ...we proposed to the Department that we would be allowed retain that funding and they would have included that in their allocation to NAHB even though the funding never went back to them... So the [top up] capital funding came from DoH, from our leveraging by selling NAHB property.

Mount Bolus was built on land that was transferred by the local authority for a nominal fee (MB4) and St. Bricin's was planned as a regeneration project on land already owned by the City Council (LA2, SB1) which again obviated the need to locate and acquire a suitable site. The fact that there were 'sitting tenants' on the St. Bricin's site took away some of that advantage and the details are discussed in the next chapter (LA2, SB1).

#### **Section 4 Other factors**

Pettigrew, Ferlie and McKee studied the rate and pace of change in 8 health authorities in the NHS and found '... that some contexts or environments are more receptive to change than others' (in Coghlan and McAuliffe 1992:116). It is useful to include a brief section on some other factors that were believed to have created the environment that helped to make the introduction of the new HWC services possible.

#### 4.1 Economic and political climate

The relative prosperity in Ireland at the time that the FOLD, Mount Bolus and St. Bricin's schemes were originally planned was linked by three participants to a favourable climate in which to develop new service initiatives like the FOLD schemes (LA1, LA2, MB4).

[LA 2] The timing was also very good. There was a lot of money around at the time; the Celtic Tiger was flying. It made an awful lot of sense to do it.

Capital funding for voluntary social housing certainly had become more accessible and the terms more favourable to voluntary housing associations than previously (LA2) and the FOLD and Mount Bolus schemes in particular benefitted from the period of Irish prosperity in the early to mid-2000's. Improvements in the Irish economy provided a positive stimulus for the development of these schemes.

Two study participants spoke of the political will that had developed around the need for more housing at the time the FOLD schemes were being planned which they believed had translated into the prioritisation of housing projects on the Irish political agenda (F1, LA2).

[LA1] Housing was flavor of the day at the time. Housing was from a political point of view, social housing, affordable housing was very very high on the political agenda at the time. So therefore any solutions to housing problems were being greeted with open arms. There was a housing crisis at the time: local authority Directors of Housing met regularly to discuss mutual problems.

[LA2] The DOE was pushing for more and more housing starts. So there weren't that many obstacles in the way at the time. And also there were a number of housing associations coming on the scene at the time...

One local authority participant noted that the local authorities in Dublin and Cork were in a better position than others around the country to undertake housing with care developments because they were better resourced generally (LA1). The implication was that, if the FOLD schemes had been proposed outside of Dublin or Cork, development plans were much less likely to have been pursued or realised.

An HSE participant observed that not only were the local authorities in Dublin and Cork better resourced but so also were the health boards and the supposition was that this was because they were subject to most of the political and media pressure surrounding the problem of delayed discharges already mentioned above in the context of discussion about the FOLD scheme developments. An HSE manager observed that the funding made available to the health boards in

Cork and Dublin, aimed at facilitating the hospital discharge of older people, was not available to health boards outside the Dublin area at the time.

[HSE2] I would have been trying to drive an agenda around sheltered housing in my own area, where we did not have anything like the access Dublin had to those packages of money.

#### *4.2 Previous history*

Past experience of working with the health board to develop other types of services was cited by two local authority participants as a factor that helped to moderate any hesitations that Fingal and Dublin City housing authorities might have had about entering into joint ventures with the NAHB (LA1, LA3). From a Fingal Council perspective, a precedent for working with the NAHB had been established which created the mindset necessary to support the Cherryfields initiative.

[LA1] The health board was looking to de-tenant St. Ita's Portrane... We made houses available so they became a community house for these people... This is one of a number of initiatives that we were involved in. Because of all those initiatives, the housing strategy, getting more involved with the voluntary bodies, getting involved with the health board to build houses, it was all part of an initiative that was moving at the time.

A stakeholder from Dublin City Council similarly observed that the FOLD schemes were more of a logical progression than a radical departure for the local authorities.

[LA3] it was what we wanted to happen. But it is different from what came before in a way. In another way, it isn't. Because we have homeless projects that would have health service provision.

In Fingal and Dublin, collaborative housing developments with the health board for other client groups had already taken place so the case study schemes were only an extension of what the local authorities were already doing; this helped to create the environment necessary for plans to progress (LA1, LA3). The mutual understanding and trust between local authority and health board stakeholders that contributed to the successful progression of the FOLD projects had already begun to be built during earlier projects that crossed the health and housing divide (LA1, HSE13).

#### *4.3 Health service structures*

A final factor that was seen by one person from the NAHB to have facilitated the progression of the FOLD schemes had to do with the structure of the health services before the HSE was set up.

[HSE1]The difference there is... The FOLD was generated at a time when I worked in the NAHB and we were an autonomy in ourselves.

We were a decision making body in ourselves. It was a smaller structure  
...closer to the ground decision making.

The suggestion was that the old health board structures made it easier to plan and progress new service initiatives because decisions were made locally and proposals did not have to be pushed up the lines of authority. Study participants believe that health service structures have a bearing on future service development and this is discussed in greater detail in Chapter 6.

## Section 5 Discussion

Schon was one of the first to suggest that 'Given the underground resistance to change...[a] new idea either finds a champion or dies' (1963 in Taylor et al 2011:412). Section 1 presented the perceptions of study participants about the significant role played by individuals (including themselves) from each of the three agencies involved in driving the case study scheme initiatives. Participants identified individuals who in their view displayed the characteristics associated with 'champions of change' as defined by Taylor et al

[They] typically share personality characteristics such as confidence, enthusiasm and persistence, demonstrate high levels of personal power, and excel at exercising influence [Taylor et al 2011:413].

These identified champions had the leadership skills required to 'capture the hearts and minds' of those on whom service implementation depended (Pasmore 2011). They were able to convince others that HWC services were needed and they communicated a vision of HWC that made it easy to understand how HWC would be an improvement on the status quo (Kotter 1996, Heslin and Ryan 2008, Soo et al 2009, Taylor et al 2011, Crosby and Bryson 2011, Hendy and Barlow 2011). This was critical to getting necessary 'buy in' from those whose cooperation was necessary in order to develop and deliver a service model that was largely unknown up to that time in Irish older people's services (Fernandez and Rainey 2006). The champions displayed passionate commitment to the HWC model which was in most cases inspired by knowledge or experience of services that had been developed elsewhere that made it easy to imagine what the new HWC services would look like (Kotter 1996). The champions developed a credible 'change vision' and communicated it in such a way as to capture the enthusiasm of others (Kotter 1996). The champions in the FOLD initiatives in particular demonstrated extraordinary persuasive powers which helped them to build commitment and shared understanding across health and housing service boundaries which can stand in the way of interagency service development (Cameron et al 2001).

The data shows that the case study champions were motivated to lead the case study scheme initiatives by a combination of self-interest and altruism (Pasmore 2011); they were under pressure to resolve certain problems facing their own agencies but they did also hope to improve services for the older people. The balance of these concerns varied according to their roles and responsibilities and also to the particular circumstances related to each case study scheme. Borins suggests that among the different conditions that cause public service innovators to try to introduce change are political pressure, a crisis, or internal problems in the organisation including resource constraints (2002:502) and the data suggests that this was the case for local authority and health board champions involved in the FOLD initiatives. Local authority champions expressed concern about the situation of certain categories of vulnerable tenants, but it was the management problems created by these people that lent urgency to the need to do something about it (Kotter 1996). For the health board, urgency was created by the need to add long stay beds to the system in response to the political crisis that had developed in the acute hospitals (Kotter 1996, Coghlan and McAuliffe 2003, Pasmore 2011). From this perspective it did not much matter what type of beds were on offer; the particular service model was less important than the perception that the new schemes would help to diminish pressure on the Department and the NAHB by reducing the number of patients waiting for hospital admission which was being documented in the national newspapers on a daily basis.

Voluntary housing champions were not oblivious to the opportunities that the case study schemes presented to promote their own self-interest (for example FOLD's desire to expand services into the Republic) although the findings from O'Connell Court and Mount Bolus suggest that the balance of priorities for those housing associations was tipped towards the altruistic desire to provide services that would be of benefit to older people, whether it be the bestowal of respect and dignity or the provision of services close to home (Pasmore 2011).

Establishing the need for HWC services provided the necessary motivation for what was essentially a move away from the familiar into uncharted waters (Kotter 1996, Coghlan and McAuliffe 2003, Pasmore 2011) but the data in Section 1 suggests that the specific desire to address the unmet needs of people with dementia was not central to the concerns of the local authorities or the HSE champions when the FOLD schemes were being planned or to the voluntary housing associations involved in the O'Connell Court, Mount Bolus and St. Bricin's initiatives. A FOLD champion is credited with the inclusion of dementia specific beds in the FOLD schemes; she brought the template from Northern Ireland and created the vision for the development of a

HWC model for people with dementia. It was on visits to Northern Ireland that the champions became convinced of the appropriateness and desirability of the HWC model (Armenakis and Harris 2009). Given that there were so few specialist dementia services being developed in the HSE at the time, it is extraordinary that half of the beds in Cherryfields and Anam Cara were being ring fenced for people with dementia; without FOLD's participation, it is questionable whether dedicated services would have been included in the plans.

Dedicated services for people with dementia were added on to the original plans for St. Bricin's and even then were restricted to the provision of short term respite and rehabilitation (Kotter 1996). O'Connell Court only began to identify the need for dementia specific services when a number of the homeless residents began to display signs of dementia although once it was recognised a deep commitment to providing services to people with dementia developed. In Mount Bolus, people with dementia were included in the larger group of vulnerable older people targeted for HWC services; no *separate* specialist services were planned or developed. The data suggests that the commitment to a vision of HWC for people with dementia was not the primary motivation of many of those involved in the development of the case study schemes.

Although the St. Bricin's champions were influenced by the FOLD initiatives and Mount Bolus champions took their inspiration from other high support services that had been developed elsewhere in Ireland, there is no evidence to suggest that they were developed as part of a national agenda to introduce a new model of long term care for people with dementia; there is no evidence of either an alliance or a network working towards that end.

The champions who drove the case study initiatives had the authority to make planning decisions and at a practical level, they saw opportunities that others didn't see to support and promote the new initiatives. The availability of CAS funding was one such opportunity and the findings show that it was an important 'trigger' for the development of the case study schemes (Paton and McCalman 2008); it was CAS funding that made HWC seem possible and the availability of capital funding made it an attractive proposition to all concerned. The availability of CAS funding made HWC development a feasible proposition (Kotter 1996, Armenakis and Harris 2009), a means to an end. The evidence from Mount Bolus best illustrates the project momentum derived from being able to build the physical premises from which planned services are to be delivered even in the absence of surety about what would happen next. The availability of sites on which to build gave the FOLD and St. Bricin's projects a similar boost and made proposed plans more appealing at the beginning stage than they would have been otherwise.



The data in Section 4 shows the influence of contextual variables on the introduction of a new service in the public sector including political, economic and historical factors that create the climate for service development (Jick 199 in Metre 2009, Nadler 1998, Fernandez and Rainey 2006, Dopson et al 2008). Political priorities dictated that the supply of social housing be increased and the local authority champions in Dublin were able to capitalise on that to support the FOLD schemes although HWC was outside the normal scope of their business. Health board champions likewise were helped by the fact that the FOLD schemes would solve a political problem in Dublin. The shared history of inter-agency working between the local authorities in Dublin and the NAHB created the trust necessary to advance plans for the FOLD schemes (Cameron et al 2001). Health Board structures prior to the formation of the HSE made it easier to progress ideas conceived at local level, and national economic prosperity made the likelihood of public sector service development in general greater. Above all, the data in Section 4 underscores the importance of timing and luck to any proposed service initiative (Pasmore 2011).

The findings in this chapter help to explain what made the case study schemes possible. The common denominators were the availability of CAS funding and champions who drove the projects. But the data suggests that these factors were in turn influenced by a number of other factors and concern about the unmet needs of people with dementia was only a minor factor. Ultimately it was the combination of these factors that created a positive environment for the introduction of HWC and not any single one. In spite of the optimistic note on which the case study initiatives got their start, the data in the next chapter suggests that the champions faced many serious challenges when they tried to implement service plans.

## Chapter 5 What were the barriers to service implementation?

The previous chapter outlined the combination of factors that were critical to the development of the case study schemes including the central involvement of individual champions who believed that the new schemes would address identified problems for older people and their own agencies, the capital funding opportunity provided by the CAS scheme and other internal and external factors that created a positive environment for service development at the time. But Pasmore (2011) cautions that 'No matter how clear the need for change and how well framed, issues in implementation are certain to arise' and the findings from the case studies confirm that the implementation of the case study initiatives was indeed extremely challenging.

The data in this chapter shows that from the perspective of study participants, the challenges involved in the implementation of the case study schemes were not primarily related to the fact that planned services were targeted at people with dementia but rather were related to more basic issues around the introduction of a new service model for the long term care of older people as a group.

For the FOLD schemes, O'Connell Court and Mount Bolus, the serious complications arose after they were built. In the case of St. Bricin's, which never progressed beyond the planning stage, the problems became apparent before building was to begin and were never resolved. In spite of differences in the way in which the five case study schemes developed and differences in outcomes, clear themes emerged across the case studies. The challenges encountered by participants from one case study resonated with the challenges experienced by the others.

The findings in this chapter are grouped around themes that emerged from the data analysis. The first broad theme concerns the resistance that developed to the introduction of the HWC model itself and the factors that contributed to it, and these are discussed in Section 1. The second broad theme relates to the barriers created by the lack of 'fit' between HWC and existing health and housing systems and structures which neither enabled nor supported service operations (Nadler 1998). These are discussed in Section 2. A final theme concerns the difficulties associated with inter-agency service development caused by the different priorities and expectations of partner agencies, and this is the focus of discussion in Section 3.

## Section 1 Resistance to the HWC model

This section presents the findings regarding the resistance to the case study schemes as experienced by study participants. Eighteen participants from both the HSE and the voluntary housing associations involved in the FOLD, O'Connell Court and Mount Bolus case study scheme initiatives spoke of the resistance of health professionals. This resistance was mainly reflected in both their reluctance to make referrals to the new HWC schemes and also in reluctance to provide services to HWC residents. The findings suggest that many factors contributed to this resistance and they are outlined below.

### *1.1 Confusion and lack of awareness about housing with care*

A FOLD manager observed that during the commissioning stage of Cherryfields it became '...glaringly obvious that the HWC model was unknown in Ireland' (F2). Even among those who were directly involved in the case study initiatives, only a minority were familiar with the concept of HWC before they became involved and in most cases any knowledge they had was acquired from previous work experience outside of Ireland (HSE5, HSE6, HSE7, HSE11, HSE04). Apart from this relatively small circle of stakeholders, few people had ever heard of HWC and fewer still understood its implications. This lack of understanding led to confusion that made it difficult to attract appropriate referrals. The FOLD schemes were sometimes confused with conventional sheltered housing schemes when they opened.

[HSE1] And because remember we have a long history of sheltered housing with a caretaker bit, particularly in Dublin, and it was just seen as a housing service. And those perceptions are still there...

[HSE8] I think there was less agreement from maybe some of the nurses themselves when we developed it further. They were quite happy to refer somebody to it but they saw it still as the old Dublin City Council model of sheltered housing and didn't really understand that we were seeing it as a much more supportive level of housing.

One HSE participant recalled that some local councilors thought that the new FOLD units could be used as hostels for unruly tenants (HSE12).

[HSE12] [There were]... a number of councilors who also saw [the FOLD schemes] as a 'catch-all' in terms of anybody who was difficult in their area. The ones that used to refer on were people who were in sheltered housing with alcohol problems and were noisy and causing problems and they wanted them referred...

Such misconceptions about the nature of services and where they fit into the wider scheme of social housing caused some problems for the champions, but greater problems resulted from the

tendency of many people to assume that the case study schemes were the same as nursing homes not least because, to the uninitiated, they look like nursing homes.

[F3] And I think people thought, [we were] treated just the same as if we were a nursing home...Yes, it took people awhile to understand that we weren't a nursing model and they didn't understand what the concept of housing with care was. And the hospitals didn't understand.

[HSE10] ...the view of the GPs in the area was that FOLD was an institution; The GP that [eventually] took on FOLD as a caseload had been working with another nursing home and was very familiar with the nursing home model and felt/assumed that there would be very little difference [between FOLD and a nursing home].

This confusion about the nature and extent of services was not exclusive to the FOLD initiatives; one O'Connell Court participant recalls being asked regularly by health board officers, 'Are you fish or fowl? Are you a nursing home or are you *not* a nursing home?' (OC1). An HSE stakeholder spoke of personal confusion about the type of services to be delivered in Mount Bolus.

[MB2] In my discussions with the group, which were very straight and very honest, I would have mentioned that from my perspective, it was caught somewhere between (in terms of the physical structure) a nursing home and a nursing home [In other words, Mount Bolus looked like nothing other than a nursing home]. I think there was a lack of clarity around definitions.

According to six FOLD participants, even three to four years after Cherryfields and Anam Cara opened, the HWC service model was still not understood by many people in the local HSE areas who either continued to make inappropriate referrals or made no referrals at all (F2, F4, F5, HSE3, HSE11, HSE12). A FOLD manager initiated meetings with hospital discharge teams in 2009 with a view to educating staff about the nature and capacity of services in Cherryfields because of the obvious confusion that still existed (F5). Other FOLD managers recalled having undertaken similar exercises shortly after Cherryfields opened in 2006 and at intervals after that for the same reason (F2, F3). The findings show that it was a big challenge to keep others informed about the nature and scope of FOLD services. The development of mutual understanding was made more difficult by the shortage of nursing home beds in North Dublin at the time and the pressure hospitals were under to effect discharges; it became necessary to constantly re-iterate what the FOLD schemes could and could not do (F2, F5, HSE12).

More surprising perhaps than the confusion about the nature and scope of FOLD services is the total ignorance on the part of some health professionals working in the same HSE area about FOLD's existence even years after the two schemes opened. A local HSE manager recalled that up

to the end of 2010 there were still community nurses who were completely unaware of the existence of Anam Cara, although it had been open for 4 years.

[HSE3] One thing that struck me, I sent around information, time and time again to our PHNs but I would have fielded calls on many occasions years after Anam Cara opened, saying I have this little lady who was wandering and she's not bad enough to go into a nursing home; what do I do with her? And I would say, have you considered FOLD and the response would be what's FOLD? ...I would have thought that over time [the message would have gotten through that] we have these services available. But there seems to be a big gap. I don't know how many times I had that same conversation.

In the context of the dearth of dementia specific services generally in the HSE, it seems quite extraordinary that the availability of the new dedicated services for people with dementia in the FOLD schemes remained unknown to many health professionals.

In spite of the belief on the part of FOLD and HSE managers that they had done all that they could to disseminate information about the new HWC services, five participants felt that more could have done to explain HWC services to other health professionals before the FOLD schemes opened (F5, HSE4, HSE5, HSE6, HSE7).

[HSE4] So maybe FOLD could have done some more around, well we're going to do this and this is how we're going to do it and what it's gonna look like.

[F5] Really what should have happened was, somebody should have gone into Connolly Hospital, sat down with the hospital, sat down with the social workers, with the people in the community and said, this is what we are and this is what we do. And it might have helped.

It was suggested that if there had been wider consultation in the early planning stages with those affected by the new service developments, there would have been less confusion about it and perhaps more importantly, less resistance to it.

[HSE5] A lot more public consultation initiative not just within community care, the whole hospital, GP agenda... I think if they had gone... first and explained what they do and what they are about, instead of after the event, I think we would have avoided a lot of problems. A lot of education to the hospitals... to all wards to give them an understanding... around what it is we are about.

Although a large number of NAHB managers and some health service providers were involved in planning the FOLD schemes, some important groups such as hospital discharge teams were

believed to have been left out during the planning stages and this was seen as a cause of later problems.

[HSE7] I think the thing is actually about having the involvement of all parties when you're developing a new model... that's what's happening now but it didn't happen in the planning stages.

It is interesting to note that in the case of the FOLD schemes, HSE managers in Dublin had little trouble accepting the concept of HWC .

[F1]The ones at [senior management] level understood but their [service] managers and the staff under them didn't fully understand... It took awhile for the community, I suppose the hospitals, the PHN team and families as well to understand the concept of [HWC] with no nurses on site.

HSE senior managers had been closely involved with the FOLD developments from the earliest planning stages; they had the opportunity to see the HWC model in operation and were committed to implementing it in contrast to HSE managers in Cork or the Midlands who were not as involved in during the planning stages (MB2, OC1).

### *1.2 Challenge to the status quo*

Ignorance and confusion about the HWC model was a barrier to the implementation of the case study schemes but a greater barrier was the resistance that developed against it because it challenged people's ideas about what older people need and the way that their needs should be met. The problem for health professionals was always that the HWC schemes were not nurse managed and there were no nurses on site<sup>13</sup>. In the words of an O'Connell Court participant, HWC 'pushed people to think outside the box [and] Quite a lot of people don't want to do that' (HSE05). Others observed similarly

[HSE2] There was a lot of resistance to it...The absolute critical difference is that it wasn't a medical model, a nursing home model... Traditionally all our dementia care in Ireland was located in long term residential care, public and private, which is very

much shaped and driven and populated by nursing and medical practice. So this was a move away from that into a different model of care...[and it] met with much skepticism.

[F1] ...one of biggest hurdles has been the acceptance by the medical

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<sup>13</sup> O'Connell Court employs team leaders who have a nursing background but they are not employed as nurses and are not identified as nurse managers, and the unit manager is not a nurse. Mount Bolus did not employ nursing staff and there are no nurses directly employed by FOLD in either Cherryfields or Anam Cara.

sector (the medical and nursing professions) that HWC can work and you don't need a nurse to look after someone. That was a huge thing...

[F2] Other health care professionals would steadfastly say, '...yeah, yeah that's all fine, but where are your nurses? The challenge was how to change a mindset that doesn't want to change...There were some quite resistant health professionals.

An HSE senior officer observed that the resistance that developed was based on ageist attitudes and expectations about what older people need which he contrasted with expectations regarding the care of children.

[HSE1]And the perception is that older people are frail and therefore they need nursing home. We have a manager who came out of child care and he said, why are we building institutions for older people when we have tried to dismantle them in child care? The argument across the table was that well, these people are old and frail, while a child may improve, these people won't. Society thinks like that as well and the community thinks like that as well.

Another HSE officer concluded that 'We expect less for older people than for ourselves' (MB1) to explain the prevailing assumption in Ireland that older people whose needs could not be met at home required nursing home care. Some of the resistance that developed against the introduction of the case study scheme services did so because HWC challenged that assumption.

### *1.3 Perceived health and safety risks associated with HWC*

Several participants observed that the absence of nurses contributed to a lack of confidence in a model which depended on care assistants rather than nurses to deliver support and care (HSE1, HSE2, HSE4, HSE5,OC1).

[HSE1] ...our own professionals who felt that there was high end care being delivered by care staff and there were huge vulnerabilities ...how can you have a care assistant looking after very vulnerable older people... there's a block about it because it's almost non-professionalised.

[HSE 8] It was a lack of trust in it was the basic thing... And the Geriatricians were fully up for it but didn't want to refer either. What they were referring was the well elderly as such. They felt they [FOLD] really wouldn't be able to manage someone who required high nursing care - maybe high nursing care isn't the right term... They erred on the cautious side.

This lack of confidence led many people in the health sector to the conclusion that the HWC model posed risks to residents (F2, MB4, HSE1, HSE2, HSE9, HSE11).

[HSE1] I suppose our own professionals had to be worked with in order to support the service. The whole risk-taking element, the

risk taking piece was something they certainly weren't very happy with.'

[HSE9] Lots of people wouldn't believe it would work. Mostly professionals, nursing and medical people who like tradition, who like surety and would try to convince me that I needed 12 nurses on duty night and day, and I would say, no. 'They'd be all killed in their beds' and I'd say oh no, this is their home.

The belief that older people would not be safe unless there was round the clock nursing was strong.

The HWC model prioritises residents' independence, and as one O'Connell Court stakeholder observed, 'with independence comes risk' (HSEO2). An HSE manager referred to a nursing colleague and her perceptions about the level of risk associated with the FOLD model.

[HSE3]...she's the medical model and one of her criticisms of the model would be that there's an allowance [for risk]. That's there. There has to be readiness to allow that this is a home from home model and within that, there is going to be risk...the medical model that wants to just protect people in a nice way.

While the model itself raised concerns about risks to residents, the fact that HWC was not subject to the same standards or regulations as nursing homes exacerbated these concerns according to six HSE participants from the FOLD, O'Connell Court and Mount Bolus case study schemes. HWC schemes were not inspected by the health boards prior to the establishment of the Health Information Quality Authority (HIQA) and they remained outside the HIQA regulatory system at the time of writing. Several people spoke of the unease this caused among health professionals and health service managers (HSE1, HSE5, HSE 10, MB2, HSEO3, HSEO7).

[HSE10] ...particularly amongst some of the professionals, [inspection would] increase their comfort in dealing with the model. That they would feel that, oh well, it does fit in to some inspection process. It is regulated and I'm more comfortable referring my clients to it. The fact that it doesn't fall under an inspection process is possibly a barrier for some people.

The implication was that regulation would guarantee a level of certainty around the safety of residents. The absence of regulation made some health professionals reluctant to make referrals because of the perceived risks to residents in the HWC schemes.

#### *1.4 Risk of a second move*

The data suggests that some of the resistance to the HWC model that developed resulted from the belief that residents would have to move again as their dependency levels increased, in other words they would not be able to 'age in place' in the case study schemes. According to two HSE managers, it was a barrier to getting support for the FOLD HWC initiatives (HSE1, HSE12).

[HSE12] This is what the medical people would say, well people



with dementia come into FOLD and then in a year's time they have to go somewhere else... But people couldn't see past that maybe you'd have a good few years in FOLD and then when you became really ill... they didn't see was it worth it.

One such critic believed that it would be better to send an older person directly into a nursing home than to refer them to HWC if there was a chance they would have to move again (HSE11).

[HSE11] I still have huge problems with the fact that, if people do become very physically dependent, there's an expectation that they would move on. Because it is very traumatic for them to move again.

The findings suggest that for some health service stakeholders and for families, the possibility that a person might have to move out of HWC as their dependency increases made them reluctant to refer people to HWC services. For all of its faults, nursing home care did provide the security of knowing that residents would not have to move again.

### *1.5 Practical implications for health professionals*

Resistance developed against HWC because it was a new and unfamiliar service and perceived by many health professionals to be inappropriate as well as risky. But it also developed because of the perceived practical implications of the HWC model for those expected to provide services to the new schemes including: community nurses (PHNs), therapists, consultant physicians and GPs in the 'patch' where the schemes were situated. According to a number of HSE and housing association study participants, PHNs were among the most vocal in their opposition to HWC (HSE1, HSE2, HSE3, HSE5, HSE12, HSE03, F2,MB4, OC1) and their views were especially important because of the critical role they were expected to play in both monitoring health and delivering nursing services to HWC residents.

According to two HSE participants, HWC services were viewed as unwelcome competitors for already scarce health board funding (HSE9, HSE12). One spoke of a consultant doctor who challenged the new FOLD developments in the belief that they would 'undermine traditions and hurt [existing] services' (HSE9). The other observed that

[HSE12]...it was so stressful at the time because you had so many people telling you what was wrong, you know. ...I'd say people had their own agenda, they wanted new in-patient units built and things like that, you know, and they saw the money going into this and they said, well that's no use.

But fear about the diversion of funding away from other projects was a minor consideration compared to more widespread concerns of nurses in particular about the practical implications of

HWC for their work practice. The delivery of services to HWC residents represented a departure from the normal routines of community health professionals whose work up to then was delivered in people's homes or in health service clinics. An HSE manager noted the shift in thinking which would be required in order for nurses to agree to take on the role of delivering nursing services to HWC residents.

[HSE03]: If you had significant nursing needs, care needs, and you were living [in O'Connell Court] then nurses who were trying to provide support in terms of PHN services would have said, well I'm primarily looking after people living in their own homes. Somebody who's living in an institution...there needed to be a shift.

Apart from GPs, community health professionals, including nurses and therapists had never previously worked in congregate care settings.

[HSE3]...You can talk all you want about Primary Care but there's a problem there because [community services staff] have never gone into nursing homes and they consider that it's like a nursing home.

According to a small number of FOLD participants, there was confusion among the community nurses in particular about what exactly would be expected of them; they were uneasy about their role and responsibilities vis a vis residents who were grouped together in large units (HSE5, HSE10, F5).

[HSE5] The PHNs...didn't understand the concept. They were going in and they felt it needed an appointed nurse to go in every day, to do the rounds... It comes up and we have to revert back to what we're about. And that is delivering clinical nursing care as we would do to any other person in the community setting.

Community nurses found it hard to reconcile the idea of delivering home care in a residential care setting and it took a considerable period of time to negotiate terms of reference for them (HSE1, HSE5, HSE12, OC1).

A small group of participants believed that concern about personal accountability was another issue that contributed to the resistance to HWC. Lack of faith in a non-nursing model led to fears on the part of some PHNs in particular that if they did get involved in providing a service to residents and something went wrong, they would be held responsible (HSE6, HSE8, HSE1, HSE03, MB4).

[HSE6] ...There were all the usual fears about effectively a new nursing home in the area, when things went wrong who's going to [take responsibility]

It was safer to facilitate nursing home admissions which absolved the PHNs of further responsibility for patient care (MB4).

A very practical issue for PHNs that emerged from the FOLD, O'Connell Court and Mount Bolus case studies was the fear that engaging with the HWC schemes would increase caseloads to unmanageable proportions (HSE5, HSEO3, OC1, MB4). They expected that they would have to deliver nursing services to every resident in a scheme and that residents would require around the clock nursing. These fears were related to the fact that residents were congregated together in large numbers and also to the expectation that every resident would be as heavily dependent as nursing home residents.

[HSE03] It's a bit of an issue; it always caused tension, because people will then fall back on saying, well I can't be going in there providing a 24 hour nursing service.

[OC1]: The PHN for O'Connell Court, I can understand at the time said, 'I am not taking on 69 new clients in this area. This is my area; you just parachuted in and... I'm telling my Superintendent that I can't'.

[MB4] There was a real fear and a real sense among the senior public health nursing people in this area that, they have enough on their plate... It was like we have to mind our brief.

These concerns about caseloads were placed in the context of the general under-resourcing of community services by one senior HSE manager who observed that

[HSE05] Community services are not resourced to provide services to sheltered housing. There was a fear that the level of community supports that would be required will be in excess of what the HSE can deliver on. ...some of those teams really are terribly overstretched and under resourced...

Finally, several study participants believed that PHN resistance was also related to the threat that HWC posed to their status and position as nurses (HSE1, HSE2, HSEO3, HSEO5, OC1, F2, MB1). HWC is predicated on the assumption that the role of PHNs is critical but secondary to that of unit care managers and care staff in the day to day; it was suggested that this threatened nurses' customary position in Irish health services for older people. Participants noted that Irish nurses were used to being in control of patient care and that in this respect, they were different from their counterparts in other jurisdictions, including Northern Ireland (HSE1, HSE2, HSEO3, HSEO5, OC1, F2, MB1).

[HSE2] I think there would have been a lot of resistance to [HWC]...Well, I'd put it down to the fact that the nursing profession is very strong in Ireland...

[HSE1] The nursing fraternity are the ones that are most engaged [in patient care] on a 1-1 basis...They have even become more professionalised in their approach because they are now embedded in a nursing fraternity of care and all the rest. And what they hold on to... There is a tradition in nursing of *control*

in this country, of sort of taking control of the overall care of the patient. ...it's a huge challenge and do not underestimate it from that respect.

Two HSE managers gave examples of nurses' reluctance to relinquish authority over patient care. One cited the strong resistance from nurses that emerged when it was proposed that they would no longer be responsible for home help and personal care services around the country (HSE1). The other recalled PHN resistance that had developed against a proposal to situate a meals service for older people in a local pub to illustrate the point that nurses took a traditional institutional approach to services for older people (MB1).

A small number of study participants associated PHN resistance to HWC with nursing education and training (MB1, HSE05, OC1). One participant suggested that nurses are not accustomed to collaborating with other disciplines (HSE05) and that this presented problems for service initiatives like HWC that require interdisciplinary work and cross sector cooperation.

[HSE05] They don't seem to have this sense that it would be much better to partner up, to collaborate more. That numerous people can contribute to health care as opposed to just one way of doing it.

It is interesting that despite concerns about personal accountability and the impact on their caseloads, several participants believed that PHNS would have liked greater involvement in managing and delivering services in the case study schemes (HSE1, HSE2, HSE05, OC1, MB1). They suggested that nurses were not happy that what they considered to be nursing roles were being usurped by others with no professional nursing background.

### *1.6 GP resistance: Cherryfields*

A problem specific to Cherryfields arose when the scheme opened and local GPs refused to provide their services to new residents admitted from outside the Hartstown area.

[HSE 10] FOLD was initially taking from quite a large catchment area... so you'd have someone coming from outside the geographical area, maybe from Swords or Malahide, who had their medical services in Swords or Malahide and then to place them without a service in FOLD would present a difficulty. So the GP issue was key to placing people successfully...

This presented a very serious challenge because of the critical importance of being able to access GP services for residents when needed (HSE8, HSE9, HSE10, HSE12, F1, F2, F3). Cherryfields residents who came from the Hartstown area continued to have access to their own GPs but for all others, GP services had to be negotiated. A FOLD manager recalled the difficulties involved.

[F3]...It was terrible, it was a nightmare...The resident would arrive at

the door, we'd ring the GP and be told, I'm not looking after them... I remember one time ringing at least 26 doctors in the Dublin 15 area and not one of the doctors would take the residents. ...if they came from outside the catchment area, we had to assign them a new doctor and that was so difficult.

A HSE manager observed that GPs' refusal to provide a service was influenced by the '... perception that they would have to deal with high end cases like those traditionally within custodial type long stay facilities' (HSE1) and in this way they were like their colleagues from the community nursing service. According to some, a general shortage of GPs in North Dublin at the time was also a factor (F2, HSE8, HSE13). However the majority of those interviewed for the FOLD case studies believed that the main reason why residents in Cherryfields were unable to access GP services was that there was no financial incentive for the GPs to take on new patients under the GMS payment system at the time.

[HSE10] ...they couldn't get beyond the fact that there was a nursing rate [of payment] which was applicable for nursing homes and that [they thought] should also be applicable to FOLD Housing With Care. And that was quite a difficult issue which wasn't resolved for a significant period of time.

The enhanced payment that GPs received for nursing home residents did not apply to residents in Cherryfields because it was not a registered nursing home. This was the key source of GP resistance and according to participants from FOLD and the HSE, it was one of the biggest barriers to commissioning the FOLD scheme. The first residents moved into Cherryfields in June 2006 and it wasn't until November/December of that year that access to GP services was fully organised (F3). In the interim, only a limited service was available from the out-of-hours GP service and the situation was made worse by the fact that during this period, a number of patients were admitted directly from acute hospitals and some of these were already quite vulnerable when they arrived (HSE5, HSE6). A FOLD manager spoke of the repercussions.

[F3] The worst thing was, when D Doc came over to visit the residents, because he didn't know the residents, and because D doc was only there to give short courses for antibiotics or anything else, the first thing he would say is 'Send them into hospital.' So obviously our residents were going into hospital for minor things that they shouldn't be going in for...

In the short term, staff in Cherryfields had to send residents to A&E to access basic medical assessment and treatment services which they felt that residents should have been able to access from their own GP. This imposed immediate unnecessary pressure on staff as well as trauma for the residents concerned (F1, F2, F3, HSE4, HSE5, HSE6, HSE7, HSE10, HSE12) and it also had longer term negative implications which are discussed in the next chapter.

### *1.7 Psychiatric services*

A number of study participants identified problems around access to psychiatric services as another barrier to HWC implementation (HSE8, HSE11, HSE 12, N3, HSEO1). When Cherryfields opened, FOLD managers were unable to access psychiatric services for some residents with mental health problems, including people with dementia, because of the way that catchment areas were drawn up and because of protocols regarding new referrals (HSE8). Residents who moved from areas which were outside the catchment area, even residents who had previously been receiving a psychiatric service in the area where they lived, were treated as 'new' patients on admission to Cherryfields, and service protocols dictated that new patients had to routinely wait for six months in order to be accepted for treatment. One participant blamed the problems that arose in Cherryfields on FOLD's lack of planning, suggesting that there was 'no organised follow up' planned for these residents before they were admitted (HSE11). But two HSE managers believed that the six month rule was unreasonable and inequitable (HSE8, HSE12). The problem of catchment areas in the psychiatric services was not unique to North Dublin; a Cork participant observed that psychiatrists were 'infatuated with this flipping catchment area thing' which was seen to seriously limit access to services in contrast to the situation with respect to geriatrician services (HSEO1). Another participant talked about the problems that catchment areas created in the West.

[N3] It's terrible that people that live up the road, because they don't live in \_\_\_\_\_ can't access the service. That has happened.

Questions were raised by participants about the implications of strictly enforced catchment areas that made it difficult for HWC providers to implement service plans and that imposed hardship on residents.

### *1.8 Resistance from other sources.*

Apart from the resistance of health professionals including GPs as outlined above, resistance to HWC from other sources was identified in interviews with participants from the Cherryfields, O'Connell Court and St. Bricin's case studies.

#### *1.8.1 Residents and local councillors.*

The data shows that resistance from local residents and local councillors developed when the Cherryfields and St. Bricin's HWC service initiatives were being planned (LA1, LA2, LA3). According to a local authority participant involved in the development of Cherryfields, the problem arose

because Cherryfields is situated in a private residential area and residents believed that the scheme would have negative implications for the neighbourhood.

[LA1] ...there were still objections from the local community about FOLD because they regarded it as social housing with the stigma attached... [One councillor] said, no they're social housing tenants, they're going to be walking around with disability in this community, they're going to create havoc in this community. It was to overcome that type of perception.

Opposition to the development of Cherryfields proved to be short-lived and was resolved by meetings with residents and councilors (LA1) but the opposition that developed against St. Bricin's had far more serious consequences. The opposition to St. Bricin's focused on plans to incorporate the existing green space into the new scheme, and it caused serious delays in the planning permission process.

[SB1] ...the neighbours opposite it...they opposed it because we were taking away their open space. ...and then the councillors who had agreed to the proposal, changed sides and opposed the proposal. So we had to go through protracted planning appeals and eventually we got planning permission in 2008 for the scheme...

A Dublin City Council participant believed that as well as the loss of green space, St. Bricin's residents shared the fears of Cherryfields' neighbours that 'troublesome' people might move into the redeveloped scheme with negative consequences.

[LA 2] ...there were also a few difficult situations with the residents in the area who were concerned...that we were talking about significantly increasing the number of units and concern that maybe the City Council would change its mind and put troublesome people in. The fact that there were a number of significant security issues over the years, including the murder of a man... brought that kind of air of distrust to it. They're the kind of dynamics that were at play there that made it more difficult.

Opposition to St. Bricin's was prolonged and the length of time that it took to resolve it caused almost a two year delay in the planning process which contributed significantly to bringing development plans to a standstill (SB1, LA2).

### *1.8.2 Resistance from nursing home sector*

Further resistance to O'Connell Court emanated from the private nursing home sector in the early 1990's. This resistance took the form of a formal objection being raised in the Dail.

[OC1] ...with the emergence of the nursing homes there would have been an argument from the private nursing homes against O'Connell Court, complaints would have been made to the Dail and to politicians that we were taking their business from them.

It was suggested that private nursing homes saw this HWC scheme as an unwelcome competitor for business. There was no other evidence in the findings of concern by the private nursing home sector about HWC development.

## **Section 2: Structures and systems**

Section 1 focused on the challenges associated with the HWC model itself that presented especially at the implementation stage. HWC was unfamiliar and it challenged accepted cultural norms and expectations in Ireland about the long term care of vulnerable older people. In this context, it is not surprising that it also did not fit into any of the existing formal structures and systems that were organised to support the delivery of long term care services in Ireland, and this is the focus of discussion in Section 2. This lack of 'fit' (Nadler 1998) led to a number of immediate practical problems for stakeholders that had to be confronted once the case study schemes reached implementation stage.

Kotter warns that an organisation's systems and structures can undermine a change vision and refers to 'strong structural silos' that can stand in the way of its implementation (1996:101-115). The most dramatic example of structural silos that emerged from the findings was the huge barrier created by existing funding structures and systems in the health services that made it extremely difficult for stakeholders to source revenue funding for the case study schemes.

### *2.1 Revenue funding*

The last chapter showed how CAS funding acted as a major catalyst for HWC development, but the evidence in this section suggests that (with the exception of St. Bricin's) much less attention was paid by the champions during the early planning stages to the critical issue of the on-going resources needed to operate the case study schemes once they were built. The evidence from interviews with key stakeholders shows that it took time and energy and ingenuity in some cases to source adequate funding to operate the case study schemes and that this problem was never completely resolved. The findings from the FOLD, O'Connell Court and Mount Bolus case studies suggest that the case study HWC schemes were poorly resourced from the start (OC1, MB3, MB4, HSE3, HSE8, HSE10, HSE12). Participants described the 'disconnect' between the housing and health funding systems that on the one hand facilitated building of the case study schemes but on the other provided no straightforward way to fund their on-going operation (HSE03, HSE1, N4, SB1). Capital funding from the social housing budget could be accessed for the building of HWC schemes but revenue funding was much more difficult to source. The modest HSE budget for sheltered housing created in 2005 (see pp 30-31) when divided up between the four health board



regions would only cover a miniscule proportion of revenue costs (N4) and other funding sources had to be identified.

The champions had to be creative and work around a system that did not formally acknowledge HWC as a legitimate long term care alternative. One Mount Bolus participant suggested that the middle ground occupied by HWC made it difficult to access funding (MB2).

[MB2] ...we would have developed a Home Care Package initiative, re-engineered our Home Help services in an effort to keep people at home. That's at one end of it. At the other you have Fair Deal, and the access to long term care it has opened up. My view is, and I've reflected this, is that they're caught in the middle. It doesn't fit into Fair Deal. [You can get] revenue funding through subvention system for nursing homes but not for this.

How then was revenue funding accessed to operate the case study schemes? As suggested above, the circumstances and variables with respect to the case study schemes were different and so also was the way in which key stakeholders addressed the problem of revenue funding. For this reason, the responses to lack of revenue funding in each of the case study schemes are discussed separately in the following sub-sections starting with O'Connell Court which was developed first.

### *2.1.1 O'Connell Court*

There was no health board involvement in the original development of O'Connell Court scheme in the late 1980's and no health board commitment to fund services prior to its opening.

[OC] I know that other services, some around longer than here, they refused to open services until they had funding from the HSE. That was the mistake I would have made. We provided services and ended up fighting for funding afterwards...

Participants from O'Connell Court spoke of the continuous battle to find the money to fund services from the start. The expectation was that they would eventually source revenue funding mainly from the health board, but participants spoke of promises made by both the health board and the local authority that did not translate into funding for some years and of their inability to meet service objectives due to lack of resources (OC1, OC2).

[OC1] I had no revenue funding for the first three years...Through an overdraft, fundraising and not paying the Revenue Commissioners we paid for the services ourselves. For the first three to four years, there was no funding coming from the health board. Now it started out with 10,000 from 1989 but for the first 3 years they would have pleaded inability to pay and so did the City Council. ...we eventually threatened to sue.

Delays in statutory funding were put down to the poor state of the Irish economy in the late 1980's and resultant public sector cutbacks (OC1). Revenue costs were covered with great difficulty and promised funding only became available after the housing organisation took legal action in 1992/93 (OC1). Revenue funding was eventually secured from the health board in the form of a Section 65 grant and subsequently from Cork City Council after it was discovered that another voluntary organisation was receiving a Homeless Allowance on behalf of its residents.

[OC1] ...I made up my mind, I'm not letting City Hall off. It took...constant, constant, constant barragement of meetings, coaxing, persuading, getting people on site. They gave me the bed nights for 25 of my units; we have a lot more but that's what we agreed on... You can have all the aspirations you want but unless you have the basic funding. But we've had to fight hard to get our funding.

With the Homeless Allowance came a Section 15 grant from the health board. 'When you get bed nights from the City Council, the HSE Adult Homeless Section gives you money towards the care services you are providing' (OC1). Benefits in kind from the Community Welfare Officers, private donations, the use of FAS schemes and volunteer labour helped to reduce the bank overdraft that was a constant feature in O'Connell Court (OC1, HSE06). Study participants observed that revenue funding problems were never resolved and the implications for service sustainability are discussed in the next chapter.

### *2.1.2 The FOLD schemes*

A critical difference between the FOLD scheme initiatives and the other case study schemes is that the burden of responsibility for sourcing revenue funding for the FOLD schemes fell to the NAHB; in the three other cases, the voluntary housing associations had to assume most of the responsibility. The NAHB had made a commitment in writing in the Service Level Agreement (SLA) with FOLD to fund care costs up to a maximum amount and that payment would be made on the basis of the number of beds that were occupied (FOLD 2006). Additional revenue was to be generated by FOLD from the rent paid by residents to cover accommodation costs.

When Cherryfields opened, it became obvious that the recruitment of suitable candidates would be difficult and this posed an immediate problem for FOLD who had already employed managers and staff who had to be paid before the unit even opened, regardless of the number of residents in situ (F1, F2). Under the SLA with the health board, revenue funding with which to operate Cherryfields was to be paid on a per capita basis only when residents were admitted. The site for Cherryfields had been chosen because the NAHB already owned it but it was situated in Hartstown, an area with a predominantly young population, and there were few people on the

Fingal County Council housing list from which to draw prospective residents (LA1, HSE8, HSE10, HSE11).

[HSE8] And one aspect was that there wasn't a captive [housing] waiting list in Fingal, because Fingal don't have a history of sheltered housing in the first instance, so they didn't know where they were going to draw them from. But there always a slight concern about the site, which effectively turned out to be a problem at the end in relation to customer base.

This contrasted with the situation in Anam Cara located in Glasnevin, an area of Dublin which had a large population of older people in local authority housing, including many in sheltered housing, as well as a long waiting list for sheltered housing. It became obvious that other ways would have to be found to fill beds in Cherryfields. Some flexibility was exercised by Fingal County Council who allowed people from housing lists in adjacent counties to be considered for admission (LA1, F1, HSE9).

[LA1] But we could 'play at the margins of the percentages'; in other words if there were vacant units and there weren't enough people coming through from the local authority list, you could qualify them as social tenants so you could fill them.

For FOLD the priority was on filling beds, but even if suitable candidates could be found for admission to Cherryfields there was a problem because despite the formal commitment made by the NAHB in the Service Level Agreement to provide revenue funding, there was no obvious source of funding with which to honour it when the time came (HSE3, HSE8, HSE9, HSE12). All NAHB funding was otherwise committed and no distinct budget for the FOLD schemes had been established.

[HSE8] That's the problem; it never really got into the Service Plan. That's why we ran into trouble in the end; ...we had buildings but no way of operating the service.

A NAHB senior manager was blamed for not ensuring that the FOLD schemes were included in the NAHB Service Plan which would have led to the creation of a specific budget to fund services (HSE3, HSE8, HSE12). What was or was not done to create a dedicated NAHB budget for the FOLD schemes is not known but the end result was that the FOLD schemes opened without a budget to cover the cost of operations. This posed an immediate problem for FOLD who had already hired managers and staff who had to be paid before the unit even opened, regardless of the number of residents in situ (F1, F2). It was also a problem for the NAHB who had to find revenue funding from other budgets in order to meet their commitments in the SLA with FOLD (HSE3, HSE8, HSE10).

In the absence of a dedicated budget for HWC revenue funding, NAHB senior managers saw an opportunity to fund revenue costs using Delayed Discharge Initiative (DDI) funding that had been allocated to alleviate pressure on acute hospital beds in Dublin and Cork by facilitating the discharge of older people (HSE8, HSE12, HSE13). The expectation (if not the direction) was that DDI funding was to be used to pay the individual costs of care in private nursing homes. The decision was made by NAHB administrators to divert a portion of the DDI funding they had received to cover care costs in the FOLD schemes.

[HSE13] ...we intended to use the nursing home funding [DDI funding] to apply to this as well...people thought it was only for nursing homes. But when we looked at it, we saw that it was for care of the elderly so we thought that by using different terminology, we could use some of that funding [for the FOLD schemes]...

DDI patients were admitted to Cherryfields directly from acute hospital and without reference to the nurses and GPs who would be expected to provide these patients with services once they were admitted; these people brought DDI funding with them thus alleviating the revenue funding problem for both the NAHB and FOLD. In addition, a smaller number of people admitted from hospital to Cherryfields were funded using Home Care Package (HCP) funding which was just beginning to feature in community care budgets (HSE8, HSE12). As was the case for DDI funding, older people occupying acute hospital beds were again prioritised for HCP funding but significantly, the aim was to return older people to the community and this gave the HSE the latitude to allocate some HCP funding to FOLD applicants (HSE8, HSE12, HSE13).

Funding was still not sufficient to cover the care costs of residents in Cherryfields and revenue funding also had to be sourced for Anam Cara which was due to open in 2007. According to two participants who were directly involved, a political decision was made by senior HSE officials with regional and national responsibility for older people's services to allocate all of the national budget for sheltered housing in 2007 to the NAHB to help cover revenue costs in Cherryfields and Anam Cara (HSE1, N4, N5).

[HSE1]... at that particular stage we were looking for funding...in order to be able to run both Cherryfields and Anam Cara. There was a specific piece given for sheltered housing and that element of that budget all went towards those two facilities because there was a deficit.

Revenue funding for Cherryfields and subsequently Anam Cara was thus cobbled together using DDI funding, Home Care Package funding, and the national budget developed to support voluntary sheltered housing providers across the country. But as one HSE participant observed the budget was never adequate.

[HSE3] We always had a deficit; running costs for FOLD were about

2 million and we only managed to get 1 million in funding. ...the funding came AFTER and we never got our full funding. We'd get the money but then we'd show a deficit and have to make it up from other budgets. And we didn't really make it up fully.

According to several FOLD case study participants, the decision to admit DDI patients in order to source revenue funding had unanticipated negative repercussions (HSE1, HSE5, HSE6, HSE10, HSE11, HSE12, F2, F5) including the referral of a significant minority of residents to A&E shortly after, already mentioned in the context of the lack of GP services at the time (see p. 110). Many of these never returned to Cherryfields and had to endure the additional trauma of moving again into a nursing home. Lack of GP services was a contributing factor and five participants suggested that inappropriate referrals from the acute hospitals was another. They argued that in their eagerness to discharge so-called 'bed blockers', acute hospital staff had inappropriately referred DDI patients to Cherryfields who should have been placed in nursing homes (HSE5, HSE6, HSE11, F2, F5).

[HSE5] If... you were trying to exit some inappropriate person from your acute hospital [referral to Cherryfields] was viewed as an exit strategy. That's why the kind of the people who went there first were inappropriate, not all of them but some of them.

This episode took place over only a relatively short space of time and the problem was solved subsequently when access to GP services was negotiated and admissions criteria more strictly enforced (HSE5, HSE6, HSE12, F2, F3), however the data from interviews with several participants suggest that it attracted considerable negative attention not only in Dublin but also in other parts of the country. This served to undermine the reputation of FOLD and the 'FOLD model' particularly among decision makers in the health services (HSE1, HSE2, HSE4, HSE5, HSE10, HSE12, HSEO4). In particular, it raised lasting doubts about FOLD's ability to deliver on the promise to support vulnerable older people up to the end of their lives.

[HSE10]...there would have been a lot of anecdotal tales told about FOLD and their inability to cope with individuals. ...that the FOLD model wasn't working, that there were too many hospital admissions, and that they couldn't support people in the community appropriately.

And it conveyed a negative impression of the HWC model to those who otherwise may have been interested in replicating it.

[HSE1] There was a lot of interest [in replicating the FOLD model] at the time, when the FOLD developments took place, but that has abated, it didn't go anywhere. The teething problems [in Hartstown] at the beginning sent out a bad message.

An HSE service manager who explored the FOLD model with a view to developing services outside Dublin observed

[HSEO4] ...we looked into trying to encourage FOLD to come here. ...We felt that they didn't meet the needs... That once people got a certain level of dementia, they needed the nursing home model. That window of opportunity for the FOLD type patients, between home and nursing home, was too short. That's what we concluded. [We heard that residents in FOLD had to move again within]...less than a year. I heard that people ended up in A&E – I'm talking about maybe 4-5 years ago.

This person heard nothing over the years subsequently to allay concerns about the capacity of HWC to support residents as their dependency level increased which were generated by stories about what happened in Cherryfields. HWC services continued to be dismissed as a template for future service development on foot of stories heard years before (HSEO4).

The data suggests that the champions may have been so seduced by the availability of capital funding with which to build the FOLD units that they neglected to give sufficient attention to securing funding with which to operate them once they were open. It also demonstrates the complex interrelatedness of the factors associated with the introduction of a new service model (Pasmore 2011) that makes it difficult to discuss any one factor in isolation.

### *2.1.3 Mount Bolus*

Accounts about how the Mid-Offaly Housing Association expected to cover operating costs when Mount Bolus opened were not wholly consistent particularly regarding the proportion of costs to be covered by the HSE and whether HSE revenue funding would be required at all in the long term. The HSE were only peripherally involved during the building stages of the Mount Bolus project and provided benefits in kind in the form of advice and support around fitting out the new facility through the secondment of a health board procurement officer (MB2, MB3, MB4).

However, as was the case for O'Connell Court, no formal commitment was made by the HSE to fund revenue costs in advance of its opening (MB3, MB4) and a request for top-up capital funding had already been turned down during the late planning stages (MB2).

According to one housing association participant, there was an assumption that 'the HSE would support the project with a yearly stipend' which had happened in another supported housing project in County Limerick; the expectation was that this 'stipend' would offset at least some of the service costs (MB4). The same person recalled that 'Initial meetings with the HSE to secure this funding were fruitful' (MB4). An HSE stakeholder claimed that no specific request for annual

revenue funding had been received although there was the suspicion that the HSE would be expected to provide revenue funding in the long term (MB2).

Although the housing association assumed that the HSE would provide some financial assistance, the expectation was that they themselves would be able to fund service operations through the collection of rents and charges provided that residents were given access to support services provided by the HSE (MB3, MB4). Revenue funding for Mount Bolus would thus largely depend on filling beds as was the case for the FOLD schemes. It was anticipated that it would take time to achieve full occupancy but that with the help of the HSE, suitable candidates would be identified. In the meantime, the plan was to borrow from the banks to cover running costs in the first few years until the scheme was fully occupied (MB3, MB4).

But when Mount Bolus opened it proved impossible to find adequate numbers for admission and the subsequent intake of residents was much slower than anticipated (MB3, MB4). People from the area who had emigrated in their youth had been targeted for services during the planning stages but these failed to materialise after the service opened (MB2, MB4). Nor was there a large number of people on local authority housing lists in the region from which to draw. In retrospect, it was acknowledged that the recruitment of new admissions should have been extended beyond the immediate area to ensure larger numbers (MB4). When the housing association asked the HSE to help identify suitable candidates, referrals were not forthcoming. Two participants (MB1, MB4) claimed that the lack of referrals was a reflection of the reluctance of the community nurses to engage with the HWC model (see p. 103) whilst others had different explanations. The first explanation was the belief top up that Mount Bolus had been built in the wrong place (MB2, HSE1, N5).

[MB2] I'm also aware of retirement villages...[including one in Moate]. They're doing fine; they're in a different geographic location. Mount Bolus is quite rural. Moate isn't a metropolis but it is a town and the facility is located bang in the middle of the town. I'm not saying you can't do it in Mount Bolus but it's a little more difficult.

In addition to its location 'in the middle of a bog' as one HSE officer put it (HSE1), it was also suggested that some older people in the community who had been identified by the HSE as potential candidates for Mount Bolus were actually not interested in moving there. Two participants believed that when given the option, Irish older people preferred to receive required care in their own homes rather than in a residential care setting like Mount Bolus (MB2, MB3). In this interpretation of events, it wasn't the *unwillingness* of HSE staff to engage with the new HWC scheme that caused the problem but rather their *inability* to find suitable candidates from the sparsely populated locale who were willing to take up places in the new scheme.

The contingency plan to borrow from the banks until full occupancy could be achieved proved equally impossible. By the time that Mount Bolus opened, the banks that had already loaned the housing association top up capital funding, were not then in a position to lend more money due to the downturn in the economy (MB1, MB3, MB5). The housing association then looked to the HSE for 'seed funding' to cover the running costs in the short term but this request for the HSE funding was also turned down (MB2, MB3, MB4).

[MB4] ...they came out and they had a meeting with us and basically they gave us, that was towards the end of her time, it was Spring 2009, they gave us the 'heads up' that they were running out of money themselves to run their own hospitals and units and everything and they were cutting back in every respect with services and unfortunately we were gone, in terms of their planning. We weren't in the picture at all.

In the meantime, Mount Bolus had admitted a small number of tenants and a skeletal staff were employed to meet their needs. As revenue funding alternatives were exhausted, paid staff were dismissed, committee members worked as volunteers to fill service gaps and money accrued from the rents from the other housing schemes operated by the Mount Bolus committee was used to cover costs (MB4). The expectation that access to HSE community services (i.e. home helps and PHNs) could be used to offset service costs was never realised (M1). According to one stakeholder, as the Mount Bolus committee ran out of funding options, rumours began to circulate that the scheme might have to close and this discouraged potential candidates from applying for admission.

[MB3] I suppose people talk, and... Once word like that got out that there was a risk that the place might close, then people would no longer move into it. It defeated itself... So that was the crucial thing. Once that went out, they couldn't fill it.

Fears that Mount Bolus might close became a self-fulfilling prophecy. In the absence of secure revenue funding, the service was not sustainable (MB3, MB4). Mount Bolus closed in September, only a few months after it opened (MB4).

The findings suggest that the closure of Mount Bolus seriously undermined confidence in the feasibility of HWC as a service alternative in the Irish context. Three senior HSE and DOE/CLG officers pointed to the Mount Bolus project as a notorious example of what should not happen in future (HSE1, N5, MB2). For DOE, the closure of Mount Bolus caused embarrassment because significant capital funding was allocated by the Department to build a unit that was not being used (N4, N5)

[N5] We have a situation which is causing us a lot of concern at the minute



where we have invested something like 3m-3 ¼ million in a new facility in the Midlands, a brand new facility. 32 units of accommodation built with CAS funding and it's lying idle...

Concern was expressed about the waste of taxpayers' money involved and the suggestion was that the local authority gave CAS funding approval without adequate checks being carried out about the future sustainability of the project (N5). An HSE senior manager suggested that the easy availability of CAS scheme funding had allowed the Mount Bolus housing association to proceed with what was considered to be indecent haste. For two HSE senior managers and the representative from DOE the closure of Mount Bolus represents the failure of a voluntary housing association to consult adequately with the HSE during the planning stages of a project (MB2, HSE1, N5).

[MB2] But they built it anyway; it was virtually up out of the ground before we were asked.

[HSE1] Many [sheltered housing associations] tagged on to the housing boom and just built for the sake of building. There's the example of one down there in Offaly... They built with no cognizance whatsoever... with no level of connectivity at all [with the HSE] ...there was money available through DOE to go that route rather than building the two together from a care perspective and say how could HSE and housing work effectively together to develop a service around it.

It was suggested that the housing association involved had been on what was described as a 'solo run' without adequate consultation with the HSE about how the unit would be funded once it was built (HSE1, MB2, N5).

The failure to fill beds led to the closure of Mount Bolus within only a few months of opening, and a number of participants spoke of Mount Bolus as a failed project (HSE1, MB2, N5); the clear suggestion was that its closure sent a signal to housing and health stakeholders to proceed with extreme caution when considering the possibility of future joint initiatives like Mount Bolus. One housing participant suggested that the lesson learned by DOECLG is to stick to housing and not get involved in future projects like Mount Bolus that depart from the Department's main function.

[N4] There have been comments [in DOECLG] like 'How the hell did we ever end up paying for this here?' That issue of demarcations is still there.

Another participant maintained that members of the voluntary committee who undertook the Mount Bolus project lacked the capacity and expertise to operate the High Support Unit once it was built.

[MB4] The biggest lesson learned was that... there's a huge difference between

building a building and running a service.

The experience of trying to recruit new residents for admission and keep the unit in operation had been a much bigger drain on the volunteers than had been anticipated (MB4).

There was agreement that if the economic situation had not become so bad in Ireland at the time that Mount Bolus opened, the necessary interim revenue funding would have been available if not from the HSE then from the banks (MB1, MB2, MB3, MB4, HSE1, N5). All agreed that the timing of the initiative was most unlucky.

#### *2.1.4 St. Bricin's*

St. Bricin's was planned with the full knowledge and participation of the HSE, according to key stakeholders from Dublin City Council and the housing association involved (SB1, LA2, LA3). As was the case for the FOLD schemes, plans for St. Bricin's were predicated on the assumption that the HSE would provide funding to cover the care costs of residents with high dependency needs (including people with dementia) and the plans also depended upon HSE revenue funding for the day care centre as well as top-up capital funding to build it (SB1). According to a housing association participant, substantial HSE funding was to be a cornerstone of the scheme development, but as was the case in O'Connell Court and Mount Bolus, no formal written commitment had been made by the HSE up to the time that Planning Permission was approved in 2008, and HSE funding never actually materialised. The housing association were unable to get a firm commitment of funding from the HSE and the ASI who were to provide dementia services within the project were also unable to access HSE funding (N6, SB1). The HSE ultimately formally withdrew from the project in early 2009 and the reason given to the housing association was that they had plans to develop day care at another site (SB1). Without the promise of HSE funding for day centre operations and for the running of planned dementia specific services within the scheme, the project was abandoned.

The lack of a defined HSE budget line for HWC was thought by one stakeholder to be primarily responsible for that fact that the St. Bricin's project did not progress (SB1). The belief was that if a dedicated budget for HWC development had been established, HSE revenue funding might have been forthcoming for the redevelopment of St. Bricin's. But other participants observed that given the changed economic situation in Ireland, even funding that was previously committed would not have been available to complete the project (LA2, LA3). A local authority participant pointed to planning permission delays which meant that HSE funding was being sought just at the time when both housing and health budgets began to be under threat (LA2). As was the case in Mount Bolus, timing was an important factor.

## *2.2 Service charges levied to case study scheme residents*

Another funding issue that presented problems during service implementation concerned the charges levied to HWC residents in the two FOLD units. Although it was not discussed by study participants in the context of revenue funding, local HSE managers spoke of the challenges presented by the fact that there was no clear financial assessment process in place with which to determine charges to FOLD residents (HSE3, HSE10).

[HSE10] If you're going into a nursing home, there is a clear financial assessment process. If you're in a nursing home, there's a financial assessment and everybody knows where they stand. When FOLD Cherryfields was set up, there was no financial assessment process in place.

Two different charging systems were developed for Cherryfields and for Anam Cara; in Cherryfields draft Home Care Package guidelines were used to determine charges but in Anam Cara the nursing home regulations were used. So-called 'private' applicants including all homeowners were expected to pay full service costs (HSE3, HSE10). Local managers feared that both charging systems were subject to legal challenge because of the arbitrary way in which they were determined.

[HSE3] There's no statutory basis for that, no legislation. I think we always felt that we were out on a limb, that if we were challenged we could be in a right pickle. Both myself and [local manager] wrote a number of times to the Local Health Manager but we got no direction on it. We were told it couldn't be included in Fair Deal but it wasn't home care either. We were in No Man's Land.

The final section in this chapter presents the findings with respect to the other barriers associated with inter-agency collaboration that made HWC service implementation challenging.

### **Section 3 The challenges presented by inter-agency working**

By definition, HWC development requires inter-agency cooperation (O'Connor et al 1989, Cox 1999), and the findings presented above suggest that systemic issues like catchment areas and service protocols can act as barriers to achieving necessary cooperation between the agencies involved in service implementation. This section focuses on other factors that can undermine the working relationship between agencies. The FOLD case studies present a particularly good opportunity to examine some of the particular challenges associated with inter-agency working in the context of HWC development in Ireland because the FOLD schemes were always planned as partnership ventures between the NAHB, the local authorities and FOLD housing association from

the beginning. However, the findings from FOLD are supported by the findings from O'Connell Court, Mount Bolus and St. Bricin's which also identify problems associated with inter-agency collaboration.

### *3.1 Conflicting priorities*

Participants from Dublin City Council and DOE spoke of the conflicting agendas of housing authorities and the health boards that made the allocation of places in the FOLD schemes somewhat fraught (LA2, LA3, LA4, NA4, NA5). Dublin City Council prioritised the needs of people on the local authority housing list while the NAHB prioritised people in the community who could not access needed long term care services. From a local authority perspective, there was no problem in the case of applicants who were already on the local authority housing list who were also in need of care, but difficulties arose when the health board referred older people for admission to the schemes who were not on the housing list. The evidence shows that this conflict of interests created tension between the partners.

[LA3] We drew up an agreement with FOLD and the HSE as to how the allocations would work...It's woolly then; they think it's a nursing home scenario... The system under CAS is quite clear on how people are allocated the units. We had to copper fasten it... they should be on our list or coming from one of our units – or in need of housing...

But they have to be in need of housing; it's a housing project.  
It's not a nursing home...

Local authority officers were convinced that care needs alone could not establish eligibility for services in the FOLD schemes (LA3, LA4) and CAS regulations were invoked to support this view. Because the capital funding with which the FOLD schemes were built was contingent on the majority of residents meeting social housing eligibility criteria, local authority officers felt obliged to allocate the majority of FOLD places to people on the housing list ( N5, LA3, LA4). Problems arose when some of the people on the housing list were not deemed suitable by the NAHB because they either did not need HWC services or because HWC services were inappropriate to their needs (LA1, LA3, LA4). Likewise, many of the people that the health board referred for admission to the new schemes were not acceptable to the local authority because they were not eligible to be on the housing list (LA1, LA3, LA5). The challenge was to find common ground and achieve the desired balance by developing an allocations policy that satisfied both groups.

[LA1] How to reconcile housing and care needs. We were really trying to match two things that were incompatible; people had to qualify for housing tenancy, so is housing tenancy or mental

disability the priority. They're incompatible; in one sense so you had to try and get a happy marriage between two things that don't even speak the same language.

One local authority participant observed that control of services was an issue; 'It's almost a territorial thing, I suppose... Who's calling the shots then; is it housing or health?' (LA3).

Although they were prepared to exercise some flexibility with respect to eligibility local authority officers still felt it necessary to attend allocations meetings in order to make sure that prospective tenants at least roughly complied with social housing eligibility criteria (LA3, LA4) in other words, to protect their interest. Participants from Dublin City Council and FOLD said that negotiations around the allocation of places involved some give and take on both sides and it is now less of a problem than it was when the FOLD schemes opened (LA3, LA4, F2, F3).

### *3.2 Expectations*

The findings suggest that some of the problems that developed during the implementation of the FOLD schemes resulted from the unrealistic expectations of FOLD managers who had no previous experience of working in the Republic of Ireland (F1, F2, HSE3, HSE5, HSE6, HSE8). One such problem developed around revenue costs in Cherryfields which were much higher than had been projected during the planning stage. The FOLD schemes had been promoted as a cheaper alternative to nursing home care, and this had great appeal for the HSE as the cost of nursing home care began to increase dramatically.

[HSE8] ...it was sold to us as a cheaper model of private nursing home care which at the time was averaging between 1000-1400/bed/week. We were told by FOLD that this would be around 650/week. Eventually we realized, it became more expensive, I think the running costs around 900/week...

Two HSE participants attributed the cost differential to FOLD managers' unrealistic expectations that 'they could employ people for the same salary they could employ somebody in Northern Ireland' (HSE4, HSE8).

It was suggested by an HSE senior manager that revenue costs was '...one of the issues that bedeviled [HWC] at the start' and another HSE manager recalled that the high revenue costs in the raised questions for some people in the health services about whether the FOLD schemes represent value for money.

[HSE2] So, you know, it seemed to be that you had this very high cost residential care and rightly or wrongly, I don't know the exact details but there was this sense that, for not much less, you were only getting middle of the road care...

[HSE4] I maintain they're the dearest B&B in Dublin...I'm not taking away from the care element of them. But they cost about 7-800/week and [residents] provide their own furniture, their own toiletries, all that's right but it is a significant cost of care. Their GP services are GMS, their chiropody. I have a question about what we get for that money other than a different kind of care. High cost for what we get.

It is interesting to note that little apparent value is put on the acknowledged provision of 'a different kind of care' by above health professional. The message that this stakeholders took from the FOLD experience was, why change what we're doing if it is going to turn out to be just as expensive as what we are already doing.

Three participants believed that staff training challenges faced by FOLD managers identified earlier were also at least partly a function of unrealistic expectations (F1, F2, HSE3).

[HSE3] FOLD found the whole staffing bit a lot more difficult than they anticipated... Particularly the Irish staff many who are non-nationals. ...getting staff to think in a different way and not to fall into those traditional modes of caring... They struggled with that; I don't think they realised how difficult it would be down here.

Again FOLD's experience was limited to Northern Ireland where HWC was better established as a long term care model and staff more familiar with the concept.

A third misunderstanding developed around access to community services. A FOLD manager concluded that FOLD were naïve in assuming that community services would automatically be available to support vulnerable residents in Cherryfields (F2). They were caught unaware when in the first instance they were unable to access GP and other community services for residents when Cherryfields opened.

[F2] We in FOLD thought we had been led up the garden path. We had received assurances from the HSE that services would be provided and that proved not to be the case. Assurances given but not delivered.

Two FOLD managers acknowledged that, in retrospect, FOLD should have insisted on getting a written commitment from the NAHB to the effect that required services would be available before Cherryfields opened (F1, F2).

### *3.3 Challenges involved in working with the HSE*

Based on the data analysis, there was a consensus amongst stakeholders from both the statutory and voluntary housing sectors that it was particularly hard for them to plan and develop HWC services in partnership with the health boards/HSE; this was critical to the progression of plans

because of their heavy reliance on the HSE for revenue funding. One housing sector participant observed that 'there was tremendous possibility of partnership [but] the difficulty from my perspective has always been trying to create a workable partnership with the HSE' (SB1).

Partnership with the HSE was difficult for a number of reasons. Participants from FOLD, Dublin City Council and O'Connell Court spoke of the lack of continuity of health board managers which made partnership with the HSE difficult (F2, LA2, LA3, OC1). A FOLD manager spoke of the 'unsettled operating environment' created by the reshuffling of HSE managers in North Dublin following the Leas Cross scandal which undermined efforts to bed down services in Cherryfields after it opened (F2).

[F2] There were a series of acting Managers of Services for Older People, ...who weren't there long enough for us to get these sorts of resolutions [like GP access] put into place.

The reorganisation of health services was another problem identified by two Dublin City Council participants (LA2, LA3). One observed '...you had the Eastern Health Board then [it] was reorganised and then reorganised again...You had different people for different structures (LA2). It was argued that the large number of people from the HSE who attended planning meetings and the movement of HSE managers during the planning stages of Anam Cara and St. Bricin's made negotiations cumbersome.

[LA3] We would go to meetings and there would be the design team for FOLD, there would be a representative from FOLD management, there would be maybe two people from Dublin City Council and then there would be ten to twelve people from the HSE. One would be looking after car parks, one would be looking after access for food... it was cumbersome and sometimes all of those people sitting around the table didn't guarantee that they could make a decision. It still had to go somewhere else for somebody to make a decision and that was frustrating.

This centralisation of decision making which came with the establishment of the HSE in 2004/2005 was believed to have undermined the implementation of plans for both Mount Bolus and St. Bricin's (HSE1, MB1, SB1)

[HSE1] Bricin's came in at a time of the HSE and the HSE is layer upon layer upon layer. ...Decision making remains at the top of the organisation rather than down and that's a difficulty in lots of ways. ...Who actually makes the fundamental decision here around a complete change of service delivery? And that's where it stops.

[SB1] it struck me at the time that within the HSE it was partly the process of change in the HSE where everything was being centralised. And you had

people at local level who were really afraid to make a decision on anything. In organisational behaviour terms, for the people there, they were afraid to make a decision to commit to any resources but they were equally afraid to say, no we can't really commit this because we have no money, which would have been a cleaner way of dealing with it

Finally, the lack of clarity about *how* decisions are actually made in the HSE was noted by a retired health board manager and his contention was that as decisions about new service initiatives are passed up the line of management, the 'essence' of the project is lost, it loses priority and implementation is seriously undermined (MB1). With specific reference to Mount Bolus, he observed that the momentum created by the champions was lost and 'the project just fizzled out' (MB1).

Housing participants and even some participants from the HSE argued that the HSE was a difficult partner with which to conduct negotiations around service development and that this was a barrier during the planning and implementation stages of the case study schemes. Stakeholder perceptions about HSE resistance to innovation are discussed further in the next chapter.

#### **Section 4 Discussion**

This chapter outlined the findings with respect to the challenges faced by the case study champions during the implementation stage, the stage in the change process when according to Pasmore 'All hell breaks loose' (2011:272). The findings are organised around three central themes. Section 1 focused on the barrier to service implementation created by resistance to the HWC model itself, mainly but not exclusively from health professionals, which manifested itself in the reluctance or refusal to make referrals or to provide services to HWC residents. Section 2 presented the findings on the way that existing structures and systems in the organisations involved in HWC development created an 'operating environment' which was not conducive to HWC development (Nadler 1998). Section 3 looked at the particular challenges presented by the inter-agency nature of the case study projects.

According to change theory, resistance can be expected when any proposals are made for the introduction of significant change (Kotter 1996, Nadler 1998, Paton and McCalman 2008) but it will be particularly strong when the proposed change challenges the organisational culture, including the 'shared tacit assumptions...passed on from generation to generation within an organisation and organisation members do not see them anymore because they are taken for granted' (Coghlan and McAuliffe 2003:59). The data in Section 1 suggests that the introduction of HWC threatened the strong culture in Ireland that interprets old age as pathology and dictates that services be delivered through a medical model. HWC posed a particular threat to health professionals who have a stake in maintaining current medical and nursing model systems that



reinforce that culture (Paton and McCalman 2008). The resistance of health professionals to the HWC model can be interpreted as sign of a dominant culture striving to protect itself and maintain 'the way we do things around here' (Coghlan and McAuliffe 2003:59).

Community nurses were being asked to leave their comfort zone and take on new and different responsibilities; they had never before been asked to deliver services to residents in a group setting. While the introduction of HWC was believed by HSE decision makers to be necessary and positive, for others whose daily workload and work practice would be affected by its introduction, HWC represented a loss (Harvey 1995:22); for GPs the HWC model represented the loss of potential income, for nurses the loss of position and authority and the loss of time for other clients, for neighbours of Cherryfields and St. Bricin's the loss of green space and peace and quiet, and for private nursing homes the loss of potential business. There was no incentive for them to support the new service initiatives.

Nursing concerns about their role and responsibilities vis a vis HWC represent a wider phenomenon already identified in the Irish nursing literature. In a report commissioned by the All Ireland Gerontological Nurses Association, Heath refers to the concerns of Irish registered nurses about 'the reduction in numbers of RGNs in residential care staffing mixes' and the 'undervaluing of their work in residential care', specifically in the context of the 'shift from hospital type services towards social/household models that support normal living' (2010:54). A report on nursing roles in residential care settings in the U.S. suggests similar concerns on the part of American nurses.

Culture change...poses a number of dilemmas for nurses... In implementing culture change, nursing homes report anecdotally that nurses have difficulty in making the operational changes associated with resident –directed care. RNs are perceived as resistant to change, a stance associated with perceived or real threats to nursing autonomy, regulatory related issues and the professional nurse's scope of practice and accountability.  
[Burger et al 2010:25]

Given the strength of the prevailing organisational culture in the health services in Ireland and the stake that nurses in particular had in maintaining it, nursing resistance to the HWC model was inevitable.

The data suggests that these reservations about the HWC model reflected health professionals' self-interest but also their concern for the health and safety of HWC residents who they believed needed a higher level of care and protection than HWC could offer, especially given the absence of on-site nursing services. The US literature on HWC links service quality with access to nursing and medical services and identifies the lack of *access* to nursing services in some Assisted Living facilities as an issue that needs to be addressed (Hyde et al 2007, Wallace 2003, Wilson 2007).

The ability of HWC residents to access nursing services when needed is a legitimate concern but the expectation that HWC residents would not be safe unless there was a nurse manager and nursing staff present 24/7 suggests the ageist stereotyping of ageing and older people (Butler 1989) who are assumed to be different from the rest of us and in need of special care and protection. There was no specific reference in the findings to suggest particular concern about the perceived risks posed to people with dementia by the absence of nurses or the lack of regulation, although it may have been implicit in the concerns about the health and safety of HWC residents cited by study participants as a barrier to service implementation. It is interesting in the context of this study that Butler coined the term 'ageism' in 1968, after encountering opposition to the acquisition of public housing to house older people in northwest Washington (1989).

The findings in Section 1 raise obvious questions about why the people on whom project implementation depended, including the PHNs and the GPs - the people with the ability to 'derail' the project, had not been better prepared for what was to come *before* the case study schemes opened (Nadler 1998). The FOLD case studies demonstrate that 'telling people something does not mean that they hear, understand or accept it' (Coghlan and McAuliffe 2003:126). Continuous communication and the participation of as many stakeholders as possible during the planning stages would have led to better understanding of the HWC model and what it has to offer and would have also provided the opportunity for the resisters to air the fears and grievances that made it harder to engage them in joint service delivery (Coghlan and McAuliffe 2003, Pasmore 2011). Better communication would have helped to establish the trust and mutual understanding which is critical to establishing the stability needed to successfully implement plans for the introduction of a new service (Fernandez and Rainey 2006).

Resistance can obstruct but it can also be used constructively to build better working relationships and improve plans (Nadler 1998). Practical issues like caseloads might have been resolved with better planning and fears about risks to older people (including the perceived risk of a second move) might have been reduced by frank discussion early on with housing association providers about quality assurance, risk management and health monitoring, all legitimate areas of concern (Moriarty and Manthorpe 2010). The issue of payments to GPs was harder to resolve but the development of detailed service implementation plans (Coghlan and McAuliffe 2003) would have flagged it earlier as something that needed to be either resolved or compensated for when Cherryfields opened. Again, better communication and wider consultation during the planning stages would have reduced if not eliminated the resistance that was displayed during the implementation stage of the case study initiatives (Coghlan and McAuliffe 2003).

The data in Section 2 discusses the barriers that were created by a lack of fit between HWC and existing structures and systems within and across the housing and health sectors. The most serious of these was the lack of revenue funding to cover HWC service costs and this reflected the fact that HWC was not a recognised service alternative and thus it had no claim on HSE budgets. The data from all of the case studies supports Fernandez and Rainey's contention that without the provision of adequate resources to support a planned change, efforts to implement change are seriously undermined (2006:6); in this regard budget deficits were a serious problem for O'Connell Court, the FOLD schemes and Mount Bolus from the start and they eventually led to the closure of Mount Bolus. Lack of revenue funding led to the eventual abandonment of plans for St. Bricin's.

Hasenfelt and English suggest that the big challenge in introducing innovation is to source uncommitted funding with which to support it and that this often requires a 'shift in the distribution of resources' which is rarely easy (1974:681). The lack of a dedicated HSE budget for HWC was undoubtedly a barrier to sourcing funding for all of the case study schemes, but the Cherryfields findings best show the problems involved in redistributing already committed funding in a large organisation and the creativity and focused determination that was required in order to identify potential sources of funding and bend the rules when necessary in order to get access to it. The contribution of the champions cannot be denied.

The data from Cherryfields and Mount Bolus illustrates that it is not possible to consider any single factor involved in the implementation of a change initiative in isolation (Nadler 1998, Burnes 2009, Pasmore 2011). In each case location had an impact on service take-up which in turn directly affected revenue funding. But the reluctance of health professionals to make referrals and older people's long term care preferences were other factors thought to have impacted on service-take up which in turn affected housing associations' ability to raise necessary funding. The Cherryfields data shows how one decision made in order to progress implementation, for example the decision to situate Cherryfields in Hartstown, can have unintended knock-on effects (poor service take up) that actually undermine implementation (Pasmore 2011).

The need for better planning seems obvious from the case study data but the counter argument is that if the champions had delayed plans until such time as money was firmly secured, the schemes might never have been developed at all. It is also clear that better planning would not have completely resolved the revenue funding problem in all cases. But the development of a detailed feasibility study or implementation plan (Coghlan and McAuliffe 2003) at least would have allowed for the development of contingency plans and provided an opportunity to discuss available funding alternatives and the implications for both HWC providers and service users with

all project partners *before* schemes reached the building stage. The data does not explain the process by which HWC charges for the FOLD schemes were determined, but it is clear that the implications of what was decided were not well thought out by the HSE.

Time taken to formalise agreements with hospitals would have helped to ensure that HWC residents received required follow up services and prior discussion with the psychiatric services would have at least clarified the limitations of the services that would be on offer. The development of feasibility studies and implementation plans along with better communication and wider participation during the planning stages (Coghlan and McAuliffe 2003) would undoubtedly have made the implementation of the case study schemes smoother but events in Mount Bolus and St. Bricin's remind us of the critical importance of timing and the fact that sometimes bad luck and unanticipated external events can override any plans regardless of the level of their sophistication and can ultimately lead to unsuccessful outcomes (Pasmore 2011).

The findings in Section 3 demonstrate that parallel to aligning systems in order to marshal the resources necessary to progress the introduction of a new service is the need to align stakeholders' priorities and expectations about service aims and objectives (Pasmore 2011). Kotter refers to the need to develop a 'guiding coalition' to develop trust and a common goal so that stakeholders can collaborate as a team (1996) but the data shows that this is not easy to achieve. The findings confirm the findings of research carried out in the UK about the difficulties associated with achieving the inter-agency collaboration particularly across the health and housing divide (Cox 1999, Cameron et al 2001, Dutton 2009). The findings from the FOLD case studies illustrate the mistrust and misunderstandings that can develop between stakeholder groups even when they are involved in a formal partnership which again might not have developed if there had been better consultation and preparation. For example, if allocation protocols had been worked out in detail well before Cherryfields opened, it would have helped to reduce the tension that developed between Dublin City Council stakeholders and the NAHB. FOLD expectations about service costs, access to community supports and staff training would have been more realistic if more research had been undertaken at the outset and time taken to focus on the details of what would be required in order to operate services and achieve service aims.

The problems that housing participants attributed to health board structures are a feature of many public sector organisations (Hasenfelt and English 1974, Zegans 1992, Fernandez and Rainey 2006). While there was nothing that the local authorities or voluntary housing associations could have done to completely overcome some of these internal health board issues, their effect might have been diminished by more frequent consultation between the partners and the development

of a detailed implementation plan that would spell out in writing the respective roles and responsibilities of partner agencies (Coghlan and McAuliffe 2003). The absence of a national framework like the national Strategy to Address Adult Homelessness in Ireland (DOE 2008) or the National Housing Strategy for People with a Disability (DOECLG 2011) made those negotiations more difficult. The HSE in particular had no mandate or obligation to support HWC development or delivery and the organisational culture in the HSE provided no incentive for decision makers to take the risks necessary to introduce a new service like HWC. In that context, the role played by the champions in progressing plans for the case study schemes was remarkable.

The data presented in this chapter contributes to an understanding of the process involved in HWC development and the complex range of factors that created obstacles to HWC service implementation in the five case study schemes. The findings show that the fact that people with dementia were targeted for services was not a particular barrier to service implementation; service implementation problems were more basic and centred on the difficulties involved in introducing a new social model of long term care for older people without adequate planning and in especially in the absence of funding structures and systems to support its development.

The next chapter looks at the implications of the factors discussed in this chapter and other factors considered critical to the future development of HWC for people with dementia in Ireland.

## **Chapter 6 What is the climate for further HWC development for people with dementia?**

The obstacles identified in the previous chapter suggest that despite the somewhat favourable environment during the planning stages, the implementation of the case study initiatives was in every case a struggle. The fact that plans for only four of the case study schemes were actually realised and only three are still in operation at the time of writing suggests the magnitude of the challenges involved in the development of HWC for older people in Ireland. The data shows that by the time Mount Bolus closed in 2009, the momentum for HWC development may have already been lost; the failure to progress plans for St. Bricin's suggests that the time for HWC development may have been only fleeting.

This chapter uses the data from interviews with study participants to examine the current climate for the further development of HWC for people with dementia in Ireland. It is organised around the themes that emerged from interviews with stakeholders about future HWC development in Ireland and the factors that will influence it. Section 1 explores participants' attitudes to the HWC model and its suitability as a long term care alternative. Section 1.1 looks at participants' perceptions about the need for HWC, Section 1.2 focuses on the perceived benefits of HWC, and Section 1.3 presents the data on perceived weaknesses of the HWC model. Section 1.4 discusses the identified need for a review of existing services and Section 1.5 presents participants' views about demand for HWC and related factors. Section 1.6 concludes Section 1 with a discussion about the need to generate demand for HWC.

Section 2 discusses the climate for further HWC development from the different perspectives of housing and health agencies and the special interest groups representing people with dementia. It asks if HWC is on the agenda and how much priority if any is being placed on it.

Section 3 presents data related to the operating environment for HWC development. The focus is on the factors that will impact on future HWC development and it asks whether the conditions are more or less favourable than when the case study schemes were being planned and developed. The chapter concludes with a discussion of the findings presented in this chapter.

Data from interviews with all 43 study participants were drawn on for this chapter; the findings from the workshop held on 11 November 2011 are also incorporated where appropriate.

## Section 1 Attitudes to Housing with Care

### 1.1. *Is further HWC development needed?*

All but one study participant acknowledged that there was a need to develop HWC services or something like it and they used much the same arguments that provided the original rationale for the case study scheme although their arguments lacked the urgency and the immediacy of the original champions. The arguments included the need to address gaps in service provision, dissatisfaction with existing nursing home services and the desire to improve the quality of life for older people whose needs were not being met. Eight participants claimed that there was also the need to provide choice of service alternatives in the Irish long term care system (HSE1, HSE2, HSE3, F3, N6, N8, HSE04, MB1) and this was put forward as justification for further HWC service development.

[N6] But there has to be choice. And I think the principle of choice has been discussed in various ways and I think we have to actually begin to work how that choice is enabled.

Only one HSE person believed that further HWC development was not needed (HSE11); this health professional spoke of the progress that has been made in recent years to develop community services.

[HSE11] ...there's lots of people that they [FOLD] might have been expecting to go into care are actually relatively easily supported at home with home support services, even though you could say that they're not as well supported as they should be. But still, lots of people are now supported at home that weren't in the past.

This was the unique view of one person and all others acknowledged the need for HWC and many of these also identified the benefits of HWC compared to nursing home care.

### 1.2 *Perceived benefits of HWC*

A large number of housing and health sector participants said that the case study schemes proved to them that it was possible to support people with dementia in a HWC setting (HSE06, HSE4, HSE5, HSE6, HSE7, HSE8, HSE12, LA2, LA3, F1, F2, OC2).

[HSE8] Certainly there are people [with dementia] who are being managed in FOLD schemes and have not had to move on and that's the proof of the pudding.

[HSE06] I think the first part about group living being cumbersome and impractical requiring high levels of supervision, to some extent I think O'Connell Court would disprove that. It's not at all cumbersome and people

are very safe in O'Connell Court but there isn't the sense that they're being monitored constantly. They have freedom as well.

Apart from proving that HWC settings can provide *adequate* care and support to people with dementia, the case study schemes also proved that HWC services can provide a *better* quality of life to people with dementia because they can enjoy a level of independence and autonomy in HWC units that is difficult to realise in a more institutionalised setting (HSE4, HSE5, HSE6, HSE7, HSE8, LA2, LA3, OC1, F1, F2).

A FOLD manager noted that risk management rather than restraint or risk avoidance is used in HWC settings and this allows people with dementia a greater level of freedom to participate in normal daily life than they might have in nursing home settings (F1). Two HSE participants stated that the FOLD schemes demonstrated that social care settings can offer the opportunity to try out new and different approaches to the care of people with dementia that would not be attempted in a nursing or medical setting (HSE6, HSE7). A nurse manager pointed to the suitability of a social care model as opposed to a medical model for people with dementia who are not in need of continuous nursing care. Another nurse manager acknowledged that

[HSE4] ...there's absolutely no doubt it's the right way to go, because I think too often people with dementia are just plopped inappropriately in residential care. Sometimes their needs are about support, supported living needs as differentiated from supported care needs really. But the next thing they know they're in an inappropriate setting with other people who are not cognitively impaired or where they're in shared facilities... where the medical model is forced upon them. There's a requirement on them to almost conform to things.

For one local authority participant, the main lesson [from the Anam Cara project] was that it proved that it was possible to develop HWC through partnership between housing associations, the HSE and the local authorities (LA2) although he suggested that a framework for coordination between the housing and health sectors would make future service development easier.

The case study initiatives proved that it was possible to develop HWC services in Ireland and also proved that HWC could adequately support people with dementia. Many study participants were enthusiastic about the positive benefits of HWC and the advantages of HWC over nursing home care and the focus of much of the discussion was on their belief that HWC offers a better quality of life to residents than can be achieved in a nursing home setting

However, the data in section 1.3 shows that in spite of their appreciation of the merits of HWC, a number of HSE participants had reservations about the HWC model as a template for long term care.



### *1.3 Perceived weaknesses in the HWC model*

A number of HSE participants had misgivings about the HSE model and their concerns related mainly to the fear that ageing residents will have to leave HWC and move again into a nursing home when their dependency levels increase (HSE1, HSE4, HSE11, HSEO2, HSEO4). This issue arose in discussions about the resistance that developed to the case study schemes (see pp 99-110), but it featured even more prominently in discussions about future HWC development. An HSE stakeholder stated

[HSE11] I think it's critical... I still have a problem with people having to move on because I don't think it's fair. And I do think that's a key issue because one move is enough for any person. One move is enough.

Another agreed and asked 'How many moves can any one of us adapt to in a lifetime? After the age of 65, how many times do you want to move?' (HSEO4). Two participants believed that the perceived trauma involved in a second move was an issue not only for older people but also for their families.

[HSEO2]...people want solutions. If my mother is unwell, I want a solution that's going to be permanent. Cause if I make the decision that she goes somewhere, I don't want to have to face another move.

It was suggested that in some cases, fears about the anticipated trauma involved for family members discouraged health service managers and providers from referring older people to HWC services.

[HSEO4] I suppose, you could say we're being paternalistic. ...if I think that somebody doesn't have the emotional or social resources or... If you have ambivalent relatives or split relatives... AND you anticipate that it's only going to be for a short time [you wouldn't refer them to HWC because] you wouldn't have the resources to support people making that transition.

A senior HSE officer recalled the damage done to the reputation of the HWC model by the Delayed Discharge Initiative experience in Cherryfields when a number of residents admitted from acute hospital had to be admitted to A&E within a short space of time (see pp 119-120). He also spoke of the negative fall-out for the HSE following the recent closure of public residential care units which gave another reminder to decision makers that moving older people from one unit to another is something to be avoided.

[HSE 1] It comes up in discussion. We're being criticised because we've got this issue of moving the elderly. Even where we've had issues of private nursing homes closing down, we know that, obviously the move is upsetting. We have a huge fallout, 40% mortality rate. So we don't want to do that.

A second move was believed to be a bad thing for older persons and also for family members; it also caused political problems for the HSE. For these reasons, the risk that HWC residents might have to move again undermined the case for the further development of HWC services.

The data in this section shows that many participants placed value on the benefits of HWC for people with dementia but were concerned about the length of time that residents would be able to stay in HWC if their dependency levels increase. Some HSE participants involved in the FOLD case studies recommended that a review of existing services should take place before any decisions are made about future development and their views are presented in section 1.4

#### *1.4 Need for a review*

A number of study participants suggested that existing HWC services needed to be reviewed in order to determine whether they are achieving stated objectives and at what cost (HSE1, HSE3, HSE5, HSE13, HSEO3). Four of the FOLD case study participants believed that the HWC vision as presented originally has been compromised and that services have become more institutional than they were when Cherryfields and Anam Cara were opened (HSE3, HSE4, HSE5, HSE8).

[HSE3]...I don't think they've gone far enough; they don't have nurses and they have kept people there until they died. But I don't think they've gone quite far enough with the mission that I was sold... It didn't quite go there for us.

[HSE8]...I had a feeling when I was in Derry that there was a normality of life and that people were free to wander around and did wander around and ate as they wished in the small communities. I'm not so sure that has realized itself in what I've seen in (FOLD scheme); I think there's still a sense of collective living and ...it's almost [institutional]

One argued that the survival of the model depends on a review of existing services so that any problems associated with its operation can be identified and put back on track (HSE3).

(HSE3) Because if they continue the way they are, somewhere down the line, there's a risk that they'd be subsumed into a nursing model or the difference

between them and a nursing home will be less and less. It would be worth having a review ...and see whether we can move closer to that.

Another stressed the importance of determining the comparative costs of HWC before a case is made for further development (HSE1).

[HSE1] It's about us adjusting accordingly and seeing that, we can put in

various levels of different services at appropriate times rather than going for the expensive model, because it is. Particularly now we are being challenged from a private/public perspective; we have to publish our costs of care nationally...

Although HWC is still perceived as being a less costly option than nursing home care (HSE1, N4), costs in the FOLD schemes exceeded expectations; up to now there has been no detailed analysis of the comparative costs of the FOLD services. An HSE manager observed that an independent review of existing HWC services and their costs would improve service accountability and increase confidence in the model, especially considering the substantial HSE funding involved.

[HSE5] Apart from reviewing the SLAs you need to carry out audits of the social care model and be assured that the care that they are in receipt of is what you are paying for/what was agreed. ...So then we're accountable for what we're spending. We're approving the client going in there... it's a service funded by the HSE and we need to be able to stand over it.

This person anticipated that such a review would also show the benefits of partnership working including the economies of scale that could be achieved by inter-agency projects like HWC (HSE5). Two study participants believed that relatives should be included in any review (HSE13, HSE03) one arguing for the general need for increased consumer participation in service planning and evaluation in the HSE. Only two people made specific reference to the need to include older people themselves in a review of existing services (HSE03, N2)

The next section looks at the data relating to participants' views about whether HWC services are actually something that Irish older people want.

### *1.5 Demand for HWC services*

A prerequisite to the successful introduction of change is the build-up of a sense of urgency around the need for change (Kotter 1996). On the assumption that HWC development was more likely to take place if there was evidence of popular 'demand'<sup>14</sup> for HWC, participants were asked if they had experienced any pressure to provide HWC services to older people, if anyone had complained about the lack of available HWC services or asked that they be developed. It is important to note that in discussion with study participants, the terms need, demand and want were often used interchangeably. Most references to demand for HWC were made in the context

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<sup>14</sup> Demand is defined for purposes of this study as an act of demanding or asking for something. It is not used as it is used in economics to mean willingness and ability to purchase a commodity or service. (Merriam Webster Dictionary. [www.merriam-webster.com/dictionary/demand](http://www.merriam-webster.com/dictionary/demand) Accessed 31 August 2013)

of discussions about what stakeholders believe Irish people *want* or *would want* with respect to having their long term care needs met.

Study participants in general had not experienced any 'demand' for HWC services. Nobody had put pressure on them to develop HWC services for older people or for people with dementia. They believed that lack of demand for HWC at least partly explained why HWC development has been so limited in Ireland up to now and they offered a number of factors that they believed were related to lack of demand.

#### *1.5.1 Lack of availability of HWC*

Four participants argued that when services are not available, people don't ask for them. The number of HWC schemes in Ireland is still so small that few people are even aware of HWC as a long term care option (LA4, HSE4, N2, N3).

[N3] There's no demand because people don't think about it... It's like this housing for the elderly that's in a lot of the towns around the West; people won't ask for it, but when they see it there, they want it.

In contrast, the ready availability of nursing home services makes nursing home care the obvious choice for most Irish older people in need of long term care.

[N8] Look at the expansion of the private nursing homes in the 90's... And we see the impact of that; the impact is that once the beds are there, we'll use them.

The argument was that when there are no other services available, no thought is given to possible alternatives. The findings in Chapter Five demonstrate that even when services are available and nearby, they may not be known to those living and working in the area; when services are not available, there is less chance that people will understand that HWC is a possible long term care alternative.

The following three sections present data related to the perception of a number of study participants that even if HWC services were more widely available, HWC might not be the preference of Irish older people and their families.

#### *1.5.2 Irish preference for home care*

Irish people's preference for home care over residential care was offered by a number of participants as a factor inhibiting demand for HWC services (N2, N4, N6, N7, HSE2, HSE3, M3).

[N6] There is no obvious demand for housing with care though it is taken for granted in Scotland. People are not prepared to move lock, stock and barrel into a supported environment if they can get services at home.

[HSE03] No, our system says we'll provide you with home support, we'll give you nursing home care and we see them in a continuum. So people would say, why would you move out of your house, go into another house just to get that kind of a package? Should you not be getting that in your own home and that's part of the problem.

It is interesting to note that, although a housing association participant attributed the low take up of services in Mount Bolus to nursing resistance to HWC (MB3, see p 121), two HSE participants believed that it illustrated what they believed was Irish people's preference to receive needed services in their own homes (MB2, MB3).

A number of participants associated Irish people's preference for home care with attachment to the family home. While Irish older people are not so different from others in their desire to remain living at home for as long as possible, the importance placed on home ownership in Ireland was believed to be something that marked Irish people out from at least some of their European and North American counterparts (N2, N4, N7, HSE2, HSE03). It was suggested that by the time Irish older people finally make the move from home, their needs are so great that there is no question that they need anything less than nursing home care (HSE03). Reference was made to the 'sanctity of the family home' (N7), the high percentage of home ownership among the older Irish population (HSE2) and to the fact that the size of a person's estate was a 'testament to your success' in Ireland (HSE03). The public outcry that developed around the assessment of property values to determine eligibility for Fair Deal funding was cited as evidence of the reluctance of both older people and their families in to relinquish the family home (N7, N8, N4). A voluntary housing participant observed that the 'strong pull factor towards the family home could be a disincentive to going into supported housing' (N4).

### *1.5.3 Expectation that the family will provide care*

A small number of participants argued that another reason for Irish people's apparent lack of interest in HWC was because the sense of family responsibility was still so strong in Ireland and there was the expectation that families would look after their older relatives who are in need of support and care (HSE04, N7, N8)

[N8] I think it's strong here. I think there is, in the ether at least, a view

that, if you don't look after your parents in some way, that it's still considered to be a negative thing.

The contrast was made with other countries where the family was not expected to play such a large role in providing care. The implication was that Ireland are behind other nations in this respect and that demand for formal long term care might develop in years to come (N7, N8).

#### 1.5.4 Irish failure to plan for the future

A number of participants believed that lack of demand for HWC in Ireland was related to what they saw as the unwillingness or inability of Irish people to plan for their own future.

[N8] If you think about planning for ageing, personal planning for ageing, personal planning for retirement, personal planning for long-term care. People are myopic in a sense that – who does this? Very few people in Ireland. What do we think about when we think about this? The only thing we think is that I don't want to be in a nursing home.

This tendency leads Irish people to put off making decisions about their own future care; planning for contingencies during the transition between full health and possible physical and/or mental decline does not typically take place (HSE1, HSEO2, HSEO4, N8).

[HSEO4] I think nobody thinks about their future. Older people, people retire at 65. In America they will have already got their one story bungalow; people don't do that here. I think they think they're going to live forever. ...I just think Irish people just haven't faced up to the need to plan for old age. And they only do something when a crisis arises.

[HSE1] ...we wait for a stroke, into an acute hospital and the decision making is taken from you.

The result is that interventions come too late when the possibility of anything short of nursing home care becomes highly unlikely.

One participant observed the paradox that the least preferred long term care option available is the one that continues to be expanded (N8) and two participants attributed this to planning failures at national level; they observed that the Irish know what they *don't* want, that is nursing home care, but little thinking has gone into establishing what it is they do want (N8, HSE4).

[N8] The question needs to be asked, what do we want to get from our health and social services for older people? What we expect is critical.

The lack of a cohesive older persons' strategy in Ireland was seen by one voluntary housing sector participant to be a manifestation of the absence of forward planning at national level (F4). She contrasted the situation in Ireland with that of the UK where

[F4] ...every local authority was obliged to have an older persons' strategy to cover the next 20 years....And what the local authorities started doing there was replacing their existing sheltered accommodation... and they either

sold that land off or re- configured the existing developments into Extra Care, which would allow for people to remain in their homes...when they became more frail or in greater need of personal care.

It was argued that better planning would result in the identification of the need for supported housing which then would generate demand for it (F4).

### *1.6 Need to generate demand for HWC*

Three participants believed that, although lack of demand was sometimes used as an excuse for not introducing new services, it was unrealistic to assume that it would develop spontaneously (MB1, N2, N8). They believed that in order to make the case for the further development of HWC services, demand has to be created and this involves both raising awareness of HWC and also providing incentives for its development.

[N2] One of the things about sheltered housing in Ireland, if you wanted to increase demand for it, it would need to be more acceptable to people, so therefore they'd need to know more about it and what's in it and what it's about. And it's difficult because it's not out there.

[MB1] Businesses are created on the basis that they will generate the need. You have to get a critical mass; you have to get a certain number in before people will want to go in. Takes time. Have to convince people of the need for something and also the benefit for them. No one ever did anything unless there was something in it for them.

Several participants noted that expectations had to be changed about how to meet long term care needs in order for demand for new services to be generated (N4, N6, HSE1, N8).

[N8] One of the things we need to do is to experiment and innovate. Housing for people with dementia; evaluate it; create an expectation if it's good; create a demand among people through information about what works, what doesn't work. Why this might be a good idea; who it might be a good idea for.

While it was suggested that the responsibility for creating demand should be shared between stakeholders in the health and housing sectors, the voluntary housing sector came in for particular criticism from one key HSE stakeholder for not doing more to promote the housing with care model in Ireland. [HSE1]

[HSE1] The Minister was very vocal around the whole area of the cost of long stay care. I would have thought, the [voluntary housing sector] would have come in and said there was an opportunity there. We only hear about the HSE and about private nursing homes... We never hear from the voluntary sector... would they not come along and say, we can really produce an alternative here.

Similar criticism was leveled at organisations that represent the interests of older people, including people with dementia, which are thought to be too narrowly focused on the promotion of home care services (HSE1, N4). It was thought that these organisations could be doing much more to raise the profile of Housing with Care and other long term care alternatives to nursing home care.

A small number of stakeholders believed that the Age Friendly Counties Initiative would provide the opportunity to generate demand for HWC by informing older people about new service model alternatives and giving older people the chance to think about the way that they themselves would like to have their long term care needs met. They suggested that with better information and the opportunity to discuss service alternatives, older people would then be in a position to make informed choices about service options which can then be prioritised for service development (N2, N5, HSE1).

[HSE1] Here we are as a county, we've invited over 100 older people to consult with and we'll have all of the statutory and voluntaries there from both the County Councils, ourselves from the HSE and all the other voluntaries as well and say, what are you actually looking for? What would you like in your community? What should a county have? ... Where do you actually want to be?

One outcome of this public consultation exercise would be the development of older people's interest in HWC which would help create the demand necessary to drive further HWC development (HSE1, N5, N2).

## **Section 2 Is HWC development for people with dementia on anybody's agenda for future service development?**

Section one presented the data with respect to participants views about the strengths and weaknesses of the HWC model and its suitability as a template for future service development. Data in the last section introduced the idea that HWC may not be a suitable response to the needs of Irish older people whose long term care expectations and preferences may be different from their counterparts in other countries. Section 2 explores whether HWC development for people with dementia is on the agenda in the housing and health sectors or in organisations representing people with dementia.



## 2.1 Health sector agenda

Participants were asked if any progress had been made to put HWC development on the health sector agenda. Stakeholders with a national brief in the HSE and the DOHC were more optimistic than their counterparts working at local level about the attention that dementia and dementia services are currently receiving in the health sector at national level (HSE1, N1, N2). They cited the participation of the HSE in the development of the National Dementia Strategy, the audit that had been undertaken of all dementia specific services in the HSE, and the development of staff training on dementia awareness and practice to demonstrate the priority that the HSE is placing on dementia and the development of dementia services.

[N2] The fact that there will be a Dementia Strategy developed, that symbolises the awareness in the Department. There are so many issues that are on the Department's doorstep; the fact that it is actually going to develop a strategy for dementia is a huge thing [given competing interests and needs].

It was further suggested that the Positive Ageing Strategy (again headed up by DOHC) would be taking into consideration the predicted increases in the number of 'oldest old' and the large percentage of people within that category that will develop dementia (N2). It was anticipated that the development of dementia specific HWC could be a future by-product of new national policies (HSE1, N1, N2).

Other HSE participants with local or area responsibility were much less convinced that dementia care services were being prioritised for development in the HSE in spite of the work that had commenced on the development of a National Dementia Strategy and the Positive Ageing Strategy. Five HSE participants believed that dementia continues to be a largely neglected area in the health services where there is little acknowledgement that the needs of people with dementia are different from the needs of other vulnerable older people (HSE4, HSE5, HSEO1, HSEO3, HSEO7). The low priority placed on dementia care in the HSE was thought to reflect wider societal views about dementia and dementia care.

[HSE4] People don't care what happens to people with dementia in this country... No need for specialist dementia services has been identified... and there is a lack of priority given to people with dementia in Ireland.

Two HSE participants felt that dementia care was actually receiving less priority within the HSE than previously; they noted that although HSE community units were originally intended to provide services for people with dementia and other high dependency needs, over time they have increasingly been used to provide generic long stay nursing care services with no dedicated or

specialist dementia services in evidence (HSEO7, HSE4). An HSE manager suggested that in order for HWC for people with dementia to be expanded, there would need to be '...a big sea change in terms of how we view residential care...When people see dementia and housing they would say, hmmm that doesn't work...you can't supervise them, you can't look after them' (HSEO7). Two study participants talked about the stigma and fear surrounding dementia in Ireland which they believed resulted in conservative attitudes about what constitutes appropriate dementia care (N6, N8).

[N8] I think all the time we're talking about people with dementia or people with any sort of cognitive issues is...stigma, some link to ageism, link to fear...and anxiety...which again impacts negatively on our ability to think beyond the convention. People are afraid of this... they don't know how to deal with it, they don't know how to organise, they're fearful of the outcomes, so again you go back to what you know best and that is [nursing home] care. I think there are elements of that all the time when you're talking about people with dementia.

A lack of sophistication in our thinking along with ageist assumptions about older people were also thought to have limited Irish aspirations and expectations to the point where no thought is given to anything except services at opposite ends of the care spectrum, home care and nursing home care (HSE1, HSEO4, MB1).

[HSEO4] I don't think we're a sophisticated enough society yet to have acknowledged that need [for services like housing with care]. Maybe older people are not valued enough to think that they should have a fuller, broader life that one of these assisted living facilities can provide.

An HSE senior officer referred to 'current paternalistic notions about dementia' and the belief that 'doctor knows best' that causes HSE decision makers to shy away from supporting the development of alternative social models like HWC for people with dementia (HSE7). Others spoke of the way that the organisation of services for older people in Ireland contributes to limited expectations about long term care models in Ireland (HSE1, HSEO3, MB4).

[HSE1]...we have a medical system which almost determines and requires that you require a hospital.

[HSEO5] All of your assessments, all of our processes to get state support is invested in, it needs a medical doctor, it needs the multi-d team, it has to be signed off by a Geriatrician.

A FOLD case studies participant suggested that there is uncertainty about what service model to introduce even among those health professionals who recognise the need for better dementia services; 'We don't know what model we want in Ireland' (HSE4).

An HSE manager with experience in the disability services believed that there was no reason why HWC cannot be developed for people with dementia but added 'It's just not on the agenda. It's not on anybody's agenda' (MB2). Participants believed that the continued strength of the medical model in older people services prevents HWC from receiving any priority on the HSE agenda and they also pointed to an organisational culture that undermines the development of new services.

### *2.1.1 HSE organisational culture*

Two HSE senior managers were highly critical of the culture in the HSE which they argued made it more difficult for staff to think outside the box or introduce change (MB1, HSE04). One of these stated that the development of new initiatives in the HSE depends too heavily on individuals who must 'proceed at their own peril' (MB1) and another agreed that there were high personal costs involved in driving new service initiatives like HWC.

[HSE04] You know you have to have huge energy to get stuck into some of these projects; there's no natural service development within the HSE unless you happen to be working with somebody in administration or management for the HSE who are prepared to take up the gauntlet and the cause along with you and drive it. And I know people do, that's how things do change but it's at huge personal cost to a couple of people...

It was claimed that there was no incentive for individuals in the HSE to lead new initiatives like HWC which inevitably involve risking failure (MB1, HSE2, HSE06, N4).

[MB1] But what's in it for people in the HSE to take a risk like this? Nothing. That is the bottom line. There's nothing in it for the HSE. ... If you're in the public service, you get no reward for innovation but could be hung out to dry if something goes wrong.

Given the lack of reward for trying something new and the risk that a new project might fail, HSE managers are discouraged from introducing new services like HWC, especially in times when money is scarce. It is easier and less complicated to keep doing what has always been done.

[N3] I think... the excuse for not doing anything at the moment is money. I think no matter what needs to be done, it won't be done because it'll be thrown back that we don't have the money for this. It wasn't done before, so they have nothing to keep up. If it was in place before, they have to keep it up. But there's nothing in place so you're starting new.

Another stakeholder maintained that 'the negative influence of scandal' in Irish public services also stifles the search for service alternatives by keeping the focus on the things that can go wrong (N8).

[N8] There's a focus on what's not being done rather than on solutions. [Risk management is] seen as responsibility of the regulatory agency, the responsibility of others... Absorption with what is wrong with the system doesn't allow us to say, how do we construct something that we actually value?

Three participants believed that a blame culture fuelled by the media reinforces HSE preoccupation with safety and risk and makes decision makers reluctant to take chances especially with a client group considered to be particularly vulnerable (MB1, N3, HSEO3).

[HSEO3] You had a thing in the paper, somebody left a nursing home and was found dead. Look at the organisational response to that? What did they do wrong with that person?, Instead of saying, well this was somebody with dementia; it could happen to anybody.

They suggested that an organisational culture that prioritises risk aversion influences HSE decision makers to believe that it is in their interest to do nothing. The resultant HSE inertia was believed to be holding back the introduction of new services like HWC; HSE structures were perceived to be another inhibiting factor.

### *2.1.2 HSE structures*

Two HSE participants observed that hierarchical structures in the HSE undermine innovation by removing decision making from local managers (HSE1, MB1). The contrast was made between the time when the FOLD schemes were being developed and the time when Mount Bolus and St. Bricin's were being planned to illustrate the inhibiting influence of cumbersome HSE structures on the development of new services (MB1, HSE1). FOLD initiatives were planned at a time when the health boards were autonomous, decision making bodies; one participant recalled that 'It was a smaller structure [with] closer to the ground decision making' that empowered local managers to make decisions (HSE1). A Mount Bolus stakeholder observed that

[MB1] At least when the health boards were there, ...there was always the danger that [new initiatives] were going to be raised at those meetings... But that went with the formation of the HSE and you had layers and layers and layers of staff. It's like if you're dealing with a grievance, if you're not dealing with the principals, as the grievance goes up the line and...it becomes totally different and it gets lost, the essence of it. Then if... you say, well I have no answer for that tonight, then you get bored and you say, I'm better off out of this.

A senior HSE officer agreed that HSE structures 'dampen down the enthusiasm [for new service initiatives] from ground level; by the time it gets up to policy level, it's almost poles apart' from what had been initially proposed (HSE1). The same person believed that the proposed restructuring of the HSE would solve that problem and allow for the better harnessing of local enthusiasm around projects like HWC although this optimism was not shared by any other study participants.

## *2.2 Housing sector agenda*

### *2.2.1 National housing agenda*

Two housing participants observed what they believed to be a shift in national housing policy in recent years away from the provision of long term supported housing that negatively impacts on HWC development for older people as well as for other groups (LA4, SB1). Using homeless services as an example, one observed that although there 'has always been an identified need for it...currently in the homeless agency, the whole move has been to get rid of transitional housing...' (SB1). The other participant agreed that the housing authorities now 'want every person to live out in the community as an independent person... they're trying to ensure that sheltered housing ...will never be built again' (LA4). Both considered this shift in policy to be a backwards step. A local authority participant noted that it had taken 10 years or more to build up the momentum to develop HWC services in Dublin and believed that the potential to implement plans for additional services was now lost at least in part because of this shift in housing policy (LA4).

A DOE participant did not allude to this perceived shift in housing priorities but did reiterate the clear division between housing and health, suggesting that 'high support services' for people with dementia were clearly the business of the HSE and not housing authorities (N5). He noted that none of the housing bodies in Ireland have the provision of HWC for people with dementia as their 'core function' (N5). For this participant, the closure of Mount Bolus provided the rationale for the re-alignment of Department priorities along more traditional lines; although HWC as a concept was not dismissed, it was made clear that the Department had only a limited role to play in its development (N5).

### *2.2.2 Voluntary housing agenda*

According to a representative of a voluntary housing agency, the majority of small housing associations (who operate 20 housing units or less) would not have either the interest or the resources with which to develop dementia services themselves (N4).

[N4] It's included under 'high dependency'. Occasionally you would hear it mentioned. Awareness is growing... but when people go out to develop a housing scheme, they're not thinking about tenants with dementia.

It is usually only when sitting tenants already well known to staff develop dementia that dementia care becomes an issue for voluntary housing organisations who then struggle because they lack the resources necessary to care for these tenants (N4, SB1).

[N4])...even the [housing association] boards would say, God, we have a duty of care, a moral duty but we can't care for these people, we don't have the skills necessary and we need to get the HSE involved very quickly. There'll be issues there; what are the options for the older person, the boundary issue. Nursing home or other 'step up facilities' – are there not other options?

The priority then becomes finding a way to move tenants with dementia on to what are considered to be more appropriate settings.

Despite the obvious challenges involved, the data shows that there are a small number of housing associations that are very interested in either developing or expanding services for people with dementia, and these include the housing associations associated with the O'Connell Court, FOLD and St. Bracin's schemes (OC1, F4, SB1). A voluntary housing representative observed that a small number of the larger housing associations would have both the competence and the willingness to do so (N4).

[N4] Yes, there's a cohort or a cadre of [voluntary housing associations] who feel... that they can build on existing services. If the structures were in place, they feel they have the good will from the community...There are around 25 bodies that now think they could move on...

Four voluntary housing participants suggested that, in lieu of CAS funding, existing supported sheltered housing facilities could be used as a foundation on which to further develop HWC services (N4, F4, OC1, SB1). The housing units are already there, as are the communal facilities from which to deliver support services and one participant observed that

[N4] In the current climate there won't be a huge amount of new building for our sector or even for the HSE, that'll not happen. So why not focus on what we've got at the moment and build on existing services with the providers that are keen... The bottom line is there is infrastructure there.

The development of satellite services, using large housing associations as a resource to support smaller housing schemes within a geographic area was offered as one way that services might be developed in rural areas without the need for major capital expenditure (N4). Housing

participants believed that a positive environment exists in the voluntary housing sector within which to further develop HWC services and also a template to guide it (N4, LA3, F4, OC1).

A meeting was held recently in the ICSH to bring together HSE representatives and housing association managers who are providing 'high support' services to older people to discuss future service development (N4); this confirms the commitment of some voluntary housing providers to further HWC development. Although the focus of discussion at the meeting was not on the development of dementia services, those in attendance included representatives of groups providing HWC to people with dementia (N4, HSE1, HSE2).

### *2.2.3 Dublin City Council agenda*

Two Dublin City Council housing officers indicated that local authority enthusiasm for the FOLD schemes did not diminish after they were built, and plans for a number of other schemes (including St. Bricin's) were subsequently developed by the Council in partnership with other agencies including the Alzheimer Society of Ireland (LA2). These housing officers were happy to collaborate with the HSE and voluntary organisations to implement the service plans that have been developed, but like their colleague in DOE, they do not see the provision of dementia services in these schemes as their responsibility (LA2, LA3). The willingness exists in the local authority to build these planned HWC schemes, but at the time the fieldwork was being carried out, most of these plans had been put 'on hold' because of the lack of public finance with which to fund them (LA2, LA3). Since the fieldwork, plans for the St. Bricin's scheme were re-activated and re-worked but the housing association involved withdrew from the project in 2013 and plans to include a dementia unit were dropped from the project proposal the previous year (Dublin City Council undated Notes).

[LA3] And some projects in recent times have fallen, like we've designed them to include Alzheimer type units in our schemes. The project (St. Bricin's) hasn't gone any further. We were hoping to bring it back...

A Dublin City Council participant predicted that even if existing plans are re-activated, the specialist dementia service element will not be included (LA3).

[LA3] ...what we'll end up with is the standard senior citizens scheme not a FOLD type scheme.

There was pessimism about the realisation of planned dementia specific housing developments because of the additional funding required and the problems already identified around sourcing funding from the HSE (LA3). The impression given is that HWC for people with dementia is low

down on the list of current priorities but that the situation could change if funding became available.

#### *2.4 Special interest groups' agenda*

The data shows that the development of home care and home support services is the priority for both of the organisations whose representatives were interviewed for this study. But it also reveals that both groups have explored HWC development in the past (N3, N6, SB1, LA2), although in both cases the HWC vision for proposed services was somewhat limited. The first group considered building two bedroom housing units on the grounds of an existing nursing home for people with dementia, but the model envisioned was mainly aimed at providing support to carers who would come to live in the units with the person with dementia (N3).

[N3] Because I felt [carers] were isolated with Alzheimers, they were out on their own , especially at that time. They were afraid to talk to anybody. I thought if they all came together, it would be a lovely idea. They could talk about their problems together...

HWC units were thought to be unsuitable for people with dementia who lived alone because they would be at risk of wandering off; the adjacent nursing care unit was considered to be the appropriate place for these people (N3). This person's view was that HWC was a good way to support carers but not suitable as a long term care alternative for individual people with dementia.

The other participant spoke of plans drawn up in 2004/2005 for the building of a 20 unit HWC scheme on a site outside of Dublin on which a day centre had already been built; additional land adjacent to the day centre had been offered to the organisation by the local county council (N6). The plan was to provide sheltered housing for people with low dependency needs in 18 of the units and to convert two remaining units into a high support facility with 'supervised care' for people with dementia needing short-term rehabilitation or respite. It represents a more modest version of what was proposed for the St. Bricin's scheme.

[N6]The high dependency piece ... what we thought was, the worst thing that can often happen when somebody broke a leg or whatever had no place to go without supervision. And the other thing was that was something that was attractive to some of the Consultants because that's one of their concerns; what happens if there is an acute episode or accident.

This organisation was involved in planning a number of other HWC service developments to include services for people with dementia but in each case, the HWC vision was limited. Planned



services were aimed at providing short-term respite and rehabilitation only. Little thought had been given by either of the groups that represent people with dementia to the idea of using the HWC model to deliver long term care services to people with dementia in spite of the trend elsewhere to do so (See Chapter 1).

The data in the next section shows that most of those interviewed for this study believe that, whatever the merits of pursuing the further development of HWC services, further service development is not a feasible option in Ireland anytime in the near future. The factors identified with this pessimism are included in Section 3.

### **Section 3 Operating environment for HWC development**

Section Three explores 'readiness' for further HWC development in Ireland in terms of the availability of resources and the alignment of structures and systems necessary to support it (Pasmore 2011). It includes discussion of the factors thought to have a particular impact on the development of HWC for people with dementia.

Participants were asked to identify factors that would be critical to the future development of HWC for people with dementia. The intention was to find out what needed to be done in order to progress service development, but the emphasis in their responses in almost all cases was on the factors that they believe will have an adverse effect on future HWC development. There was unanimity with respect to the factor that would have (and indeed already has had) the greatest inhibiting influence on service development.

#### *3.1 Economic recession*

The overarching issue that provided the background to discussion with participants about future HWC development was the poor state of the Irish economy and the belief was that there would be no funding available with which to develop any public sector services in Ireland in the short term at least. The dismal economic outlook in Ireland was considered to be the factor most critical to future HWC development by all voluntary housing stakeholders. A FOLD champion concluded that

[F1] Finance is the big issue for the future...The present economic climate is not conducive [to further HWC development].

The economic recession in Ireland already contributed to the closure of Mount Bolus and the failure to progress plans for St. Bricin's. A participant from the St. Bricin's case study recalled that ' It seemed to be then, that with budgets tightening from 2008 onwards, within the HSE and

everywhere, people were just battening down the hatches, trying to maintain what they had' (SB1).

Housing participants believed that the recession will extend into the foreseeable future and no one who was interviewed was optimistic about the possibility of any significant public service development in the coming years including HWC development. A local authority stakeholder summed up the feelings of others in both the housing and health sectors.

[LA4] I think there's ten years of no movement now. The eye is on the financial situation and nobody's moving off the perch to do one single thing now.

Three HSE interviewees and one local authority participant recalled that there was a lot of interest in developing HWC services after the FOLD schemes opened in 2006-7 but that initial enthusiasm had abated due to changed times and a changed economy (HSE1, HSE12, LA2).

[HSE1] ...the whole idea was that sheltered housing was to become [a bigger feature of service provision]. It would have been discussed at our Task Group..., made up of the 4 regions... And we were looking at options, particularly around the flexibility... [but] funding stopped... It didn't develop any further than that.

A small number of study participants said that the dramatic deterioration in public sector finances had already resulted in cuts to HWC budgets and that the effect of these budget cuts was greatest on HWC for people with dementia because of the higher costs involved in training staff and providing services to people who may need 24/7 supervision (N3, F1, F4).

[F1] It's the unpredictability of people with dementia and their inability to express what's happening. They can't tell you what's wrong. Wandering, can't remember to eat etc. A lot of risks. More support is needed. Nocturnal wandering, mixing up night and day, that breaks down caring arrangements. That's when people need to move. That's what makes them different and harder to manage – not impossible if resources are provided.

They argued that budgets were already inadequate to address the special needs of residents with dementia; budget cuts made it even more difficult. An O'Connell Court participant observed that funding cuts meant less discretionary spending including spending on the extra staff required to individualise care (F5). She argued that funding shortages made it difficult to achieve HWC service objectives and the correlation was made between social activity and residents' health and well being.

[OC1] I have to beg borrow or steal for ...Social activities and stimulation and all that kind of thing. That's needed. It's companionship, activity and enjoyment in later life that I think

promotes positive health, positive mental attitude. No budget for that...

She believed that funding was critical to the quality of life for HWC residents and particularly for residents with dementia who benefit greatly from social interaction which they may not be able to initiate themselves (OC1).

A number of participants believed that the economic recession in Ireland was a threat to the sustainability of existing HWC services for people with dementia with negative implications for HWC residents. But all study participants felt that the economy was having an even bigger impact on the development of new HWC services. Discussion with participants focused on the shift from a capital funding model to a leasing model for the development of social housing (LA2, LA3, N4, N7, F4, SB1).

### *3.2 Capital funding*

As outlined in Chapter 5, capital funding available through the DOE Capital Assistance Scheme (CAS) provided the opportunity to build or acquire premises for all of the case study schemes. As such it provided the momentum necessary to move the projects forward. But the data shows that in recent years CAS funding has been radically reduced to the point where it is inaccessible to most voluntary housing associations providing special needs housing, including those that might wish to develop HWC services for older people (N7, LA3, SB1, N4). The decrease in available CAS funding reflects changes in national housing priorities that have resulted from huge reductions in the housing capital programme since 2009; these have affected not only the voluntary sector but also local authority housing development. A DOE stakeholder noted that capital funding had been reduced from €1.2 billion in 2008 to €0.5 billion in 2010 to €400 million in 2011 which is the amount that was spent on voluntary housing alone only three years ago (N7). The CAS budget did not disappear but has shrunk dramatically, and any funding left in that budget in 2011 was committed to housing projects that were already in the pipeline according to a voluntary housing stakeholder (N4).

### *3.3 Social Housing Leasing Initiative*

For participants from the voluntary housing sector, the loss of CAS funding represents an almost fatal blow to the development of *purpose built* HWC facilities and its effective replacement by the Social Housing Leasing Initiative (SHLI) introduced in 2009 has done nothing to generate optimism about future service development (F4, N4, SB1, N7). The main distinction of the SHLI is that it promotes and facilitates the leasing of existing housing stock from the private sector rather than the building of new housing units. This poses problems for housing associations wishing to

develop HWC services because of the unsuitability of most of the housing stock (apartment buildings built during the Celtic Tiger years that were left unfinished and unoccupied) that is available for leasing under the SHLI scheme(SB1, F4, N3, N5, OC1).

[N5] ...the type of supply that's coming through...that's revenue funded, largely it's private, it's not suited for specific needs, for example people who have high dependency or let's say higher dependency who need on-site supports.

It was noted by a small number of stakeholders that the design of available housing stock in general is not appropriate to meeting the needs of vulnerable older people (F4, N3, N4, HSE07). For example, problems were identified with available units that do not provide the space or environment required to meet the needs of people in wheelchairs or people with dementia (F4). Many of the housing units available for leasing do not meet desired specifications for energy efficiency which pushes operating and maintenance costs up (F4). The cost of re-designing or retro-fitting available housing stock was considered to be prohibitive in many cases. An HSE stakeholder observed that 'with CAS funding gone, if no appropriate building is available, [special needs] housing groups are at a loss' (HSE07).

O'Connell Court is the only one of the case study schemes that is not purpose built; although CAS funding was used to acquire the original premises, the SHLI scheme was used to lease the hotel in which services are currently situated (OC1). The O'Connell Court case study demonstrates that it is possible to use the SHLI to acquire vacant buildings for the purpose of providing HWC services but it also illustrates the drawbacks. The move to a vacant hotel in 2011 involved no mortgage and the terms of the lease signed by O'Connell Court with the local authority imposed no additional financial risks on the housing association (OC1, see Appendix1). However, while the arrangement suited O'Connell Court in the short term, the housing association always planned to lease the hotel as an interim measure only; the longer term plan was to build purpose built facilities when the necessary finance could be organised (OC1). Although the hotel is more modern than the previous convent premises, it is still in need of major refurbishment and the configuration of rooms is awkward from the perspective of delivering services to older people (OC1, HSE05). About 1/3 of the building is unsuitable for use. One HSE participant observed that the inadequacy of O'Connell Court premises makes it more difficult to make a case for further HWC development (HSE05).

Voluntary housing participants in general believed that available housing stock is generally unsuitable for the provision of HWC services to older people. But the alternative, which is to build new facilities, was thought to present almost insurmountable challenges because of the perceived

financial risks involved for housing associations (N4, SB1, F4, OC1). Under the SHLI, voluntary housing bodies must borrow money on the private market or through the Housing Finance Agency (HFA) in order to build new facilities and both options are problematic (SB1, N4, F3, LA3). According to two housing sector participants, HFA funding can only be accessed by negotiating many administrative 'hoops'; only one housing association had received approval for HFA funding up to the time of the fieldwork in the Spring of 2011 (LA3, SB1). Using private finance to develop HWC was believed to put housing associations at considerable financial risk, and according to four housing sector participants, this is the major problem even for the larger housing associations unless they have additional assets that they can use to offset capital costs, for example land (SB1, N4, LA3, SB1). One participant observed that most Irish banks would not be in a position to provide finance to housing associations anyway but that even if private loans could be obtained '...the financial model....is extremely risky' (SB1).

[SB1]The government is proposing a social leasing model whereby you would use private finance to acquire properties or design and build and you'll get 80% of the market rent to pay back the loan. It doesn't work for any property worth above €100,000; it's like this State is trying to go from 100% capital grant into a 100% private finance regime with all the risk being placed on the voluntary body in one fell swoop. No country in Europe is like that.

The same person argued that if housing associations opted to use the SHLI to finance HWC development they would be vulnerable because of the risk that they would not be able to generate enough revenue to cover their loan re-payments and other costs. Under the SHLI, voluntary housing associations 'could literally make the wrong deal and [go] bankrupt...' (SB1).

A FOLD manager similarly concluded that, while the SHLI could be used to develop conventional sheltered housing, it was not suitable for HWC development (F4). The financial risks had discouraged FOLD from following through on the plans for a number of other HWC initiatives.

[F4] Obviously we would love to develop more facilities, housing with care and sheltered. [But] The only way forward ...is through a leasing model...[but] it's a long drawn out process. ...we would have to source private... which would not be easy in this financial climate [or through] the Housing Finance Agency...which also carries its risks with it.

From this stakeholder's perspective, apart from the issue of having to borrow money, the requirement to sign up for a long term mortgage makes the SHLI much less attractive than the CAS scheme for voluntary providers in terms of being able to recover HWC costs. From a voluntary housing sector perspective, the introduction of SHLI along with the effective withdrawal of CAS funding has seriously slowed down if not actually stopped the development of new build

special needs social housing in Ireland and the belief was that it would continue to do so into the future (SB1, F4, N4, OC1).

A local authority housing officer observed that the SHLI was not designed to stimulate new service development but rather to ‘...mop up the [housing] surplus that’s been there after the last number of years’ (LA3). A DOE participant acknowledged that the dramatic reduction in CAS funding was inhibiting the development of special needs housing including HWC and also that the SHLI had been slow to take off (N5). This stakeholder recognised that only the larger housing organisations were likely to be approved for HFA funding but did not discount the possibility that the SHLI could be used to develop HWC services (N5).

### *3.4 Revenue funding structures and systems*

The findings in this section show that a large number of participants from the HSE and the voluntary housing sector believe that the challenges involved in sourcing revenue funding for HWC services are nearly as great a threat to future HWC development as the scarcity of capital funding. When asked why it is so difficult to find revenue funding for HWC, they cited a number of issues that all have to do with the way that long term care is financed in Ireland and the first of these is the inflexibility of the Nursing Home Support Scheme.

#### *3.4.1 Nursing Home Support Scheme restrictions*

Many stakeholders identified restrictions imposed by regulations in the Nursing Home Support Act 2009 (known as Fair Deal) as a serious inhibiting factor to further HWC development and delivery (HSE 1, HSE5, HSE6, HSE10, HSEO1, HSEO7, MB1, F2, N2, N7, N8). The Fair Deal scheme was put in place to provide consistency and equity to the way that older people’s entitlement to statutory funding to meet long term care costs was determined (DOHC website undated) and as such, it was an improvement on what went before. But Fair Deal funding can only be used to cover care costs in registered nursing homes and not costs in other care settings including HWC, and participants believed that if that restriction was lifted, it would free up the funding necessary for the development of alternative long term care services including HWC.

The argument was that if Fair Deal funding could be used by older people to pay for HWC services, that funding would help to offset revenue HWC costs in the same way that it does in public or private nursing care facilities (F1, F2, HSE1, HSE3, HSE10). That would put housing associations in a much better position to offer the level of care and support services required by older people with dependency needs and they would thus be encouraged to develop HWC services. An HSE

senior manager stated that efforts to persuade the Department of Health to divert Fair Deal funding had so far failed (HSE1).

In the meantime, it is easier for the HSE to keep referring older people to nursing homes than to struggle to find revenue funding out of other already committed budgets in order to support HWC service development or delivery (HSE1, HSE2, N8). In the words of one participant

[N8] Fair Deal has served to copper fasten the existing system [by absorbing all of] the time and energy and resources' in the HSE.... It's a paradox; the more we fund, the more we concentrate on [existing] long term care [services] and the less likely we're going to get the care for older people that we probably believe in. It's good for everyone except older people.

The inflexibility of Fair Deal regulations was thought to inhibit HWC development by denying HWC providers a source of possible revenue funding but several FOLD case study participants from the HSE and the voluntary housing sector believed that Fair Deal regulations had an especially negative impact when combined with the way that eligibility and charges for HWC are determined.

#### *3.4.2 HWC Eligibility and Charges*

Charges to residents are another way that HWC providers can obtain funding with which to pay service costs. However, the potential for voluntary housing associations in Ireland to source revenue funding for HWC through rent and other charges to tenants is limited by DOE regulations that stipulate that eligibility for social housing should be restricted mainly to applicants with low income and assets (DOE March 2011). Rents in voluntary housing schemes have to be negotiated with the local authority and, for the majority of tenants, rents are kept at a very low level (F4 ,LA3). Furthermore, under DOE regulations, only a small percentage of 'private' tenants who might be expected to pay higher rents and charges can be admitted to any housing scheme in receipt of DOE funding (F2, HSE13). Eligibility restrictions were a particular source of concern for both HSE and FOLD managers from the FOLD case studies because unlike O'Connell Court, the FOLD units attract interest from a range of income groups and not just from people eligible for council housing (HSE3, HSE10, F1, F2). Three study participants argued that if FOLD could admit a greater proportion of people with higher incomes, more revenue could be generated in the form of higher charges (F1, F4, HSE13). One HSE decision maker concluded that the way that the system was set up was 'short sighted' in terms of the practical realities involved in funding HWC service development (HSE13).

Several FOLD participants had another related concern about the system that had been developed in the NAHB for levying charges to 'private' FOLD applicants (including all homeowners). Instead of using the Fair Deal means assessment system<sup>15</sup>, a crude binary system was developed whereby those eligible for social housing pay very low charges for accommodation and all services and those with higher incomes including all homeowners pay full service costs.

[HSE3] There was a category called 'private funding'... We included the family home in our assessments...and [homeowners] were expected to pay full costs. For the others, ...[the health board] would essentially pay the full care costs... So you had people in FOLD who had sold their house and are spending their money to pay for their care €850 euros/week, ballpark. The homeowner would pay the whole amount. Others pay on average €108.

The inequity in the cost of care for prospective HWC candidates caused disquiet among HSE managers and so did the high charges imposed on 'private' residents which were roughly equivalent to what would be charged in a private nursing home at the time (HSE3, HSE10). If these same candidates chose to go into a nursing home, they would likely be eligible for some level of Fair Deal funding, but if they go into one of the FOLD units, they are not eligible. This was thought to discourage them from applying for even the small number of places available to private applicants in the FOLD schemes (F1, F3, F4, HSE3, HSE10, HSE13).

[F3] The biggest problem we've run into... Anybody who is a home owner, it wouldn't be cost effective for them to move into Housing with Care and that has had an impact on our business. Because with Fair Deal it would be cheaper for them to go to a nursing home.

[F1] We are under pressure... It is tempting for families to choose nursing home because of the money aspect...[because they] are not entitled to payment under Fair Deal.

FOLD and HSE participants believed that this 'all or nothing' approach to charges led some older people to choose nursing home care instead of HWC in spite of the fact that they would have preferred HWC and it was more appropriate to their needs. The current system also denied FOLD the possibility of subsidising the care costs of people with low incomes with revenue generated from charges to those with higher incomes who can afford to pay a larger percentage of care costs (F1, F3, HSE3, HSE10, HSE13).

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<sup>15</sup> Fair Deal applicants undergo a means assessment of their income and assets and most applicants who own their own homes can expect to receive some level of funding to cover long term nursing home costs.



### 3.5 Lack of HSE strategic framework

Several study participants argued that there had never been any formal acknowledgement by the HSE about its role or responsibility for either funding or providing HWC services<sup>16</sup> in spite of repeated social policy recommendations dating back to the Care of the Aged report in 1968 (N3, N4, N7, LA3, OC1, HSEO3, SB1). A voluntary housing stakeholder observed that

[SB1] ...the HSE, for reasons best known to themselves, have never been able to respond to [those recommendations]. My perception of the HSE in terms of this is it's very much ad hoc, hoping that approved bodies will bear the cost and they put in some very incremental, usually insufficient funding.

Participants pointed to the continued absence of either a national housing policy for older people or a strategic framework that identifies an HSE obligation to support HWC development and delivery and argued that if there was such a mandate, the establishment of more compatible funding systems with which to support HWC development and delivery would have been established (N3, N4, N7, LA3, OC1, HSEO3, SB1).

Housing sector participants put the onus on the HSE to resolve the revenue problem (SB1, N4, LA3, N7) but one HSE official observed that the 'conversation' about an HSE role in supporting long term care service options other than nursing home care has never taken place, and exploration of alternative services similarly never been acknowledged or addressed in any formal way by the HSE (HSEO3).

[HSEO3] In terms of HSE, we need to have a conversation that gets a decision that challenges the push towards nursing home. ...And we have to decide, is this something we're supporting or not? Is it our business or not? What makes it our business? Is it entirely our business or is this something that should be done collectively with the housing authority, so that we have a systemic approach.

The same officer suggested that the discussion about HSE support for HWC must also include discussion about the tax system which has encouraged the proliferation of nursing homes and also about the role and relationship of the HSE *vis a vis* the housing authorities (HSEO3). HSE commitment to HWC remains ambiguous<sup>17</sup> and this is believed to be central to the funding issues that figured prominently in discussions with study participants about structural and systemic barriers to further HWC development. But the findings show that it is the combination of funding

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<sup>16</sup> When I approached the DOH to request an interview for this study I was referred in the first instance to DOE because it was a 'housing matter'. (Telephone conversation 9 June 2011)

<sup>17</sup> In this context it is instructive that the Inter-Departmental Committee on Sheltered Housing which was established in 2008 never issued a final report (N4, LA3). The ICSH hoped that this committee would help to clarify the respective roles and responsibilities of the HSE and the housing authorities with respect to revenue costs.

and the introduction of regulation that many believe will have the biggest negative impact on future HWC development.

### *3.6 Regulation*

As outlined in Chapter 5, lack of regulation of HWC services and the perceived risks associated with that contributed to the resistance that developed against the introduction of the case study schemes as outlined. One might conclude that the introduction of regulation would increase confidence in HWC and legitimise it as a long term care alternative. However, the findings in this section show that several study participants were concerned that if regulation were to be introduced it will come at too high a cost to service providers and also to residents; they believed that the combination of regulation and the revenue problems outlined above will threaten both the sustainability of existing services and the future development of HWC (HSE1, N2, N3, N4, N7, OC1, OC2).

Participants who raised the subject during interviews had no objection to the idea of regulation, but three participants suggested current nursing home regulations were not appropriate to the regulation of HWC services and argued that separate social care regulations that are more pragmatic and proportional need to be developed before HWC regulation is introduced (N3, N4, HSE07). A special interest participant identified the need for dementia specific regulations that are sensitive to the particular needs of people with dementia, arguing that existing nursing regulations with respect to dementia care were inadequate and had been '...tagged on at the back [as] an afterthought' (N3).

Participants supported regulation in theory but they had serious misgivings about the consequences of regulation for HWC providers as well as for older people. The first concern was that regulation would increase service costs to unmanageable proportions (HSE1, N2, N3, N7, OC1, OC2, N4). There was a fear that the introduction of new rules and regulations would drive service costs up so much that some providers would either go out of business or stop providing specialist services for people with high dependency (OC1, OC2, N4). A related concern was that regulation would work to undermine service flexibility by forcing service providers to prioritise health and safety at the expense of quality of life for residents and rigidly define what housing associations must and must not do if they accept responsibility for vulnerable older people (N3, N4, OC1). Stakeholders believed that regulation would limit HWC providers' ability to create an environment in which to provide individualised care and would also restrict the independence of residents.

The impact of the increased costs and restrictions on service delivery associated with the introduction of regulation were considered to be a particularly serious barrier to the development of HWC for people with dementia by several participants (HSE1, N2, N3, N4, N7, OC1, OC2). One health sector participant anticipated that the process of defining the boundaries between HWC and nursing care for regulatory purposes will lead to the imposition of strict limits on the amount of care that is allowed to be provided in a HWC setting (N2). Three housing sector participants believed that regulation would make people with dementia more vulnerable to being refused admission (OC1, OC2, N4). This was already a concern for O'Connell Court managers, and the findings from the O'Connell Court case study suggest that these worries are justified. In recent years, in the absence of regulation by an independent agency, Service Level Agreements (SLA) have been drawn up between O'Connell Court and the HSE to regulate both the admission and discharge of residents. The SLA stipulates that O'Connell Court '...can only accept tenants who are capable of residing in the community with the community services available'(OC1) and it is now the responsibility of the HSE Aged Care Team to determine who meets this criterion (HSE03, OC1,OC2). Applicants who do not are now refused admission and residents whose dependency increases beyond the defined limit must in theory at least, move out<sup>18</sup>. O'Connell Court stakeholders observed that since the HSE assumed responsibility for admissions approximately ten years ago, the number of people with dementia who have been admitted to O'Connell Court has dropped considerably (OC1, OC2).

[OC2] Persons who have a diagnosis of Alzheimer or Dementia can function very well in supported sheltered accommodation. For the first 10 to 14 years of O'Connell Court, no one had a great problem with us providing supported accommodation for the above, however as more regulation was introduced, sheltered housing is no longer accepted as the ideal housing option.

People with dementia who would previously have been targeted for admission to O'Connell Court are now deemed ineligible by the HSE, and there was the fear that this pattern would increase with the introduction of regulation to the point where no one assessed as dependent would be accepted in future (OC1, OC2). They predicted that the combination of budget cuts and regulation could force O'Connell Court to revert to providing conventional sheltered housing in future.

#### **Section 4 Discussion**

This chapter explored the climate for further HWC development in Ireland, including the factors thought to be particularly relevant to the future development of HWC services for people with

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<sup>18</sup> According to an O'Connell Court manager, residents sometimes refuse to move which can delay the process, and on some occasions it is difficult to find an alternative placement in a nursing home which again delays the process.

dementia. Kotter notes that unless stakeholders believe that a new idea is imaginable and desirable, they will not support it (Kotter 1996:67-83) Section 1 looks at the data related to participants views about whether HWC development *should* take place and if so, should existing HWC models be replicated. It also presents participants' views about whether Irish older people and their families would want HWC services if they were available.

The data in Section 1 shows widespread acknowledgement of the need for HWC and the potential benefits to residents but they also show misgivings about the HWC as a long term care model because of concerns about the risk that residents will have to move again into a nursing home when their needs exceed a certain threshold. The findings in the international literature suggest that these reservations are justified. The consensus in the literature on HWC for people with dementia is that some residents will have to move from HWC into a nursing home setting at some stage and furthermore that people with dementia are more vulnerable to being moved on, even from specialist HWC dementia units (Zimmerman et al 2001, Henwood 2009, Garwood 2006). But there is also agreement that many people with dementia can continue to live in HWC settings up to the end of their lives if staff are trained to work with people with dementia and if residents can access adequate services when needed (Vallely et al 2006, Cox 2006, Zimmerman et al 2001). Factors critical to decisions regarding discharge of HWC residents include the costs involved in supporting or supervising vulnerable residents, the approach taken to risk management and the mix of residents (Cox 2007, Garwood 2004, Garwood 2006, Zimmerman et al 2001).

The failure to monitor and review existing HWC services highlighted by some HSE participants represents a serious planning failure and a lost opportunity. In the absence of a review, it is impossible to determine whether planned HWC services have achieved stated objectives, whether they are cost effective and what the benefits are to service providers and service users. All of that information is necessary to building a case for further service development. A review of the FOLD initiatives might have dispelled some of the concerns that contributed to resistance that developed to the HWC model and it also would have allowed for adjustments to be made to the original model when problems are identified (Coghlan and McAuliffe 2003). A review would have acknowledged successes and helped to consolidate HWC services within older people's services and within the mindsets of stakeholders (Coghlan and McAuliffe 2003). It would have helped to lay the foundation for further service development.

The data on participants' perceptions about the lack of demand for HWC in Ireland are interesting because they point to the influence of cultural norms, expectations and even personality traits on long term care preferences and 'demand' for services . The data support Kenna's research findings which associated the priority placed on home ownership in Ireland with the slow

development of housing services generally in Ireland (2000) and that may be critical to understanding the limited development of HWC. Participants implied that Irish people are different from their counterparts in other countries where HWC has developed to a much greater degree and that. The belief among HSE managers and decision makers that Irish older people would not want HWC services even if they were available takes urgency away from the need to develop HWC and pushes HWC further down the list of service development priorities (Kotter 1996, Coghlan and McAuliffe 2003).

The data in Section 2.1 shows optimism on the part of national health sector participants about the prospects for the development of HWC for people with dementia and this might be partly explained by their vested interest in promoting the idea that progress is being made on the national front with respect to improvements in the health services (Pasmore 2011). Recent developments including the Genio projects which involved the commitment of significant HSE funding, and the promise of a National Dementia Strategy by the end of 2013 (Genio website undated) would seem to support the view that dementia and dementia care higher on the health agenda than previously. However, many if not most of the recommendations made in the Action Plan for Dementia over fifteen years ago have yet to be implemented (O'Shea 2007:3) and the data on the HSE organisational culture and HSE structures in this chapter serves as a warning that the development of HWC for people with dementia could take a very long time even if it does appear in policy statements. The absence of a national housing policy for older people and the lack of a framework for HWC development are other critical inhibiting factors.

HSE participants with more local responsibilities did not share the optimism of their national counterparts and two people even suggested that dementia care was receiving less priority than in the past. Participants noted the incompatibility of the HWC model with the dominant medical model in older people's services and some of their observations demonstrate that the concerns that led to the resistance displayed by health professionals when the case study schemes were being implemented have not gone away. Kotter warns that 'you can drive [resisters] underground or into the tall grass. But instead of changing or leaving, they will often sit there waiting for an opportunity to make a comeback' (1996:131). The data suggests that the future development of HWC depends on the resolution of at least some of the concerns of those who will be affected by the introduction of HWC services through better communication, wider participation and the preparation of detailed implementation plans (Coghlan and McAuliffe 2003).

The findings from the housing sector suggest that a recent shift in housing policy may discourage HWC development for all groups including HWC for people with dementia, but the findings from participants in the voluntary housing sector and in Dublin City Council show a certain level of

commitment that could provide the foundation on which to develop future services. There are dormant plans which could be re-activated, willingness in the voluntary housing sector to expand or develop services and an existing infrastructure on which to build. However, the willingness of housing providers to pursue the further development of HWC for people with dementia is contingent upon the availability of funding which is currently not available. In the current economic climate, the extra costs involved in the development of HWC for people with dementia push any plans for service development much further down the list of priorities for both local authority and voluntary housing providers and leads to what Pasmore refers to as 'regression to old habits' (2011), in this case a retreat to core functions which is the provision of conventional housing.

The findings from the special interest groups representing people with dementia and their carers are most interesting in that they suggest that, in spite of the trend towards dementia specific HWC development in other western countries, it is not currently a priority for the Irish interest groups. It is also interesting to note that both groups see only a limited role for HWC although one might have expected these organisations to be the biggest advocates for change in the way that the long term care of people with dementia is delivered in Ireland. The data raises questions about possible differences between what individuals with dementia would want for themselves and what organisations representing them think they need.

Pasmore notes that unpredicted shifts in the external environment can 'make current plans obsolete' (2011:284) and Borins observes that inadequate resources resulting from such shifts at a political level are a common obstacle to the introduction of innovative programs in the public sector (2000:504). There was consensus among voluntary housing participants that the downturn in the Irish economy which resulted in the shift in national housing policy from a capital funding model to a leasing model for social housing has halted the development of all HWC services for people with special needs. This shift has made HWC development an unrealistic proposition. The data in Section 3 shows that even if the capital funding problem was sorted, HWC services would still not fit into 'the formal structures, systems and processes' used in the HSE to fund long term care (Nadler 1998); the bias towards nursing home care in Fair Deal regulations (Cahill et al 2012) presents another major obstacle to HWC development. Although the data from the FOLD case studies on service charges is very limited, it does provide a good example of the incompatibility of existing funding systems to HWC development and delivery. It also highlights the negative implications of using social housing regulations to dictate both eligibility and charges for a service that provides accommodation *and* care. It raises practical and ethical questions about the current system of charges which has the effect of restricting the access of some older people for whom HWC may be the most appropriate long term care option and also their preference.

The introduction of regulation represents an external constraint thought to have an especially negative impact on HWC for people with dementia. The fears expressed by study participants about the introduction of regulation are supported by the UK and US literature on the implications of HWC regulation for people with dementia (Moriarty and Manthorpe 2010, Golant and Hyde 2008, Bernard et al 2007). Hyde et al observe that regulation 'may have the paradoxical effect of... put[ting] strictures on admission and discharge criteria that prevent Assisted Living from serving those with the highest level of impairment' including and especially those with cognitive impairment (2008:67). Moriarty and Manthorpe observe that an 'overly cautious approach to risk is disempowering for people with dementia...can prevent them from doing things that most people take for granted...and also act as a barrier to offering people with dementia a full choice of services and support...' (2010:6). Regulation is something that will have to be negotiated if HWC is to be developed on any scale in Ireland and the literature suggests that it is not easy to achieve the right balance between protection and the individual rights of people with dementia (Oldman 2000, Garwood 2008).

The findings in Section 3 show that the climate for further HWC development is poor; the resources necessary for HWC development are not available; existing structures and systems do not support HWC development and regulation was seen as a threat to the sustainability and development of HWC for people with dementia in particular. Reductions in CAS funding and the introduction of the SHLI render the current HWC business model obsolete; eligibility regulations create inequity and restrict access to services. Fair Deal Regulations provide a 'perverse incentive' towards nursing home care at the expense of other long term care alternatives including HWC and in so doing undermine social policy objectives aimed at the provision of care in the most appropriate setting (Cahill et al 2012).

The findings in this chapter show that now is not the ideal time for the further development of HWC in Ireland as there are too many constraints including lack of resources and lack of the alignment of systems and structures necessary to achieving the successful implementation of change (Pasmore 2011). In the circumstances, almost all housing sector participants believed that HWC development was not a realistic possibility in the near future (Kotter 1996). The findings in this chapter suggest that HWC has not been sufficiently embedded (Fernandez and Rainey 2006:172) in either the prevailing culture of long term care in Ireland or in health and housing systems and structures to ensure that it will endure as a model for future service development. In the words of Nadler, it has not been 'baked into the fabric' of the organisations involved in its development (1998:80).

Pasmore observes that after change has been implemented, loss of focus, shifting priorities and turnover of key champions are threats to the sustainability of change as are resource starvation, exhaustion and unpredictable shifts in the external context (2011:282). He refers to this phenomenon as 'change drift' which may be an apt description of what has happened since 2008/2009 to diminish the momentum for the development of HWC for older people including people with dementia in Ireland.



## **Chapter 7      Conclusions**

Section 1 of this final chapter presents conclusions drawn from the research. Section 2 discusses research strengths and its contribution to the literature. Section 3 discusses the limitations of the study. Section 4 makes recommendations for further research and Section 5 includes recommendations for Irish policy and practice based on key findings.

### **Section 1   Conclusions drawn from the research**

The findings from this study help to explain the very limited development of HWC for people with dementia in Ireland up to now. The evidence suggests a failure to gain widespread acceptance of HWC as an alternative long term care model for vulnerable older people in Ireland and the lack of a coherent strategy to support or guide HWC service development (Kotter 1996, Coghlan and McAuliffe 2003). While dissatisfaction with the heavy reliance placed on nursing home care in Ireland is acknowledged, there is no evidence of consensus around the need for HWC development in that context. Systemic and structural obstacles to the introduction of the HWC model have never been removed and ad hoc efforts to overcome them in the short term achieved only limited success and in some cases further undermined confidence in either the desirability or feasibility of HWC as a long term care alternative (Kotter 1996). Three of the case study schemes continue to operate but no evaluation has ever been undertaken to assess the extent to which service objectives have been achieved; one scheme closed and plans for another failed to progress. In the wake of a dramatic economic recession in Ireland, almost none of the stakeholders interviewed believed that the time was right for further HWC development.

The findings support Coghlan and McAuliffe's contention that change initiatives that challenge tacit assumptions about the way things are usually done are the most difficult to implement (2003:59). The heroic struggles of the HWC champions in Ireland described in this study illustrate the challenges involved in introducing a social model of long term care into a culture still strongly dominated by a medical or nursing model of care for older people in general. Many of the issues faced by the case study champions are the same as issues faced by those who develop HWC in other countries. These include the challenge of sourcing adequate funding to cover costs, the misunderstandings and mistrust that can develop across agency boundaries and the hybrid nature of HWC which makes it hard to define and hard to place within existing services and systems developed to support the long term care of older people. But the study's findings suggest that it may have been even more of a challenge in Ireland because of the continued strength of a culture that equates long term care for older people with nursing home care and the existence of a rigid

funding mechanism that dictates that long term care funding can only be allocated for care in a nursing home setting. This contrasts with the situation in other countries where HWC services are being developed systematically. In Ireland the idea of providing long term care for people with dementia in a social care setting is almost unthinkable, although it is an acceptable long term care alternative for an increasing number of people in northern Europe, the UK, North America, Australia and other countries where the development of HWC for people with dementia is a growing trend.

The study's findings suggest that the breakthrough that appears to have been made in other countries to change thinking about the way that long term care is delivered to older people has not yet taken place in Ireland. It took place for children many years ago and more recently for adults with disability for whom 'independent living' has been the aspiration and group homes the norm in Ireland (DOE 2011b) but it has not taken place for older people. With this breakthrough for people with disability came modifications to the capital funding system that allowed social housing funding to be used to build HWC and other funding mechanisms developed to provide revenue funding in the form of grants and statutory benefits and allowances. That is yet to happen for older people in Ireland for whom 50-100 bed or more nursing care units remain the only residential long term care option.

The case study schemes might have marked the beginning of the shift in thinking required to make the breakthrough necessary to progress HWC development for older people in Ireland as well as the requisite restructuring of housing and health systems, but the data suggests otherwise. It leads to the conclusion that the development of the case study schemes does not represent any significant challenge to prevailing attitudes about the long term care of older people and furthermore has not made it any easier for others to take up the HWC cause. HWC remains as inaccessible as it ever was and Irish older people continue to be denied the choice of long term care settings. Changes are being effected within the nursing home sector (public and private) to improve the environment in nursing homes to make them more like HWC settings (Morgan-Brown et al 2012), and the improvement of homecare services continues to be the focus of much attention in older people's services, but HWC for older people and most especially for people with dementia is not on anybody's agenda, particularly at a time when public sector funding is scarce.

HWC development was never going to be easy in the Irish context because of the mindsets, systems and structures that stood in its way but mistakes were made during the planning and development of the case study schemes that may make it even harder than it was before they were developed. Better planning would have prevented many of the problems that arose in

Cherryfields and better planning might have resulted in more widespread acceptance of HWC as a legitimate long term care model. The health board champions and the housing associations involved have to take some responsibility for the planning failures described in this thesis. But other factors contributed to the mixed outcomes of the case study schemes that were not under the control of the champions and this study confirms that the success of the introduction of any innovation also depends partly on timing and luck (Pasmore 2011).

It is undeniable that the Mount Bolus and St. Bricin's projects were more difficult to progress because they were developed at a time when the health services were being restructured and the Irish economy entering into a deep recession. Mount Bolus failed ultimately when the funding required to cover service costs could not be sourced. The St. Bricin's project was doubly unfortunate because by the time that planning permission was obtained, not only was revenue funding impossible to obtain but so was capital funding. Better planning might have improved the chances for the survival of the Mount Bolus unit but bad timing was also a critical factor.

O'Connell Court developed almost as a personal mission and services were developed on a weak foundation; O'Connell Court services have always been under-resourced and budget constraints and the introduction of regulation may force managers to revert to providing more conventional sheltered housing. O'Connell Court is typical of many voluntary sector housing services for older people in Ireland that were developed with missionary zeal by local community groups (ICSH 2005:15). It represents a valiant attempt to meet the needs of vulnerable older people using systems that do not support the HWC model but the findings suggest a service development model that is no longer viable or adequate.

The FOLD schemes are the only case study initiatives that included the discrete provision of dedicated dementia services in specially designed units equipped with assistive technology. As such, they should provide a beacon for future service development. But the findings show that some HSE stakeholders in the same geographic area were not aware of their existence several years after they opened and that some of the early champions now believe that the HWC vision has not been realised in the FOLD schemes. In spite of pressure on budgets, Cherryfields and Anam Care continue to operate, but in the absence of a review, it is impossible to evaluate their potential as a template for future HWC development.

That the case study initiatives were planned at all is a tribute to the energy and commitment of the champions who drove them. But they were developed on shaky foundations and the environment was never conducive to HWC development and is even less favourable now. The data leads to the conclusion that the time may have come and gone in the short term at least for HWC development for older people in Ireland. Some of the original housing and health sector

champions have retired and those that remain are exhausted from the effort of trying to fit HWC into a system and culture that does not accept it as a valid long term care alternative (Pasmore 2011). The current economic recession has contributed to a renewed reluctance to try to challenge that culture by introducing new service models.

A striking finding that emerged from the data is how little dementia featured in discussions with stakeholders about the development of the case study schemes, given that each scheme was planned to provide (or was providing) services for people with dementia. There is evidence of a swell of enthusiasm at the time that the FOLD schemes were built but it is not clear if the ability of HWC to address the unmet needs of people with dementia was central to the vision that guided service development. People with dementia were in most cases included in the larger group of vulnerable older people who were of concern, for pragmatic as well as altruistic reasons (Pasmore 2011).

The challenges involved during the implementation stage had little to do with the fact that the case study schemes were targeting people with dementia; the challenges encountered were at a more basic level. The resistance that developed was resistance to the idea that older people as a group (and not just people with dementia) could be cared for safely in social care settings and this may be related to the Irish long term care culture which assumes that all older people whose needs cannot be met at home need nursing home care. That culture needs to change if HWC development for older people is to progress, and the data suggests that an even bigger 'sea change' is required before HWC becomes widely accepted as a long term care alternative for people with dementia. Apart from a culture change, there is a need to change structures and systems in the health and housing services, particularly the funding systems that support that culture and obstruct the introduction of social model alternatives. There is also the need to change the organisational culture in the HSE that works against the introduction of innovation.

## **Section 2 Research strengths and contribution to the literature**

The Irish HWC literature to date has focused on assessing the scope and scale of existing services and on what is required in terms of resources and policy in order to increase the supply of services (Interdepartmental Committee 1968, O'Connor et al 1989, Cullen et al 2007). The HSE comes in for particular criticism in policy documents for not making a commitment to fund HWC service development delivery. The main contribution of this study to the Irish literature is to highlight for the first time the practical implications and perceived risks of HWC development from a health service perspective that help to explain the apparent lack of political will in the HSE to make such a commitment. The findings on the resistance that developed to the case studies schemes are particularly illuminating in this respect; they illustrate the continued strength of the

medical model in older people's services in Ireland and the difficulties of implementing changes that threaten accepted norms and expectations as well the professional interests of those health professionals who have a stake in maintaining the status quo. This has to be factored into any future efforts to develop HWC and it also has implications for others wishing to introduce new social models in the Irish health system.

The findings provide a good example of what the OECD identified as weaknesses in project management and implementation skills in Irish public sector organisations (OECD:2008). By highlighting the pitfalls and special challenges involved in the development of services that depart from the norm and the negative implications of poor planning, these research findings could lead to improved project management and better service implementation outcomes for future service initiatives in the Irish public sector. If applied, the lessons learned could improve service planning and influence the outcomes of other service initiatives in Ireland.

This study has generated data that helps to position Ireland among other western countries that are in the process of developing services to respond to the needs of a growing population of older people and as such also makes a contribution to the international literature. The findings confirm the continued strength of the medical model in older people's services and the existence of cultural values and norms that distinguishes Ireland from many other western countries where the development of social model service alternatives has progressed further. It will be of interest to researchers carrying out comparative studies on HWC development and the development of other nursing home alternatives for older people. The data will also be of interest to those conducting research on the preferences and long term care expectations of older people in other countries and may be of particular interest to researchers in countries where the development of service alternatives like HWC development is also at a very early stage and also slow to progress.

This thesis provides an excellent example of the way that change theory can be used to analyse why some efforts to introduce new service models fail while others succeed. It adds to the change implementation literature by offering new case studies that confirm the complex interaction of factors in the internal and external environment that provide opportunities but also act as constraints on service implementation (Nadler 1998, Coghlan and McAuliffe 2003). The mixed outcomes in the case studies illustrate the critical importance of adequate resources but also external factors (Pasmore 2011). The data on the resistance of health professionals to the HWC model is of particular interest because it demonstrates clearly the power of 'tacit assumptions' that help to maintain the status quo in any organisation (Coghlan and McAuliffe 2003) and the challenges involved in trying to graft new ideas onto an resistant culture (Kotter 1996). The

findings make a valuable contribution to the literature on the challenges involved in the introduction of new practices and services in public health sector organisations in particular.

Through the interviews conducted and the workshop hosted, this study has already helped to raise awareness and understanding of HWC as a concept and as a template for future service development in Ireland. By generating some discussion and debate, it has helped to acknowledge HWC as an alternative to the dominant nursing home model that currently absorbs almost all of the resources allocated to the long term care of vulnerable older people in Ireland. Although the systemic obstacles to HWC development are no less now than they were when the research was undertaken, it is hoped that this study will in time contribute to an eventual awakening in Ireland to the possibilities and benefits that HWC has to offer to older people as a group and to older people with dementia who are particularly vulnerable to the limitations and excesses of services developed and delivered within a medical model framework.

### **Section 3 Study limitations**

This study was ambitious and required the acquisition of knowledge about a number of topics (social housing, dementia care, inter-agency collaboration, innovation) across several research 'divides' including housing, health, and dementia care and this did not allow for an in depth study of a number of issues that emerged from the data. There are many topics that merit much more intensive investigation than was possible with a broad brush approach to what is a very complex topic. It was a challenge to absorb the information offered in interviews and throughout the fieldwork it was necessary to go back to the literature to understand the data that was being generated. The huge volume of data emerging from the case studies posed challenges with respect to the organisation as well as the interpretation of the findings. While there were distinct disadvantages to selecting a research topic that was so broad, it was very useful to capturing the dynamic nature of HWC development and the complexity of factors involved.

An obvious limitation of this research is the fact that the views of older people were not solicited for inclusion in the data relating to the climate for future HWC development. The data presented includes the views of housing and health managers about HWC as a service model and what they perceive to be the views of older people, but it does not add anything to our knowledge about what older people themselves think about HWC. Evidence from the international literature (Wilson 2007, Tinker et al 2013, Howe et al 2013) suggests that given the choice, older people prefer HWC over nursing home care and it would have been interesting to explore the views of older people including HWC residents, especially given the data suggesting that some HSE managers believe that HWC would not be the preference of Irish older people or their families. The findings point to the need to generate demand for HWC in order to create the urgency

required to progress service development; this cannot be achieved without consulting older people themselves.

The HWC schemes selected for this study fit into the category defined above, but it is very possible that there are other voluntary housing schemes providing services for small numbers of people with dementia. Charleville in County Cork is an example of a 'supported housing scheme' that aims to provide full care' to older people including those with disability<sup>19</sup>. Many other housing associations may be supporting individual tenants who develop dementia while in residence, but typically they do not have a policy of admitting people who have already been diagnosed as having cognitive deficits nor do they ring fence services for people with dementia<sup>20</sup>. The list of cases selected for this thesis may not be exhaustive but time constraints prevented a complete trawl of all voluntary housing schemes in operation in Ireland at the time of the fieldwork in order to identify more cases and no other schemes were identified during extensive discussions on the topic with stakeholders from either the health or housing sectors.

I am aware of a number of dormant proposals for the development of HWC services involving Dublin City Council and voluntary sector service providers including FOLD and the Alzheimer Society of Ireland and closer scrutiny of these and other similar proposals unknown to me might have provided new and different data especially with respect to future service development. Yin observes that convenience, access and geographic considerations influence the selection of cases (2009:93). St. Bricin's was chosen because it is situated in Dublin where I live and because access to those involved in its planning was available to me. St. Bricin's is representative of a number of cases in which the development of HWC services for people with dementia was planned; it was used to represent this group of unrealised HWC developments but it may not be typical, and this is a limitation of this study.

HSE participants were over represented in the sample of people selected for this study and this reflects the large number of HSE officers who were involved in the FOLD scheme initiatives in particular. There was very high turnover of HSE managers in the mid 2000's when the health services were being structured (see p.150 for details about the impact of the lack of continuity of HSE managers on inter-agency negotiations). The high number of HSE participants reflects that turnover and also the easy access I had to HSE officers having only recently retired from the HSE myself. The data for the other schemes which were not developed through a formal partnership with the HSE relied on far fewer participants and that is a limitation of this study.

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<sup>19</sup> Interview with ICSH participant 11 May 2011

<sup>20</sup> Interview with ICSH participant 11 May 2011

In recent years there has been considerable activity in the private sector around the development of 'independent living' units on the campus of existing private nursing homes. Data relating to demand for services and the experience and expectations of private sector stakeholders about the HWC model would have strengthened the findings by helping to put the development of the case study schemes into a wider perspective. It would have enriched the findings on funding structures and the impact of Fair Deal on HWC development and demand for HWC services in particular. Time and space constraints dictated the omission of such private sector initiatives in Ireland and this is another limitation of the study.

Only the views of local authority housing officers from Dublin were included in the study. Dublin County Council in particular is different to most other local authorities around the country in that it has a more progressive record with respect to the development of social housing for people with special needs (Cullen et al 2007). It would have been interesting to hear the views of local authority officers from outside Dublin which might have differed from those of their Dublin counterparts.

#### **Section 4 Recommendations for research**

A key recommendation arising from this study is that an independent evaluation of existing HWC services be undertaken. This is critical to informing any further discussion or debate about HWC as a long term care alternative for older people with dementia in Ireland. Current information about service costs and benefits is anecdotal. An independent analysis is required to determine the comparative costs of HWC and nursing home care, the benefits to all stakeholders, and what aspects of existing HWC service provision work and do not work from the perspective of service providers, funders and service users. Critical to such an evaluation is the inclusion of the views of HWC residents themselves. Family members' views are also important, but efforts should also be made to obtain the perspective of older people including people with dementia, many of whom are still capable of expressing observations and preferences with respect to their care environment (Downs 1997, Dewing 2002) HSE managers appeared to put little value on the benefits of HWC for older people; a service evaluation is required in order to determine the benefits as well as the costs of HWC.

There is also a need for research to be undertaken on the demand for HWC services that includes the views and experience of private nursing home providers, residents in independent living units and older people in order to inform future policy and planning. Such research should include the impact of Fair Deal on service take up.



## Section 5 Recommendations for Policy and Practice

The study shows that much more work needs to be done to raise awareness of social model alternatives to nursing home care for older people in general and also for people with dementia. The data points to the need to start with the special interest groups that represent people with dementia in Ireland. The lack of priority placed on HWC and perceptions about the limited potential role of HWC in the overall provision of services for people with dementia is remarkable considering the work that has been undertaken in other countries to pro-actively target people with dementia for HWC services (Mollica 2009, Tinker et al 2013) and to promote HWC as a long term care alternative with particular benefits to people with dementia (Zimmerman et al 2001, Vallely et al 2006).

There is also the obvious need to change the mindsets of stakeholders in the health services about long term care alternatives for older people including people with dementia. Without the commitment and support of the HSE, HWC development will not take place even if the economy suddenly improves and resources again become available for service development because of the huge number of other conflicting priorities facing health service decision makers. The data showed reservations on the part of a number of HSE administrative officers and health professionals about what they see as the risks of HWC to older people. Training of health and housing officers and staff in risk management is essential to progressing a HWC agenda for people with dementia. The merits of HWC for people with dementia are well documented and ways need to be found to disseminate that information and engage the relevant health and social care workers in discussion about HWC as a service alternative.

This study led to the conclusion that HWC development would not progress unless the culture of long term care in Ireland changed, but changes to the structures and systems that support this culture at the expense of social model alternatives like HWC are also essential. The findings of this study show an obvious need to change the way that long term care funding is allocated in Ireland because of its bias towards nursing home care. Funding should not be dictated by the care setting in which long term care is delivered but rather by the needs of individual older people in whatever care setting is most appropriate; this particular Rubicon has been crossed in all of the other countries cited in this thesis and it needs to be addressed as soon as possible in Ireland. The promised review of the NHSS (Fair Deal) scheme should be prioritised and should include +consideration of funding systems developed in the UK and other countries to allow long term care funding to be used in HWC settings as well as in nursing home settings.

The situation of HWC development within the social housing framework needs to be revisited because of the negative implications for HWC providers and for older people, and this is directly

related to the problem of long term care funding mechanisms identified above. Current regulations that stipulate that HWC residents in voluntary housing schemes be eligible for social housing restrict the access of older people with higher incomes and assets (including all homeowners) to HWC services. This undermines the achievement of the much documented Irish social policy goal of delivering long term care in the most appropriate setting (DOHC 2001) and also lowers the threshold of revenue that can be raised by HWC providers from rents and charges. Recommendations by Grant Thornton to change eligibility requirements should be considered in the context of creating more equitable access to services but also of generating income for HWC providers (2009) especially given the reduction in statutory funding now available for the development of social housing. Similarly charges for HWC services in both the public and private sectors need to be reviewed.

There are lessons to be learned from the disability sector in Ireland who have made that breakthrough in thinking that is so central to the introduction of change to the way that long term care is delivered. The recent Housing Strategy for People with Disabilities (DOECLG 2011) provides the necessary framework for the inter-agency development of HWC; a similar framework could be developed for older people. Likewise the small group housing that is the norm in the disability sector (DOE 2011b:35) provides an Irish model for the development of HWC for people with dementia. But the findings show that it is not the lack of a template that inhibits HWC development in Ireland but rather the lack of will and inspiration to introduce a new service model that challenges the dominant culture of long term care for older people.

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## APPENDIX 1: Detailed description of the five case study initiatives

### *1. O'Connell Court<sup>21</sup>*

O'Connell Court originally occupied a former convent in a residential area of central Cork City which was acquired in 1989 by the voluntary housing association of the same name established to provide housing for homeless older people. 66 residents were originally accommodated in the old premises which date back to the 19th century and earlier, and during the 1990's residents included up to twenty people with dementia (OC1). Because of concerns about health and safety, in 2011 O'Connell Court services moved to a hotel situated in Togher outside Cork City that had been earlier vacated by its owners. O'Connell Court are now 'sub-tenants' of Cork City Council and pay a nominal rent to occupy the premises; the original 3 year lease signed in 2011 was recently extended for another 2 years (OC1). Togher has a high proportion of council housing and is recognised as an area of disadvantage with attendant economic and social problems (Cork Local Voluntary Youth Council 2013). The population includes a mix of young families and older people.

O'Connell Court is situated at a busy intersection; there is a Catholic church next door and a grocery store, barber shop, primary school, pub, GAA club and a few other small shops in the immediate vicinity. A bus that goes into Cork City every day stops outside the main entrance. There is a gate at the entrance, a car park and some areas planted with shrubs in front of the building. The building is two storey and downstairs there is a reception area with hotel-type podium and desk; living room chairs and couches are arranged in clusters in the reception area for residents and visitors who choose to sit there. A large dining area is situated off the reception area with a raised alcove that doubles as an activity room. Other rooms include a television room, an office for managers and staff, and a corridor that leads to 13 of the total 50 double bedrooms. Another corridor leads to toilets and an area used by the Cork Alzheimers Foundation (CAF) to provide day care for people with dementia from the community. It is rented by CAF and is separately managed. Upstairs are the remaining bedrooms and function rooms that are not used by O'Connell Court because there is no lift going up to them.

The new premises in Togher were described by the manager as an improvement on the old convent; it is more modern, all rooms have en suite bathrooms and the bedrooms themselves are quite spacious, given that except in one case where two sisters share a room, individual residents occupy what were built as double rooms. But the number of bedrooms dictated that the number

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<sup>21</sup> The data gathered for this section came from direct observation during site visits, interviews with case study scheme managers, interviews with other study participants and available documentation.

of residents had to be reduced from 66 to 51, and about 1/3 of the total space, configured and outfitted as function rooms, is not used. According to the manager, the move from city centre caused considerable upset to residents at the time, some who had lived in the old premises for 20 years and were used to being close to city centre (OC1). But that has diminished over time and the advantages of being situated in a small community were noted including the fact that it is easier to engage with the locals who are now familiar with those O'Connell Court residents who are able to move about the area.

There are 19 staff positions in O'Connell Court with some staff job sharing. Staff include the manager, a part time receptionist, team leaders, care support staff, cooks, one maintenance person and one domestic worker. The manager previously worked in the social services. The four team leaders have all had some training in nursing; although they are not employed as nurses strictly speaking, part of their brief is to supervise and administer medications. For each of the 4 shifts, there is a minimum of one team leader and two care support staff on duty to look after 51 residents (a ratio of 1 staff to 17 residents), with the manager taking on whatever jobs there are to do when needed (OC1). Volunteers come daily and are relied upon to organise activities including art classes, walking groups and health promotion campaigns. They also visit residents who get few visitors and they accompany residents in taxis when they go to outpatient clinic appointments. There is a long tradition of resident involvement in a writing group in O'Connell Court and a collection of poems and essays by residents has been printed and distributed for several years as part of the Bealtaine Festival (HSEO5). O'Connell Court residents are currently involved in 'Get Vocal' an intergenerational community development project funded by Age and Opportunity aimed at increasing the participation of older people in the community. Other partners in the project include the HSE Primary Care Team, local schools and businesses. Residents participated in a quiz at City Hall at Christmas that included two students and two older people from all Cork parishes. After the quiz, one of the residents involved stated his pleasure at having been identified as representing Togher and not O'Connell Court (OC1).

The greatest proportion of O'Connell Court residents are referred by the HSE Psychiatry of Old Age Team and the Homeless Services from both the HSE and the local authority with a diminishing number in recent years from Geriatricians and hospitals (OC1, OC2, HSEO2). Residents are also referred to O'Connell Court from other housing agencies, from PHNs with some self-referrals. The Aged Care Evaluation Team from the HSE have been directly involved in admissions and discharges since 2000/2001 (HSEO3, HSEO5, OC1). The Team carry out an assessment of every person referred for admission and they also assess residents who are being discharged from hospital following an acute episode. In addition, the Aged Care Evaluation Team conduct bi-annual assessments of 'borderline' residents to determine if their needs can continue to be met in

O'Connell Court. The CSAR assessment tool is used and the criteria for admission include applicants' ability to carry out Activities of Daily Living and other indicators of physical and mental capacity (OC1, HSEO3). There is currently a waiting list for places in O'Connell Court.

There is overlap between residents of O'Connell Court who come with mental health problems and those that are categorised as homeless (OC1). Two housing association participants observed that while in the 1990's about a quarter of residents had cognitive impairment including Alzheimers, the number is now reduced to only a few (OC1, OC2). The Psychiatry of Old Age team have a close relationship with O'Connell Court; there are weekly visits from the community psychiatric nurse and the psychiatrists also visit (OC1, HSEO4). PHNs visit as needed as do other HSE Primary Care Team therapists and typically there are now no delays in accessing a service that is requested. Ophthalmology services are provided on site by a company that accepts medical card holders and a local dentist provides an excellent service to residents according to the manager (OC1).

An HSE Community Worker visits regularly and is involved in decisions regarding funding to O'Connell Court; the current incumbent was involved in the development of the 'Get Vocal' initiative (HSEO5). Chiropody is provided by a chiropodist employed by O'Connell Court who visits as needed. Hairdressing is provided on site and Alcoholics Anonymous support (including occasional meetings in O'Connell Court) is available to residents. Counselling can be accessed through the Mental Health Services. A Minister of the Eucharist gives communion to residents who desire it; those who are able attend mass in the church next door. Residents who can use the bus do so and those needing to attend out-patient appointments are transported in taxis.

O'Connell Court residents pay €68/week in rent that covers the cost of their accommodation, heat, electricity, maintenance and cleaning. In addition they pay charges for other services that include meals, personal care, laundry, hairdressing, chiropody, taxis, clothing and activities. Depending on their incomes, residents pay up to a maximum of €82/week in service charges, bringing total charges up to a maximum of €150/week (OC1). O'Connell Court pays the balance of drug charges not fully covered by the medical card. All residents are social welfare recipients with no other income or assets and twenty two qualify for rent allowance. In the application form it is stated that those admitted may not be able to remain living in O'Connell Court if their needs cannot be met there (O'Connell Court brochure: undated). The manager stated that although some residents sign rent books when they move in others (including those addicted to alcohol or drugs) are given a 'license' to reside there with certain conditions imposed<sup>22</sup>. All are considered to have the rights of tenants in any rented accommodation, that is they cannot be evicted without

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<sup>22</sup> An O'Connell Court website dated 2013 states that applicants 'currently addicted to alcohol or using drugs will not be accepted.



due process (OC1). The O'Connell Court website states that a €13 million project to redevelop the old convent buildings is planned (O'Connell Court website: 2013).

## **2. Cherryfields**

Cherryfields is located in an area of a northwest suburb of Dublin populated mainly by young families including a significant proportion of non-nationals who settled in Ireland during the Celtic Tiger years. It is situated in Fingal County, a relatively new local authority area established in 1993 (LA1) in was the Northern Area Health Board catchment area, now HSE North East. The site was owned by the health board before plans for Cherryfields commenced (HSE 1, HSE8, LA1). Cherryfields is surrounded by housing estates and there are shops and a pub in close proximity to it. Formal planning for this development started in late 2001-2002, the building began in 2004 and the facility opened in 2006 (F1). Cherryfields is better resourced than O'Connell Court in terms of the standard of the physical facilities and staffing ratios.

To the casual observer, Cherryfields is not unlike a modern nursing home in appearance, although there are no nurses, no staff in uniforms or medical equipment in evidence. Cherryfields is a purpose built two storey brick building with an attractive open 2 storey atrium area at the entrance to the building. This area has seating for residents, a television and staff offices. Off this central area, there are single en suite rooms for all residents, individualised with residents' own furniture and other effects, which serve as both bedroom and sitting room. The design of the building was aimed at allowing resident movement within a safe environment (F2). The bathrooms are designed to be disabled friendly and the living/sleeping space is slightly larger than usually found in a conventional nursing home (F1). Assistive technology is used to support individual residents, particularly those with dementia, and it includes bed sensors that alert staff to unusual movement in and out of bed, 'wander alerts' that let staff know if someone wanders out of their room, and 'fall alarm' pendants that tell staff when someone has fallen (F2).

Residents' rooms are arranged in groups of 8 along corridors named for Dublin streets; at the end of each corridor there is a small kitchenette/dining area used by residents from respective corridors. Upstairs an open balcony provides a space with seating which connects to the corridors in which residents' rooms are located and also with the day centre area. The ground floor accommodates 27 people with dementia or dementia related conditions; some of these may also have physical frailty but not all (F2). The upper floor, which can be accessed by lift, accommodates 29 older people defined as 'frail elderly', that is people with physical frailty rather than cognitive impairment. Although the atrium area is attractive to the eye, FOLD managers suggested that because it is accessed directly through the front door, residents' privacy is compromised (F2, F3).

Communal areas include a 'library' with a small collection of books as well as a computer and pool table. There is a small bar which accommodates about 20 people which is opened on special occasions but also used as the smoking room for residents living downstairs. There is also a ground floor bath and assisted shower, a shop and a music room as well as a laundry and kitchen where all of residents' meals are prepared.

Accommodation for two day centres was included in the plans for Cherryfields. Day centre accommodation on each floor includes a large day room/dining area, disabled toilets and shower, a smaller activity room/kitchen and an office. At the time of the fieldwork, the day centre on the ground floor was not in use however the day centre area on the first floor was being used 2 days/week by the Alzheimers Society of Ireland to provide day care for people with dementia living in the community. Since then, ASI day care services have been expanded and moved downstairs and a nurse managed HSE day care centre for older people in the community occupies the upstairs space (F3).

Three two bedroom bungalows were built on the periphery of the main building and the intention was to use them for couples where one person had dementia, but those plans were not realised because of a failure to identify suitable applicants from either the local authority or the NAHB (F2). The bungalows are now allocated to couples or individuals who meet local authority eligibility criteria for Council housing and they operate independently of Cherryfields (F2).

The total staff complement includes kitchen staff, laundry staff, domestic staff and care staff. The ratio of care staff to residents is one staff to 8/10 residents upstairs and one staff to five residents downstairs. All care staff are trained in dementia care and move between the ground floor and first floor. Care staff have training up to Fetac Level 5 and almost all care staff including the manager have had previous experience working in a nursing home. Care staff operate a key worker system and their role includes monitoring and supervision, personal care, and activities with an emphasis on promoting health (F5).

An HSE Primary Care Centre completed after Cherryfields opened physically adjoins Cherryfields, although access to it is separate. Primary Care Services accommodated in the Centre include the Out-of-Hours GP service, Community Nursing, Occupational Therapy, Speech and Language, Nutrition, Physiotherapy and Community Welfare Services. Residents of Cherryfields access community services in the Health Centre in the same way as people living in their own homes although Community Nursing is accessed from another health centre. Health centre staff also provide support to Cherryfields staff in the form of advice and training (F3, F5).

Connolly Hospital is the nearest acute hospital to Cherryfields. Apart from providing A&E services and physician services (including Geriatrician services) on an out-patient and in-patient basis, the

Geriatrician Outreach Team work closely with staff to assess the needs of applicants for places in Cherryfields and to monitor the health needs of residents on a regular basis, including conducting on-site assessments when necessary (F2, F3, F5, HSE6, HSE7). Psychiatry of Old Age services both refer patients for admission and also provide an on-going service to residents with mental health problems (F2, F3, F5, HSE11).

The service model as described in the Service Level Agreement between FOLD and the HSE aims '...to deliver a model of individualised care and support which is responsive to the full range of complex needs of the resident and based on individual assessment of need that is reviewed regularly' (NAHB 2006). The main difference between the services delivered to residents with dementia and so-called 'frail elderly' is the level of supervision that the former group receive (as evidenced by higher staff ratios on the ground floor) and the level of direction with respect to activities. The residents upstairs take a greater role in dictating their own daily routines and activities (F2, F3, F5).

Residents of Cherryfields receive 'room and board', social care, personal care, health monitoring, assistance with medications as required, and may also avail of activities organised by staff which include; music therapy and arts and crafts (F2). Outings to the local pub or to concerts or shows are scheduled periodically as are visits from local schools and voluntary groups. Age Action facilitate monthly Advocacy meetings which are attended by approximately 20 people; the minutes are transcribed and given to the Manager (F5).

Heating and electricity costs as well as laundry and cleaning are included in weekly charges. Residents typically pay rent of 108 euros/week and for the majority of residents, most if not all of the social care costs are paid by the Health Service Executive (HSE10). Care costs were €875 /week at the time of the fieldwork. Residents with income and assets above the eligibility for social housing threshold, including those who own(ed) homes, pay full care costs (HSE10).

Referrals to the FOLD schemes come mainly from the local authority, HSE community services, and the hospitals but also include a number of self-referrals (F2, F3, F5). Applicants for admission to the FOLD schemes must demonstrate both a need for housing and a need for social care and support (F3). An Allocations Committee which includes HSE, FOLD and local authority representatives considers all applications (HSE 10, F2, F3). In general, applicants must be on the local authority housing list or be eligible for same although allowance is made for the admission of a small percentage of 'private' applicants<sup>23</sup> and a medical assessment carried out by a GP or a Consultant physician is required. People between the ages of 55 and 65 are eligible for admission

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<sup>23</sup> As stipulated by the DOE social housing regulations.

in cases where they can pay the full cost of accommodation and care themselves or where costs can be met by the HSE (FOLD 2011).

Residents sign a 'license to occupy' prior to admission with conditions that restricts their right to permanent residency in certain circumstances (F1). These conditions include; knowingly causing a nuisance to other residence and knowingly endangering the safety of the home or well-being of other residents. (FOLD 2011).

Families are expected to continue to be involved with residents after admission and most do so although the level of involvement varies according to FOLD managers (F5). Residents are expected to supply their own toiletries which are usually purchased by family members who also may assist in purchasing clothing and other personal items. Family visits are encouraged and there are few limits imposed in terms of formal visiting time restrictions (F5). Some residents are able to go to the local post office, shops and pub themselves but most do so accompanied by family members or FOLD staff. There are regular outings and local school children are invited in for special events

### **3. *Anam Cara***

Anam Cara was planned at the same time as Cherryfields, using roughly the same design principles; it was the second of two projects managed by the same FOLD senior manager and it opened in 2007 (F1). Staffing, services and activities in the two facilities are much the same in both units as is the organisation and allocation of services. As such, it is mainly the differences between Anam Cara and Cherryfields that are detailed in this section and information is derived from site visits, available documentation and interviews with FOLD and HSE managers.

Anam Cara consists of a two story purpose built brick building with accommodation for 55 residents which like Cherryfields, was built on land owned by the health board. But unlike Cherryfields, there are two health board nursing care facilities for older people on the same site which is situated in a well- established residential neighbourhood in Glasnevin in North Central Dublin. Anam Cara is also adjacent to a Dublin City Council sheltered housing scheme scheduled for re-development by FOLD and Dublin City Council (LA3); the aspiration is to develop independent living units on the site but plans are currently on hold (F4, LA3).

The Anam Cara site is smaller than Cherryfields and this dictated slight deviations in the layout of the building (F2). The entrance is through a reception area (with offices) separate from the atrium which functions as a sitting area for residents. This affords residents more privacy than in Cherryfields where the main entrance opens directly into the atrium area (F2). Anam Cara is physically attached to the more modern of the two health board (now HSE) community nursing

units on the site and staff can move between units using a common corridor on the first floor. Residents' rooms are situated along two corridors that stretch out from the atrium area. Anam Cara was built with two day centre areas, one upstairs and one on the ground floor which like Cherryfields were not being used to full capacity at the time the fieldwork was carried out in 2011. The upstairs day centre was being used by the HSE to provide a nurse managed community day care facility but the downstairs day centre was vacant (F3, HSE4). More recently, the ASI have been using the downstairs facilities to provide day care services for older people with dementia living in the community (F3).

There is no health centre on the campus that Anam Cara shares, however offices for the Community Intervention Team, some of the Primary Care Team and the Community Geriatrician adjoin Anam Cara. Services can be accessed by Anam Cara residents by appointment or sometimes on short notice in an emergency (F3). Public Health Nurses visit regularly to treat residents and also give advice and support to staff: they work under the direction of the same Director of Public Health Nursing who manages the community nursing services available to residents in Cherryfields.

Unlike Cherryfields, meals are prepared in the main kitchen of the adjacent community nursing unit; the kitchen in Anam Cara is only used to plate the food cooked next door. Anam Cara in turn do the laundry for both units and a beautician service is shared between them. The development of 'shared services' between the two facilities was undertaken to minimise service costs and maximise efficiency and these arrangements are working well, according to stakeholders (F2, F3, HSE1, HSE4, HSE13). There is some movement of residents between the two units although the numbers are very small (HSE4, F3). The Director of Nursing in the community nursing unit was a member of the Steering Group during the planning and building stages of Anam Cara's development and has given advice and support to FOLD staff over the years but has no direct role in the running of Anam Cara (F2, F3, HSE4).

A group including a FOLD manager, HSE managers and a local authority representative make decisions about admissions to Anam Cara and the criteria for admission are the same as for Cherryfields (FOLD Policy Handbook undated). At the time of the fieldwork, the financial assessment carried out by the HSE to determine how much residents must pay for care and support services in Anam Cara was based on the nursing home subvention assessment rather than the Home Care Package Guidelines used in Cherryfields; charges to some residents were thus typically higher than the maximum €108 paid by residents eligible for local authority housing in Cherryfields (See Chapter 6 for details.)

Anam Cara residents go to the local post office to collect their pension if they are able and also to local shops and a nearby pub. More dependent residents are brought to the pub on occasion. Residents from Anam participate in activities organised by the adjacent nursing unit and vice versa. A Neighbours Day organised for the first time in 2009 was poorly attended but there were plans to hold another (F3).

#### **4. Mount Bolus Case**

The Mount Bolus High Support Unit for older people (referred to herein as Mount Bolus) is situated in the village of Mount Bolus which is 15 kilometres from Tullamore, the nearest big town. The village contains a church, pubs, a convenience store which also houses a post office. It is located a short distance off the main road in a small residential area that includes a sheltered housing scheme, social housing for families as well as private houses. The surrounding area is rural and sparsely populated.

Mount Bolus was built as the third phase of a social housing programme developed by the Mid-Offaly Housing Association with the support of the Congregation of the Sisters of Mercy (Sisters of Mercy website). The programme began with the building of a small sheltered housing scheme consisting of ten houses and a small resource centre in the early 1990's (Offaly Express website). The second phase was undertaken in 1999/2000 in collaboration with Respond Housing Association who provided architectural services and advice at the building stage (MB4). Phase 2 included the building of 12 social housing units for couples with young children and a larger resource centre that housed a kitchen for the preparation of meals-on-wheels, an oratory and a communal area for meetings and activities (MB1). The health board provided grants for outfitting the kitchen and also paid the salaries of the home helps employed to deliver services to residents of the sheltered housing scheme (MB1).

In 2002, discussion began about the development of a high support unit for older people who were no longer able to live totally independently but not so dependent as to need nursing home care, and the target group included older people with cognitive deficits (MB3, MB4). The unit was to be located on a piece of land owned by the County Council very near the existing sheltered housing scheme. A nominal sum of €1000 was charged to the housing association for the transfer of the property (MB4). Respond again provided architectural services at the initial planning stages but the decision was then made by the housing association to engage a local architect to complete the plans.

The High Support Unit opened in 2009 and consists of a modern two storey structure built to a high standard and situated on a slight incline surrounded by lawns. It was built to provide social care and support to older people including those living abroad who wished to return to County

Offaly. It was anticipated that people in the earlier stages of dementia would be among the frail older people accommodated in Mount Bolus (MB4). There are 30 single bedrooms with en suite bathroom facilities. Entrance is through a large reception area and facilities include a lounge area for residents and visitors, kitchen, dining area, a library, activities room, a treatment room for chiropody and other services, staff offices and a chapel. GP, nursing and therapy services were to be accessed for residents as needed in the same way that they are accessed by people living in the community (MB4). When the unit opened, staff included a manager (from a business background) and a small number of care assistants and volunteers from the community including housing association members (MB3, MB4).

Admission was limited to older people who were eligible for the county council housing list and also eligible for rent allowance (MB4)<sup>24</sup>. Residents were charged approximately €220/week to cover accommodation, the cost of meals, laundry and non-nursing supervision. The expectation was that 'sundry expenses' would be covered by relatives and general fundraising and that rent allowance would offset total service costs estimated to be around €340/week. The families of residents would also be expected to work in partnership with the housing association to support their relatives.

The housing association assumed that referrals would be forthcoming from the community nurses, the local authority and the hospitals; they also hoped that the new unit would attract the interest of older people born in the area who were living abroad and wished to return home (MB1, MB4). But in the event, only six residents were admitted to Mount Bolus High Support Unit after it opened in May 2009. One of these residents had been living alone in Dublin and was in the early stages of dementia, and there were fears about her safety: she moved to Mount Bolus because of family connections in the area. Others came from the midlands. They were described as a 'mixed bunch' who were physically well when they were admitted, although two people became ill shortly after admission, including the resident who moved from Dublin whose health deteriorated significantly within a short time (MB4).

The High Support Unit closed only months after it opened in 2009. The resident from Dublin moved into a nursing home and the other residents were supported to either return to their families or find alternative accommodation. The Unit remained vacant for almost two years until the Acquired Brain Injury organisation (ABI) signed a lease to use it as their Midlands base of operations in 2011.

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<sup>24</sup> The information about charges and service costs and admissions was sent by email by a Mount Bolus participant following consultation with housing association committee members.

## **5. St. Bricin's Park**

The St. Bricin's Park HWC project (St. Bricin's) was part of Dublin City Council's Strategy for Accommodation for Elderly Persons in Dublin City' which had two objectives, the 'Redevelopment of existing DCC complexes replacing bed-sits with one/two bedroom apartments [and] Maintaining a strong focus on enhancing support and care services' (Dublin City Council undated). In this context, in 2004 Dublin City Council requested Circle Voluntary Housing Association to undertake the redevelopment of St. Bricin's. Plans included the demolition of an existing Dublin City Council sheltered housing scheme for older people built in the 1970's on 2 acres of land in the North West Inner City; the old scheme consisted of 68 bedsit units laid out in three blocks. One of the units was used to deliver meals on wheels and other services to residents and older people in the area (Letter from DCC to DEHLG 3 Feb 2009).

The original redevelopment plan was to design a mixed tenure scheme of affordable, general needs and sheltered housing for older people (SB1). The plans changed subsequently and a new proposal was put forward for a scheme exclusively for older people that would include 18 two bed units and 64 one bed units. Six of the two bed units were to be allocated to Cheshire Ireland for persons with disabilities, and a 12 bed Respite Unit for people with Alzheimer's was to be included to be managed and staffed by the Alzheimer Society of Ireland (ASI). The Respite Unit would 'feature a secure sheltered environment with its own garden area, individual bedrooms and a shared kitchen, dining and living room' (Irish Times 5 June 2007:4). A Day Care Centre providing meals, assisted bathing, medical treatment, hairdressing and other services was central to the plans and was to be managed by Circle Housing Association. Following further consultation, the plans changed again to include only 6 two bed units, and the idea of involving Cheshire Homes appears to have been dropped from the plans although the Alzheimer's unit remained (Dublin City Council correspondence 3 Feb 2009). Planning Permission was granted for the revised proposal in 2008 (SB1).

Tenants targeted for the new scheme included current tenants of the old sheltered housing scheme and other older people who were either on or eligible to be on the Dublin City Council housing list. These tenants would be expected to pay rent of about €60/week depending on their circumstances and day care and service costs would be extra (Irish Times 5 Dec 2007). Those tenants who were eligible were expected to receive rent allowance from the Community Welfare Officer to offset their housing costs (SB1). There was no data available to indicate how eligibility for the Alzheimer's unit would be determined or about charges for services in the unit.

At the beginning of January 2009 it became apparent that the HSE would not proceed with plans to contribute to the capital and revenue cost of associated with the proposed Day Care Centre.



(Dublin City Council Notes undated). In May 2009, the Alzheimer Society of Ireland formally withdrew from the St. Bricin's project (Dublin City Council notes). A revised proposal was submitted by Circle Voluntary Housing Association to DOEHLG in 2010 for the development of 76 sheltered housing units for older people, to include 16 two bed units and 60 one bed units but in April 2013 they withdrew from the project. Dublin City Council then made the decision to 'examine the options to refurbish/remediate the complex' (Dublin City Council 9 April 2013). There are some tenants still in residence in St. Bricin's Park but the number of vacant units reflects the difficulty in allocating what are considered to be sub-standard housing units<sup>25</sup>.

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<sup>25</sup> Telephone conversation with Dublin City Council housing officer 24 June 2013

## APPENDIX 2: Draft Report<sup>26</sup> of HSE Sheltered Housing Working Group

### ADVANCING THE NATIONAL AGENDA: Community Services

#### Sheltered Housing Working Group: *Draft Report*

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1. Introduction
2. Summary of Recommendations
3. HSE Funding for Sheltered Housing
4. Issues for Discussion at higher level
5. Appendices
  - a. Terms of Reference
  - b. Working Group Membership
  - c. Application Form for HSE Funding for Sheltered Housing
  - d. Draft Template Three Year Service Level Agreement between HSE and Sheltered Housing Service Provider
  - e. Low Support Sheltered Housing Scheme – Kilmihil Community Association Ltd, Co Clare
  - f. Medium to higher support sheltered Housing Scheme – The Charleville Sheltered Housing Services Example
  - g. Medium to higher support sheltered housing scheme – The Sue Ryder Foundation Example
  - h. High Support sheltered housing scheme – O’Connell Court, Cork
  - i. Special Needs Sheltered Housing – Funding for High Support Sheltered Housing (for people with identified special needs) The FOLD Example
  - j. Case Example – The Nestling Project
  - k. Service development involving partnership between the HSE, a local authority, sheltered housing provider, and a voluntary day care provider.

#### 1. Introduction

The Sub-Committee were asked, in the first instance, to develop criteria for the allocation of HSE dedicated funding for sheltered housing. Considerable work and consultation was involved in producing the following documents;

- Summary of Recommendations of the Sub-Committee
- HSE Funding for sheltered housing: position paper

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<sup>26</sup> The format of this report was revised because of space limitations.

- Appendix C: Application Form for HSE funding for sheltered housing
- Appendix D: Service Level Agreement template
- Appendices E – K: models of supported sheltered housing practice

The Summary of Recommendations highlights recommendations that came out of the main document, HSE Funding for Sheltered Housing: Position paper and so there is some overlap between the two documents.

The Appendices give examples of a range of ‘best practice’ supported sheltered housing developments to illustrate; a) the commitment of voluntary housing associations to providing services required by their older tenants in spite of the limited availability of revenue funding; examples where HSE funding has enabled other voluntary housing associations to develop required services at a higher level; and examples of innovative, interagency supported sheltered housing developments involving the HSE which illustrate the potential for certain areas of future development.

## 1. Summary of Recommendations

1. **The HSE budget for sheltered housing should be raised significantly** in order to meet at least the minimum costs of social care provision in sheltered housing schemes, as estimated by the ICSH in 2004 (p.4 of main report for details);

- €50/resident/week represents the estimated cost of social care in a low support social housing scheme for older people.
- €100/week/resident is the estimated cost of social care in a higher support social housing scheme for older people.

**An increase to €5m is recommended in the short-term**, although significantly more will be required in future to support sheltered housing providers to help achieve the national policy objective of keeping older people in their own communities as their dependency levels increase in old age.

Funding to individual sheltered housing providers should reflect current costs of care provision as outline in page 10 of main report.

2. The HSE should acknowledge the **important role of sheltered housing in promoting older people’s health and welfare, in meeting needs for social care and security, and in helping older people to remain living in their own communities** as their level of dependency increases. Sheltered housing is an acceptable alternative to full-time nursing home care for many older people in Ireland.

3. **Residents of sheltered housing schemes should be eligible for any community services that are available to the general population** based on an assessment of their need, including; home help services, meals services, home care grants, home care packages, domiciliary rehabilitation services, respite services, day care services and other available community services.

4. **The HSE should pro-actively support sheltered housing initiatives that provide services that complement existing HSE service provision for older people in the community.**

5. The HSE sheltered housing budget should be utilised to cover the costs associated with the development and delivery of social care services which promote health and welfare of older people and which support vulnerable older people to remain living in the community. (See list on page 2-3)

6. **Voluntary social housing associations currently providing social care services to older people should be targeted for HSE funding in the first instance.** Existing LHO budgets for community support services (home help, home care packages, meals, day care etc.) should be employed to support both voluntary sheltered housing schemes and local authority sheltered housing schemes. In the longer term, an integrated budget should be developed to support service developments in sheltered housing schemes across the public, voluntary and private sectors.

7. **Sheltered housing providers should be eligible for HSE funding subject to the completion of an Application Form (Appendix C)** and decisions should be made with reference to stated criteria for prioritisation of funding (p.6).

8. **Service Level Agreements of 3 years' duration, subject to review every 12 months, should govern the relationship between the HSE and sheltered housing providers.** SLA's should include details that ensure appropriate accountability for expenditure of public funds. (Details on p.7, sample SLA in Appendix D)

9. **An HSE officer in each Local Health Office should be named to oversee the administration of the funding scheme for sheltered housing and the monitoring and evaluation of service developments. (p.8)**

10. **The HSE should proactively seek out opportunities to develop new social care services in existing sheltered housing schemes in order to meet the needs of older residents as they age.**

11. **The HSE should also explore new models for the development of new sheltered housing services for older people with special needs** (including people with dementia) involving partnerships with the local authorities and voluntary sheltered housing associations. (See F.O.L.D. example, Appendix I)

### **3. HSE Funding for Sheltered Housing**

*It is the understanding of Sub-Committee members from the Irish Council for Social Housing and the Department of Environment, Heritage and Local Government that the dedicated funding allocated to the HSE for sheltered housing 2005-2007 was granted in recognition of the specific difficulties that voluntary housing associations encounter in accessing revenue funding for the provision of social care services to their tenants. As such, they believe that the HSE budget should be allocated exclusively to existing voluntary housing associations. Other Sub-Committee members, including members from the local authorities and the HSE, identified a need to support sheltered housing service initiatives across sectors, including local authorities, in the interests of establishing equity of access to social care services for sheltered housing residents, regardless of the provider. Obviously, overall funding for sheltered housing would need to be raised significantly if all sectors are to be included. There is brief reference to this issue later in this paper. It is against this background that the following recommendations were made.*

## 1. Funding Rationale: Promotion of 'Ageing in Place'

The Promotion of 'ageing in place' has become central to public policy statements (for example, The Years Ahead 1988) which recognise the need to facilitate older people's preference to remain living independently for as long as possible in their own homes and communities. (Garavan et al 2001, Hanlon 2005, ESRI 2006) While most Irish older people do remain living in their own homes as they age, their housing circumstances may be far from adequate and may seriously undermine their mental and physical health as well as their overall quality of life.

While some older people require repairs and adaptations to existing accommodation in order to continue living at home in comfort and safety, others need or want alternative accommodation as they grow older. (Layte et al 1999, Garavan et al 2001). Sheltered housing is a positive alternative for the latter group which not only offers older people an appropriate physical environment but also offers company, social activities, social care services, and security that may not be available to them in the family home. For some older people, sheltered housing will be the next best alternative to remaining in the family home. In rural areas, where older people often make up a greater proportion of the population, lack of access to services (including Gardai, GPs, shops, post office, laundry, hairdressing and others), geographic isolation and lack of transport combine to pose particular challenges to those older people wishing to remain living in their local communities. Sheltered housing schemes can take on a critical role in rural areas and can help to make up for the lack of availability of alternative services for people as they age.

Sheltered housing represents a social model of care which is preferable to current the dominant Irish nursing home care model in that it offers independence, privacy and dignity to older people who may need help with Activities of Daily Living as they age but who do not require continuous nursing/medical services. Some sheltered housing schemes have demonstrated their ability to support vulnerable older people who might otherwise have had to move into full-time residential care in a nursing home or hospital. **The HSE should pro-actively support sheltered housing and consider it one option in care continuum for older people who choose to avail of it.**

## 2. Principles

This Sub-Committee recommends that the following principles form the basis of future relationships between the HSE and sheltered housing providers;

a) **Sheltered housing units are individuals' homes.** As such, sheltered housing residents should have the same rights as any other citizens who live in their own homes.

b) **Residents of sheltered housing schemes should be eligible for any community services that are available to the general population in the community,** based on an assessment of their need, including home help services, meals services, home care grants, home care packages, case management, domiciliary rehabilitation, respite services, day care services and other available community services.

c) **The HSE should be particularly supportive of sheltered housing initiatives that provide social services which complement existing HSE service provision** to meet local needs.

### 3. Revenue Costs

Voluntary housing associations receive capital funding from the Department of the Environment, Heritage and Local Government for building sheltered housing schemes but this funding cannot be used to cover revenue costs. Without access to revenue funding, voluntary housing associations find it difficult/impossible to develop needed social support services for residents. This, in some cases, leads to inappropriate placement of residents in long-term nursing home or hospital care. **HSE dedicated funding for sheltered housing (2005-2007) should be allocated to offset a proportion of revenue costs associated with social support service provision in voluntary sheltered housing schemes, in the first instance.**

### 4. Capital Costs

In some cases, HSE capital funding will be required in order to cover the start-up costs of new service developments **(in the voluntary or statutory sectors) particularly in the case of sheltered housing schemes for older people with special needs. This funding should be negotiated on the same basis as revenue funding, i.e. subject to application and governed by a Service Level Agreement between the HSE and the housing provider.**

### 5. Funding Priorities

**HSE funding earmarked for sheltered housing should be used to develop and provide social support services aimed at promoting health and welfare and at supporting vulnerable older people to remain living in the community.**

These services may include provision of;

- domestic home care and personal care services
- meals services
- security/alarm systems
- social day care services
- chiropody services
- physiotherapy and other rehabilitation services
- laundry services
- information and advice services,
- recreational activities
- transport

Service initiatives that promote service integration at local level or that involve partnerships with other agencies/providers should receive priority consideration.

Services may be provided directly by the sheltered housing provider or may be purchased by them, and services may be offered to residents as well as to people living in the community. Funding may be used to pay staff salaries where services are provided directly by the housing provider.

## 6. Eligibility for HSE funding

### a) Proposals for existing services

- *Applicants must have approved status as a housing association.*
- Applicants for funding may apply by filling out a standardised HSE application form. **(See Application Form, Appendix C)**
- Applicants must include the following information in their applications for funding; location of housing project, age profile of tenants/target group, evidence of need for services, description of proposed services and breakdown of costs, service capacity and timescale for service development, etc. For high support services, details about admissions and discharge policies, eligibility criteria, assessment of need and other information may also be requested.
- Proposals must be consistent with HSE policy objectives.
- Proposed services must meet expected standards.

### b) Proposals for funding of new sheltered housing developments.

- Outline applications should be submitted prior to new service developments.
- Negotiations should take place between HSE and housing provider at the early planning stage.
- The level of detail required for new developments where substantial funding is involved will be greater than what is requested in Appendix C.
- The HSE should give written commitment to allocate funding prior to development, subject to a service level agreement of respective responsibilities.

## 7. Criteria for prioritisation of funding

- Current availability of same services to residents/older people in the locale.
- Projected impact of the service development –expected positive outcomes for older people.
- Involvement of the residents/community in service planning.
- How well services will be integrated with existing community and residential care services?
- Evidence of value for money. (How do costs of proposed services compare with costs of similar services provided by HSE or other providers?)

## 8. Funding Process

- a) Written application must be filled out and submitted to a designated HSE officer in LHO. **(See Appendix C for Application template.)**
- b) Negotiations take place between HSE and sheltered housing association around details of the proposal. This may include consultation with LHO health professionals.
- c) HSE approve Application with or without modifications to original proposal.
- d) Service Level Agreement is developed by housing association and HSE officer. **(See Appendix D for SLA template.)**
- e) HSE and housing association sign Service Level Agreement.
- f) Service Level Agreement reviewed at 12 month intervals, at minimum.

## 9. Accountability for HSE funds allocated: Service Level Agreements

Contracts/service level agreements between HSE and sheltered housing providers of 3 years' duration should be in place and should be reviewed every 12 months. (See Appendix D)

These should include details re;

- Quantum of services to be provided.
- Assessment of individual need for services.
- Staffing numbers and qualifications (as appropriate).
- Criteria for access to services.
- Defined minimum service standards (as appropriate).
- Details outlining what documentation/records/reports the HSE requires from the provider and at what intervals.
- HSE responsibilities related to payment of funds.
- Legal responsibilities of sheltered housing provider

## 10. Designated HSE Officer

**An officer should be named in each Local Health Office to oversee the administration of the funding scheme for sheltered housing.** This officer would also have a role in; liaising with housing authorities and housing associations in the planning of new sheltered housing schemes and related services; taking responsibility for processing funding applications and for administering funds; liaising with senior HSE management about issues relevant to the scheme; evaluating service developments, and working with both local authorities and the Irish Council for Social Housing to promote best practice and innovative development.

## 11. Present funding requirements and recommendations for the future.

### *Current funding levels*

There are a total of 20,000 sheltered housing units for older people in Ireland. Of these, 13,000 units are provided by local authorities and 7000 units are provided by voluntary housing organisations. (NESF 2005) It is difficult calculate the average amount of HSE funding that sheltered housing scheme providers are receiving for providing social care services to residents, however we know that the range of current payments goes from €0 per year to over €100,000 per year. (The level of HSE funding being provided in the FOLD example in Appendix I is unique and thus is not included here.) **Research by the ICSH in 2004 showed that 48 out of 79 (or 60% of) voluntary housing associations in the study were receiving no revenue funding at all to provide social care services for older residents.**

HSE new development funding for sheltered housing for older people will reach €928,000 annually by 2006 and will go up to €1.5m in 2007. Although a welcome development, if this funding were distributed evenly between all residents of voluntary housing schemes, the allocation would be **less than €130/year per unit.**

The Irish Council for Social Housing calculated the approximate costs of providing social care services in sheltered housing schemes in 2004, as below, and it is obvious that the current budget



for sheltered housing will have to be increased to meet even the minimum costs of social care services

**Current range of Social Care Costs (ICSH 2004)**

ICSH estimate that the funding required by social housing organisations in order to provide support services to older residents will fall within the following range;

<b>Type of scheme</b>	<b>Type of services provided</b>	<b>Cost</b>
Group Schemes* (15-20 units)	Visiting support services: <ul style="list-style-type: none"> <li>• Day care centre</li> <li>• Social events</li> <li>• Laundry</li> <li>• Meals on wheels</li> </ul>	€50 per week per unit <b>€2,600 per unit/year</b>  <b>Total cost: €52,000/year/ 20 unit scheme.</b>

<b>Type of scheme</b>	<b>Type of services provided</b>	<b>Cost</b>
Higher sheltered schemes* (20-25 units)	support housing On-site services include: <ul style="list-style-type: none"> <li>• Care support staff</li> <li>• Personal care assistance</li> <li>• Warden/manager</li> <li>• Meals</li> <li>• On call services</li> <li>• Chiropody</li> </ul>	€100 per week per unit <b>€5,200 per unit/year</b>  <b>Total cost: €104,000/ year for a 20 unit scheme</b>

**\*DOE definitions of categories of sheltered housing**

**Comparative Costs**

The cost of providing services to residents of local authority sheltered housing schemes would be similar. These costs are relatively low compared to the cost of direct HSE provision or the cost of other service alternatives, including individual enhanced home care packages and especially private nursing home care costs.

ICSH estimated cost of 'higher support' service provision in a voluntary sheltered housing scheme = € 5,200/year per person (unit)

Cost of a maximum enhanced 'home care package' in the Dublin region

@€525/week = €27,300/year per person

Average cost of a contract bed in a private nursing home in HSE Dublin Mid-Leinster

€40,000/year per person

The marginal costs of supporting sheltered housing providers to develop or increase provision of social care services to residents as their dependency levels increase are much lower than the alternative options of full-time institutional care. There are also advantages to voluntary service provision over direct HSE service provision, in the context of staff ceilings and other constraints. Added benefits of not-for-profit service provision include the organisational ethos and commitment of these organisations to the community in which services are situated.

### **Recommendations for Future Funding**

1. The HSE budget for sheltered housing must be raised significantly in order to meet even the minimum costs of social care provision for residents as they age. An increase in the national budget to €5m would provide lower support services (as described above) to 1923 older people per year, and 'higher support' services to only 960 older people per year.
2. HSE funding levels to each scheme should be directly correlated to the cost of social care service provision to residents whose needs have been assessed.
  - A minimum of €50/week per resident should be provided to sheltered housing schemes which offer low support social services (as outlined).
  - Funding up to a much higher level will be required to meet the social care needs of residents with special needs. (See Appendix I F.O.L.D. example)
3. The current dedicated HSE budget for sheltered housing should, in the first instance, be used to support voluntary housing associations to develop and deliver social care services for older residents.
4. Other HSE community support service budgets (home help, home care packages, meals, day care) should also be used to support new social care service developments for older residents in both voluntary sheltered housing schemes **and** local authority sheltered housing schemes.
5. An integrated budget which includes funding for provision of services to residents of both voluntary and local authority sheltered housing schemes should be established as a priority.
6. Proactive effort should be made by the HSE to determine whether, with additional funding, social housing providers could give support to residents that would diminish their need to transfer into full-time residential care in a public or private nursing home.
7. Funding should be allocated for new sheltered housing developments that target older people with high dependency needs, including dementia, as an alternative to full time nursing home care, subject to the conditions above in text.

#### ***4. Issues for Discussion at higher level (to be finalized at last meeting of WG on 5<sup>th</sup> September)***

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**A. Terms of Reference**

- To examine current policies/procedures and service initiatives
- To define 'best practice models'.
- To formulate a national position in relation to the role of sheltered housing in the continuum of care.
- To address issues relating to the provision of community supports/services in sheltered housing facilities.
- To formulate recommendations regarding appropriate models of care provision.

**B. Working Group Membership (Names removed)**

Membership	Title
Janet Convery (Chair)	Director of Services for Older People, Dublin Mid Leinster
	O'Connell Court Housing Association Cork
	Sue Ryder Foundation Centre for Housing Research
	TD
	FOLD
	Older Persons Unit, Dublin City Council
	Representing Voluntary Sheltered Housing Scheme residents
	Irish Council for Social Housing Kilmaley Day Centre, Co Clare HSE Western Area Department of the Environment, Heritage and Local Government Sheltered Housing Scheme Resident
	Development Officer, HSE Southern Area "Nestling Project" Dundalk Institute of Technology
	Research Officer, NCAOP Services for Older Person, Local Health Office, Dublin North Central



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

**SHELTERED HOUSING**

*Application Form*

Application for funding towards revenue costs associated with provision of on-site care and support services for older people in sheltered housing schemes. This Application should include the following information:

**1. Name of Sheltered Housing Provider:**

\_\_\_\_\_

**Address:**

**Tax**

**Reference/Charitable**

**Status**

**Number:**

\_\_\_\_\_

**Year Organisation was established:**

\_\_\_\_\_

**2. Contact Person for Correspondence:**

**Name:**

\_\_\_\_\_

**Position**

\_\_\_\_\_

**Address:**

\_\_\_\_\_

**Telephone No:**

\_\_\_\_\_

**Fax No:**

\_\_\_\_\_

**E-mail Address:**

\_\_\_\_\_

**3. Location of housing project**

**(a) HSE Area:**

\_\_\_\_\_

**(b) Local Authority Area:**

\_\_\_\_\_

4. **Number of housing units?**

\_\_\_\_\_

5. **Age and Gender of residents:**

<b>AGE</b>	<b>MALE</b>	<b>FEMALE</b>	<b>TOTAL</b>
Under 65	_____	_____	_____
65 – 74	_____	_____	_____
75 – 84	_____	_____	_____
85+	_____	_____	_____
<b>TOTAL</b>	_____	_____	_____

6. **Why is funding being requested? Is it for new or existing services?**

7. **Proposed date of commencement of new services:**

8. **Provide a description of in-house services already provided to tenants by the provider** (e.g. warden, meals, day care, activities, laundry, recreational activities, transport, nursing, domestic care, personal care, rehabilitation, etc)

9. **Provide a description of local community services already available to residents from HSE or from Voluntary Groups** (e.g. PHN Services, Home Help, Personal Care, Rehabilitation, Meals on Wheels, Home Care Grants, Home Care Packages, Respite, other)

10. **Total estimated costs of proposed / existing care and support services.** (Attach a breakdown of start up and annual costs such as staffing, services, overheads, etc).

11. **Estimated cost of services per person** (unit costs)

12. **Total revenue funding sought from HSE:**

**Total revenue costs for 12 month period**

13. **Funding received, if any, from other sources for service development including Section 39 HSE funding** (Please state amount of funding and funding source)

14. **Are there any other details relevant to this Application? If so, please provide below;**

15. **Signatures**

**D: Service Level Agreement Template**



**Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive**

**SHELTERED HOUSING**

**Three Year Service Level Agreement**

Beginning \_\_\_\_\_ Day/month/year

Ending \_\_\_\_\_ Day/month/year

*(3 Year Service Level Agreement between HSE and Sheltered Housing Service Provider - to be reviewed 12 monthly)*

*\*Level of detail required will vary depending on amount of HSE funding involved.*

**1. PROJECT DETAILS**

**Name of Project:** \_\_\_\_\_

**Location of Project:** \_\_\_\_\_

**Type of Housing Scheme:** \_\_\_\_\_

(e.g. low support group housing scheme for the elderly, high support sheltered housing scheme for the elderly, dedicated service for people with special needs etc)

**2. ORGANISATIONAL STRUCTURE OF HOUSING PROVIDER (AS APPROPRIATE)**

**Details of management structure:**

(Board of Management responsible for service, support staff report directly to a management committee).

**Staff and Volunteer Structure:**

### 3. CORPORATE REQUIREMENTS

- Compliant with Legislation and Corporate Governance
- Charitable Status    Number: \_\_\_\_\_
- Compliant with Approved Status regulations under the Housing Miscellaneous Provisions Act 2002
- Compliant with Health & Safety Legislation
- Compliance with Rental Regulations – Tenancy Agreements etc
- Insurance coverage
- Tax Status

### 4. RELEVANCE OF PROPOSED SERVICE DEVELOPMENT TO HSE NATIONAL AGENDA

*(e.g. For example, proposed services will support older people to stay longer in their own homes, thus preventing unnecessary and premature placement in a nursing home. Proposed services complement existing HSE community services)*

Provide details

### 5. TARGET GROUPS

(e.g. For what group are services being developed? Any resident who demonstrates need for services? Informal carers? A specific cohort of residents (75+, male residents/female residents, people with physical disability, people with dementia)

Provide details

## **6. HOUSING PROVIDER'S POLICIES - ELIGIBILITY FOR PROPOSED SOCIAL CARE SERVICES**

*(e.g. .How will residents and people in the community, if appropriate, access proposed services? Who can make referrals? What is the process? Are residents expected to pay a charge for services?)*

Provide details:

## **6. SERVICES TO BE PROVIDED WITH HSE FUNDING (INCLUDING QUANTUM OF SERVICE)**

For example;

- Employment of Care Assistant/home help worker
- Employment of warden
- Employment of part time nurse
- Employment of part-time chiropodist/therapist
- Provision of Meals
- Provision of Laundry services
- Employment of Manager
- Development of social activities

Provide details:

Indicate whether staff will be directly employed by Housing Association or will be employed on contract. Will they be full time? If part-time, how many hours of service will they provide?

Provide details:

What is anticipated service capacity (e.g. number of meals/week, number of hour's service, number of service recipients, etc?)

## **8. EXPECTED OUTCOMES FOR RESIDENTS**

What outcomes for residents are anticipated from proposed service developments e.g. improved mobility, improved nutrition, reduced social isolation? Provide details:

What criteria will be used to evaluate service development? Provide details:



**9. STANDARDS**

(HSE, or other, standards which must be met by Housing Provider in the provision of proposed services (e.g. health and safety, professional, confidentiality, training of staff etc.)

Provide details

**10. ADDITIONAL FUNDING**

Provision for additional funding required above Agreement Amount. If HSE funding does not cover all costs, how will they be met?

Provide details

**11. PAYMENT OF FUNDING**

Funding will be forwarded by the HSE to the organisation in advance for each financial period.

Details:	<b>AMOUNT</b>	<b>DATE</b>
	€ _____	_____
	€ _____	_____
	€ _____	_____
	€ _____	_____

Other details regarding payment

**12. RESOLUTION of DIFFICULTIES**

Procedures for the resolution of difficulties with respect of this Agreement. For example, 'The Administrator / Manager will meet with the HSE designated officer within 7 days following the identification of problems by either party.....' etc.

**13. SERVICE LEVEL AGREEMENT REVIEW**

Schedule of reviews for the duration of the Agreement:

1<sup>st</sup> Review: \_\_\_\_\_ 2<sup>nd</sup> Review: \_\_\_\_\_ 3<sup>rd</sup> Review:

Date of next review: \_\_\_\_\_

Who will attend reviews?

Others: Any other protocols? If so, provide details:

### **E: Example of low support sheltered housing scheme: Kilmihil Community Housing Association**

This scheme is a 'low support' sheltered housing scheme, providing 16 two bed- roomed homes for older people who require a level of support in order to remain living in the community. The project is capital funded by the Department of the Environment, Heritage and Local Government but, to date, no revenue funding has been allocated by the HSE to support this development.

The scheme is based on a social care model. Dependency and health status varies with your tenants over 65 years old, six tenants over 70 years old and six tenants over 80 years old. Four of the tenants have actually moved into the scheme from nursing homes. The health of some of the tenants has actually improved since their referral to the scheme.

Services include day care in a communal centre, with kitchen and catering facilities. The project is founded on the principle of respect for the contribution of older people to the community, and service objectives include; improve the quality of life of residents; assist residents as they become more vulnerable; provide an environment where residents can continue to participate as members of the local community. Services are aimed at supporting older people to remain living in their own community and at preventing unnecessary admission to a nursing home.

Existing social care services are funded through contributions and rely heavily on the willingness of volunteers to deliver services. Two applications for funding from the HSE have been refused.

There is demand in the area for day care services to be operated that would be accessed by tenants and older people in the community. The Association have the facilities to provide this service and have costed it as follows:

2 days day care per week x 40 older people	€120,000
	= €3,000 p.a. per person
	= €58 per week per person

This investment would prevent unnecessary admissions to nursing homes or hospitals from both residents in the scheme and in the wider community. As already noted, 4 tenants have come from nursing homes.

Provision of social care services, even at a lower level, requires dedicated revenue funding in order to ensure continuity of services for an ageing population. At modest marginal cost, a new day care service could be developed in Kilmihil which would further benefit tenants of the sheltered housing scheme but also other older people in the community.

## **F: Example of medium to higher support sheltered housing scheme: Charleville**

The sheltered housing scheme in Charleville, County Cork provides accommodation and social care services for 30 older people. This is a vital service for not only residents but also for older people living in the Charleville community.

The scheme, capital funded by the Department of the Environment, Heritage and Local Government, consists of accommodation units grouped around a communal facility which includes dining area, kitchen, facilities for people with disabilities and space for activities.

The residents in the Charleville scheme are mainly frail elderly. Services to residents include; communal meals (which can be delivered to residents' homes when necessary), support with personal care and household chores, assistance with laundry, and, in the event of hospitalisation, preparation of home for discharge. Should a resident require extra care, e.g. post-hospitalisation, there is a group house on-site which offers higher support levels.

The age structure of current residents is as follows:

### **Age category      Number of residents**

65-74 years	14 residents
75-79 years	3 residents
80-89 years	10 residents
90 years +	2 residents

The staffing of the project consists of Care Assistants and a Co-ordinator. There is also a part-time nurse and cook. The support services offered help to maintain residents in their own community, and without these services, 15 of the residents would require admission to full-time Nursing Home Care.

The total cost of running this service for 30 people is in excess of €200,000 per year (or €6,700 per person).

Current HSE funding = €86,000 per year.

The balance of costs (€114,000/year) have to be raised through co-payments from residents, donations and fundraising in the community. This is a considerable burden to be placed on a voluntary housing association.

The amount sought from the HSE for 2006 is €100,000 (€3,350 per resident/year), which still only covers 50% of total annual service costs.

### G: Example of medium to higher support sheltered housing scheme: The Sue Ryder Foundation

The Sue Ryder Foundation in Ireland is a long established voluntary housing association that has provided supported sheltered housing for older people since 1981. Sue Ryder currently manage a total of 219 units of accommodation (see Table below), and within the coming years, they plan to develop more units. The schemes are capital funded by the Department of the Environment, Heritage and Local Government but, to date, Sue Ryder do not receive any significant revenue funding with which to provide social care services to residents.

**Sue Ryder Foundation Housing Schemes**

<b>Location</b>	<b>No. of Units</b>
Ballyroan, Co. Laois	25 Units
Owning, Co. Kilkenny	25 Units
Dalkey, Co. Dublin	54 Units
Holycross, Co. Tipperary	40 Units
Kilminchy, Co. Laois	75 Units

Sue Ryder sheltered housing schemes provide support to tenants to remain living within the community, and the average age of tenants is mid '70s, however in Dalkey, Co Dublin, the average age is higher at over 80 years and in Ballyroan it is 82 years. Dependency levels among tenants vary and the model provides for additional support services to meet care needs as required. Communal areas in Sue Ryder schemes take the form of either a day room as part of the complex or a separately built centre on-site where the tenants gather for meals and social events.

Social care services typically include; the provision of meals, a supervisor on call 24 hours a day, alarm systems, day centre, social activities, laundry, hairdresser, visiting chiropodist and domiciliary nursing service. These services are provided through a combination of care workers and other support staff.

The total annual operating costs at a Sue Ryder sheltered housing scheme ranges from €5734/year per unit (in Kilminchy) to €8532/year per unit in Dalkey.

Rents only cover minimum management costs, utilities costs and the cost of maintaining the physical facilities in each scheme. The costs associated with social care services must be covered from co-payments from tenants (up to €80/week), donations and fundraising.

Recently the HSE has offered funding of €10,000 for services at both projects in Laois and this is welcome, although it only covers a fraction of total annual costs of service provision. The other Sue Ryder schemes receive no HSE funding. Continued provision of services at existing levels is unsustainable without HSE revenue funding.

Higher levels of funding (at levels suggested on page 5-6 of the main document) are required to sustain the current level of service provision and also to further develop services to meet the needs of tenants as they get older.

#### **H: Example of high support sheltered housing scheme: O'Connell Court, Cork**

O'Connell Court is a high support sheltered housing scheme for older people and for homeless adults with mental health problems. Accommodation of 66 units, including 25 units for homeless adults consists mainly of bed-sits together with lounge/dining areas, day care centre, place of worship, gardens, communal kitchen plus a catering kitchen and assisted bathroom x 1.

Support services that are available to tenants include; full /partial board, snacks, hairdressing, chiropody, security, advice & information, personal assistance, cleaning service, laundry, spiritual support, social & recreational programme, supervision of medication for persons with mental health disabilities. A part-time nursing service is also available plus dressings (when applicable). The Public Health Nurse does not currently provide a service in O'Connell Court, however there are other staff on duty 24/7, a weekly GP surgery, pharmacy delivery, paper and shop delivery service, and taxi and carer support to OPD clinics. There is a day care service and HSE staff, including the community mental health nurse and social workers, have access to a visitors' room for consultations with tenants.

O'Connell Court provide services for older persons who are social welfare recipients, and priority is given to those without relatives or family support. None of our tenants are 'private tenants'. We provide 25 units for older homeless adults with mental health issues.

There is a Service Level Agreement with HSE South. Funding is provided under Sec. 39 for home help type services. Up to Dec 2005 core funding was €68,000.00 per year for provision of these services; from 2006 funding has been increased to €135,000.00.

O'Connell Court receive the 'bed allowance' from Cork City Council for the 25 homeless beds and this amounts to €128,000.00 per annum. They also receive an annual grant of €42,500.00 under the Homeless Strategy.

Tenants pay service charges for the services they use, and charges are levied, depending on their means. Tenants retain their Social Welfare entitlements i.e. Free Fuel, ESB and other allowances.

All tenants are assessed bi-annually by the HSE to determine their suitability to remain in sheltered accommodation. HSE take responsibility for placing any tenant they deem no longer suitable. We have technical support from the HSE who assess, on our behalf, any applications received from hospitals.

Because people without family support are catered for, the association ends up providing clothes, paying for items not covered on the GMS, covering taxi fares, providing toiletries, paying life insurance arranging funerals etc.

In 2005 O'Connell Court incurred a loss of €14,750.00

There is a high level of support to tenants in O'Connell Court and costs to the HSE are relatively low, compared to service alternatives including nursing home care.

**I: Example of high Support/Special Needs Sheltered Housing: the F.O.L.D. example.**

A new 27 bed sheltered housing facility was recently developed in Hartstown in a partnership between the Department of Environment, Heritage and Local Authorities, the former Northern Area Health Board, Dublin City Council, and F.O.L.D., a social housing provider from Northern Ireland. The scheme was built on a 'campus' that also accommodates a sheltered housing unit for older people from the general population as well as an HSE Primary Care Centre. The (former) health board gave the land to the local authority as part payment for the capital costs of building the residential care units. The health board committed a further 5% of capital costs. F.O.L.D. undertook to both build the unit and also to provide care services for residents. Revenue funding to F.O.L.D. was guaranteed by the health board at a rate of €687/week per resident. This figure was derived following a budget analysis which calculated the anticipated costs of care for residents with dementia. A Service Level Agreement will govern the relationship between the HSE and F.O.L.D. with respect to this development.

The F.O.L.D. facility was developed on a social care model and aims to maintain residents until the end of their natural lives, i.e. they should not have to move later into another service if their dependency level increases unless in extraordinary circumstances. There are no nurses employed in the dementia unit; Care Managers and Care Assistants provide required day to day social care services and other health and welfare services are accessed for residents as they would be for any older person living in the community. F.O.L.D. have a distinguished record of best practice service provision in Northern Ireland, particularly in the area of social model dementia care.

The HSE revenue investment in the F.O.L.D. facility, although very high by Irish standards, represents value for money compared to the cost of specialist care in a private nursing home.

Cost of care to HSE for one resident of the F.O.L.D. dementia unit = €687/week

Cost of care per resident for one year = €35,724

The comparative cost of care (i.e. a contract bed) in a specialist private nursing home for people with dementia in the Dublin region = €1200+ per week.

The cost of care per resident in above unit = €62,400/year

The cost of care in a public residential care unit would be similar.

\*In the U.K. the Methodist Housing Association is paid £620 (sterling) per resident per week by the NHS/health trusts to provide places for people with dementia in their dedicated social housing schemes for this client group. (Using a conversion rate of €1.47 euro = £1, payments = €911.40 per week.) Increasingly, MHA are moving into the area of service provision for people with dementia and there is considerable demand for their services from the NHS. In Scotland, 'Special Needs Housing' is expanding faster than nursing home or residential care options.

#### **J: Case example: The Nestling Project**

The 'nestling project' is a collaborative initiative in the North East of Ireland, aimed at leveraging advances in sensor and home-based ICT technologies to enhance the quality of life and well-being of older people living independently in our community.

The project partners include Louth Local Authorities, Dundalk Town Council, Health Services Executive – Dublin-North East Area, Dundalk Institute of Technology, National Centre for Sensor Research – Dublin City University, Centre for Health Informatics, University of Ulster, Magahy & Co.

It aims to meet older people's aspirations to be able to 'age-in-place' in comfort and dignity.

A living, life-enriching home environment, enveloped by an integrated and pro-active community support infrastructure are the essential and interdependent elements.

The project sees ICT services, nestled in the home, as a catalyst that can fuse these twin spatial and social/healthcare streams together into a cohesive environment that can foster well-being, nourishing older peoples' motivation to maintain independence with confidence and self-belief.

The project is progressing through a three pronged approach involving

- a 15 unit pilot 'aware' homes project at Barracks St, Dundalk,
- a pilot cross-community services integration programme for older people, and
- An research centre at DKIT where our understanding of the interplay between spatial and building patterns, nestling (ambient) technologies and distributed community services can be further investigated and developed.

Together, these components provide the foundation for building the project's sustainability, and will deliver guidelines, models, demonstrators, tools, and integrated applications that can be made available to the wider population in the North East region and beyond.

These outputs can help influence the quality of new housing provision going forward, the adaptation of existing homes for aging-in-place, and the more effective, joined-up, organisation and delivery of services to older people in their homes. The models should also be expandable to other target groups such as those with physical or intellectual disabilities.

**K: Service development involving partnership between the HSE, a local authority sheltered housing provider, and a voluntary day care provider.**

The Alzheimer Society of Ireland established a new day care service for older people with dementia in a church hall in Dundrum, Co. Dublin in 2003, with funding from the HSE. Over time, the premises proved to be unsuitable; the toilets did not have disabled access, there was no shower for personal care and the cooking facilities were extremely limited. ASI looked for an alternative venue for their day care service.

Dublin City Council identified a community building adjacent to Woodstock Sheltered Housing Scheme in Ranelagh as a potential site for the re-location of the ASI day care service.

Following negotiations between the HSE, the ASI and Dublin City Council, it was agreed that Dublin City Council would bear the cost of carrying out necessary works to the community building in Woodstock to bring it up to required standard so that it could be used for day care for people with dementia. New facilities included disabled access toilets and shower, a laundry area and a new kitchen.

The HSE participated in the planning of the new service and agreed to continue to fund the operation of the day care centre following its re-location. There was agreement that residents from Woodstock who were in need of dementia specific day care could avail of the new service, as well as current service users from the wider community.



The day care centre in Woodstock currently provides services for 17 people with dementia, two days a week. The centre is used by residents and other community groups on other days.

This is a good example of three way inter-agency cooperation (between Dublin City Council, the HSE and the Alzheimer Society of Ireland) and sharing of responsibility for the provision of support services to people with dementia, including those living in sheltered housing.

### **APPENDIX 3: Information letter to case study scheme managers**

Janet Convery  
School of Social Work and Social Policy  
Trinity College Dublin

Date

#### **Development of Sheltered Housing for People with Dementia: Expectations and Experience in the Irish context.**

##### **Information for Case Study Scheme Managers**

Thank you for agreeing to participate in my PhD research on the development of sheltered housing for people with dementia and specifically for permitting me to use your sheltered housing scheme as a case study. My study will explore perceptions about the role of housing with care in meeting the long term care needs of people with dementia and the factors that have influenced development of sheltered housing for people with dementia in Ireland up until now from the perspective of key stakeholders. Your views on the challenges involved in service delivery and benefits to service users are also of interest. As one of the small number of voluntary sheltered housing organisations that provide dedicated services to people with dementia, it is very important to capture your views and experience in the research.

Below I will outline the way in which I will conduct the case studies and the protocols that will govern data collection, the writing of the research study and storage of information gathered.

##### **Case studies will involve;**

- 1) Observation of the daily activities of the scheme in communal areas (not in the bedrooms of tenants unless invited) over a period of 5 days in order to better understand what goes on there and how services are delivered as well as to familiarise myself with tenants and family carers<sup>27</sup> who may be interviewed as part of the research.
- 2) Examination of relevant documentation: policies and practice regarding people with dementia, referrals and discharges, and documents relating to the development of services for people with dementia.
- 3) Interviews with scheme Managers/agency management
- 4) Interviews with a sample of staff<sup>28</sup>
- 5) Interviews with others outside of your agency who were involved in the development of the sheltered housing scheme.
- 6) Interviews with a sample of people who make referrals to your scheme and who provide a service to tenants.

---

<sup>27</sup> Note: interviews with residents and family carers were not ultimately included in the fieldwork.

<sup>28</sup> Staff were not included in the sample of participants interviewed.

7) Interviews with a sample of tenants with dementia<sup>29</sup> about how and why they moved there and their experience of living in the scheme.

8) Interviews with a sample of family carers about their experience of the service and their expectations of it re: capacity to deliver long term care.

### **Timescale**

I expect that the work under Numbers 1, 2 and 3 to take from 1-2 weeks. Interviews with tenants and family members will take a further 1-2 weeks, depending upon their availability. I may also have to do follow-up visits with you to verify the evidence collected. I will, of course, consult with you about exact dates and I will also be mindful of the need to work around your routines and staff rotas while in *[name of sheltered housing scheme]*.

### **Selection of staff, tenants and family members for interview**

I will be asking your advice regarding selection of staff, tenants and family members for interview. Obviously I will be hoping to interview tenants with dementia who still have the ability to communicate and who you think will be able and willing to answer a few brief questions about their experience of life in your sheltered housing scheme. Similarly I will be asking you to recommend family carers<sup>30</sup> who are familiar with the scheme and who would be happy to talk to me. Obviously my ability to interview them will depend on their willingness to be interviewed and also on their availability. I will obtain written consent from participants where possible and verbal consent where appropriate and I will inform them that they can withdraw from the research at any time if they wish.

It will also be helpful to me if you would share with all staff some background to the research before I arrive and ask their permission for me to observe daily activities in *[name of case study scheme]*. I would be happy to attend a staff meeting and discuss the proposed research if that is appropriate. I don't plan to conduct formal interviews with individual care staff but it will be important for them not to be threatened by my presence during the fieldwork research.

### **Anonymity and confidentiality**

Every effort will be taken to protect the confidentiality of those interviewed, including yourself. No names will be used and nothing of a personal nature will be written in the research findings. In conjunction with the Data Protection Act, interview recordings and transcripts will be held for a period of twelve months after the submission of the final PhD dissertation and will then be destroyed. All information from the study will be stored securely in the meantime. I enclose a Consent Form for you to sign as well as a form indicating that staff have consented to the inclusion of observation in the research study. Consent, once signed, can be withdrawn at any time. There will, of course, be no negative implications for anyone who does not wish to participate in this study.

---

<sup>29</sup> See footnote 1 above

<sup>30</sup> See footnote 1 above

Thank you very much again for agreeing to participate in the research and for taking the time to read this letter. I look forward to working with you.

Yours sincerely,

Janet Convery  
PhD candidate: Living with Dementia Programme  
School of Social Work and Social Policy  
Trinity College Dublin  
converjb@tcd.ie

Supervisor: Dr. Suzanne Cahill  
School of Social Work and Social Policy  
Trinity College Dublin

#### **APPENDIX 4: Letter to Mount Bolus housing association**

Mid Offaly Housing Association  
Mountbolus  
County Offaly  
Date

Dear \_\_\_\_\_

Thank you for taking my phone call and also for offering to help to put me in touch with members of your Board. As promised, below are brief details about my PhD research which is on the subject of Sheltered Housing for People with Dementia in Ireland. My choice of research topic reflects an interest developed over the years from my experience as a member of the National Council on Ageing and Social Policy, as a member of the (then) National Council of the Alzheimer Society of Ireland and as Director of Services for Older People in HSE Dublin Mid-Leinster from 2000 until my retirement in 2009.

#### **Research methodology**

My PhD research, which is a qualitative exploratory study, is focused on the factors that made the development of three Irish high support sheltered housing schemes possible and what is required in order to sustain or replicate them in future. I have been conducting interviews with people who were directly involved in the three schemes referred to (two Housing with Care facilities developed by FOLD in North Dublin and O'Connell Court in Togher, Co. Cork) which are being presented as case studies. I am also interviewing other key stakeholders who have responsibility for housing and health services at regional and national level.

It is in above context that I am interested in talking to people who were directly involved in the negotiations and planning for the development of [x project ] The experience and views of your Board members are of great interest, particularly from the perspective of future service development.

If there is a Board member or Board members who are willing to participate in my study, I would be very grateful. As I said to you on the phone, I can come to meet them in \_\_\_\_\_ at a time and place that is convenient for them. The meeting will take no more than one hour. I am using a voice recorder to record interviews for the research but will only use it with permission. No direct quotations will be used in the final dissertation without permission.

#### **Ethical Committee Protocols: Anonymity and confidentiality**

Should your Board member(s) agree to meet me, every effort will be taken to protect their confidentiality. No names will be used and nothing of a personal nature will be written in the research findings. In conjunction with the Data Protection Act, interview recordings and transcripts will be held for a period of twelve months after the submission of the final PhD dissertation and will then be destroyed. All information from the study will be stored securely in the meantime.

I attach a Consent Form to be signed by anyone who agrees to participate in the research. There will, of course, be no negative implications if people choose not to participate in the study and consent can be withdrawn at any time.

Many thanks again for your help.

Yours sincerely,

Janet Convery

PhD candidate, Living with Dementia Programme  
School of Social Work and Social Policy  
Trinity College Dublin  
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Supervisor: Dr. Suzanne Cahill  
School of Social Work and Social Policy  
Trinity College Dublin

**APPENDIX 5: Consent Form**

Consent Form

*Please tick the boxes as appropriate*

1. I have read the information provided.       YES    NO
2. I have obtained all details about the study.       YES    NO
3. I have had the chance to ask questions and these  
have been answered to my satisfaction.       YES    NO
4. I am aware that I have the right to refuse to participate  
In this study and that there will be no negative  
Implications for me if I do.       YES    NO
5. I have based my decision to take part in  
the study on the information provided.       YES    NO
6. I am aware that anything I say will be in confidence  
and that my name will not be used anywhere in  
the research findings.       YES    NO
7. I am aware that my participation in the study includes one interview with the possibility  
of follow up contact to check the accuracy of that is recorded.       YES    NO
8. I understand that I can decline to answer any question  
and stop the interview at any stage.       YES    NO

9. I am aware that I will be asked for permission for the interview to be recorded.  YES  NO

10. I am also aware that the researcher will ask my permission before using any direct quotations in the final study.  YES  NO

11. I have been informed that I can withdraw my consent to participate in the interview at any time and without any adverse consequences.  YES  NO

12. I now consent to participate in the study.  YES  NO

DATE: \_\_\_\_\_

PARTICIPANT NAME (PRINT): \_\_\_\_\_

PARTICIPANT SIGNATURE: \_\_\_\_\_



## **APPENDIX 6: Sample letter to prospective study participant**

Senior Officer, Local Authority

### **The Development of Sheltered Housing for People with Dementia:**

#### **Expectations and Experience in the Irish Context.**

Dear \_\_\_\_\_,

Thanks very much for agreeing to be interviewed by me as part of my PhD research. As promised, below are some details about my PhD study on the subject of sheltered housing for people with dementia in Ireland. My choice of research topic reflects an interest developed over the years from my experience as a member of the National Council on Ageing and Social Policy, as a member of the (then) National Council of the Alzheimer Society of Ireland and as Director of Services for Older People in HSE Dublin Mid-Leinster from 2000 until my retirement in 2009.

#### **Background to the study**

As you may know, 'Housing with care' is an accepted long term care option for an increasing number of older people with dementia in the UK, Northern Europe and the US. However, there has been very little service development in Ireland, to date, and no research undertaken on the subject. The recent development of three sheltered housing schemes in Ireland offering dedicated services for people with dementia provides the opportunity to explore the factors that have influenced service developments in Ireland up to now. The number of people with dementia is projected to rise dramatically in the next 30 years and it is hoped that this study will stimulate and inform further discussion and debate about 'housing with care' as a service alternative for people with dementia in Ireland.

#### **Research methodology**

As part of this qualitative exploratory study, I am conducting semi-structured interviews with people who were directly involved in the development of the three sheltered housing schemes mentioned above, including the two FOLD Housing with Care developments in North Dublin and O'Connell Court in Cork, which are being used as case studies for this research. I am also interviewing decision makers who have regional or national responsibility for older people's housing and health services in either a policy or planning capacity. Your views are of particular interest to me because of your involvement with Anam Cara Housing with Care facility in Glasnevin.

#### **Interviews**

During the interview, I will be looking to explore the following; your experience of the development of Anam Cara; the issues involved in 'housing with care' service development in the Irish context; and the possibilities and challenges of future service development from a housing perspective.

The interview will take no more than one hour. I am using a voice recorder to record interviews for the research but will only use it with your permission. No direct quotations will be used without your permission.

**Anonymity and confidentiality**

Every effort will be taken to protect the confidentiality of those interviewed. No names will be used and nothing of a personal nature will be written in the research findings. In conjunction with the Data Protection Act, interview recordings and transcripts will be held for a period of twelve months after the submission of the final PhD dissertation and will then be destroyed. All information from the study will be stored securely in the meantime. I attach a Consent Form to be signed by you if you agree to participate in the research. There will, of course, be no negative implications if you choose not to participate in the study and you can withdraw your consent at any time.

I'm looking forward to meeting you as arranged on 27 April. Thanks again for your cooperation.

Yours sincerely,

Janet Convery  
[converjb@tcd.ie](mailto:converjb@tcd.ie)

Supervisor: Dr. Suzanne Cahill  
School of Social Work and Social Policy  
Trinity College Dublin

## **APPENDIX 7: Interview Schedule: Case study participants**

(For interviews with people involved in the development of the case study schemes including housing association managers, the HSE, the local authorities)

**Introduction:** The case study schemes, including the two sheltered housing schemes developed by FOLD in North Dublin, are highly unusual in the Irish context. In spite of policy recommendations dating back to 1968 (Care of the Aged Report, followed by The Years Ahead 1988, the NCAOP report on sheltered housing in 1989, the Mercer Report etc.) there has been only very limited development of high support sheltered housing or 'housing with care' services for older people in Ireland. More recently the *Towards 2016* Partnership Agreement makes a commitment to encourage the further development of sheltered housing with varying degrees of care support and the Positive Ageing Strategy also promises to set out policy in relation to the provision of sheltered housing for older people including for the integrated management and delivery of housing and related care services.

It is against this background that my research is being conducted.

**Purpose of the Research:** to explore how and why these schemes developed when they did; the implications of introducing a new social model of long term care; the perceptions of key stakeholders about what distinguishes these services from traditional residential care models; and what is required in order to sustain and replicate these developments.

### **1) How did this development come about?**

*Who initiated it?*

*Who supported it?*

*What was the sequence of events?*

### **2) What was your specific role in the development of this service?**

*How did you become involved?*

*Were you aware of this type of service prior to becoming involved?*

### **3) This is an unusual development in the Irish context. What particular combination of factors do you think made it possible?**

*How do you think it got prioritised (in service plan/budget) in the first place?*

*Why did it come about when it did?*

### **4) Was the need for dementia specific services an acknowledged factor in the development of the FOLD schemes? Did dementia figure in the discussions/plans? How was it decided to set aside half of the beds for people with dementia?(Was FOLD selling it as a dementia specific service?)**

5) ***The Action Plan for Dementia (1999) found ‘...little support during the consultation process for group-living or sheltered accommodation for people with dementia’ and that***

*‘ Group living arrangements were likely to be cumbersome and impractical, requiring high levels of supervision and a framework for coordination which is not in evidence in existing Community Care structures in Ireland’.*

*Do you think that the case study schemes represent a change in thinking about the feasibility of housing options for people with dementia? Has anything changed since publication of the Action Plan to make service development more likely?*

6) ***Do you think there was a demand for this type of service?***

*If so, where did demand come from?*

7) ***This development represents the introduction of a new social model of long term care that is different from traditional residential/nursing home care. What were the implications from your perspective?***

8) ***What other issues arose which had to be resolved in order for this development to be realised?***

*Specific to this service development?*

*Barriers that would apply to other similar development initiatives. Why are there so few such developments?*

*How were these barriers overcome?*

9) ***Is this scheme sustainable in its present form? What is required in order to sustain it/replicate it?***

10) ***What lessons were learned from the development of this service?***

*What could have been done differently? Better?*

11) ***Is there anyone else that I should interview about this development?***

## APPENDIX 8: Interview schedule for 'experts'

**Introduction:** In spite of policy recommendations dating back to 1968 (Care of the Aged Report, followed by The Years Ahead 1988, the NCAOP report on sheltered housing in 1989, the Mercer Report etc.) there has been only very limited development of high support sheltered housing or 'housing with care' services for older people in Ireland.

The three sheltered housing schemes used as case studies for this research are among the very few sheltered housing schemes in Ireland that offer 24/7 care and support and the only ones that formally offer dedicated services for people with dementia.

The *Towards 2016* Partnership Agreement makes a commitment to encourage the further development of sheltered housing with varying degrees of care support. The Positive Ageing Strategy promises to set out policy in relation to the provision of sheltered housing for older people including for the integrated management and delivery of housing and related care services.

*It is against this background that this qualitative exploratory study is being undertaken.*

### **Purpose of the Interviews with Policy Makers and Service Planners:**

To explore the views of key stakeholders about why the development of 'housing with care' services has been so limited in Ireland and what factors have influenced service development up to now.

To explore the issues associated with the introduction of what is in Ireland a new long term care service alternative.

To find out what is required in order to sustain and replicate existing housing with care services.

**'Housing with care' services are defined as; self-contained accommodation with communal facilities, the provision of meals and the provision of individualised packages of care that are flexible and adaptable to changing needs on a 24/7 basis.**

1. Are you familiar with the concept of 'housing with care'?

*Do you have personal experience of this type of service or do you know of any such services here or abroad?*

2. Does your agency/Department/organisation have a policy on housing with care/housing for older people/long term care of people with dementia? What implications does *Towards 2016* have for your organisation/agency/Department?

*May I have a copy of any related documentation?*

3. Have you been involved in policy discussions about sheltered housing/housing with care?

*In your own agency/Department?*

*In an interdepartmental forum?*

*If so, what was the thrust and outcome of these discussions?*

*What issues arose in this context?*

4. 'Housing with care' developed historically as a social model alternative to residential care for people whose needs cannot be met in their own homes.

*What have been the barriers to the development of social model service alternatives up to now? What factors have made it difficult?*

6. The Action Plan for Dementia (1999) found '...little support during the consultation process for group-living or sheltered accommodation for people with dementia' and that

*'Group living arrangements were likely to be cumbersome and impractical, requiring high levels of supervision and a framework for coordination which is not in evidence in existing Community Care structures in Ireland. (1999:61)*

*Your comments?*

*Do you think that the case study schemes represent a change in thinking about the feasibility of housing options for people with dementia?*

*Has anything changed since publication of the Action Plan to make service development more likely?*

7. Do you think 'housing with care' can be a practical option for people with dementia?

*Can it meet their needs?*

*Are there particular benefits of 'housing with care' for people with dementia?*

8. What is required in order to further develop housing with care services for people with dementia in Ireland?

*What factors might make it easier to develop housing with care services for people with dementia in Ireland?*

*What needs to change in order for it to happen?*

8. Is there anything else you would like to say on the subject?

9. Is there anyone else in your agency/Department/office I should talk to?