"
I'D PREFER TO STAY AT HOME BUT I DON'T HAVE A CHOICE
"

MEETING OLDER PEOPLE'S PREFERENCE FOR CARE:
POLICY, BUT WHAT ABOUT PRACTICE?

Contents

Acknowledgements

Definition of Terms

CARE PLANNING MEETINGS
Care Planning Meetings involve the older person, family member(s) and hospital personnel in discussions concerning the patient's illness, treatment and plans for their discharge or care outside the hospital (Hansen, Cornish and Kayser, 1998).

COMMUNITY HEALTH ORGANISATIONS (CHO)
Community Health Organisations (CHO) are responsible for the delivery of community health care services at a local level. Their aim is to enable and support integrated care within community healthcare services, between the community and acute hospital services and with wider public service organisations, such as local authorities, child and family agency, education and local voluntary organisations (HSE, 2014).

DAY CARE/CENTRES
Day Care/Centres provide a range of social and rehabilitative services for older people and people with disabilities. They are provided on a variable basis throughout the country, some provided directly by the Health Service Executive (HSE) and others in conjunction with voluntary organisations. Eligibility conditions vary from area-to-area with means tests applying in some cases.

DOMESTIC OR HOUSEHOLD CARE
Domestic or Household Care refers to Domestic Activities of Daily Living (DADLs) which are essential in order to maintain the person in their own home e.g. nutrition and environmental care such as cleaning, cooking and laundry.

HEALTHCARE ASSISTANTS
Healthcare Assistants: Some CHOs employ healthcare assistants as a back-up to Public Health Nurse (PHN) services. Their role is to provide personal care rather than domestic services, but there is some overlap between this and the role of the home help service.

HOME CARE PACKAGE SCHEME (HCP)
Home Care Package Scheme (HCP) is operated by the HSE. It aims to help people who need medium to high caring support to continue to live at home independently. HCPs consist of 'community services and supports which may be provided to assist an older person, depending on their individual assessed care needs, to return home from hospital or residential care or to remain at home' (HSE, 2012a). Individuals do not have an automatic right to the scheme, or to avail of services under the scheme as it is not established in law. The scheme is not means tested, and there is no charge or contribution to be paid for the services provided. Each HSE Area has responsibility for the operation of the scheme within the resources allocated for it in that area (HSE, 2012b).

HOME HELP SERVICE
Home Help Service is a formal state provision of care in the community. The Health Act (Section 61 (1) allows for the service to be provided free of charge (Citizens Information, 2016). Historically, home help support was mainly targeted at domestic support to older people such as assistance with cleaning, cooking and other light household tasks (DADL's). In recent years, the scope of the service has broadened with an emphasis on personal care including support with personal hygiene, washing and dressing Personal Activities of Daily Living (PADLs). Many home help providers offer a maximum of 5 hours of home help support in one week. Any additional hours required need to be sourced through the Home Care Package (HCP) Scheme.

NURSING HOME SUPPORT SCHEME (NHSS)

Nursing Home Support Scheme (NHSS) provides financial support to people ordinarily resident in the State, who need long-term residential nursing home care. The applicant makes a contribution towards the cost of this care; up to 80% of disposable income. An additional charge of 7.5% of a person's assets (the first €36,000 is disregarded) including the value of their principal residence is paid for the first three years of their time in care. The State pays the balance (DOH,2009b). The scheme covers long-term nursing home care only.

PERSONAL CARE

Personal Care refers to Personal Activities of Daily Living (PADLs) such as personal hygiene, mobility, toileting, bathing, dressing and authorised assistance with medication.

RESPITE CARE

Respite Care involves providing temporary care for a person in order to enable family carer(s) to take a short break. Respite care may be based in the community or in an institution. In practice, respite care is provided to a varying degree at a number of locations around the country – in some cases by the HSE and in others by local or national voluntary organisations.

Executive Summary

BACKGROUND
This report outlines the results of a collaborative research project undertaken by the Irish Association of Social Workers (IASW), Age Action, the Alzheimer Society of Ireland (ASI) and the School of Social Policy, Social Work and Social Justice, University College Dublin. The research gathered information on the experiences and views of social workers working across the country with older people, including people living with dementia. The purpose of the study was to investigate how the health and social care system is responding to the care needs, required supports and preferences of older people. The specific objectives were to investigate:

1. Access and availability of care and support services for older people in Ireland, including those of people living with dementia.
2. Older people's involvement in decision-making relating to care planning to meet their needs, particularly focusing on those with a cognitive impairment/dementia.
3. What community supports and services could enable older people to continue/return to live in their own home?

The research gathered the experiences of social workers working with older people across the country.

STUDY DESIGN
The research project involved two phases of data collection - a survey of social workers working with older people across the Republic of Ireland and in-depth telephone interviews. Respondents reported on their open cases concerning older people during the month of June 2015. In total 38 social workers fully completed the questionnaire, reporting on the experiences of 788 older people in their caseload for the month of June 2015.

In phase two, 21 social workers participated in in-depth telephone interviews. The interviewees were located across each of the nine CHO areas, with at least two social workers from each area participating. Across both phases, social work participants were employed in a variety of settings including Primary Community and Continuing Care (PCCC), Adult Safeguarding, Medical, Psychiatry of Later Life and Adult Mental Health services. In view of the low numbers of social workers in some CHO areas and the sensitivities of issues being explored, all data was anonymised to ensure confidentiality of participants.

GENERAL FINDINGS
The findings of this study echo previous Irish research studies, which show the preferences of older people are to remain living at home for as long as possible, receiving care when it is needed in this setting. Despite this, one of the striking findings was the lack of consistency across geographic areas and professional disciplines in both the provision of services and in how older people are involved in decision-making about their care. A difficulty, due to the reliance of the Irish system on family members to provide care, is balancing the older person's preferences and those of family carers.

It is evident from this research that older people's preference for receiving care and support in their home and community is not being realised. The present social care approach has not been resourced adequately to meet the actual needs of older people. The HSE are spending less now on home support services then they did in 2008, despite the increase in numbers of people aged 85 and over and those living with complex conditions such as dementia. Older people cannot access safe, compassionate, individualised and quality care when they need it.

ASSESSMENT

In terms of care needs assessment, aside from stated preferences, there were a number of factors which determined the provision of services/supports. For example, people were prioritised in different ways in different areas – by age, living situation, delayed hospital discharge and/or presence of dementia. For those with mental health issues and/or cognitive impairment/dementia, assessment often did not capture what supports they may have needed to live well at home and needs were understood within the narrow parameters of 'physical care needs'. Assessment was deficit based, so where a person had family members providing care, they were less likely to get any support. Social care needs, such as help with domestic tasks and social contact, were regularly excluded and not prioritised. The definite move away from providing this service was noted.

Risk was found to regularly influence the decisions of professionals and family members. In these circumstances, professional practice is defensive, often to the detriment of the older person who wanted to live in a manner deemed 'risky' by others. In such cases, the rights of the older person were often ignored and pressure brought to bear on the older person to for example, move into long-term care where it was viewed they would be 'safer'. Social workers reported regularly having to advocate for the older person's right to live 'at risk'.

ENTITLEMENT, ACCESS AND AVAILABILITY OF COMMUNITY SUPPORTS

Lack of transparency existed in relation to older people's entitlement to services with differing practices highlighted across CHO areas. For example, in some areas older people had to be in receipt of a medical card in order to access formal community-based support services while in other areas they did not. Findings also show that there are large disparities between services that are available in different CHO areas. In general, demand far outstrips what is available and participants reported discrepancies between the number of hours an older person had been assessed as needing, the level of home care hours requested, and the number of hours of home care which were actually approved. This situation regularly meant that older people did not receive the level of service that their care needs' assessment indicated. A worrying consequence of this was unnecessary or premature admission to long-term residential care.

ALLOCATION OF RESOURCES AND SERVICES

Respondents clearly believed that the acute sector is given priority over services in the community with shorter waiting times operating. Findings show that the emphasis on hospital settings led to a reactive rather than preventative approach to the health and social care needs of older people. Participants felt that greater funding should be invested in community care rather than residential care. A number of difficulties were identified in accessing formal home care services. These included:

Many recipients got lower hours of care than the number applied for;

- Minimal service availability in many CHO areas and inconsistencies between CHO areas in the types of services provided;
- The operation of waiting lists;
- Shift from domestic to personal care which didn't always meet individual needs;
- A time-to-task approach in allocating time for home-based care;
- A lack of knowledge and understanding of the care needs of complex cases e.g. people with dementia;
- Wide variations between and within CHO areas in accessing long-term residential care funding and beds;
- A significant lack of flexibility and red tape which meant applying for home care packages was often deemed more straight forward than applying for home help hours;
- Older persons were regularly obliged to go into long-term care prematurely because of the above problems in service availability.

A wide range of community-based services was considered to be helpful in supporting an older person to live at home with dignity. Where services were available they worked well in the main, with meals-on-wheels and day-care in particularly being highlighted as useful services. In addition, non-health related issues, such as transport, were identified as barriers to service access, particularly in rural areas.

LONG TERM CARE (LTC), TRANSITIONAL CARE AND RESPITE CARE

Findings show that availability of long and short-term beds varied across CHO areas, as did waiting times. It is easier to access LTC and rehabilitation beds from the acute hospital than from the community. Of particular concern was the difficulty in accessing appropriate LTC placements for people living with dementia, with nursing homes in a position to cherry-pick residents, refusing to accept people in the more advanced stages of dementia or who were deemed to have behavioural and psychological symptoms of dementia. In addition, findings highlight the dearth of dementia-specific units across the country. Transition beds were seen to be the preserve of acute hospitals to facilitate more timely discharge. This put community-based older people at a disadvantage in accessing these types of beds. In relation to respite care, participants spoke of a lack of compliance with Health Information and Quality Authority (HIQA) standards had resulted in closures and corresponding reductions in the number of available beds. This again was compounded by a general lack of available dementia specific beds.

INVOLVEMENT OF OLDER PEOPLE IN DECISION-MAKING

Findings show that there were inconsistencies in how older people were involved in decision-making about their care and there were stark variations reported between and within CHO areas. Social workers reported that many older people with a mental health issue and or/cognitive impairment/dementia were excluded from the decision-making process regardless of their level of functional capacity. Older people living with a dementia were more likely to be excluded due to:

- A status approach to dementia, where people were deemed to lack capacity
- Their family didn't want them involved
- Communication difficulties which impacted on their involvement
- No opportunity to be involved
- Their expressed preference was that they didn't wish to be involved.

In some cases, their involvement in decision-making was deemed to be tokenistic and the attitudes of Health and Social Care Professionals (HSCP), treating Consultants/GPs and families played a crucial influencing role in whether or not older people were involved. Good practices were identified specifically through strong Multi-disciplinary Team approaches.

FAMILY CARERS

Family carers were identified as key stakeholders in the care and support of older people however social workers reported that routinely older people were less likely to get formal support where an older person had family members providing care. It was also highlighted that often family carers were not provided with concrete, practical community supports such as HCP's or respite until they reached breaking point.

SOCIAL WORK

Findings also show that not only are there significant gaps in the provision of social work supports to older people nationally, but social workers also face considerable challenges in trying to carry out their role. The need for creativity by social workers when negotiating service delivery was a further key theme to emerge. Social workers reported that their role as advocates for the older person was essential in many instances in getting services or involving older persons formally in decision-making.

RECOMMENDATIONS

General

1. Ensure that the dignity, rights and autonomy of all older people, regardless of cognition or their level of functional capacity are respected in the planning and provision of services. In this regard, the definition of 'risk' must be broadened to acknowledge that there are potential risks inherent in all care and support options.
2. Provide an annual centralised ring-fenced budget for community care, allocated to CHO areas based on capitation, calculated using evidence such as OECD figures on the number of people aged 65 and over likely to require care and support over the next 10 years.

3. Provide a full compliment of health and social care professionals in each CHO area, accessible to all older people and their families, ensuring that deficits such as the current lack of social work services is addressed. All PCCC Teams nationally should have an allocated social worker. The new Adult Safeguarding Teams must be fully resourced. The absence of medical social work posts in hospitals within several CHO areas must also be addressed.

Access to Community Supports

4. Develop and implement across every CHO a single, fair, national standard for needs assessment; it is envisaged that the Single Assessment Tool can achieve this.
5. Develop and implement a fair and equitable way of allocating care and support services underpinned by legislation. All CHO areas should make information about services, eligibility criteria and the process for accessing services available to all people.
6. Ensure that the bias in the provision of future financial and staffing resources favours community-based services over residential services.
7. Oblige each CHO area to provide a range of services to meet the diverse needs of older people. Flexible domestic supports are required and supervisory supports to people with dementia are also urgently needed. Basic services should also include access to aids and appliances, home adaptations, social clubs, day centres, meals-on-wheels, befriending services, public transport, home care support services, supported housing and nursing homes.

Older People's Involvement in Decision-making

8. Implement a standardized approach to involving older people (including people with dementia) in care planning across all CHO areas, in tandem with the Assisted Decision-making (Capacity) Act 2015. Ensuring all health and social care professionals are trained in this approach is essential to implementation.
9. Implement an individual and needs-led approach to service assessment and provision - creating a care environment where the older person guides decisions about their care and support, thus ensuring their care is personalised and tailored to their needs.

Carer's Needs

10. Take carer's needs into account and provide a carer's needs assessment via the Single Assessment Tool scheme.
11. Cease the current bias against the allocation of support services to older people who have access to family carers. Assessments should be carried out in an objective manner based on identified needs.
12. Provide robust supports to family and informal carers in order to protect and sustain their important role. Full implementation of the National Carers' Strategy is key in this regard.

Access to Transitional, Rehabilitation and Long Term Care beds

13. Establish equality of access to transitional, long term care and rehabilitation beds from acute and community settings.
14. Increase the number of dementia-specific long-stay units nationally. Expand facilities which are equipped to care for people who may have behavioural and psychological symptoms of dementia or advanced dementia.

Section 1: Introduction

1.1 BACKGROUND

The purpose of the study was to investigate whether the health and social care system is responding to the care needs, required supports and preferences of older people. The specific objectives were to investigate:

1. Accessibility and availability of care and support services for older people in Ireland, including those of people living with dementia.
2. Older people's involvement in decision-making relating to care planning to meet their needs, particularly focusing on those with a cognitive impairment/dementia.
3. What community supports and services could enable older people to continue/return to live in their own homes?

The research gathered the experiences and views of social workers working with older people across the country, including people living with dementia.

1.2 ROLE OF SOCIAL WORK IN OLDER PEOPLE'S CARE

The role of the social worker in the care of older people is to represent and advocate for the person's wishes, while collaborating with other key stakeholders and establishing the supports required (IASW, 2011). They have a key role to play at the interface between the older person, their families, hospital staff and community services (Gibbons and Plath, 2009). As such social workers are well placed to provide insights into the experiences of older people accessing or needing health and social care services.

1.3 METHODOLOGY

The research project involved two cross-sectional phases of data collection - a survey of social workers working with older persons across the Republic of Ireland and in-depth telephone interviews. In both phases the social workers who participated were employed in a variety of settings including Primary Community and Continuing Care (PCCC), Adult Safeguarding, Medical, Psychiatry of Later Life and Adult Mental Health services.

The findings provide a snapshot of the situation for older people navigating the health and social care system in Ireland. The data provides an in-depth account of the care and support needs of older people, their preferences in meeting these needs, their involvement in decision-making and the barriers to accessing the care and support they need and want from the perspective of social workers working with them.

1.3.1 Research methods

Phase One of data collection, the national survey, consisted of a self-administered on-line questionnaire. Potential participants were contacted through the IASW's Special Interest Group on Older People (SIGA), other IASW Special Interest Group mailing lists and other social work networks across the country. This approach was necessary as there is no one register of social workers working with older adults and therefore respondents had to self-identify to take part in the research.

The survey involved respondents reporting on their open cases concerning older people for the month of June 2015. In total 38 social workers fully completed the questionnaire, reporting on the experiences of 788 older people in their caseload for the month in question. The majority of cases (62%) related to respondents who were working in acute hospital settings as shown in Table 1.Of those who were located outside the Dublin area, 49 cases involved people living in the Southwest (Cork/Kerry), 81 people were in the West (Galway/Sligo/Leitrim) and 75 people were located throughout the rest of the country.

Table 1: Number of cases involving older people by location and social work speciality

Area	Medical social work	Primary care	Mental health	Adult safeguarding	Later life psychiatry	Disability	Other	Total no. cases
Dublin	433	16	49	45	1	2	37	583
Other	54	42		8	90		11	205
Total	**487**	**58**	**49**	**53**	**91**	**2**	**48**	**788**

The 21 social workers who participated in Phase Two of data collection, the in-depth interviews, were located across each of the nine CHO areas, with at least two social workers from each area participating. Three social workers were interviewed in three CHO areas. This ensured a good geographical spread. Interviews lasted between 40-90 minutes. To ensure confidentiality and given the low number of social workers working with older people in some CHO areas and the sensitivities of the issues being explored, each CHO area has been assigned a random letter and will be identified as such throughout this report.

1.3.2 Data analysis
Quantitative survey data was analysed using SPSS statistical software to produce descriptive and bivariate results. The qualitative analysis set out to identify, describe and understand phenomena; interpreting the data in order to make sense of it. To ensure this an interpretive inductionist framework was applied (Kuczynski and Daly, 2002). Analysis of the qualitative data also followed an iterative data reduction process (Creswell, 2003; Crabtree and Miller, 1999; Kvale, 1997) – namely that information was extracted and data grouped for identifiable similarities and trends. Convergent themes were then noted and developed and supportive quotations were identified (Crabtree and Miller, 1999; Kvale, 1997). This analysis and supportive quotes are presented in Sections Three, Four and Five of this report.

1.3.3 Ethical approval
The research proposal, including aims and methodology were submitted to the Human Research Ethics Committee (Humanities) in University College Dublin and awarded ethical exemption as research participants were not deemed to be a 'vulnerable' population group. The proposal for ethical exemption outlined all practical steps to fully inform participants about the study and the minimisation of any possibility of harm resulting from participation, as well as an outline of plans for dissemination.

1.4 REPORT CONTENTS
The report is presented in five sections. The second examines the relevant literature and policies pertaining to older people's health and social care services and supports. The following three sections outline the key findings of the study, that is: Section Three looks at older people's care preferences, their involvement in care-related decision-making and assessment of needs; Section Four examines service provision and Section Five examines integrating care for older people and their families. The final section presents the conclusions and recommendations based on an analysis of the collected data.

Section 2: Literature and Policy Review

This literature and policy review summarises the landscape of community care and long-term care (LTC) supports for older people in Ireland. The review outlines and critically examines both policy documents and research evidence in national and international contexts.

2.1 DEMOGRAPHICS OF OLDER PEOPLE IN IRELAND
The world's population is rapidly ageing, with the proportion of people aged over 60 years expected to double from 11% to 22% between 2000 and 2050 (WHO, 2012). While this increased longevity is a cause for celebration, it also presents a societal challenge to maximize the health, functional capacity, social security and participation of older people (Donnelly and O'Loughlin, 2015).

Ireland like much of the world is experiencing unprecedented ageing of its population, for example:

- Life expectancy is now 78.7 years for males and 83.2 years for females, above the EU average of 75.5 years for men and 82.1 years for women.
- An increase of 107,600 additional people aged 65 and over is projected by 2021.
- An increase of 15,200 additional people aged 85 years and over is projected by 2021.
  (Source: HSE (2015a) *Planning for Trends and Priorities to Inform Health Service Planning 2016*)

These projected increases present significant health, social and economic challenges for policy and planning, with implications for the resourcing of services for older people and for targeted forward planning in order to meet future demands. The need for long-term care, which includes home-based nursing, community, residential and hospital–based care, is also increasing (WHO, 2012).

2.1.1 Dementia prevalence
Although dementia is not a normal part of the ageing process, age is the main risk factor. Therefore, alongside population ageing, the number of people living with the condition is expected to increase and if current trends continue this will mean a rise from 48,000 people in 2011 to 94,042 by 2031 (Pierce and Cahill, 2014). This increase is therefore a crucial consideration when planning services for older people.

People with dementia are significant users of health and social care. HSE statistics show that 37% of all long-stay beds are occupied by someone with dementia (HSE, 2015a). In addition, it is largely recognised that there is an under-diagnosis of dementia generally and the prevalence could be much higher in long-term residential care (Cahill et al, 2010). Evidence from a sample of Dublin-based nursing homes for example, found that 89% of residents had a cognitive impairment (Cahill et al, 2010). A similar pattern emerges across acute settings, A Cork-based study found that 25% of older people admitted to six hospitals in the area in 2012/13 had dementia, but only a third of this group had a previous formal diagnosis (Timmins et al, 2015).

2.2 CONSEQUENCES OF POPULATION AGEING
Research indicates that most older people would prefer to live in their own homes and to have support services provided to enable them to do so for as long as possible (Barry, 2010). The lack of legislation in relation to entitlement to community based care is contentious and there is an over-reliance on the Nursing Home Support Scheme (NHSS), as other alternatives such as supported housing options or the promotion of 'ageing in place' have not been developed within the Irish setting (Donnelly and O'Loughlin, 2015).

Evidence shows that older people also wish for their family or friends to be their principal carers and the role of health and social services should be to provide support to help them and their families realise this aspiration (Garavan et al, 2001). The HESSOP Report (Garavan et al, 2001) concludes that community health and social care services in Ireland are extremely limited and fragmented. In addition, there is no official policy framework for integrated home care service provision to older people and without any legislation governing home care in Ireland, it remains unregulated (Timonen, Doyle and O'Dwyer, 2012).

Home care services are often experienced as impersonal, inflexible, underfunded and poorly integrated with other health and social care services (SCIE, 2014). Services are not designed around the older person, but depend on how organisations are structured or who is providing the service (SCIE, 2014).

2.3 INTERNATIONAL AND NATIONAL POLICY

One of the United Nations' key principles for older people (1991) relates to older persons being able to reside at home for as long as possible (UN, 1991). 'Ageing-in-place' is a widely used concept in current ageing policy. It is defined as 'remaining living in the community, with some level of independence, rather than in residential care' (Davey et al, 2004:133). It is understood to enable older people to maintain independence, autonomy, and connection to social support (Lawler, 2001). Ensuring that people stay in their homes and communities for as long as possible, avoiding the expensive option of institutional care (Fox et al, 2015).

At a national level, *The Care of the Aged Report* (1968) was one of the first official documents to clearly articulate the policy preference for domiciliary and community based care (Timonen and McMenamin, 2002). Current policies, including policy related to dementia care, continue to be underpinned by a commitment in principle to support older people to age-in-place (National Positive Ageing Strategy, 2013; Irish National Dementia Strategy, 2014). A research review which was undertaken to support the development of the National Dementia Strategy found that community support services for those with dementia, including social work, 'were under-developed and fragmented' (Cahill et al, 2012:13). The role of social workers in supporting people with dementia and their family carers, in assessing need, advocacy, protecting rights and safeguarding health and welfare is acknowledged as important, but access to this service and other community supports

is described as extremely limited (Cahill et al, 2012:12). The broader national health policy, *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015* (DOH, 2012b), commits to caring for more people in their homes for as long as possible, rather than in residential care.

The HSE Service Plan for 2015 states that they will continue to provide a flexible and responsive service to older people in order to maximise the potential of older people to live in their own homes, close to their families and within their own local communities. There will be a greater move towards primary and community care through a model based on the principle of 'the money follows the patient' (HSE, 2015a: 55). In addition to supporting clients in their own homes, the Plan states that services will continue to be provided in order to avoid hospital admission and support early discharge through step-down, transitional care and rehabilitation beds while maximising access to appropriate quality long-term residential care when it becomes necessary (HSE, 2015a). In 2015, an additional €70 million was injected into the system to address hospital overcrowding and reduce waiting times. The majority of this amount, €44 million, was allocated to the Nursing Home Support Scheme and €30 million for transitional care beds (HSE, 2015b). Further highlighting the balance of funding weighted towards long-term residential care.

2.4 ELIGIBILITY AND ENTITLEMENT TO COMMUNITY SERVICES

In the past, studies have highlighted the need for home and community care services to be established on an equitable basis underpinned by legislation and appropriate funding (Mangan, 1997; Ruddle et al, 1997; Layte et al, 1999). *Shaping a Healthier Future: A strategy for effective healthcare in the 90's* (1994) highlighted the lack of eligibility criteria for service that was underpinned by legislation. It committed to introduce 'national guidelines on eligibility and charges, which will be applied in a uniform manner in all areas, will be introduced in respect of all services where legislative provisions are at present absent' (DOH, 1994: 36). However, these guidelines were not implemented. Revisiting the issue, a review of the implementation of the recommendations of *The Years Ahead Report* (1998) found that the discretionary nature of core services had led to a situation where older people in different areas of the country experienced considerable variations in the extent, scope and nature of services provided and in eligibility criteria being used (Ruddle et al, 1997).

Most recently in 2012, the National Economic and Social Council's (NESC) review of homecare services for older people noted the urgent need for legislation to underpin the standards of care, the need for alternative cost-effective [and] high-quality care (NESC, 2012). The NESC report also pointed to the need to develop processes that avoid the duplication of care needs assessments. In this regard, the HSE Older Persons' Care Group initiated a project in 2010 to develop and implement a new national structured needs assessment, the 'Single Assessment Tool' (SAT). The overriding objective of the SAT is to standardise care needs assessments for older people. The InterRAI™ (SAT) suite of assessment tools operate on the premise that comprehensive, standardised assessments include an evaluation of functional, psychosocial and environmental needs. Data captured in these assessment tools will be used by front-line (direct care) staff as well as managers, researchers and policy makers - hence these tools have both clinical and administrative utility. This initiative is currently being phased in.

2.5 CURRENT COMMUNITY AND INSTITUTIONAL SUPPORTS

The bulk of care for older people in Ireland is still provided by family carers who carry out unpaid work (Timonen and McMenamin, 2002). It is estimated that 89.5% of care is provided by family carers to community dwelling older adults (Care Alliance Ireland, 2015). This care, including help with personal care and household tasks, amounts to an average of 30 hours per week (Kamiya et al, 2012).

Within the Irish context, the concept of formal, non-family, care in the home comprises two categories: home help (HH) and home care packages (HCPs) (NESC, 2012). The introduction of the HCP Scheme in 2006 signified a conscious move away from institutional care and gave rise to the concept of 'a package of care', which purports to offer older people individually tailored support packages (Donnelly and O'Loughlin, 2015). HCPs were originally designed to meet the following objectives (DOH, 2009a:5-6):

- Facilitate the timely discharge of older people from acute hospitals
- Reduce inappropriate admissions
- Reduce pressure on A&E Departments
- Support older people to continue to live in their own communities
- Support carers so that they might be able to continue to provide care.

HCPs include, for example, additional home help hours, nursing services and therapy services which might be needed due to illness, disability or after a stay in hospital or following rehabilitation in a nursing home (HSE, 2012b). The majority of HCPs include a mix of public, private and voluntary care providers. At times, this can result in several organizations or teams being involved in caring for an older person. This can create difficulties in communication and coordination between services. In addition, tensions have been identified in how HCPs are delivered within the framework of what is available in that particular geographical area, which limits the effectiveness of this scheme (Brennan, 2010).

While there has been an increased national focus on promoting independence and choice for older persons (Lymbery, 2010) with policies outlining greater community supports, this has been undermined by reducing budgets to core services. Despite a 25% increase in the population of those aged 65 years and over and a near 30% increase in the population of those 85 years and over in the last seven years, there has been nearly a 2% decrease in the number of people receiving support, from 64,353 people receiving HH and HCP in 2008 to 63,245 people in 2015 (HSE, 2008; HSE, 2015c). Funding for home care services has also fallen over this same period (see Table 2).

Table 2: Yearly spend on home care services, 2008 and 2015

Service	Yearly spend in 2008[1]	Yearly spend in 2015[2]
Home Help	€211 million	€185 million
Home Care Packages	€120 million	€135 million
Total	**€331 million**	**€320 million**

[1] Department of Health(2011) Comprehensive Review of Expenditure. Dublin: Stationary Office.
[2] Catherine Byrne, Daíl Debates,2015-07-16a.848, 16th July, 2015.

In comparison, in the corresponding period, funding for long term care has increased, from €920 million in 2008 (DOH, 2011) to €988 million in 2015 (HSE, 2015b). The number of people being supported under the Nursing Home Support Scheme has also increased from 21,698 in 2010 (HSE, 2011), the first full year of implementation, to 23,965 in 2015 (HSE, 2015c). With some 4.5% of older people living in long-term residential care in Ireland this is 40% above the EU average (EPS, 2013). When compared to other European countries, Ireland has the second highest proportion of people aged 65 and over resident in nursing homes and hospitals (Drennan et al, 2012). Between 2004 and 2013 there was a 44.6% increase in the number of residents in nursing homes categorised as low dependency and a 17.6% increase in the number of residents with medium dependency (DOH, 2015), suggesting that higher levels of low-medium dependency older people in Ireland are now entering long-term residential care.

The NHSS is administered by the HSE and is resource capped. As a result, waiting lists may operate until funding becomes available (DOH, 2009b). The scheme differs from community-based services in that, for example, it is underpinned by a legislative entitlement, there is transparency in the application process and in the provision of places and there is a standardised approach to care needs and financial assessment. These key factors ensure more equitable access to long-term residential care places. It is important to note that since its introduction in 2009, social workers have played a critical role in assisting people to apply for the Scheme, recognising that it is more than an administrative task. It represents a time of crisis and change for older people and their families (Donnelly and O'Loughlin, 2015).

The impact of the cuts to funding for home care supports was highlighted by the HSE (2015a) which showed how Ireland, in the last 4 years, has slipped below international standards for the proportion of the population aged 65 and older receiving home care as recommended by the OECD, thus indicating a high level of unmet need. These authors also outline how 51% of delayed discharges between May 2013 and February 2015 were a result of delayed access to appropriate community supports (HSE, 2015a:44).

2.6 AGEISM, HUMAN RIGHTS AND DIGNITY

Ageing is not only a biological process, it is also socially constructed, and, as a result, ageism may occur at many levels for older people (Pierce and Timonen, 2010). Legislation and service provision for older people in Ireland has been given low priority which, it could be reasoned, is reflective of systemic and legislative discrimination (Donnelly and O'Loughlin, 2015). The *European Convention on Human Rights* (ECHR) protects several rights which are critical to care and support for older people: the right to respect for private and family life, which includes respect for dignity and autonomy (Article 8) and the prohibition of inhuman and degrading treatment (Article3, ECHR,1950). In addition, the United Nations Principles for Older People (1991), which relates to care, state that:

- Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.
- Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.
- Older persons should have access to social and legal services to enhance their autonomy, protection and care.
- Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.
- Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

Ireland has ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) which recognises the right to health, defined in relation to availability, access to, acceptability and quality of health facilities, goods and services. However, the right to health and personal social services is not defined in Irish legislation. Many organisations working with older people have argued that, without legislation to underpin access to these services, access is discretionary, unequal and problematic. It is difficult to obtain information about services and/or information about reliable access to them at critical points, for example, discharge from hospital, onset of disability, diagnosis of long-term or life-limiting illness. The Ombudsman has observed that people do not know where they stand in terms of their entitlements and in terms of the HSE's

obligations to provide services (Human Rights and Older People Working Group, 2013). For people with dementia it is widely recognised that they face cultural, social and economic barriers to fulfilling their rights (ASI, 2016a) and in response to this, The Alzheimer Society of Ireland and the Irish Dementia Working Group (2016a) recently published a *Charter of Rights for People with Dementia* outlining underlying principles relating to participation, accountability, non-discrimination and equality, empowerment and legality (PANEL) which are of fundamental importance in applying a human rights based approach in practice.

Sykes and Groom (2011) state that infringement of human rights are not always intentional and can result from systemic weaknesses such as inadequacies in service delivery, failure to balance different types of risk, lack of accessible information about available services, lack of standardised assessment practices and resource constraints. Health and social care services for older people have enormous potential to protect and promote their human rights. For example, the right to live their lives as independently as possible, with dignity and security, autonomy, choice and privacy (Sykes and Groom, 2011). From the perspective of older people therefore, the psycho-social dimensions of care become increasingly important as the potential for a loss of dignity increases with age, particularly as health declines (Vaarama, 2009). In this way, how older people receive and experience care provision is of critical importance as is their right to make decisions about their care.

2.7 CAPACITY AND SUPPORTED DECISION-MAKING

Despite a growing recognition of the importance of person-centred, inclusive and integrated approaches to care planning, the experience of older people's involvement in decision-making varies (DOHC, 2008). Older people are reported to have lower levels of influence over decisions in comparison with family members, which may result in them being left out of decision-making processes (Donnelly, 2012). In addition, the physical involvement of older people in care planning and decision-making does not necessarily guarantee genuine involvement (Hedberg et al, 2007; Donnelly, 2012), particularly for those older people with impaired capacity or dementia. Organisational pressures such as discharge deadlines, limited resources and time pressures can also make for hurried decision-making practices which can contribute to the older person feeling coerced (Dyrstad et al,2015) into processes and plans that are not sensitive to their needs or wishes.

In 2015, the long-awaited *Assisted Decision-Making (Capacity) Act* (ADM) was published. This Act repeals the *Marriage of Lunatics Act* (1811) and replaces the *Lunacy Regulation (Ireland) Act* (1871) and is a significant step in enabling Ireland to ratify the UN Convention on the Rights of Persons with Disabilities. The Act also replaces the Wards of Court system and extends the remit of the Enduring Power of Attorney and legislates for Advance Healthcare Directives.

The guiding principles of the ADM legislation are to replace the existing status approach to capacity. Under this legislation, cognitive capacity, regardless of age, appearance or diagnosis, is to be assumed unless shown otherwise, and a task or functional approach to capacity is to be taken. The Act replaces the 'best interest' model currently operating and introduces a model of will and preferences where people's values must be central to all decision-making and a supported decision-making approach is adopted.

It is generally accepted that the legislation will respect the rights, dignity and autonomy of people who experience fluctuating capacity (ASI, 2016b). However, it will require support structures to enable implementation, detailed codes of practice for health and social care professionals as well as an attitudinal and cultural shift in how decisions are made and in how people with impaired capacity are involved in this process; at the time of going to press the ADM Act has yet to commence.

2.8 GOOD PRACTICES IN OLDER PEOPLE'S SERVICES

Around the world, those responsible for providing support services to older people are being challenged by how best to care for rising numbers of older people with complex needs. Moreover, we must recognise that care needs can change and increase over time, particularly for people living with a progressive condition such as dementia. There is, however no mechanism to take this developing and fluctuating need into account in resource allocation.

Age UK (2013) ascertains that service design and delivery should fundamentally be based on what older people say they want and need. Care at home is cheaper than care that is provided in institutions such as hospitals and nursing homes (SCIE, 2014). Globally, older people with health or social care needs may require support or interventions from a number of services which, in turn, makes it necessary to tackle the longstanding issue of coordination across agencies and coordination of budgets (Age UK, 2013). Flexibility is critical to service delivery at a local level, alongside an acknowledgement and acceptance that 'one size does not fit all' in the care of older people (Glasby and Dickinson, 2014).

It is also important to consider that older people are especially vulnerable to loneliness and its negative effects on health and wellbeing (Age UK, 2013). Although the issue of loneliness has attracted increased attention from the non-government sector, combating loneliness has not been a priority to date in health and social care policy in Ireland (Harvey and Walsh, 2016). A recent Institute of Public Health in Ireland report suggests that 10% of older people are affected by chronic or persistent loneliness which may be linked to depression, increased nursing home admission, decreased quality of life and cognitive decline (Harvey and Walsh, 2016). It is crucial therefore that home support services address not only physical care needs but also the critical social needs of community dwelling older people in order to prevent loneliness.

Older people meanwhile, place great value on continuity of care workers, social contact with carers and building a relationship of trust. This is also paramount for people living with a cognitive impairment or dementia. In practice however, care workers are often unable to spend enough time with older people to meet these important needs (Sykes and Groom, 2011), having insufficient time to attend to anything other than the older person's very basic functional needs (Vaarama, 2009; Calnan et al, 2012). In addition, HCPs are often inflexible and the timing of care visits, especially for older people who need assistance getting to and from bed, are experienced as demeaning and degrading (Sykes and Groom, 2011).

Significantly, dignity is relevant to both those who provide care as well as those who receive it (Lloyd et al, 2012). In this context, it has been recommended that an integrated approach to assessment should be embraced. This approach would include asking family carers whether they are willing and able to continue caring (Age UK, 2013) and what supports are required in order from them to do so. In this way, an integrated assessment considers both the older person and their family or informal carer's needs in deciding what resources may best support and foster the older person's autonomy and independence, but also the important caregiving relationship.

Section 3: Preferences for Care, Involvement in Decision Making and Care Needs Assessments

This section profiles the older people using the social work services examined in the survey. It then focuses specifically on three key areas, namely older people's preferences for care, their involvement in directing their care and more broadly care need assessment approaches and practices.

3.1 THE CARE AND SUPPORT NEEDS OF OLDER PEOPLE

The 38 social workers who participated in the study provided quantitative data on cases open in June 2015. This involved 788 older people. Over a third of the older people lived alone (36%), with a smaller proportion living with a partner (26%) or family member (17%); 8.6% lived in long-term residential care, with the remaining 12% living in sheltered housing, with a friend or had other arrangements.

The level of dependency (as defined by the HSE) was varied. Figure 1 provides a breakdown of cases and dependency level by setting. It shows how 34% (n=265) of older clients in the reported sample had low dependency, 28% (n=221) with medium dependency and a slightly higher proportion 38% (n=300) reported as having either a maximum or high dependency level. Over 40% of disability and medical social work caseloads concerned older people with high to maximum dependency level.

Figure 1: Dependency level of older people across social work area (n=786*)
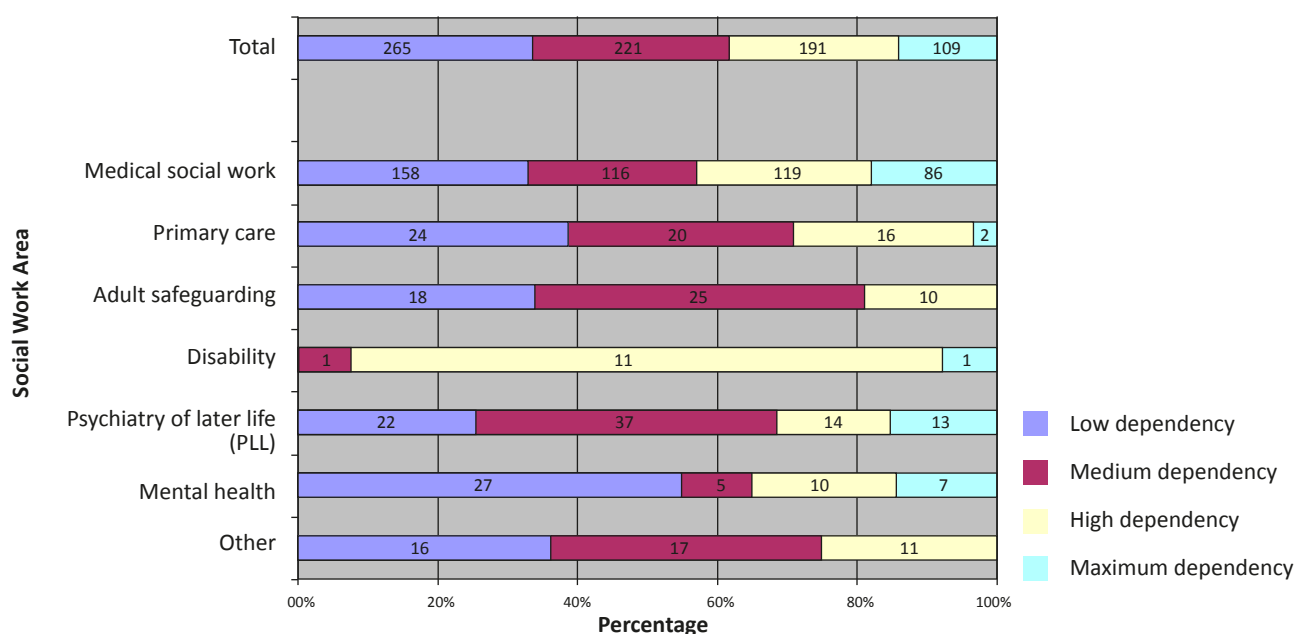
* 2 cases not reported on

One-in-four of the cases referred to in the survey data were identified as being complex cases which reflects the high and maximum dependency levels as shown above.

To gain an insight into the level of cognitive impairment/dementia among the older people referred to in the study; respondents were asked how many of their clients had a diagnosis of dementia. A high proportion (39%) or almost two-in-five had dementia.

Respondents were also asked how many of their clients they believed had dementia. This came to 44.5%, a higher figure than those with an actual diagnosis, pointing to the possibility of a substantial number of undiagnosed cases.

3.2 OLDER PEOPLE'S EXPRESSED PREFERENCE FOR CARE AND SUPPORT

Older people's preferences for care were examined as part of the research. Social workers who participated in the research reported that from their experiences the vast majority of older people wanted to receive care and support in their own homes:

> *"I have never met anyone who was happy to go to long-term [residential] care; there's a lot of grief and loss" (A16, Mental Health, Area G)*

However, it was noted that older people did not always have a choice about where they receive care:

> *"I could count on one hand the number of people who want to be in the facility. Many people eventually accept their situation – they see it as having no other choice" (A8, Medical, Area B)*

> *"Very few people want to go to LTC[3], but 'it's a necessary evil. They never want to go to LTC, it's more a case of asking them can they live with this as a compromise" (A7, Mental Health, Area G)*

Reasons for admittance to long-term care are addressed in greater detail in Section Five.

3.3 INVOLVEMENT IN DECISION-MAKING

The involvement of people in making decisions around their care is central to ensuring their care preferences are recognised. Survey respondents were asked how many of their clients were involved in decision-making related to their care planning. Of the 715 older people whose cases were examined under this question, their social worker said that 61% (n=435) were involved in decision making, 24% (n=172) were somewhat involved and 15% (n=108) were not involved at all.

Interview participants noted a cultural shift in recent years and while the numbers of older people involved in decision making is still low, there is greater evidence of a rights-based approach being adopted:

> *"I would try to educate people about older people's right to make good and bad decisions. I would insist on speaking to the older person first, and begin by saying "You are the boss", I am here to do whatever you want, to empower you" (A10, Community, Area D)*

However, practices differed and at times involvement was found to be tokenistic:

> *'They are involved in so much as they are fit to be. I have had to challenge some situations where the older person is being involved in a tokenistic way only' (A17, Medical, Area G)*

Various ways of facilitating older people's involvement was described in survey data, from one-to-one discussions between the social worker and the older person, through to care planning/family meetings or a combination of the two. Not surprising, given the study's sample, the main process for involvement was identified as discussions with a social worker as shown in Figure 2 below. Involvement through discussion with a geriatrician or Multi-Disciplinary Team meeting was also evident.
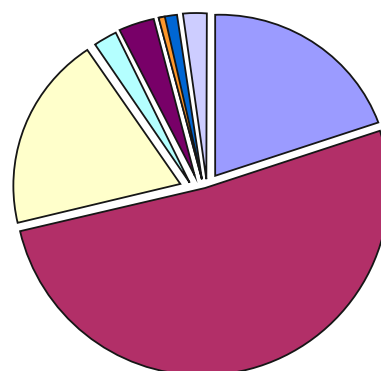

Figure 2: Method used to involve older person in decision making (n=562)

- Discussion with Social Worker 52%
- MDT care planning meeting 20%
- Discussion with Geriatrician 20%
- Discussion with PHN 3%
- Other 2%
- Discussion with PLL 2%
- Advanced Care Directive 1%
- Discussion with GP 0.36%

3 LTC - long term care

Involving people through a formal meeting was cited by many as a key element of the decision-making process between older people, their families and Health and Social Care Professionals (HSCPs). However, there was no standardised practice for this and there were variations in how people were routinely involved in these meetings:

"The older person is brought to our case conference. Where a person wishes to attend, but is physically unable, the case conference takes place in the person's home...If the person is reluctant to participate the social worker would meet them beforehand and brings their views to the table. The social worker always documents the older person's views" (A10, Community, Area D)

There were also examples of good practice, for example in a dementia specific project:

"[There is] person-centred care in the psychiatry service, [so] care planning is done with the person in their own home" (A11, Mental Health, Area D)

Positive involvement of older people was also supported through collaborative working relationships across HSCPs. The advantages of a Multi-Disciplinary Team (MDT) approach were clear and an integral part of the process of striving to involve older people in decision-making about their care. However, this approach was not always evident within the acute hospital system, where:

"There is very much a service based approach in this hospital which is strongly influenced by the consultant's personal opinion...there would be a tendency not to bring the older person into care planning meetings here" (A15, Medical, Area J)

At times the older person was excluded completely and family members made the decision on their behalf:

"Quite often the older person isn't involved and often the families make the decision for the older person...this would happen in about 90% of my cases...the situation is the same for both those with and without dementia" (A21, Community, Area F)

Health and social care professionals' dependency on family carers to facilitate discharge arrangements was often the reason the older person was completely excluded from decision-making:

"The social worker talks with the older person about plans, etc. before any discussion with family members. However, doctors don't always follow suit. Rather, they often go directly to the family and by-pass the patient. Ageism is rife in the hospital" (A9, Medical, Area B)

Participants acknowledged the difficulties they often experienced in balancing the older person's involvement, needs and preferences with that of their family members:

"Often there can be disagreements between the patient and a family member...If there is family anxiety relating to an older person remaining at home, I would try and explain things from a human rights perspective and also use the legislation to highlight that an older person can't be detained or sent to a nursing home against their will" (A12, Mental Health, Area D)

The critical role which family members play in supporting older people to remain living at home was also a factor in the decision-making process, as summed up by an interview participant:

"Families are involved 24/7, so you need to work with them. Once they feel supported and listened to, families will generally buy-in" (A6, Mental Health, Area E)

"In some instances, the older person may delegate decision-making to family members because, as one interview participant highlighted, 'they find the systems and structures so confusing and this puts them off being involved" (A16, Mental Health, Area G)

3.3.1 Decision-making and capacity

To explore the involvement of clients with dementia in the decision-making process, survey respondents were asked how many of their clients with dementia were involved in decision-making. It was reported by participants that 55% (n=166) of people diagnosed with dementia were involved in decision-making.
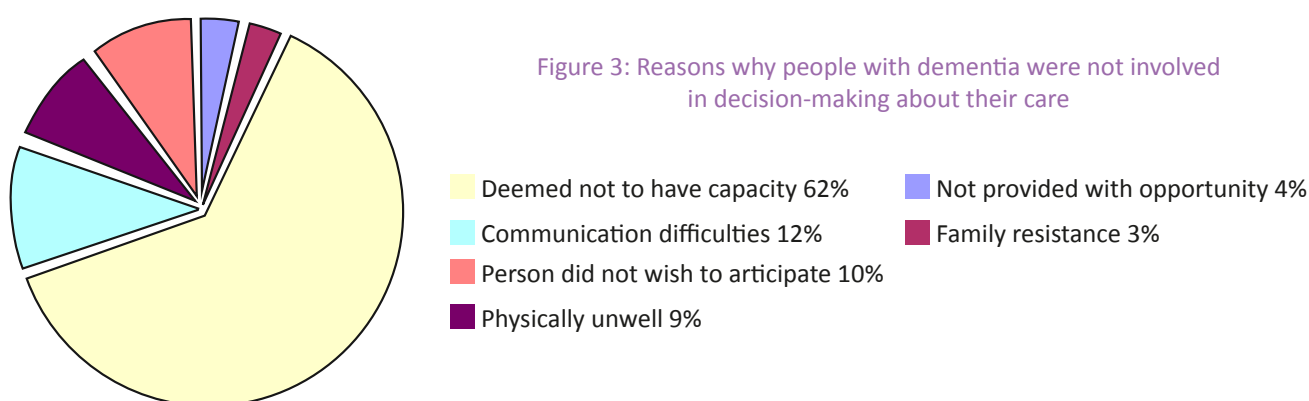
The qualitative findings provide an in-depth insight into how capacity affected involvement in decision-making. Interview participants unanimously recognised the significance of the older person's capacity in this regard:

> *"If a person didn't have capacity, I would try and involve them, or I would advocate on their behalf. There are time implications in involving them, but it is so important to do this. Different professionals have different practices, but overall, there are positive experiences and we would try and follow a person-centred model" (A16, Mental Health, Area G)*

However, other respondents reported that a person with dementia was unlikely to be involved or a status approach was taken with their involvement becoming tokenistic:

> *"For a person with dementia an assumption is made based on their MMSE[4] score about whether they can be involved or not. The social worker would try and work closely with the OT. Based on the CSAR[5], in principle, they should be involved but in practice they aren't" (A15, Medical, Area J)*

From the survey, respondents identified a number of reasons why people with dementia were not involved in decision-making about their care (see Figure 3 below). It shows that some were not given an opportunity, or their family vetoed their involvement, but in the majority of cases they were deemed not to have capacity to meaningfully take part.

Figure 3: Reasons why people with dementia were not involved in decision-making about their care

- Deemed not to have capacity 62%
- Communication difficulties 12%
- Person did not wish to articipate 10%
- Physically unwell 9%
- Not provided with opportunity 4%
- Family resistance 3%

The complexities caused by dementia were identified as a barrier to participation also by social workers who participated in the interviews. For example, the longer time it took to ascertain the person's wishes. In many cases the current care system is not seen to be supporting autonomy:

> *"There are no differences in older people in relation to any clients we deal with; they are all involved in decision-making...the elephant in the room is around capacity...the current approach is too simplistic and the current system is not fit for purpose...there is no concept of functional capacity at the moment and everything is very medically led. When they don't have capacity they're not really involved and if they are, it tends to be tokenistic" (A19, Community, Area H)*

---

4 **The Mini Mental State Examination (MMSE)** is the most commonly used test for complaints of problems with memory or other mental abilities. It can be used by clinicians to help diagnose dementia and to help assess its progression and severity. It consists of a series of questions and tests, each of which scores points if answered correctly

5 **CSAR is the Common Summary Assessment Report** which is a HSE multidisciplinary assessment form used when assessing the care needs of older people for community and long term care.

Where dementia specific staff were available to provide support, positive outcomes were reported:

> *"We have a dementia adviser in our area who is very good. Her role is so important as she is seen as someone outside the PCCC Team" (A3, Community, Area C)*

3.4 CARE NEEDS ASSESSMENT

Beyond getting the older person's input into determining their care need and what service/support should be provided, findings show that the process of care needs assessment was also informed by

   I. Subjectively based, locally determined criteria for prioritisation
   II. Level of risk perceived and risk avoidance
   III. Assessments focused on physical care
   IV. The older person's resources including family support and their social and financial circumstances.

Each of these is addressed in turn below. The theme of limited services and support also emerged, and this is addressed in greater detail in Section Four.

Several participants said that the Public Health Nurse (PHN)[6] was central to the assessment process in getting home support hours. In the majority of cases, the PHN alone, or in conjunction with a social worker, Occupational Therapist (OT) and/or family was the key decision-maker in applying for a Home Care Package (HCP):

> *"You have no control over HCP hours, you make the case, the PHN makes the assessment" (A12, Mental Health, Area D)*

It was observed that the involvement of a senior doctor could speed up the assessment and delivery process:

> *"Getting a consultant on board from Psychiatry of Later Life, means that services can usually be accessed a bit quicker" (A19, Community, Area H)*

In a similar way to best practice in involving older people in decision-making around their care, findings indicate that MDT approaches are identified as best practice in carrying out care needs assessment and in some areas this was a *'well established process'* (A3, Community, Area C). However, what was evident was there was no standardised approach and an older person may *'undergo double and triple assessments'* (A15, Medical, Area J). In one acute hospital for example, the MDT completed a CSAR-based assessment and the local community liaison PHN carried out an additional assessment, using their 'own schedules' or assessment forms. It was reported that the latter usually determined the allocation of care hours and services, regardless of whether the assessment agreed with or contradicted the initial hospital MDT assessment.

3.4.1 Prioritisation

It is commonly known that community health and social care resources are limited and a significant theme to emerge from the data was how people were prioritised within this context. Findings showed that there was no formal or standardised prioritisation process in place. At times, individuals were prioritised based on their age, whether they lived alone, their perceived vulnerability and whether they were assessed as a hospital delayed discharge. Different approaches operated in an informal way in each area:

> *"Informal prioritisation ... if they are deemed vulnerable, such as having a cognitive or mobility issue, or lacking family support" (A15, Community, Area J.)*

If *'they are over 85'* (A16, Mental Health, Area G), and/or their medical condition *'has deteriorated'* (A5, Community, Area A).

---

6 **Public Health Nurses** (PHN's) supply many basic nursing and medical needs. They often act as a point of access for other community care services. Services provided by PHNs vary from area-to-area and a number of specialist services are provided in some community care areas; these include out-of-hours nursing. The HSE is obliged to provide a free nursing service to medical card holders.

In some areas dementia was a 'red flag' for prioritisation, resulting in *'people with dementia getting services more quickly'* (A21, Community, Area F). However, this was not the case in every area, and many participants reported that there were no exceptions for people with dementia (A17, Medical, Area G).

At an organisational level, there was consensus amongst interview participants that care resources were focused on the needs of the older person being discharged from the acute hospital:

> *"Priority would be given to patients in hospitals because of bed blocking issues, both Fair Deal and Home Care Package applications for hospitals would be prioritized" (A6, Mental Health, Area E)*

In cases of elder abuse, participants spoke of working closely with the Adult Safeguarding Team, to put supports in place and these cases 'warrant getting sent up the line' (A19, Community, Area H) in order to access the required level of supports.

3.4.2 Risk aversion
In many cases the level of risk was key to decision making:

> *"The person's needs and level of risk determine care allocated" (A14, Community, Area J)*

Formal assessments therefore, were 'deficit based', with the focus being on the allocation of scarce resources to those perceived most at risk. The outcome according to this participant:

> *"Has to do with the level of risk; this results in us looking at things negatively and focusing on what people can't do, rather than what they can do" (A15, Community, Area J)*

Risk was also repeatedly cited as a strong influencing factor on family decision-making. Participants noted how families as well as professionals can be *'very cautious and risk averse'* (A6, Mental Health, Area E).

> *"Panic sets in ... concerns around risk. This directs families to look more towards LTC, even for those older people with only a mild dementia. Community services are often reluctant to go in because of risk (A15, Medical, Area J.)*

It was reported that many HSCPs are often concerned about the impact of perceived risky decisions on themselves as professionals:

> *"Many professionals have a risk mentality which usually means thinking about the risk to themselves if anything goes wrong, rather than the interests of the older person. Management, particularly nursing management do not give support" (A5, Community, Area A)*

> *"Defensive practice' is common ... if something goes wrong, people are afraid of being blamed. We are making it impossible for people to go home" (A15, Medical, Area J)*

It was noted that professions differed in their understanding of risk, as this interview participant explained:

> *"For me, I'm OK with people staying at home with risk ... but there are people we feel might do better in LTC. Once we are clear about the risks, that's the main thing. [If they say] "I would rather take the risk and die at home", we would try and respect their autonomy. There would be a lot of concern that the older person might fall and die, but at least they will die having lived their life in the way they wanted to" (A3, Community, Area C)*

3.4.3 A health and social care system focused on physical care needs
One of the most common themes to emerge from the qualitative data was that our health and social care system is focused largely on physical care needs. In all areas, priority in the allocation of services was given to older people with personal physical care requirements while older people with social needs, related to

loneliness, for example, were reported to be *'lower down the list'* (A14, community, Area J). This was reflected in the usage of needs assessments tools which have a physical/personal care focus and are not tailored to identify specific issues relating to cognitive impairment and dementia:

> *"Assessment for home support is based on the assessment used for all older people. Hence the person with dementia has to have personal care needs. However, in many instances their needs may not be for personal care, but for support to go shopping, or someone to stay with the person whilst the carer takes a break" (A7, Community, Area E)*

Another example of this is the commonly used CSAR assessment:

> *"The CSAR...is heavily reliant on the Barthel Index[7] which the nurses would usually fill out. However, a person with dementia could technically come out as having no care needs using the Barthel as an assessment tool. The need for prompting and supervision is not given as much weight" (A16, Mental Health, Area G)*

3.4.4 Available resources – role of families in care provision

It has been shown in the literature and earlier findings that there is a heavy reliance on family members to provide the main bulk of care for older people in Ireland. Participants spoke of the huge role which family carers play in supporting older people to be cared for at home. They often undertake this with little formal support:

> *"A lot of carers, I don't know how they are keeping loved ones at home needing 24 hour care. They are getting very little support from the community [services]" (A1, Community, Area D)*

This theme was also identified in how the older person's care needs was determined. For example *'where family are available, people are less likely to get a service'* (A5, Community, Area A) especially:

> *"If there is an adult child living in the house the expectation would be that they should provide care. I had a recent case of an 85 year old who lived with her 82 year old sister and it was expected that a family member would provide care" (A16, Mental Health, Area G)*

Even where some support is provided, there is *'an expectation that the family will cover weekends'* (A10, Community, Area D).

Lack of support for family carers, was a factor in determining admission into long-term care, where an older person perceived themselves as becoming a burden on family members:

> *"The person often comes to a stage where they feel it's too much of a burden and say, I want to go into a nursing home" (A11, Mental Health, Area D)*

---

7 Barthel index of daily living (Barthel) is a method of assessing and communicating to other health professionals the degree of disability in a particular individual.

The findings echo previous Irish research studies, which show that older people want to remain living at home for as long as possible and to receive care there when it is needed. A striking outcome from this research was the evidence of a lack of consistency across areas and disciplines in involving older people in decision-making about their care. Good practices were identified with MDTs playing a key role and formal meetings serving as a vehicle to promote involvement. Balancing the older person's preferences and those of family carers is a difficulty, due to the reliance of the system on family members to provide care. Disparities in how people with dementia are involved in decision-making highlights the need for clear guidelines for all HSCPs including doctors and consultants, as a status approach was often taken – if the person had dementia they were not involved. Indeed, the high number of people living with dementia using social work services was notable.
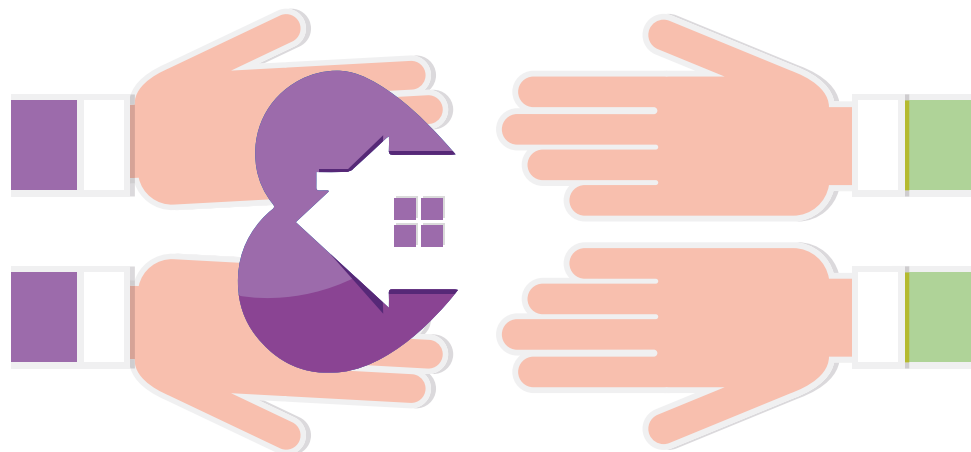
In terms of care needs assessment, outside of stated preferences, there were a number of factors which determined the provision of services/supports. For example, people were prioritised in different ways in different areas – by age, living situation, delayed hospital discharge and the presence of dementia. Risk was another key theme, which included the health care professional's fear of liability and families being protective of their loved ones. In addition, methods for assessing care need were predominantly focused on physical care needs. Worryingly, these often failed to identify the real needs of people with cognitive disability/dementia, such as the need for supervisory support. Unless individual care needs are identified, they cannot be met.

Section 4: Provision of Services

It has already been shown in the literature and in the study's earlier findings that the current health and social care system relies heavily on family members to provide care. Where families cannot provide care or the older person does not have family available, a range of formal care services are in place. These services focus on supplementing care in the home such as home help (HH) services and Home Care Packages (HCP) or providing long term care (LTC) in institutional settings.

This section outlines the findings relating to accessing these services and also sets out the themes that emerged when we examined where and how services were being provided.

4.1 ACCESSING SERVICES ON HOSPITAL DISCHARGE

Of those people who were in hospital at the time the survey was conducted, 315 clients were discharged from acute care settings. The majority 60% (n=186) were discharged home. A further 11% (n=36) were discharged to long term care, while another 12% (n=38) were discharged to transitional or interim care beds to await long term residential or community care to be put in place. Only 9% (n=29) of those discharged were transferred to rehabilitation beds. The remaining 8% (n=26) were transferred to other hospitals, the hospice, family member's home or another arrangement was put in place.

Service delays from acute settings

The survey shows that nearly 30% (n=144) of social work cases in acute hospitals in June 2015 were medically ready for discharge but were awaiting supports to be put in place. As illustrated in Figure 4, delays in discharge were most (48% of cases) likely to be due to inability to access home supports rather than LTC. Of these, the majority (n=61) were awaiting approval or implementation of a HCP, while eight were awaiting other community supports such as equipment. In 33% of cases (n=47), older people were waiting on a LTC bed.
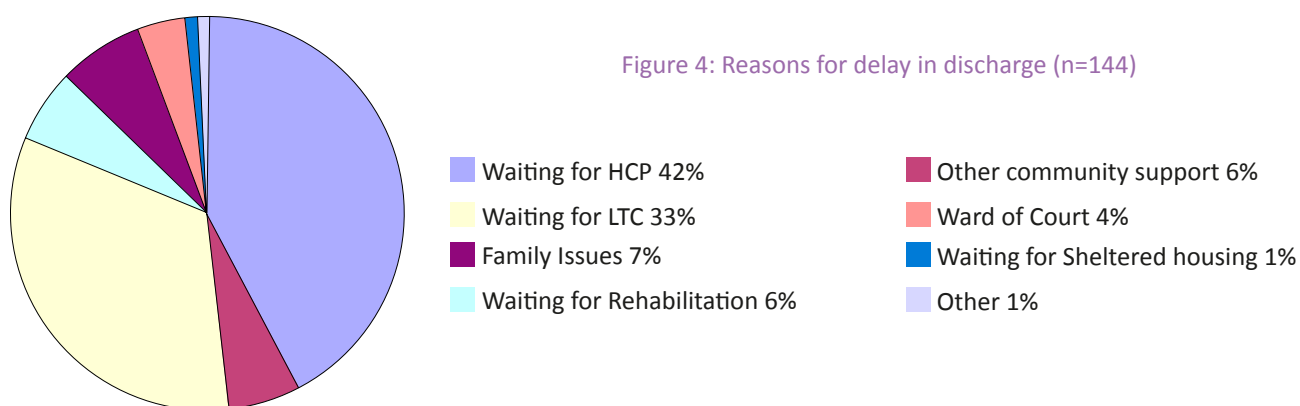
Figure 4: Reasons for delay in discharge (n=144)

- Waiting for HCP 42%
- Waiting for LTC 33%
- Family Issues 7%
- Waiting for Rehabilitation 6%
- Other community support 6%
- Ward of Court 4%
- Waiting for Sheltered housing 1%
- Other 1%

Furthermore, medical social workers who completed the survey reported that over the month of June, they had difficulty and were unable to access home help, home care assistant, Intensive Home Care Packages (IHCP), night time supervision, home adaptation grants, equipment, respite and day care for their clients.

4.2 ACCESS TO SERVICES FOR OLDER PEOPLE DWELLING IN THE COMMUNITY

Twelve social workers based in the community completed the survey. They included four in primary care, one in mental health, two in adult safeguarding, three in psychiatry of later life and two working in other areas. These community social workers had a total caseload of 257 clients who lived in the community. Of these, 37% (n=94) were waiting for appropriate services or supports to be put in place in the month of June. Community-dwelling older people also experienced delays accessing a number of services/supports as outlined in Figure 5. Like those in hospitals, social workers in the community experienced delays in accessing

HCPs, with 30% of clients waiting (n=28). However, for older people in the community, social workers found it particularly difficult to get an assessment of the older person's needs, with 35% waiting for an assessment (n=33), resulting in the older person not having their needs recognised or addressed in a timely manner.

Figure 5: Delays experienced by older people in the community (n=94)

- Waiting for Assessment by Healthcare Professional 36%
- Waiting for HCP 30%
- Waiting for LTC 18%
- Waiting for Sheltered Housing 7%
- Other 5%
- Ward of Court 4%
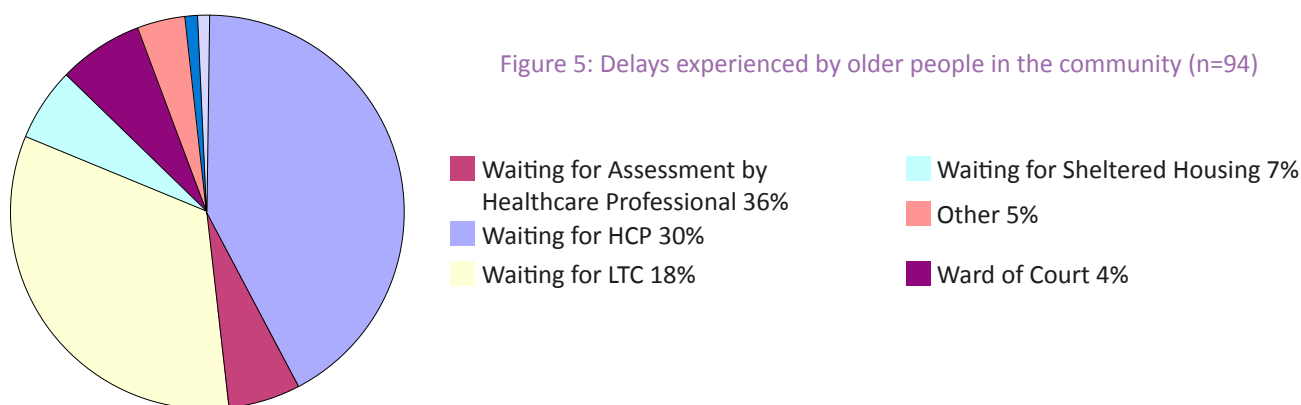
In addition, it was reported there were a group of people in the community who needed particular supports but these were unavailable including home help hours, IHCPs, night time supervision, respite and day care, Meals on Wheels and home appliances.

For older people in hospital and at home, accessing timely home care in the community was found to be more difficult than accessing long-term residential care. Waiting times for home care package approval/implementation varied from one month to six months, with applications made through hospitals receiving quicker responses. The area in which a client lived was also a differentiating factor. For other supports, like home help, an older person living in the community could wait up to a year for the service.

4.3 DIFFICULTIES ACCESSING HOME CARE AND COMMUNITY SUPPORTS

As shown above delays or difficulties were identified for both older people in the acute systems and for those accessing care from home. The latter will be addressed in further detail below.

Home Help Services

Findings from the qualitative data pointed to a number of difficulties with the Home Help (HH) service, including:

- Long waiting times
- Red tape and lack of flexibility
- Time-to-task approach
- Move away from domestic support
- Lack of recognition of psycho-social needs.

In addition, while HH services exist in all CHO areas, there were discrepancies based on geographical location.

It was reported by many participants that it was difficult to access home help support with long waiting times:

"Often the situation is that you are waiting for someone to die to access hours" (A15, Medical, Area J)

Across all areas, the available HH service was minimal and ranged from less than an hour to a maximum of five hours per week, usually Monday to Friday, between 9am-5pm. Participants stated that applying for HH hours for an older person was not a simple process, requiring tenacity and time:

"There is so much paperwork involved just to get 1 hour of HH per week...this is very stressful for the older person" (A16, Mental Health, Area G)

"I dread making HH applications...takes a huge effort...like begging, for example, a person fell out of bed broke ribs, couldn't dress...I asked for one hour per week...process took three phone calls to the PHN...wrote a three-page report; included personal care for dressing and washing needed...have to make case sound really bad. Home help co-ordinator allocated three quarters of an hour per week" (A11, Mental Health, Area D)

In addition, HH services were identified as *'very short, task oriented visits'* (A5, Community, Area A) with *'the main support provided, to get the person up in the morning'* (A1, Community, Area C).

The shift away from domestic care toward personal care meant that in many cases the person's real needs were not being met:

"Often [for] the people [in the community] we are coming into contact with...domestic tasks may be where their greatest need lies. It's that big gap, we can wash them but we can't feed them" (A3, Community, Area C)

The 'time-to-task' approach presented issues:

"It's all about minutes and tasks...[they] may allocate half an hour to a man for a shower...this ignores that, to ensure this task is carried out with dignity for the man, this task needs more time...a carer can't go in and stick the man in the shower, it is a process" (A11, Mental Health, Area D)

This approach was exacerbated by longer distances to travel in rural areas:

"Allocation of hours isn't the issue, it's getting people to do the hours ... in rural areas where people are allocated staggered hours of say a half hour in the morning and evening, it's very difficult to get people to do the time as private agencies do not pay for travel time" (A7, Community, Area F)

Interview participants argued that task focused care provision must change and a more holistic approach adopted:

"The home help needs to be allowed to sit down, have a cup of tea and chat as part of undertaking specific tasks. These types of things keep the person at home longer" (A11, Mental Health, Area D)

Determining needs within the narrow context of measurable tasks has consequences for those with complex needs, as shown in this example:

"Where they [the person with mental health issues] might be physically able to complete a task, but lack the motivation to do it ... there is definitely a lack of understanding about people who fall into this category" (A16, Mental Health, Area G)

This lack of understanding of people's distinct needs was identified as one of the biggest gaps for people living with dementia as well as *'access to supervisory hours [for people with dementia] through HH or HCP'* (A19, Community, Area H).

The psycho-social needs associated with dementia were not always understood by other professionals:

"If their only need is dementia, "Is that the only need they have?" tends to the attitudes of some services" (A16, Mental Health, Area G)

"There are also social care needs, for example, going for a walk, hospital appointments, giving family carers a break, etc., but these are not a priority" (A16, Mental Health, Area G)

Home Care Attendants

Home Care Attendants (HCA) were found to be available in some CHO areas, but in others there had been *'no HCAs for a long time'* (A5, Community, Area A). HCAs, often HSE employees, provide personal care, mainly helping an older person to shower. In many areas this role is now subsumed into home help services and the provision of home care packages. Where this role exists, participants reported that HCAs are *'hard to access'* (A20, Community, Area F), *'scarce'* (A15, Medical, Area J), with *'extremely long waiting lists'* (A16, Mental Health, Area G).

They may be limited to *'a token half hour visit, but what can any person do within half an hour?'* (A16, Mental Health, Area G), and when staff go on holiday or are sick, *'there is no one to replace them so [a] person may not get [a] bath or shower that week'* (A14, Community, Area J). Lack of dependability and flexibility in this service was also highlighted:

> *"One of the biggest problems with this service is that they won't give a specific time when they will call (could be 10am or could be 12pm) and this is problematic and bad for many of our clients. Private care agencies and HH services will give a specific time, but HCA's don't and are generally more unreliable" (A17, Medical, Area G)*

Home Care Packages

Home Care Packages (HCP) operated in all nine CHO areas, although the operation of the scheme differed between areas. In most, HCPs are targeted at older people assessed as requiring more than five hours of care per week, but the tasks included in HCPs varied. One participant described the HCP as being:

> *"More fluid'...this service is more focused on the individual and their needs, so it is flexible in the supports it can offer and can include domestic chores" (A7, Community, Area E)*

Another stated that:

> *"99% of support is for personal care. Only rarely will domestic support be provided through the HCP scheme" (A20, Community, Area F)*

The funding mechanisms for the HCP scheme were reported to differ from that of the HH, so some participants experienced slightly easier access to HCPs than to home help hours:

> *"If someone has no services, I would first try home help and then HCP, but this differs from area to area. In some areas, there is no funding whatsoever for home help, so you are advised to go straight to HCP application" (A16, Mental Health, Area G)*

In addition, waiting lists were common, particularly, where HCP applications were made from the community:

> *"There is definitely a deficit and waiting lists are in operation for community based applications and there would be priority given to hospital applications" (A20, Community, Area F)*

In the absence of a formal process, such as a centralised waiting list, one participant said that the outcome was that older people in hospitals requiring HCPs on discharge will have much quicker access as *'there is 100% availability [of HCPs] at present[8]. There are no waiting times for processing'* (A17, Medical, Area G). However, waiting times for a HCP in the community ranged from weeks to months with one participant describing the situation *'as a disaster'* (A4, Mental Health, Area A). On the other hand, in some areas, *'there are no waiting lists, and there seems to be no restriction on the number of hours provided'* (A7, Community, Area E), yet in a different area, there were no waiting lists but the *'hours available to people are limited'* (A1, Community, Area C).

---

8 Interview took place in October 2015.

Intensive Home Care Packages (IHCP)

Interview participants working in hospitals reported how they had *'managed to access one enhanced HCP of 56 hours'* (A15, medical, area J), in another hospital, a participant said *'we have been able to access intensive HCP's, up to 50 hrs per week'* (A17, Medical, Area G). However, there were no reports of social workers based in the community being able to access IHCP for the older people they are working with - *'there are no IHCPs'* (A1, Community, Area C).

Meals-on-Wheels

It was reported that the availability of Meals-on-Wheels was also influenced by geographical location:

> *"Ultimately it depends where you live" (A16, Mental Health, Area G; A15, Medical, Area J)*

In general, participants reported that where Meals-on-Wheels services were in existence, they were very good with few delays. One of the reasons given for this was that people pay for this service so it is available as required. Some services were reported to waive the charge if a person could not afford it. In some areas however, participants reported people could only access meals on three to four days per week and there were often waiting lists. Overall, the quality of the service generally depended on whether there was a voluntary service in place and how active it was. In some areas where Meals-on-Wheels were not in-situ, local businesses and restaurants, an interview participant noted, delivered meals to older people at a reasonable cost.

Respite Care

In all CHO areas, respite care was reported as being available, 'but in demand' (A3, Community, Area C). The majority of participants experienced difficulty in accessing respite care for their clients. Participants spoke of how *'there are always waiting lists of a considerable length of time'* (A3, Community, Area C; A21, Community, Area F), and of having to *'to book months in advance'* (A5, Community, Area A). One interview participant pointed out that the closure of public units due to an inability to comply with HIQA standards, had severely affected the number of respite beds available (A17, Medical, Area G).

Day care

Availability of day care services also varied widely between areas, and it was described as *'generally widely available'* to *'pretty good where it exists'*. In some areas the type of day care provided did not meet the needs of individuals: *'there is more of a focus on "social day-care" and less day-care is available that provides nursing or personal support'* (A3, Community, Area C). In contrast, another participant stated *'there is no such thing as social day-care'* (A19, Community, Area H).

Waiting times for day care varied, with some participants reporting waiting times of up to five months. In one centre the waiting time was more than a year, and it was seen by some social workers as somewhat futile to even refer clients.

Lack of transport, was also reported as being a barrier to accessing day care, particularly in rural areas:

> *"The biggest challenges are isolation and transport. Once you get into services, there is excellent day care service for people over 65. Waiting lists apply to some ... the problem is getting people there, especially in rural parts of county" (A11, Mental Health, Area D)*

The case study following illustrates the role transport plays in facilitating older people to engage with services.

4.3.1 Discrepancies between assessed need and number of HCP hours approved

Delving a little deeper to explore access to the appropriate number of home care hours available, survey respondents were asked how many older people in their caseload for the month of June were able to access the appropriate number of home supports/HCP hours. Medical social workers indicated that of the total number of older people receiving home care (n=100), a high percentage (40%) did not receive the number of hours they had been assessed as needing.

Figure 6 shows the level of home care hours approved through hospital applications and for community applications. The majority of those discharged from hospital requiring home care were receiving between 13 and 21 hours; which reflects the high to maximum levels of dependency reported by survey respondents. However, only seven were receiving an intensive home care package. In contrast, the majority of applicants from the community received 5 hours or less.

Figure 6: Home support hours approved
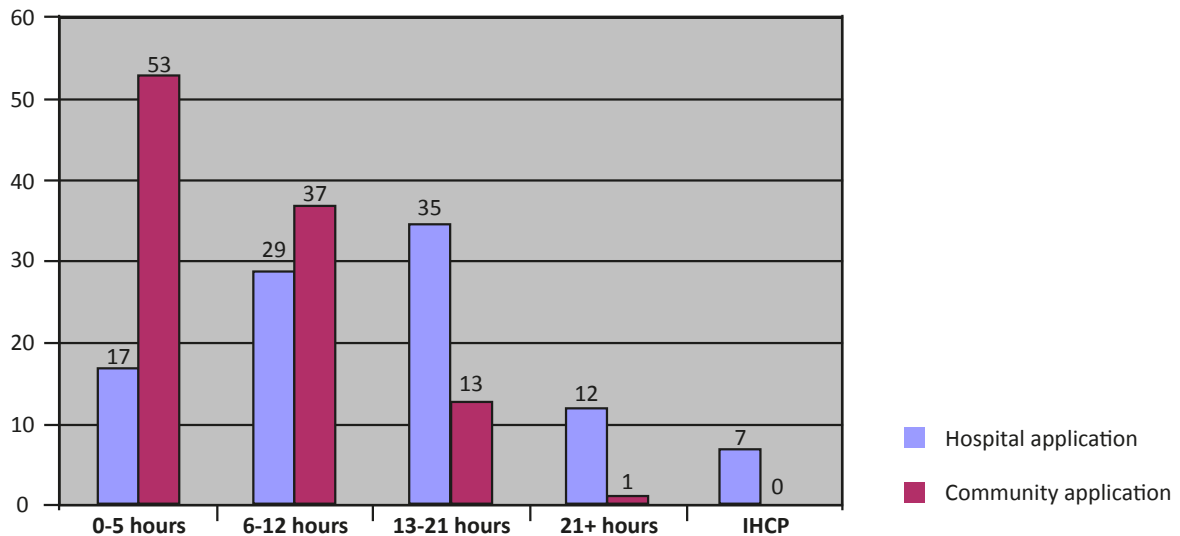
The qualitative data supported the survey data on the geographic variations in the availability of HH and HCP hours. The allocation of HCP hours to an area was not based on demographics, but set budgets. Therefore, in areas with a high proportion of older people, hours are *'spread more thinly'*. Demand for HCP hours frequently outstrips supply, with over half of the participants reporting a difference between the HCP hours the older person was assessed as needing, the amount applied for and the hours granted:

"This is mostly down to differences in professional opinions. [The] Liaison PHN may contradict and disagree with [the] initial hospital MDT assessment so once again a double or triple assessment of need takes place and it also means that the initial social work assessment is questioned" (A15, Medical, Area J)

"There would always be a difference in the number of hours approved due to lack of resources, so you get less hours than you applied for. If you asked for a call 7/7, you would usually get 3/7 though some times that would be increased" (A19, Community, Area H)

Case Study - Joe

Joe was allocated a Home Care Package of five and half hours per week for the following tasks:

- 30 minutes for getting Joe up five days a week
- 15 minutes extra allocated twice a week to help Joe with shower
- 30 minutes for 'back to bed call' in the evening is provided (at around 7pm) five days per week (A1, Community, Area C)

To ensure the older person gets the support they had been assessed as needing, one participant admitted that they and their colleagues regularly asked for more hours than required because they knew that generally whatever they asked for would be reduced regardless of the older person's circumstances. This was echoed by a number of other participants, one of whom commented that this stance *'...is ethically fraught'* (A16, Mental Health, Area G).

4.3.2 Abiding by the 'rules' and lack of flexibility

The lack of flexibility in the provision of hours and the limited types of support available were also identified as a having a huge impact on older people. It was reported that *'it is very difficult at present and things are much more rigid than they used to be'* (A15, Medical, Area 15). The lack of an individualised, needs-led approach was repeatedly cited by participants as a concern:

> *"There would be no exceptions made in relation to approving domestic support, even if the older person has no family or is socially isolated. What I am told is 'We cannot approve hours or support for domestic tasks" (A19, Community, Area H)*

> *"The formal carer may be allowed make a sandwich and leave it for the person's lunch, but cooking of a hot meal is not allowed" (A1, Community, Area C)*

Interview participants reported having 'to be creative' (A1, Community, Area C) in response to this:

> *"There is no means of accessing domestic support anymore unless it is piggybacked onto personal care. For example, if a carer is helping a person get out of bed in the morning, it may also be possible for them to make the bed (A17, Medical, Area G)*

> *"[With a HCP] the maximum a person can get is three calls per day. Due to budget constraints, it is usually only support for personal care which can be accessed, but if you can make an argument that it's cost effective, sometimes they will bend the rules in relation to meal preparation" (A18, Mental Health, Area H)*

Rigidity within home care service provision was also evident where simple things like assisting an older person into their car or applying non-prescription cream (A5, Community, Area A) were not permitted.

In the different CHO areas, local rules also applied to eligibility criteria and having a medical card could determine access to home care supports, appliances and the PHN service, as illustrated by these interview participant quotation:

> *"Even to apply for a HCP you need a medical card" (A20,Community, Area F)*

> *"A person without full medical card cannot be provided with equipment or primary care counselling" (A7, Community, Area E)*

> *"OTs now also won't supply new equipment to people who don't have a medical card, but there is some leverage (A19, Community, Area H)*

In contrast another respondent said:

"I'm not aware of the medical card being used to determine services"(A14, Community, Area J)

There was consensus amongst participants that available home care services did not meet the diverse needs of the individual older person. The narrow criteria used to determine need, and therefore eligibility for home care supports, excluded many older people from having their needs adequately met in the community.

4.4 LONG TERM RESIDENTIAL CARE

In the month of June, survey respondents working in hospitals reported that in the majority of cases, applications for NHSS funding were processed within 8 weeks, many applications taking less than 4 weeks. Respondents working in the community experienced longer waiting times, with the majority waiting 3 months or more for applications for NHSS funding to be processed.

In terms of waiting for a suitable placement, as illustrated in Figure 7, the majority of clients in hospital waited less than 3 months, whilst those in the community the majority waited over 3 months.

Figure 7: Waiting times for LTC placement*
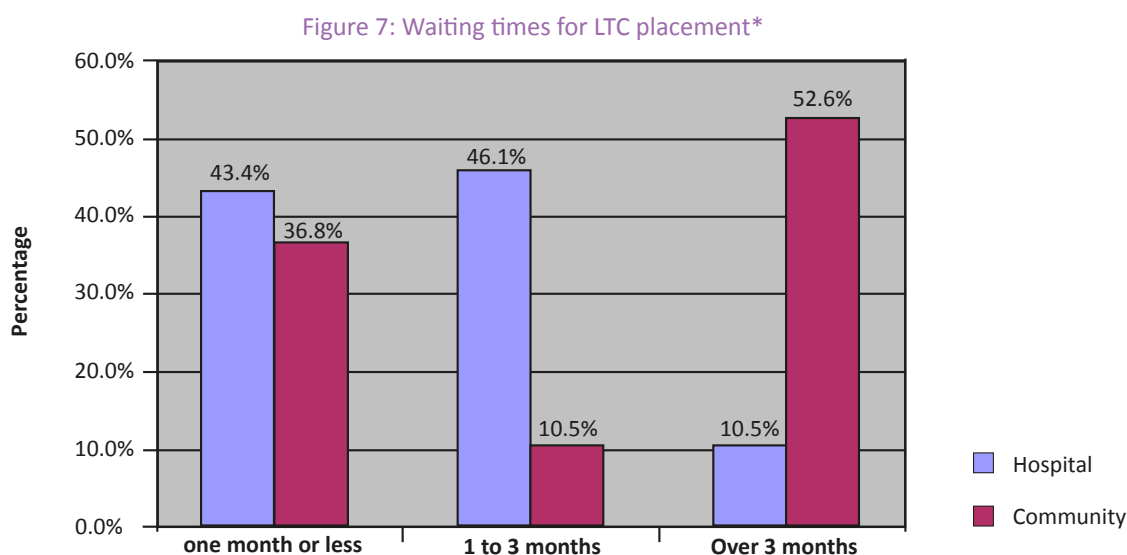
*Hospital (n=76) and Community (n=19) included cases closed as LTC placement identified.

The qualitative data highlighted that the delays in accessing LTC beds related to variance in the availability of such beds across areas. In some areas, participants reported high concentrations of nursing homes, while in other areas, nursing home beds were unavailable so the older person has to move away from his or her local community to get a bed:

"Accessing a suitable placement within geographical area is another problem; for those with older siblings who wish to visit the older person in LTC, often their siblings will have to travel a great distance as the nursing home can be quite far away" (A15, Medical, Area J)

Even within an area, there can be variations in bed availability. For example, in Area E, one participant noted that *'waiting times vary ... [they] really depend on when a bed becomes available. There is a shortage of beds in the area'* (A7, Community, Area E). On the other hand, another stated that *'it is generally easy to access nursing home beds as there are a high number of nursing homes in the area'* (A6, Mental Health, Area E).

The LTC process varied in many respects across and within geographic areas. A small number of areas experienced only short waiting times while others faced waiting times of several months or longer. However, participants did note a reduction in waiting times in the twelve months prior to the interview date.

The waiting times for approval of funding under the Nursing Homes Support Scheme (NHSS) varied also from area-to-area: *'On average 2-4 weeks'* (A5, Community, Area A; A18, Mental Health, Area H) to *'about eight weeks [for funding] to be released'* (A15, Medical, Area J).

However, in some areas, there were *'waiting lists to access funding and it can take up to three months for funding to be released'* (A6, Mental Health, Area E). Other issues included:

> *"Financial information may be difficult to access and a Ward of Court or Power of Attorney is required. These, along with Care Representative Applications, can hold things up and getting family members to agree can be a challenge. There are often family disputes or they may not accept that the older person requires LTC" (A20, Community, Area F)*

Waiting on Ward of Court decisions were reported to take seven to eight months (A4, Mental Health, Area A).

Another difficulty is the situation for farming families:

> *"People with farms can find it difficult to access NHSS funding because they may be charged for longer [on their farm] than the standard 3 years" (A4, Mental Health, Area A)*

Once again, it was seen as *'easier to access LTC beds from hospital'* (A1, Community, Area C; A15, Medical, Area J; A12, Medical, Area D).

Because of the demand for nursing home beds, participants reported that *'nursing homes more than ever are cherry-picking who they will accept'* with even public nursing homes refusing to admit people who are deemed to have high-dependency needs (A17, Medical, Area G):

> *"Some private nursing homes say they don't take 'walking dementia'" (A10, Community, Area D)*

> *"Nursing Homes are private business so [they] can cherry pick. On a couple of occasions, nursing homes have brought residents with challenging behaviours to A+E [Accident and Emergency] and refused to take them back. One example was a man, 85 years old, in a wheelchair who was dropped to A+E because his behaviour was too challenging for the nursing home to deal with ... he spent months in the Department of Psychiatry whilst a new nursing home placement was found. He died three weeks after being admitted to a new nursing home"*
> *(A12, Mental Health, Area D)*

> *"I have heard of three nursing homes [who] asked the family to take their relative out of the home because they could not manage [their] care" (A5, Community, Area A)*

Accessing places in dementia specific units was reported as particularly difficult due to lack of available beds:

> *"Just three to four a year, so waiting times generally are between 10 and 12 months because the facility is popular" (A8, Medical, Area B)*

4.5 SHORT TERM CARE AND REHABILITATION BEDS

Transitional Beds
The policy and practice focus of transitional beds is very much to alleviate the pressure on acute hospitals in larger urban areas, particularly in areas where people are awaiting the outcome of their NHSS application and/or a suitable nursing home bed:

> *"Those who have applied for the nursing home loan or State support are usually transferred to transitional care beds and there is a lot of pressure on us from discharge planning" (A15, Medical, Area J)*

Funding for transition beds is separate to the NHSS funding, and so was judged easier to access:

"Easier to access for transition beds, where person is waiting for the LTC process to be completed" (A14, Community, Area J)

Hence as this participant pointed out:

"I have a real problem with hospitals being used as gatekeepers and we have no access to transitional beds [for older people in the community]" (A3, Community, Area C)

Rehabilitation beds
Rehabilitation beds were not freely available, particularly for older people in the community:

"There are rehab beds in [the hospital] but only two community rehab bed ... so there's a lot of demand" (A3, Community, Area C)

Where an older person gets an opportunity for rehabilitation it can really make a difference, as Joan's case illustrates:

Case Study - Joan
Joan didn't want to go to LTC, but her family believed this was the best solution to meet her care needs. Joan was admitted to the rehabilitation unit for two weeks' respite. Prior to going in, Joan was very unsteady and it was hard to understand how she managed to self-care at all. Joan 'did brilliant' in rehabilitation and she was able to get around and undertake ADLs.

Tweaking home support hours also made a difference, Joan was initially allocated two hours over four days, however subsequently greater flexibility was allowed and the hours were spread over five days, which helped to better meet Joan's individualised care needs (A10, Community, Area D).

SECTION SUMMARY
The research shows that there were real differences in the capacity of individual social workers to access services from acute or community settings. Older people in acute services had shorter waiting times and access to more extensive services. It was also evident in the lack of access to intensive HCP's for community dwelling older people. However, delays were evident across all care settings.

Many difficulties were identified in accessing formal home care services, with lower hours given than the number applied for. Issues included:

- Minimal service availability and the operation of waiting lists
- The shift from domestic to personal care which didn't always meet need
- A time-to-task approach and a lack of understanding of the care needs of complex cases e.g. people with dementia
- A significant lack of flexibility and red tape which meant applying for home care packages was deemed most straightforward than applying for home help hours.

There was also a lack of transparency in older people's entitlement to services. Different CHOs took different approaches. In some CHO areas, for example, an older person had to have a medical card in order to access formal support services such as home help support, while in other areas this was not necessary. In relation to respite care, lack of compliance with HIQA standards had meant a reduction in the number of available beds. Nursing homes were also seen to cherry pick residents; reluctant to take those with advanced dementia. This was compounded by a general lack of available dementia specific beds.

Section 5: Integrating Care for Older People and Their Families

5.1 THE CONSEQUENCES OF BEING UNABLE TO ACCESS APPROPRIATE SUPPORTS

Findings show that without family support and appropriate formal supports there were serious consequences for older people, particularly in enabling them to remain living at home:

> *"Household tasks cannot be replicated if there isn't a family member to do these...it's impossible for someone to continue living at home if there is no one to supervise them making tea or meals" (A19, Community Area H)*

A lack of appropriate types of support, such as supervisory hours, could mean someone going into long-term care unnecessarily:

> *"Lack of supervisory hours is definitely leading to more people going to LTC. Persons with dementia are often slower or need more assistance and prompting in carrying out tasks. However, HCP Case Managers often don't recognise this and don't allocate extra time to accommodate this" (A17, Medical, Area G)*

> *"People with dementia are often pushed towards LTC because of the lack of services and the length of wait times" (A4, Mental Health, Area A)*

> *"It can also be because the older person lives alone and is lonely during the day. Some people could definitely stay at home a little longer" (A6, Mental Health, Area E)*

Lack of appropriate housing was also cited by participants as an issue that negatively affected people, for example, a person living in a standard hostel who now required more care and had to move out of the hostel (A14, Community, Area J). However, in many cases there was nowhere for that person to go, except to a nursing home.

Waiting lists and delays in funding also limited older people's options for returning home after an illness:

> *"Sometimes the delay is what triggers LTC. The longer people are in hospital, [the more] it decreases their chances of managing or going home" (A 15, Medical, Area J)*

Overall, the picture that emerged from the qualitative data is a home care service that is poorly resourced and simply cannot meet the real needs of older people. On paper, clients appear to be getting a service, but in reality the support provided may be minimal, less than an hour a week, despite the older person having being assessed by professionals, including a MDT, as requiring more hours. It appears that, as this participant contended:

> *"Senior Managers would prefer to have services in name rather than no services" (A12, Mental Health, Area D)*

Where an older person is perceived as vulnerable, *'the easiest option as opposed to the right one, is often taken'* (A13, Mental Health, Area J). Participants accused the system of making it easier to place someone in LTC than to help them stay at home because of locally derived 'rules'. One social worker gave the following example:

> *"An older person living alone in a rural area who is at risk of falls, doesn't have family or close friends and is unable to complete the [HCP] form, because of bad sight or literacy issues, may be encouraged to go into [a] nursing home, even though their care needs are not always such that they need nursing home care, but because the LTC option is 'easier in the long term' (A1, Community, Area C).*

The findings outlined in section three of this report show that the preferences of older people are to remain living in their own homes and to receive the necessary care and support which will enable them to do this. However, in reality, this is often not the case. Of the survey respondents working in acute hospitals, 14 respondents reported that of their clients discharged to LTC (n=36), to transition beds to await LTC bed (n=7) or those delayed in hospital awaiting LTC (47) in June, over 50% (n=47) wished to and could have remained at home, if the supports outlined in Table 3 were made available (the person may have required more than one of these services).

Table 3: Supports that would have enabled older people to remain at home

Unavailable support service	Number of people affected*
Home Care Packages	4
Intensive Home Care Packages	18
Flexible care support	4
Night time care support	21
Increased or more regular respite	7
Increased or flexible day care	4
Supported housing	4
Home adaptation	1

It is evident from this table that a higher level of support was required for some clients to remain at home such as night time care support and Intensive Home Care packages. However, access to lower level of supports such as increased or more regular respite, flexible day care, supported housing and home adaptation could have also facilitated some of the older people to remain at home.

5.2 AVOIDING UNNECESSARY ADMISSION TO LONG-TERM CARE

As is clear from the list above the absence of flexible community supports was identified as one of the barriers to being able to stay at home. The qualitative data supported this, with the majority of participants identifying the need for increased flexible, person-centred, community based/home supports:

"Increases in home-based supports including technology, awareness raising in the community, half-hour visits - sometimes 3-4 hours care per day isn't enough to sustain people at home. Overnight care is also very problematic as this is unavailable" (A20, Community, Area F).

"Monitoring and supervision issues need to be looked at and there is also a huge gap in terms of befriending for people who are lonely and also support with shopping" (A3, Community, Area C)

"More home support, home helps that take the person shopping, in rural areas if person can't drive, how can they access their pension, manage their finances, they must depend on neighbours or pay privately. If NHSS money [was] given to [the] local area, this would bring about change in the types of support availabl" (A1, Community, Area C)

In some areas, good practices were being followed and the benefit of providing a more flexible and a person-centred approach to the provision of services was evident. A participant said that access to *'very good respite services'* was the reason for low admissions to LTC in that area (A2, Community, Area C). Others pointed to positive changes brought about through the provision of home-care support to meet the specific needs of people with dementia.

"A family up all night, can get a dementia support worker who will stay over for example 2 nights in the week to allow the carer have a full night sleep, it keeps the family going, people are looking for very little" (A11, Mental Health, Area D)

Participants were keen to stress the crucial role voluntary organisations played in providing more flexible services that meet the social and emotional needs of the older person:

> *"Voluntary bodies will often fill the gap such as St Vincent de Paul, who have a visiting service'"(A18, Mental Health, Area H)*

> *"The Carer's Association and the Alzheimer Society of Ireland, there might be a bit more flexibility in relation to household tasks" (A19, Community, Area H)*

Participants felt that being able to access supervisory hours, however limited, from the Alzheimer Society of Ireland (ASI) was 'invaluable', as having someone to stay with the person allowed the carer to take a break and was *'an opportunity for social engagement for the person with dementia'* (A7, Community, Area E).

Another commented:

> *"The request for supervisory hours would usually go to ASI. Too many carers from different organisations is very difficult and challenging for the person with dementia as they can't form relationships or build trust, often we would just try to stick to carer support from ASI for continuity of care" (A6, Mental Health, Area E)*

Other supports which were identified as important in meeting people's preferences for care in the community included daily call services, befriending services, sitting services and overnight home respite *'which allows the older person to stay in their own home, rather than become upset in a different environment'* (A10, Community, Area D).

Home support services that offer consistency in staffing were mentioned as important. Frequently, participants noted the difficulties caused by changes of staff over the course of the day, where an older person was receiving up to three calls a day (morning, afternoon and evening) with each call from a different carer:

> *"The older people can be frustrated by this and often dispense with, or refuse the service because of this. Some have gone into a nursing home because of this" (A5, Community, Area A)*

The role of the family carer should be supported appropriately, rather than being refused a service, or getting a reduced service (A2, Community, Area C). Participants cited issues such as carer burnout, particularly where the person being cared for has a dementia, as the primary reason why older people went into LTC:

> *"The main reason for a person's admission to LTC is dementia. The family members can no longer support the person if they are getting up at night wandering" (A14, Community, Area J)*

Participants argued that providing home support in *'a more flexible and creative way before a family reaches 'breaking point''* (A1, Community, Area C) is the way forward. Another participant noted the need for:

> *"More floating supports for carers. Some people are having to go to LTC because their home supports have been reduced. Or it can be because there is too much of a break between care cycles ... the gaps between "care intervals" are too great, for example, if an older person is only getting an AM and PM call" (A15, Medical, Area J)*

Participants also highlighted how official attitudes to services for older people are 'completely' different to that found in disability services, where a PA (personal assistant) system operates, *"[The] carer works with and not for the older person"* (A5, Community, Area A).

Participants believed that the current LTC funding structure was a deterrent to the development and provision of care in the community:

"We ideally need the equivalent of the Fair Deal scheme...for people who want to stay at home in their community. We are ultimately incentivising people to go to LTC under the current system" (A19, Community, Area H)

"If there was the same amount of money put into funding community supports as there is to LTC, a lot more people would be at home. There seems to be a reluctance to spend money locally" (A15, Medical, Area J)

5.3 THE ROLE OF ADVOCACY

Advocacy emerged as critical in enabling older people to access appropriate care and support. This was highlighted by every single participant as they referred to the need to *'fight for'* and *'make a strong case'* for the older people they were representing. Social workers viewed advocacy as an important and central part of their role which they see as essential to ensuring that older people's expressed wishes and preferences are communicated and supported:

"The real issue for me is the vulnerability of older people in the community who have no access to social work support" (A12, Mental Health, Area D)

"If the social worker doesn't advocate for them, then in my experience usually nobody does. There is a massive tension between discharge planning and what the older person and their family want. The family will try and advocate for proximity [geographical] in nursing home placement and also for social work supports" (A15, Medical, Area J)

The danger of not having an advocate is that you won't get a service:

"If you have no one to advocate for you, you have no chance of getting any support services...misfortunes without this [middle class] background or family will get less" (A12, Mental Health, Area D)

Advocacy was seen as crucial for people living with dementia, particularly when it comes to decision-making:

"In relation to people with dementia, it's much harder to advocate for them as their families are usually more vocal. We would still try to elicit their views and present them to the rest of the team...part of the decision-making process would be that the social worker would meet with the older person even in cases where they are being made a ward of court as they still have rights" (A20, Community, Area F)

The challenge of navigating through the health and social care system was noted. This is not only a challenge for those using services but also for those working within it:

"You don't know who to call or what will be allocated. I'm a trained social worker and often I can't find out who is the HCP Case Manager for a particular area, so what's it like for older people and their families?...Access to information is a big problem as systems and structures are constantly changing" (A16, Medical, Area G)

Social workers also mentioned the challenges created by how current health and social care systems are organised:

"The way services are organised does impact on things because as community social workers we are under the Social Care Directorate. However, services for people over 65 are under the Manager of Services for Older People (SFOP). We can only strongly advocate, but decision-making and budget responsibility lies with SFOP" (A3, Community, Area C)

Several participants vented their frustrations about the lack of new social work posts for older people. This problem was noticeably more pronounced in some CHO areas in comparison to others and mentioned across care settings e.g. acute and community settings:

"They didn't see a merit in employing hospital social workers and we have continually highlighted that as a huge risk...the hospitals then chose to spend the funding on discharge planners rather than social workers" (A19, Community, Area H)

Other participants highlighted the lack of social work support for older people across all social work specialities including PCCC, Medical, Psychiatry of Later Life and Adult Safeguarding. It is obvious that not only are there significant gaps in the provision of social work support to older people nationally, but that social workers face considerable challenges in trying to carry out their role.

5.4 THE REQUIRED CHANGE

Survey respondents were asked how they felt the needs and wishes of older people could be better met. Advocacy and the role of social work were identified as crucial as outlined in section 5.3 above. Other fundamental changes identified were:

I. The adoption of a rights-based approach which requires a cultural change involving

"Providing information regarding interventions and by respecting the older person choices, decisions, right" (Survey Respondent 1).

"A change of attitude is required, elderly patients with confusion are too readily dismissed and excluded from decision making' (Survey respondent 29).

"Shifting ageist attitudes by actually including older people, actively engaging them, empowering them, not treating them as separate or talking over' (Survey Respondent 33).

II. Improved collaborative working

"Connections and networks are the two biggest elements to ensuring positive outcome for people seeking supports." (A12, Mental Health, Area D).

"Better coordination of services" (Survey Respondent 20).

III. Increase in trained personal and upskilling for relevant professionals

"More PHN's are needed and Primary Care Social Workers to support vulnerable clients in the community" (Survey Respondent 20).

"Including training - time and fully trained personnel" (Survey Respondent 13).

IV. Better guidance through supportive policies and implementation of legislative change

"I think the awaited Assisted Decision Making (Capacity) [Act] will be helpful in this regard. Also, agency policies that promote inclusion" (Survey Respondent 8).

5.5 SECTION SUMMARY

The need for flexibility and creativity when negotiating service delivery was a key theme to emerge, helping to avoid unnecessary admission to long-term care. This was essential to enable older people to stay at home or access the services that would be most appropriate to their needs. A wide range of community-based services was seen to be helpful in supporting an older person to live at home with dignity, however often these services are unavailable. Similar to findings in Section Four, the lack of supervisory hours and night-time carer support was seen to contribute to the premature admission of older people with dementia to nursing home care.

Family carers were identified as key stakeholders in this process and they should also be supported to enable them to continue to offer care at home. As it is, they often receive little or no practical support in caring for an older person, until they reach breaking point.

All of the evidence indicates that the acute sector is given priority over the community leading to a reactive rather than preventative approach to health and social care of older people. Participants felt that in order to have a better balance in funding services, the monetary resources should positively favour and bias community care rather than residential care.

Participants highlighted the importance of advocacy in arguing for appropriate, timely and flexible services. They also suggested how social workers could support the empowerment of older persons through a range of mechanisms including advocacy, changes to policy and practice and improved collaborative working relationships. It was also highlighted that significant gaps in the provision of social work posts are a critical concern resulting in older people and their family carers having little or no access to a social worker in many CHO areas.

Section 6: Conclusions and Recommendations

Older people have a right to respect for private and family life which includes respect for autonomy and dignity. It is evident from this research that this right is not being met within the current system of care provision. Practices such as geographical inconsistency in the provision of services, defining 'need' within the narrow parameters of 'physical care' and excluding older people from decision-making have consequences for older people's autonomy and dignity. Based on the findings of the literature review, the survey and in-depth interviews with social workers, a number of recommendations as to how to support older people requiring care to live fulfilled and dignified lives for as long as possible in their own homes can be made. These recommendations relate to wider organisational issues but have at their centre protection and promotion of the older person's right to autonomy and dignity and that of their carers.

1. Ensure that the dignity, rights and autonomy of all older people, regardless of cognition or their level of functional capacity are respected in the planning and provision of services.

RECOMMENDATION

Broaden the definition of 'risk' to acknowledge that there are potential risks inherent in all care and support.
Risk was found to regularly influence the decisions of professionals and family members. In these circumstances, professional practice is defensive, often to the detriment of the older person who wanted to live in a manner deemed 'risky' by others. In such cases, the rights of the older person were often ignored and pressure brought to bear on the older person, for example, to move into long-term care where they will be viewed as being 'safe'. Social workers reported regularly having to advocate for the older person's right to live 'at risk.

The right to make choices that others may view as risky should be respected. The older person should be empowered to guide professionals in decisions about the care and support they need, and how they want those needs to be met, thus ensuring their care is personalised and tailored to their needs.

RECOMMENDATION

Implement a standardized approach to involving older people (including people with dementia) in care planning across all CHO areas, in tandem with the Assisted Decision-making (Capacity) Act 2015. Ensuring all health and social care professionals are trained in this approach is essential to implementation.
Findings from this research show that there were inconsistencies in how older people were involved in decision-making about their care. There were stark variations reported between and within CHO areas. Social workers reported that many older persons with a mental health issue and or/cognitive impairment/dementia were excluded from the decision-making process regardless of their level of functional capacity.

In some cases, their involvement in decision-making was deemed to be tokenistic and the attitudes of health and social care professionals, treating Consultants/GPs and families played a crucial influencing role in whether or not older people were involved. Good practices were identified specifically through strong MDT approaches and care planning meetings with involvement of the older people

2. Family carers should be fully supported in their role.

RECOMMENDATION

Take carer's needs into account and provide a carer's needs assessment via the Single Assessment Tool scheme.
Family carers were identified as key stakeholders in the care and support of older people however social workers reported that routinely older people were less likely to get formal support where an older person had family members providing care. It was also highlighted that often family carers are not provided with concrete, practical community supports such as HCPs or respite until they reached breaking point. Family and

informal carers should be robustly supported in order to protect and sustain their important role and this valuable resource. Full implementation of the National Carers' Strategy is key in this regard.

3. Services are planned and provided in a consistent way across CHO areas to meet the individual needs of older people.

RECOMMENDATION

Provide an annual centralised ring-fenced budget for community care, allocated to CHO areas based on capitation, calculated using evidence such as OECD figures on the number of people aged 65 and over likely to require care and support over the next 10 years.
Participants who took part in this research, all agreed that the system was under resourced and their energy went into trying to negotiate or be creative in accessing services within a strict budgetary environment. The available scarce resources are spread so thinly now that older people needing support in some areas must wait for a person receiving a service to die or move into a nursing home to gain home help or home care package hours. The HSE has less to spend now on home support services then they did in 2008, despite the increase in number of people aged 85 and over and those living with complex conditions such as dementia. Funding allocated to the community care schemes such as Home Care Packages are not based on head of population or the number of older people within an area requiring support.

RECOMMENDATION

Develop and implement across every CHO a single, fair, national standard of needs assessment; it is envisaged that the Single Assessment Tool can achieve this.
Older people undergo numerous assessments, and in the end may not receive the support they require to live full and dignified lives. This was found to be particularly relevant for people living with dementia/ cognitive impairment/mental illness, whose care needs are often not captured by the assessment process as needs were understood within the narrow parameters of 'physical care needs'.

Hence despite huge resources going into the assessment process, assessment was found to be deficit based. For example, a person with dementia was unlikely to be allocated supervisory hours; where a person had family members providing care, they were less likely to get any support. Social care needs, such as help with domestic tasks and social contact, were regularly excluded and not prioritised. A holistic, proactive approach to support the older person to lead an active, socially engaged life should be adopted.

RECOMMENDATION

Develop and implement a fair and equitable way of allocating care and support services underpinned by legislation. All CHO areas should make information about services, eligibility criteria and the process for accessing services available to all people.
The research findings show that there is a lack of transparency in relation to how older people gain access to services with differing practices highlighted across CHO areas. For example, in some areas older people had to be in receipt of a medical card in order to access formal community-based support services while in other areas they did not. There were a number of other factors which determined the provision of services/ supports. For example, people were prioritised in different ways in different areas – by age, living situation, delayed hospital discharge and/or presence of dementia.

RECOMMENDATION

Oblige each CHO area to provide a range of services to meet the diverse needs of older people.
Findings show that there are large disparities between the services that were available in different CHO areas. In general, demand far outstripped what was available and participants reported discrepancies between the number of hours an older person had been assessed as needing, the level of home care hours requested, and the number of hours of home care which were actually approved. This situation regularly meant that older persons did not receive the level of service that their care needs' assessment indicated. A worrying consequence of this was unnecessary or premature admission to long-term residential care.

Participants felt that greater funding should be invested in community care rather than residential care. Where services were available they worked well in the main, with meals-on-wheels and day-care in particularly being highlighted as useful services. In addition, non-health related issues, such as transport, were identified as barriers to service access, particularly in rural areas.

Care and support services have not developed to meet the specific needs of this cohort of older people. For example many older people live alone and their families now live in urban areas or abroad. For these older people, not being able to access support with domestic tasks or night time supervision can mean their only choice is to move into a nursing home. The wider needs of older people could be met through the development and provision of supports, particularly a range of domestic support that are flexible enough to meet the older person's needs; supervisory support to people with dementia; basic services such as access to aids and appliances, home adaptations, social clubs, day centres, meals-on-wheels, befriending services, public transport, home care support services and supported housing.

RECOMMENDATION

Develop services and supports targeted at older people who have been acutely unwell, be it in hospital or at home, and those who have a progressive conditions such as dementia in all CHO areas to ensure access to transitional, rehabilitation and long term care beds.
These services should include rehabilitation, enablement services, transition beds, respite beds, LTC beds, dementia specific facilities with the capacity to care for those who may have behavioural and psychological symptoms of dementia or advanced dementia. Older people in the community should not be discriminated against in favour of those being discharged from hospital.

Findings show that availability of long and short-term beds varied across CHO areas, as did waiting times. It was easier to access LTC and rehabilitation beds from the acute hospital than from the community. Of particular concern was the difficulty in accessing appropriate LTC placements for people living with dementia. Nursing homes were in a position to cherry-pick their residents, refusing to accept people in the more advanced stages of dementia or who were deemed to have behavioural and psychological symptoms of dementia. In addition, findings highlight the dearth of dementia-specific units across the country. Transition beds were seen to be the preserve of the acute hospitals to facilitate more timely discharge. This put community-based older persons at a disadvantage in accessing these types of beds. In relation to respite care, evidence shows that a lack of compliance with HIQA standards had resulted in closures and corresponding reductions in the number of available beds. This again was compounded by a general lack of available dementia specific beds.

RECOMMENDATION

Provide a full compliment of health and social care professionals in each CHO area, accessible to all older people and their families, ensuring that deficits such as the current lack of social work services is addressed.
Findings show that not only are there significant gaps in the provision of social work support to older people nationally, but social workers also face considerable challenges in trying to carry out their role. The need for creativity by social workers when negotiating service delivery was a further key theme to emerge. Social workers reported that their role as advocates for the older person was essential in many instances in getting services or involving older persons formally in decision-making. All PCCC Teams nationally should have an allocated social worker. The new Adult Safeguarding Teams must be fully resourced. The absence of medical social work posts in hospitals within several CHO areas must also be addressed.

CONCLUSION

Older persons requiring care and support in many instances have no choice but to move into residential care settings, due to the under-development of community-based services and inconsistency of provision across the country. This is despite the overwhelming preference of older people for 'ageing in place', their right to private and family life and a state policy that commits to support older people to remain in their homes for as long as possible. For policy to become practice the recommendations outlined must be implemented to ensure the development and provision of services that meet the diverse needs of the increasing number of older people who will require support over the next decade.

Bibliography

Age UK (2013) *Improving Later Life. Services for Older People-What works.* Available at: www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Services-what_works_spreads.pdf?dtrk=true.

ASI *see The Alzheimer Society of Ireland*

Barry, U. (2010) *Elderly care in Ireland - provisions and providers*. UCD School of Social Justice Working Papers: 10c(1):1-34,University College Dublin.

Brennan, J. (2010) 'From Community care to Residential Care: Personal social services and older people'. In S. Quin and P. Kennedy (eds) *Ageing and Social Policy in Ireland*. Dublin: University College Press.

Cahill, S, O'Shea, E. and Pierce, M. (2012) *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*, Dublin and Galway: Living with Dementia Programme, Trinity College Dublin and Irish Centre for Social Gerontology, National University of Ireland, Galway.

Cahill, S., Diaz-Ponce, A., Cohen, R and Walsh, C. (2010)The Under-Detection of Cognitive Impairment in Nursing Homes in the Dublin Area: The need for on-going cognitive assessment. *Age and Ageing*, 38(1):128-130.

Calnan, M., Tadd, W., Calnan, S., Hillman, A., Read, S and Bayer, A. (2012) 'I Often Worry about the Older Person being in that System': Exploring the key influences on the provision of dignified care for older people in acute hospitals. *Ageing and Society*, 33(2): 465-485.

Care Alliance Ireland (2015) *Family Caregiving in Ireland*. Available at: http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf.

Catherine Byrne, Dail Debates,2015-07-16a.848, 16th July,2015. Available at: https://www.kildarestreet.com/debates/?id=2015-07-16a.848

Citizens Information Ireland (2016) *Citizens Information Board*. Available at:http://www.citizensinformation.ie/en/

Council of Europe (1950) *Convention for the Protection of Human Rights and Fundamental Freedoms* (European Convention on Human Rights, as Amended) (ECHR) Art 3, 1950.

Crabtree, B. and Miller, W. (1999) *Doing Qualitative Research*, (2nd Ed). London: Sage.

Creswell, J. (2003) *Research Design: Qualitative and Quantitative approaches*. (2nd Ed).Thousand Oaks, CA: Sage.

Davey, J., de Joux,V., Nana,G and Arcus, M (2004) *Accommodation Options for Older People in Aotearoa/New Zealand*. Wellington, New Zealand: Centre for Housing Research Aotearoa.

Department of Health (1994) *Shaping a Healthier Future*. Dublin: Stationary Office.

Department of Health (2007) *The Health Act*. Dublin: Stationary Office.

Department of Health and Children (2008) *National Strategy for Service User Involvement in the Irish Health Service*, 2008-2011. Dublin: Stationary Office.

Department of Health and Children (2009a) *Evaluation of Home Care Packages November 2009*. Available at:health.gov.ie/blog/publications/department-of-health-and-children-evaluation-of-home-care-packages/

Department of Health(2009b) *Nursing Home Support Scheme Act*. Dublin: Stationary Office.

Department of Health(2011) *Comprehensive Review of Expenditure. Dublin: Stationary Office*. Available at: health.gov.ie/wp-content/uploads/2014/03/doh_review_expenditure.pdf.

Department of Health (2012a) *National Carers Strategy*. Dublin: Stationary Office.

Department of Health (2012b) *Future Health - The Strategic Framework for Reform of the Health Service 2012-2015*. Dublin: Stationary Office.

Department of Health (2012c) *Long Stay Statistics*. Dublin: Stationary Office.

Department of Health (2012d) *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*. Dublin: Stationary Office.

Department of Health (2013) *National Positive Ageing Strategy*. Dublin: Stationary Office.

Department of Health (2014) *The Irish National Dementia Strategy*. Dublin: Stationary Office.

Department of Health (2015) *Health in Ireland – Key Trends 2014*. Available at: health.gov.ie/wp-content/uploads/2014/12/JD605-DHC_Key-Trends_2014WEB_03.12.14.pdf.

Department of Justice (2015) *The Assisted Decision Making (Capacity) Act*. Dublin: Stationary Office.

DOH *see Department of Health*

DOHC *see Department of Health and Children*

Donnelly, S (2012) *'Family Meeting or Care Planning Meeting? A Multidisciplinary Action Research Study in a Hospital Setting'*. (Unpublished PhD thesis), Trinity College Dublin: Ireland.

Donnelly, S.M., Carter-Anand, J., Cahill, S., Gilligan, R., Mehigan, B. and O'Neill, D. (2013) 'Multi-professional Views on Older Patients' Participation in Care Planning Meetings in a Hospital Context'. Practice: *Social Work in Action* 25 (2).

Donnelly, S. and O'Loughlin, A. (2015) 'Growing Old with Dignity: Challenges for Practice in an Ageing Society' In A. Christie, B. Featherstone, S. Quin, and T. Walsh (eds). *Social Work in Ireland: Changes and Continuities*. Basingstoke: Palgrave Macmillan.

Drennan, J., Lafferty, A., Treacy, M.P., Fealy, G., Phelan, A., Lyons, I. and Hall, P. (2012) *Older People in Residential Care Settings: Results of a National Survey of Staff-Resident Interactions and Conflicts*. Dublin: NCPOP & University College Dublin.

Drystad, D.N., Laugaland, K.A. and Storm, M. (2015) 'An Observation Study of Older Patients' Participation in hospital Admission and Discharge- exploring patient and next of kin perspectives'. *Journal of Clinical Nursing*, 24:1693-1706.

ECHR *see Council of Europe*

EPS Consulting (2013) *The Business Case for the Outsourcing of home Care Provision and a More Efficient Use of Fair Deal Funds*. March.

Fox. S., Kenny, L., Day, M. R., O'Connell, C., Finnerty, J. & Timmons, S. (2015) *Report on the Housing and Support Needs of Clúid's Older Tenants*. Dublin: Clúid Housing.

Garavan, R., Winder, R. and McGee, H. (2001) *Health and Social Services for Older People (HeSSOP)*. Dublin: NCAOP.

Glasby, J. and Dickinson, H. (2014) *Partnership working in health and social care* (2nd ed). Bristol: The Policy Press.

Gibbons, J. and Plath, D. (2005) 'Everybody puts a lot into it!' *Single session contacts in hospital social work'. Social Work in Healthcare* 42(1): 17-34.

Hansen, P., Corinsh, P and Kayser, K (1998) 'Family Conference as Forums for Decision-making in Hospital Settings'. *Social Work in Health Care* 27(3):57-74.

Harvey, B. and Walsh, K. (2016) *Loneliness and Ageing: Ireland, North and South*. Dublin: Institute of Public Health in Ireland.

Health Service Executive (2008) *Health Service Executive Annual Report and Financial Statements 2008*. Available at: http://www.hse.ie/eng/services/publications/corporate/arafs08.pdf

Health Service Executive (2011) *Health Service Executive Annual Report and Financial Statements 2011*. Available at: www.hse.ie/eng/services/publications/corporate/annualreport2011.pdf

Health Service Executive (2012) *National Healthcare Charter, National Advocacy Unit, Quality and Patient Safety Directorate*. HSE.

Health Service Executive (2012b) *Home Care Packages*. Available at: http://www.hse.ie/eng/services/list/4/olderpeople/homecarepackages

Health Service Executive (2014) *Community Health Organisations Report*. Available at: www.hse.ie/eng/services/publications/corporate/CHOReport.html

Health Service Executive (2015a) *Planning for Trends and Priorities to Inform Health Service Planning 2016*. Available at: www.hse.ie/eng/services/publications/planningforhealth.pdf

Health Service Executive (2015b) *Emergency Department Taskforce Report*. Available at: http://hdl.handle.net/10147/575347

Health Service Executive (2015c) *HSE Performance Report 2015*. Available at: http://www.hse.ie/eng/services/publications/corporate/performancereports/sept15pr.pdf

Hedberg, B., Cederborg, A-C. and Johanson, M. (2007) 'Care-planning Meetings with Stroke Survivors: Nurses as moderators of the communication'. *Journal of Nursing Management*, 15(2): 214-221.

HSE *see Health Service Executive*.

Human Rights and Older People Working Group (2013) *Human Rights and Older People in Ireland*. Policy Paper. Dublin.

Irish Association of Social Workers (2011) *The Role of the Social Worker with Older Persons*. The Irish Association of Social Workers' (IASW) Special Interest Group on Ageing (SIGA). Available at: www.iasw.ie/attachments/d82b4fe7-b766-4792-83d7-75eefb001b6c.PDF.

Inter-Departmental Committee on the Care of the Aged Report (1968). Dublin: Stationery Office.

International Covenant on Economic, Social and Cultural Rights *see United Nations General Assembly*

IASW *see Irish Association of Social Workers*.

Kamiya, Y., Murphy, C., Savva, G. and Timonen, V. (2012) *Profile of Community-Dwelling Older People with Disability and their Caregivers in Ireland*. Dublin: TILDA.

Kuczynski, L. and Daly, K. (2002) 'Qualitative Methods for Inductive (Theory-generating) Research: Psychological and sociological approaches'. In L. Kuczynski(Ed.) *Handbook of Dynamics in Parent-child Relations*. Thousand Oaks, CA: Sage.

Kvale, S. (1997) *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.

Lawler, K. (2001) *Aging in place: Coordinating housing and health care provision for America's growing elderly population*. Washington, DC: Joint Center for Housing Studies of Harvard University & Neighbourhood Reinvestment Corporation.

Layte, R., Fahey, T. and Whelan C. (1999) *Income, Deprivation and Well-Being Among Older Irish People*. Dublin: National Council on Ageing and Older People.

Lloyd, L., Calnan, M., Cameron, A., Seymour, J. and Smith, R. (2012) Identity in the fourth age: perseverance, adaptation and maintaining dignity. *Ageing and Society*, 34, 1-19.

Lunacy Regulation (Ireland) Act 1871 *see Ward of Court*

Lymbery, M. (2010) 'A New Vision for Adult Social Care? Continuities and change in the care of older people'. *Critical Social Policy*, 30: 5-26.

Mangan, I. (1997) 'Equity, Consistency and Comprehensiveness: The Need for a Legislative Framework to Govern the Provision of Essential Services for Older People' in Conference Proceedings: Review of the Implementation of The Years Ahead: A Policy for the Elderly and Implications for Future Policy on Older People in Ireland. Dublin: National Council on Ageing and Older People.

National Clinical Programme for Older People (2012) *Specialist Model of Services for Geriatric Care*. HSE/RCSI.

National Economic and Social Council (2012) *Quality and Standards in Human Services in Ireland: Residential Care for Older People*: No 128 July, 2012:NSESDO

NESC *see National Economic and Social Council*

Pierce, M. and Cahill, S. (2014) *Prevalence and Projections of Dementia in Ireland*: 2011 – 2046. Dublin: Genio.

Pierce, M. and Timonen, V. (2010) *A Discussion Paper on Theories of Ageing*. Dublin: Centre for Ageing Research and Development in Ireland.

Ruddle, H., Donoghue, F. and Mulvihill, R. (1999) The Years Ahead Report: A Review of the Implementation of its Recommendations. Dublin: National Council On Ageing and Older People.

SCIE *see Social Care Institute for Excellence*.

Social Care Institute for Excellence (2014) *Commissioning Home Care for Older People*. Available at: www.scie.org.uk/publications/guides/guide54/files/guide54.pdf.

Sykes, W and Groom, C (2011) *Older People's Experiences of Home Care in England*. UK: Equality and Human Rights Commission.

The Alzheimer Society of Ireland and The Irish Dementia Working Group (2016a) Charter of Rights for People with Dementia. Available here: www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx

The Alzheimer Society of Ireland (2016b) *Assisted Decision Making Legislation Position Paper* (in press).

The Care of the Aged (1968) *Report of an Inter-Departmental Committee*. Dublin: Stationery Office.

Timmins, S., Manning, E., Barrett, A., Brady, N., Browne, V., O'Shea, E., Malloy, D., O'Reagan, N., Trawley, S., Cahill, S., O'Sullivan, K., Woods, N., Meagher, D., Ni Chorcorain, A. and Linehan, J. (2015) Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. *Age and Ageing* doi: 10.1093/ageing/afv13

Timonen, V. and McMenamin, I. (2002) 'The Future of Care Services in Ireland: Old Answers to New Challenges?' *Social Policy and Administration*, Vol. 36 No. 1,20-35.

Timonen, V., Doyle, M. and O'Dwyer, C. (2012) 'Expanded, but not Regulated: Ambiguity in home-care policy in Ireland'. *Health Social Care Community*. 20 (3): 310-8 5.

UN *see United Nations.*

United Nations, 1991. *United Nations Principles for Older Persons*. Available at: www.un.org/ageing/un_principles.html

United Nations General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: http://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf

Vaarama M. (2009) 'Care related quality of life in old age'. *European Journal of Ageing*, 6:113–125.

Wards of Court - Lunacy Regulation (Ireland) Act of 1871.Availableat:http://www.opsi.gov.uk/acts/acts1871/pdf/ukpga_18710022_en.pdf

WHO *see World Health Organisation*.

World Health Organization (2007) *Global Age-Friendly Cities: A Guide*. Geneva: World Health Organization.

World Health Organization (2012) *Interesting facts about ageing*. Available at: www.who.int/ag

Notes

Notes