Spotlight

Home Care for Older People – Seven Policy Challenges

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Abstract

The home is commonly considered the most desirable place for older people in need of care to receive it. Due to population ageing and other demographic factors, the share of paid home care is growing. Currently, this developing sector is largely unregulated and lacks a national policy framework. However, the Department of Health is undertaking a consultation to inform plans for "a new statutory scheme for home care services". This *Spotlight* provides an overview of the operation of the home care sector in Ireland and identifies a number of current policy and legislative challenges.

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Legal Disclaimer

Summary: Seven Policy Challenges in Home Care for Older People

Determining eligibility and entitlement	Approx. 50,000 people are in receipt of publicly-funded home care. However, there is no statutory entitlement to it. As a result, there is a lack of clarity and consistency about who is eligible for services, and how services are allocated (e.g. there is regional variation). A significant policy challenge is weighing up arguments that emphasise the scarcity of resources against claims of social justice, entitlement or rights, to determine an acceptable and affordable level of statutory entitlement.
Selecting a funding model	Publicly-funded home care is available free at the point of use. However access is limited by available resources – this is a supply-led scheme. Greater demand for home care services is putting upward pressure on public spending (of €408m in 2018). It is likely that providing sufficient services, in the short to medium term, will require raising additional revenue (through taxes or charges) or re-allocating funds from another publicly-funded service. There is a choice to be made between different methods of funding home care in the future. Options include general taxation, care insurance, and applying a similar model to the Nursing Home Support Scheme (NHSS) (also known as the 'Fair Deal Scheme').
Finding the right mix in service provision	A key policy question is how *publicly-funded* services would be best delivered – that is, what mix of public, private and voluntary bodies should be organising and providing home care.
Introducing effective regulation	There is currently no statutory regulatory regime for home care and no external oversight of private home care. The challenge is to put in place a regulatory system that balances successfully the benefits of regulation (such as improved quality) against costs (e.g. a potential loss of choice, and direct and indirect financial costs to the State (taxpayers), industry and individuals as users of services).
Sustaining informal Care	The bulk of care that enables people to live at home is provided by informal carers (generally unpaid family and friends). Determining and implementing the optimal incentives and supports to sustain this is a key challenge. A combination of employment supports, income supports and health and social care supports is likely to be considered.
Securing a care workforce	Care work is labour intensive and there are considerable challenges to be met to ensure the availability and retention of suitably qualified staff, not least by securing favourable pay and conditions. Moving <u>all</u> care into the formal labour market is likely to be a consideration. However, tensions may arise between the rights and claims of workers and the demand for affordable care.
Developing alternatives to nursing home care	The policy challenge here is to develop stronger services and supports across a spectrum (such as sheltered / supported housing and reablement interventions). A particular issue is that these services cross traditional professional and sectoral boundaries which can be hard to bridge. A further factor is the scoping of eligibility criteria.

Introduction

> *"Home care…refers to activity or work that is performed to assist someone living in his or her home. It has its roots in unpaid and often invisible work of women, which in many countries, …was re-defined to some extent as the responsibility of the welfare state in the latter part of the twentieth century"*[1]

This *Spotlight* focuses on older people (age 65 and over), though many of the issues raised are pertinent to those aged under 65 years in need of home care. While the majority of over 65s report good health[2], those who do have health and care needs, in general, prefer to stay in their own homes. In these circumstances, family and friends provide the bulk of care informally. It is generally unpaid.

Nonetheless, in recent decades there has been a marked expansion in the formal or professional (paid) care sector in Ireland – funded both publicly through the Health Service Executive (HSE) and privately by individuals and families. HSE funded home care is made available to clients without charge, it is however, subject to resource constraints and there are waiting lists in operation. It is supplemented by other forms of community-based care such as meals-on-wheels and day care which have also grown.

However, there were cutbacks to services in the recent recession and there are current and forecast future demand pressures as a result of demographic and social factors, with population ageing being the foremost of these.

In addition, while the concept of home care (supporting people who want to stay at home for as long as possible) has strong support, there is no national policy specifically for home care for older people. Thus, the formal home care sector and its provision have developed without a policy framework or legislative footing. And, it has been argued that the funding mechanisms in place bias care towards residential / nursing home care. [3]

Under the heading, "*Working to Make our Older Years Better Years*", the Programme for Partnership Government (2016) promises to improve home care. The Department of Health is currently undertaking a consultation on home care (including regulation and funding of same) with a view to introducing a statutory home care scheme. There is a statutory scheme, the Nursing Home Support Scheme (also known as the 'Fair Deal Scheme'), providing financial support for those in need of <u>residential</u> care.

This *Spotlight* looks at the current context of provision and payment for services and sets out the high level policy questions facing policymakers seeking to determine strategy in this area. It is structured as follows:

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[1] Ceci, C, Bjornsdóttir, K and Purkis, ME (2012) 'Introduction: Home, Care, Practice – Changing Perspectives on Care at Home for Older People', in Ceci C, *et al* (Eds.) *Perspectives on Care at Home for Older People.* New York: Routledge.
[2] See Central Statistics Office (2015) Irish Health Survey; also findings from the Irish Longitudinal Study of Ageing (Tilda) here.
[3] See for example, Wren, MA, Normand, C, O'Reilly, D, Cruise, S, Connolly, S, & Murphy, C (2012). *Towards the Development of a Predictive Model of Long-Term Care Demand for Northern Ireland and the Republic of Ireland.* Belfast: Trinity College Dublin (available here).

Part 1 - Background

- Home care policy
- Home care structures
- Spending, activity and cost-effectiveness
- Need and capacity
- Demographics and demand

Part 2 - Policy Challenges

- Determining access: eligibility, entitlement or right?
- Selecting a funding model
- Finding the right mix of service provision
- Introducing effective regulation
- Sustaining informal care
- Securing a care workforce
- Developing other alternatives to nursing home care

Part One: Background

Home care policy

The concept of home care has strong, long-standing support across national health and ageing policies, dating back at least as far as the 1980s.

A preference for home care over residential care is embedded in many health and related policies, such as *Future Health* – the strategic framework for health service reform, and the Carers' Strategy[4], Positive Ageing Strategy[5] and National Dementia Strategy[6]. In 2017, the Oireachtas Committee on the Future of Healthcare recommended (amongst other things) the introduction of universal entitlement to home care.[7] Home and community based care are also included in strategies designed to relieve pressure on acute hospitals and moves to more integrated care – that seek (amongst other things) to present a joined-up service to patients and to avoid hospital admissions.

The importance of home care is also recognised in European Union level policy. For instance, the following is among the 20 principles informing the European Pillar of Social Rights:

> "Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services."[8]

The Health Information and Quality Authority (HIQA) has contended:

> "There is a consensus that Ireland needs to move away from the current hospital-centric model of care and to introduce integrated care pathways across primary, community and secondary health and social care structures. HIQA believes this should be expedited. Such a model would promote seamlessness in the transition of people across services, providing multi-disciplinary care at the lowest level of complexity closer to where people live."[9]

There have been clear policy statements, dating back a number of years, making a commitment to move resources out of the acute healthcare sector and into community care services. For instance, in 2008, the then Taoiseach, Brian Cowen, TD, stated:

> "The whole purpose of health service reform is to take resources from the acute hospital sector and spend more resources in the community sector."[10]

Part of the HSE's focus on community care involves a more towards more integrated care (as advocated for by HIQA – see above). This movement is a reaction to the fractures and gaps people experience between different parts of the health and social services. The aim of integrated care is to join up health and social care services and improve quality by prioritising patient

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[4] http://health.gov.ie/blog/publications/national-carers-strategy/ (for Strategy and Progress Reports)
[5] http://health.gov.ie/wp-content/uploads/2014/03/National_Positive_Ageing_Strategy_English.pdf
[6] http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf
[7] Houses of the Oireachtas Committee on the Future of Healthcare (2017) *Sláintecare Report.*
[8] European Commission: https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en [accessed 07/12/2017]
[9] Health Information and Quality Authority (2017) *Submission to the Special Oireachtas Committee on the Future of Healthcare.*
[10] Dáil Debates, *Leaders' Questions, May 21 2008.*

outcomes and experiences. The HSE has a specific integrated care pilot programme for older people.[11]

At government level, current broad policy set out in the 2016 Programme for Government (PfG) commits to improving home care as part of a range of measures to support older people, as illustrated in the extract below.

Programme for Government (2016) Commitments:

"To remain independent at home, some older people need the support of home help. Currently there are 10.3m hours funded by the HSE annually. We will increase funding for home care packages and home help every year.

The provision of home care ranges from excellent to irregular for recipients across the country. We will introduce a uniform home care service so all recipients can receive a quality support, 7 days per week, where possible."[12]

The Government has also promised to review the management, operation and funding of home-help services.

As noted above, at present the Department of Health is undertaking a consultation on the establishment of a statutory home care scheme (this commenced in mid-2017).[13] It acknowledges that while home care is mostly used by older people in Ireland it is of relevance to people with disabilities and others (such as those leaving hospital).

The Department received 2,500 responses (including 1,700 online) to the call for submissions from the public on establishing a new statutory home care scheme (the closing date for those was at the start of October 2017 and there are further consultation phases planned). The Department reported in November 2017 that it had analysed the results of the 1,700 online responses.[14]

In terms of timeframe for any resulting change, the Department indicated:

> "We think developing the proposals and having the legislation enacted will take two to three years."[15]

However, as shown below, demographic pressures are more immediate, and there have been calls for additional funding to be put in place in the meantime.[16]

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[11] https://www.hse.ie/eng/about/Who/cspd/icp/older-persons/
[12] http://www.merrionstreet.ie/merrionstreet/en/imagelibrary/programme_for_partnership_government.pdf
[13] Department of Health (2017a) *Noticeboard: Consultation on Home Care Services*; 6 July 2017. See also consultation document: Department of Health (2017b) *Improving Home Care Services in Ireland: Have Your Say!*
[14] Ms. Frances Spillane, Department of Health, appearing before the Joint Oireachtas Committee on Health, 15 November 2017.
[15] Ms. Frances Spillane, as before.
[16] Family Carers Ireland (2017a) *Submission to the Department of Health on the Creation of a Statutory Home care Scheme*.

Home care structures

As noted above, most home care is provided by relatives and friends, mostly unpaid, though social welfare supports may be available.

At present formal home care provision and funding can be described as mixed – sources of funding include private and public (HSE) and provision is by public, private and voluntary organisations.

The HSE funds and provides a range of services for older people with care needs in their own homes. The HSE's rationale is two-fold – to support people to stay at home for as long as possible if that is their wish and to alleviate pressure on acute hospitals by providing care at home instead. Of particular interest, in this *Spotlight*, are HSE-funded home help and home care packages.

In addition, people arrange and pay for home care privately. These various types of care are set out in Table 1. (See more on this mix in the section below on '*Finding the Right Mix of Service Provision*', pg. 25).

Table 1: Structure of home care provision

Type of home care	Description
Informal	
Family / friend caregiver - Unpaid	The bulk of home care is provided by family members / friends mostly in an unpaid capacity. Informal care is viewed as critical in providing hands-on care and taking a role in managing / co-ordinating with formal care providers.
Formal (Professional) home care	
Health Service Executive (HSE) Arranged by the HSE and provided by HSE or under contract by voluntary or private providers.	**Home help service** - providing help with housework, shopping, or sometimes may provide more personal care like help with dressing, bathing etc. **Home Care Packages (HCPs)** – extra services and supports over and above the normal community services. The content of the 'package' of care if flexible – each may include extra home help, nursing, physiotherapy, occupational therapy, speech & language therapy, day care services, respite care, etc. **Intensive Home Care Packages (IHCPs)** – a more intense range of the same services as under HCP – much fewer in number.[17]
Private	Paid for by individuals / families - care provided by agencies or individuals. Approximately one in five carers providing this type of care is not attached to an agency.

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[17] Atlantic Philanthropies provides funding towards some of these Intensive Home Care Packages.

No charge for users of publicly funded home care

Home help and home care packages are allocated based on need and availability of resources rather than ability to pay. And there are no charges for these services. Though, the Department of Health has indicated that the current law may permit charging. [18]

Publicly funded home care is organised through nine HSE Community Health Organisations (CHOs)). However, there are inconsistencies across the country in how State funded home care is delivered. The Department of Health has highlighted that: "This means that the availability of services can vary from place to place and at different times of the year."[19]
And though the Department of Health states that services are available for free with no means test, a research study published in 2016 reported that, according to social workers, in some cases home care was only available to those with medical cards.[20]

Tax relief

Many people purchase home care from private providers (which may be used on its own or as a top-up to publicly-funded care). Tax relief is available for the purchase of private care (in some circumstances).[21]

Other Supports

Home care is one element of a range of supports available for older people. Other supports include:

The Nursing Home Support Scheme:[22] The significant policy development in recent years has been the introduction, on a statutory basis, of the Nursing Home Support Scheme (NHSS) also known as the '*Fair Deal Scheme*'. This Scheme provides public funding for long-term **residential** care, along with means-tested co-payments from the person in receipt of care. The Scheme includes the option of paying part of the contribution from one's assets after death. It has been argued that the implementation of the Fair Deal Scheme – in the absence of any similar, structured scheme for home-based care – has been to the detriment of community-based services and **may draw people into residential care prematurely**.

Housing Adaptation Grants and Mobility Aid Grants: These grants are provided to assist people in staying in their own homes[23] and there is evidence that adaptive grants - allowing people to make home renovations to maintain their ability to function at home - are cost-effective supports.

Respite Care: Respite care may be provided to give carers a break from their caring role. Respite or temporary 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 Health Service Executive (HSE) and in others by local or national voluntary organisations.[24]

Day Care: Day centres or day care centres provide a range of social and rehabilitative services for older people and people with disabilities (provided by the HSE / voluntary bodies).

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[18] Department of Health (2015) *Review of the Nursing Home Support Scheme*.
[19] Department of Health (2017) *Improving Home Care Services in Ireland: Have Your Say!* [Consultation document].
[20] Donnelly, S, O'Brien, M, Begley, E and Brennan, J (2016) *'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?* University College Dublin. School of Social Policy, Social Work and Social Justice.
[21] See Citizens Information website re: Tax Credits for Home Carer.
[22] http://www.hse.ie/eng/services/list/4/olderpeople/nhss/
[23] See Citizens Information website re Mobility Aids Grant Scheme and Housing Adaptation Grant.
[24] See Citizens Information website re Respite Care.

Specialised day centres include centres that provide day activation, such as recreational, sport and leisure facilities, and specialised clinic facilities that provide a combination of medical and rehabilitation services. Day centres are provided on a variable basis throughout the country.   Day centres providing medical care are less widely available. Access to day centres is by referral and the eligibility conditions vary from area to area with means tests applying in some cases.[25]

Social Welfare Supports for Carers: .See details on page 33.

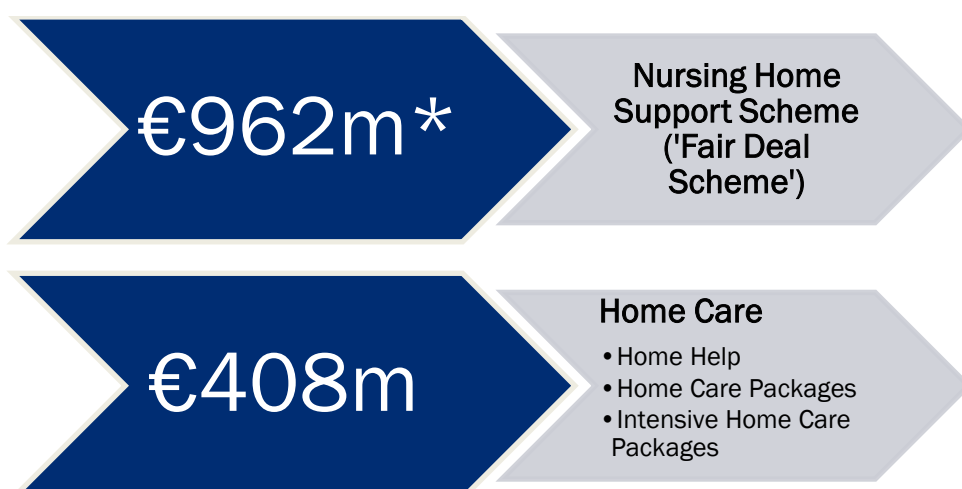[25] Citizens Information website: *Day Centres and Day Care*

Spending, activity and cost-effectiveness

Public spending on home care

The overall State funding allocated for home care in 2018 is €408m[26] (an increase from €376m in 2017). The Nursing Home Support Scheme budget for 2017 was €962m[27] (€22m more than 2017), providing services to about 4% of older people. Figure 1 below shows the level of spending on home care and the Nursing Home Support Scheme.

Funding for home care supports is to increase in 2018 to €408m (an additional €32m on the 2017 budget).[28]

Figure 1: Public spending on home care and residential care - 2018 Resource Allocation

€962m* — Nursing Home Support Scheme ('Fair Deal Scheme')

€408m — Home Care
• Home Help
• Home Care Packages
• Intensive Home Care Packages

Source: Data from Health Service Executive (2017) *National Service Plan 2018*.

Activity levels

About 50,000 people (or about 8% of over 65s) are in receipt of publicly funded home care. While more than 23,000 people (about 4% of this age group) receive support under the Nursing Home Support Scheme. See Table 2 below for details. A recent HSE indicators report stated that 14% of people aged 70+ living in the community have received home care services in the previous 12 months.[29]

The 2018 target for the number of home help hours to be delivered was unchanged from the 2017 target of 10.57 million.

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[26] Health Service Executive (2017) *National Service Plan 2018*.
[27] HSE (2016) *National Service Plan 2017*.
[28] For further information on this see Dáil Éireann Written Answers, 6 December 2017.
[29] Health Service Executive and Department of Health (2016) *Positive Ageing 2016 – Indicators Report.*

Table 2: Activity levels - home care vs residential care

Service / Scheme	No. of people	Proportion over 65s (approx.)
Nursing Home Support Scheme	23,334	4%
Home Help and Home Care Packages (10.57m home help hours, 20,175 Home Care Packages and 235 Intensive Home Care Packages**)	50,000 (approx.)	8%

Source: No. of recipients Health Service Executive (2017) *National Service Plan 2018*. Proportions calculated by Oireachtas L&RS using base from Central Statistics Office *Census 2016 population data*.
**Specialised home care packages for people with dementia (provided in previous years in agreement with and jointly funded by charitable organisation, Atlantic Philanthropies).

Table 3, below, presents the ten-year trend in the provision of home help hours and client numbers. This shows that both the number of hours and the number of people in receipt of home help have reduced over this period, though numbers have grown following lows in 2012 and 2013. In the same period, Home Care Packages were introduced and their take up has risen over time.

Table 3: No. of home help hours provided (millions) and no. of clients 2008-2017

	2008	2009	2010	2011	2012	2013	2014	2015	2016*	2017*
No. of hours (millions)	12.63	11.97	11.68	11.09	9.88	9.74	10.3	10.4	10.6	10.6
No. of clients	55,366	53,791	54,000	51,000	45,705	46,454	47,061	47,915	49,000	49,000

Source: HSE *Annual Reports and Financial Statements 2008-2015;* and HSE *Annual Service Plan 2017*.
*2016 data – expected outturn; 2017 data – target.

Cost Effectiveness

The issue of assessing cost-effectiveness of home care over other modes of care is complex with particular issues arising, amongst others, around costing informal care and ensuring comparability of intensity of care between home care and other settings.

There are a number of studies indicating that community based services, such as home care, are more cost-effective than nursing home care, with less evidence providing comparison with acute (e.g. hospital) care. For example:[30]

- A major Canadian research programme published in 2001 demonstrated the cost-effectiveness of home care over <u>residential</u> nursing home care in most circumstances when part of integrated care systems.
- The same study had mixed findings when comparing the cost-effectives of home care to <u>acute</u> care and noted measurement difficulties.

A large study looking specifically at the costs of home care vs residential care for those with dementia across eight European countries found home care to be more cost-effective than nursing

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[30] Hollander, M and Chappell, N (2002) *Synthesis Report – Final Report of the National Evaluation of the Cost-Effectiveness of Home Care*. National Evaluation of the Cost-Effectiveness of Home Care and Centre on Aging, University of Victoria.

home care for people with dementia (other than those with the lowest levels of independence in the activities of daily living (ADL), such as dressing, washing, toileting).[31]

The literature indicates that home and community based care has the potential to be cost saving in the right circumstances   However, overall, the evidence of cost-effectiveness is partial – in that some of the literature identified is dated and as it draws largely on other jurisdiction ns cannot be applied to the Irish situation without caution. Other measures of system performance, such as quality, are discussed below in the section looking at regulation.

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[31] Wubker, A, Zwakhalen, SMG, Challis, D, Suhonen, R, Karlsson, S, Zabalegui A, Soto, M, Saks, K and Sauerland, D (2015) 'Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries'. *European Journal of Health Economics*, 16:689-707.   The eight countries examined were: Estonia, Finland, France, Germany, The Netherlands, Spain, Sweden and the UK [though data appear to be just from England].

Need and capacity

> *"…entitlement without the capacity to respond on the supply-side will mean rationing and most likely by continued waiting lists." (Sláintecare Report by the Oireachtas Committee on the Future of Healthcare, p.54).[32]*

Despite the significant spending on home care there remains unmet need. According to the Department of Health and HSE:

- Almost one in five (19%) people aged 50+ report unmet need for a community care service.[33]

The Department of Health acknowledges that services are unable to keep up with demand – approximately 4,600 people are on waiting lists for home care (this includes new applicants and those waiting for additional hours).[34]

An inadequacy in the hours of home care is a key issue in the home care literature. For instance, independent research by the Irish Association of Social Workers, Alzheimer Society of Ireland, Age Action and UCD found that allocated hours often fell short of what was required. That research also found that hours of provision for individuals were stretched thinly, with the result that people may be counted as in receipt of a service but it was not meeting their needs.[35] Official sources echo this finding, with the Department of Health acknowledging that it is common for insufficient hours to be allocated and stating that the service falls short of demand by a magnitude of about 10%.[36]

The advocacy organisation, Age Action, contends that:

> "Unmet need is associated with a variety of negative consequences that can affect the health and well being of the older person. These range from relatively minor consequences, such as feeling distressed because housework is not done, to major consequences, such as being able to eat when hungry."[37]

This shortfall in publicly funded care is likely to drive people to pay for private home care. A recent review of home care undertaken on behalf of the HSE found:

> "No firm figures are immediately available in regard to the number of people self-financing their home care without reference to the HSE but it is likely to be a significant and growing factor as HSE resources are limited and supply becomes more constrained."[38]

However, this option is only available to those with the means to take it up.

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[32] Available here.
[33] HSE and Department of Health (2015) *Positive Ageing 2016 – Indicators Report.*
[34] Department of Health (2017) as before; p.8.
[35] Donnelly, S; O'Brien, M; Begley, E and Brennan, J (2016) as before.
[36] Department of Health (2015) *Review of the Nursing Home Support Scheme.*
[37] Age Action (2017) *Pre-Budget Submission 2018 to the Department of Health.*
[38] Mazars (2016) *Health Service Executive – Services for Older People: Activity & Resource Review: Home Care Services.* p.12.

Demographics and demand

While the figures above show that services are not able to keep up with current demand, this demand is projected to grow substantially. It is well known that population changes are putting pressure on healthcare systems in Ireland and many other countries. As well as overall population growth, the older population is projected to increase in both the short and medium-term. The statistics below highlight some of the key issues as they relate to older people in Ireland.

A growth in life expectancy is driving growth in the older population – with significant expansion expected in the number of older people (aged 65 and over) and especially those aged 80 years and over in the coming decades.

Figures 2 and 3 below show population estimates (which are by their nature subject to a degree of uncertainty) over almost twenty years – to 2036.

The population aged 65 and over is expected to grow by between 79% and 84% in this time.[39] Highlighting the current nature of change, the Department of Health notes that:

> "Each year this cohort [aged 65 years and over] increases by 20,000 people."[40]

Figure 2: Population growth projections - <u>aged 65 years and over</u> – 2016-2036 [41]

2036

1,118,000 - 1,146,000

(79 % - 84% growth)

2016

624,000
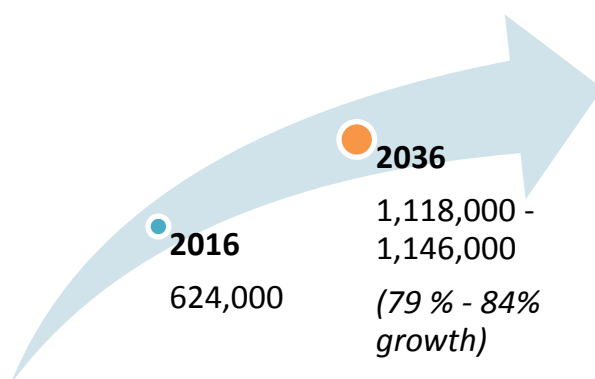
Far greater growth - of between 127% and 132% - is expected in the population aged 80 and over by 2036. As it is the oldest old who require the most care, this change has the potential for the biggest impact on health services overall (see below for ESRI projections of impact of population change on demand).

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[39] Different fertility and migration assumptions produce different estimates.
[40] http://health.gov.ie/blog/press-release/department-of-health-publishes-health-in-ireland-key-trends-2016/
[41] Central Statistics Office (2013) Population and Labour Force Projections, 2016-2046; p. 38-43 and Tables 1-6.

Figure 3: Population growth projections - aged <u>80 years and over</u> – 2016-2036 [42]

2036

338,000 - 345,000

(127-132% growth)

2016

149,000
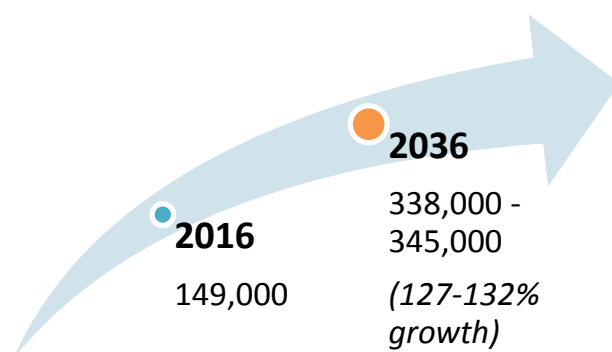
The ESRI has forecast that while some trends may alleviate the demand for care - such as lower disability rates and older couples remaining alive together longer - these will not be sufficient to offset the increasing demand for care resulting from the anticipated increases in the older population shown above.[43]   Former Minister for State with responsibility for Older People, Helen McEntee, TD, stated:

> "According to the figures, the number of people over the age of 65 will double in the coming years while the number of people over the age of 85 will treble. Currently, 11 people per day are diagnosed with dementia, and this number will only increase. It is estimated that approximately 20% of the over 65 population receive some form of community-based support service annually from the State."[44]

Implications of demographic trends for demand for home care

In October 2017, the ESRI published estimates of future demand for healthcare (up to 2030) as a result of a growing and ageing population. Their report projects substantial increased demand across all health services, including home care and residential care. Despite some data limitations, specifically on home care (including <u>public and privately-funded</u> care), it reported that:

- The demand for **home care packages** is projected to increase by between **44-66% by 2030**, from a level of 15,000 in 2015; and
- The demand for **home help hours** is projected to increase by between **38-54% by 2030**.[45]

The ESRI stated:

> "The additional demand projected…for the years to 2030 will give rise to demand for additional expenditure, capital investment and expanded staffing and will have major implications for capacity planning, workforce planning and training."[46]

Though not currently available, the ESRI intends to incorporate projections of the impact of increases in demand on healthcare expenditure into future work in this area.

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[42] Central Statistics Office (2013) as before.
[43] Layte, R (Ed.)(2009) *Projecting the impact of demographic change on the demand for and delivery of health care in Ireland.* Dublin: Economic and Social Research Institute.
[44] In Dáil Éireann, 26 January 2017.
[45] Wren, MA, Keegan, C, Walsh, B, Bergin, A, Eighan, J, Brick, A, Connolly, S, Watson, D and Banks, J (2017) *Projections of Demand for Healthcare in Ireland, 2015-2030: First Report from the Hippocrates Model.* Dublin: Economic and Social Research Institute. p. xxvii
[46] Wren, MA *et al* (2017) as before.

Constituency Dashboards from the Oireachtas Library & Research Service

The Oireachtas Library & Research Service constituency dashboards provide an interactive online visualisation of Census 2016 data, including **demographics**, for each of the Dáil constituencies.

The dashboards are currently (January 2018) in beta version and are available here: https://beta.oireachtas.ie/en/constituency-dashboards/

Part Two: Policy Challenges

Determining access: eligibility, entitlement or right?

The HSE is empowered, but not obliged, to provide or fund community care services such as home care. So, unlike GP care and in-patient care, there is no statutory entitlement to home care in Ireland. The introduction of legislation to underpin community care services has been recommended since the 1980s. A current Department of Health consultation about developing a statutory home care scheme is intended to result in policy and legislative action in this area. In terms of a timeframe for this, in November 2017, a Department official estimated that "…developing the proposals and having the legislation enacted will take two to three years".[47]

Effect of lack of entitlement

Various groups have identified the effect of lack of entitlement to home care regarding funding, access, public knowledge, the development of services, and dominance of residential care:

- In 2002, the Equality Authority[48] argued that: "It is unlikely that adequate funding will be provided for services unless there is a clear entitlement to services."[49]

- The Older and Bolder campaign group[50] contended that "…without legislation to underpin access to these services, access is discretionary, unequal and problematic."[51]

- The Ombudsman has observed that people do not know where they stand regarding entitlements to care and in terms of the HSE's obligations.[52]

- The National Economic and Social Forum suggested that the lack of legislation "has possibly arrested the expansion of community based care services."[53]

- Trinity College Dublin academics, Wren *et al*, have argued: "The home help service has no statutory basis and its patchy provision, combined with the system of state subsidy for residential care, biases utilisation towards residential care."[54]

Recommendations of advocacy groups

Numerous carer / older people advocacy groups have called for the introduction of a statutory entitlement to home care. In 1988, the Government appointed a Working Party on Services for the Elderly, in their report, *The Years Ahead*, they recommended the introduction of:

> "…an obligation on health boards to provide services to support dependent elderly people and their carers in the home."

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[47] Ms Frances Spillane, Department of Health, appearing before Joint Oireachtas Committee on Health, 15 November 2017.
[48] Now dissolved, its functions are included in those of the Irish Human Rights and Equality Commission.
[49] Equality Authority (2002) *Implementing Equality for Older People.*
[50] It is not clear from sources identified whether this group remains active.
[51] cited in Seanad Éireann Public Consultation Committee (2012) *Rights of Older People.*
[52] Cited in HCCI (2013) *The Business Case for Outsourcing of Home Care Provision and a More Efficient Use of Fair Deal Funds.*
[53] Cited in Brennan, J (2008) 'From community care to residential care: personal social services and older people', in Kennedy & Quin, as before. p.130.
[54] Wren, MA, *et al* (2012).as before.

The National Council on Ageing and Older People (the former statutory body[55] with a function to advise the Minister for Health on matters relating to ageing and older people) backed and continued to make the same recommendation:

> "The Council reiterates its call for legislation governing the provision of essential services to older people…[It] wishes to see the following services designated as core services underpinned by legislation and appropriate statutory funding: the Home Help Service, Meals-On-Wheels, Day Care, Respite Care, both inside and outside the home, Paramedical Services and Sheltered Housing."[56]

In 2012, Seanad Éireann Public Consultation Committee supported this cause when their *Rights of Older People* report recommended:

> "That clarity of available entitlements for older people is made a priority and that those entitlements should be given a statutory footing."[57]

The Equality Authority (since merged into the Irish Human Rights and Equality Commission) has made the case for an individual to be entitled to the same level of State support for care whether they are in the community or in residential care.[58]

Elsewhere, there has been debate regarding the benefit of establishing a right to healthcare (more broadly) rather than an entitlement. In 2014, the Constitutional Convention voted, with a majority of 85%, for the enumeration of certain economic, social and cultural rights in the Constitution.[59] A right to essential healthcare and the rights of people with disabilities were among these.[60]

Introducing entitlement - likely resource implications

At present publicly-funded home care is provided on a fixed budget allocation, meaning it is what is termed a **'supply-led'** service – there is a certain amount of supply (determined by funding allocated each year) and it is rationed out (e.g. by using waiting lists or stretching the number of hours across clients).

The introduction of statutory entitlement would change home care to a **'demand-led'** scheme – similar to the medical card scheme. This would mean that no matter how many people applied, assuming they met the entitlement criteria, their needs (however defined) would have to be met. The meaningfulness of any entitlement would be tested by the availability of services (e.g. entitlement to services may be undermined by a lack of access due to lengthy waiting periods).

The creation of a demand-led scheme would likely raise arguments about:

- Assessment criteria (health and financial);
- The level at which entitlement can realistically be set; and
- Affordability.

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[55] Now dissolved.
[56] In O'Shea, E (2000) *Costs of Caring for People with Dementia and related Cognitive Impairments.* Dublin: National Council on Ageing and Older People.
[57] Seanad Éireann Public Consultation Committee (2012) *Rights of Older People.*
[58] Equality Authority (2002) *Implementing Equality for Older People*
[59] https://www.constitution.ie/AttachmentDownload.ashx?mid=5333bbe7-a9b8-e311-a7ce-005056a32ee4
[60] It may be of interest to note that Germany has a 'Charter of Rights for People in Need of Long-term Care and Assistance'. Source: Holdsworth, L and Ruppe, G (2013) 'Palliative care within long-term care systems', in Leichsenring, K, Billings, J and Niews, H (Eds.)(2013) *Long-term care in Europe – Improving Policy and Practice*. Basingstoke: Palgrave Macmillan.

The policy challenge – Determining access: eligibility, entitlement or right?

In essence, the policy challenge is to weigh those arguments that emphasise supply and demand and the scarcity of resources against claims of social justice or entitlement. A key question is what types of services (domestic chores, personal care etc.) would be covered under any new scheme.[61]

Ultimately, the creation of a statutory entitlement would likely require raising additional revenue (through taxes or charges) or re-allocating funds from some other publicly-funded service.

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[61] In Israel, for example, only personal care is covered under the public home care scheme - not domestic help with tasks such as shopping, cooking and laundry. Unless informal carers assist, older people must pay for private services or go without (source: OECD (2017) *Preventing Ageing Unequally*.).

Selecting a funding model

Public spending on home care comes from general taxation, with allocation based on need but, as noted above, it is effectively rationed as it is subject to resource constraints. If services are to continue at current levels – that is, the same proportion of older people receiving the same level of supports - (even without allowing for any quality improvements) there will be a need to spend more money as the population expands.

In 2015, the Department of Health stated that to keep up with demand it estimated that the HSE home care budget would need to increase from €315m in 2014 to €467m in 2024 (a 48% increase).[62] As noted above, though not currently available, the ESRI intends to incorporate the impact on healthcare expenditure into future work on projections of demand.

This demand for additional resources arises in the context of overall population growth with consequent increase in demand for public services / spending. In addition, the increased older population will also increase pressures on other types of health spending (e.g. primary care and residential care) and Exchequer spending in other areas such as pensions.

The increasing demand for home care is common to other jurisdictions. In 2017, the Health Research Board (HRB) published a study examining the funding and regulation of home care in four countries – Scotland, Sweden, Germany and the Netherlands. It found that despite different funding models, each country was introducing or increasing co-payments for individuals and tightening eligibility criteria in order to deal with increasing demand.[63]

In Ireland, there is official agreement on the need to re-orient care (and related budgets) away from acute hospitals and into the community. The Department of Health has indicated that:

> "The decision to adjust the model of care provision to increase emphasis on community based services and supports has already been taken in principle."[64]

A number of commentators, including the Law Reform Commission, have called for the introduction of "a long term plan to fund long term care."[65]

Models for consideration are outlined below.

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[62] Department of Health (2015) as before.
[63] Kiersey, RA and Coleman, A (2017) *Approaches to the regulation and financing of home care services in four European countries: An evidence review*, Dublin: Health Research Board.
[64] Department of Health (2015) as before.
[65] Law Reform Commission (2011) *Legal Aspects of Professional Home Care*.

Funding options include:

Tax-based finance (current method of public funding)
Tax-based funding relies upon available revenues. Such systems can be adjusted to fluctuations in demographic or economic conditions.[66] In theory, benefits and services can be provided on a universal basis. The issue of acceptability is key concern in terms of potentially raising taxes. And in practice it is hard to fund universal coverage and this may give rise to means testing. Tax-financed services are exposed to the risk of cut backs at times of economic downturn. Scotland and Sweden[67], have long standing, rights-oriented home care sectors that are largely tax funded.

Private insurance
Tax relief could be used to support the take-up of private long-term care insurance (this applies to private health insurance at present). The suitability of voluntary private health insurance for long-term care is hampered by, among other things, the expectation that few younger people would take up such insurance, making it too expensive for those who did.

Social insurance
A social insurance system could be a stable form of income, and, if mandatory, would have the desired inter-generational transfers. The link between payments and entitlements might make this an acceptable finance method. However, contributions would have to be made for people not in work and it may be difficult to control expenditure. Also, it raises issues of competitiveness. The Netherlands and Germany have long-term care insurance systems that cover both home and residential care.[68]

Applying a similar scheme to the Nursing Home Support Scheme (NHSS)
Applying a modified version of the current NHSS would mean charging people for home care in accordance with their means. Individual contributions could be calculated based on income and assets, with public finances potentially meeting any shortfall. This form of finance could include a loan-style element repayable after death. However, unlike the NHSS, the level of contribution from individuals would have to take into account the potentially higher living costs of those in the community compared with those in residential care.

Amending the NHSS to include home care
This has been provided for in a Private Members' Bill introduced by Willie O'Dea, TD – the *Nursing Home Support Scheme (Amendment) Bill 2016*.[69]

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[66] Department of Health (2015) *Review of the Nursing Home Support Scheme*.
[67] https://sweden.se/society/elderly-care-in-sweden/
[68] Kiersey, RA and Coleman, A (2017) *Approaches to the regulation and financing of home care services in four European countries: An evidence review*, Dublin: Health Research Board.
[69] Link to debates of this Bill here.

Consideration of the option of applying the NHSS model, or similar, to home care was proposed in a 2015 Department of Health report[70] and, in 2016, by the Director General of the HSE.[71] In November 2017, Ms Frances Spillane, Department of Health, told the Joint Oireachtas Committee on Health that:

> "The Department is of the view that a stand-alone funding scheme designed specifically for home care is needed, together with an effective system of regulation."[72]

The Department's home care consultation document seeking public views on healthcare asked:

> "Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?"[73]

A further question asked whether people would be willing to pay for private care themselves. Ms. Spillane, Department of Health, told the Joint Oireachtas Committee on Health that:

> "The preliminary analysis reveals that the majority of respondents would be willing to contribute."[74]

However, the consultation document did not present or ask people's opinions about any other funding options (such as tax-based finance and private or social insurance systems).

This type of funding model (asked about in the consultation) - that would see people having to make means-tested co-payments for home care - has been criticised by Consultant Geriatrician and advocate for older people, Professor Des O'Neill (who also objects to the NHSS). He has argued that:

> "…it would be tragic and indeed shameful if we let ourselves be fooled twice [the NHSS being the first] into allowing ourselves as we age to be the only group to have eligibility for healthcare so dramatically diminished on a repeated basis."[75]

Family Carers Ireland has argued that:

> "We are happy to explore the different funding options for home care, including co-payment, but only after it has been agreed what a new home care system will look like and the range of supports and services that it would and should include."[76]

And

> "A new Statutory Home Care Scheme cannot be an excuse for charging for the existing, poor quality services on offer. Families could not, and would not, consider paying for such inadequate service provision. Family Carers Ireland has lobbied for many years for a statutory entitlement to home care, but what this cannot mean is a right for Government to simply charge for the current system of home care which is inequitable, inconsistent, fragmented and insufficient." [77]

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[70] Department of Health (2015) as before.
[71] Mr Tony O'Brien appearing before the Dáil Committee on the Future of Healthcare - Oireachtas Debates *Official Report, Committee on the Future of Healthcare, 30 November 2016*.
[72] Joint Oireachtas Committee on Health, 15 November 2017.
[73] Department of Health (2017) as before.
[74] Joint Committee on Health, 15 November 2017.
[75] O'Neill, D (2016) 'We were duped by the 'Fair Deal' health scheme and now it's happening again', *The Irish Times*, 23 August 2017.
[76] Family Carers Ireland (2017) *Press release: Family Carers Ireland rejects Governments initial plans for new Home Care Scheme*
[77] Family Carers Ireland (2017) *as before.*

The Alzheimer Society of Ireland (ASI) has argued for taxation or social insurance for a universal system of health and social care, including dementia care. According to the ASI such a system should be "based on need and not ability to pay." [78]

While Irish Rural Link[79] has stated:

> "A Fair Deal type scheme for home care would allow [a] person to remain in their own home while also give that person and their family peace of mind that they had their level of healthcare needs met."[80]

Stakeholders agree that whichever funding system is selected it must be as effective and equitable as possible and be financially sustainable in the long-term.

The policy challenge – selecting a funding model

Publicly-funded home care is available free at the point of use. However access is limited by available resources – this is a 'supply-led' scheme. Greater demand for home care services is putting upward pressure on public spending (of €408m in 2018). It is likely that providing sufficient services, in the short to medium term, will require raising additional revenue (through taxes or charges) or re-allocating funds from another publicly-funded service.

There is a choice to be made between different methods of funding home care in the future, with stakeholders emphasising the case for equity and sustainability. Each potential method has its own distinct advantages and disadvantages. Options include general taxation, care insurance, and applying a similar model to the Nursing Home Support Scheme (NHSS) (also known as the 'Fair Deal Scheme').

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[78] Alzheimer Society of Ireland (2017) *Submission to the Department of Health Consultation on home care*.
[79] Irish Rural Link is a national network of organisations and individuals campaigning for sustainable rural development in Ireland and Europe.
[80] Irish Rural Link (2017) *Submission to the Department of Health Home Care Scheme. October 2017*.

Finding the right mix of service provision

A 'mixed economy of welfare'

The provision of Ireland's health and social services has been described as a 'mixed economy of welfare'. This phrase describes the composition of the sector as a mix of public, voluntary and private providers and funding. The contracting out (or 'outsourcing') of home care to the private or voluntary sector or its provision directly by the HSE is the result of the policy choices that construct this mix.

Contracting out or funding of non-governmental organisations (NGOs) (public or private) is a common feature of Irish social provision. It has been argued by Muiris MacCarthaigh and Colin Scott, University College Dublin, that contracting out of services:

> "…has been a defining feature of Irish government since independence. In areas as diverse as overseas aid, primary education and hospitals, NGOs have been entrusted with considerable state authority and funding." [81]

Further, they contend that this contracting out has often taken place:

> "…without corresponding accountability and audit procedures."[82]

Current mix of providers and funding sources

Publicly-funded home care services are provided either directly by the HSE or through service agreements with private and voluntary sector providers. Approximately 85% of publicly-funded Home Help is provided directly by the HSE and not for profit providers. It is estimated that approximately 60% of the Home Care Package (HCP) service is delivered by arrangement with external providers.[83]

It has been argued that home care is being privatised 'on the quiet'[84], and private provision promoted 'by stealth'.[85] The ESRI has estimated that private home help provides about one-quarter of all home help hours.[86] In November 2016, then Minister of State with responsibility for Mental Health and Older People, Helen McEntee, TD stated that there were no plans to privatise the proportion of care currently provided by the HSE.[87]

Arguments for and against private sector provision

Clearly the preference for public over private service provision, or vice-versa, is a long-running, ideologically informed, policy debate.

Those in favour of private provision would note its flexibility, especially in terms of being able to provide round-the-clock care – a model of service provision that public services (such as social work) have struggled with. In addition, the perceived benefits of competition in controlling costs and driving consumer focus, choice and quality would also be valued.

[81] MacCarthaigh, M and Scott, C (2009) *"A Thing of Shreds and Patches": Fragmenting Accountability in a Fragmented State* UCD Geary Institute Discussion Paper Series.
[82] MacCarthaigh, M and Scott, C (2009) as before.
[83] Helen McEntee, TD, Minister of State for Mental Health and Older People, Dáil Éireann, PQ - Written Answers – 18 October 2016.
[84] O'Neill, D (2017)
[85] Office of the Ombudsman (2012) as before.
[86] Wren, MA *et al* (2017) as before.
[87] Dáil Debates, Written Answers - 22 November 2016.

Private sector stakeholders are keen to cement and extend their role in providing home care. In addition, nursing home providers wish to enter the home care market, with Nursing Home Ireland, a trade organisation representing private nursing homes, arguing:

> "The 430+ private and voluntary nursing home providers, who have 'stepped up to the plate' to meet our ageing population's… residential care requirements, have the experience, knowledge and proven track record to deliver specialist care services in our communities."[88]

Those who would argue against private provision may favour public services that seek to promote social solidarity and reduce inequalities. They may also highlight that the money that goes to profit when contracting out services would be better spent directly on services through the public or voluntary sectors. Opponents may also raise concerns about the quality of employment in the private sector.

The policy challenge – Finding the right mix of service provision

A key policy decision in relation to publicly-funded care is how services can be best delivered, that is, what mix of providers is desirable.

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[88] Nursing Homes Ireland (2016) *Submission to the Dáil Committee on the Future of Healthcare.*

Introducing effective regulation

Why regulate?

People receiving care in their homes may be vulnerable and have no-one on site to protect them. While nursing homes are subject to regulation - registration, quality standards, inspection and possible sanction - at present home care is not subject to a statutory regulatory framework. There are no statutory requirements around who can provide home care, e.g. mandatory minimum training / qualification requirements across the sector (save for regulated professions such as nurses) and no statutory care standards.

The HSE has quality standards for its own services and has put in place uniform quality standards for its contracted services.[89] However, these have **no reach over privately contracted home care** services.

The need for regulation in this sector has been highlighted over a number of years. Dr. Kieran Walsh and Prof. Eamon O'Shea of NUI, Galway have argued that:

> "The regulation of older adult care in Ireland has been less than satisfactory in the past."[90]

And that:

> "…the continued absence of regulation in the private home care sector means that older people may be at risk in their own homes."[91]

In the same vein, the Health Information and Quality Authority (HIQA) has highlighted the need for oversight of home care:

> "From HIQA's knowledge of the sector, and from evidence gathered in other jurisdictions, we firmly believe that people in receipt of care services in their own homes are markedly vulnerable and require the protection of a system of regulation in the sector sooner rather than later."[92]

Stakeholder recommendations

Many stakeholders, including, the Law Reform Commission (LRC), have recommended that home care be subject to the same type of oversight by HIQA as residential care.[93] This would require primary legislation (possibly by way of amending the *Health Act 2007)*. The LRC noted that in its consultations around home care it received no submissions opposing this proposed approach. As noted above, HIQA is in favour of such regulation.

A Private Members' Bill (sponsored by Senators Colm Burke, Neale Richmond and Maura Hopkins) proposing to introduce such regulation was initiated in 2016 (as of January 2018 this Bill was at Order for Committee for Seanad Éireann).[94]

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[89] See http://www.hse.ie/eng/services/news/media/pressrel/newsarchive/2012archive/june12/Approvedhome care.html and http://lenus.ie/hse/bitstream/10147/120850/1/hcpsguidelines.pdf
[90] Walsh, K and O'Shea, E (2009) *The Role of Migrant Care Workers in Ageing Societies: Context and Experiences in Ireland.* Irish Centre for Social Gerontology, NUI Galway. page. v.
[91] Walsh, K and O'Shea, E (2009). as before. page v.
[92] Health Information and Quality Authority (2016) *Safeguarding – everyone's responsibility*. Speech by Phelim Quinn, CEO. 17 November 2016.
[93] Law Reform Commission (2011) as before.
[94] *Health (Amendment) (Professional Home Care) Bill 2016; 2nd stage debate, 9 Nov. 2016*.

Government commitments

The LRC's recommendation was taken up by the previous government in its *Future Health* strategy (2012), which undertook to introduce primary legislation to provide for regulation of home care. However, this legislation was not brought forward.

The *Programme for a Partnership Government* (2016) indicates an intention to introduce a uniform service to standardise the quality of home care provision:

> "The provision of home care ranges from excellent to irregular for recipients across the country. We will introduce a uniform home care service so all recipients can receive a quality support, 7 days per week, where possible."[95]

In early 2017, then Minister for State, Helen McEntee, TD, stated:

> "The development of a statutory home care scheme is a priority for me and my Department'.[96]

The burden of regulation on providers

The OECD and the European Commission have highlighted that heavy regulation in the care sector may create high administrative burdens for providers.[97] They also argue that too much regulation can stifle innovation or discourage providers from going beyond minimum standards.[98]

However, established private providers in Ireland appear to welcome the prospect of regulation. Private home care provider, Home Instead, and industry representative group, Home and Community Care Ireland (HCCI) have argued in favour of regulation in the sector.[99] One issue HCCI hope that regulation will address is what they call a 'black market in care', which they describe as follows:

> "An important point to note about the 'black market' in home care, is that it is not as we traditionally understand, with murky dealing happening in the back of vans. Black market home care is often provided by people with the best of intentions - friends, relations and neighbours trying to do what they believe is the right thing. However, there is also the 'cash in hand' side of the business, where advertisements are answered by unknown people, with unknown qualifications. There are a large number of carers operating on the black market on a cash-in-hand basis. The issues for either type of care are significant. Black market carers are not paying taxes or properly trained or insured, leaving many people in vulnerable situations in the event of an issue arising."[100]

HCCI argues that there are further problems in the sector, such as a lack of oversight of privately hired carers, and lack of insurance and employment standards for these workers. It argues that:

> "Regulation of the sector and clarity around live-in care could…help to discourage black market providers to the benefit of patients and the economy [by] contributing to increased PRSI and tax income."[101]

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[95] Government of Ireland (2016) *Programme for Partnership Government*.
[96] Dáil Éireann, 26 January 2017.
[97] OECD and European Commission (2013*) A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*; OECD Health Policy Studies, OECD Publishing.
[98] OECD and European Commission (2013) as before.
[99] See: http://www.hcci.ie/news/pdf/2015-05.pdf
[100] Home and Community Care Ireland (Undated) *Presentation to the Joint Oireachtas Committee on Jobs, Enterprise and Innovation.*
[101] https://www.oireachtas.ie/parliament/media/committees/jobsenterpriseandinnovation/HCCI-presentation.pdf

These providers speak on behalf of the more formalised part of the sector – private sector companies that provide care to individuals directly or through HSE contracts. They may take a different view to other stakeholders – e.g. the individuals (sole traders) working directly for clients and those clients themselves. These groups may be affected most by the introduction of regulation, e.g. by the imposition of minimum qualification standards, insurance requirements etc.

Against quality regulation?

It may be believed that no-one would argue against quality measures, but this is not the case. Leichsenring *et al* (2013) find that:

> "Many professionals have argued that quality management is yet another bureaucratic exercise that takes away time from working with users."[102]

While this resistance may arise where regulations are understood as a 'box-ticking exercise', there is evidence that quality management can improve care services and be embedded as central to daily practice, and there are some tools and methods available to support this.[103]

The Migrant Rights Centre of Ireland (MRCI) argues that the lack of standards for home care, along with a lack of transparency around costs, has led to 'huge competition' within the sector. The MRCI contends that:

> "This has resulted in a flooring of the cost of services which has negatively affected both care standards and working conditions."[104]

In relation to the effectiveness of regulation, the OECD and European Commission note that experience in other jurisdictions indicates that:

> "Despite regulation, compliance and enforcement may not be strong enough. There are still questions regarding the effectiveness of fines, warnings and threats of closure."[105]

The English regulator, the Care Quality Commission, points out that regulation on its own is not enough to deliver improved services, stating:

> "Regulation is an important lever in setting expectations, monitoring, inspecting and rating services and taking enforcement action when it is required. But it takes a collective effort from staff, providers, commissioners and funders as well as other national organisations all listening and responding to the voice of people using services, their families and carers to truly make a sustainable difference to quality."[106]

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[102] Leichsenring, K. *et al* (2013) p.190.
[103] Leichsenring, K. *et al* (2013) p.190.
[104] Migrant Rights Centre Ireland (2014) *Migrant Workers in the Home Care Sector: Preparing for the Elder Boom in Ireland.*
[105] OECD and European Commission (2013) as before.
[106] https://medium.com/@CareQualityComm/cqcs-valentine-s-day-message-to-the-adult-social-care-sector-a85a7c892461#.nq4y1r2pq

Issues in designing home care regulations

There are particular challenges in designing regulatory systems to support quality home care services. These include:

The Home as a unique setting
Regulating home care presents unique challenges due to the nature of the setting as the clients' personal space - with the attendant vulnerabilities and boundaries - and the use of the home as a workplace for carers.

Standardisation vs. individualisation
Incentives designed to create desired behaviours among providers must be considered for the possibility of unintended consequences. There may be a tension between a drive for standardisation of practice and the need for flexibility to respond to an individual's needs.[107] MS Ireland has stated that family carers report a lack of flexibility in services.[108] While Inclusion Ireland[109] has made the case that: "Home care supports should work well with other aspects of a person's life."[110]

Measuring the right things
The literature indicates a need to consider the use of outcome based measures of quality (such as users' quality of life, choice and dignity) rather than input based measures (such as labour and infrastructure). [111]

Supporting quality
Researchers examining systems across Europe report that there can be a disconnect between legally mandated quality systems and supports and enabling measures – such as staff training, organisational development and funding of projects to promote continuous improvement within and between organisations.[112]

Provision of consumer information
Consideration should be given to the translation of inspection reports into useful consumer information. In England, the Care Quality Commission provides consumer information - rating services across the following categories: safe, effective, caring, responsive and well-led. [113]

Dynamic field
Quality in long-term care provision is a field under development and subject to challenge in other jurisdictions. In the UK both regulatory bodies[114] and respective quality and registration regulations / powers[115] have been changed several times in recent years, while German providers have mounted a legal challenge to quality indicators imposed there. [116]

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[107] OECD and European Commission (2013) as before and Leichsenring, K. *et al* (2013) p. 188.
[108] MS Ireland (2017) *Submission to the Department of Health consultation on home care*.
[109] The National Association for People with an Intellectual Disability.
[110] Inclusion Ireland (2017) *Submission to the Department of Health consultation on home care*. September 2017.
[111] Leichsening, K, Henk, N and van der Veen, R (2013) The Quest for Quality in Long Term Care', in Leichsenring, K *et al* (Eds.) *Long-term care in Europe – Improving Policy and Practice.* Basingstoke: Palgrave Macmillan. p.181.
[112] Leichsening, K, Henk, N and van der Veen, R (2013) as before. p. 181.
[113] See: http://www.cqc.org.uk/content/ratings
[114] See: House of Commons Library (2007) *Briefing Paper on the Health and Social Care Bill 2007-08; Research Paper 07/81, 23 November 2007.*
[115] See: House of Commons Library (2013) *Briefing paper on the Social Care Bill 2013 -14.* Research Paper 13/71, 11 December 2013. Also UK Department of Health (2014) *Care Bill becomes Care Act 2014*; and Care Quality Commission (2009) *Tough new powers for adult social care watchdog*.
[116] Leichsenring, K. *et al* (2013).

The policy challenge - regulation

The policy challenge is to design a regulatory system that balances successfully the benefits of regulation against the related cost.

The potential benefits of regulation include its potential to prevent the abuse of vulnerable service users, and improve the quality of care (as experienced by the cared for) by setting/raising, monitoring, and enforcing standards. It should also have the effect of standardising care and may be used as a method of moving all care into the formal economy.

The potential costs of regulation include a loss of choice on the part of those cared for (for instance, where only those with particular qualifications may be permitted to provide care), and direct and indirect financial costs – costs to the State and industry of establishing and maintaining a regulatory regime and the chance that such costs will be passed on to service users. Another potential negative effect could be the loss of paid relatives / friends as a source of care – where the regulatory burden may cause them to cease providing care or, in the case of future cohorts, choose not to provide care in the future.

Sustaining informal care

"Formal care and informal care should be viewed as complementary." [117]

The National Carers' Strategy **defines a carer** as:

"…someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty."[118]

While the CSO defines an informal carer in relation to their voluntary status:

"Someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability."[119]

Number, hours and roles

Over 195,000 informal carers[120] play a critical role in providing about 90% of all care. These mostly unpaid friends and family members (sometimes known as family carers) provide the vast bulk of care required (over 6.6 million hours of care each week for those with long-term illness, health problem or disability). Six out of ten informal carers are women and many carers are older people themselves. Since 2011, there has been an increase in the number of carers (8,000 (4.4%) more people) and in the number of hours of care they provide (see Figure 4 below).

Figure 4: Key caring statistics from Census 2016[121]

195,000 Informal Carers (4.1% of population)	**About Carers**
• Provided 6.6 million hours of care per week on average; • An average of 38.7 hours of care per week (an increase of 5.1% over 2011 figures).	• 61% are women/39% men; • Over 11,000 carers aged 65 years and over provide more than 28 hours of unpaid help per week each.

Informal carers are particularly important for their roles in instrumental day-to-day, hands-on care and for their part in negotiating and organising other forms of care for the care recipient – seeking services, making appointments etc.

Recent estimates have put the value of informal care in Ireland at **between €2.1 billion and €4 billion per year**.[122]

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[117] European Foundation for the Improvement of Living and Working Conditions (2015) *Working and caring: Reconciliation measures in times of demographic change* Publications Office of the European Union, Luxembourg.
[118] Department of Health (2012) as before.
[119] http://census.ie/and-communities/census-for-carers/
[120] Central Statistics Office (2017) *Census of Population 2016 – Profile 9 Health, Disability and Carers.*
[121] Central Statistics Office (2017) *as before.*
[122] Hanly, P and Sheerin, C (2017) 'Valuing informal care in Ireland: Beyond traditional production boundary', *Economic and Social Review*, Vol. 48 (3), Autumn 2017, pp.337-364.

Costs of caring

Carers' groups observe that:

> "Providing care can be both enriching and rewarding where expectations placed on Family Carers are reasonable and adequate supports are provided."[123]

However, for many carers the task may come at a significant cost – for instance loss of or reducing opportunities for employment and an increased risk of mental health problems (the OECD puts this at 20% greater than the general population).[124] Advocacy groups for carers highlight the physical, emotional, social and financial toll that caring can take.[125] And indeed, the Department of Health has stated that more than one in four carers (27%) aged 50+ report a high level of stress or distress.[126]

Current supports

Social Protection Payments

The State supports carers financially through a number of social protection schemes. In 2016, carers received €686m in Carer's Allowance and Carer's Benefit (about 3.45% of all 2016 social welfare expenditure) and about €172m in Carer's Support Grants (these payments are not made exclusively to those who care for older people). Table 4 below shows the number of people in receipt of payment and the amounts spent per scheme.

Table 4: Social Protection Payments to Carers (Allowance and Benefit), 2016 and 2017[127]

Payment (year)	Number of people in receipt of payment	Spending (€000)
Carer's Allowance (2016)	70,459	653,667
Carer's Benefit (2016)	2,710	32,746
Carer's Support Grant (2017)	90,212*	172,321

Source: Department of Employment and Social Protection (2017) *Annual Report – Statistical Information on Social Welfare Services 2016*.p. 14 and 22;

*The number of people in receipt of this payment includes those in receipt of Domiciliary Care Allowance and Prescribed Relative Allowance in addition to those in receipt of the carers' payments listed above.

Carer's leave

Employees may take Carer's Leave from their work to care for someone in need of full-time care.[128] When on this protected leave (available for a maximum of 104 weeks) the carer's job is kept open for them on their return. It is not paid leave but, if they meet the criteria, those taking carer's leave may receive social welfare payments (see above). This leave is not available to those who need/wish to provide part-time care.

There is a Family Leave Bill on the Government's current legislative programme.[129]   Minister of State, David Stanton, TD, has stated that the intention of this Bill is to: "… consolidate all existing

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[123] Care Alliance Ireland (2016) *Budget 2017 – Recognising and Respecting Family Carers in Ireland as Key Partners in Care*

[124] Organisation for Economic Co-operation and Development (2017) *Preventing Ageing Unequally*, OECD Publishing, Paris.

[125] Family Carers Ireland (2016) *Budget 2017 – Achieving Fairness for Family Carers*

[126] HSE and Department of Health (2015) *Positive Ageing 2016 – Indicators Report.*

[127] Department of Employment and Social Protection (2017) *Annual Report – Statistical Information on Social Welfare Services 2016*.p. 14 and 22.

[128] See Citizens Information webpage here.

[129] Legislative Programme, Autumn 2016.

family leave legislation such as parental leave, carer's leave, maternity leave and adoptive leave into one Act while making necessary amendments and improvements."[130]

GP Visit cards – promised for Carer's Allowance recipients

In December 2017 the Minister for Health announced that additional funding would be provided in 2018 for GP Visit Cards for all recipients of Carer's Allowance (i.e. those who do not already qualify on means or age grounds).[131] This will be "subject to the drafting and enactment of the necessary legislation."[132]

National Carers' Strategy

The *National Carers' Strategy* published in July 2012 sets the strategic direction for future policies, services and supports provided by Government Departments and agencies for carers. It sets out:
- guiding principles,
- goals and objectives addressing priority areas (income support, health, information, respite, housing, transport, training, employment, children and young people with caring responsibilities) and
- a '*Roadmap for Implementation*' containing 42 actions to be achieved on a cost-neutral basis in the short to medium term.

However, the Strategy's ambition was limited by the constraints on public spending at the time and it acknowledged that most of its actions included were selected for the quality of being 'budget neutral'.   A second phase of the strategy - one backed with appropriate resources - has been called for by the advocacy group Family Carers Ireland.[133]

What influences the sustainability of informal care?

The public healthcare system, as currently resourced and organised, could not replace all the care currently provided by informal carers in addition to what it already provides. Family carers have been described as 'the linchpin to the success of community care'.[134]

However, there are challenges to the sustainability of this care:
- **Demographic**: Demographic trends noted above indicate that, given the increasing number of older people and smaller family sizes, fewer people are likely to be available to undertake caring roles in the future. The ageing of carers is also a factor.
- **Social factors:** Dispersal of family groups due to work or other factors and greater female workforce participation has the effect of reducing the availability of those traditionally associated with providing informal care.[135]

Home care used as a support to informal care

It has been argued that home care has a key role to play in sustaining informal carers. Research by the Family Carers' organisation highlighted that formal home care allows family carers time away from their caring role to pursue their own interests or undertake tasks such as shopping. It may also alleviate the need to undertake some physical tasks.[136]

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[130] See PQ reply, Dáil Éireann, 10 October 2017, Parental Leave.
[131] The allocation of additional funding for respite care was also announced.
[132] Department of Health, Press Release, 12 December 2017.
[133] Family Carers Ireland (2016) as before.
[134] http://www.icsg.ie/content/new-report-dementia-ireland-launched-minister-health
[135] HSE Planning for Health (2015) cited in Care Alliance Ireland (2016) Analysis of Home Care Supports Funded by the HSE 2008-2016 – Briefing paper 1.
[136] Stokes, Ann (2010) *The Caring Reality of Family Carers: An exploration of the health status of Family Carers of people with Parkinson's disease*, Care Alliance Ireland and Parkinson's Association Ireland.

One small piece of Irish research has indicated that home care is an important support, allowing informal carers to continue in work noting:

> "…that the lack of sufficient community and home care services often presents an insurmountable barrier to paid employment for Family Carers."[137]

Though the research highlighted the impact of the limitations of current publicly funded provision for some:

> "…several had sought additional home care support through paid carers in the private sector due to these inadequacies."[138]

Further research indicates that people with informal carers may be less likely to receive HSE home care supports - a recent study of social workers' views highlighted that at times having a family carer may mean a person is <u>less likely</u> to be allocated formal support. [139] Social workers also reported that people with family carers may not be provided with concrete support such as HCPs or respite until the carer reaches "breaking point".[140]

The policy challenge – Sustaining informal care

The challenge facing policy makers is to determine and implement the optimal incentives and supports to sustain informal care provision, which may include:

Employment supports

One of the objectives of the National Carers' Strategy is to "enable carers to remain in touch with the labour market to the greatest extent possible."[141] Supporting informal carers to continue in paid employment helps them to continue caring for people thus avoiding or delaying admission to residential care. Research by the European Foundation for the Improvement of Living and Working Conditions shows that carers who can combine work and care report having a better quality of life and higher self-esteem than those who can not.[142] Additionally, they can contribute towards their own pension and social protection entitlements and be productive in the economy. While their continued caring helps to avoid or delay admission to residential care for the person they care for. The Foundation has identified policy measures to support informal carers to combine work with care, including:[143]

- appropriate long-term care services to support dependent persons and their families,
- income support and other 'flexicurity' measures for carers;
- rights and regulations in the employment field; and
- practical measures that can be implemented by employers at company level.

At European level, the European Commission put forward a proposal for legislation (a Directive) in April 2017 aiming to enhance work / life balance by giving all employees an entitlement to five days carer's leave.[144,145] This proposed leave is intended to allow workers to care for a direct relative

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[137] Cited in Stokes, A (as before) http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf
[138] Stokes, A (2010) as before, p.
[139] Donnelly, S *et al* (2016) as before.
[140] Donnelly, S *et al* (2016) as before.
[141] Department of Health (2012) *National Carers' Strategy*
[142] European Foundation for the Improvement of Living and Working Conditions (2015) as before.
[143] European Foundation for the Improvement of Living and Working Conditions (2015) as before.
[144]European Commission (2017*) Press Release: Delivering on the European Pillar of Social Rights – Commission adopts first concrete initiatives*; Brussels, 26 April 2017; http://europa.eu/rapid/press-release_IP-17-1006_en.htm
[145] This proposal aims to advance the delivery of the European Pillar of Social Rights (the implementation of which is in the hands of Member States, social partners and civil society, as well as European Union institutions).

who is sick and would be compensated at least at the same rate as sick pay. This short-term leave would not replace existing long-term leave arrangements in place in Ireland.

Home and respite care supports

Improved access to and adequacy of hours of formal home care and respite supports have been called for by advocacy groups. Care Alliance Ireland has called for:

> "Efficient respite services and home-based support targeted at both the needs of the Family Carer and care recipient have a significant role to play in making sure that Family Carers receive regular and sufficient amounts of rest, thus enabling them to continue in their role and having a positive health impact."[146]

Income supports

Issues include whether social protection payments provide adequate compensation for lost earnings and ensure informal carers are not financially burdened as a result of their caring role. Also there have been calls for property tax exemption for homes where intensive care is provided (though this would seem only to benefit owner-occupiers).

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[146] Stokes, Ann (2010) *The Caring Reality of Family Carers: An exploration of the health status of Family Carers of people with Parkinson's disease,* Care Alliance Ireland and Parkinson's Association Ireland.

Securing a care workforce

While many professionals work in people's homes (such as occupational therapists) this section refers for the most part to home help and care assistant type roles.

Professional care for older people is an expanding, labour-intensive sector with potential for substantial employment growth (from and estimated base of 40,000 workers – see below). While the literature indicates that many long-term care workers describe their work as meaningful, they also find it physically and emotionally demanding.[147,148] In addition, employment in the sector has been characterised as 'precarious'. In this context, in order to meet growing demand, employers seeking to attract care workers must compete with other sectors of the economy where the work itself and the terms and conditions may be considered more favourable. The Government's 2017 *National Strategic Framework for Health and Social Care Workforce Planning* includes a consideration of home care workers.

Size and composition of workforce

The industry group Home and Community Care Ireland (HCCI) has estimated that 40,000 people are employed in home care across the public, voluntary and private sectors.[149] Specifically on publicly-funded employment, there are some (rather dated) figures on home help workers – according to a HSE census there were approximately 20,300 home help workers funded by the HSE in 2007.[150] More recent data show that, in 2014, the HSE was directly employing 9,100 home help workers.[151]

The 2007 data showed that an overwhelming majority of home help staff were women (98%) working part-time (99%); and they were older on average than the workforce more generally.[152] The World Health Organisation has highlighted the gender element of healthcare work:

> "…women's employment, especially in health-care related work, is often not measured and not valued appropriately."

Terms and conditions of employment

A low paid sector

In the care for older people sector, pay is considered to be low. According to the OECD, internationally, wages in home care tend to be lower than in institutional care (for the same level of qualification).[153]

Research by NUI Galway academics, Dr Kieran Walsh and Professor Eamon O'Shea found that low pay leads to "…low morale, higher rates of turnover, and ultimately poorer quality of care

[147]Walsh, K and O'Shea, E (2009) *The Role of Migrant Care Workers in Ageing Societies: Context and Experiences in Ireland.* Irish Centre for Social Gerontology, NUI Galway.

[148] Colombo, F *et al* (2011) *Help Wanted? Providing and Paying for Long-term Care.* OECD Health Policy Studies, OECD Publishing; p.182.

[149] Estimated by the industry body, Home and Community Care Ireland, cited in Wren, MA *et al* (2017) as before, p. 239. See: https://www.oireachtas.ie/parliament/media/committees/jobsenterpriseandinnovation/HCCI-presentation.pdf

[150] FÁS and the Expert Group on Future Skills Needs (2009) *A Quantitative Tool for Workforce Planning in Healthcare: Example Simulations*, Dublin: FÁS.

[151] Mazars (2016) *Health Service Executive – Services for Older People – Activity & Resource Review: Home Care Services.* Available here: http://www.lenus.ie/hse/handle/10147/621444

[152] FÁS and Expert Group on Future Skills Needs (2009) as before.

[153] Colombo, F *et al* (2011) as before. p.173.

delivery among all carers".[154]   Indeed, both care workers and older people have questioned the value put on older people and care work given the low wages in the sector.

Walsh and O'Shea argue that care work, particularly the work of care assistants, should not be considered low skilled work due to the wide range of professional skills and personal attributes required.

There are also concerns that HSE staff and privately employed staff have different terms and conditions. Family Carers Ireland has contended that HSE staff enjoy better terms and conditions (e.g. through the use of annualised hours contracts rather than if-and-when contracts, and the exclusion of some hours – such as weekend or nights).[155]

Privately hired home care workers

The Irish Longitudinal Study of Ageing found that a large minority of paid care workers are not attached to any provider organisation (i.e. they are working independently).[156] This raises questions about the quality of their terms and conditions of employment and the role of older people or their families as employers.

The Migrant Rights Centre in Ireland (MRCI) has stated that:

> "A significant proportion of elder care in private homes is informal, undeclared and provided by undocumented migrant workers."[157]

'Living in' blurs boundaries

While no data were identified indicating their number, the literature on home care identifies particular issues for care staff who 'live-in' (i.e. workers employed directly by older people or their families who live in the older person's home). It suggests that living-in blurs the boundaries between private and professional, personal and public matters.[158]   According to the Migrant Rights Centre, in Ireland, issues for live-in workers include: lack of distinction between working hours versus off-duty time, working without employment contracts, sick pay and cover, a lack of supervision, and potential undeclared work amongst others.[159]

Migrant workers

Internationally, care work, including home care for older people, is frequently undertaken by migrant workers. Across countries this group share a very stable profile - being female, middle-aged and low paid.[160] It is not unusual for their work to be undocumented / irregular. In Ireland, the

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[154]Walsh, K and O'Shea, E (2009) as before.

[155] Family Carers Ireland (2017) *Submission to the Department of Health on the Creation of a Statutory Home care Scheme*.

[156]Kamiya, Y *et al* (2012) *Profile of Community Dwelling Older People with Disability and their Caregivers in Ireland.* The Irish Longitudinal Study on Ageing. TCD, Dublin.

[157] Migrant Rights Centre of Ireland (2015) *Migrant workers in the home care sector: preparing for the elder boom in Ireland*.

[158] Green, Ohad and Ayalon, Liat (2015) 'Whose Right Is It Anyway? Familiarity with Workers' Rights Among Older Adults, Family Caregivers, and Migrant Live-In Home Care Workers: Implications for Policy and Practice', *Educational Gerontology*, 41.7: 471.

[159] Migrant Rights Centre Ireland, Carers Association and SIPTU (2012) *Employment Guidelines for the Home Care Sector: The Workers' Perspective.*

[160] Rodrigues, R, Huber, M & Lamura, G (eds.) (2012) *Facts and Figures on Healthy Ageing and Long-term Care.* Vienna: European Centre for Social Welfare Policy and Research.

proportion of migrant care workers has been estimated to be 27%[161] and reliance on migrant care workers is predicted to increase in the long-term.[162]

A study, by the Migrant Rights Centre, of migrants' employment conditions in this sector found that while some migrants reported good terms and conditions, there was a:

> "…high degree of non-compliance with basic labour law standards among those surveyed. There is a significant level of exploitation of migrant workers within private nursing homes and private homes."

Migrant workers may be marginalised and so may older people, especially frail older people with care needs, leading to the argument that the needs of some members of these groups are tied together.

Recruitment and retention problems

There are difficulties with recruiting and retaining staff in nursing homes[163] and in home care across a range of roles (professional roles such as occupational therapy and home help and care assistants).[164] Representatives of the nursing home sector have argued that a shortage in supply of suitably qualified staff is a key challenge to all operators both in terms of guaranteeing adequate standards of care, and ensuring the viability of their businesses. While, Mr Fiacre Hensey, of the voluntary sector representative group National Community Care Networks[165], has stated:

> "…the [lack of] availability of carers is the biggest problem across the country in the delivery of home care services."[166]

Improved economic conditions, and the resulting greater availability of employment choices in other sectors may result in potential workers being attracted to better prospects and terms and conditions outside of care work. However, it is possible that Brexit may give Ireland an advantage in recruiting migrant care workers – by retaining the free movement of people within the EU, while the UK may restrict migrants' labour market access.

The World Health Organisation calls for 'decent working conditions'

While not specific to home care, a recent (2016) High Level Commission established by the World Health Organisation identified the following key issues for providing 'decent working conditions' in the health sector:

> "In seeking to promote decent work for all women and men working in the health economy, several issues need to be addressed. These include poor wages and benefits, the absence of social protection and unsafe working conditions. Inadequate salaries may oblige workers to take on multiple jobs, which can damage both health services and workers' welfare. Career planning and development opportunities are particularly important, not least to combat gender inequality. Achieving a decent quality of living requires a focus on issues such as accommodation, transport, the availability of necessary equipment and treatments, and the risk of professional and personal isolation and burnout."[167]

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[161] Migrant Rights Centre of Ireland (2012) *Who Cares? The Experience of Migrant Care Workers in Ireland.*
[162] Walsh, K and O'Shea, E (2009) *The Role of Migrant Care Workers in Ageing Societies: Context and Experiences in Ireland.* Irish Centre for Social Gerontology, NUI Galway.
[163] http://www.nursinghomesireland.ie/medical_articles/staffing.aspx
[164] Mazars (2016) *Health Service Executive – Services for Older People – Activity & Resource Review: Home Care Services.* Available here: http://www.lenus.ie/hse/handle/10147/621444.
[165] The National Community Care Networks organisation represents 26 not-for-profit home care providers in Ireland.
[166] Appearing before the Joint Oireachtas Committee on Health, 15 November 2017.
[167] World Health Organisation (2016) *Working for Health and Growth – Investing in the Healthcare Workforce*; p.31.

The Commission also found that use of rural and other allowances could act as important incentives and they emphasised the need to prevent all forms of discrimination.

Better working conditions support better care

Besides the value of workers rights for their own sake, the quality of staff working conditions has been shown to have an impact on the quality of care.[168] There is also growing evidence that long-term care (LTC) can be considerably improved by involving and rewarding staff to work on improvements.[169]

In the USA, the potential for expanding the roles of lower paid home care workers (often those who spend most time with the client) has been highlighted. This is seen as a way to improve their working conditions and to potentially save money – through involving them in more proactive management of their clients' health and healthcare (e.g. ensuring they take medication, monitoring their condition(s), ensuring they attend doctors' appointments etc.) with a view to preventing relapses that result in costly hospital stays or moves to long-term care.[170]

The Department of Health consultation on home care is looking at the issue of staff training. MS Ireland[171] and the Alzheimer Society of Ireland[172] are in favour of mandated minimum training standards for formal carers and argue for condition-specific training (e.g. dementia specific training).

A further development may be the professionalisation of roles through their inclusion in the CORU[173] registration of health and social care professionals. 'Social Care' is a designated profession in legislation[174], though a register has not yet commenced.[175] However, a decision on whether home care workers (such as home helps) would be included on the register may be contentious. It may be difficult to balance the need to maintain the care workforce (i.e. not to put in place conditions that act as a disincentive) and the introduction of professional registration requirements such as gaining qualifications.

The policy challenge – Securing the care workforce

A key challenge in meeting the growing demand for home care, is ensuring the availability and retention of suitably qualified staff, not least by securing favourable pay and conditions. This includes consideration of how to move all care into the formal labour market. However, there may be a tension between the rights of workers and the demand for affordable care.[176]

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[168] Leichsenring, K, *et al* (2013) as before; p.189.

[169] Leichsenring, K, *et al* (2013) as before; p.189.

[170] Porter, Eduardo (2017) 'Home health care: Shouldn't it be work worth doing?', *New York Times*, 29 August, 2017.

[171] MS Ireland (2017) as before.

[172] Alzheimer Society of Ireland (2017) as before.

[173] CORU is Ireland's multi-profession health regulator.

[174] *Health and Social Care Professionals Act 2005 (amended)*

[175] See CORU site for update on the work of the Registration Board: http://www.coru.ie/en/about_us/update_on_the_registration_of_social_care_workers

[176] Migrant Rights Centre (2012) as before.

Developing other alternatives to nursing home care

It has been argued that, for older people in need of care, the alternative to living at home is primarily seen as a move to a nursing home. However, the Department of Health cites figures indicating that about 13% of people in nursing homes have low dependency needs – that is they do not necessarily need nursing care.[177] As noted, above, home care is one of a range of community based supports for older people. And the development or enhancement of further models of care has been called for.

Sheltered or supported housing

The expansion of sheltered housing, to act as a more acceptable and affordable[178] alternative to nursing home care, has long been recommended as a level of support for those unable to live alone or independently any longer.

Sheltered or supported housing refers to housing where older residents live in individual, appropriately designed dwellings but share on-site facilities and have access to on-site support staff.[179] The housing itself is generally provided by housing associations, and it can be seen as part of a continuum of care services for older people.

However, at present sheltered housing is not widely available in Ireland and where it does exist, the availability of supports on site is variable – with issues arising around the funding of care supports.[180]

Surveys indicate that where people in Ireland can not stay at home any longer they would prefer sheltered housing over nursing home care. The ESRI has recommended that where residential investment is being made it should focus on sheltered housing over nursing homes.[181]
Currently the HSE is working with Dublin City Council on a 'housing with care' strategy.[182]
The Box below presents an overview of the Danish approach to older people's care needs – characterised by a distinct and purposeful move <u>away</u> from residential care.

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[177] Department of Health (2015) as before.p.65.
[178] Norris, M and Winston, N (2008) 'Housing and accommodation for older people', in P Kennedy and S Quin (Eds.) *Ageing and Social Policy,* University College Dublin Press.
[179] Norris, M and Winston, N (2008) as before.
[180] Irish Council for Social Housing (2005) *An overlooked option in caring for the elderly: A report on sheltered and group housing provided by housing associations in Ireland*. Dublin: Irish Council for Social Housing.
[181] Wren, MA (2009) as before.
[182] HSE (2017) *Annual Report 2016*; p.54.

Denmark –home care and sheltered housing preferred over nursing homes

No new nursing homes have been developed in Denmark since the passing of a law on dwellings for older people in 1987.[183] Since then home care and supported and sheltered housing have been strongly favoured, through legislation and policy, over residential care. Data show that by using legislation, Denmark has radically reduced reliance on nursing homes – fewer Danish older people live in nursing homes compared with other EU countries.[184] The number of nursing home places fell from 27,600 in 2001 to approximately 9,400 in 2009.[185] It has been reported that the costs of care were contained at the same time.[186] As a result, Denmark is held up as an example of a country that has successfully implemented a move away from nursing home care.

How does it work?

All Danish citizens are eligible for home help and home care including round-the-clock care. Generally, support is based on need rather than means. And the supply of a variety of sheltered housing and other adapted / supported dwellings was increased in recent decades. Residents pay rent related to the running costs but, depending on income, this may be offset by housing welfare benefits.[187]

Some research on the Danish system has shown good levels of satisfaction with the level and quality of services available, though some recent literature highlights conflicts around proposed cutbacks.[188] In addition, there have been issues about variation in the quality of services between municipalities (local authorities charged with planning, funding and some delivery) and the need to promote autonomy and choice for those receiving care.[189]

Similarities and differences to Ireland

As in Ireland, in Denmark older people wish to stay in their own homes as long as possible and home care is paid for from general taxation (though in Ireland there is an unknown level of privately paid for care / top-up care). However, there are some notable, relevant differences between Ireland and Denmark. For instance, in Denmark:

- There is, in general, a greater tolerance of State intervention;
- The older population was largely steady during the initial years of the policy so a growth in nursing home beds might not have been expected – however the large reduction is clearly the result of policy; and
- There are lower cultural expectations of and reliance on informal (family) care.

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[183] Schulz, E (2010) *The long term care system for the elderly in Denmark*, European Network of Economic Policy Research Institutes and Assessing Needs of Care in European Nations; p.1.

[184] Schulz, E (2010) as before.

[185] Olejaz, M *et al* (2012) *Health Systems in Transition – Denmark*. World Health Organisation, European Observatory on Health Systems. Vol. 14. No.2.

[186] Stuart, M and Weinrich, M (2001). 'Home and community based long-term care: Lessons from Denmark', *The Gerontologist*, 41 (4), 474-480.

[187] Schulz, E (2010) as before.

[188] Schulz, E (2010) as before.

[189] Stuart, M and Weinrich, M (2001) as before.

Reablement interventions

Reablement is a service that seeks to restore function to people – after a period in acute hospital for instance. Rather than providing just traditional home care to assist a person in their daily activities, reablement programmes provide intensive, short-term services (typically six to eight weeks) aiming to improve / restore people's ability to look after themselves.

Reablement interventions are provided in New Zealand and Australia, and in 2010 about 80% of English local authority areas had such programmes.[190]

A recent review of evidence found that reablement services can have positive effects on health related quality of life and reduce health service usage.[191] Other evaluations have shown it to be more cost-effective than conventional home care.[192] NHS North East England notes:

> "Introducing reablement has led to significant cost savings…through reductions in the number and size of care packages needed after reablement and reduced need for care home placement."[193]

In Ireland, a HSE pilot reablement programme in Dublin North Central in 2013-2014, reduced or eliminated need for future home care services among three out of four participants (these were applicants for HSE home help or home care packages).[194] This has now become an established and award-winning service.[195] At least one private provider is also offering reablement services.[196] Advocacy group, Age Action has proposed the national roll-out of publicly-funded reablement services, arguing that this could be achieved on a cost-neutral basis.[197]

Some literature suggests that reablement is not very well defined and greater attention is needed regarding who it works for, how and in what circumstances.[198] However, such programmes appear to offer promise and could be implemented more widely here.

The potential of technology

The potential of technology to improve the lives of older people in need of support has been demonstrated in a number of initiatives[199]– and is under development in others – such as the EU funded ProACT digital health technology project led by TCD researchers seeking to support older people with chronic conditions.[200] The further development and implementation of new technology offers some promise in supporting independence and reducing reliance on more intensive forms of care.[201]

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[190] NHS North East *et al* (2010) *Reablement: a guide for frontline staff.*
[191] Tessier, A *et al* (2016) ʻEffectiveness of Reablement – A Systemic Review', *Healthcare Policy*, May Vol. 11 (4), 49-59.
[192] Expert Working Group on Frailty (2016) ʻReablement and Frailty Discussion Paper', in *International Federation on Ageing Expert Papers – Reablement and Older People*. IFA Copenhagen 2016 Summit.
[193] NHS North East *et al* (2010) *as before.*
[194] Rooney, Barbara (2016) *Reablement – Dublin North Central*. Presentation.
[195] Irish Healthcare Award 2015.
[196] See: https://myhome care.ie/portfolio-view/reablement/
[197] Age Action (2015) *Pre Budget Submission 2016*, to the Department of Health.
[198] Legg, L *et al* (2016) ʻA systematic review of the evidence on home care reablement services.', *Clinical Rehabilitation*, Vol. 30(8) 741-749.
[199] See for instance the EU funded ENABLE project which found that assistive technologies could promote independent living for people with dementia in a cost-effective way.
[200] See: https://www.tcd.ie/news_events/articles/new-health-technology-project-led-by-trinity-to-improve-older-people-s-lives/6903
[201] See media article about robots carrying out caring tasks: https://www.theguardian.com/technology/2016/nov/06/robot-could-be-grandmas-new-care-assistant

A note of caution - potentially widening the net?

One note of caution on developing alternative care models is that they may appeal to and draw in those who do <u>not</u> currently use existing services or those who use the least intensive services rather than those who use most services. As such they may **'widen the net'** – becoming <u>additional</u> services rather than replacing more expensive or less desirable types of care. This indicates a need for careful consideration of intervention objectives and targeting.

The policy challenge – Developing other alternatives to nursing home care

The policy challenge here is to consider ways of developing stronger services and supports across a spectrum. The particular challenge may be that these supports cross traditional professional and sectoral (including funding) boundaries - for example across different parts of the health sector and between health and housing sectors.

Further to this, the scoping of such supports and their eligibility criteria need to be carefully considered to ensure effective targeting.

Conclusion

In general, older people with care needs want to stay in their own homes. Most of their care is provided by informal carers, largely unpaid. Nonetheless, professional home care is an expanding field, largely due to an increasing number of older people.

Official policy is supportive of keeping people with care needs at home for as long as possible by supporting informal carers, funding formal care supports and / or home improvements. Advocates for informal carers are seeking improvements in the areas of income replacement and 'flexicurity' along with greater respite and home care supports.

Meanwhile, shortcomings in the provision of publicly-funded formal home care have led to inadequate hours of care, waiting lists, and a growth in private care provision for those who can afford it.

With the development of a statutory scheme on the horizon, policymakers must consider the significant challenges presenting in this dynamic sector – such as decisions about who should care, what type of supports are required, the oversight of care quality and how to secure the funding of care into the future – many of which raise key ideological questions.

Conclusion