
Profile of Community-Dwelling Older People with Disability and their Caregivers in Ireland

Kamiya, Yumiko*, Murphy, Catriona**,
Savva, George* and Timonen, Virpi*
* Trinity College Dublin
**Dublin City University

On behalf of the TILDA Team

May 2012

Copyright © The Irish Longitudinal Study on Ageing 2012

The Irish Longitudinal Study on Ageing
Lincoln Place
Trinity College Dublin
Dublin 2

Tel.: +353 1 896 4120

Email: tilda@tcd.ie

Website: www.tilda.ie

ISBN: 978-1-907894-02-2

Key Findings

- Among community-dwelling older people in Ireland, 11% of men and 14% of women aged 50 or over have at least one limitation in daily activities. This translates into 164,000 older adults with care and support needs living in communities across Ireland.
- The vast majority of caregivers for community-dwelling older people are unpaid (89.5%). The remaining 10.5% are paid caregivers.
- Among older people who get help with personal care and household tasks, assistance from family members and friends amounts to 30 hours per week on average.
- The majority of main caregivers are aged 50 and over. This reflects the enormous contribution that the ageing population is making to the care of older family members.
- Spouses are most frequently identified as the main caregiver.
- Seven out of 10 main caregivers are women.
- Of paid caregivers, 62% are contracted through the formal home care sector. 38% are not affiliated to any organisation or company.
- Among spouse carers, 11.7% receive the carer's allowance or carer's benefit. This finding calls for discussion on additional ways of supporting ageing spouse carers.

Acknowledgements

We would like to acknowledge the vision and commitment of our funders, Irish Life, the Atlantic Philanthropies and the Department of Health, which is providing funding on behalf of the State. We would also like to state that any views expressed in this report are not necessarily those of the Department of Health or of the Minister for Health. We also thank the members of the TILDA Translational Research and Policy Implementation sub-committee for their advice and support. In particular, we wish to acknowledge the support and leadership of Professor Rose Anne Kenny, the Lead Principal Investigator of TILDA.

Contents

1. Introduction	1
2. Prevalence of disability by presence of ADL/IADL limitations	3
3. Receipt of help by older adults with disability	14
4. Caregiver characteristics	18
5. Conclusions	24
References	26

1

Introduction

The dramatic increase in life expectancy over the last century has resulted in an increase in the number and share of older people in populations across the world. The rapid ageing of populations in developed countries over the next few decades is expected to increase the demand for, and hence expenditure on, long-term care¹. In Ireland, the proportion of older people aged 65 and over in the population is expected to rise from the current 11.4% to 22.4% in 2041. While the projected changes in the population aged 65 and over are striking, changes for the group aged 80 and over are even more dramatic. Between 2011 and 2041, the proportion of people aged 80 and over in the population of Ireland is projected to rise from 2.8% to 7.3% (Kenny and Barrett, 2010).

Population ageing has implications for the sustainability of pension, health care and social care systems. In this report, we will focus on social care. The term social care is used to denote assistance with activities of daily living (ADL) and with instrumental activities of daily living (IADL). ADL are the basic tasks of everyday life that pertain to personal care, such as eating, bathing, dressing, toileting, and moving about². IADL are activities performed by a person in order to live independently in a community setting, such as housekeeping, preparing meals, shopping, using the telephone, taking medications correctly and managing money³.

In Ireland, as in most other countries, the bulk of the social care of older persons is provided by family caregivers, primarily spouses and adult children, especially daughters. One of the central reasons for this is the relatively low (direct) cost of family care in comparison with state-financed long-term care. Another implicit reason is the belief that receipt of care in the community and family context helps to maintain central, often life-long, social relationships and thereby contributes to the well-being of older persons.

1 Recent OECD projections (Lafortune and Balestat, 2007) estimated that under a conservative scenario, average public expenditure on long-term care will increase from 1.1% of GDP to 2.3% by 2050 across OECD countries.

2 The original ADL scale was developed by Katz and colleagues who described them as "...activities which people perform habitually and universally", p.94).

3 The IADL scale is derived from a set of validated questions developed by Lawton and Brody (Lawton and Brody, 1969).

This report provides information on social care⁴ received by community-dwelling older people who report difficulty with at least one activity of daily living (ADL) or one instrumental activity of daily living (IADL). The report also characterises the main care givers⁵. The data comes from the the first wave of the Irish Longitudinal Study on Ageing (TILDA), a prospective study of 8,175 participants representative of the community-living population aged 50 and over in Ireland. TILDA uses ADL and IADL measures as the starting point in analysing the population with disability⁶, because stated difficulties in these activities are the most objective way of identifying individuals who have difficulties with everyday tasks. It should be noted that people with cognitive impairment who were unable to provide written consent to participation were not included in the study; the prevalence of disability and other estimates presented in this report are, therefore, conservative and not reflective of the care needs of the older population living in institutional care settings such as nursing homes.

The report is organised as follows. Section 2 describes the prevalence of disability in the older population by sex, education, marital status, living arrangements and location (Dublin/ urban area other than Dublin/rural area). It also examines the prevalence of each IADL/ADL difficulty, the percentage of older people receiving help with IADL/ADL difficulty, the prevalence of the use of equipment to assist with ADL difficulties and the most common equipment used. Section 3 reports details of older people receiving help, the hours and type of help caregivers provide, and their relationship to the care recipient. Section 4 describes the characteristics of the carers and examines the receipt of social welfare supports by the carers of older people. The source of the care provided is also examined. Section 5 summarises and flags policy issues arising from the findings.

4 Social care can be provided by formal or informal carers (or both formal and informal carers in tandem). Informal care refers to care provided by family, friends and neighbours, typically free of charge. Formal care is paid for (by the recipient, family members, or via state supports) and can be provided either in recipient's home or in an institution. The providers of formal care can be drawn from the public (State), private (for-profit) or non-profit sectors, or from the grey labour market (Timonen, Doyle and Prendergast, 2006).

5 Institutional long-term care is not dealt with in this report as people in nursing homes were not included in Wave 1 of TILDA.

6 The Disability Act (2005) defines disability as "...a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment". This definition of disability contains the concept "substantial restriction" which is seen as a restriction that – (a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and (b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability. This definition is in line with the International Classification of Functioning, Disability and Health (ICF) by the World Health Assembly in May 2001. However, in geriatric practice, disability is described as a transient or permanent inability to carry out daily tasks. Given the focus on assessing the prevalence of disability and social care needs, it was agreed that the focus should be on limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Therefore, the specific definition of disability adopted in this report is in line with geriatric literature, where disability is defined as people reporting one or more ADL or/and IADL limitations.

2

Prevalence of disability by presence of ADL/IADL limitations

TILDA respondents were shown two separate cards listing ADLs and IADLs and in each case the following text was read out to them: "Because of a health or memory problem, do you have any difficulty doing any of the activities on this card? Exclude any difficulties you expect to last less than three months".

Show card for ADLs

- 1 Dressing, including putting on shoes and socks
- 2 Walk across a room
- 3 Bathing or showering
- 4 Eating, such as cutting up food
- 5 Getting in or out of bed
- 6 Using the toilet, including getting up or down
- 7 None of these

Show card for IADLs

- 1 Preparing a hot meal
- 2 Doing household chores (laundry, cleaning)
3. Shopping for groceries
- 4 Making telephone calls
- 5 Taking medications
- 6 Managing money such as paying bills and keeping track of expenses
- 7 None of these

Table 1 shows the prevalence of limitations in IADL only, ADL only, and both ADL and IADL limitations. Overall, 11% of men and 14% of women aged 50 and over have at least one limitation in daily activities (either ADL or IADL or both). More specifically, 4% of older people have IADL difficulties only, 5% have ADL difficulties only, and 4% have both ADL and IADL difficulties. When we relate these percentages to the population, the minimum (conservative) estimate of the number of older people with IADL difficulties only is 50,400, ADL difficulties only is 60,400 and both ADL and IADL difficulties is 52,900. Among the over 80s, 16,400 have IADL difficulties only, 7,960 have ADL difficulties only and 19,900 have both ADL and IADL difficulties. In total, this amounts to 163,700 people aged 50 and over, among them 44,260 people aged 80 and over. There is a clear age gradient as the prevalence is greater at older ages. In each age group, women were more likely to have limitations than men. The prevalence of limitations in the oldest age group (age 80 and over) is 27% for men (9% with IADL only, 7% with ADL only and 11% with IADL and ADL difficulties), while for women it is 39% (15% with IADL only, 7% with ADL only, and 17% with IADL and ADL difficulties).

Table 1: Prevalence of disability by age and sex

	Not disabled	IADL disability only	ADL disability only	IADL & ADL disability	N
Male					
50-64	92.1	2.0	4.4	1.6	2,079
65-79	85.7	2.5	7.9	3.9	1,397
80+	73.2	8.7	6.6	11.5	268
Total	88.7	2.6	5.7	3.0	3,744
Female					
50-64	91.6	2.9	2.7	2.7	2,589
65-79	83.5	5.6	5.1	5.8	1,481
80+	60.6	15.2	6.8	17.5	361
Total	85.6	5.1	4.0	5.3	4,431
Total					
50-64	91.8	2.5	3.6	2.2	4,668
65-79	84.5	4.1	6.4	4.9	2,878
80+	65.4	12.7	6.7	15.2	629
Total	87.1	3.9	4.8	4.2	8,175

The next tables examine the prevalence of disability in the older population by marital status, living arrangements, education and location (Dublin/urban area other than Dublin/rural area). Examining disability by marital status, it is well known from the research from developed countries that health status, morbidity, and mortality differ systematically by marital status for both sexes. Married persons are healthier and have lower death rates than single, widowed and divorced persons (Goldman, Korenman and Weinstein, 1995). **Table 2** indicates some differences in baseline disability by marital group. Among both men and women, widowed persons are most likely to have limitations in IADLs (9%), ADLs (5%), and both ADLs and IADLs (10%), partly due to their older age. Never married men and women were also more likely than married men and women to have limitations in IADLs (4% vs. 3%), ADLs (5% vs. 4%), and in both ADLs and IADLs (4% vs. 3%). Separated/divorced older people appear to be more likely to have limitations in daily activities than married or never married older people, although the numbers were smaller and the confidence interval was wider, thus yielding a less precise estimate.

Table 2: Prevalence of disability by age and marital status

	Not disabled	IADL disability only	ADL disability only	IADL & ADL disability	N
Married					
50-64	92.8	2.2	3.0	2.0	3,582
65-79	86.3	2.7	7.2	3.8	1,845
80+	72.1	10.0	9.1	8.8	211
Total	90.0	2.6	4.5	2.8	5,638
Never married					
50-64	90.9	2.6	4.5	1.9	431
65-79	86.2	3.5	6.2	4.1	291
80+	67.3	8.5	5.7	18.5	69
Total	87.2	3.5	5.2	4.1	791
Separated/ divorced					
50-64	85.9	4.8	6.6	2.6	427
65-79	79.5	5.1	4.6	10.9	120
80+	66.7	0.0	33.3	0.0	4
Total	84.5	4.8	6.5	4.2	551
Widowed					
50-64	89.0	2.1	4.3	4.6	228
65-79	79.9	8.0	4.8	7.3	622
80+	61.7	14.9	5.4	18.0	345
Total	75.5	9.3	4.9	10.3	1,195
Total					
50-64	91.8	2.5	3.6	2.2	4,668
65-79	84.5	4.1	6.4	4.9	2,878
80+	65.4	12.7	6.7	15.2	629
Total	87.1	3.9	4.8	4.2	8,175

Living arrangements and family characteristics affect the availability of family caregivers and the need for paid services. **Table 3** describes the prevalence of disability by age and living arrangements. Of older adults living alone, 19% had no limitation in IADL/and or ADL. By comparison, 12% of older people living with spouse, and 11% of those living with others (including living with children) have no ADL/IADL limitations. Examination of those aged 80 years and over revealed a higher prevalence of disability among those living with others compared to those living alone. This pattern suggests that as disability arises at or persists into older age, older people and their families adapt their living arrangements in an effort to provide informal care within the home.

Table 3: Prevalence of disability by age and living arrangements

	Not disabled	IADL disability only	ADL disability only	IADL & ADL disability	N
Living alone					
50-64	88.0	3.3	5.6	3.1	684
65-79	82.0	6.0	5.8	6.1	818
80+	66.2	12.5	5.8	15.5	318
Total	81.1	6.3	5.7	6.9	1,820
Living with spouse					
50-64	91.2	2.3	3.3	3.2	1,535
65-79	86.6	3.0	7.2	3.1	1,517
80+	73.1	9.8	8.9	8.2	189
Total	88.1	3.1	5.4	3.4	3,241
Living with others					
50-64	93.3	2.3	3.1	1.3	2,449
65-79	82.6	4.4	5.3	7.8	543
80+	54.0	16.9	6.2	22.8	122
Total	89.6	3.4	3.6	3.4	3,114
Total					
50-64	91.8	2.5	3.6	2.2	4,668
65-79	84.5	4.1	6.4	4.9	2,878
80+	65.4	12.7	6.7	15.2	629
Total	87.1	3.9	4.8	4.2	8,175

Socio-economic status (SES) is a powerful predictor of disability, morbidity and mortality in older populations (Duncan, Daly, McDonough and Williams, 2002). In general, indicators of SES are based on education, occupation, income and wealth. **Table 4** examines the relationship between disability and education. There is a clear negative relationship between education and disability. Overall the prevalence of at least one limitation in daily activities is 20% for those with primary education only, and less than 10% for those with secondary or tertiary education. The excess disability among those with primary education only, compared with those with tertiary education, is present in all age groups. The prevalence of ADL and IADL disability among respondents with primary education is 3% for ages 50–64, and 17% for ages 80 and over. For those with tertiary education, the prevalence rates are 1% for ages 50–64 and 9% for age 80 and over, i.e. considerably lower than for those with only primary education.

Table 4: Prevalence of disability by age and education

	Not disabled	IADL disability only	ADL disability only	IADL & ADL disability	N
Primary/none					
50-64	87.1	4.5	5.1	3.2	957
65-79	81.0	5.4	7.3	6.4	1,198
80+	62.5	14.8	5.6	17.1	349
Total	80.4	6.6	6.2	6.9	2,504
Secondary					
50-64	93.2	1.9	2.9	2.0	2,119
65-79	88.5	2.7	5.6	3.3	965
80+	70.5	9.4	9.0	11.0	179
Total	91.0	2.4	3.9	2.7	3,263
Third/higher					
50-64	93.9	1.5	3.3	1.3	1,592
65-79	88.5	2.8	5.4	3.3	714
80+	76.4	4.2	10.4	9.0	98
Total	92.0	1.9	4.1	2.1	2,404
Total					
50-64	91.8	2.5	3.6	2.2	4,668
65-79	84.5	4.1	6.4	4.9	2,878
80+	65.4	12.7	6.7	15.2	629
Total	87.1	3.9	4.8	4.2	8,175

Table 5 shows the prevalence of disability by location (Dublin, urban area other than Dublin, and rural areas) to illuminate possible differences in disability by location. Overall, there are no substantial differences by location. However, examining by age group, the prevalence of IADL/ADL differs somewhat by location. For example, 13% of those aged 80+ living in Dublin have an IADL disability compared to 14% of same age group in other urban areas and 12% in rural areas. In the same age group, 10% of people who live in Dublin have ADL disability compared to 5% of people living in another city/town, and 6% of people living in rural areas. Of people aged 80 and over who live in Dublin 9% have both ADL and IADL difficulties, while the corresponding percentage is 13% among those who live in another city/town, and 18% among those who live in rural areas.

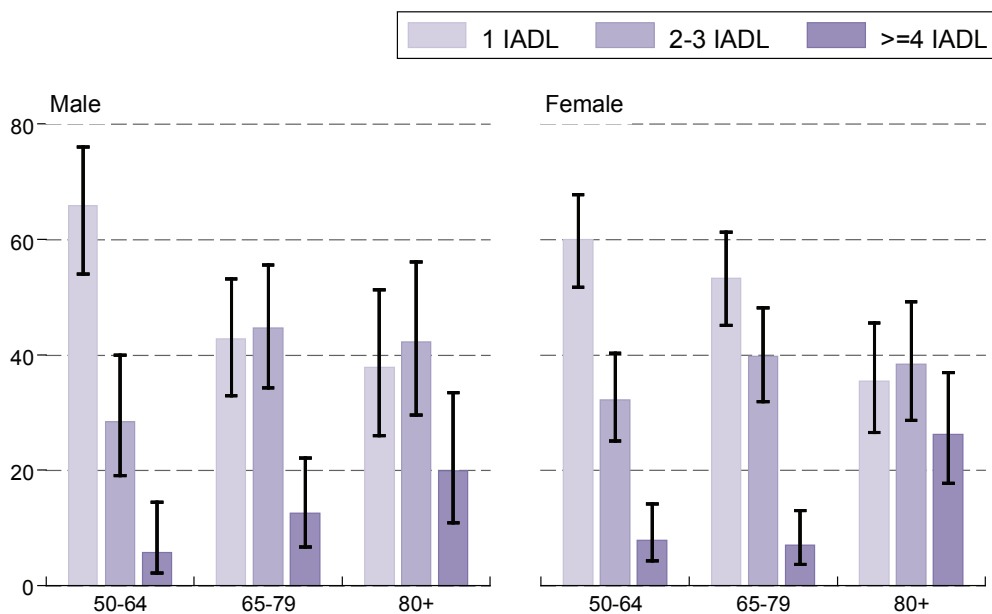
Table 5: Prevalence of disability by location

	Not disabled	IADL disability only	ADL disability only	IADL & ADL disability	N
Dublin City or County					
50-64	91.5	2.6	3.9	1.9	1,076
65-79	83.1	5.4	7.7	3.8	712
80+	68.0	12.5	10.1	9.4	148
Total	86.7	4.4	5.7	3.2	1,936
Another Town or City					
50-64	89.1	3.3	5.0	2.6	1,311
65-79	84.6	4.6	6.2	4.6	817
80+	67.6	14.4	4.7	13.2	184
Total	85.7	4.7	5.4	4.2	2,312
A Rural Area					
50-64	93.5	1.9	2.6	2.0	2,275
65-79	85.0	3.3	6.0	5.6	1,344
80+	63.3	12.0	6.4	18.3	296
Total	88.1	3.3	4.0	4.6	3,915
Total					
50-64	91.8	2.5	3.6	2.2	4,668
65-79	84.5	4.1	6.4	4.9	2,878
80+	65.4	12.7	6.7	15.2	629
Total	87.1	3.9	4.8	4.2	8,175

It is important to examine the prevalence of ADL/IADL limitations by the number of difficulties present, as the challenges involved in overcoming and addressing these difficulties become more evident as they increase in number. Considering only those who reported any difficulties with IADL/ADL, there is a clear age gradient as the mean number of IADL and ADL increase by age group (table not shown). Considering those with IADL difficulties, the mean is 1.7 for age group 50-64, 1.6 for age group 65-79, and 2.0 for age 80 and over. The mean ADL is 1.6 for age group 50-64, 1.9 for age group 65-79, and 2.5 for age 80 and over.

Figure 1 shows the percentage of the older population with only one IADL difficulty, two or three IADL difficulties, and four or more IADL difficulties. As described in previous tables, there is a gradient of greater presence of IADL limitations at older ages, especially at 80 and over. Of those who have IADL difficulties, the proportion of men with 4 or more difficulties is 6% for age group 50-64, and 20% for age 80 and over, while for women it is 8% for age group 50-64, and 26% for age 80 and over.

Figure 1: Percentage of older population with one, two-three, and four or more IADLs

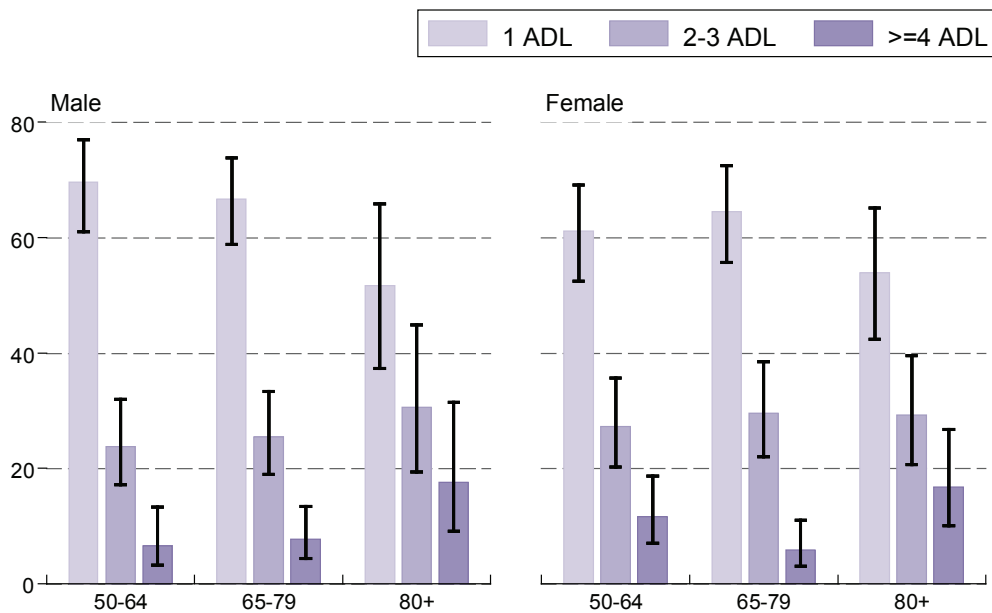


Note. N = 599; Error bars correspond to 95% confidence intervals

7 Subsequent waves will include people from these groups as some respondents from the first wave may develop cognitive/physical impairments or move into institutional care.

Figure 2 shows the percentage of the older population with only one ADL difficulty, two or three ADL difficulties, and four or more ADL difficulties. There is again a clear age gradient. For example, the proportion of men with more than four ADL difficulties is 7% for age group 50-64, and 18% for ages 80 and over, while for women it is 12% for age group 50-64, and 18% for ages 80 and over. Because the TILDA survey did not include older people with severe cognitive impairment or those who are living in institutions, the prevalence of four or more ADL difficulties in the total older population is likely to be higher than presented here.

Figure 2: Percentage of older people with one, two-three, and four or more ADLs



Note. N = 699; Error bars correspond to 95% confidence intervals

For those who reported IADL difficulties, **Table 6** describes the prevalence of each IADL difficulty, and the percentage of older people receiving help with it. The IADLs which older people receive most help with are related to household chores such as shopping for groceries (92%), preparing a hot meal (85%) and doing household chores (81%). In interpreting Tables 5 and 6, it should be borne in mind that some older people have more than one IADL/ADL limitation

7 Subsequent waves will include people from these groups as some respondents from the first wave may develop cognitive/physical impairments or move into institutional care.

Table 6: Percentage of those with specific IADL(s) difficulties receiving help

	Prevalence (%)	Receiving help (%)
Preparing a hot meal	2.7	84.9
Doing household chores	5.2	80.5
Shopping for groceries	4.5	92.3
Making telephone calls	0.1	71.0
Taking medications	1.2	78.5
Managing money	1.8	75.4
Total	8.0	75.0

For those who reported ADL difficulties, **Table 7** reports the prevalence of each ADL difficulty, the percentage receiving help with each ADL difficulty, prevalence of the use of equipment or device, and the most common equipment used. Getting dressed, including putting on socks and shoes is the most frequently reported difficulty with ADL (9.3%). Among this group, 30% receive help and almost 15% use equipment to get dressed. The most common equipment used is a device for putting on socks. Bathing or showering is the second most common ADL reported (5.2%). Almost half of those who have difficulty with bathing receive help (49%). Fifty-six per cent use an aid, most commonly a walking frame or stick (62%) or a hand-held shower (56%). Of the 3% who report difficulty in getting in or out of bed, 29% receive help. Thirty-five per cent use an aid. The most common equipment is a walking stick (56%), followed by a walking frame (26%). Two per cent have difficulty in walking across a room and 37% receive help. In this group, 72% use an aid and the most common aid is a walking stick (55%), followed by a walking frame (50%). Almost 2% had a difficulty going to the toilet. Of those, 22% receive help. Forty-four per cent use an aid and the most common equipment used is a portable toilet (68%) followed by grab rails (58%). Finally, one per cent has difficulty with eating and among them, 25% received help. Nine per cent used special utensils or special dishes. Overall, we note considerably higher proportions of older people receiving help with IADL than with ADL difficulties.

Table 7: Percentage of those with specific ADL(s) receiving help and use of assistive devices

	Prevalence	% Receiving help	Use of the equipment	Most common equipment used
Get dressed	9.3	30.0	14.7	Device for putting on socks
Walking	1.9	36.5	72.4	Walking stick
Bathing	5.2	49.0	56.3	walking frame or stick
Eating	1.1	24.5	9.1	N/A
Getting in or out of bed	2.7	29.0	35.0	Walking stick
Going to toilet	1.7	22.0	44.0	Portable toilet
Total	9.0	17.0	N/A	N/A

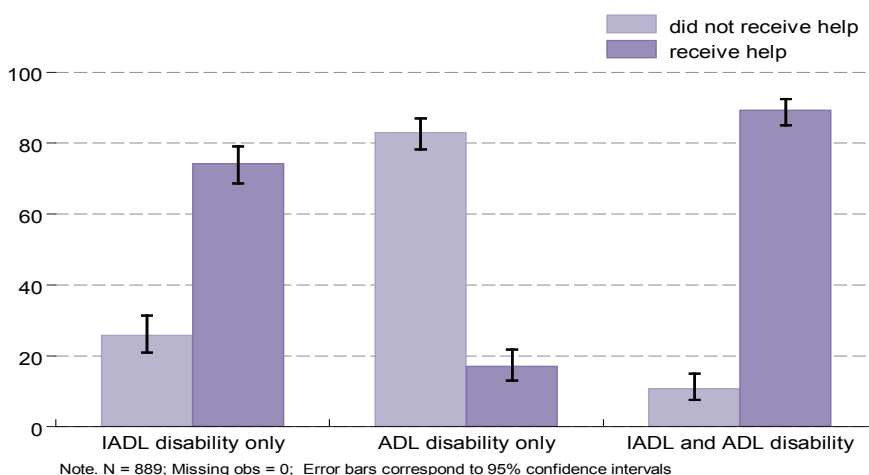
3

Receipt of help by older adults with disability

In order to understand how individuals and families organise care, the TILDA questionnaire captures information on up to 12 caregivers by caregiver task. For ADL, we ask the following question: “who most often helps you with getting across a room/dressing/bathing/eating/getting in out of bed/using toilet?”. For IADL difficulties, we ask the following questions by two different tasks: “who most often helps you with preparing meals/doing household chores/shopping for groceries/making telephone calls/taking medication?” and “who most often helps you to manage your money?”. In this section, we examine the availability of help for those with disability. Then, we examine the multiple caregivers who provide care to older people. Later, we focus mainly on the primary caregiver, i.e. the person who most frequently provides care.

Figure 3 shows that among older people with only IADL limitations, 25% received no help, among those with ADL limitations, 83% did not receive any help, and among those with combined IADL and ADL limitations, 12% did not receive any help. The proportion of people who did not receive any ADL help is high, but it should be noted that 80% of those with only ADL difficulties reported “difficulties with dressing, including putting on shoes and socks”. The fact that those who report difficulty in “dressing, including putting on shoes and socks” do not report any difficulties with IADLs suggests that these individuals might have difficulties in bending down to put on shoes or lacing them, but no major difficulties that would impact on their ability to live independently.

Figure 3: Percentage with ADL/IADL/Combined ADL and IADL difficulty receiving help



Receipt of help was examined by increasing levels of IADL and ADL difficulty (table not shown). No help was received by 85% of those with only one IADL. However, the proportion of older people not receiving help decreases as the number of IADL difficulties increases. For example, 8.8% of those with two IADL difficulties do not receive help, while 5% of those with three IADL difficulties do not receive help. However, everyone with 4 or more IADL difficulties receives help. The same trends can be seen for the ADLs, where 76.5% of those with only one ADL difficulty do not receive help, while 14% of those with 2 ADLs, 6.1% from those with 3 ADLs, and 3.4% for those with 4 or more ADL difficulties do not receive help.

Total hours of care provided for those with disability

In TILDA, respondents who reported having any ADL or IADL difficulties were asked the following questions “During the last month, on about how many days did [NAME of helper] help you?” Subsequently, the respondent is asked “On the days [NAME of helper] helps you, about how many hours per day is that?”. The total hours of help per day received from all helpers were multiplied by the days per month that individuals received help. Those with only IADL difficulties receive on average 67 hours per month of informal care compared to 8 hours per month for those with ADL difficulties only⁸. Those with difficulties in both ADL and IADL receive on average 118 hours of informal help per month; if averaged over the week, this amounts to 30 hours per week and, therefore, represents an intense level of care inputs for this population group.

This section will focus on caregivers identified by respondents with one or more ADL or IADL disabilities. In the TILDA questionnaire we distinguished the different types of caregivers by their level of responsibility and caregiving tasks (i.e. helping with ADL, IADL [preparing meals/doing household chores/shopping for groceries/making telephone calls/taking medication] and managing money). The *primary caregiver* or *main caregiver* was identified by care recipients, based on who provided the largest number of hours (“Who most often helps you with getting across a room/dressing/bathing/eating/getting in or out of bed/using toilet?”). *Secondary caregivers* were identified by the care recipients as carers who performed tasks at a level similar to that of the primary caregiver, but with fewer hours provided. Therefore, secondary caregivers only provided care in conjunction with primary caregivers (“Does anyone else help you with these activities?”). *Tertiary and subsequent caregivers* were identified in the same way as other caregivers but provide fewer hours of care than the primary one. Caregiver may appear here multiple times. For example, a main ADL helper may also be the main IADL helper or a caregiver could be a main helper for one type of care and a secondary helper for another type of care.

⁸ Readers are reminded that 80% of those with only ADL difficulties reported “difficulties with dressing, including putting on shoes and socks”.

Table 8 sets out different types of caregivers by the carer’s relationship to the care recipient. Care recipients were able to list up to four caregivers in the TILDA survey. We examine here only those who have difficulties and report that they receive regular help. Examining by types of caregivers and by care-giving tasks gives different profiles of the caregivers. For example, care recipients with greater levels of dependency, i.e. with ADL difficulties, are more likely to have a spouse (50%) as a main caregiver followed by children (26%). With respect to IADL, which requires less intensity in care, the spouse is still the main helper (39%) but the proportion of those who receive help from their children is higher than among those with ADL difficulties (34%). Unlike primary caregivers, the majority of secondary, tertiary and fourth caregivers are children, followed by non-relatives and other relatives than children or spouse.

Table 8: Carer’s relationship to the recipient of help

	Spouse	Children (in-law)	Other Relatives	Non Relatives	Total
Main helper					
ADL helper	51.5	25.8	3.9	18.8	100.0
IADL helper	39.0	34.0	5.0	22.0	100.0
Money	50.5	33.3	9.7	6.5	100.0
2nd helper					
ADL helper	4.0	60.8	12.0	22.9	100.0
IADL helper	6.3	63.4	6.8	23.5	100.0
Money	5.6	61.1	11.1	22.2	100.0
3rd helper					
ADL helper	0.0	69.7	9.1	21.2	100.0
IADL helper	4.2	65.6	7.3	22.9	100.0
Money	0.0	60.0	20.0	20.0	100.0
4th helper					
ADL helper	0.0	50.0	20.0	30.0	100.0
IADL helper	7.9	65.8	5.3	21.1	100.0
Money	0.0	66.7	33.3	0.0	100.0

Carers

In total 1,017 carers were identified by TILDA respondents. Characteristics of the carers are identified in **Table 9**. Additional information is provided on the characteristics of main carers and other carers (second, third and fourth carers).

Table 9: Characteristics of carers by age, sex, relationship to the care recipient and labour market status (n=1,017)

Characteristics		Main carers (n=570) %	Others carers (n=447) %	All carers (n=1,117) %
Age	<16 years	0.7	2.9	1.7
	16-49 years	19.6	39.8	28.5
	50-64 years	29.5	15.7	23.4
	65-79 years	16.1	2.7	10.2
	80+ years	2.5	0.4	1.6
	Unknown	31.2	38.0	34.2
Sex	Female	68.2	67.8	68.0
	Male	31.4	31.8	31.6
Relationship	Spouse	43.5	5.6	26.8
	Child/adopted Child	25.4	57.3	39.4
	Non-relative	21.2	22.6	21.8
	Other relative	9.8	14.5	11.9
Labour Market Status	Full-time employed	7.2	17.0	11.5
	Part-time employed	5.3	6.7	5.9
	Self-employed	2.5	2.7	2.6
	Unemployed	4.2	4.7	4.4
	Retired	20.7	1.8	12.4
	Permanently sick or disabled	11.4	2.2	7.4
	Homemaker	10.7	4.9	8.2
	Other	2.5	3.1	2.8
	Missing*	35.6	56.8	44.9

*Note a large amount of missing data in relation to the known labour market status of carers.

4

Caregiver Characteristics

Main carers had an older age profile than other carers, close to a fifth were over age 65 years compared to 3% in the other carer group. Where the age of the carer was unknown, the carers were mostly non-relatives. Approximately 70% of all carers identified were female. The majority of carers were related to the care recipients (80%). Main carers were predominantly spouses (44%) whereas the majority of second and subsequent carers (57.3%) were children of the care recipient.

Information on labour market status of carers was limited. In general, complete data was available on carers who were related to the care recipient (either a spouse or a child). The extent of the missing data is detailed in the table. Consistent with the older age profile of the main carers, many are retired (20.7%) or homemakers (10.7%). The proportion of main carers who are permanently sick or disabled (11.4%) is of concern, suggesting a significant burden of care on informal carers who are themselves experiencing disability. Future waves of TILDA will enable examination of possible changes in the caregivers' labour market status as the care needs of the recipient and the carer evolve.

Informal care

The vast majority of all carers (89.5%) were identified as unpaid informal carers. Only 10.5% (n=107) of all carers received payment for the care provided. A range of publicly funded financial supports are available to informal carers through the Department of Social Protection. These financial supports are available to carers providing care to individuals of all ages.

The carer's allowance is a means-tested social assistance payment for carers primarily aimed at people on low incomes who look after a person in need of full-time care. From January 2012, an eligible carer under 66 years of age, caring for one person is entitled to an allowance of €204 per week plus an additional €29.80 per week for each dependent child. Those caring for two or more people are entitled to a higher payment. A half-rate carer's allowance is available for carers already in receipt of another social welfare payment or where two carers provide care in an established pattern on a part-time basis. Older carers in receipt of a State pension may be eligible for this half-rate carer's allowance depending on a means test. The number of recipients of carer's allowance increased by 4.9% between 2009 and 2010. In 2010, 50,577 carers received a carer's allowance, 20,981 of whom received a half-rate carer's allowance (Department of Social Protection, 2011b).

Carer's benefit is a social insurance payment for individuals who leave the workforce for up to 2 years to care for a person in need of full-time care. From January 2012, an eligible carer looking after one person is entitled to a benefit of €204 per week and an additional €29.80 per week for each dependent child. Those caring for two or more people are entitled to a higher payment. This payment is available to carers for a period of 104 weeks only. If caring extends beyond this period the carer, if eligible, may transfer to the carer's allowance scheme. In 2010, 1,642 carers received this payment (Department of Social Protection, 2011b).

Recipients of carer's allowance and carer's benefit are automatically entitled to an additional annual respite care grant of €1,700. This payment is also available to informal carers providing full-time care who do not qualify for carer's allowance or carer's benefit, subject to certain conditions. The number of recipients of the respite care grant in 2011 was 70,000 (Department of Social Protection, 2011a).

In the first wave of TILDA, 122 respondents aged 50 years and over indicated that they had a carer who was in receipt of a carer's allowance or carer's benefit.

This corresponds to 22,046 individuals in the population (95% CI 17,779-26,312).

Based on these figures, it appears that less than half of all carer's allowances and carer's benefits are paid to the carers of those aged 50 years and over, with the remainder being paid to those caring for children and younger adults. This is a surprisingly low proportion of financial support for the carers of older people by comparison to others requiring full-time informal care. This finding requires further investigation in relation to the distribution of financial supports to the informal carers of older people.

Analysis revealed that 13% (n=133) of carers were in receipt of carer's allowance or carer's benefit. Eleven care recipients had two carers, each of whom was in receipt of an allowance. It is likely that these carers were in receipt of half-rate allowances, however, full-rate and half-rate allowances were not separately identified in this study. Almost 80% of recipients of carer's payments were identified as main carers which suggests that these payments are well targeted. A higher proportion of recipients provided IADL care (57%) compared to ADL care (42%) (Table 10).

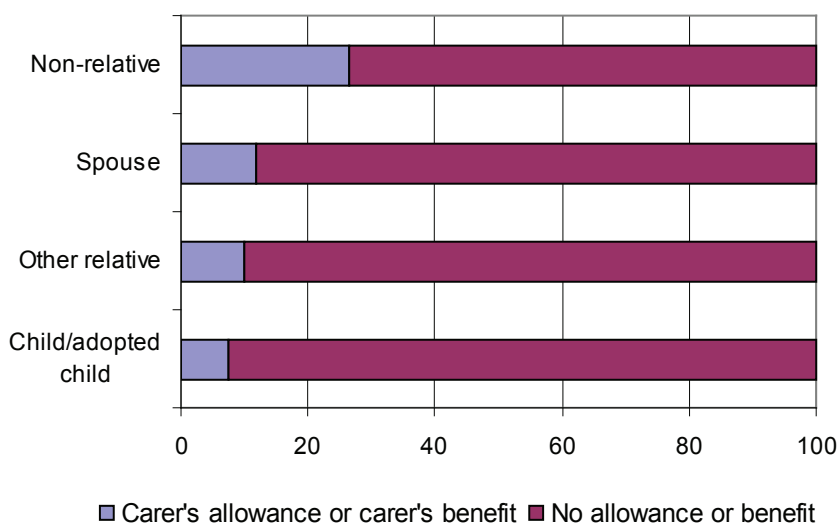
Table 10: Carers in receipt of carer's allowance by type of care provided

Type of help provided	Main carer n (%)	2nd carer n (%)	3rd carer n (%)	4th carer n (%)	Total
ADL	49 (37)	4 (3)	3 (2)	0 (0)	56 (42)
IADL	56 (42)	14 (10)	5 (4)	1 (0.8)	76 (57)
Financial	0 (0)	1 (0.8)	0 (0)	0 (0)	1 (0.8)
Total	105 (79)	19 (14)	8 (6)	1 (0.8)	133 (100)

Analysis of the relationship between the care recipient and carer in receipt of carer’s allowance or carer’s benefit was conducted. Close to half of those in receipt of carer’s payments were identified as non-relatives. This is a surprising finding given that only a fifth of all carers identified in the study were non-relatives (Table 8).

Amongst spouse carers, only 11.7% receive the carer’s allowance or carer’s benefit compared to 26.6% of all non-relative carers (Figure 4). It is surprising to find a higher proportion of non-relatives compared to spouses and other relatives in receipt of these payments. One explanation for this finding is that many of the carers identified are not providing “full-time” care which is a condition of receipt of the allowances described. A second explanation is that the availability of the allowances and conditions attached may not be widely known, especially amongst older spouse carers. This is most likely to apply to the availability of the half-rate carer’s allowance which was introduced in 2007 for individuals already in receipt of another type of social welfare payment including the State pension. Another explanation for this finding may be that spouses do not readily identify themselves as being a carer. Rather, they see themselves as the husband or wife of a loved one who has become ill or disabled.

Figure 4: Carer’s relationship to the care recipient by receipt of carer’s allowance or carer’s benefit (n=133)

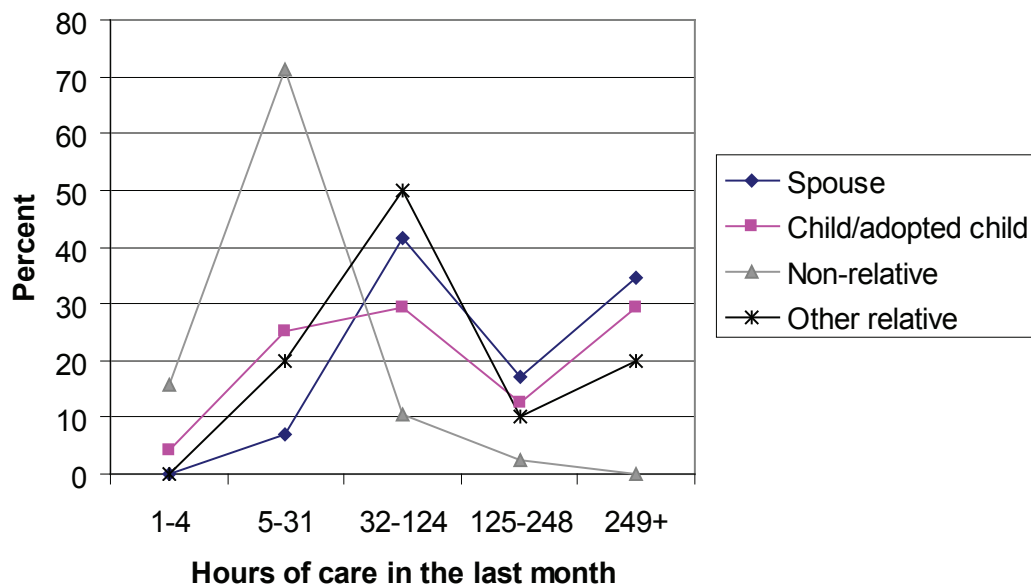


Main carers in receipt of carer’s allowance and carer’s benefit

The intensity of care as measured by the number of hours of care provided by main carers in receipt of carer’s allowance and carer’s benefit was examined (n=105). Respondents were asked “During the last month, on about how many days did [NAME of helper] help you?” Subsequently, the respondent was asked “On the days [NAME of helper] helps you, about how many hours per day is that?” Some

respondents indicated that the total number of hours of care received in the previous month was quite low. Of the main carers receiving carer’s allowance or carer’s benefit the intensity of care was found to be highest among those carers who were related to the care recipient and lowest in non-relative carers (Figure 5). These findings suggest a large variation in the contact hours between carers in receipt of care payments and care recipients, with family members providing intense levels of care. Explanations for this variation may relate to co-residency status and the receipt of half-rate allowances by some of the carers.

Figure 5: Main carers in receipt of carer’s allowance or carer’s benefit by intensity of care hours provided (n=101)



Formal care

A mixed economy of formal home care is in existence in Ireland with the State, the non-profit and the for-profit (private) sectors providing services. Prior to the late 1990s, home care in the form of home help and personal care was provided mainly by the public sector with a strong voluntary sector (mostly religious organisations) operating at local level. Professionalisation of the voluntary sector has taken place in recent years. Workers are now waged and the role of the religious communities is minimal in running these organisations (Timonen and Doyle, 2007). As a result, it is now more accurate to describe this sector as “non-profit” as opposed to “voluntary”. The non-profit sector carry out fundraising activities in addition to receiving State funding on an annual basis through Section 39 grants. This sector predominantly provides home help services (focusing on assistance with IADL difficulties) on behalf of the State in Dublin and larger towns; within smaller towns, rural and semi-rural areas the HSE is the predominant provider of home help services.

The expansion of home care services in the mid-2000s and the introduction of an enhanced level of home care (home care packages) resulted in a rapid expansion of the for-profit private sector (Timonen, Doyle and O'Dwyer 2012). Home care packages are multidisciplinary in nature, they include assistance with both ADL and IADL difficulties in conjunction with home nursing and therapy services including occupational therapy and physiotherapy. In 2009, an estimated 128 for-profit private providers were operating in Ireland (PA Consulting Group, 2010), and by the end of 2010 this was estimated to have increased to 138 (Brady, 2010). The for-profit sector provides home care services on behalf of the State (for the most part via the home care packages) and to private clients who pay the costs out-of-pocket. An analysis of the home care market conducted on behalf of the Irish Private Home Care Association (PA Consulting Group, 2010) estimated that 70% of formal home care was provided by the Health Service Executive (HSE), 23% by the non-profit sector and 7% by the private for-profit sector.

TILDA respondents were asked "Does [helpers name] receive regular payment from you, your family or from an agency or organisation to help care for you?" Only 10.5% (n=107) of all carers received payment for the care they provided. Paid carers were predominantly non-relatives (87%) and female (93%).

Where payment was received by the caregiver, the respondent was asked to identify the source of the payment (**Table 11**). Two-thirds of paid carers were found to be associated with formal home care provider organisations. The remainder were identified as originating outside the organised home care sector.

Table 11: Source of paid carers (n=107)

Source of paid carer	Private Agency	Non-profit Organisation	HSE	Family or friend paid to help	Other
% (n)	9.3 (10)	3.7 (4)	48.6 (52)	16.8 (18)	21.5 (23)
% (n)	61.6 (66)			38.3 (41)	

Paid carers associated with provider organisations

Paid carers associated with home care provider organisations only account for 6.5% of all carers (n=66 out of a total of 1,017). The majority of paid carers from the formal home care sector are provided by the HSE (79%), private agencies (15%) and non-profit organisations (6%). The origin of carers from the formal home care organisations identified in this report differs from the market share identified in the PA report discussed above. The large proportion of paid carers from the HSE is an expected finding. However, the proportion of paid carers from the private sector is higher than expected given previous estimates of total market share. The continued

expansion of the private sector is likely to explain some of this increase. The low level of paid carers from non-profit organisations is unexpected. One possible explanation for this is that respondents had difficulty in differentiating between carers from non-profit organisations and from the HSE. The majority of paid carers associated with provider organisations (91%) were not related to the recipient of care. In a small number of cases children and other relatives were found to receive payment from the HSE to provide care.

Paid carers outside the organised home care sector

Paid carers outside the organised home care sector account for 4% of all carers (n=41 out of a total 1,017). This is a low figure, but surprisingly high when compared to the proportion of carers originating in the formal home care sector discussed above (6.5%). Paid carers outside the organised home care sector represent a grey market in care. An examination of the relationship between this group of paid carers and the care recipient revealed that 81% of carers were not related to the care recipients. This suggests active sourcing of unrelated paid carers outside the organised care sector. This grey market in older person's home care is at the moment poorly understood in the Irish context, yet it is an important component in understanding the totality of home care in Ireland. The invisibility of this group of paid carers outside the formal care sector must be considered in current debates on the regulation of home care.

5

Conclusions

Disability at older ages has a strong gender dimension. Among people aged 80 and over, more than one third of women and one quarter of men have difficulty with performing tasks that are essential to independent living in the community. When we relate these percentages to the number of older women and men in the population, the minimum/conservative estimate among the over 80s with IADL difficulties only is 16,400, ADL difficulties is 7,960 and both ADL and IADL difficulties is 19,900. The higher percentage of people with ADL/IADL difficulties among older adults who are widowed (in comparison with those who are married) also translates into considerably higher numbers of women than men being affected by disabilities. In many ways, therefore, care needs in older age are an important gender issue. It is also interesting to note that a considerably higher proportion of women than men disclose difficulties with IADL across all age groups, reflecting perhaps the gendered nature of these domestic tasks.

Nearly one in five older adults who live alone have ADL/IADL restrictions, whereas those who are living with a spouse, partner or others are affected to a lesser degree. This shows that in many cases those who are most affected by disability are also least able to draw on help and support from within their own household.

Among the central findings of this report is the strong social gradient in ADL/IADL disability, with 20 per cent of the older adult population with primary schooling only being affected, in contrast to the considerably lower prevalence among those with secondary or higher education. Similar to other key findings, the finding on the social gradient also translates into the heaviest disability burden on those who have the weakest (material and financial) resources to deal with disability and to access care – this calls for carefully formulated policy responses that are able to reach this group of older adults.

The preponderance of spouses as carers is also evident in the data, which in turn points in the direction of 'the older carer' becoming an increasingly significant underpinning of help and care in the community (see also Wren, 2009). Among these spousal older carers, women are in the majority as they tend to outlive their husbands. A large proportion of family caregivers provide care in tandem with other commitments and restrictions. Main caregivers are less likely to be in employment (full time or part time) compared to other caregivers and many suffer from a

long-term sickness or disability themselves. This in turn raises questions around the assessment of carers' needs and the adequacy of help and support that these potentially challenged caregivers are receiving, both to meet their own needs and those of the care recipient. Seven out of ten primary caregivers (whether family or paid carers) are women, and women's share is particularly high among paid caregivers (nine out of ten). These findings further highlight the gendered nature of not just care needs but also care provision. Among paid carers who provide care in the home, the considerable number of those who are not attached to any provider organisations raises questions about how the provision of care to older people in their own homes can best be regulated and monitored.

References

- Brady, A. (2010). Statement by Minister for Older People Áine Brady T.D. on home care services. Press Release, from <http://www.dohc.ie/press/releases/2010/20101213.html>
- Department of Social Protection. (2011a). "Almost 70,000 carers to receive Respite Care Grant this year-€658 million will be spent on schemes to support carers in 2011". Press Release
- Department of Social Protection. (2011b). Statistical Information on Social Welfare Services 2010. Dublin: Department of Social Protection.
- Duncan, G. J., Daly, M. C., McDonough, P., and Williams, D. R. (2002). "Optimal Indicators of Socioeconomic Status for Health Research". *American Journal of Public Health*, Vol. 92, No.7.
- Goldman, N., Korenman, S., and Weinstein, R. (1995). "Marital Status and Health among Elderly". *Social Science and Medicine*, Vol. 40, No.12, pp. 1717-1730.
- Katz, S., AB, A. B. F., Moskowitz, R., BA, B. A. J., and Jaffe, M. W. (1963). "Studies of illness in the aged. The Index of the ADL: a standardized measure of biological and psychosocial function". *JAMA*, 185, pp. 914-919.
- Kenny, R., and Barret, A. (2010). "Introduction" in A. Barrett, G. Savva, V. Timonen and R. A. Kenny (eds.), *Fifty Plus in Ireland 2011. First Results from The Irish Longitudinal Study on Ageing*. Dublin: TILDA.
- Lafortune, G., and Balestat, G. (2007). "Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and the Future Implications", *Health Working Papers*. Paris: OECD.
- Lawton, M., and Brody, E. (1969). "Assessment of Older people: Self-Maintaining and Instrumental Activities of Daily Living". *Gerontologist*, Vol. 9, pp. 179-186.
- PA Consulting Group. (2010). *Analysis of Irish Home Care Market*. Dublin: Irish Private Home Care Association.

Timonen, V., and Doyle, M. (2007). "Worlds apart? Public, private and non-profit sector providers of domiciliary care for older persons in Ireland". *Journal of Aging Studies*, Vol. 21, No.3, pp. 255-265.

Timonen, V., Doyle, M., and Prendergast, D. (2006). *No Place Like Home - Study of Domiciliary Care Services for Older People*. Dublin: The Liffey Press.

Timonen, V., Doyle, M. and O'Dwyer, C. (2012). "Expanded, but not regulated: Ambiguity in home care policy in Ireland". *Health and Social Care in the Community* (online early access).

Wren, M.-A. (2009). "Long-term health and social care" in R. Layte (ed.) *Projecting the Impact of Demographic Change on the Demand for and Delivery of Health Care in Ireland*. Dublin: Economic and Social Research Institute (Research Series No. 13), pp. 100-123.