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Social care: need for and receipt of help

5

Natalie Mapleshorpe, Robin Darton, Raphael Wittenberg

Summary

- This chapter presents information about the need for and receipt of social care among adults aged 65 and over. Most of the chapter is based on Health Survey for England 2014 data. Where bases are too small for robust analysis, 2013 and 2014 data have been combined.
- Participants aged 65 and over were asked whether they needed help with a list of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are activities relating to personal care and mobility about the home, and IADLs are further activities important to living independently.
- 24% of men and 33% of women aged 65 and over needed help with at least one ADL, and 21% and 34% respectively needed help with at least one IADL.
- Overall, 11% of men and 13% of women aged 65 and over had received help with at least one ADL in the last month, and 14% and 26% respectively had received help with at least one IADL.
- The need for help increased with age. 13% of men and 21% of women aged 65-69 needed help with ADLs, compared with 46% and 59% respectively aged 85 and over.
- Receipt of help, although at a lower level than need, also increased with age. 6% of men and 9% of women aged 65-69 received help with ADLs in the last month, compared with 26% of both sexes aged 85 and over.
- There was also variation according to household income, with greatest need and highest proportions receiving help in the lowest income tertile. For instance 32% of men and 36% of women in households in the lowest income tertile needed help with ADLs, compared with 10% and 27% respectively in the highest.
- Participants who reported that their general health was bad or very bad had significantly greater need for help than others in this age group (67% of men and 76% of women needed help with ADLs, compared with 8% and 9% respectively who said their health was very good). Those reporting bad health were most likely to report that they were in receipt of care (41% and 43% with bad/very bad health received help with ADLs in the last month, 2% and 1% with very good health).
- 21% of men and 29% of women aged 65 and over had some need with at least one ADL that was not met, and 13% and 18% respectively had some unmet need with at least one IADL.
- Among people who had received help with ADLs in the last month, 82% of men and 75% of women had received this solely from unpaid helpers, including relatives, friends and neighbours. The picture was similar for IADLs.
- Help with ADLs was most frequently provided by a spouse or partner (75% for men, 46% for women), followed by daughters and sons. Help with IADLs was most frequently given by a spouse or partner for men (46%) and a daughter for women (38%).

- The majority of those receiving help with ADLs or IADLs reported having received this kind of help for a year or more (82% of men and 85% of women).
- The amount of help provided by spouses or partners varied. Around half helped for less than ten hours per week (50% for men and 56% for women), compared with around a third who provided 20 or more hours of help a week (35% for men, 31% for women). Most other helpers who provided care did so less for than ten hours per week.

5.1 Introduction

5.1.1 Background

Since 2011, coverage of the Health Survey for England (HSE) has been expanded to include a section on adult social care. Each year, the survey includes questions for older people (aged 65 and over) about their need for, receipt of, and payment for care, and questions to all adults about their provision of unpaid care. These questions are now a core module of the survey, so that consistent data are collected and trends may be monitored in the longer term. This chapter provides findings about the need for social care among older adults, whether they receive care and how it is provided. Chapter 6 provides information about the providers of care.

5.1.2 Social care in England

Care and support enables people to do the everyday things that most take for granted: things like getting out of bed, getting dressed and going to work; cooking meals; seeing friends; caring for their families; and being part of the community.¹

More specifically, social care involves provision of help with personal care and domestic tasks to help people live as independently as possible. It affects the daily lives of several million people in England. Some 1.05 million received community-based services arranged by their local authority in 2013- 2014² and at least a further 270,000 buy care privately.³ While those who need care and support are of all ages, many are older people needing help because of problems associated with long-term physical or mental ill-health, disability or problems relating to old age;¹ of the 1.1 million who received community-based care, 672,000 were aged 65 and over.²

A central aspect of the policies of successive governments has been to help people maintain their independence in their own homes for as long as possible. The availability of early, preventative interventions has been seen as a means of helping to reduce the need for more intensive levels of support or crisis interventions at a later stage.^{1,4} However, both the previous and the current administrations have identified a range of long-standing issues related to the provision of social care, including a greater focus on reactive rather than preventative services; variations in levels and the quality of services; a lack of good information and advice; and a lack of coordination between health, housing and social care agencies.^{1,4}

A number of factors have been seen as imposing further pressures on the demand for care services. These include the growth of the ageing population, other demographic changes such as changes in the birth rate, changes in family structures and migration between urban and rural areas, as well as changes in expectations.⁵ In particular, the growth in the number of people with dementia is expected to exert substantial pressure on care services.^{1,5} Successive governments have emphasised the importance of the personalisation of services, to help people take greater choice and control over the services they receive and to stay as independent as long as possible.^{1,6,7} An important aspect of this is the introduction of personal budgets to enable people to take charge of their care and support budget.

The Government published *A vision for adult social care*⁸ in 2010 and a White Paper *Caring for our future: reforming care and support*¹ in July 2012. The reforms to adult social care announced in the White Paper and enacted in the Care Act 2014⁹ will have substantial impact on the assessment of care needs, determination of eligibility for care, financing, commissioning and provision of adult social services. The reforms include the introduction of national minimum eligibility criteria from April 2015. Care accounts associated with the life-time cap on care costs were originally planned from April 2016, but the introduction of the cap has been postponed, probably until 2020. The HSE has collected data each year on how many hours of community based care received by older people received, and in 2013 collected more detail about patterns of care; this will provide valuable information with which to assess the impact of the reforms.

5.1.3 Data on social care

Before the development of the social care module used in the HSE, survey data on the need for and receipt of social care was limited. This module of questions was developed for use in population surveys and economic evaluations, looking at older people. Within this module both shorter and longer versions are available.¹⁰ While the short module of questions has been included in HSE each year since 2011, a longer module was included in 2013, with extra details about for instance payments, patterns of care and adaptations to the home to help with care needs. A similar module of questions was included in Wave 6 of the English Longitudinal Survey on Ageing (ELSA) for which data are now available.¹¹ The longer version is also included in ELSA Wave 7 in 2014/15, from which data will become available in future.

The HSE does not cover people in care homes. Within the community, it focuses on older people, who constitute by far the largest group receiving care; robust data are needed as policy is developed for the future funding of social care in old age. While social care may be needed by and provided for people of any age, and information about social care for children or for adults aged under 65 would be valuable, the sample size for the HSE (and most general population surveys) does not deliver sufficient numbers of social care recipients in these age groups for robust analyses of the different social care client groups. Consequently, the module of questions about help needed, receipt of care and payments for care are asked of older people only.

5.2 Methods and definitions

5.2.1 Methods

The current module of social care questions was developed in 2009 and 2010 and first used in the HSE 2011. The aim of the module is to deliver robust data on the need for and receipt of social care services, the characteristics of people providing and receiving unpaid care, and on people receiving formal care and support. More detailed information about the module can be found in the 2011 report.¹²

HSE 2014 included the ‘core’ short module which was included in 2011 and 2012. A longer module was included in 2013, and in 2014 a small number of questions from the longer module were retained, relating to payments (not reported in this chapter).

Most of the chapter is based on Health Survey for England 2014 data, but for some analyses where bases are small, 2013 and 2014 data have been combined.

5.2.2 Definitions

Measuring need for and receipt of social care: ADLs and IADLs

The need for and receipt of social care is measured using a number of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are activities relating to personal care and mobility about the home that are basic to daily living, and IADLs are activities which, while not fundamental to functioning, are important aspects of living independently. The ADLs and IADLs used in the HSE were carefully selected to represent a full range of key activities and are shown in Table 5A.¹³

Table 5A

When all ADLs are grouped together they are categorised in tables as ‘any personal activities’. When all IADLs are grouped together they are categorised as ‘any instrumental activities’.

Need for help and unmet need

For each ADL and IADL, participants aged 65 and over were asked whether they could carry out the activity on their own, manage on their own with difficulty, only do the activity with help, or could not do it at all. The last three categories have been combined to identify those who have at least some difficulty, and therefore at least potentially need help with the

ADLs	IADLs
Having a bath or shower	Doing routine housework or laundry
Using the toilet	Shopping for food
Getting up and down stairs	Getting out of the house
Getting around indoors	Doing paperwork or paying bills
Dressing or undressing	
Getting in and out of bed	
Washing face and hands	
Eating, including cutting up food	
Taking medicine	

activity. Where ‘need’ for help is discussed in the chapter, it refers to people in these three categories.

If participants indicated that they needed help for any ADL or IADL, they were then asked whether they had received any help in the last month. For the IADLs relating to shopping, housework and paperwork, participants were asked to exclude help which was provided simply because of the way household responsibilities were divided.¹⁴

Unmet need has been identified where participants indicated that they needed help with a particular ADL or IADL (that is, could manage it with difficulty, could only do it with help, or could not do it at all), but had not received any help with it in the last month.

Formal and unpaid help

Participants who had received help in the last month with ADLs or IADLs were asked who had provided help; the ADLs and IADLs were grouped, as described above. They were shown two show cards, listing formal and unpaid carers as shown in Table 5B. In previous reports unpaid carers have been referred to as ‘informal’ carers, to make the distinction from formal carers. However, the term ‘unpaid’ carer is preferred, to avoid any implication that these carers provide more casual or less important care.

Table 5B

Formal carers	Unpaid carers
Home care worker/home help/personal assistant	Husband/wife/partner
Member of the reablement/intermediate care staff team	Son/son-in-law
Occupational therapist/physiotherapist	Daughter/daughter-in-law
Voluntary helper	Grandchild/great grandchild
Warden/sheltered housing manager	Brother/sister (including in-laws)
Cleaner	Niece/nephew
Council’s handyman	Mother/father (including in-laws)
Other	Other family member
	Friend
	Neighbour

5.3 Need for and receipt of care among older adults

5.3.1 Ability to perform ADLs and IADLs, by sex

The majority of people aged 65 and over reported that they were able to do all the ADLs and IADLs on their own without help. Where people did have some problems, they were most likely to say that they could manage on their own with difficulty. Much smaller proportions said that they could only do these activities with help, or could not do them at all, and these three groups have been combined to form a group who have at least some difficulty, and therefore at least potentially need help.

Nearly a quarter of men and one third of women aged 65 and over needed help with at least one ADL (24% and 33% respectively). Similar proportions, 21% of men and 34% of women, said that they needed help with at least one IADL.

Figure 5A shows the proportions of adults aged 65 and over who needed some help with individual ADLs. Men and women aged 65 and over most commonly needed help with getting up and down the stairs, followed by having a bath or shower, and dressing and undressing. They were least likely to need help with washing face and hands, eating (including cutting up food), or using the toilet. The pattern of need was broadly similar for both sexes, but women were more likely than men to report needing help with most ADLs. The exception to this pattern was for help with taking medicines, where men were slightly more likely to report needing help than women.

Taking medicines showed a slightly different pattern from most other ADLs, with a higher proportion of older people saying they needed help than that they could manage on their own with difficulty. Chapter 6 shows that, among unpaid helpers providing substantial levels of care, helping with taking medicines was the most frequently mentioned ADL.

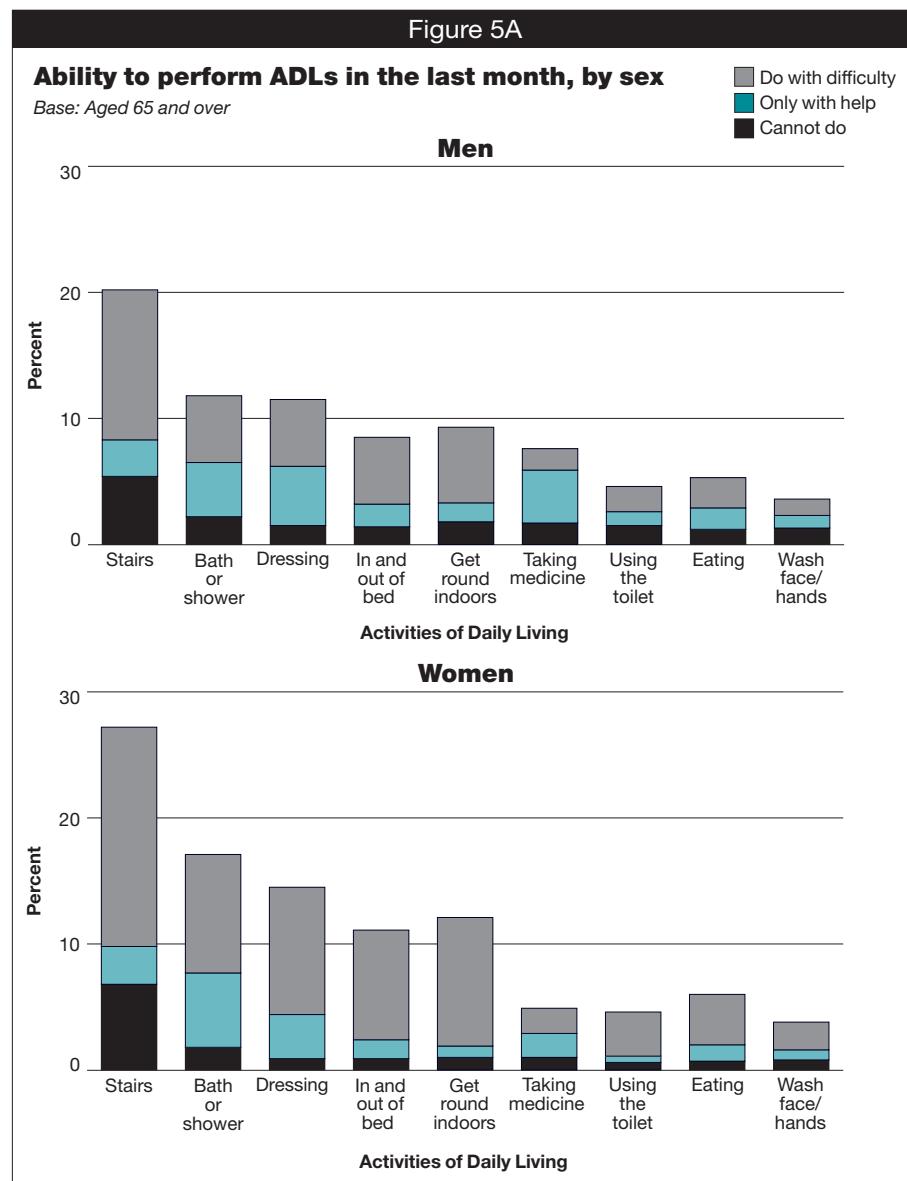


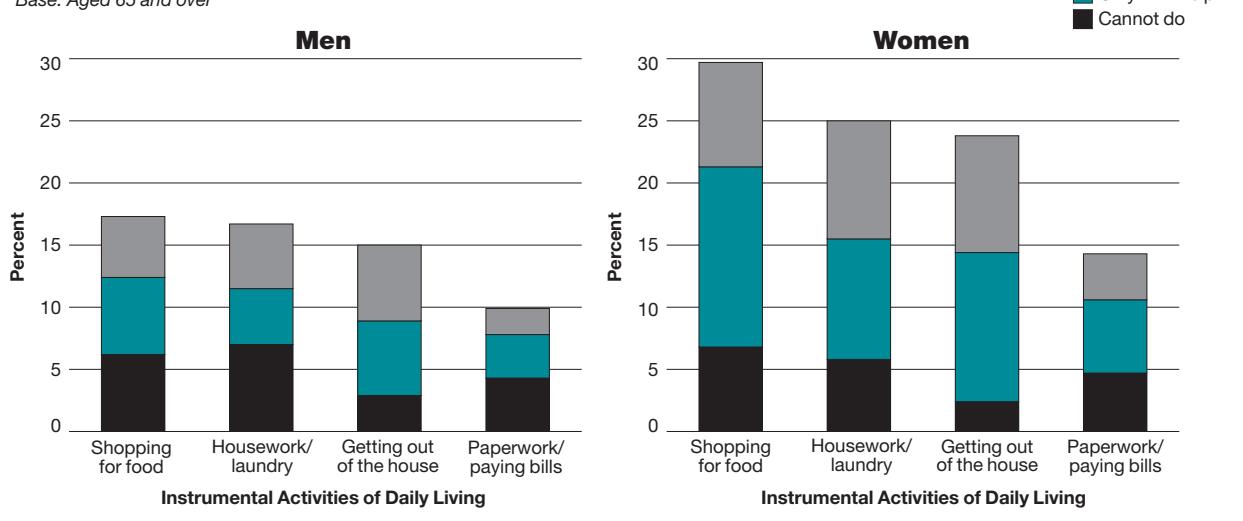
Figure 5B shows the proportions of men and women aged 65 and over who needed some help for IADLs. For each, women were more likely to need help than men were. Although similar proportions needed help overall with ADLs and with IADLs, the proportions needing help with individual IADLs (apart from doing paperwork and paying bills) were generally higher than for individual ADLs.

Table 5.1, Figures 5A, 5B

Figure 5B

Ability to perform IADLs in the last month, by sex

Base: Aged 65 and over



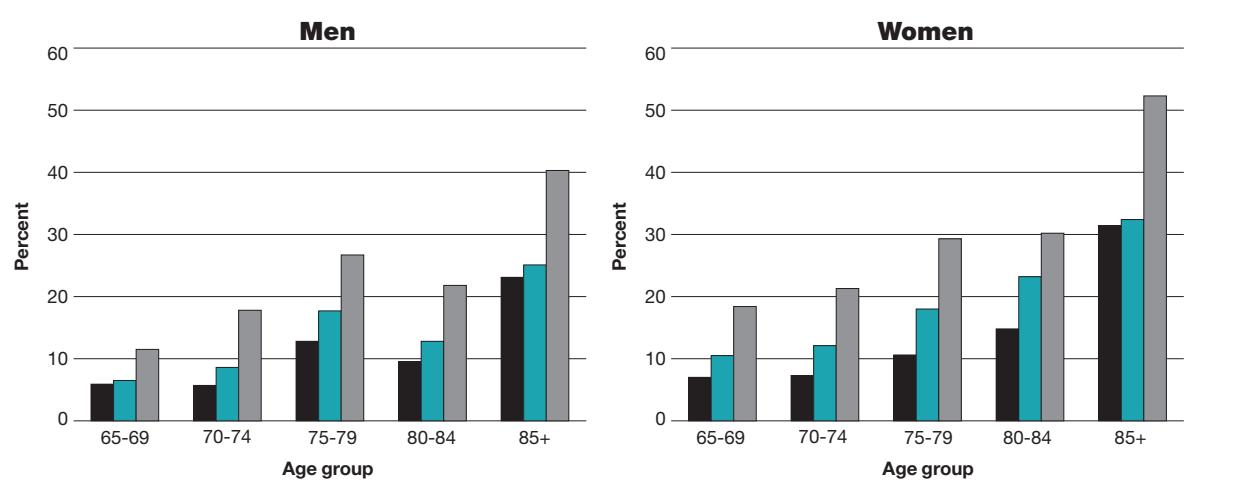
5.3.2 Need for and receipt of help, by age and sex

The proportions of men and women who needed help with ADLs and IADLs increased with age. These increases across age groups were particularly marked for the ADLs for which people most frequently needed help; using the stairs, having a bath or shower, dressing and undressing and getting around indoors. Three of these are shown in Figure 5C (dressing and undressing followed a very similar pattern to having a bath or shower, and is not shown separately).

Figure 5C

Need for help with key ADLs last month, by age and sex

Base: Aged 65 and over

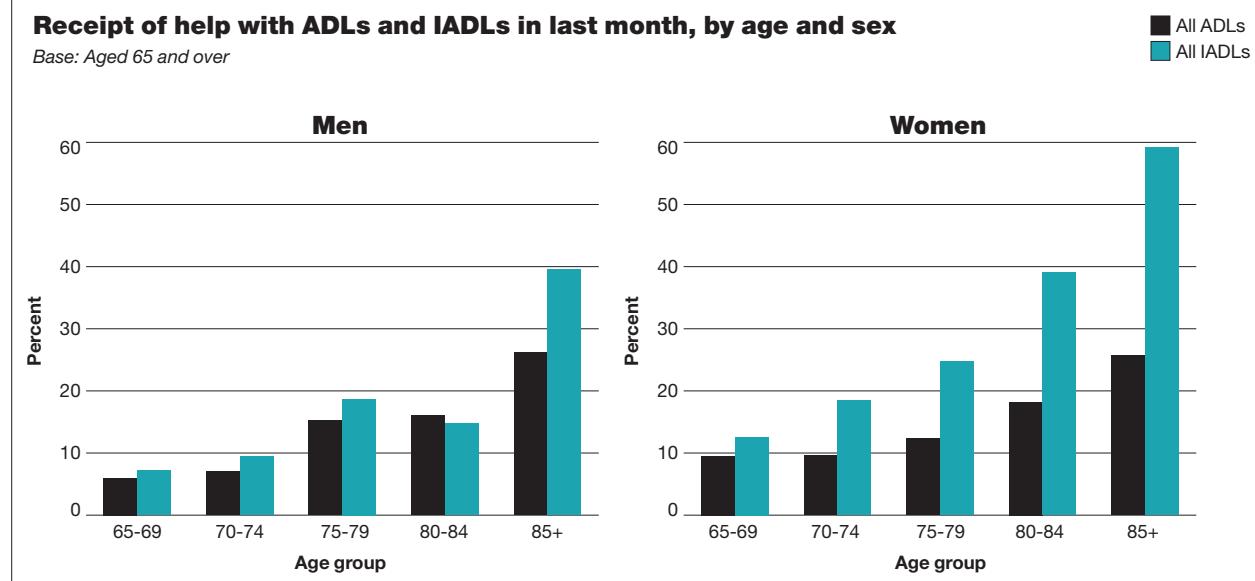


In 2014 (as in 2013), only adults who said that they needed help with any task were asked whether they received help.¹⁴ Similar proportions of men and women (11% and 13% respectively) had received help with at least one ADL in the last month. Women were more likely to have received help with IADLs; 14% of men and 26% of women had received help with at least one IADL.

Figure 5D shows how these proportions varied by age. As with need, the proportions receiving help with ADLs increased with age. There was a similar pattern for IADLs.

Those who received help in the last month for a particular activity may not be the same people as those that needed help. Unmet need, the difference between the proportions needing help and those receiving it, is discussed in Section 5.3.5 below.

Figure 5D



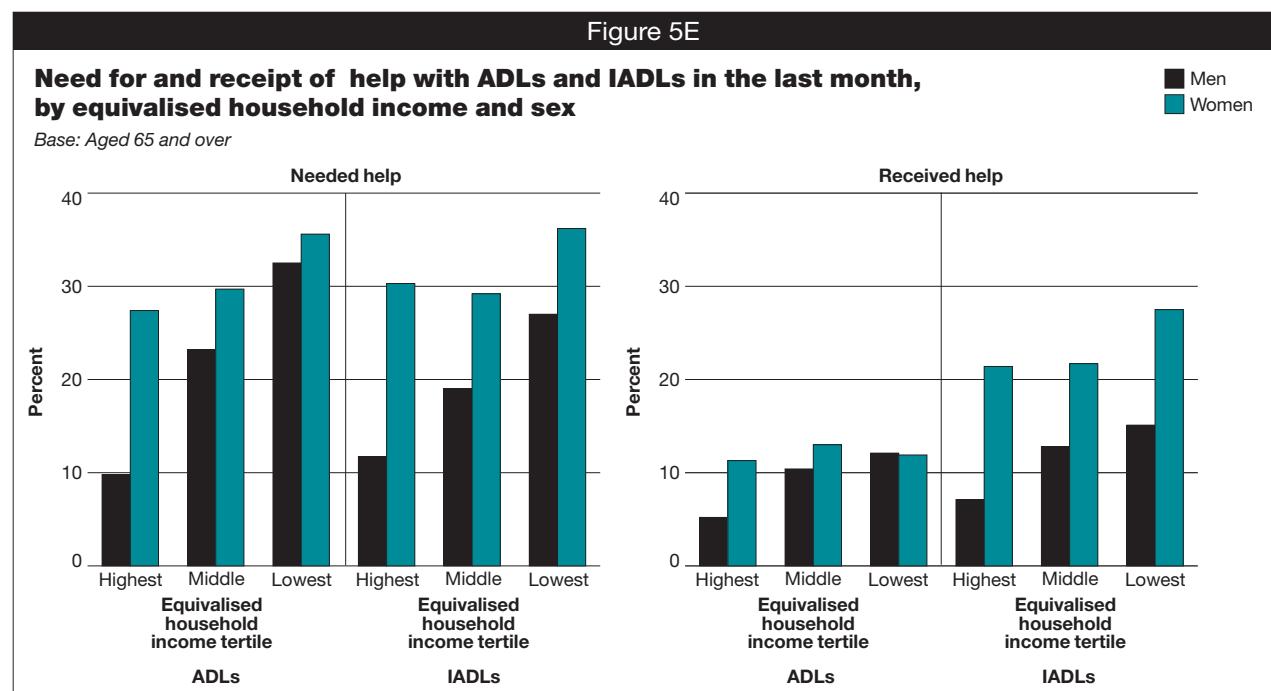
5.3.3 Need for and receipt of help, by equivalised household income

Equivalised household income takes into account the number of people living in the household. The tertiles (thirds) of equivalised income are based on the distribution of income for all households, and by definition approximately one third of the whole sample falls into each tertile. This does not apply to adults aged 65 and over; the distribution of income across tertiles is not equal within this age group.¹⁵

Figure 5E shows how both need for and receipt of help varied with income, for both ADLs and IADLs. There was a clear relationship between income and the need for help with activities, with the greatest need among men and women with the lowest income. Women at all levels of income were more likely than men to need some help with ADLs, but with less variation across the income groups, so that the difference between men and women was greater in higher income groups. There was a similar, though statistically non-significant, pattern for IADLs.

The proportions of men and women receiving help with ADLs did not differ significantly with income. For IADLs, men and women in lower income households were more likely than those in better off households to receive help.

Table 5.5, Figure 5E

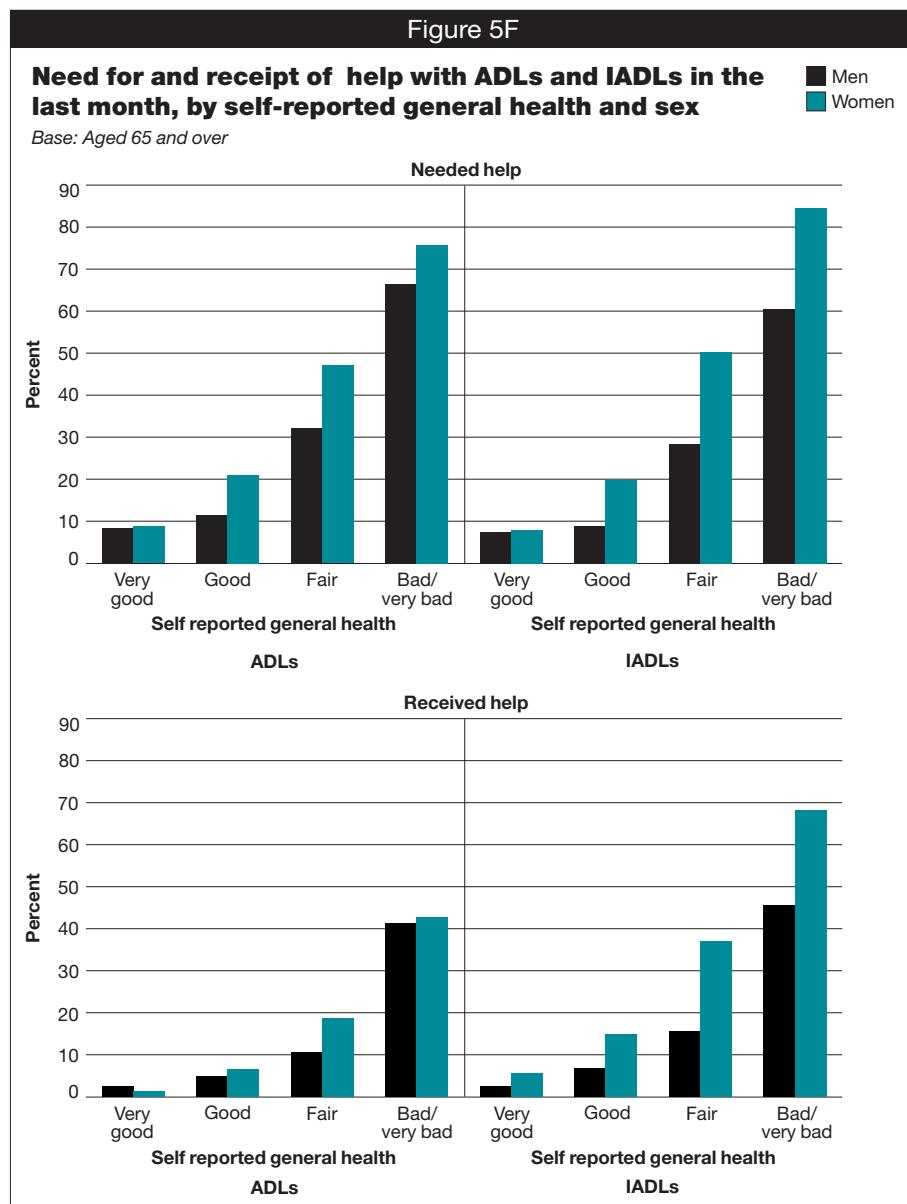


5.3.4 Need for and receipt of help, by self-reported general health

Participants were asked whether their general health was very good, good, fair, bad or very bad. Figure 5F shows that need for and receipt of care increased markedly as self-reported health declined. The majority of the group in worst health had needed help with ADLs in the last month. A similar pattern was observed for IADLs.

For both ADLs and IADLs the proportions of men and women aged 65 and over who were receiving help also increased as self-reported health became worse, and were significantly higher among those with bad or very bad self-reported health.

Table 5.6, Figure 5F



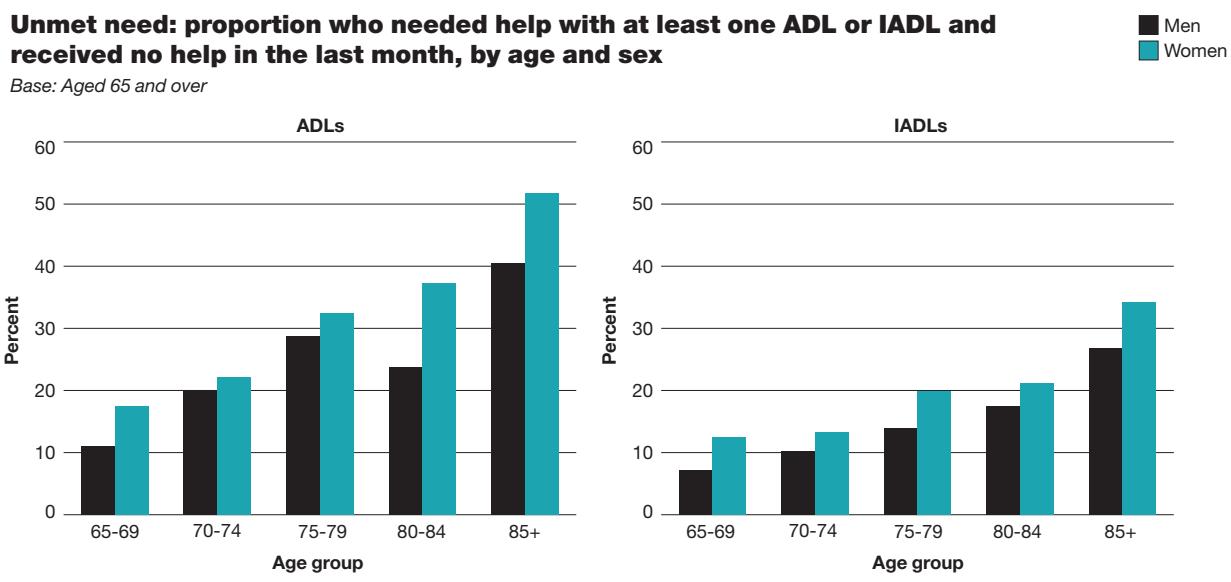
5.3.5 Prevalence of unmet need

Unmet need has been defined as the proportion of adults aged 65 and over who reported being able to manage a particular ADL or IADL with difficulty, only with help, or not at all but who did not receive help with that activity in the last month. The assumption is that those who have at least some difficulty with an activity may need help.

21% of men and 29% of women aged 65 and over had some unmet need with at least one ADL. 13% and 18% respectively had some unmet need with at least one IADL.

As Figure 5G shows, unmet need increased with age for ADLs and IADLs. Consequently, 40% of men and 52% of women aged 85 and over had some unmet need for help with ADLs, and 27% of men and 34% of women of this age had some unmet need for help with IADLs.

Figure 5G



The activity with the highest level of unmet need among older people was getting up and down stairs (16% of men and 22% of women overall, and 26% and 42% respectively among those aged 85 and over).

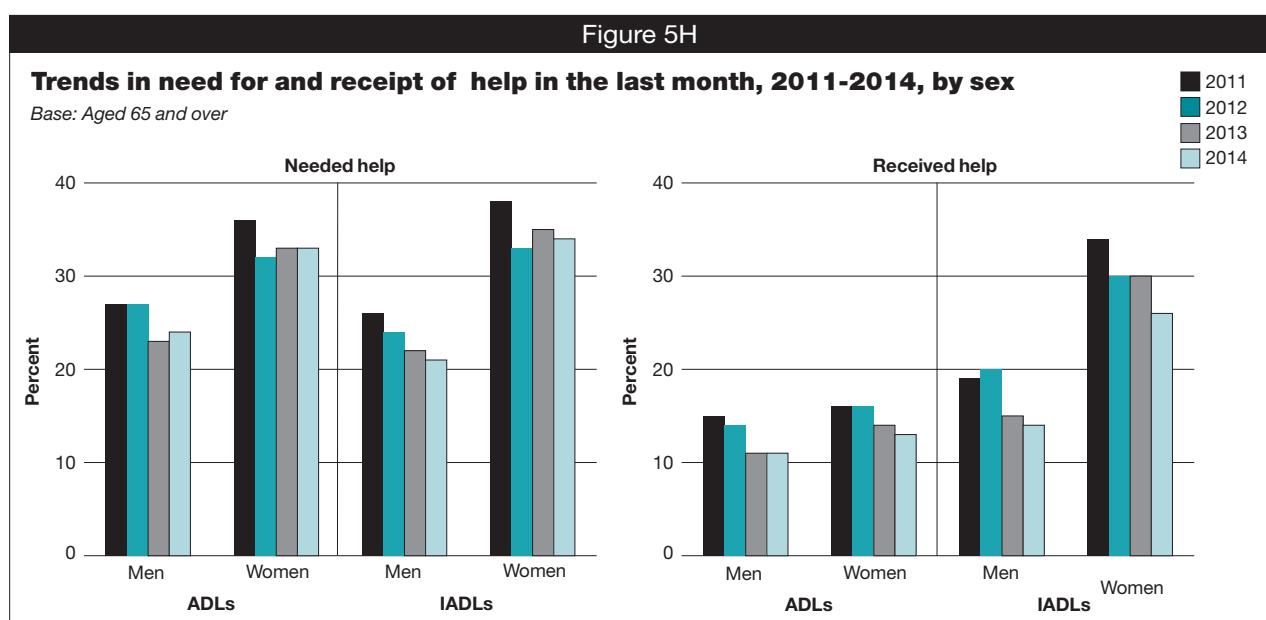
Table 5.7, Figure 5G

5.3.6 Need for and receipt of care and unmet need, 2011 to 2014

While the proportion reporting that they needed help with ADLs and IADLs has remained broadly similar between 2011 and 2014, there are some indications that levels among men may be slightly lower in 2014. Figure 5H shows the proportions needing and receiving care for ADLs and IADLs each year. The differences for women are not statistically significant, with the exception of receipt of help with IADLs. However, the 2014 levels for men are significantly lower in 2014 than in 2011 for need for help with IADLs, and for receipt of help with both ADLs and IADLs.

The levels of unmet need have remained similar between 2011 and 2014.

Table 5.8, Figure 5H



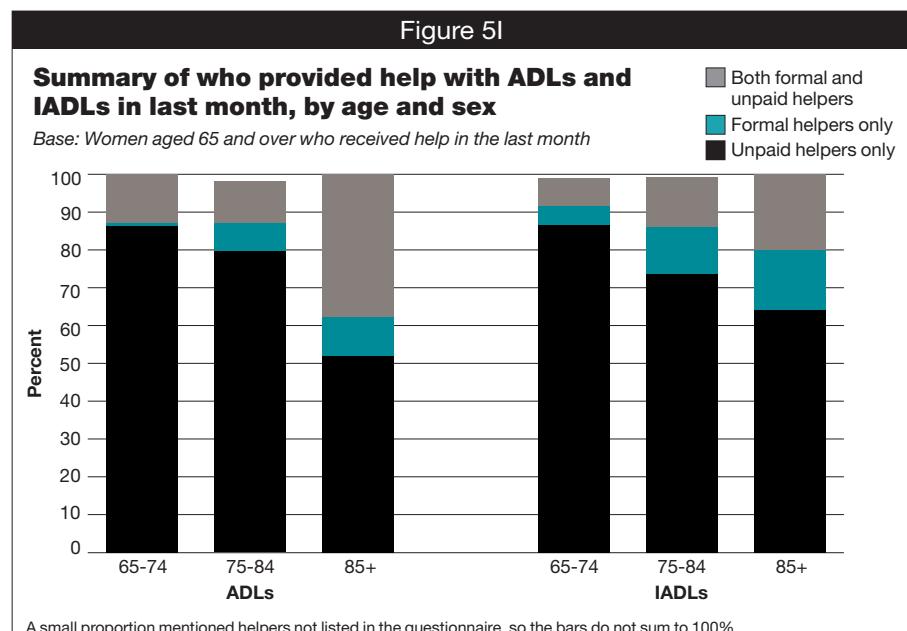
5.4 Sources of care

5.4.1 Unpaid and formal helpers

Most people aged 65 and over who had received help in the last month had received this from unpaid helpers only. 82% of men and 75% of women who were receiving help with ADLs did not receive any formal support, and similar proportions of those receiving help with IADLs also received help solely from unpaid helpers (80% and 75% respectively).

Figure 5I shows how sources of help varied with age for women; the pattern was similar for men but base sizes are very small and so the data are not shown.¹⁶ Not only were older people more likely to be receiving help (see Section 5.3.2), but this help was more likely to come from formal helpers, alone or in combination with unpaid helpers. This reflects the increasing care needs among the oldest groups, and may also reflect the fact that older people, and particularly women, are more likely to have been widowed and to be living alone.¹⁷

Table 5.9, Figure 5I



5.4.2 Sources of unpaid help

Figure 5J shows which unpaid helpers had provided care, for ADLs and IADLs. The analysis is based on data from 2013 and 2014 combined in order to compensate for the small numbers of men and women in each age group who had received this type of care.

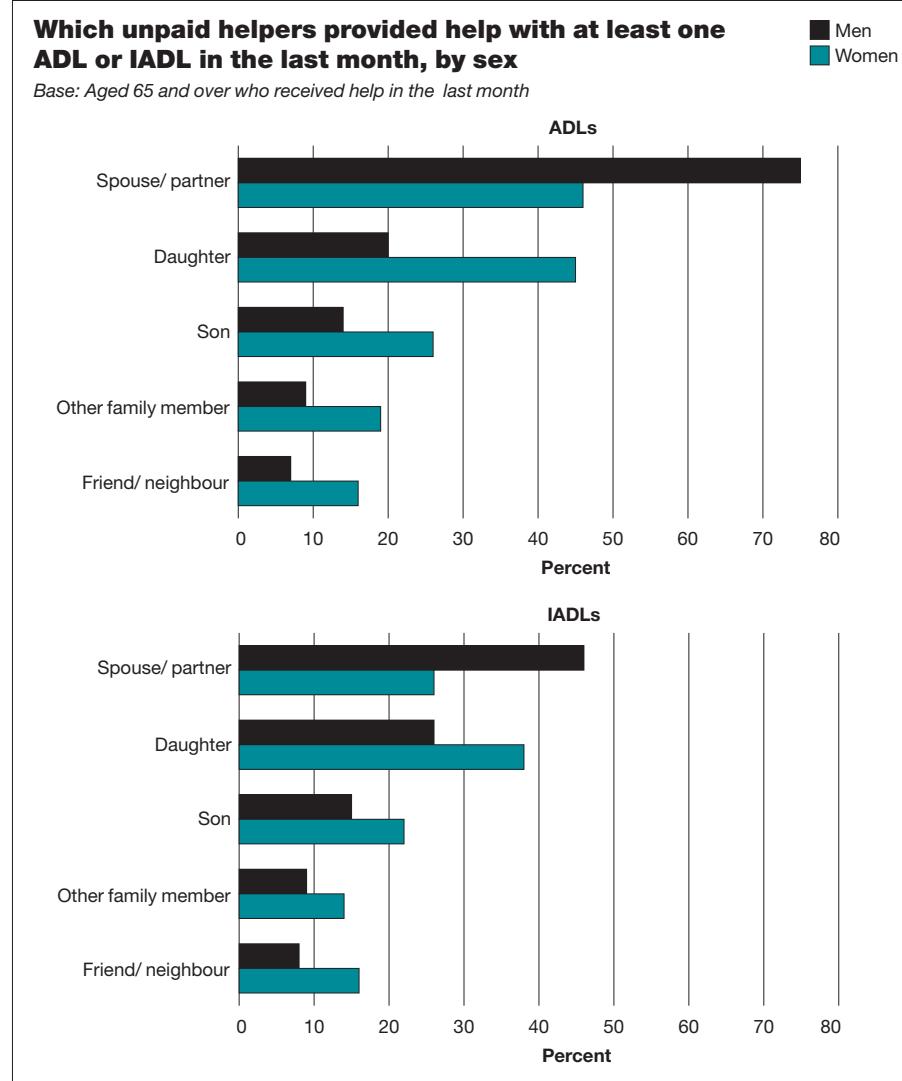
The unpaid helper most frequently reported by those who had received help with ADLs in the last month was their spouse or partner (75% of men and 46% of women). The difference between men and women reflects the higher proportion of women who were widowed; the majority of men and women aged 65 to 75 received help with ADLs from a spouse, but among women aged 85 and over who had received help, only one in five had been helped by their husband or partner.¹⁸

The next most commonly mentioned unpaid helpers were daughters (including daughters-in-law). Women were as likely to report having received help from a daughter as a spouse (45% of women, compared with 20% of men). 14% of men and 26% of women had received help from sons (including sons-in-law). Smaller proportions reported help from other family members, friends or neighbours.

Help with IADLs was most frequently given by a spouse or partner for men (46%) and a daughter for women (38%).

Table 5.10, Figure 5J

Figure 5



5.4.3 Sources of formal help

This analysis is based on data from 2013 and 2014 combined in order to compensate for the small numbers of men and women in each age group who had received formal care.

The formal helper most frequently reported as providing help with ADLs was a home care worker, personal assistant or home help. Among those who had received help with ADLs in the last month, 12% of men and 21% of women had received help from a home care worker. Where help had been received with IADLs, 11% of men and women had received this from a home care worker. For ADLs, help from home care workers increased with increasing age. The same was true for women, but not men, receiving help with IADLs.

Table 5.11

5.4.4 Length of time care had been received

The majority of those who received any help with ADLs and IADLs reported having received this type of care for a year or more (82% of men and 85% of women).

Table 5.12

5.4.5 Number of hours of care in the last week from unpaid helpers

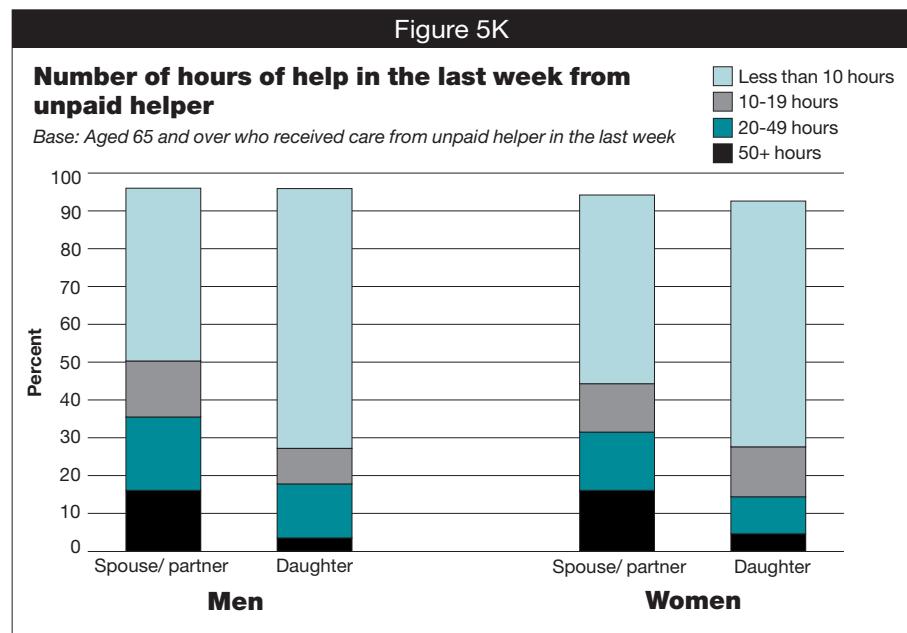
Those who received unpaid help with ADLs and IADLs were asked about the number of hours of care they received in the last week. Again, the analysis is based on data from 2013 and 2014 combined in order to compensate for the small numbers of men and women in each age group who had received care.

Reported numbers of hours of care provided by spouses in the last week were similar for both men and women, as shown in Figure 5K. 50% of men and 44% of women who were

receiving care from a spouse had received at least 10 hours of care in the last week, including 35% of men and 31% of women who received 20 or more hours of care, and 16% of men and women who received 50 or more hours of care from their spouse.

The pattern was different for those who received help from their daughters, who are likely to live elsewhere and may have other responsibilities for work and family. Among those who received help from their daughters, the majority received less than 10 hours of help in the last week. Within this group, 27% of men and 28% of women received 10 or more hours of help, including 18% of men and 14% of women who received 20 or more hours, and 4% of men and 5% of women who received 50 or more hours of help from their daughters. The pattern of care received from sons was broadly similar.

Table 5.13, Figure 5K



5.5 Discussion

Need for and receipt of help

Just under a quarter of older men and a third of older women needed help with at least one ADL (24% of men and 33% of women), and slightly under half of these received at least some help (11% of men and 13% of women). However, the majority of older people who needed some kind of help with ADLs had at least some unmet need (21% of men and 29% of women), even if they were also receiving help with other ADLs. The definition of 'need' for help in this analysis includes people who were able to do tasks on their own with difficulty, as well as those who could not do the task without help or were not able to do it at all; and being able to do something with difficulty was more common than the other two categories. Therefore, unmet need in this context may include cases where older people were just managing to achieve many of the tasks. However, with increasing age and frailty, their ability to do so is likely to diminish.

The picture was slightly different for IADLs, particularly among women. The proportions of older men and women who reported needing help with at least one IADL (21% and 34% respectively) were similar to those needing help with ADLs. However, a higher proportion received at least some help with IADLs (14% of men and 26% of women), and fewer reported unmet need (13% and 18% respectively).

Sources of care

The majority of older people who received help with ADLs or IADLs received help from unpaid helpers, but the people in older age groups were more likely to receive help from formal helpers or a combination of formal and unpaid helpers. Men were most likely to

receive unpaid help with ADLs and IADLs from their spouse or partner. Women were also most likely to receive unpaid help with ADLs from their spouse or partner, but were more likely than men to receive help from a daughter or a son, and were more likely to receive help with IADLs from a daughter than from their spouse or partner.

Most formal help with ADLs was provided by home care workers, whereas other formal helpers were more involved in providing help with IADLs, especially for women.

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- 10 The project *Developing Improved Survey Questions on Older People's Receipt of, and Payment for, Formal and Unpaid Care* was funded by the Nuffield Foundation and the Department of Health, and carried out by NatCen Social Research, the Personal Social Services Research Unit (PSSRU) at the London School of Economics and University of Kent, and the Health Economics Group at the University of East Anglia. A description of the study outcomes and documentation can be found at www.natcen.ac.uk/our-research/research/social-care-questions-for-over-65s/
- 11 www.ifs.org.uk/ELSA
- 12 Craig R, Mindell J (eds). *Health Survey for England 2011: Volume 1 Health, Social Care and Lifestyles*. Health and Social Care Information Centre, Leeds, 2012. www.hscic.gov.uk/pubs/hse11report
- 13 The ADLs and IADLs included in the social care module allow an approximation of the Barthel Index, a measure of ability to live independently at home for older people. This is not included in this analysis, but was covered in the 2011 and 2012 HSE reports.
- 14 There was a change to the routing of these questions from 2013 onwards. Originally, all aged 65 and over were asked whether they needed help with each ADL and IADL, and then regardless of their answers they were asked whether they had received help for each. Many participants had neither needed nor received help, and found the repeated questions onerous. Therefore the change in 2013 meant that only those who said they needed help with at least one ADL or IADL were asked about whether they had received help. Analysis indicated that only a very small number of participants who said they did not need help for any ADL or IADL had actually received any help, and this change therefore has a negligible impact on results.
- 15 Full details on the way that equivalised household income is derived can be found in the Glossary to this report, *Volume 2, Methods and documentation, Appendix C*.
- 16 A small proportion of participants mentioned that they had received help in the last month, but did not identify any individual formal or unpaid helpers; therefore the bars in Figure 5l do not all sum to 100%.
- 17 In the 2014 HSE sample, the proportions of men living alone increased from 22% of those aged 65 to 74 to 33% of those aged 85 and over. The proportions of women living alone increased from 29% of those aged 65 to 74 to 65% of those aged 85 and over.
- 18 In the 2014 HSE sample, 65% of women aged 85 and over were widowed compared with 35% of men in this age group.