The care and support of older people – an international perspective

Summary and key findings

- In most, if not all, countries the primary form of care and support for older people is family and informal care.

- In most, if not all, countries the majority of care and support of older people is carried out by women, but often, in oldest age, men are more likely than women to be a carer.

- Changing family structures and work patterns have reduced the availability of women as carers.

- In several countries, the shortfall of carers has led to the use of cash payments to incentivise informal care.

- In Europe, although marriage bonds have weakened, the multi-generational structure of the family remains strong.

- Although co-residence of older people with their adult children has decreased, geographical proximity and the potential for everyday support remains high.

- Care and support for older people is a reciprocal process with many older people providing child care. In France, Denmark, Sweden and the Netherlands 50-60% of grandparents provide some child care.

- Multigenerational households and the number of siblings to provide care is in decline worldwide but increased longevity has meant multigenerational (beanpole) families are becoming more common.

- The only viable option for funding the care and support needs of the current generation of older people is from current taxation and/or insurance contributions (including those paid by more affluent older people themselves).
Care and support for older people – International perspective

Care and support for older people

Care and support in older age is a broad-reaching concept. Not all support takes the form of ‘care’ and, in its broadest sense, care and support can mean any assistance that an older person needs to live their lives successfully. It is sometimes taken to mean support, excluding statutory health and housing service, but that is not always the case.

Support can be further categorized into emotional support, informational support, and instrumental support. Emotional support has been reported to be especially valuable, with significant physical and psychological health outcomes. Social support can be seen as an older adult’s perception of emotional support (i.e., positive social interactions) received from their social network members.¹

In international research and reports, care and support for older people, whether formal or informal and family care, tends to focus on the care of long-term conditions and on (integrated) health and social care rather than low level prevention measures.

In most countries the dominant framework for care and support for older people is ‘ageing in place’, allowing older people to stay in their own homes for as long as possible. Even in countries with a long tradition of making residential and nursing home care available, the current tendency, for economic and philosophical reasons, is to support older people at home for as long as possible, with residential care being used as a last resort towards the end of life.²

Different caring models

The Nordic welfare model, or ‘social democratic regime’, is known for its generosity and extensive coverage, where both welfare benefits and publicly organised welfare services are concerned, and the Nordic countries, represented here by Finland and Sweden, are often ranked as having the world’s most developed social policies.

¹ Chen and Feeley (2013), Social support, social strain, loneliness, and well-being among older adults
² Lievesley et al (2011), The changing role of care homes
Australia represents the 'liberal' regime - seen in some anglophone democracies - in which social rights are rather limited, social welfare focuses primarily on people with low incomes and most families are expected to purchase the services they need from the market. Britain, also often categorised as a 'liberal' welfare system, is perhaps better understood as a 'mixed' model in which residual and market elements combine with universalism.

Japan and Taiwan, both East Asian countries featuring familistic legislation, are influenced by Confucianist culture, in which families have traditionally provided the economic support and care needed by their members. East Asian welfare systems are often described as 'productivist', prioritising economic growth and providing only very limited public services and social security for their citizens. However, this image is now somewhat outdated, as these countries have recently launched universal long-term care insurance (Japan) and health care insurance (Taiwan) schemes.3

Family and informal care

Across the world, care provided by families is the backbone of long-term care, but it is difficult to maintain or increase it in the face of falling support ratios, urbanisation and migration, and changing working patterns.4

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3 Kröger and Yeandle (2013) Combining paid work and family care: Policies and experiences in international perspective
4 Hope et al (2012), Creating Sustainable Health and Care Systems in Ageing Societies
In most countries, the predominant and first form of care and support for older people is informal care from family and friends with women foremost in the caring role. That is not to say that women are more likely to be carers than men at all ages. At older ages, men are smaller in number than women but, in many countries, those that survive are more likely than their female counterparts to take on a caring role, possibly reflecting the greater likelihood of having a surviving partner in need of care.\(^5\)

Glendinning et al (2009) provide a comprehensive view, based on SHARE and other data, of family and informal care across Europe (see pages 29 to 30). Seventy-six percent of main carers of older people are women, 50% are children of the older person with half spending more than 24 hours per week in the caring role. A key motive for caring is love, reciprocity and/or ‘wanting to do something in return’. Regional variations are apparent with a less developed formal care system in Mediterranean Europe creating greater pressure on informal carers. There is also an East-West divide with eastern EU countries placing greater pressure on family carers.\(^6\)

The availability of family support for older people is affected by changing family structures, increased divorce rates and the tendency for children to live separately from their parents. Even without changes in

\(^5\) Rodrigues et al (2012), *Facts and figures on healthy ageing and long-term care. Europe and North America*

\(^6\) Glendinning et al (2009), *Care Provision within Families and its Socio-Economic Impact on Care Providers*
family structure however, the increasing tendency, in many countries, for women to take paid work, affects the availability to care, of those who currently take on most of the caring role.\(^7\)

### Employment rates of working-age women (15–64), 1970–2010 (%)

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Note: \(^1\) Figure for 1971.

Sources: OECD (2010a, 2011b); CNS (2011). Taiwan figures from secondary data analysis based on unpublished data set from the Directorate General of Budget, Accounting and Statistics, Executive Yuan, Taiwan.

From: Kröger T and Yeandle S (eds) (2013), Combining paid work and family care

Rising female employment rates imply that women are no longer available to undertake unpaid family care responsibilities full-time, as many did in the past. At the same time, a more feminised workforce necessarily contains more carers than ever before. With women, caring entered the world of paid work on a large scale, helping to bring about a development with implications for men as carers too. Part-time employment offers one way of trying to combine work and care and the share of part-time work in total employment rose in OECD countries from 11% in 1990 to 17% in 2010.

\(^7\) Kröger and Yeandle (2013), Combining paid work and family care: Policies and experiences in international perspective
Changes in health and environmental conditions are more likely to trigger support within families than changes in the economic conditions of households such as the self-perceived ability to make ends meet or the passage to retirement.8

Intergenerational family transfers and support depend on the resources of the givers, needs of the receivers and closeness of the relationship. The transition to retirement appears to have an impact on the amount of social support that is given to other family members, such as elderly parents or young grandchildren. The onset of illness for many older Europeans is accompanied by an increase in support from their family members, in conjunction with professional services. In countries where rates of intergenerational cohabitation and proximity are high, the support given to less independent older parents is high.9

Family support is a two-way process10 and many older people provide care for young children as grandparents or in a similar role. In France, Denmark, Sweden and the Netherlands between 50% and 60% of grandparents provide some childcare compared with just 40% in the Southern European countries. However, regular and intensive grandparental childcare is more common in Southern Europe, with 20% of grandparents in Italy providing almost daily childcare compared with just 2% of grandparents in the Netherlands.11

Worldwide, especially in Africa, although less common, skipped generation households, households where grandparents look after their grandchildren in the absence of their own children, are increasing over time.12

While in the past younger and older adults used to live together under the same roof providing reciprocal support for the entire life-course, recently, especially in the more developed countries, co-residence has been replaced by “intimacy at a distance”. Even when living separately, parents and children have frequent contacts and mutual exchanges and provide long-term care when necessary. Intergenerational solidarity is strongly based on ties of affection and a feeling of mutual obligation. An indicator of intergenerational relations is the frequency of contacts between parents and adult children living separately from them. In countries with available data, at least a third of people aged 60–79 years meet one of their children more than once a week.13

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8 Ogg and Renaut (2013), Ageing and intergenerational support: the role of life course events
9 Attias-Donfut, Ogg and Wolff (2008), Evolution of Social Support
10 Brugiavini et al (2013), Long-term care and reciprocity: does helping with grandchildren result in the receipt of more help at older ages?
11 Glaser et al (2013), Grandparenting in Europe: family policy and grandparents’ role in providing childcare
12 United Nations Economic Commission for Europe (2010), Advancing intergenerational solidarity
13 UNECE (2010) - Advancing intergenerational solidarity: UNECE Policy Brief on Ageing No. 8 August 2010
Global changes in family structure

While many countries now have an ageing population, the stage of the demographic transition varies greatly from country to country. Despite these demographic differences, certain common themes emerge. Most prominent is a decline in the number of multigenerational households in recent years, observed in the majority of countries. Older populations are disproportionately made up of women, and the majority of older women are widowed and the majority of older men living in couple relationships. Gender also is evident in patterns of care provision, with women identified as primary carers to older people. Older women are also often primary care givers to grandchildren.
The prevalence of multigenerational households differs by country type, and generally high income countries have a lower proportion of multigenerational households and low and middle income countries a higher proportion of households, although other cultural and social factors differentiate between countries that are similar in many other ways. Furthermore, while household structures have changed substantially in higher income countries, and the proportion of multigenerational households has declined against a context of economic and social change, although intergenerational relations evolve, they remain essentially intact.14

As life expectancy increases in most nations, so do the odds of different generations within a family coexisting. In more developed countries, this has manifested itself as the “beanpole family,” a vertical extension of family structure characterized by an increase in the number of living generations within a lineage and a decrease in the number of people within each generation.15

For present older Europeans the family has remained a strong provider of institutional and everyday integration. The historical decline of marriage has not yet reached them directly. The marriage bond weakens however with increasing age, and especially so for women. On the other hand, the multigenerational structure of the family remains strong. Even though co-residence of older people with their adult children has decreased, geographical proximity – and thus the potential for everyday support – is high, and increases in the wake of critical life events. There are moreover high rates of frequent contact between parents and children. While this is true for Western Europe as a whole, there are important differences among the ‘strong family countries’ in the South and the ‘weak family countries’ in the North.16

In the near future, informal carers may not be as available as they are today. This prediction, linked to the growing needs of an ageing population, has led in most countries (with the exception of Scandinavian countries) to the introduction of direct or indirect cash benefits, as an important tool of long-term care policies, in various forms: as care allowances, i.e. financial benefits paid directly to the informal carer, in recognition of their contribution to care and in order to secure their availability as care providers; as an attempt to reduce the higher costs of formal services that are subsidised by public authorities; as attendance allowances, i.e. financial benefits paid to the person in need of care to allow for more choice and autonomy in finding flexible care arrangement. In some countries these resources are used to pay for personal assistants, including on the grey or black market, who are often emigrant care workers. The increasing use of both cash benefits and migrant care workers has created a mixed care workforce (informal family carers, migrant workers, personal assistants, formal professional care staff). The boundaries between informal and formal care are becoming increasingly blurred.17

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14 Kneal (2012) Global Perspectives on Multigenerational Households and Intergenerational Relations
15 Li et al (2007), Why population aging matters: A global perspective
17 Triantafillou et al (2010), Informal care in the long-term care system: European Overview Paper
Working carers

While caring does not lead to reduced work hours in case of low caring responsibilities, the impact of caring increases with care intensity. A 1% increase in hours of care is associated with a reduction in the employment rate of carers by around 10%, while a 1% increase in hours of care translates, on average, into slightly more than a 1% decrease in hours of work. Care leave and flexible work arrangements help carers address the balance between workplace obligations and caring responsibilities, and so can induce the supply of both.

Two-thirds of the OECD countries for which information is available have statutory rights to leave to care for people with chronic conditions or LTC needs. Paid leave is restricted to slightly less than half of the countries, and typically limited to less than one month or to cases of terminal illness, while the amount paid is often so low that use is limited.\(^{18}\)

Social Networks – Family contact

A 2008 cross-national\(^ {19}\) study revealed regional and other variations in patterns of family and informal care. In terms of contact with family, friends and participation in social groups and organisations, the data revealed a divide between Southern and Eastern European countries (and Austria) on the one hand and Northern and Western European and non-European English speaking countries on the other. Respondents from the former group tended to have greater levels of family contact, a smaller number of friends and less likelihood of involvement in social organisations. Social network patterns in Japan, the only Asian country in the study, differed from both these clusters, having the highest proportion living in multiple person households, but a low level of contact with family with whom they did not reside.

In all countries the majority of respondents (74%) saw a close relative at least once a week, although the country average varied between 89% in Spain and Italy to only 66% in New Zealand. All countries agreed on the importance of the spouse as a source of support although rates of marriage and widowhood varied considerably.

Across all the countries, women had on average greater frequency of contact with family than men, whilst overall men had higher social participation rates than women even when controlling for age. In most countries, men also reported more close friends on average, but paradoxically men were also more likely to report having no close friend, and to see their closest friend less frequently than women.

Levels of close family contact were on average marginally lower among employed persons. Working was found to have a positive effect on non-familial social networking, in particular involvement in social and community groups. No evidence was therefore found that working in older life undermines the increased social networking that is often aspired to through retirement and voluntary early retirement. Paid employment was more likely amongst the non-European sample, and northern Europeans.

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\(^{18}\) OECD (2011), *Help wanted? Providing and paying for long-term care*

\(^{19}\) Haynes (2008), *Social Networks amongst older people and their implications for social care services: A cross national comparison*
A negative association was found between social expenditure on care in countries and the average level of family contact, and between expenditure and the proportion living in multiple person households in each country. However, this association was dependent upon the extreme cases of regimes with particularly high and low expenditure. When these are excluded from the analysis, this association is not evident. On the contrary, to some extent it can be argued that strong family networks within countries are not necessarily incompatible with comparatively generous public social care provision. Austria is an example of a country with strong family networks accompanied by higher levels of expenditure. Over 81% of the sample in Austria saw an adult child at least once a week, compared to an average of 73% in the 18 countries. Austria had above average OECD expenditure on long term care as a proportion of the population over 80 in 2001 and a developing profile of social care services.

**Funding long-term care**

Writing in 2004, and having considered a number of options in other countries, Glendinning, Davies, Pickard and Comas-Herrera concluded that the only viable option for funding the care and support needs of the current generation of older people was from current taxation and/or insurance contributions (including those paid by more affluent older people themselves). They noted that, in none of the countries that have adopted this approach is there any evidence of intergenerational conflict. Alternative models include Provision of a minimum safety net, Universal funding systems, and Progressive universalism funding mechanisms.

**Integrated health and social care**

A recent international study of integrated health and social care concluded that there is no single organisational model or approach that best supports integrated care. The starting point should be a clinical/service model designed to improve care for people, not an organisational model with a pre‐determined design. Integrated care is a process that must be led, managed and nurtured over time. Initiatives often have to navigate and overcome existing organisational and funding silos. Fully integrated organisations are not an end in themselves but a means to an end. Information and communication technology is potentially an important enabler of integrated care and professionals need to work together in multidisciplinary teams (with clearly defined roles) or provider networks – generalists and specialists, in health and social care. Success is more likely where there is a specific focus on working with individuals and informal carers to support self-management.

For older people with complex health and social care needs, integrated care often means a single point of entry – designating a case manager who helps with assessing needs, sharing information, and co‐ordinating care delivery by multiple formal and informal caregivers. Results from a Commonwealth Fund

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20 Glendinning et al (2004), *Funding long-term care for older people: lessons from other countries*
21 Fernández et al (2009), *How can European states design efficient, equitable and sustainable funding systems for long-term care for older people?*
22 Goodwin et al (2014), *Providing integrated care for older people with complex needs: Lessons from seven international case studies*
survey show that case managers were found to be more common in some countries (78 per cent in the United Kingdom and 73 per cent in the Netherlands) than others (41 per cent in Sweden and 43 per cent in the United States), while there was wide variation in the extent to which electronic records are shared among professionals (55 per cent in New Zealand, 14 per cent in Canada). From the patient perspective, there was variation in the proportion of patients who were contacted by a health professional as part of follow-up (31 per cent in the United States, 16 per cent in Australia and Canada). About one in five primary care doctors reported that other providers failed to share important information. The United Kingdom had the lowest proportion of doctors (7 per cent) reporting this problem.

**Varying International experiences**

It has already been noted that formal care and support is more developed in the northern countries of Europe than in the Mediterranean ones. In Iceland formal care is likely to be residential rather than home based and there is little overlap with informal care. In the Netherlands, as in the UK, Australia, New Zealand, Japan and many other countries, there is a move away from residential care towards care and support at home, while recently, Sweden has experienced a dip in its levels of tax-funded home care following restrictions at municipal level.

Despite recent industrialisation and migration to the cities, China is still predominantly a rural economy with care and support provided by neighbours and the family at home. China has a very large ageing population and the one child policy has created a strain on support networks. There were however in 2010, in Beijing, over 300 ‘aged care facilities’ aimed mainly at the richer middle classes.

Other Asian countries in development, for example South Korea, are perhaps moving away from the Confucian ethos of respect for elders and filial piety and have recently introduced a form of long-term care insurance.

In the USA, the number of older people with disabilities living in the community who received care from family, friends, or paid caregivers has changed little over time, despite substantial growth in the older population, while the use of assistive devices has grown substantially. Although a small but growing number of older people with disabilities receive only formal services, the vast majority continues to receive family care.

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23 Sigurðardóttir (2013) *Patterns of care and support in old age*
24 Tinker et al (2013), *Assisted Living Platform - The Long Term Care Revolution*
26 Wiles et al (2011), *The Meaning of “Ageing in Place” to Older People*
27 Passingham (2008), *Reforming care and support – learning from Japan*
28 Szebehely and Trydegård (2012), *Home care for older people in Sweden: a universal model in transition*
29 Li et al (2007), *Why population aging matters: A global perspective*
30 Browning and Yang (2013), *Challenges in the provision of community aged care in China*
31 Jin Wook Kim and Young Jun Choi (2013) *Farewell to old legacies?: The introduction of long-term care insurance in South Korea*
European and North American research programmes

Key data sources for studies of the care and support of older people include the English Longitudinal Study of Ageing (ELSA) in England, the Survey of Health, Ageing and Retirement in Europe (SHARE) and EUROFAMCARE, a study carried out in 2003 in six countries (Germany, Greece, Italy, Poland, Sweden, United Kingdom) representing the different types of welfare-states in. Each country collected data from about 1,000 family carers who care at least four hours a week for their dependent elderly (65+) family members in different regional sites. The family carers were interviewed face-to-face at home using a joint family care assessment.

The University of Michigan Health and Retirement Study (HRS) is a longitudinal panel study that surveys a representative sample of more than 26,000 Americans over the age of 50 every two years. Supported by the National Institute on Aging and the Social Security Administration, the HRS explores the changes in labour force participation and the health transitions that individuals undergo toward the end of their work lives and in the years that follow.

Houser et al (2010), Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community
Review of the literature

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Within each section, the reviewed literature is listed in reverse chronological order with the most recent publication first.
## a) International overviews

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Integrated care is a process that must be led, managed and nurtured over time. Initiatives often have to navigate and overcome existing organisational and funding silos.  
There is no single organisational model or approach that best supports integrated care. The starting point should be a clinical/service model designed to improve care for people, not an organisational model with a pre-determined design.  
Fully integrated organisations are not the end (goal).  
Greater use of ICT is potentially an important enabler of integrated care, but is not a necessary condition.  
Professionals need to work together in multidisciplinary teams (with clearly defined roles) or provider networks – generalists and specialists, in health and social care. However, patients with complex needs that span health and social care may require an intensity of support that goes beyond what primary care physicians can deliver.  
Important service-level design elements of care for older people with chronic and multiple conditions include holistic care assessments, care planning, a single point of entry, and care co-ordination.  
Success is more likely where there is a specific focus on working with individuals and informal carers to support self-management.  
Personal contact with a named care co-ordinator and/or case manager is more effective than remote monitoring or telephone-based support.  
The report also outlines key features of the health and care system in Australia, Canada (Quebec), The Netherlands, New Zealand, Sweden, The United Kingdom (England) and The United States. |

While the number of older people in need of care is projected to at least double, governments are struggling to deliver high-quality care to people facing reduced functional and cognitive capabilities. Based on a recent OECD and EC report, this policy brief looks at data and policies to measure quality in long-term care and drive standards of care up. It considers: the measures of long-term care quality that are collected; the main regulatory approaches to encourage quality of long-term care; and how care processes can be better standardised for better quality. It outlines the measuring and monitoring of long-term care in Australia, Canada, Germany, the Netherlands, Portugal, Sweden and the United States.


This book studies the experiences of working carers and the welfare and labour market policies that affect them in three different welfare systems: (1) the public sector-centred Nordic welfare model; (2) the private sector-dominated liberal democracies; and (3) the family-centred East Asian states. In each of these types of welfare system, two countries are analysed. The Nordic welfare model, or 'social democratic regime', is known for its generosity and extensive coverage, where both welfare benefits and publicly organised welfare services are concerned, and the Nordic countries, represented here by Finland and Sweden, are often ranked as having the world's most developed social policies.

Australia represents the 'liberal' regime - seen in some anglophone democracies - in which social rights are rather limited, social welfare focuses primarily on people with low incomes and most families are expected to purchase the services they need from the market. Britain, also often categorised as a 'liberal' welfare system, is perhaps better understood as a 'mixed' model in which residual and market elements combine with universalism. Japan and Taiwan, both East Asian countries featuring familistic legislation, are influenced by Confucianist culture, in which families have traditionally provided the economic support and care needed by their members. East Asian welfare systems are often described as 'productivist', prioritising economic growth and providing only very limited public services and social security for their citizens.

However, this image is now somewhat outdated, as these countries have recently launched universal long-term care insurance (Japan) and health care insurance (Taiwan) schemes.

These three types of welfare system were chosen for study to enhance understanding of dissimilarities and similarities in the situations of working carers under different welfare arrangements and in different parts of the world. Comparisons are made not only between, but also within, each type, enabling two versions of the same welfare model to be contrasted. This provides new material on the cases of England, Sweden and Japan, and brings working carers in Finland, Australia and Taiwan into comparative analysis for the first time. Reconciliation between work and family responsibilities is a global challenge and research needs to address it as such. The goal of this volume is to provide knowledge of the conditions of working carers that has relevance for the development of policies all over the globe.

Continued...
Most existing research on combining work and family care — focused solely on one group of working carers: those providing support to older family members. This book distinguishes three different groups of carers: (1) those providing support to parents/parents-in-law in their old age; (2) those caring for or helping a disabled son or daughter (or one with a serious illness or long-term condition); and (3) those caring for a partner affected by illness or disability. Caring for a disabled son or daughter is substantially different from caring for a partner, and both types of care differ in many respects from caring for an older parent. These three different sets of care relationships also reflect caring in different parts of the life course. Caring for disabled children usually starts early in parenthood when parents are in their late 20s, 30s or early 40s (although it may last for decades), while caring for older parents typically begins when offspring reach their late 40s or 50s. Caring for a partner often occurs in old age but is also a common experience in the decade or so before retirement for people of working age. This divergence in care relations and life phases means that the circumstances, difficulties and resources of these three groups of carers differ in important ways, with specific implications for the reconciliation of work and family life. The book gives each of these groups of working carers the attention they merit in their own right.

The book analyses the experiences of the three groups of working carers and the policies that affect them, offering a perspective on the relationship between the policy context and human agency. This is done through comparative analysis of public policies, employment practices and family behaviour. The book addresses issues of critical importance not only for how social care is delivered and framed in national policy making, but also for how work is organised to enable women and men, across the life course, to combine paid work with the unpaid care of family members whenever long-term sickness, disability or frail old age is encountered. The ultimate goal of the volume is to offer empirical and conceptual insights as well as policy lessons that can contribute to the development of support to working carers in various national contexts and welfare state models.
A comprehensive system of long-term care for people with dementia comprises both health and social care services - diagnostic and medical continuing care services; informal family care (the cornerstone), supported and supplemented as necessary by paid home caregivers; respite opportunities, high quality care homes; and palliative end-of-life care.

Reducing transitions into care homes is an important part of high income country governments’ cost-containment strategies. It is often claimed that people with dementia would prefer to live at home for as long as possible cared for by their family, that this option is associated with better quality of life, and that care at home is cheaper than care in a care home.

None of these rationales is fully supported by evidence. Care in care homes is a preferred option for a significant minority of older people, particularly when presented with a scenario of dementia with complex intensive needs for care. Currently available evidence suggests that subjective quality of life is similar for those with dementia cared for in care homes and those cared for at home, and may even be better in care homes for those in the advanced stages of dementia. Societal costs of care in care homes and care at home are similar, when an appropriate cost/value is attached to the unpaid inputs of family carers.

Care in care homes is, and will remain, an important component of the long-term care system for people with dementia. Currently around one-third to one-half of people with dementia in high income countries, and around 6% of those in low and middle income countries are cared for in care homes. Demographic, social and economic trends are likely to increase demand for high quality formal care services (paid care at home, or in a care home), particularly in low and middle income countries where they are very rudimentary.

Caregiver multi-component interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain. This is also the only intervention that has been proven to reduce or delay transition from home into a care home. Such interventions seem to be particularly effective when applied early in the journey of care. Nevertheless, we are aware of no governments that have invested in this intervention to scale-up provision throughout the dementia care system, and hence coverage is minimal.
This report develops an Ageing and Health Sustainability Framework of key actions and innovations that will help countries assess and enhance the robustness of their health systems.

Getting the financial system right – reconciling growing demand with limited resources:
Countries need to break the links between old age, poverty and ill-health. They can best do this by introducing social pensions and enabling older people to work longer, reflecting increased life expectancy. Extending the working age should itself bring economic benefits as well as health benefits, by offsetting the expected reductions in the support ratio and filling gaps in the workforce. Another important way of maintaining incomes is by making it easier to send remittances home: one successful model is that of M-Pesa in Kenya, which uses mobile phone technology for the purpose. However, public funding of care is unlikely to provide the whole solution. Alternatives are needed. Health insurance can take innovative forms: for example, the long-term care insurance introduced in Japan, or the very low-cost health insurance enabled by the Grameen Health Insurance programme in Bangladesh. In high-income countries, there is a trend of enabling older people who are asset-rich but income-poor to turn their assets into income in order to help fund care costs.

Helping families to care – increasing the supply of informal care.
Care provided by families is the backbone of long-term care. But it is difficult to maintain or increase it in the face of falling support ratios, urbanisation and migration, and changing working patterns. One option is to direct cash and services to support carers. Another is to use technological innovations to provide information and support: an example is the new “Grouple” online tool from the UK. And, as we see in Singapore and India, governments can innovatively incentivise or reinforce traditional family caring responsibilities through the tax system and other regulatory measures.

Prevention and self-management – reducing the demand for care.
Prevention and self-management go together. Prevention programmes have historically focused on younger or working-age adults, but there is increasing recognition of the value of prevention programmes aimed at older people. Among the key ways of reducing demand are these: improving health literacy, targeting physical activity, exploiting new technology, encouraging best use of medicines, and delivering services focused on increasing functionality and self-management. We feature innovations in each of these areas. However, the prevention agenda needs to broaden if it is to tackle social isolation, engage communities more widely, adapt or develop homes, and make cities more age-friendly places. Innovations in each of these areas are available and scalable.

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<th>Author and Source</th>
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<td>Hope P with Bamford S-M, Beales S, Brett K, Kneale D, Macdonnell M and McKeon A (2012) <em>Creating Sustainable Health and Care Systems in Ageing Societies: Report of the Ageing Societies Working Group 2012</em>, Imperial College</td>
<td>Care at home and in the community – improving value for money in care supply: Conventional service delivery is often based on institutional hospital care and a supply of trained health professionals – all relatively expensive. Moreover, different professionals often work in organisational silos, and fail to integrate services to achieve best value and best care. Countries obviously need high-quality institutional care and health professionals who deliver care according to best practice. But to make care more affordable, countries also need to provide or develop services that rely less on the conventional model of health care, and to overcome barriers to integrated care. New technologies are now available to help integration and to deliver care less expensively to wider populations in their own homes or communities. When people need longer-term or hospital care, there are alternatives that can offer better value and better quality of life. Examples include: telemedicine as in Denmark, patient hotels as in Sweden, and new smartphone devices to diagnose eye diseases at an early stage. Supply can also be improved by fully involving older people and carers in the design and delivery of services. Such services tend to suit the patient’s needs better, and are more likely to be home- or community-based. A radical alternative to publicly provided care services in England is to give older people the equivalent budget and let them direct or buy the care that they need to achieve the outcomes they want.</td>
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<td>EveryChild and HelpAge International (2012) <em>Family first: Prioritising support to kinship carers, especially older carers</em>, EveryChild and HelpAge International</td>
<td>This paper makes the case for greater support to kinship care, and gives guidance on the most effective means for supporting kinship carers and the children in their care. It focuses on grandparent care as the most common and often least adequately supported form of kinship care, and is a collaborative effort between EveryChild and HelpAge International. It suggests that greater collaboration is needed between agencies striving to achieve child rights and those working on greater protection of older people’s rights. For so many children outside of parental care, and for so many grandparents, there is great interdependence between these two goals.</td>
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<td>Kneal D, ILC-UK (ed) (2012) <em>Global Perspectives on Multigenerational Households and Intergenerational Relations</em>, ILC Global Alliance</td>
<td>This report initiates a dialogue on multigenerational households and intergenerational relations from a global perspective. This report reviews the status of multigenerational households and intergenerational relations in specific countries that vary widely in terms of social attitudes, population structure, cultural traditions and economic development. The theme of the report was developed jointly by ILC-India and ILC-UK, through shared concerns about changes in household structures, and anxiety about ways of maintaining intergenerational relations. This report features contributions from: Argentina; Czech Republic; Dominican Republic; France; India; Japan; Netherlands; Singapore; South Africa; and the United Kingdom. Continued...</td>
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For some of the countries represented in this report (e.g. the Czech Republic, the Netherlands, and the UK), the global economic crisis has brought intergenerational issues to the fore recently. This has prompted a critical examination of relationships between younger and older people within multigenerational households and families, and beyond in non-familial intergenerational relationships. Some of this has been on the macro-level, with much of the rhetoric pitching younger generations against older. Other countries meanwhile (e.g. South Africa and Singapore) have emerged relatively unscathed from the economic crisis, and in these countries other changes in social attitudes, and economic development of a different sort, are drivers of change in intergenerational relations and household structures. While all countries now arguably have an ageing population, in some countries represented in this report, fertility rates have dropped below replacement level and their populations have been ageing for a considerable time; some Western countries already have an older population that is now fairly closely approximate to the size of the younger population (under 16 years). Yet other countries represented in the report are still in an intermediate stage of demographic transition with the younger population significantly greater in size than the older population, albeit with rapid growth in the number of older people.

Despite these demographic differences, certain common themes have emerged in the reports of the different countries. Most prominent among the themes is a decline in the number of multigenerational households in recent years, observed in the majority of the countries. Gender is another common theme, with older populations disproportionately made up of women, and the majority of older women widowed and the majority of older men living in couple relationships. Gender is evident moreover in patterns of care provision, with women identified in several countries as primary carers to older people (Argentina, Dominican Republic, France, India, South Africa, Singapore, UK) - and most probably the case in all countries. In several countries (Dominican Republic, India, South Africa) older women are also often primary care givers to grandchildren, although this role is not mentioned specifically in other countries, particularly those with a low prevalence of multigenerational households.

The prevalence of multigenerational households differs by country type, and generally high income countries have a lower proportion of multigenerational households and low and middle income countries a higher proportion of households, although as mentioned, other cultural and social factors differentiate between countries that are similar in many other ways. Furthermore, while household structures have changed substantially in higher income countries, and the proportion of multigenerational households has declined against a context of economic and social change, research does show that although intergenerational relations evolve, they nonetheless remain essentially intact.
This ILC-UK report, drawing on the ideas, issues and challenges of integrating care raised at the Conference on Integrated Care for Frail Older People, examines the potential benefit of integrating health and social care services for frail older people in a global context. It highlights that while financial, cultural and logistical barriers exist, countries should continue to work towards integrating health and social care services given its possibilities for cost-efficiency, freeing up acute healthcare facilities and benefits for service users. This report covers:

- the need for integrated care;
- the current global context of care for frail older people;
- the benefits and challenges of integrating health and social care services for this group;
- priorities for action in advancing the issue of integrated care worldwide.

What is integrated care?
Integrated care is a mechanism for ensuring joined up service responses and safeguarding the quality of care received by patients. The term ‘integrated care’ describes a variety of approaches to these issues, for example some schemes have used care coordinators; and others joint meetings with professionals from different aspects of health and social care to manage care pathways for patients. Older people have ‘complex and interacting needs, and they often require treatment and care from a range of professionals and carers, services and agencies at the same time’, and as such would benefit from increased integration in their service provision.

Key benefits of integrating health and social care services:
For service users - reduces complexity in their service provision, enhances the quality of services they access.
For service providers – cost effective, reduces lengths of hospital stay; inappropriate hospital admissions and decreases long term care admissions.

Key barriers to integrating health and social care services:
Finance - a lack of financial provision available despite efficiency benefits in costs and resources through service integration.
Practicality - integration requires communication and cooperation between existing health and social care services, potentially causing fractions in shared responsibility for patients.
Culture – some countries report a greater focus on the health of younger rather than older people; others suggest that state provision of health and social care can lead to a culture of dependency.
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<td>Taylor R (ILC-UK) (2011) <em>Ageing, Health and Innovation in OECD countries</em>, Paris: Organisation for Economic Co-operation and Development</td>
<td>All OECD countries are experiencing unprecedented demographic change characterised by increasing longevity, a growing older population and falling birth rates. While significant differences remain between different OECD countries, the long term trends are similar and convergence looks likely to occur in the coming decades. These demographic changes are leading to a lower old age dependency ratio (the ratio of working age to non-working age people), which presents challenges for the social solidarity and long-term sustainability of health, social care and pensions systems. The paper outlines two philosophically different ways of approaching the challenge of demographic change. The first, which the paper calls the &quot;zero sum approach&quot; is to see it as a problem that requires today's working people to pay more and those drawing on social security systems to receive reduced benefits and to rely more on themselves. This approach risk intergenerational conflict as &quot;productive&quot; working people are asked to pay more to support the healthcare, social care and pensions of non-working people who may be perceived as having had an easier life. The second way of looking at the problem is to take a life course approach. The life course approach sees demographic change as a challenge and an opportunity. Different generations do not compete for resources and all can play constructive albeit different roles in society. The life course approach believes that policy reform should be innovative and seek to support active and healthy ageing rather than simply increase contributions and cut benefits. The paper looks at a number of innovative policy reforms in different OECD countries including health checks for the over 40s in the UK, Japan's long term care insurance system and the use of mobile phone technology to support older people or people with chronic diseases.</td>
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<td>National Institute on Aging, National Institutes of Health; World Health Organization (2011) <em>Global Health and Aging</em>.</td>
<td>This report provides a demographic, contextual overview... The world is on the brink of a demographic milestone. Since the beginning of recorded history, young children have outnumbered their elders. In about five years time however the number of people aged 65 or older will outnumber children under age 5. Driven by falling fertility rates and remarkable increases in life expectancy, population aging will continue, even accelerate. The number of people aged 65 or older is projected to grow from an estimated 524 million in 2010 to nearly 1.5 billion in 2050, with most of the increase in developing countries. The remarkable improvements in life expectancy over the past century were part of a shift in the leading causes of disease and death. At the dawn of the 20th century, the major health threats were infectious and parasitic diseases that most often claimed the lives of infants and children. Currently, non-communicable diseases that more commonly affect adults and older people impose the greatest burden on global health. Continued...</td>
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In today’s developing countries, the rise of chronic noncommunicable diseases such as heart disease, cancer and diabetes reflects changes in lifestyle and diet, as well as aging. The potential economic and societal costs of noncommunicable diseases of this type rise sharply with age and have the ability to affect economic growth. A World Health Organization analysis in 23 low- and middle-income countries estimated the economic losses from three noncommunicable diseases (heart disease, stroke, and diabetes) in these countries would total US$83 billion between 2006 and 2015. Reducing severe disability from disease and health conditions is one key to holding down health and social costs. The health and economic burden of disability also can be reinforced or alleviated by environmental characteristics that can determine whether an older person can remain independent despite physical limitations. The longer people can remain mobile and care for themselves, the lower are the costs for long-term care to families and society.

Because many adult and older-age health problems were rooted in early life experiences and living conditions, ensuring good child health can ensure benefits for older people. In the meantime, generations of children and young adults who grew up in poverty and ill health in developing countries will be entering old age in coming decades, potentially increasing the health burden of older populations in those countries.

With continuing declines in death rates among older people, the proportion aged 80 or older is rising quickly, and more people are living past 100. The limits to life expectancy and lifespan are not as obvious as once thought. And there is mounting evidence from crossnational data that—with appropriate policies and programs—people can remain healthy and independent well into old age and can continue to contribute to their communities and families.

The potential for an active, healthy old age is tempered by one of the most daunting and potentially costly consequences of ever-longer life expectancies: the increase in people with dementia, especially Alzheimer's disease. Most dementia patients eventually need constant care and help with the most basic activities of daily living, creating a heavy economic and social burden. Prevalence of dementia rises sharply with age. An estimated 25-30 percent of people aged 85 or older have dementia. Unless new and more effective interventions are found to treat or prevent Alzheimer's disease, prevalence is expected to rise dramatically with the aging of the population in the United States and worldwide.

Aging is taking place alongside other broad social trends that will affect the lives of older people. Economies are globalizing, people are more likely to live in cities, and technology is evolving rapidly. Demographic and family changes mean there will be fewer older people with families to care for them. People today have fewer children, are less likely to be married, and are less likely to live with older generations. With declining support from families, society will need better information and tools to ensure the well-being of the world’s growing number of older citizens.
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<td>Organisation for Economic Co-operation and Development (2011) <em>Help Wanted? Providing and Paying for Long-Term Care</em>, OECD</td>
<td>As life expectancy pushes into the late 70s for men and well into the 80s for women, ever more people want help in order to be able to live their lives to the full for as long as possible. How will demographic and labour market trends affect the supply of family and friends available to care for us? Can we rely on family carers as the sole source of support for frail seniors? Should family carers and friends be better supported, and if so how? Can we attract and retain care workers -- is it just a matter of paying them better? Will public finances be threatened by the cost of providing care in the future? What should be the balance between private responsibility and public support in care-giving? Can we reduce costs by improving efficiency of long-term care services? The topics covered by this publication are :- Long-term Care: Growing Sector, Multifaceted Systems; Sizing Up the Challenge Ahead: Future Demographic Trends and Long-term Care Costs; The Impact of Caring on Family Carers; Policies to Support Family Carers; Long-Term Care Workers: Needed but Often Undervalued; How to Prepare for the Future Long-term Care Workforce?; Public Long-term Care Financing Arrangements in OECD Countries; Private Long-term Care Insurance: A Niche or a “Big Tent”?; Where To? Providing Fair Protection Against Long-term Care Costs and Financial Sustainability; Can We Get Better Value for Money in Long-term Care?</td>
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<td>Schoen C, Osborn R, Squires D, Doty M, Pierson R and Applebaum S (2011) <em>New 2011 Survey Of Patients With Complex Care Needs In Eleven Countries Finds That Care Is Often Poorly Coordinated</em>, <em>Health Affairs</em> 30 (12) : 2437-2448</td>
<td>Around the world, adults with serious illnesses or chronic conditions account for a disproportionate share of national health care spending. We surveyed patients with complex care needs in eleven countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States) and found that in all of them, care is often poorly coordinated. However, adults seen at primary practices with attributes of a patient-centered medical home—where clinicians are accessible, know patients' medical history, and help coordinate care—gave higher ratings to the care they received and were less likely to experience coordination gaps or report medical errors. Throughout the survey, patients in Switzerland and the United Kingdom reported significantly more positive experiences than did patients in the other countries surveyed. Reported improvements in the United Kingdom tracked with recent reforms there in health care delivery. Patients in the United States reported difficulty paying medical bills and forgoing care because of costs. Our study indicates a need for improvement in all countries through redesigning primary care, developing care teams accountable across sites of care, and managing transitions and medications well. The United States in particular has opportunities to learn from diverse payment innovations and care redesign efforts under way in the other study countries.</td>
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This paper identifies innovative ideas and suggestions already in circulation in the UK and globally that would contribute to better lives for older people with support needs; suggests improvements to these ideas and suggestions; and makes conclusions in relation to diversity amongst older people with high support needs, care issues and broader social issues.

Older people with high support needs — and older people generally — are not a homogeneous group. Stereotypes are pernicious and fail to take into account that:

- Older people range across a broad age span: from ‘getting oldies’ at 55 to the steeply rising numbers of people over 100 years old, encompassing low to high support needs across this sweep. It is unrealistic and unhelpful to expect identical interests across this spectrum.

- Older people in the UK are diverse in ethnic origin and upbringing and often have widely different expectations of ageing. Differences of income, family background and culture in its broadest possible sense have similar impacts: differences between rural living and urban life are hardly less important.

- Baby boomers experience versions of the same problems that have beset previous generations. We have collectively assumed that the ‘baby boomer’ generation will not go quietly into older age. We look for them to ‘expect services to reflect their needs and make a fuss if they do not. In particular we expect them to refuse the post-poor house/poor law, be-grateful-for-what-you’re-offered attitudes deemed to have characterised the generation that lived as adults through the privations of the war and the 50s.

It is already clear that this last point is only partially true. Age slows most of us down. Resource poverty and physical frailty slow many down further. It is, in the end, less easy to man the barricades at 100 than it was at 20, particularly if your support needs are high. A proportion of the baby boomers, characteristically, will fight for change — but they cannot be expected to win all our battles for us. This is a form of stereotyping in itself and needs correcting: an innovation that older people are increasingly insisting upon is recognition of their own diversity.

The past 30 years has seen enormous gains in terms of support for older people with high needs - but it has also seen losses. Low level and preventative care, for example, is reduced to a nubbin. There has been a continuous rhetoric of innovation in the care of older people but the reality is meanly allocated domiciliary care scraped out to the thinnest minute, residential care that few look forward to and neglectful and abusive hospitals.
This paper reviews policies in the area of healthy ageing. With the ageing of OECD countries’ population over coming decades, maintaining health in old age will become increasingly important. Successful policies in this area can increase the potential labour force and the supply of non-market services to others.

They can also delay the need for longer-term care for the elderly. A first section briefly defines what is meant by healthy ageing and discusses similar concepts – such as “active ageing”. The paper then groups policies into four different types and within each, it describes the range of individual types of programmes that can be brought to bear to enhance improved health of the elderly. A key policy issue in this area concerns whether such programmes have a positive effect on health outcomes and whether they are cost-effective.

Looking at specific programmes, the material covered by this review also suggests that important improvements to the health and welfare of older cohorts seem possible from some combination of: delaying retirement, increased community activities, improved lifestyles, health-care systems that are better adapted to the needs of the elderly, particularly where they are combined with more emphasis on cost-effective prevention. However, this study also finds that, while there is considerable evidence that certain policy instruments can help improve the health status of the elderly, it remains unclear as to which are the most (cost) effective. Thus, more research is needed in this area if policy choices are to be (more) evidence-based. But whatever the choice of specific programmes, progress towards healthy ageing would probably be enhanced by placing individual programmes within broader policy frameworks that bring together the full range of measures so as to make them mutually reinforcing.

Regional patterns

In terms of contact with family, friends and participation in social groups and organisations, the data revealed a divide between Southern and Eastern European countries (and Austria) on the one hand and Northern and Western European and non-European English speaking countries on the other. Respondents from the former group tended to have greater levels of family contact, a smaller number of friends and less likelihood of involvement in social organisations. Social network patterns in Japan, being the only Asian country in the sample, differed from both these clusters, having the highest proportion living in multiple person households, but a low level of contact with family with whom they did not reside.

In all countries the majority of respondents (74%) saw a close relative at least once a week, although the country average varied between 89% in Spain and Italy to only 66% in New Zealand. All countries agreed on the importance of the spouse as a source of support although rates of marriage and widowhood varied considerably.

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Gender differences
Across all the countries, women had on average greater frequency of contact with family than men, whilst overall men had higher social participation rates than women even when controlling for age. In most countries, men also reported more close friends on average, but paradoxically men were also more likely to report having no close friend, and to see their closest friend less frequently than women.

Attitudinal variations
The ISSP included a number of attitudinal questions, including whether adult children have a duty to look after elderly parents. Countries with higher levels of family contact were more likely to have above average levels of agreement with this statement.

Paid employment
Levels of close family contact were on average marginally lower among employed persons. Working was found to have a positive effect on non-familial social networking, in particular involvement in social and community groups. No evidence was therefore found that working in older life undermines the increased social networking that is often aspired to through retirement and voluntary early retirement. Paid employment was more likely amongst the non European sample, and northern Europeans.

Social expenditure on care
A negative association was found between social expenditure on care in countries and the average level of family contact, and between expenditure and the proportion living in multiple person households in each country. However, this association was dependent upon the extreme cases of regimes with particularly high and low expenditure. When these are excluded from the analysis, this association is not evident. On the contrary, to some extent it can be argued that strong family networks within countries are not necessarily incompatible with comparatively generous public social care provision. Austria is an example of a country with strong family networks accompanied by higher levels of expenditure. Over 81% of the sample in Austria saw an adult child at least once a week, compared to an average of 73% in the 18 countries. Austria had above average OECD expenditure on long term care as a proportion of the population over 80 in 2001 and a developing profile of social care services.
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This report provides an overview of global ageing including sections changing family structure, shifting patterns of work and retirement and evolving social insurance systems.

In countries with very low birth rates, future generations will have few if any siblings. As a result of this trend and the global trend toward having fewer children, people will have less familial care and support as they age. As life expectancy increases in most nations, so do the odds of different generations within a family coexisting. In more developed countries, this has manifested itself as the “beanpole family,” a vertical extension of family structure characterized by an increase in the number of living generations within a lineage and a decrease in the number of people within each generation.

People currently divorced constitute a small proportion of older populations. This will soon change in many countries as younger populations with higher rates of divorce and separation age. In the United States, for example, 9 percent of the 65-and-over population is divorced or separated compared to 17 percent of people age 55 to 64 and 18 percent of people age 45 to 54.

Childlessness is another important factor that will affect caregiving but has received relatively scant attention. In modern societies, around 20 percent of women do not give birth. Rising percentages of childless women are seen in Europe and North America and, increasingly, in Latin America and Southeast Asia as well.

The number, and often the percentage, of older people living alone is rising in most countries. In some European countries, more than 40 percent of women age 65 and older live alone. Even in societies with strong traditions of older parents living with children, such as in Japan, traditional living arrangements are becoming less common.

Although data on less developed countries are inconsistent, the most common picture shows workforce participation rates decreasing for older men and increasing for older women. The latter trend will have important implications for the ability of women to accumulate and control economic resources in older age.

Just as the tendency to work at older ages varies from country to country, so do the routes workers take to retirement. These routes may involve working part time, leaving career jobs for transition jobs, or leaving the workforce because of disability. In South Korea, the average worker leaves company employment at age 54 but then engages in part-time or low-wage employment for another 14 years before retiring completely at age 68.

In 1960, men on average could expect to spend 46 years in the workforce and a little more than one year in retirement. By 1995, the number of years in the workforce had decreased to 37 while the number of years in retirement had jumped to 12. Estimates for Italian men in the year 2000 suggest a median retirement age of less than 59 years and a retirement duration of nearly 21 years.

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The Chinese Experience: Rethinking Social Security in an Emerging Market Economy:

Although China is rapidly urbanizing, it remains a predominately rural country. The majority of Chinese workers are not yet covered by any formal pension system. Among those who have been and are now covered, there has been a steady rise in the number receiving formal pensions during the past 25 years. Concurrently, there has been a sustained decline in the ratio of covered workers to pensioners in China, a trend that threatens the well-being of the Nation's formal old-age security system. Following a decade of experimentation, a new framework for old-age security emerged in the mid-1990s. The intent is twofold: (1) To replace cradle-to-grave support provided by State-owned enterprises with an expansion of coverage beyond the State sector and (2) to introduce pooled funding, which deflects risk. The new system includes a defined benefit pension providing a 20-percent replacement rate of the average wage and a defined contribution individual account. Owing to the unfunded liabilities of the former system, individual accounts have remained largely notional as today's workers pay for today's pensioners.


Examination of the policies and experiences of other countries in the funding of long-term care reveals a number of difficult choices, for which there are no simple technocratic solutions. To take but one example, providing support for long-term care in the form of cash payments appears to have the potential to maximise choices for older people (so long as a range of support options on which those payments can be spent actually exists). However, to the extent that such payments are intended wholly or partially to constitute incentives for informal care-giving, they may severely compromise the choices and independence of carers. Similarly, extensive systems of means testing and co-payments may contain costs and enhance economic sustainability, but at the potential expense of improved efficiency and equity (depending on the type of means test).

Examination of arrangements for funding long-term care in a number of other countries reveals the following conclusions:

There are limits to how far any system of funding long-term care can be protected from wider economic pressures and performance. Even Germany, whose long-term care insurance system contains a substantial number of highly effective mechanisms for controlling social insurance expenditure, is not immune to pressures arising from continuing high unemployment and budget deficits. Moreover, as the proportion of total spending from social insurance is held constant and that from private sources correspondingly increases, the equity and other performance criteria of the scheme may be adversely affected.

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None of the countries included in this study has introduced a funded insurance scheme for long-term care. Requiring one generation effectively to pay twice for long-term care appears substantially to risk intergenerational conflict, without any obvious counterbalancing gains in sustainability. Countries such as Germany, the Netherlands and (in part) Japan that have adopted social insurance principles for funding long-term care have all introduced pay-as-you go schemes. Other countries rely on mixtures of national and local taxation (with varying levels of private contributions from user co-payments and means tests). Funding the care needs of current generations of older people through current taxation and/or insurance contributions (including those paid by more affluent older people themselves) therefore appears to be the only viable option. Moreover, in none of the countries that have adopted this approach is there any evidence of intergenerational conflict.

Debates about the funding of long-term care necessarily need to include both the mechanisms by which revenues are raised and the mechanisms by which these are allocated. Methods of allocating resources – particularly the micro-allocation processes associated with individual needs assessments and the incentives attached to more or less costly types of care (including informal care) – directly impact on the equity, efficiency and ultimately the sustainability of any particular system.

Successive UK governments have tended to adopt a relatively incremental and piecemeal approach to long-term care policies. It may, for example, be more realistic to consider the adoption of a number of specific incremental measures, such as national eligibility criteria or lower user charges, than the wholesale implementation of an entirely different system. However, despite the strengths of the UK system of funding long-term care, this approach has arguably also contributed to the current inequitable divergence between English and Scottish arrangements. Moreover, the experience of other countries shows that radical changes could realistically be considered. The recent experience of Japan shows that system-wide change can be accomplished, even in the face of strong institutional and cultural traditions.

Developments in Australia during the 1980s and in Austria in the 1990s were similarly accomplished despite major constitutional barriers.

In summary, the experiences of other countries show that radical system-wide transformations in arrangements for funding long-term care can be accomplished. However, the nature of those changes, and their relative costs and benefits over and above current arrangements, requires full and open political, economic, social and ethical debates. Such debates hold the key to the long-term sustainability of the future funding of long-term care in the UK.
b) Europe overviews

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<td>Verbeek-Oudijk D, Woittiez I, Eggink E and Putman L (2014) <em>Who cares in Europe? A comparison of long-term care for the over-50s in sixteen European countries</em>, Den Haag: SCP Publications</td>
<td>Long-term care for people with chronic health problems in the Netherlands is undergoing radical reform. Local authorities are being given a central role in implementing long-term care, care insurers are being given responsibility for personal and nursing care, and fewer people are eligible for long-term residential care. The reforms are accompanied by spending cuts, but are also intended to enable people to continue living at home for as long as possible, where necessary with support. Against the background of these major changes, it is important to look at how other countries in Europe organise and deliver care for people with long-term health problems. What developments have taken place in long-term care? What health problems do people have in these countries? For what forms of care are they eligible and what support are they offered in practice? This study compares long-term care and its utilisation by people aged over 50 living independently in the Netherlands and fifteen other European countries. Characteristics of the different care systems are combined with the outcomes of a large-scale survey of users of care in Europe. This comparative and empirical approach provides input for the policy debate about a sector that is set to undergo radical changes in the coming years.</td>
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<td><strong>Key points:</strong></td>
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<td>. Older Europeans continue to be ‘givers’ rather than ‘receivers’ of support</td>
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<td>. Support received by older Europeans from their family involves mainly care, not cash</td>
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<td>. Ill health and poverty place high demands on intergenerational support</td>
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<td>Do important events that people experience impact on patterns of intergenerational support? Theoretical perspectives on how intergenerational relations change over time, have stressed the importance of the timing of individual changes relative to family life stages. The changing circumstances of individuals occur in conjunction with changing family structures, and these transformations converge with historically created opportunities or constraints.</td>
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<td>Earlier research on how intergenerational exchanges operate has stressed that the regularity and intensity of support is higher in Southern Mediterranean countries. A deterioration in the self-perceived ability of the household to make ends meet financially is notably not associated with a greater probability of receiving support. In general, these results confirm the significant rise in the probability of receiving support that is associated with advanced age and the onset of disabilities, suggesting that families continue to be involved in the social care of their older members when their health deteriorates.</td>
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<td>Intergenerational exchanges of practical and financial support continue to exercise an important role in the context of Europe’s population ageing. Families respond to the needs of their older members that arise following the onset of an illness, disability or frailty, and changes in living arrangements. The SHARE data show that changes in health and environmental conditions are more likely to trigger support within families than changes in the economic conditions of households such as the self-perceived ability to make ends meet or the passage to retirement. Although it is too early to know whether families will step in to support older Europeans who are at a greater risk of poverty due to the economic crisis, the results presented in this chapter suggest that changes in economic circumstances are not currently associated with increased family solidarity. More long term research is needed to determine whether the economic crisis has precipitated levels of illness and disability that would not normally have been observed within the older population and whether therefore, families will be under increasing pressure to provide social care for their older members.</td>
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Key findings

The study shows that across Europe grandparents, and grandmothers in particular, are playing a major role in providing both intensive and occasional care for their grandchildren. 44% of grandparents in the 11 European countries studied provide grandparental childcare without the child’s parents present, while in Britain the British Social Attitudes (BSA) survey showed that 63% of grandparents with a grandchild under 16 do so.

Younger grandmothers who are fit, healthy and with younger grandchildren – the most likely to be providing care for their grandchildren – are the very women that governments across Europe are aiming to encourage to stay in paid work for longer, in order to increase productivity and pay for their own pensions, health and social care in later life. Their vital but invisible role in providing childcare, whether intensive, regular and/or occasional, is likely to conflict with their own ability to self finance their old age, especially as widow’s benefits in both state and employer pension schemes are eroded.

England and Wales, like the US, has experienced an increase in the prevalence of skipped-generation households – households consisting of grandparents and grandchildren but without the parents. This rose from 0.25% of adults aged 35 and over living in such households in 1981 to 0.42% in 2001. These households are likely to experience poverty and disadvantage. No other European country studied so far follows this pattern.

Our study shows considerable variations in the characteristics of grandparents across the European countries studied. English grandparents are relatively young, more likely to be in paid work and have more grandchildren on average than grandparents in the remaining 11 European countries. In England one in four (23%) grandparents aged 50 and over are in paid work, compared with an average of just one in seven across the other 11 countries studied. Only Denmark and Sweden have a higher percentage of working grandparents.

While overall grandparents in the European countries studied provide high levels of childcare, there are striking variations in the intensity and frequency of the care provided. In France, Denmark, Sweden and the Netherlands between 50% and 60% of grandparents provide some childcare compared with just 40% in the Southern European countries. However, regular and intensive grandparental childcare is more common in Southern Europe, with 20% of grandparents in Italy providing almost daily childcare compared with just 2% of grandparents in the Netherlands.

Across the European countries studied grandparents who are younger, with higher educational levels, in better health, and whose youngest grandchild is under age six are more likely to provide childcare. Differences in the characteristics of grandparents in the different countries (such as age and marital status) explain some of the differences in grandparental childcare across the 12 European countries, however there are significant differences between countries too.

Continued...
The research finds that different family policy contexts are associated with varying patterns of grandparental childcare. In countries such as Sweden and Denmark (and to a lesser extent, France) where parents are expected to work full-time, formal childcare is widely available, and there is generous maternity pay and support for mothers who stay home - grandmothers play a far more limited role in providing intensive childcare, but are still significantly involved in providing occasional and less intensive care for grandchildren.

In Portugal, Spain, Italy and Romania, where welfare payments to parents and mothers at home are limited, there is little formal childcare and few opportunities for mothers to work part-time, grandparents provide a great deal of intensive childcare for their grandchildren.

Moreover, in these countries, mothers who do work often do so for 40 plus hours a week, and since there is little affordable formal childcare, there is greater reliance on intensive care by grandmothers. With the exception of Romania, in these countries there is less of a role for grandparents providing occasional or less intensive care without the parents present.

In the UK, Germany and the Netherlands where public support for families is varied but less universal, childcare coverage is patchy and often provided by the market rather than the state, and the norm is that women work part-time, grandparents generally play a middling role in both intensive childcare and occasional/less intensive childcare. In these countries a smaller proportion of those mothers in full-time work do so for long hours, leading to less reliance on intensive childcare by grandmothers. In the Netherlands, which has by far the highest proportion of mothers working part-time and very few mothers working full-time, and where formal childcare is widespread, there is very little intensive grandparental childcare by grandparents.

In general, countries with the lowest usage of formal childcare, Hungary, Portugal and Romania, have the highest percentages of grandmothers caring intensively for their grandchildren, and countries with the highest usage, Sweden and Denmark, have the lowest percentages of grandmothers providing intensive childcare.

In countries with higher percentages of older women in paid work there is less involvement of grandmothers in intensive childcare.

Given that grandmothers aged 50 to 69 who are not in paid work are the most likely to provide childcare, the plans of European governments to extend retirement ages and increase female labour force participation at older ages are likely to conflict with their role in providing childcare, and therefore has significant implications for labour market participation by younger mothers and for pension acquisition and the financial security of mid-life women.

Being older does not inevitably lead to being dependent. Nonetheless, there are a number of factors underling the ageing process that involve a probable increase in the need for support in both health issues and carrying out daily activities. Family is still an essential source of informal care for older relatives, a source of care in which gender plays an important role. Several studies confirm that women provide more intense and frequent care than men. However, this gender inequality, as well as the importance of family in the provision of informal care to family members, can be mitigated or strengthened by the social context or the state.

Several approaches have been proposed to account for the variability of the social functions of the family. Esping-Anderson\(^1\) distinguishes familialistic from de-familialistic regimes, describing the first as a regime where the public policy assumes that it is the responsibility of the household to ensure the welfare of their members, whereas in the second the policies are in place to reduce the individual’s dependence on household and kinship. Leitner\(^2\) describes familialism types considering not only the policies to relieve families from providing care, but also the ones that actively promote family care. His clustering exercise is particularly relevant to our study, because it is based on a gender-sensitive theoretical concept of familialism and it is applied to the variety of policies on older population care in Europe.

Leitner\(^2\) identifies explicit, implicit and optional familialism regimes in the countries of Europe. Explicit familialism regimes assign the responsibility of care for older individuals to the family, to which benefits are paid, and they provide few formal support services, such as domiciliary care (Austria, Belgium, France and Germany). In implicit familialism welfare regimes, the state neither supports family care through cash payments nor provides generous public care services. In such settings, support between adult children and their parents is encouraged through a strong normative system that is based on filial and moral obligations (Greece, Italy, Portugal, Spain and the Netherlands). Finally, in the optional type of familialism regimes, generous professional and financial services are provided to dependent older people through cash-for-care programmes, relieving families of the responsibility of caring for their older members (Denmark, Finland and Sweden). Eastern European countries, which formerly were part of the socialist block, do not yet have a fully defined system. Consequently, in the research that is presented in this chapter they will be grouped separately, as proposed by other authors in similar realms of inquiry.


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<th>Author(s)</th>
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<td>Brugiavini A, Buia R E, Pasini G and Zantomio F (2013)</td>
<td>Long-term care and reciprocity: does helping with grandchildren result in the receipt of more help at older ages? In Börsch-Supan A, Brandt M, Litwin H and Weber G (Eds) Active ageing and solidarity between generations in Europe - First results from SHARE after the economic crisis, Berlin: De Gruyter</td>
<td>In four out of ten households, older adults provide help to their grandchildren. Caring for grandchildren increases the likelihood to receive help from adult children later in life. Substantial in-kind transfer of care services between generations is likely to benefit welfare state budget.</td>
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<td>Leichsenring K, Billings J and Nies H (eds) (2013)</td>
<td>Long-Term Care in Europe: Improving Policy and Practice, Palgrave-MacMillan</td>
<td>This book challenges the prevailing discourse centred on the problems of demographic change and long-term care provision for older people by focusing on solutions emerging from progression and improvement in policy and practice. Building on ample research in 13 European countries, evidence is provided for how the construction of long-term care systems can be taken forward by practitioners, policy-makers and stakeholder organizations. By focusing on prevention and rehabilitation, the support of informal care, the enhancement of quality development as well as by decent governance and financing mechanisms for long-term care, stakeholders may learn from European experiences and solutions on the local, regional and national levels.</td>
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A German study comparing housing initiatives for older people in The Netherlands, Denmark, the United Kingdom, France and Finland.

The European comparison shows that the approaches promoting living in old age in the Member States analysed extend beyond the design and adaptation of living space and include involvement in society as well as the active integration of the elderly in the (residential) surroundings. These approaches are supplemented by measures to design age- or generation-appropriate infrastructure and the provision of local supportive services. An example is the British strategy "Lifetime homes, lifetime neighbourhoods", that not only puts focus on the current challenges for housing, but also on the importance of the living environment for well-being and independence of elderly people ("inclusive and sustainable neighbourhoods"). Common trends may be identified despite cultural and political differences that exist between the states:

An important area of action and a large challenge for all of the states observed is barrier-free design and/or the adapting of existing housing stock where the majority of European senior citizens live. Accordingly, in Finland and the United Kingdom for example, programmes were put in place to provide funding for minor adaptations and repairs in private households. In the case of new constructions, increasing emphasis is being placed having buildings be adaptable and flexible (e.g. "Opplussen" in the Netherlands).

With regard to the development of new housing forms, a broad range of different arrangements has been developed across Europe in the past several years where the distinction between out-patient and in-patient care is becoming ever more blurred and focus is increasingly being placed on providing care on-site. In addition to old age and nursing homes, there is a variety of professional residential facilities offering care services (assisted living, sheltered housing, and shared housing17), day and short-term care through to the arrangements that help to live in one's own home and to receive care from family members and/or friends if needed. A further initiative, to support living in one's own home, are preventative home visits in Denmark and Finland for senior citizens who do not yet receive out-patient care and support. The goal of those visits is to promptly recognise a need for care and to support senior citizens in planning independent lives.

The coordination of actors and services on-site is a focus in many of the national programmes. The goal of the French "MAIA" is, for example, creating integrated service provision on-site for dementia patients which are coordinated by case managers. At the European level, the European project HELPS seeks out new forms of cooperation between cities, home owners, care services as well as civil society and neighbourhood communities.

Continued...
In addition, local information and advice play an important role for the elderly and their family members. The British programme "FirstStop" provides independent information and advice for older people, their families and carers about care, housing and supportive services in later life in order to sustain independent living. Service includes a website, a national Advice Line and a face-to-face service delivered by its local partners. In Denmark, a counselling centre for shared housing communities was set up that provides advice to the elderly in relation to planning, constructing and founding shared housing communities.

Furthermore, the states are looking into the use of technical help and assistance for in-home support for senior citizens (such as fall prevention) and to relieve care personnel.

On the whole, the consequences of demographic and societal change make the development of new housing forms necessary across Europe that support the desire of elderly people to spend their lives in familiar surroundings. In this respect, it must be taken into account that senior citizens are not a homogeneous group, but rather vary with respect to their needs, interests, lifestyles and financial options. Accordingly, differentiated and flexible provision is required that, for example, also takes into account the needs of the growing group of elderly people with migrant background. In addition, challenges for the Member States are presented by the prevention of social isolation and loneliness in old age on the part of the growing number of older single persons and single-person households. Points of contact in the neighbourhood, home visit programmes, shared housing communities and intergenerational housing concepts may be starting points. An additional challenge is the accessibility of services for all senior citizens in light of declining retirement income and reductions in government-provided services. Finally, the development of adequate concepts for rural areas also represents a challenge for many Member States. In this respect, increasing ageing and relocation on the part of family members who could otherwise provide support urgently require new solutions.
| Costa-Font J and Courbage C (eds) (2011) Financing Long-Term Care in Europe, Palgrave-Macmillan | The ageing of the European population brings new financial risks that call for state, market and societal responses. In 2011, the first baby-boom generation is turning 65, and forecasts predict that the size of the old-age population in need of long-term care will double in the next 50 years in Europe. However, how different countries are responding to the challenge of financing long-term care is still a question open to further examination, including the role of market development, changing intergenerational contracts and especially the constraints of state intervention.

Growing long-term care needs in several European countries as well as the reshaping of traditional modes of care-giving further increase the pressure for sustainable funding of more comprehensive long-term care systems. This book examines different forms of partnership and the potential cooperation of state, market and societal stakeholders. It not only offers a full understanding of the institutional responses and mechanisms in place for financing old age but also provides a deep analysis of both the demand and supply factors underpinning the development of financial instruments to cover long-term care needs in Europe. |
| AGE Platform Europe in partnership with the Committee of the Regions and the European Commission (2011) How to promote active ageing in Europe. EU support to local and regional actors, AGE Platform Europe | Following an introduction summarising demographic changes that are transforming European societies and how active and healthy ageing can mitigate the effects of demographic change, the first major section of this document sets out - in thematic chapters - the types of activities that local and regional actors can implement to achieve the objectives of active ageing and solidarity between generations. Numerous projects already having received European funding are presented for each EY2012 theme, to demonstrate what is possible and inspire new examples.

In the second major section, the document presents an outline of the most relevant funding opportunities available at EU level - often via national and regional managing authorities - to support new active ageing projects. The brochure aims to make clear the practical potential of European programmes to support active ageing projects involving local and regional actors, particularly through reference to illustrative examples.

Links to further information on the projects and programmes mentioned are provided throughout the document to help readers access information beyond the limits of this text. Useful additional tools, publications and sources of information have also been included. |
The major focus of this policy brief is on intergenerational solidarity at the family and community level, following commitment 9 of the United Nations Economic Commission for Europe (UNECE) Regional Implementation Strategy for the Madrid International Plan of Action on Ageing, as quoted on the first page of this publication. This brief considers various dimensions of intergenerational solidarity ranging from family networks to care and volunteering.

The Madrid International Plan of Action on Ageing emphasizes that solidarity between generations at all levels — in families, communities and nations — is fundamental for the achievement of a society for all ages. Solidarity is also a major prerequisite for social cohesion and a foundation of formal public welfare and informal care systems.

Welfare systems rely strongly on intergenerational solidarity as younger generations support older ones. Economic crises, high unemployment rates or changes in the rules of the game or the terms of intergenerational contracts can all create tensions among generations. Those tensions can be further accentuated when older persons and pensioners are wrongly portrayed by policymakers as a burden to society.

Intergenerational relations take place in all social contexts of everyday life and can be expressed at different levels: among family members living under the same roof or living separately; within the social network of friends, acquaintances, neighbours and colleagues; and in the society as a whole. However, it is within families and communities that older people interact with members of the younger generations and that the foundations of solidarity are laid. At the family and community level, intergenerational ties can be valuable for everyone.

The relationships among family members can be in both directions, as older people often provide significant financial support, care and education of grandchildren and other kin while, later in their life-course and as the prevalence of disability rises with age, they are more likely to become recipients of care.

Policies should be targeted to the strengthening of solidarity through equity. The ageing of the population is occurring in a rapidly evolving social context where the size of families is decreasing, the role of extended families is diminishing and perceptions in respect of intergenerational support and caring for older persons are changing.

This process tends to unsettle traditional relationships between the generations. In particular, it affects the relationship between parent and child, which is, and historically has been, the most powerful and durable of bonds between human beings in all countries.

For instance, traditional lifelong co-residence as a basic means of providing mutual support of younger and older adults has been replaced by “intimacy at a distance” with frequent contacts and exchanges between generations and sustained provision of long-term care. Thus, even when living separately, parents and children maintain strong ties of affection and feelings of mutual obligation. Continued...
The trend towards separate residence of older persons is widespread. In fact, there is a global trend towards independent forms of living arrangements among older persons — mainly alone or with a spouse or partner only — and a corresponding decline in co-residential arrangements.

Although less frequent, skipped generations households, i.e., households where grandparents look after their grandchildren in the absence of their own children, are increasing over time. Policy approaches should respond to the consequences of changes in the structure of families and the role of its individual members.

Institutionalization is an option for those who have difficulty managing on their own or who need specialized medical services. Among older people, a higher proportion of women than men and of “older old” (over 75 years old) than “younger old” live in institutions.

To better respond to the preference of people in need of assistance and to face the increasing costs of institutionalization, in many countries long-term care policies have devoted more and more attention to the possibility of remaining at home, promoting “ageing in place” in the community, in opposition to the trend towards increasing institutionalization. However, it is acknowledged that, when not adequately assisted, family caregivers can be overburdened. Moreover, due to the increase in female labour-force participation, a contraction in “female caregiving potential” is possible. The interplay between family members and community members is affected by the existing legal and policy frameworks. Institutional frameworks can be oriented to support the choice and desire of family members to care for frail old parents and other family members in need and/or to support individual autonomy, thereby partially lightening intergenerational dependencies and the gender division of labour.

1. There is evidence that in most European countries (with the exception of the Scandinavian countries), informal carers still provide most of the care delivered to older people in need of LTC, including hands-on care. Their financial contribution is estimated to range from 50 to 90% of the overall costs of LTC, thus surpassing the contribution of the formal care system. Also in this regard informal carers are thus to be considered as co-providers of care.

2. The length of time for which informal care is provided and the high risks for health and social status, as well as the ageing of informal carers, means that they should also be considered as service users with their own needs for support as clients of formal care providers. This is reflected in the obligations of the Swedish municipal policy to provide support measures to informal carers.

3. There is also evidence that, in the near future, informal carers will not be as available as they are today. This prediction, linked to the fact that LTC financial sustainability is threatened by the growing needs of an ageing population, has led in most countries (again with the exception of Scandinavian countries) to the introduction of direct or indirect cash benefits as an important tool of LTC policies with various rationales: as care allowances, i.e. financial benefits paid directly to the informal carer, in recognition of their contribution to care and in order to secure their availability as care providers; as an attempt to reduce the higher costs of formal services that are subsidised by public authorities; as attendance allowances, i.e. financial benefits paid to the person in need of care to allow for more choice and autonomy in finding flexible care arrangements; in some countries these resources are used to pay for personal assistants. Also on the grey or black market. who are most often emigrant care workers.

4. The increasing use of both cash benefits and migrant care workers has created a mixed care workforce (informal family carers, migrant workers, personal assistants, formal professional care staff) operating with varying intensity in the planning, organisation and delivery of LTC service provision. The boundaries between informal and formal care are thus increasingly blurred.

5. The low status and low level of professional recognition of care workers in the field of LTC, although rarely explicitly acknowledged, is linked to a corresponding difficulty in the recognition of informal carers as a new type of worker. This in turn has strong implications for the way governments are acting to guarantee for a qualified LTC workforce, as it is not only informal carers’ contributions to caregiving that are likely to be reduced in the future, but recruitment and retention of the formal workforce is already currently problematic, with gloomy future perspectives.

6. Gaps also exist in the way professional and informal carers work together and share responsibility for supervising and implementing the care process, which may result in conflicts between them. The dynamics of the ‘triangle of care’ consisting of the formal carer, the informal carer and the older person in need of care constitutes the central unit of analysis at the service delivery (micro) level, leading to the necessity for professional care providers to understand and assume responsibility for managing the care process.

Continued...
7. There is also strong evidence at the service delivery (micro) level that there may be conflicts between the older person’s and the informal carer’s needs and expectations, i.e. the older person’s choices may not always be in line with the needs or expectations of their informal carers and vice versa. This raises the issue of whose needs are being addressed when formulating an informal care policy and how to optimally link measures targeting informal carers with an overall LTC policy.

8. Training of both informal and formal care providers is a key issue in improving the status of care work and its recognition through better pay and working conditions. In addition to their professional training, formal care staff need training in how to assess the needs of and provide support to informal carers. At the same time, also informal carers need training in caring techniques and how to look after their own physical and mental health.

9. There is clear evidence that intensive caring correlates negatively with being active in the labour market, raising the dilemma of finding an appropriate balance between caring and working, while taking into account both informal carers’ and older people’s needs and choices. The SHARE survey provides substantial indications that providing an adequate level of formal services can promote both caring and working.

10. Finally, there is strong evidence that the division of responsibilities for the care of older persons between the family and the state is a crucial element in the formation of both general LTC policies and specific policies for informal carers. The extent to which responsibilities are shared and linked to practice, the different combinations of types of provision (in cash and in kind), the mix of specific and non-specific measures, as well as the critical issue of conditions for access to all measures and services are essential elements in assessing informal care policies.

This report aimed to explore the state of the art and the current development of prevention and rehabilitation (P&R) within long-term care (LTC). It has been confirmed that the topic is in an initial state of development, at research, policy and practice levels, and much development is required. However, the national reports also showed a great range of diverse health and social care systems embedded in different cultural and political contexts and developments trying to build a wide range of conditions for P&R implementation. A number of topics at policy and practice level emerged as important for most, if not all, of the participating countries as in general, P&R within LTC require complementary perspectives.
Apart from explicit preventive or rehabilitative interventions, topics of professional quality and care integration are seen as having substantial preventive and rehabilitative effects. Conversely, poor quality, gaps and overlaps in care pathways render poor health outcomes. Furthermore, we need to include the general societal environment and its importance for P&R for older people with LTC needs. Elements such as social support or disability-friendly space can act either to promote or impede preventive or rehabilitative processes.

One of our main conclusions is that governments’ efforts to promote the integration of P&R in LTC need to handle steering instruments carefully.

Market instruments can counteract collaborative processes needed to shape comprehensive care pathways. Therefore competitive instruments need to be oriented towards enabling or at least not undermining the cooperation needed for integrated care pathways.

The form of local governance also impacts significantly on opportunities for integrated LTC pathways and shapes the opportunity for users to participate in these matters.

Key points raised around embedding P&R within LTC at a national, systemic level are that the need for investment in P&R is becoming more widely acknowledged amongst EU countries and that steps towards embedding P&R within LTC can be recognised in all countries in initiatives such as: national awareness raising events and multidisciplinary preventive and rehabilitative services in community settings.

However, initiatives in P&R mostly tend to be small-scale, time-limited pilot projects.

All national reports described that there was some distance to travel in terms of national policy, culture, financial incentives and organisation of services before LTC systems would take on a truly preventive and rehabilitative nature.

There is also often a lack of research and evidence of benefits needed to roll out interventions on a national level.
Alzheimer Europe is uniquely placed to carry out country comparisons in relation to particular issues which surround dementia. These comparisons highlight the sometimes stark differences between the European countries' approaches as well establishing commonalities. We have carried out four such comparisons on:  
a) Homecare: In 2005 our homecare project revealed tremendous differences between countries, (particularly in terms of State responsibility, funding, the role of families and the actual availability of home care services) whilst finding common ground other areas (eg. a lack of any specific reference to people with dementia in laws and documents pertaining to the provision of homecare services).  
b) Advance directives: A comparative project on the legal status of advance directives in Europe carried out in 2006 also revealed differences between participating countries, with a few countries (Greece, Portugal and Turkey) being omitted as the concept of advance directives was found to be practically unknown. The project resulted in the publication of Alzheimer Europe’s position on advance directives which provides information on the legal, ethical, medical and personal and practical issues surrounding the use of advance directives in the case of dementia.  
c) The Reimbursement of anti-dementia drugs: In 2006 Alzheimer Europe conducted a survey on the reimbursement of anti-dementia drugs. This survey revealed that people with Alzheimer's disease do not have equal access to existing dementia treatments in Europe as access is subject to a great many restrictions with huge variations in access between European countries being found.  
d) Social support: As part of the European Collaboration on Dementia (EuroCoDe) project, Alzheimer Europe carried out a survey into the level of social support provided to people with dementia and their carers in the member states of the European Union, as well as in Switzerland, Norway and Iceland. This revealed variations as well as a lack of services for people with dementia. Recommendations were drawn from this survey and published in the 2008 Alzheimer Europe Yearbook. |
European demographic trends are well documented. It is estimated that the number of people aged 65-plus will increase by 77 per cent by 2050; the old age dependency ratio is expected to double during the same period. Population ageing leads to an increasing share of old and very old people in the population, with increases in degenerative and chronic diseases leading to new patterns of morbidity. Although advanced age and chronic disease do not necessarily or automatically lead to a need for care, demographic ageing nevertheless serves as a useful proxy indicator of demand for long-term care. Moreover, carers themselves are expected to become older; to become more diverse; and to belong to smaller family networks because of declining fertility, increased divorce rates, greater geographical and time distance between family members, and broader socio-economic trends towards individualisation. Additional demands on family members are likely to arise from the development of new medical technologies that enable even people with the most complex health conditions to be cared for at home.

Informal and family care has recently developed a high profile within EU policy forums. In the context of anticipated trends of demographic ageing, family care is critically important in ensuring the sustainability of long-term care systems and limiting increases in public expenditure in member states. At the same time, however, family care responsibilities may impact on the future economic competitiveness of the EU by restricting the opportunities of a substantial minority of the working age population to engage in paid work and earn a taxable income.

Patterns of informal care, societal attitudes towards informal and family care, and the roles of the state in supporting families in their responsibilities for family care-giving, vary widely across the EU.

There are clear indications of regional differences in attitudes towards carers and/or in (public) long-term care regimes; depending on the dominant regime, more or less responsibility is placed on the shoulders of carers and potential carers. In countries where families are assumed to be primarily responsible for the care of older and disabled people, fewer resources are available for formal services, thus placing greater burdens on informal carers and often taking their input for granted, despite the opportunity and other costs incurred. These costs are reflected in a lower quality of life among carers in the Mediterranean countries compared with carers in countries like the UK and Sweden. Alber and Köhler\(^1\) identify an East-West divide, with Eastern EU countries placing greater pressures on carers; more care provided within the same household, especially by people over 60; and with a higher incidence of carers who also have responsibility for dependent children. According to Eurofamcare, inter-country differences in patterns of care for older people also reflect different employment patterns, particularly among women; and differences in the prevalence of extended, multi-generational family households. Furthermore, Kröger\(^2\) found that in Southern European countries time to care for one’s children appeared to be sacrificed to care for an elderly relative, whereas in Northern European countries childcare responsibilities reduced the care given to older relatives.

**Continued...**
The SHARE study also suggests that family care co-varies with socio-economic status; lower socio-economic status tends to be associated with the provision and receipt of informal or family care (although the evidence is not extensive). However, causal relationships between socio-economic status, poor health leading to needs for care and the prevalence of care-giving are complex. Are lower socio-economic groups or individuals more likely to provide more informal care because the opportunity costs of reduced labour market participation are less pronounced; or does extensive informal care-giving lead to reduced social mobility; or do both reflect the impact of a third, underlying variable such as the poor health status of both carers and people needing care?

It is also reasonable to assume that the prevalence and nature of informal care will differ between rural and urban areas within any member state, because of the difficulty of providing extensive formal services in sparsely populated rural areas and their poverty compared to urban areas.

Carers of older people

The most extensive data on carers focuses on carers of older people or carers supporting elderly parents. The Eurofamcare study found that:

- Seventy-six per cent of main carers of older people were women.
- Carers’ mean age was 55.
- Nearly 50 per cent of carers were children of the older person.
- The median number of hours of caring was 24 hours a week, the mean was 45.6 hours a week.
- The average caring episode lasted for five years.
- Forty-one per cent of carers were also in paid work.
- About one in four carers lived further away from the older person they were supporting than ten minutes by car or public transport.
- Caring involved meeting health needs (sometimes including nursing and medical care); providing emotional and psychological support; helping with mobility and transport; helping with domestic tasks; providing emotional, psychological and social support; managing finances; dealing with welfare agencies; and organising formal care services.
- Caring, although rewarding for many, often had adverse physical and psychological consequences, as well as additional financial costs and/or loss of income. Depression and exhaustion were common, especially among those caring for more hours per week, over a long period and/or without (social) support.
- A key motive for caring was love, reciprocity and/or ‘wanting to do something in return’.
- For half of carers, a perceived absence of alternative options was a key reason for providing care.

Continued...
The Eurostat study (2007) on health care and long-term care provides – so far unique – EU(30)-wide data on those who cared for their parent(s) during the last year.

- Carers performed – on average – three caring activities (not counting visits).
- Almost every carer provided personal care (IADL) such as help with getting dressed, feeding, washing or bathing or going to the toilet.
- Half of the carers also helped with finances, administration and liaising with professional services.

Reflecting the prevalence of older people as the recipients of care and the roles of adult children in providing that care, there is a concentration of carers in the 50-64 age group. This is confirmed by a wide range of data sources. Although the EU is currently primarily interested in the relationship between care obligations and labour market activities, the prevalence of older carers will become increasingly important in future, as more spouses or partners of elderly people become carers. There is currently very little evidence on the circumstances of carers who are themselves elderly.

As the European population ages, the age of carers will increase as well. Moreover, as carers grow older, the intensity of care-giving increases, with economically inactive people aged 70-plus spending on average 25 hours a week caring. Older spouse carers are likely to have very substantial care burdens; they are more likely to be co-resident carers; to have health problems of their own; and also more likely to be caring for a partner with a deteriorating and stressful cognitive condition such as dementia. Evidence is needed of measures that are effective in supporting older carers. Without these, older carers may be at greater risk of breakdown, with consequent implications for younger generation family members and/or increased risks of admission to expensive institutional care.

Moreover, the European Employment Strategy is encouraging the extension of working life. Research into the growing care responsibilities of older people, as well as those of current working age, will therefore be needed to inform policy measures aimed at helping people stay in work for longer.

Assessing different options for the funding of long-term care – that is, nonmedical assistance provided to people with physical or mental health needs to help cope with the everyday activities of life – raises three key issues. First, it requires an assessment of the future need for long-term care services across the population, and of its broader socioeconomic repercussions. Second is the rationale for using public funds for funding long-term care, and how this varies depending on the specific country context. Finally, it begs the question of the way in which funding arrangements can be implemented in order to maximize fairness and efficiency in the system.

The case for public sector intervention for long-term care funding is strong. The lifetime costs of long-term care services can be substantial and may deplete the assets of all but the richest service users. State supported collective funding solutions can make sure that enough protection is provided to those in greatest need, and/or with the least ability to pay, and help avoid catastrophic costs. The private sector has failed to provide a sustainable insurance system that can cover a large proportion of the population; although in some countries it does provide a complement to state support. Neither is a continued reliance on family support possible for all. Differing national contexts, such as the relative importance placed on the formal long-term care sector, societal values, reliance on family care and resource constraints, will all play a role in determining which funding mechanism is adopted. More universal systems, for instance, have been located typically among Nordic and, more recently, other northern European countries. In southern and eastern European countries, public social care systems have been based around the concept of a safety net, whereby public support is selectively targeted to those in greatest need and with lowest financial means. Differences in social values will affect, for instance, the distribution of support between users with and without informal carers, and whether the state concentrates on providing a safety net for those unable to afford care charges, or whether it offers equal support to all.

Provision of a minimum safety net

One policy option is the provision of a system that minimizes state intervention, and concentrates support on one population subgroup: those individuals lacking the financial ability to pay for the cost of services. In “safety-net” systems public resources available for long-term care are cash-constrained and do not necessarily change with needs. Thus they can be very effective in controlling state expenditure. They are usually funded through a combination of general (central and/or local) tax revenue and user charges levied at the point of need, calculated on the basis of means-tested rules.

Continued...

Universal funding systems

An alternative option is a system that provides cover for the entire population. This implies significantly greater levels of state expenditure than in a safety-net system. It should promote greater equality and social cohesion, ensuring that all people meeting need criteria can access services regardless of their financial status. Almost all universal systems are progressive, raising much revenue from a combination of earmarked contributions and payroll taxes. Co-payments may still be levied for some services.

Tax-funded systems can also employ expenditure constraints and define eligibility criteria to make the best use of existing resources. Universal social insurance long-term care systems typically assess eligibility on the basis of clear, algorithm-driven, written rules linking levels of disability to entitlement to certain levels of state support. This offers a more transparent allocation process and provides greater assurances about the service users’ “rights” to support. As a result, social insurance expenditure is needs driven, rather than budget constrained.

Progressive universalism funding mechanisms

A third approach combines universal entitlement to state help with a means-tested element, which ensures that those in greatest financial need receive the greatest amount of state support. These systems, grouped under the banner of progressive universalism, aim to minimize state financial commitments while retaining an element of universality. This is intended to promote social cohesion and provide some insurance benefits to all, while limiting (relative to universal schemes) state expenditure.

The universal nature of support can increase public support for the system among those who would not qualify for entitlement to some benefits under the minimum safety benefit system. This support increases as the income of the potential care recipient decreases. As in the case of universal schemes, this can also have the effect of raising the profile of long-term care services, and can reduce the stigma attached to the receipt of care in means-tested systems.
This brief excursion into some of the longitudinal aspects of social support in the SHARE survey has explored how different domains in the lives of older Europeans affect their capacity to give or receive social support. The findings confirm the general trends that intergenerational family transfers and support depend on resources of the givers, needs of the receivers and closeness of the relationship. The transition to retirement appears to have an impact on the amount of social support that is given to other family members, such as elderly parents or young grandchildren. The onset of illness for many older Europeans is accompanied by an increase in support from their family members, in conjunction with professional services. In countries where rates of intergenerational cohabitation and proximity are high, the support given to less independent older parents is high. With population ageing at the forefront of many policy European policy initiatives, these results provide a clear message.

- Older Europeans who are currently entering retirement play a crucial role in the domestic economy of caring and support, not only for their own family members but also for other members of their social network and indeed even in a voluntary or semi-professional capacity.
- The increased demand for carers can in part be met by recently retired persons who for the most part remain active and in good health.
- At more advanced ages however, the heavy tasks of caring that are undertaken by spouses will require a complement of more flexible quality professional services. If these services are not developed in line with increasing demand, older carers themselves risk health problems that could lead to the loss of their autonomy, thereby adding to the already increasing demand for care services.

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<th>Authors</th>
<th>Title</th>
<th>Description</th>
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<tr>
<td>Attias-Donfut C, Ogg J and Wolff F-C (2008)</td>
<td>Evolution of Social Support: In Börsch-Supan et al, First Results from the Survey of Health, Ageing and Retirement in Europe (2004-2007): Starting the Longitudinal Dimension, Mannheim Research Institute for the Economics of Ageing (MEA)</td>
<td>This brief excursion into some of the longitudinal aspects of social support in the SHARE survey has explored how different domains in the lives of older Europeans affect their capacity to give or receive social support. The findings confirm the general trends that intergenerational family transfers and support depend on resources of the givers, needs of the receivers and closeness of the relationship. The transition to retirement appears to have an impact on the amount of social support that is given to other family members, such as elderly parents or young grandchildren. The onset of illness for many older Europeans is accompanied by an increase in support from their family members, in conjunction with professional services. In countries where rates of intergenerational cohabitation and proximity are high, the support given to less independent older parents is high. With population ageing at the forefront of many policy European policy initiatives, these results provide a clear message. • Older Europeans who are currently entering retirement play a crucial role in the domestic economy of caring and support, not only for their own family members but also for other members of their social network and indeed even in a voluntary or semi-professional capacity. • The increased demand for carers can in part be met by recently retired persons who for the most part remain active and in good health. • At more advanced ages however, the heavy tasks of caring that are undertaken by spouses will require a complement of more flexible quality professional services. If these services are not developed in line with increasing demand, older carers themselves risk health problems that could lead to the loss of their autonomy, thereby adding to the already increasing demand for care services.</td>
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<td>Bolin K, Lindgren B and Lundborg P (2008)</td>
<td>Informal and formal care among single-living elderly in Europe, Health Economics 17 (3) : 393-409</td>
<td>The aims of this study were to analyse (1) whether informal care, provided by children or grandchildren to their elderly parents, and formal care are substitutes or complements, and (2) whether this relationship differs across Europe. The analyses were based on cross-sectional data from the newly developed SHARE (Survey of Health, Ageing, and Retirement in Europe) database. We found (1) that informal and formal home care are substitutes, while informal care is a complement to doctor and hospital visits, and (2) that these relationships in some cases differ according to a European north–south gradient. Instrumental variable methods were used and the results highlight the importance of accounting for the endogeneity of informal care.</td>
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Molinuevo D (2008) Services for older people in Europe: Facts and figures about long term care services in Europe, European Social Network

This report was compiled as a working paper for the European Social Network policy and practice group on long term care for older people. It focuses on the situation in the countries represented in the working group: Belgium, Germany, Iceland, Poland, Romania, Sweden and the United Kingdom. European comparative maps show that while the UK is on the second tier, after Scandinavia, for expenditure on older people's care as a percentage of GDP its population has the highest risk, along with Spain and Latvia, of pensioner poverty.

Figure 8: At-risk-of poverty rate (%) for persons aged 65 years and over in 2006\textsuperscript{5}.

\begin{figure}
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\includegraphics[width=\textwidth]{at-risk-of-poverty-map.png}
\caption{At-risk-of poverty rate (%) for persons aged 65 years and over in 2006.}
\end{figure}

\textsuperscript{5} Percentage of elderly people with an equivalised disposable income (before social transfers) below the risk-of-poverty threshold. The risk-of-poverty threshold is set at 60 % of the national median equivalised disposable income after social transfers. Equivalised disposable income is defined by the European Statistical Office as the household's total disposable income divided by its equivalent size. Social transfers include social assistance and benefits related to unemployment, family, education and housing. Retirement and survivor's pensions are counted as income before transfers and not as social transfers.
This chapter looks at changing family structures, the evolution of social support, changes in financial transfers, social productivity and quality of life, and informal care and labour force participation.

Changing family structures

- For present elderly Europeans the family has remained a strong provider of institutional and everyday integration. The historical decline of marriage has not yet reached them directly.
- The marriage bond weakens however with increasing age, and dramatically so for women.
- On the other hand, the multi-generational structure of the family remains strong. Even though co-residence of the elderly with their adult children has decreased, geographical proximity – and thus the potential for everyday support – is high, and increases in the wake of critical life events. There are moreover high rates of frequent contact between parents and children.
- While this is true for Western Europe as a whole, there are important differences among the ‘strong family countries’ in the South and the ‘weak family countries’ in the North. Of the two Eastern European countries, Poland belongs to the ‘strong family’ regime, while the Czech Republic tends towards the ‘weak family’ regime. The North-South gradient is especially noticeable with respect to rates of co-residence and frequency of contact among adult family generations.

The evolution of social support

- Older Europeans who are currently entering retirement play a crucial role in the domestic economy of caring and support, not only for their own family members but also for other members of their social network and indeed even in a voluntary or semi-professional capacity.
- The increased demand for carers can in part be met by recently retired persons who for the most part remain active and in good health.
- At more advanced ages however, the heavy tasks of caring that are undertaken by spouses will require a complement of more flexible quality professional services. If these services are not developed in line with increasing demand, older carers themselves risk health problems that could lead to the loss of their autonomy, thereby adding to the already increasing demand for care services.

The determinants of adult children choice to provide care to their parents.

- Children choose simultaneously how much time to spend working and caring. Such a result has important policy implications: as an example, a public intervention in favour of female labour market participation is likely to reduce the amount of care provided to elderly people, thus from a global perspective it may not be welfare enhancing.
- Other siblings’ help reduce each child propensity to provide care. With respect to care provision the altruistic motive dominates the strategic bequest one. From a policy point of view, such a result has two implications. First, any targeted intervention on wages or informal care provision of a particular group of citizens is likely to have an impact on the whole population via this substitution effect. Second, changing the laws ruling bequests – in particular sharing of it among direct inheritors – has little effect on care provision.
Demographic, epidemiological, social, and cultural trends in European countries are changing the traditional patterns of care. The next decades will see increasing rates of care-dependent older people and noncommunicable diseases as the leading cause of chronic illness and disability. The break-up of the traditional large family group and urbanization will also lead to gaps in the care of older or disabled family members. These changes in needs and social structure require a different approach to health and social sector policy and services since a disease-oriented approach, alone, is no longer appropriate. An answer to these issues could be home care, a sustainable approach to prevent the need for unnecessary acute or long-term institutionalization and maintain individuals in their home and community as long as possible. Technological innovation together with new and modern forms of service delivery organization can represent a viable solution to developing home care in Europe provided that health care systems can further enhance integration and coordination. This publication is part of the work of the WHO Regional Office for Europe to present evidence for health policy- and decision-makers in a clear and understandable form. It explains why health and social services should provide high-quality and targeted home care for disabled and older people. It provides evidence for the effectiveness of home care, shows how it can be improved and explains the need to ensure equitable access. The publication also explores the varied cultural and care contexts in different countries and reveals how to educate professionals and the public about these issues. This booklet seeks to broaden awareness, stimulate debate and promote action.

As the numbers of older people rise in Europe, the importance of long-term care services in terms of numbers of users and expenditures can be expected to grow. This article examines the implications for expenditure in four countries of a national entitlement to long-term care services for all older people, based on assessed dependency. It is based on a European Commission-funded cross-national study, which makes projections to 2050 of long-term care expenditure in Germany, Italy, Spain and the UK. The policy option investigated is based on the German long-term care insurance scheme, which embodies the principle of an entitlement on uniform national criteria to long-term care benefits. The research models this key principle of the German system in the other three participating countries, with respect to home care services. The study finds that, if all moderately/severely dependent older people receive an entitlement to formal (in-kind) home care, the impact on expenditure could be considerable, but would vary greatly between countries. The impact on long-term care expenditure is found to be the least in Germany, where there is already an entitlement to benefits; and the greatest in Spain, where reliance on informal care is widespread. This article discusses the policy implications of these results.
Many European and national reports have been written about the issue of care for older dependent people. This report is designed to focus on family carers of older people and their situation while later we consider how services do and do not help those who, in virtually every country studied in this report, provide a vast amount of care and support – those termed family and informal carers.

In all EU countries, the responsibility for the provision of and payment for long term care is divided between the four sectors of what has been termed the “welfare diamond”, namely:

- Family and informal care sector
- State or public sector
- Voluntary and non-governmental-organisation (NGO) sector
- Care market or private sector

The balance of care provision in each country depends on a mixture of factors such as tradition, legal responsibilities, health and social policy, national budgets and national wealth and, last but not least, demographic trends regarding fertility levels and life expectancy, which affect the availability of informal family carers.

There are substantive differences between countries in Europe as to how care is provided. Those with poorly funded welfare states and a continuing association between poverty and old age, such as Greece and Spain, are associated with low service provision limited to those who can pay or who lack alternative sources of care, whereas in those countries with very high taxation, such as Denmark, demand for services as a taxpayer’s right is high. However since demand is potentially infinite, even countries which provide services as a citizen’s right inevitably have to introduce a system of rationing, usually based on needs assessment (objective assessment of need for a service) and means testing (income and assets assessment of the older people and / or family carers) to ascertain the older person’s ability to make a financial contribution to payment for care. The former Communist regimes with their previous welfare infrastructures are gradually being reconstructed with a plurality of partners from state, local authority, NGO and private sectors.

Despite wide variations in systems of formal care provision for dependent older people, in all the 23 EUROFAMCARE countries the vast majority of care is provided by individual family members within the informal care sector. In countries such as Sweden, where the state has traditionally been a main provider of care, the need to contain increasing costs, in combination with the stated preferences of older people themselves to remain in their home environment for as long as possible, has led to what has been described as a “rediscovery of family care”. This involves various measures to promote and support the increased participation of the informal care sector via the public and voluntary / NGO sectors.

This Review provides a summary of services available and the legal support for family care of older people in each of the 23 European countries studied.
### Study Findings

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<td><strong>Austria</strong></td>
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<td><strong>England</strong></td>
<td><strong>See Europe – Overviews section above</strong></td>
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<td>Ismail S, Thorlby R and Holder H (2014) <em>Focus On: Social care for older people. Reductions in adult social services for older people in England</em>, Health Foundation; Nuffield Trust</td>
<td>This report describes the scale and nature of reductions in publicly funded social care for older adults in England that have occurred in part as a result of the Coalition Government’s efforts to reduce public sector spending following the financial crisis of 2008. In 2010, the government published spending plans that reduced central government grants to local authorities (who are responsible for funding social care) by 26 per cent in real terms between 2011/12 and 2014/15. Local government spending overall, which includes income from Council Tax and other charges, was projected to fall by 14 per cent in real terms. In June 2013, the government followed this with a further 10 per cent reduction in grants for 2015/16. The majority of local authorities have responded by cutting spending on most categories of local government-funded activities, including social care for older adults. In 2009/10, local authorities in England spent £10.6 billion (in 2009/10 prices) in gross terms on social care for older adults, compared with £9.8 billion in 2012/13, a reduction of 7 per cent. Real-terms net current spending (that is, excluding income) fell by 15 per cent, from £7.8 billion in 2009/10 to £6.6 billion in 2012/13. ** These cuts to social care budgets for older adults have been implemented in a number of ways, including tightening eligibility for publicly funded support to concentrate resources on those with the greatest needs, increasing the fees payable by users, reducing the fees to providers of care, and generating savings from service redesign and reduced administrative costs. Continued...</td>
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56
Spending on residential care for older adults was reduced by £331 million between 2009/10 and 2012/13, equating to a 13 per cent reduction. Real-terms net expenditure on nursing homes for older adults was reduced by £160 million over the same period (a 15 per cent reduction).

Services in the community for older adults have seen the biggest reductions, with £539 million taken out of home and day care alone – a 23 per cent reduction in expenditure. Other community-based services have also contracted, with spending on meals reduced by 46 per cent between 2009/10 and 2012/13. Some of this reduction may have been offset by a 36 per cent rise in spending on direct payments; however, this rise consists of a relatively modest £90 million of additional expenditure in cash terms.

Cuts in spending have been accompanied by reductions in the number of older people receiving publicly funded services, particularly in the community, which fell by 26 per cent in 2012/13 compared with 2009/10 (245,855 fewer older adults received services in 2012/13 compared with 2009/10). Some of the most significant falls were in meals (59 per cent reduction or 54,795 fewer individuals) and day care (35 per cent reduction or 36,480 individuals). Only the number of older people receiving direct payments appeared to increase and even then only by 10,250 (an increase of 20 per cent in the two years between 2010/11 and 2012/13).

These reductions in spending and volume of social care services for older adults have occurred against a backdrop of growing demand for social care among the over-65s, as the population ages. According to the last national Census (2011), 29 per cent of respondents aged over 65 reported that they were limited ‘a little’ from a disability or illness expected to last more than 12 months, while a further 28 per cent reported that they were limited ‘a lot’. There was also a 2 per cent rise between 2001 and 2011 in the number of respondents reporting that they cared for people for more than 20 hours a week.

The combined effect of cuts in net spending and in the number of people supported is that a growing number of older people are having to use their own resources to support themselves or go without care. Research suggests that the level of unmet need varies widely across different types of help needed, but overall a third of women and a fifth of men over the age of 65 report having unmet needs for some activities of daily living (ADLs).
Older people with high support needs want a wider choice of care and support. They also want to be of value and to make a contribution. Many models of care and support are based on mutually valued relationships and older people’s contributions, but most operate beneath the radar of public sector commissioners.

There is increasing interest in initiatives that draw on the assets of individuals and communities and that aim to strengthen community capacity. Such developments can be extremely cost effective and lead to good outcomes for people. Martin Knapp, of the London School of Economics, assessed the cost effectiveness of a number of models and found the following:

- **Time banking**: Cost per member per year = £450; savings per member per year = more than £1,300 (conservative estimate)
- **Befriending**: Cost per person per year = £80; savings per person per year = £300
- **Community navigator scheme**: Cost = £480; savings = at least £900 per person in the first year alone.

Similarly, an evaluation of Shared Lives found that, compared with traditional residential placements, savings range from £46 to £995 per week, depending on the service user.

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<td>Carrier J, National Development Team for Inclusion (NDTI) (2013) <em>Commissioning care and support for older people with high support needs</em>, Joseph Rowntree Foundation</td>
<td>Older people with high support needs want a wider choice of care and support. They also want to be of value and to make a contribution. Many models of care and support are based on mutually valued relationships and older people’s contributions, but most operate beneath the radar of public sector commissioners.</td>
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<td>Bamford S-M and Berry C (2012) <em>Long term care for older people, social productivity and the ‘big society’: the case of dementia</em>, London: 2020 Public Services Hub at the RSA</td>
<td>In this paper, Sally-Marie Bamford and Craig Berry argue that social productivity could provide a helpful framework for considering how to construct sustainable social care services. They remind us that these are services that have never fallen squarely within our Beveridge-derived welfare model. Many of the social assumptions that positioned them outside of the fold after the war – such as female domesticity – no longer hold, but in other ways the range of needs described under the heading of ‘social care’ remain too diverse, too social, too intimate to sit neatly within a welfare model that is entirely publicly provided and publicly funded, even if financial resources were more plentiful. A Big Society analysis is strong in recognising the innately social aspect of social care, but weak when it comes to considering the implications for public policy.</td>
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<td>Sigurðardóttir S H (2013) Patterns of care and support in old age, School of Health Sciences, Jönköping University</td>
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<td><strong>Iceland</strong></td>
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<td>This study describes the situation for community living older people, 65 years of age and older in Iceland, analyzing their needs for care and services and how these needs are met. The study analyzes the relationship between the main providers of help and care, the formal caregivers and the informal carers. The study further depicts what kinds of care and support older informal caregivers provide and receive themselves and analyze what factors are related to providing care alone or in combination with other caregivers, informal and formal. The study also analyzes the relationship and mutual support between grandparents and grandchildren and whether there are gender differences in intergenerational relations and support.</td>
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<td>As little research has been conducted on informal care in Iceland, it is important to show the importance of the informal carers in the care paradigm.</td>
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<td>The study indicates that older people in Iceland are receiving help and care from both informal and formal carers but informal help provided by family members seems to play a major role in supporting older people in their home. The great majority of the respondents with Instrumental Activities of Daily Living (IADL) limitations and Personal Activities of Daily Living (PADL) limitations received either informal or formal help but not both. The care and help provided is more often help with domestic tasks than with personal care. However, when the need increases the formal system steps in. It is not clear whether the informal care is a substitute for the formal one.</td>
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<td>As the formal help provided is rather sparse, it is suggested that when the need for personal care increases, the older person moves into a nursing home instead of increasing the formal care in the home. Women more often than men are the sole carers, and daughters are more important carers for older people than sons are.</td>
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<td>Older informal caregivers were alone in their caregiving in almost half of the cases and women more often than men.</td>
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<td>One third provided help with several tasks, such as help with errands and surveillance or keeping company in addition to ADL help. Older caregivers provide care even when they need help themselves.</td>
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<td>The results indicate that grandparents and grandchildren exchange more emotional than practical support. The emotional support provided and received by the generations is of great value. Gender influences the contact frequency between the generations, as women more often cultivate ties between grandparents and grandchildren.</td>
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| National Economic and Social Forum (2005) Care For Older People: NESF Report No. 32, Dublin, Ireland: NESF | A wide-reaching overview of the care of older people in Ireland - including a comparative review of the care of older people in the UK, Australia, Canada, Denmark, Finland, France, the Netherlands, Sweden and New Zealand. Summary of Key Recommendations

* Bring public spending on care services for older people up to at least the OECD average of 1 per cent of GDP over the next five years, at an additional cost of €500 million
* Develop a National Action Plan on Ageing
* Root out ageism and promote positive ageing
* Clarify entitlement to core community care services and introduce unified and holistic assessment of need
* Increase financial support for homecare
* Strengthen co-ordination, implement care and case management
* Develop standards of care across the system and emphasise quality of life outcomes
* Positive ageing training should be delivered to all relevant staff (policy-makers, managers and care staff)
* Maintain and develop housing stock
* Develop a National Strategy on Caring |
The Netherlands, like the UK, has an ageing population; those aged 60+ are projected to increase from 23 to 30 per cent of the population, and the Age Support Ratio to decrease to below 4, by 2050. Despite having the same Life Expectancy as in UK, Healthy Life Expectancy in the Netherlands is over 4 years longer. If this is not a measurement artefact, it has important implications for long term care and suggests further research is needed to discover the reason for the difference. One possible factor is the lower poverty rate in the Netherlands among those aged 65+, which is about one fifth of the UK rate but there may be other factors such as the pro-cycling culture and a traditional culture that is more egalitarian and socially-cohesive.

Furthermore:

1. Dutch older people are less likely than British to live with their children and informal care is low, formal home care high, relative to international levels.

2. Spending on long term care falls less heavily on individuals in the Netherlands than the UK (7 compared with 36 percent of the total) due to a contributory social insurance scheme that covers home-based personal care and long term institutional care for all those with chronic conditions. Thus the risk of very heavy costs falling on vulnerable individuals is avoided by sharing the cost across the whole population.

- However, there has been a shift in recent years from collectively organised and funded long term care in the Netherlands, and also from residential to home-based care by family and private providers. Eligibility for care funded by social insurance has been tightened and copayments based on income (but capped) have been introduced. Financial compensation to informal carers for their care work is now excluded as is most publicly funded help with housework. The latter may be supported by the Local Authority, depending on the user’s income and circumstances. Personal Budgets have been ended for new users since 2010. These changes have been implemented mainly to save costs to the state-sponsored social insurance fund; but they might put more pressure on informal carers.

Continued...
### Tinker A, Ginn J and Ribe E (2013) Assisted Living Platform - The Long Term Care Revolution: A study of innovatory models to support older people with disabilities in the Netherlands, King’s College London

...continued

- Technical innovations are evident in telehealth, telecare, and schemes to combat isolation through extending internet use, including the facility for video-conferencing with family members and wider community. However, these are not yet widespread and it is doubtful to what extent they can replace, especially for confused older people, the reassurance and comfort of helpful human care.

- For older people with only light or moderate disability, age-proof housing, senior cohousing and local initiatives for neighbourhood-based care using volunteers demonstrate the viability of such innovations and their potential to delay entry to a residential institution. Co-housing tenancies for older people from several ethnic minorities has enabled them to live near to others from their own culture.

- For those with more intensive care needs, innovations in accommodation-with-care, mostly set up by non-profit organisations, emphasise re-creating home-like small households within larger complexes. These aim to promote maximum autonomy within a ‘normal’, safe and familiar environment; they include provision for dementing residents.

- Civil society organisations have pressed for a person-centred approach to care, one which gives voice and choice to disabled people while promoting re-ablement and preventing deterioration in health. Social relationships, allowing for frequent face-to-face interaction, are recognized as vital to older people’s health and well-being. Experts say more development on these lines is needed, especially reaching out to isolated individuals, and

- Opportunities exist for businesses to expand in the area of long term care. For example, as care providers in partnership with housing associations and also to invest in internet-based systems designed to promote social interception and combat loneliness.

### Scotland

Pleace N (2011) The Costs and Benefits of Preventative Support Services for Older People, Centre for Housing Policy, University of York

This paper is a brief overview commissioned by Scottish Government Communities Analytical Services. This paper reviews the evidence on the cost effectiveness of preventative support services that assist older people with care and support needs to remain in their own homes. The costs of these preventative support services are contrasted with the costs of specialist housing options, such as sheltered and extra care housing and also with the costs of health services, as part of reviewing the value for money of preventative support services (PSS).
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One aspect of universalism in Swedish eldercare services is that publicly financed and publicly provided services have been both affordable for the poor and attractive enough to be preferred by the middle class. This article identifies two trends in home care for older people in Sweden: a decline in the coverage of publicly funded services and their increasing marketisation. We explore the mechanisms behind these trends by reviewing policy documents and official reports, and discuss the distributional consequences of the changes by analysing two data sets from Statistics Sweden: the Swedish Level of Living surveys from 1988/1989 and 2004/2005 and a database on all users of tax deductions on household and care services in 2009. The analysis shows that the decline of tax-funded home care is not the result of changing eldercare legislation and was not intended by national policy-makers. Rather the decline was caused by a complex interplay of decision-making at central and local levels, resulting in stricter municipal targeting. The trend towards marketisation has been more clearly intended by national policy-makers. Legislative changes have opened up tax-funded services to private provision, and a customer-choice (voucher) model and a tax deduction for household- and care services have been introduced. As a result of declining tax-funded home-care services, older persons with lower education increasingly receive family care, while those with higher education are more likely to buy private services. The combination of income-related user fees, customer-choice models and the tax deduction has created an incentive for high-income older persons to turn to the market instead of using public home-care services. Thus, Swedish home care, as a universal welfare service, is now under threat and may become increasingly dominated by groups with less education and lower income which, in turn, could jeopardise the quality of care.
| **United Kingdom** |  
| Grundy E (2010) *The care of older people in the United Kingdom: problems, provision and policy*, London School of Hygiene & Tropical Medicine |

The large increase in the number of very old people in many developed societies will inevitably lead to greater requirements for assistance of various kinds. A collaborative group in the UK have been working on Modelling Needs and Resources of the older population to 2030 (MAP2030) taking account of probable changes in the size, structure and marital status distribution of the older population together with projections of disability, household composition and financial resources of older people. Results suggest that even maintaining current levels of provision (which many think inadequate), would require the proportion of GDP spent on long-term care to double by 2030. Policy makers thus face a challenging, and very important, task when making decisions about care systems for older people. Policies that promote healthy ageing and lead to better co-ordination of services are crucial for meeting these challenges.

Despite variations in level, type and financing of long-term care in Europe, some common threads, and a tendency towards some convergence in levels of provision, have been identified. Thus ‘generous’ providers such as the Nordic countries and the Netherlands have been trying to reduce levels of provision, particularly of institutional care, while countries such as Greece and Spain have recognised a need to expand services. The UK Royal Commission on long-term care noted that there was a consensus internationally that long-stay wards in general hospitals were not the most appropriate, or efficient, settings for long-term care. Secondly, in most countries provision of nursing home beds had expanded as an alternative to hospital based care while provision in old-people’s homes had been curtailed. The latter are increasingly regarded as no longer necessary because of improvements in housing, advances in home based technologies (both specialist and general) and more targeted home care for people with a high level of disability. Similarly, home care functions have been changing. Thus in the UK traditional ‘home helps’ who at one time spent much of their time on domestic tasks which are no longer needed or are much less demanding (such as lighting fires, cleaning grates and washing clothes) have now evolved into home carers who spend their time on providing personal care. (Recent budgetary constraints mean that to an increasing extent older people will only receive home care if their needs are assessed as ‘critical’, although this may prove counter-productive if it leads to more rapid deterioration in those not allocated assistance). A third important lesson is that deterioration in function in older people usually does not follow a gradual course but is precipitated by an acute episode of illness or injury or some similar event. As a result admissions to institutions are often from hospital, rather than from home.
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<th>Reference</th>
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<td>McKee K J, Brown J and Nolan M (2006) Services for Supporting Family Carers of Older Dependent People in Europe: Characteristics, Coverage and Usage - The National Survey Report for the United Kingdom, Eurofamcare</td>
<td>This survey of older people and family carers in the UK found that the primary reasons for taking up the caring role were emotional bonds, a sense of duty and a personal sense of obligation. While only just over 40% of carers had used service in the past six months, 90% of older people had used at least one service, mainly medical and nursing services. 27% of older people had used technical equipment or home environment adaptation while 20% had used home based personal care services. Barriers to accessing services were given as lack of information an perceived poor quality of services but the main reasons for not using needed services were given as bureaucratic and complicated procedures (28.3%) or the cared-for’s lack of co-operation (27.8%). The types of support which the highest proportion of carers indicated to be very important related to information needs, both in terms of information on the availability of help (76.6%) and information relating to the cared-for’s condition (66.5%). Next came types of support relating to the cared-for older person’s needs, in terms of support for activities (62.9%) and environmental enhancement (62.5%). Over half of our carers also rated as very important support that helps plan future care (60.2%), and support that provides opportunities, either to have a holiday or take a break from caring (59.3%), to enjoy activities outside of caring (57.9%), or to spend more time with one’s family (55.0%).</td>
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<td>Welsh Government (2014) A framework for delivering integrated health and social care for older people with complex needs, Welsh Government</td>
<td>This document provides a framework for the integrated care of older people with complex needs in Wales. The purpose of the Framework is to focus on older people with complex needs and ensure they have a strong voice and control over their care and support. It places a strong focus on preventative services and support to maintain well-being. It is about ensuring services, care and support are designed, co-ordinated and delivered effectively, to meet the outcomes that are important to people and their carers. It provides the opportunity to create a truly integrated system. This should have the following key characteristics: It should be built with and for people and the local community. Services should be co-designed with the people who will use them. It should be a consciously planned and managed system, built on ambition. Working closely together, all partners will need to refocus their activities around those people receiving care and ensure existing barriers to integrated working and delivery are eliminated. It should involve all partners, including local authorities, health, housing, the third and independent sectors.</td>
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## Study Findings

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<td>Kazeze Z (2008) <em>Social protection and ageing in Malawi</em></td>
<td>Older persons are important and have contribution to make in socio-economic development. It is important, therefore, that the implications of ageing issues in Malawi are understood, especially the challenges older persons face and to respond to the challenges and opportunities of ageing. To fully understand the challenges and opportunities, there is need to understand factors that determine the well-being of elderly persons. Among these are: active participation in society and development; work and the ageing labour force; rural development; migration and urbanization; access to knowledge, education and training; intergenerational solidarity; eradication of poverty; income security; social protection/social security and poverty prevention; health promotion and well-being throughout life; older persons and HIV and AIDS; universal and equal access to health care services; housing and living environment; care and support for care givers; neglect, abuse and violence etc. MIPHA and the AU Policy Framework and Plan of Action on Ageing provide frameworks for mainstreaming ageing in the development processes. It is the primary responsibility of government, at national level to implement the recommendations in these policy instruments. Social protection and development outcomes are linked. Social protection should be viewed as a development strategy in reducing poverty. As noted in the paper, poverty is the greatest threat to elder persons. Social protection and development complement each other. General lessons on social protection pensions show that these programmes are feasible and affordable. The programmes have positive impact on the elderly, other vulnerable groups and society as a whole.</td>
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e) Asia – China, Japan, South Korea and Thailand

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By 2050 25% of the population of China will be aged 65 years and over but 60% of the total population live in rural areas.

Rural areas are ageing faster than urban areas due to the internal migration of younger people to large cities.

Traditional forms of care support in China include Family based care (family obligations); Assistance from neighbours (neighbour obligations); and Assistance from "rich" people (moral obligations).

Family based care - Family obligations: The family is at the centre of all aspects of rural life in China and hence the care and financial support of older people resides within the family. The traditional Chinese economy is based on rural family based enterprises; philosophers such as Confucius and Mencius advocated good treatment of elders and filial piety; Traditional beliefs- Having children is important for ‘a happy old age’; ‘Sons will care for you in old age.’

Assistance from neighbours- Neighbour obligations: Neighbours will assist if the family is facing difficulties; This is an extension of a sharing culture in rural settings: Farmers share water resources and tools of production; Neighbours are seen as part of the extended family; Traditional beliefs: ‘Love other’s elders as your own.’

Assistance from “rich” people - Moral obligations: Sort term assistance in times of great need or on special occasions (e.g. Chinese New Year; Local landlords and Party members (“the rich”)) generally had a good relationship with the farmers; Rich people have a ‘moral obligation’ to assist people and treat them 'like their children'; Helping those in need can improve your image; not doing so will mean that you "lose face."

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Social transitions and changes to family based care:

Formally instituted in the 1980s the one child policy has put a strain on family based care. In the early 1980s farmers were permitted to leave their villages to find outside work. Young people and older people stayed in the villages.

During the 1980s, the concept of family narrowed to a nuclear family with dependents often living away from the family bread winner. Family-based care is still very common today but is under threat from the one child policy, urbanization and internal migration.

Self care and caring for others

Older Chinese people now recognise that they cannot rely totally on their families for care and support. Self care and the care of one’s spouse is accepted as a consequence of the current economic climate. Older people may also be providing care to their grand children.

“Formal” aged care

Formal aged care in China has become more common as older people accept that they need to find and pay for care resources outside the family. In Australia formal aged care includes community care (services to the home) and residential aged care (nursing homes). These are heavily subsidised through the taxation system. While community care approaches maybe preferred by older people they are virtually non-existent in China. The alternative to family and self care in China is self funded aged care accommodation/homes.

Case Study: Aged Care Homes in Beijing

In 2010 there were 366 aged care facilities in Beijing and around one third were run by the private sector. Of the 55,809 beds available, 24,525 were provided by the private sector. The provision of aged care homes is seen as a growing market for investment aimed at the richer middle class.

Do older Chinese people want to live in aged care homes?

The views of older people regarding living in aged care homes has changed over the last 10 years. A recent survey by the China Research Centre on Ageing showed that the percentage of older people who were willing to move to an aged care facility dropped from 18.6% in 2000 to 11.3% in 2010.

Continued...
The alternative: Community care in China?

In Australia “ageing in place” is a key policy approach. The central idea is that older people should be supported to age in their own homes and communities. To achieve ageing in place community care packages (food, housework, nursing services etc.) are provided to older people. While the push in China is to build aged care homes to accommodate its burgeoning older population, like other older citizens, the older person in China has a preference to age in place in their own home and community. There will be a growing market for services in the home but government policy needs to promote this approach.

Challenges for aged care in China

The sheer numbers of older people. A growing gap between rich and poor, and little government financial support for older people: User pays approach. Little commitment to ageing in place. Gap in workforce skills in the care of older people. Rural/Urban differences in demography and in the capacity to provide support.

** See International - Overviews section above **
Passingham A (2008) Reforming care and support – learning from Japan, Counsel and Care

Despite this, both the scale of major system-wide change introduced and the principles of equity and universal accessibility for all citizens that underpin the care insurance programme in Japan are impressive. While a care insurance model may not be the perfect answer to all the current difficulties in the social care system in England, it has certainly shown that radical reform rather than piecemeal change can be successfully implemented without negative political implications.

South Korea


South Korea has been experiencing unprecedented socio-economic transformations in which an ageing population is widely regarded as a key challenge. As an unlikely consensus on state intervention in care has emerged since early 2000, South Korea has achieved rapid development of welfare state programmes. The introduction of long-term care insurance (LTCI) in 2008 is one of the important steps. However, it is highly debatable whether the Korean welfare state has departed from its path of both developmentalism and Confucianism. This paper aims to analyse the nature of LTCI in South Korea, and to examine whether its introduction could mean a divergence from these two policy legacies. This research has reached an ambiguous conclusion. The regulatory role of the government and concerns about the costs of LTCI are regarded as a developmental legacy, whereas Confucian legacies seem to be withering away since LTCI shifts care responsibility from the family to the state. However, the study found that the state has difficulty in regulating the market and costs, and deeply embedded familialism seems difficult to overcome.

Thailand


Intergenerational relations between older age parents and their children remain pervasive in Thailand. Over 70% of older persons live with or next to a child. Material assistance from children remains substantial. Desertion of elderly parents is quite rare. Family members, particularly children, are the main persons providing assistance to frail older persons. Nevertheless, co-residence with children has declined and living alone or only with a spouse has increased. Given projected smaller family sizes of future cohorts of older persons and the increasing migration of their children, these trends are certain to continue. Widespread access to telephones helps elderly parents to maintain social contact with distant children. Still, reduced numbers of adult children and their increased migration pose challenges for personal care of the elderly. Clearly adaptations by family and state are needed if the quality of life of Thai elders is to continue to improve.
f) Australia and New Zealand

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<td>Provide integrated aged care services to people in their homes</td>
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<td>As part of the aged care reforms introduced through the National Health Reform Agreement, from 1 July 2012 the Australian Government will take full funding and policy responsibility for aged care for non-Indigenous people 65 years of age and over and Indigenous people 50 years of age and over. This will include the basic support services used by many older Australians which allow them to remain in their homes. By unifying responsibility for all aged care services under the Commonwealth, the Government will deliver more integrated services, allowing older Australians to transition between different levels of care as their needs change.</td>
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<td>To achieve this, the Australian Government will establish the Commonwealth Home Support Program by 1 July 2015 to provide basic support services such as domestic assistance and transport to older Australians. The new program will improve the efficiency of these services by consolidating the existing Home and Community Care (HACC) Program, the National Respite for Carers Program (NRCP), the Assistance with Care and Housing for the Aged Program (ACHA) and the Day Therapy Centres (DTC) Program. The Government will also ensure that these programs can continue to meet the needs of Australia's ageing population by applying real growth funding to the NRCP, DTC and ACHA components of the program from 1 July 2014 in line with the growth that is applied to HACC.</td>
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<td>In 2012-13, the Department will build working relationships with over 1,200 aged care providers that will be covered by the Commonwealth Home Support Program to transition to the new arrangements, while ensuring continuity of services in the transition period. As agreed under the National Health Reform Agreement, there will be no substantial changes to service delivery under HACC until 2015.</td>
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Offer support to carers

The Australian Government will continue to support carers in their role through the delivery of a number of initiatives. From July 2012 there will be additional funding for planned and emergency respite services delivered through the National Respite for Carers Program and additional funding for counselling and assistance through the National Carer Counselling Program.

From 1 July 2014, the Australian Government will establish a network of Carer Support Centres. These new centres will complement the Aged Care Gateway. These centres will provide more preventative assistance for carers to reduce reliance on emergency respite. The centres will also manage emergency respite and the provision of carer specific information, education and training, counselling as well as appropriate referral to other community care services.

Australia is one of the most culturally diverse nations in the world. People from Culturally and Linguistically Diverse (CALD) backgrounds are a significant and growing proportion of the Australian population aged over 65. They have made important contributions to the Australian community in helping build the prosperous and culturally rich country that we live in today. Around 20 per cent of people aged over 65 years were born outside Australia which equates to more than 600,000 people. By 2021, more than 30 per cent of Australia’s older population will have been born outside Australia.

While 14 per cent of Australians are aged over 65, this proportion varies significantly among a number of CALD communities due to migration patterns. For example, of those people in Australia who were born in Latvia, Lithuania, Estonia or Slovenia, more than 60 per cent are aged 65 years and over. Conversely, of those living in Australia who were born in South Korea, Taiwan or Afghanistan, less than five per cent are aged 65 years and over.

It is important to recognise that older Australians from CALD backgrounds are not a uniform group. The diversity within Australia’s CALD community is significant. Australians identify with more than 300 ancestries and there are more than 260 different languages spoken in Australia today, including Indigenous languages.

The needs of different CALD communities and individuals within those communities vary considerably. These distinct needs must be recognised and catered for in the aged care system to ensure that it has the capacity to respond to the individual person regardless of their cultural or linguistic background. All individuals are cultural beings embedded within the cultural and linguistic paradigms of their families, social groups, community, education and experiences.

The strategy includes a goal to Monitor and evaluate the delivery of ageing and aged care services to ensure that they meet the care needs of older people from CALD backgrounds, their families and carers.
Yates I and Root J; COTA Australia (2010) Caring for Older Australians: Submission to the Productivity Commission Inquiry into Aged Care, COTA Australia

We are advocating a new aged care system based on the principles in the National Aged Care Alliance’s Leading the Way: A New Vision for the Support and Care of Older Australians, in the development of which COTA played a key role, utilising feedback from older people.

In line with those principles we are proposing fundamental change that puts individual people at the centre of the system and attaches funding to them rather than to service providers. Individuals would have an entitlement to funding to meet their assessed needs and have more control over what type of services they use and who provides them. This in turn should lead to a more responsive system that meets older people’s changing needs in a more flexible and timely way.

The first step in is to ensure that people’s needs are assessed appropriately and that people are aware of the support and care services that are available so they can exercise the right of choice. To do this we are proposing the establishment of a network of “Gateways” that provide information, initial assessment and approval, and direct referral to lower level support and care services. Gateways will have the capacity to ensure there are regular reappraisals of people’s needs and to refer them for further assessment if required.

For people with higher and more complex needs comprehensive assessments would be undertaken by an independent assessment service (Care Assessment Service) building on the model of the current Aged Care Assessment Teams but moving them away from state health department control.

The Gateway will have explicit responsibility for assisting individuals to access appropriate care, either in the community or where necessary in a residential facility.

The assessment of needs will be translated into a level of funding to which people will have immediate entitlement. The submission identifies a number of ways this funding could be allocated such as vouchers; allocations with providers; with a third party budget holder; or some combination. All of these warrant more investigation. Individuals and carers must have the choice about how much control and responsibility they want and so there may need to be a range of options.

Older people consistently express their desire to remain living in their community for as long and with as much independence as possible. In order to achieve this funding for community support and care needs to be substantially increased. Many people go into residential care because the level of funding and number of community care packages available does not currently support enough care at home.

We advocate that funding for accommodation and support and care should be separated and that government subsidies for support and care be the same regardless of where the care is delivered.
| **National Aged Care Alliance (2009) Leading the Way: Our Vision for Support and Care of Older Australians, NACA** | The Australian National Aged Care Alliance calls for a range of readily available support and care services linked seamlessly into the broader health system. These include easily accessible primary health care services; transition care after any acute health episode so no-one has a long term aged care assessment while acutely unwell; restorative and rehabilitative services to provide the greatest opportunity of getting back to full function after acute care; support and care services for people living with dementia; and palliative and end of life care.

Most people will receive care and support in their own homes, whether that is a 'family home' of long standing, or a retirement village, community or publicly owned housing, or a private dwelling chosen by people as their own later life housing option.

Some people’s needs or circumstances will require them to access residential care and other supportive accommodation options. They may require constant care at a cost that can only be met in a supportive accommodation setting; or they may prefer the security of constantly available support staff due to their advanced frailty and/or cognitive impairment.

People will contribute to the costs of care according to their capacity to pay, and no-one fails to access care because they cannot afford it. The costs of accommodation are separate to care costs and people either purchase or rent, or enter loan/licence arrangements for accommodation as they choose.

NACA argues that fundamental reform is necessary to achieve this vision. The elements of reform needed for better care and support of older people are: Promoting a society for all ages; Consumer focused, user friendly and equitable services; Entitlement to robust community care is front and centre - within a seamless continuum of care and support services; Care and Support should be properly funded and flexibly and equitably financed; There should be a framework of support for informal carers and families; Continuous improvement and quality control. |
| **Aged and Community Services Australia (2005) A framework for our future, ACSA** | It is now well understood that Australia’s population is ageing. With the growth in numbers of older people will also come greater diversity in their care needs, preferences and aspirations. Our system of care will need to overcome current limitations and develop new approaches to care to effectively meet this larger and more diverse pattern of demand.

Aged and Community Services in Australia: A Framework for Our Future maps out some desirable directions for the future of aged and community care services, building on what we know about the present and what we can reasonably anticipate about future needs.

The Framework aims to advance the development of:

A system of care which enables people who need support, and their carers, to live optimally in the home and community of their choice.

Continued... |
Aged and Community Services Australia (2005) A framework for our future, ACSA

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Australia's aged care and broader health care systems are often claimed to be as good as any in the world. To the extent that this is true it is not a reason for complacency. There are issues in the current systems which need to be addressed such as underfunding, over regulation, workforce shortages and, not least, the capacity of services to work together in a coordinated way to meet the often complex and changing care needs of older people, people with a disability and their carers.

While the main focus of the Framework is on the aged and community care service system as we normally understand it, its scope is also broader, taking in a range of other relevant care services and considerations, not bound by the limitations of specific current programs.

The features of a system of care that is able to meet the challenges of the future include: improved, more accurate resource allocation; new service responses to people's care needs including a greater emphasis on short term care options; better linkages between different parts of the care system; making better use of available resources, both human and technological; developing a broader range of housing options and new ways of combining housing with care. The requirements of rural communities will need special attention if we are to avoid the, often well-intentioned, mistakes of the past of imposing uniform solutions on very different local contexts.

Our reliance on bigger and bigger residential care facilities, driven by the economics of care provision, is likely to come in for serious questioning from both practitioners and consumers and we are only on the threshold of exploring the potential of technology to expand the range of options in terms of providing better, more flexible care.

The Framework embodies a set of principles. These include the importance of providing choice and flexibility in meeting increasingly diverse care needs and preferences. It is important to value care recipients and not to see them simply as sources of costs. Building on people's strengths is as important as providing services that address their inability to manage some things for themselves.

Developing a much stronger capacity to respond to people's needs across and beyond the boundaries set by discrete funding programs, jurisdictions and old habits must be a fundamental design principle for better care in the future.

ACSA sees that an important part of its leadership role in the aged and community care industry is to seek to secure the best possible future for our members and the people they serve. While the Framework is not a set prescription or a recipe for the industry, it poses the questions that we must consider as we prepare to meet the known challenges of the future. ACSA plans to further develop some of the specific themes in the Framework in a series of supporting papers and is keen to discuss the concepts and propositions contained in it with interested stakeholders.
This Discussion Paper will increase the understanding of issues facing care services for older people in rural, regional and remote Australia and propose some options for ensuring that services are available locally and have a viable future.

Most people would prefer to age in their own place – be that their own home or in a form of supported accommodation. Where possible an individual should be able to pass through the various stages of ageing in one location. They would make the transition from complete independence in their own home, to being at home with some care, and then potentially to low care in a residential aged care facility and to high care. They may choose to move to more convenient accommodation, such as a retirement unit, as their needs change. Ideally this can occur without having to shift from their home area and local networks. This is clearly more difficult to put into practice in rural areas where there is a smaller range of helping services and aged care homes available.

New Zealand

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<th>Authors</th>
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<tr>
<td>Wiles J L, Leibing A, Guberman N, Reeve J and Allen R E S (2011)</td>
<td>The Meaning of “Ageing in Place” to Older People, <em>The Gerontologist</em> doi: 10.1093/geront/gnr098</td>
<td>This study illuminates the concept of “ageing in place” in terms of functional, symbolic, and emotional attachments and meanings of homes, neighbourhoods, and communities. It investigates how older people understand the meaning of “ageing in place,” a term widely used in ageing policy and research but underexplored with older people themselves. Design and Methods: Older people (n = 121), ranging in age from 56 to 92 years, participated in focus groups and interviews in 2 case study communities of similar size in Aotearoa New Zealand, both with high ratings on deprivation indices. The question, “What is the ideal place to grow older?” was explored, including reflections on ageing in place. Thematic and narrative analyses on the meaning of ageing in place are presented in this paper. Results: Older people want choices about where and how they age in place. “Ageing in place” was seen as an advantage in terms of a sense of attachment or connection and feelings of security and familiarity in relation to both homes and communities. Ageing in place related to a sense of identity both through independence and autonomy and through caring relationships and roles in the places people live. Implications: Ageing in place operates in multiple interacting ways, which need to be taken into account in both policy and research. The meanings of ageing in place for older people have pragmatic implications beyond internal “feel good” aspects and operate interactively far beyond the “home” or housing.</td>
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### g) North and South America

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| Plouffe L (2013) The Future of Health and Health Care in an Ageing World: A Focus on Brazil, the Dominican Republic and the United States of America, ILC-Brazil | Disease trends in the three countries examined here do not portend significant improvements in the health of the increasing older populations in the near future. The current landscape of health policies and services suggests that both the Dominican Republic and Brazil will be the victims of their own success as improved primary care services increase the number of older persons living longer who will eventually require care and support for disability and frailty. However, there is a dearth of services required to support and care for older persons with chronic or increasingly complex needs as they age. In the Dominican Republic and in Brazil, both service infrastructure and financial coverage are lacking for care beyond primary and acute care. In the US, major barriers include a system that is organized around the provider rather than the patient, as well as inadequate public health care coverage. Meeting the needs of older persons in the US health care system will entail adjusting existing laws, financing and reimbursement mechanisms, insurance policies and practice models that protect existing provider practices and constrain innovations in health care delivery. Taking into account the variations in service capacity among the countries examined here, some directions are proposed to guide policy for the future.  

# Strengthen health promotion and disease prevention and self-care programs for older adults.  
# Continue to strengthen primary care by improving the gerontology and geriatrics training in all streams of medicine and in all health professions.  
# Implement proven care practices to favour comprehensive and flexible management of health service offered by health professional teams.  
# Foster local coordinated networks of community support services. This includes creating more age-friendly settings and services to prolong and enhance functionality and wellbeing.  

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| Plouffe L (2013) | *The Future of Health and Health Care in an Ageing World: A Focus on Brazil, the Dominican Republic and the United States of America*, ILC-Brazil | ...continued  
These services should support both the older person and the informal caregiver.  
  
#Increase the availability of affordable/subsidized good quality institutional care based on assessed levels of individual health needs. This will include adopting cost-effective models of public/private long-term care financing that exist already in some countries.  

#Invest in research to evaluate the implementation and the impacts of new health policies and practices on wellbeing and on health system costs.  
Because Brazil has a particularly strong capacity for data collection and research, this country can contribute significantly to the evidence base for policy in countries with emerging economies.  

| USA | Chen Y and Feeley T H (2014) | Social support, social strain, loneliness, and well-being among older adults: An analysis of the Health and Retirement Study, *Journal of Social and Personal Relationships* 31 (2) : 141-161 | This study proposed that, among older adults, higher support and lower strain received from each of the four relational sources (spouse/partner, children, family, and friends) were associated with reduced loneliness and improved well-being and that loneliness might mediate the relationship between support/strain and well-being. Structural equation modeling was conducted using a national sample of adults aged 50 years and older (N = 7,367) from the Health and Retirement Study. Findings indicated that support from spouse/partner and friends alleviated loneliness, while strain from all the four sources intensified loneliness; higher support and lower strain from various sources directly and indirectly improved well-being, with indirect effects mediated through reduced loneliness. It was concluded that, in later life, various sources of support/strain engender distinct effects on loneliness and well-being, and loneliness serves as one of the psychological pathways linking support/strain to well-being.  

| USA | Leopold T, Raab M and Engelhardt H (2014) | The transition to parent care: Costs, commitments, and caregiver selection among children, *Journal of Marriage and Family* 76 (2) : 300-318 | This research traces the process of caregiver selection among adult children longitudinally, investigating how transitions to parent care were influenced by previous constellations of caregiving costs and commitments within sibling groups. The authors use data from 6 waves (1998–2008) of the Health and Retirement Study, selecting a sample of families (N = 641 parents comprising N = 2,452 parent–child dyads) in which they observed at least 1 adult child becoming a caregiver to a previously self-sufficient parent. Among cost-related factors, this transition was predicted primarily by between-sibling differences in previous geographical distances to the parent and, to a lesser extent, competing demands in work and family spheres. The indicators for caregiving commitments showed the importance of reciprocity, path dependency, and parental expectations as motivational forces affecting the process of caregiver selection among adult children. Gender effects revealed the primacy of the mother–daughter tie, as daughters were overrepresented only in transitions to mother care.  

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<th>Reference</th>
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<td>- Trend #1: The number of older people managing disabilities exclusively with assistive devices has increased dramatically.</td>
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<td>- Trend #2: The number of older people with disabilities living in the community who received care from family, friends, or paid caregivers has changed little over time, despite substantial growth in the older population.</td>
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<td>- Trend #3: A small but growing number of community residents age 65+ with disabilities is receiving only formal services, but the vast majority continues to receive family care.</td>
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<td>- Trend #4: Among older community residents with disabilities who received family care, the number receiving supplemental formal care increased from 1984 to 1994 but has since declined back to 1984 levels.</td>
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<td>- Trend #5: Spouses and children continue to be the primary family caregivers; gender disparities persist.</td>
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<td>- Trend #6: Private resources have been the primary payment source for services in the community.</td>
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<td>- Trend #7: The total hours of formal “skilled care” have declined, while the hours of family care have held steady.</td>
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**See Europe – Overviews section above**
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<th>Source</th>
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<tr>
<td>Silverstein M and Giarrusso R (2010) Aging and Family Life: A Decade Review, <em>Journal of Marriage and Family</em> 72 (5) : 1039-1058</td>
<td>This review summarizes and critically evaluates the major empirical, conceptual, and theoretical directions that studies of aging families have taken during the first decade of the 21st century. The field has benefited from an expanded perspective based on four overarching themes: (a) complexity in emotional relations, (b) diversity in family structures and households, (c) interdependence of family roles and functions, and (d) patterns and outcomes of caregiving. Although research on aging families has advanced theory and applied innovative statistical techniques, the literature has fallen short in fully representing diverse populations and in applying the broadest set of methodological tools available. It discusses these and other frontier areas of scholarship in light of the aging of baby boomers and their families. Improvements in life expectancy have changed the structure of multigenerational families; joint survivorship within and across generations has resulted in extended periods of support exchanges (including caregiving) and affective connections over the life span. At the same time, relationships in aging families have become more fluid and less predictable, as reduced fertility and increased rates of divorce, remarriage, and stepfamily formation have altered the microcontext in which intergenerational, spousal, and sibling relationships function. The implications of increased diversity in kinship structures for such practical outcomes as support and caregiving to older family members have yet to be parsed but remain important concerns in light of declining filial commitment and the aging of support providers and recipients. Despite efforts to represent aging families more holistically, empirical research in this area still tends to be segmented by relational type, specifically affiliations between parents and adult children, grandparents and grandchildren, husbands and wives, and siblings.</td>
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<td>Vincent G K and Velkoff V A (2010) <em>The Next Four Decades: The Older Population in the United States: 2010 to 2050</em>, US Census Bureau</td>
<td>This report provides older population projections for the United States from 2010 to 2050. The number of people in the oldest old age group is projected to grow from 5.8 million in 2010 to 8.7 million in 2030 and 19 million by 2050. In 2050 those aged 85 and over will make up 4.3% of the US population. The total dependency ratio is projected to increase from 67 to 85 between 2010 and 2050, largely because of a rapid increase in the old age dependency ratio from 22 in 2010 to 35 in 2030 followed by a more gradual increase to 37 by 2050. In 2050 the non-Hispanic population aged 65 and older is projected to reach 71 million, up from 37.4 million in 2010, almost doubling. In comparison, the Hispanic population aged 65 and older is projected to grow from 2.9 million to 17.5 million, a more than six-fold increase.</td>
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Chuck W. Gould, Former President and CEO of Volunteers of America argues that...

“There is a bias in the current senior care system that favours institutional care and sends many seniors to nursing homes prematurely. The current Medicare system is acute-care focused, so it does not effectively provide for the management of chronic care or preventative care. Under the current system, nursing home care is considered to be an entitlement, while care and support in the home is not. This is a sad situation, but one that can be changed. Often, home care is much less costly than nursing care, but people are forced out of their home and into a more expensive institution in order for their care to be covered. I believe there is a better way and it can be done.” "The culture of nursing home care is evolving. It is moving more toward smaller facilities designed with “neighbourhoods” that feature dedicated care workers specialized in certain types of care. At Volunteers of America, most of our nursing facilities today are divided into different areas, each designed to address a certain set of needs.

Transitional care units are for those who need temporary care and have an average stay of about 14 days; memory units care for those with conditions like Alzheimer's and have an average stay of about one year; and traditional long-term care units, which are funded by Medicaid. The new wave of older Americans on the horizon is fiercely independent and looking for ways to remain that way for as long as possible. Nursing homes will remain an alternative, but not as we have come to think of them. I think it is important to note that there already has been a sharp decline in the number of older Americans relocating to dedicated retirement communities. The average age of new senior housing/independent living residents has increased significantly and today is age 82.

This is one of the reasons Volunteers of America already has invested heavily in technology that allows seniors to live independently longer. One such technology is called WellAware, which uses a suite of sensors that non-intrusively monitor the health status of seniors living in eldercare facilities or in their own homes. The technology provides caregivers with information about the physical status of those being monitored, and flags any variances in patterns of daily living so caregivers can respond quickly.”
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