

Support for carers of older people – some intranational and national comparisons

**A review of the literature prepared for the
Audit Commission**

by

Caroline Glendinning

**National Primary Care Research and Development Centre at
the University of Manchester**

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Preface

This literature review of some intranational and international comparisons of support for carers of older people is one of three literature reviews that were commissioned by the Audit Commission as part of its study of support for carers of older people in England. It was carried out in 2003 by Professor Caroline Glendinning of the National Primary Care Research and Development Centre at the University of Manchester.

Linda Pickard, Research Fellow at the Personal Social Services Research Unit at the London School of Economics carried out a second literature review of the effectiveness and cost-effectiveness of support and services to carers of older people and a third literature review of carers of older people and employment.

The views expressed in these literature reviews are the authors.

All three literature reviews can be accessed at www.audit-commission.gov.uk/olderpeople. The literature review of the effectiveness and cost-effectiveness of support and services to carers of older people and the literature review of carers of older people and employment are also available as printed copies from Audit Commission Publications, P O Box 99, Wetherby, LS23 7JA.

The report of the Audit Commission's study of support for carers of older people is one of five supporting reports to the Audit Commission's report *An Ageing Society*. The other supporting reports focus on:

- ◆ a changing approach;
- ◆ building a strategic approach;
- ◆ supporting frail older people; and
- ◆ assistive technology.

An Ageing Society, the report on the study of support for carers of older people and the other four supporting reports can all be accessed at www.audit-commission.gov.uk/olderpeople

David Browning
Associate Director
Audit Commission

Introduction

During 2003 the Audit Commission conducted a study of services and support for the carers of older people in England, with a particular emphasis on the implementation of the national Carer's Strategy. In order to place this study in context, a background study was commissioned into the approaches taken in a number of other countries to supporting carers.

The Commission wished to examine whether the different countries within the UK had taken a different approach from England to supporting carers and whether there were any innovative developments in Scotland, Wales and Northern Ireland from which England could learn. A number of other countries were also included in the review. The choice of countries was to some extent pragmatic and influenced by the ease of obtaining information in English about the current situation.

Nevertheless, the countries outside the UK that are included in this review represent a range of different approaches and developments. In the Republic of Ireland, families have traditionally provided the bulk of care for older people although Ireland, like the UK, is distinctive in providing a cash benefit for carers to replace lost earnings. In Germany, the introduction of long-term care insurance has aimed specifically to support and encourage informal care-giving. In Sweden, where both women and men are assumed to be full-time members of the labour market, informal care-giving has not been extensive because of the high levels of social services provided to older people themselves. Only recently, particularly with demographic changes and the increasing numbers of older carers, has attention focused on supporting carers. In both the Netherlands and Australia there is heavy reliance on informal carers to supplement scarce social services. However, in both countries there are active and articulate carers' organisations that lobby at national levels and provide extensive local networks that offer information, advice and support.

Despite their different approaches, all the countries studied are aware of the vitally important role of family and friends in supporting older people and are, in a variety of different ways, experimenting with new kinds of services, benefits and other innovations that can support carers.

The information contained in this report was correct at the time it was compiled, during summer 2003. However, given the rapid pace of change in many countries, its long-term accuracy cannot be guaranteed.

Wales

The Welsh Carers Strategy builds on both the English strategy *Caring about Carers* and the Welsh Assembly's Strategic Plan for improving health and wellbeing *Better Wales.com*. It sets out priorities in the following areas; initiatives which appear distinctive to the Welsh Strategy are noted.

Health and social care

- ◆ Proposed initiatives include:
- ◆ including the needs of carers in Health Improvement Programmes;
- ◆ bringing the Carers' Strategy to the attention of higher education institutions responsible for training GPs and other primary care professionals; and
- ◆ involving carers in social work and social care training.

Information

The Implementation Plan includes:

- ◆ an information strategy, to gather more information about carers and how best to respond to their needs, with the aim of producing a Wales Carers' Information Pack; and
- ◆ in collaboration with carers' organisations, establishing a carers' website.

Support

Support initiatives include:

- ◆ investment of a £9 million Carers' Special Grant to increase the quantity, diversity and flexibility of facilities to enable carers to take a break;
- ◆ free concessionary bus travel for older and disabled people; and
- ◆ plans for legislation to empower local authorities to make direct payments to carers; to run voucher schemes for short-term respite care; and to charge carers for services they receive.

Employment

Employment initiatives include:

- ◆ encouragement to employers, especially in Assembly-sponsored public bodies, to respond to the needs of employed carers – with the National Assembly itself providing a lead in carer-friendly employment practice.

The establishment of a Carers' Review Panel was proposed, to undertake annual reviews of the Implementation Plan.

The Second Annual Report on the implementation of the Welsh Carers' Strategy (June 2002) notes the following additional achievements:

- ◆ carers are to have a right of representation on Local Health Boards (nomination forms are placed on the Carers' Strategy website);
- ◆ 6 weeks free home care on discharge from hospital, from April 2002;
- ◆ an 'all-Wales' publicity campaign run in autumn 2000, to encourage carers to identify themselves and make their needs known;
- ◆ carers Information Pack and carers' leaflets distributed through GP surgeries, public libraries, social services departments, carers' organisations, leisure centres and sub-post offices; and
- ◆ free bus travel for carers travelling with someone to whom they are providing care; and
- ◆ health Professional Wales is promoting the development of flexible working practices and carer-friendly employment policies across NHS trusts in Wales.

Scotland

The Scottish Executive's Strategy for Carers

This strategy also bears considerable similarities to the English Carers' Strategy. It includes:

- ◆ plans to create additional, more flexible services for carers, including respite care;
- ◆ the introduction of national standards for these services;
- ◆ monitoring by the Scottish Executive (SE) of the performance of health and social services for supporting carers;
- ◆ introduction of new legislation to allow carers' needs to be met directly; and
- ◆ better, and more targeted information for carers.

Methods for achieving these objectives include:

- ◆ an investment of £10 million to be distributed by social services as grant aid for carers' services, including respite care; and consultation with local carers' organisations over spending plans for these resources. From April 2000, local authorities are required to report in detail on the use of these resources;
- ◆ the Community Care Implementation Unit will identify and promote good practice in relation to both planning processes and the development of good quality services;
- ◆ a commitment to legislation that entitles carers to an assessment of their own needs, regardless of any assessment of the person being cared for. Legislative proposals were subsequently drawn up in consultation with a Carers' Legislation Working Group that included carers' representatives;
- ◆ a publicity campaign on the Carers' Strategy and the services available to carers;
- ◆ extension of the NHS Helpline to provide information on support for carers; and
- ◆ as an employer, the Scottish Executive provides information on carers' issues to employees and also operates a career break scheme.

Community Care and Health (Scotland) Act 2002

This legislation and accompanying guidance makes explicit the principle that carers are 'key partners' in providing care, rather than service users themselves. As partner providers of care, they therefore need adequate resources to enable them to continue giving care.

The legislation introduced the following new statutory rights for carers:

- ◆ substantial and regular adult carers are entitled to an assessment of their ability to care, independently of any assessment of the person they care for;
- ◆ local authorities have a duty to inform eligible carers of their right to an assessment; and
- ◆ local authorities have a duty to take account of the care provided by a carer, and the views of the person receiving care and the carer, before deciding what services to provide.

SE Ministers were also given powers to require NHS Boards to draw up Carer Information Strategies informing carers of their rights under the legislation.

Northern Ireland

A number of UK-wide initiatives have been implemented in Northern Ireland, including:

- ◆ changes to Invalid Care allowance to enable claims from carers aged 65 plus; to continue payment for 8 weeks after the death of the person being cared for; and increase the amount that can be earned while receiving CA;
- ◆ increase in Carer Premium paid with means-tested benefits;
- ◆ allowing time spent caring to count towards entitlement to a second pension;
- ◆ a question in the 2001 Census;
- ◆ entitlement for carers to have an assessment of their needs.

The National Strategy for Carers also covered Northern Ireland. However, in October 2000 the NI Minister for Health, Social Services and Public Safety commissioned a strategy for carers in Northern Ireland. The working group that was set up to develop the strategy produced a document, Valuing Carers. This document proposed a substantial number of new measures, under the broad headings of:

- ◆ **Information and training:** Recommendations included involving carers in hospital discharge planning; identifying carers; health and social services trusts and other organisations to prepare handbooks for carers about local services.
- ◆ **Support services:** Recommendations included that Health and Social Services Trusts are to inform carers of their rights to an assessment; the results of carers' assessments to be recorded separately from that of the person receiving care; a review of funding arrangements for respite care services; improved responses to complaints; training for carer advocates.
- ◆ **Employment:** Recommendations included the promotion of carer-friendly employment practices; development of training schemes appropriate for former carers.
- ◆ **Help for young carers**

Other recommendations included the appointment of a carer liaison post in every Health and Social Services Trust.

In addition, the Northern Ireland Equality legislation (s75 Northern Ireland Act 1998) encourages consultation with carers and carers' groups throughout the policy process.

Republic of Ireland

Context

Traditionally the family has taken responsibility for the care of older people. The role of women as primary carers is made explicit in the Irish Constitution and there remain strong moral obligations on families to provide care. The state, Church and voluntary organisations have traditionally played a subsidiary role to the family. Statutory social welfare services remain poorly developed, although there has recently been recognition of the need to support carers.

Carer's Allowance

A benefit to provide financial support for carers – the Prescribed Relatives Allowance – was introduced as early as 1968, in response to concerns about the absence of any financial support whatsoever for unmarried adult children caring full-time for older relatives. Because of its very restrictive eligibility criteria, coverage of the PRA was always very low and it was replaced in 1990 by the Carer's Allowance. The Carer's Allowance is a means-tested benefit for carers with very low, or no, income, who live with someone needing full-time care and attention; the latter must be in receipt of one of a number of disability benefits. Apart from these benefit 'passporting' arrangements, it is the carer who is entitled to the Allowance in her/his own right and payment is made directly to the carer. However, the level of the Carer's Allowance is very low and, as an income replacement benefit, recipients are precluded from receiving any other form of social welfare benefit concurrently.

When the Carer's Allowance was introduced in 1990, it was paid to 1,240 people; by 1998, over 11,000 carers were estimated to be receiving the Allowance.

Other financial benefits for carers:

Carers with private incomes can obtain full tax relief on payments they make for the care of older people in private nursing homes.

- ◆ Carers receiving the Carer's Allowance are entitled to a free Travel Pass in their own right.
- ◆ A tax allowance can be claimed if a tax payer or her/his spouse is permanently incapacitated and someone is employed to care for her/him. The maximum amount that could be claimed was €9,523 (£6,630) in 1997/8.

Social welfare services that can benefit carers

Coverage of statutory health and social services for older people is very limited. Social workers, old age psychology and psychiatry, and rehabilitation services are all very scarce. There is no legislative imperative requiring local Health Boards to provide community care services to support older people at home; consequently medical and health services have taken priority over social welfare services in the allocation of resources.

A substantial proportion of day centres, meals services and home help services are provided by voluntary organisations, with some funding in the form of grants from the Health Boards. However the processes for allocating these resources have been *ad hoc* and channels of communication between the statutory and voluntary sectors have remained poor; this has inhibited longer-term strategic planning of service developments.

Although home help services exist in most parts of Ireland, coverage is very limited, with only 3 per cent of people aged 65plus receiving services. Moreover, most home help recipients live alone. The extent to which formal welfare services for older people actually benefit carers is very limited, because if there is a carer then little formal support will be offered – or, more usually, none at all. Older people's receipt of community care services is usually subject to a means test and this also takes the carer's means into account.

Carers do not have any statutory entitlement to an assessment of their needs.

Voluntary organisations for carers

A number of national voluntary organisations for carers campaign for better support for carers. Campaigns have been organised to increase the value of the Carer's Allowance and to convert it from an income replacement benefit into a payment for care-giving that reflects the actual level of care being given. Other campaigns have included demands for an annual entitlement of up to 10 days paid leave for carers in employment; better consultation with carers in planning services; and entitlement to regular respite care.

Support services for carers are all provided by voluntary organisations. Support services include:

- ◆ information and referral services;
- ◆ alarm and home monitoring services; and
- ◆ respite care through home sitting services and temporary institutional placements.

However the availability of these services is far from universal, particularly in rural areas.

Conclusions

Because of its strong historical emphasis on family responsibilities, Ireland has a shortage of long-term care provision; moreover, statutory home help services are targeted at older people living alone. Although the Carer's Allowance can be claimed by carers in their own right, both its coverage and level remain low. Carers' organisations have been active and vocal over the past 15 years in lobbying for better support for family carers, and most support that is available for carers is provided by these and other voluntary organisations.

Germany

Context

Social insurance remains the main framework for social protection in Germany, with firm legal codifications of rights and entitlements – although these are fragmented between the various social insurance schemes covering pensions, sickness, accident and unemployment. A fifth branch of social insurance, covering long-term care needs, was phased in from 1994, following considerable pressure to shift the costs of long-term care from the sickness insurance and local, means tested, social assistance schemes. Membership of German social insurance schemes is compulsory for all economically active people employed more than 18 hours a week, making social insurance coverage almost universal. Membership of the care insurance scheme is mandatory for everyone who has sickness insurance coverage. It is a 'pay as you go' insurance scheme, so current contributions fund claims from current cohorts of older people and others needing long-term care.

All support for carers in Germany is provided through the long-term care insurance (LTCI) scheme. Thus a carer's access to any support is entirely dependent on the insurance entitlement of the older person receiving care.

Entitlement to care insurance

An older person's eligibility is determined through a standard, national medical assessment of the amount of help regularly required with activities of daily living. The amount of help needed determines the level of benefit payable (at one of three 'care dependency' levels). Benefits can be received in the form of a cash payment (at a lower value); or in the form of professional home care services (worth nearly twice as much); or as a combination of the two. The level of the cash benefit option ranges from €205 (£145) to €665 (£469) per month, depending on the level of 'care dependency'. The cash benefit option is only payable if the care insurance recipient is able to secure adequate home care from relatives, friends or neighbours. The cash benefit is awarded directly to the person needing care, who may then pass it on to a family carer. Despite its significantly lower value, the cash option has proved much more popular than 'in kind' services.

Other care insurance benefits for carers

Once an older person's entitlement to care insurance has been established, a number of other benefits can be received which are of potential benefit to family carers. These are:

- ◆ **Respite, holiday or stand-in care:** Informal carers providing home care can take up to 4 weeks holiday a year, during which LTCI will pay up to €1,688 (£1,775) for substitute professional home care services. The same entitlement is available if the usual carer is ill. However the normal carer must have been caring for at least 12 months prior to the date of absence in order to qualify.

- ◆ **Technical aids:** Care insurance beneficiaries are entitled to receive special home nursing equipment; and grants up to €2,557 (£1,804) to adapt the home.
- ◆ **Insurance cover:** Care insurance pays the retirement pension and accident insurance contributions of informal carers who are employed for less than 30 hours a week and provide unpaid home care for at least 14 hours a week. In 2000 the long-term care insurance funds transferred more than €1 billion (£696,280,000) to the pension funds, thereby providing cover for nearly 600,000 carers. Informal carers are also automatically covered by the statutory accident insurance scheme while they are providing unpaid home care.
- ◆ **Direct support for carers:** Care insurance beneficiaries who have chosen the cash option have a home visit from a nurse employed by the care insurance fund every 3-6 months, depending on the level of care dependency. This is partly to monitor the quality of care being received and partly to provide advice and support for carers. However no information is available on the acceptability or effectiveness of these visits, from the perspectives either of carers or the LTCI funds. The LTCI funds are also required to offer free nursing care courses for informal carers; again there is no evidence on their take-up or effectiveness. Carers are also entitled to retraining opportunities if they want to return to paid employment after a period of care-giving.

Recent developments in care insurance

The assessment of eligibility for LTCI was initially criticised for its bias in favour of older people with physical, rather than mental health problems. A recent reform (the Dementia Care Act 2002) therefore provides additional LTCI benefits for people with cognitive impairments, in order to alleviate the stress on their carers. These are:

- ◆ an additional personal budget of €460 (£320) a year that can be spent on respite or relief care provided by a home care agency or voluntary organisation; and
- ◆ additional advice and support services for carers of older cognitively impaired people.

Evaluation and conclusions

There appears to be no national organisation whose remit is to represent and advocate on behalf of carers; instead such functions tend to be carried out by specialist organisations representing older people with specific conditions like Alzheimer's disease.

Informal, family care has always been the predominant form of support for older people in Germany and the introduction of LTCI was intended to encourage and support this informal care. Indeed, the requirement that care dependency must be both considerable and demonstrably long-term (at least six months) means that a substantial degree of family care is likely to have been invested even before an application for LTCI is made. LTCI has halved the numbers of older people living in nursing homes who are dependent on means-tested benefits to pay for their care, suggesting that fewer older people are now admitted; indeed, waiting lists for admission have virtually disappeared. LTCI has also stimulated a growth in more

flexible home care services; since 1992, the number of home care agencies has increased from 4000 to 13,000. This is in turn reflected in the growing numbers of LTCI beneficiaries who now opt to receive at least part of their benefits in kind rather than cash (up from 12 per cent in 1995 to 35 per cent in 2002).

The cash benefit option was always intended to encourage and support – but not replace – informal care and was never intended to meet all the costs of informal care. Since the benefits in kind option (in the form of services) are not sufficient to meet all the care needs of an older person, particularly for people assessed at the highest level of care dependency, LTCI beneficiaries who choose benefits in kind will almost certainly also rely on some informal care. Overall, two thirds of all dependent older people rely on informal care.

Almost two thirds of the public regard LTCI as an incentive to provide informal care and informal carers themselves regard the cash benefit option as a token recognition of their work. It appears that the LTCI has acted as an incentive to increase the capacity of care provided informally; the number of informal care-givers per care-dependent person has increased significantly, while the proportion of care-dependent people without an informal care-giver has halved. About a third of main care-givers are spouses, while another third are daughters (in-law).

However, the fact remains that informal carers have no entitlements of their own whatsoever to benefits or services. Access to support is entirely dependent on the eligibility of the older person for LTCI. Moreover, although the carer of a LTCI recipient then has automatic entitlement to insurance cover, his/her opportunity to benefit from the other elements of the LTCI (the cash allowance, respite care and equipment/home adaptations) depends on the discretion and agreement of the older person.

Sweden

Context

Two features of the Swedish welfare state shape provision for carers. First, it has long been assumed that women as well as men are active members of the labour market; therefore initially limited provision for carers focused on the introduction of leave entitlements to enable them to combine care and employment. Secondly, there is a well-developed system of formal care services for older people, which reduces their need to rely on family carers. The Social Services Act requires municipalities (which are responsible for social and long-term care services) to assist older people to live independently, in a safe environment and with respect for their self-determination and privacy. Home help services are extensive; they include help with domestic tasks and social activities and can offer 24-hour home-based care if necessary. Support from family members is regarded as voluntary and as a supplement to, not a replacement for, social services. Nevertheless, a series of studies from the 1980s onwards has documented the increasing role of families in providing care.

Three factors lie behind the growing prevalence of informal care. First, demographic changes (particularly the growing numbers of older spouse carers) have recently prompted the development of a range of support services by local municipalities; this is also consistent with the expressed preferences of carers themselves, for services rather than cash payments. Secondly, the Swedish economic crisis of the early 1990s restricted the capacity of municipal services to meet growing demands. Married older people and those with moderate health problems were particularly affected by reductions in home help and other domiciliary services. Thirdly, the Adel reforms of 1992, as well as consolidating the responsibilities of municipalities for long-term care, involved a concerted shift from institutional care to supporting older people in their own homes (or in supported housing).

Cash benefit for closely-related persons

This entitlement for carers forms part of the health insurance scheme. It was introduced in 1989. A working age close relative who takes care of a seriously ill person is entitled to compensation in the form of sickness benefit for up to 30 days of lost earnings. This is intended to cover terminal and emergency care-giving, not long-term informal care, and is restricted to a total of 30 (not necessarily consecutive) days in the lifetime of the person receiving care. The care relief benefit can be paid only if the elderly person receiving care consents to the arrangement.

Initially the benefit was restricted to care provided in the person's own home. However, in 1992 it was extended to include situations where the sick person is in hospital or a nursing home and in 1994 was increased from 30 to 60 days. As the assessment for this benefit is carried out by local social insurance offices, there may be some regional variations in eligibility depending on local practices.

Cash payments for carers

Introduced in 1992, a *direct cash payment* can be made by the municipality if there is a need for home care and the family is willing to serve as care provider. The payment is made to the older person and is used as compensation for the cost of care to the family. The level of payment is based on the number of hours of care needed by the older person, following an assessment by the municipality's home care organiser. Take-up of this payment is thought to be low, partly because families do not know about the payment and partly because of different eligibility criteria used by different municipalities. This payment is likely to be received by older carers. In 2002 it was received by 2,940 men and 2,573 women.

If an older person needs more constant care and attention, a family member can be employed by the municipality as a *paid kin care-giver*. This arrangement has been available since the 1960s and was introduced to compensate family members for their additional responsibilities that resulted from a shortage of long-term hospital beds. It reflects concerns about the poor financial status of daughters who had to stay at home to care for a parent and is used primarily by family members of working age.

The salary paid to employed kin care-givers is based on the number of hours of help needed by the older person and is equivalent to the hourly rate of pay received by 'regular' home helps or the lowest rate paid to nursing assistants. The salary is paid by the municipality, is taxable and includes social insurance benefits, such as entitlements to sickness benefit and pension credits. Care receivers pay a home help service fee to the municipality exactly as they would if they were receiving conventional home care services.

Paid family care-givers usually have to give up other paid employment, unless they can combine care-giving with part-time work. In most municipalities, paid kin care-givers have worse terms and conditions than employed home helps and nursing assistants; for example, they lack rights to time off and holidays, do not receive payments for unsocial working hours and have no job security. Despite this, the salary is widely appreciated by paid kin care-givers, as social recognition of their work as carers.

Despite the fact that the government has promoted financial support for carers, the number of relatives paid as care-givers has declined, from around 19,000 in 1971 to approximately 4,000 in the mid-1990s; by 2002, 2,021 people were paid as kin care-givers. In 1989 the overall proportion of older people cared for by paid kin care-givers was 2 per cent of all home help recipients, although this varied between local municipalities from 1 per cent to 10 per cent.

Social services support for carers – 'Carer 300'

The public profile of informal carers increased throughout the 1990s. The balance between public and informal care has shifted, so that the total volume of help needed by older people is now shared more evenly between municipal home help services and informal carers. Municipal home help services now tend to be targeted on the most frail and isolated older people. However, other public services have expanded considerably, including transport, security alarms and meals-on-wheels; these are all likely to reduce the demands on family carers.

In January 1998 a new regulation was introduced into the Social Services Act that required social services to reduce the workload of carers who care for their sick, elderly and disabled relatives, through the provision of 'support and relief'. As a consequence, in the 1999–2001 National Plan of Action for the Elderly, central government allocated to local municipalities grants totalling 300 million SEK (£22,996,729). This money was intended to stimulate new developments for carers (all carers, not just carers of older people). Special attention was directed to the development and support of voluntary sector projects for carers ('Carer 300'). The projects funded through 'Carer 300' were voluntary, demonstration projects; municipalities had to bid for the necessary funding.

An evaluation of 'Carer 300' showed that the new projects were slow to get going. However, innovative schemes did gradually develop; these included:

- ◆ home-based respite care schemes – substitute care provided in the older person's own home;
- ◆ counselling and advice for carers, for example about the management of particular diseases;
- ◆ carers' support groups and other opportunities for carers to meet together;
- ◆ holidays and other opportunities for recreation for carers;
- ◆ health checks and access to health-related activities. For example, in the municipality of Varberg, funds from 'Carer 300' were used to invite carers to visit a GP and district nurse for a health check and discussion about their health; carers were also invited to take part in health-related activities such as massage, discussions about diet and visits to a spa; and
- ◆ education for staff in identifying and responding to the needs of carers.

Older carers, as well as working age carers, are able to access all these support services.

When the 'Carer 300' funding ended in 2001, several municipalities decide to carry on working with carers. 'Carer 300' has highlighted the importance of the work done by carers; it has also increased levels of support for carers, which is now broader and more varied than before. However, there is still no information on the numbers of carers; what proportions of carers receive supporting services from their municipalities; or information on the relative effectiveness of the different forms of support for individual carers.

A 1999 national plan to develop the Swedish health care system also highlighted the priority of supporting carers. An agreement between all the municipalities emphasises their responsibility to improve support for carers over the years 2002-2004.

Evaluation and conclusions

The main sources of support for carers reflect the wider priorities in the Swedish welfare state, of active labour market participation for women and men; the treatment of care-giving as a 'proper job'; and expectations of comprehensive service provision for older people. Traditionally a small proportion of carers have received payments for

their work (including employment on similar terms to municipal home helps). Only recently, reflecting acknowledgement of growing numbers of older carers, have support services developed. However these have been funded through time-limited resources; involve extensive voluntary sector activities; and have developed unevenly across the country, depending on the policies and priorities of the relatively autonomous Swedish local municipalities.

Netherlands

Context

Like Germany, health and welfare services in the Netherlands are funded through social insurance, with separate insurance (funders) and independent, non-profit provider organisations. Long-term care services are funded from a special national fund, set up by the 1968 General Act on Exceptional Medical Expenses (AWBZ) and financed by tax-related contributions from all citizens, supplemented with central government funding.

Dutch estimates are that 11 per cent of the adult population is involved in informal care-giving, particularly help with household and domestic tasks and to people living in another household. Over the past decade, considerable tensions have arisen, with women's organisations and organisations representing older people both calling for greater inputs of formal services; and pressures on these services to make economies where possible (including relying on informal help). In particular, developments in home care and home nursing services during the 1990s included budget cuts; the restructuring of services; and the introduction in 1998 of an upper limit of three hours a day of home care. These measures have increased the role of family carers in supporting people with extensive care needs; have increased the profile of family carers within public and policy debate; and have prompted government investment in the Dutch carers' national organisation.

On the other hand, appropriate housing is an integral element of community care provision in the Netherlands, and this helps to reduce older people's need for assistance, for example with getting around the home.

Services that can support carers

The provision of home nursing and home care services for older people is covered by the AWBZ insurance scheme. Assessment of need for these services takes account of help that is provided by family members (ie it is not 'carer blind'); 80 per cent of the independent regional bodies that carry out assessments say they take the help provided by carers into account. There are regional differences in these assessments, but lobbying from carers' organisations is likely to lead to greater consistency.

Home care provider organisations can respond to the identified needs of carers by contributing to the funding of local carers' centres. Indeed, the role of the home care provider organisations has increased since 1998, when the Ministry of Health formally extended their remit to include the provision of support for home carers. No additional resources were allocated for this function, but it is now possible for home care provider organisations to seek reimbursement from care insurance organisations for a new category of activities – 'support of family care'.

The development of advocacy services for carers and information to support specialist technological care-giving at home are both slow. There are also complaints that

available forms of respite care (home care, day care, institutional-based respite) are of limited variety and availability and not straightforward to access.

Carers' organisations

The Dutch Carers' National Association was established in 1993. It provides information and advice; supports the establishment of local carers' organisations and support centres; and promotes new initiatives to support carers.

A wide – but potentially fragmented - range of support is available, including carers' contact and support groups; information; telephone-based support systems; volunteer schemes to provide a break for carers; and carers' centres. Information booklets for carers are produced by organisations representing older people. Around 48 support centres for carers have been developed by voluntary organisations and/or home care provider organisations.

Individual personal budgets

Since 1995, the Netherlands has experimented with the introduction of individual personal budgets where, instead of an allocation of home help and home nursing services, older people are given a sum of money (PGB – Persoons Gebonden Budget) with which they can purchase their own services. In order not to destabilise the existing home care provider organisations, this option was initially only implemented on a small scale. Unlike direct payments in England, personal budgets can be used to purchase help from relatives, including spouses, as well as from commercial provider organisations. In these instances, relatives are given a contract covering the care they will provide in return for payment from the older person's personal budget. In 1998, 21 per cent of personal budget recipients were using it to pay relatives to provide care.

Evaluations of the impact of the personal budget suggest that it does not necessarily increase the availability of family care; both those receiving cash and those receiving services in kind receive approximately the same levels of informal care. However, where a personal budget is used to pay family members to provide care, there are reports of family members feeling under an open-ended obligation to be available and therefore sometimes imposing restrictions on their availability (for example, at weekends).

Supporting carers in the labour market

The 1998 Act to Finance Career Interruptions permits employees to take leave for at least half of their regular working hours for between 2 and 6 months and extendable by local labour agreements to 18 months. The person taking leave receives a payment of €11 (£8) an hour, up to a maximum of €436 (£320) for leave of 38 hours or more a week. Additional periods of leave can be taken so long as there is at least a year between them.

Absence from employment during these periods of care-giving is not taken into account in assessing entitlements to sickness, disability or unemployment benefits.

Other financial subsidies for carers

Individual rental subsidy – if the provision of care at home avoids admission to institutional care, the income of the person receiving care is not included in the means-tested assessment of eligibility for a rent subsidy.

Tax rebates – households providing care to an older person can claim tax rebates for exceptional medical expenses; and higher personal allowances for everyone over age 65.

There is no benefit or payment that acknowledges and compensates for the costs of care-giving.

Evaluation and conclusions

Despite reductions in the availability of residential care, and a ceiling on the intensity of home care provision to three hours a day, there is little official policy interest in carers and few mainstream statutory resources allocated to their support. Meanwhile the introduction of rigorous assessment and care plans, and the opportunities to pay family members under the personal budget scheme create explicit formal demands on carers. The new rights to leave from paid work are only a framework and the details remain to be negotiated between employers and employees' organisations; moreover they will be of limited benefit to the large number of working age women carers who do not work or who only work part-time.

Australia

Context

Responsibilities for health and welfare provision in Australia are split. The governments of the eight States and Territories are responsible for licensing and registration of all health care practitioners and facilities and for the direct provision of hospitals and community health services. The Commonwealth Government has gradually assumed an increasingly important role in the financing, organisation and provision of care, including the subsidy of nursing home care; Medicare (which provides almost free access to healthcare for all Australians); and a range of community support services. Funding for the Home and Community Care Programme (HACC) programme, introduced in the mid-1980s to expand the range of services to people requiring support to live independently at home, is shared between the Commonwealth and State governments. However, there are continuing tensions about the appropriate allocation of responsibilities between the State and Commonwealth governments, accompanied by accusations of cost-shifting.

There is an extensive mix of public, voluntary and private providers of both residential and community based services - Australia has always had a 'mixed welfare market'.

The overall position of carers

Since the development of the Aged Care Reform Strategy in the mid-1980s, there has been a shift in the emphasis of Australian policy, away from institutional to community support. This has involved a tightening of access to residential care and an increase in spending on community support services. As a consequence, both the profile of carers in the community-based care of frail older people, and the range of services that might assist them, have increased substantially. The Carers Pension (see below) was introduced in the early 1980s and carers have been a recognised target group in community care legislation since the mid-1980s. A range of information and other forms of support for carers themselves are provided through a network of Commonwealth Carers' Centres (see below). However, carers have no entitlements to assessments or services in their own right; these are provided to the older person.

Services for older people from which carers can benefit

Australian Aged Care policies prioritise the provision of community-based services for older people themselves, mainly through the HACC programme and the increasingly important Community Aged Care Packages (CACPs). The HACC programme includes domestic help, home modifications and maintenance, personal care, community nursing, food services, respite care, assessment and referral, carer support, transport and some allied health services. With joint State and Commonwealth funding responsibilities, HACC services are provided by local government, community, voluntary, religious and charitable organisations and also by some commercial providers.

Assessment and access to services

Access to both residential and HACC services is dependent on assessment by a multi-disciplinary Aged Care Assessment Team (ACAT). Referrals to ACATs come from professionals or from older people and carers themselves.

Carers have no independent right to an assessment of their needs. The ACAT operational guidance describes assessment as the process of developing 'a comprehensive understanding of the needs and capabilities of an older person (and their carer/advocate)'. The guidance emphasises the right of an older person to have a carer or advocate with them during the assessment, particularly when the person being assessed has a cognitive impairment and when assessing during a hospital stay; and asserts that the care needs and preferences of the client and carer 'are paramount' (no distinction between the two or possible conflict of interest are apparently recognised). Carers can subsequently assume responsibility for co-ordinating service provision, in the place of a formal care co-ordinator.

Information about services for older people and carers

The Commonwealth Government funds 65 **Commonwealth Carelink Centres**; these can also be accessed by a freephone number. The Carelink Centres are run by a range of different voluntary, religious, community, private, local and state government organisations that already provide services in the region. They provide information about community care, aged care, disability and other support services; eligibility criteria; and assessment processes. Information is available in English and 16 other languages, with special provision for Indigenous and vision impaired clients; translation services are also available to help make contact with services.

The Commonwealth government also funds **Commonwealth Carer Resource Centres** – one in each State/Territory capital city, with national co-ordination by the National Commonwealth Carer Resource Centre. These Carer Resource Centres provide a range of support for carers (information, training, carers' groups and special events to highlight the profile of carers).

Additional services may be funded by the individual State/Territory governments. For example, New South Wales (NSW) allocates A\$5.1m (£3 million) a year to a 'Care for Carers' programme. This is a joint initiative with NSW Health to support carers through the provision of counselling, training, respite and transport and initiatives to improve the responsiveness of health and community care workers to the needs of carers.

Respite care

Respite care is particularly promoted as a service for carers; this can be home-based, in a day centre or in a residential care home. A network of 65 **Commonwealth Carer Respite Centres** provides advice and information, co-ordinates access to respite services and can also arrange 24-hour emergency care. Access to respite care in a Commonwealth-subsidised aged care home depends on an assessment of the older person's needs by an ACAT. Up to 63 days subsidised respite care is possible in any one financial year (with possible extensions of up to 21 days, following further assessment by the ACAT).

Users are required to pay charges for respite care in a residential home of up to A\$25 (£10) per day; a 'prepayment' (a deposit of up to 1 week's fee or 25 per cent of the total) may be required to secure a respite place. For community-based respite, charges are payable on a sessional or hourly basis.

Carers complain of difficulties in accessing affordable respite services; low quality respite care; limited flexibility; long waiting lists for HACC and health care services; and high costs of transport to access services.

Carers' organisations

Carers Australia is 'the national voice of carers'; this is the peak organisation of the carers associations in each of the eight States/Territories. The *State/Territory Carers Associations* provide information and referral to ACATs; support services such as counselling; carer support and friendship groups; advocacy and lobbying; newsletters; education and development for carers and providers; and co-ordination of respite services. The State/Territory Carers Associations also operate their local Commonwealth Carer Resource Centre.

Social security benefits for carers

There are two benefits for carers:

- ◆ **Carer Allowance:** This is a Commonwealth government benefit, payable to carers looking after an older person who requires full-time care on daily basis and shares the same home as the carer. It is not an income-replacement benefit, so it is neither means tested nor treated as taxable income. Eligibility for the allowance depends on an assessment of an older person's functional ability by an ACAT. In 2001/2, 271,483 people received The Carer Allowance, worth A\$43 (£17) a week.
- ◆ **Carer Payment:** This is an income replacement benefit for carers looking after someone 'in need of constant personal care or supervision at home for six months or more'. Eligibility is determined by an assessment of the dependency level of the person receiving care. The Payment is also asset and income tested and not payable in addition to an existing pension, or to carers working or studying for more than 20 hours a week. It is paid at the same rate as the aged care pension and disability pensions (which are set at 25 per cent of average weekly earnings). Most of the 67,260 people (2001/2 figures) receiving the Payment are of working age.

Applications for both benefits can be made by phone to a freephone number.

However, according to Carers Australia, the eligibility criteria for both benefits are extremely high, so their coverage is limited. Where they are paid, they are too low to compensate for giving up paid work, or to meet the extra costs of illness, disability and care-giving. Moreover, access to respite and other services can be very difficult in remote rural areas.

Care-giving and paid employment

There are no formal legal entitlements or policies to support carers who also have paid employment. In 1998 almost half of all main carers of working age were reliant on state benefits (compared with 20 per cent of the general population who did not have caring responsibilities) and 73 per cent of main carers are in the lowest three quintiles of the distribution of cash income. Carers Australia is campaigning for greater workplace flexibility for carers; greater support for carers who have had to give up paid work but wish to re-enter the labour market; support services to help carers remain in or return to employment; and consideration of the needs of carers in the development of state and private pensions policies.

Cross national summary of policies for working carers

The economic implications of care responsibilities are potentially substantial. A recent US study of the costs of productivity lost through care-giving estimated that US businesses lose between \$11.4 billion (£6,841 million) and \$29 billion (£17,402 million) every year – and these costs will rise as the numbers of employed care-givers increase. In the UK, the business case for supporting working carers (in relation to issues like performance, absenteeism and recruitment costs) has been made by the Industrial Society; there are also strong links with wider arguments about redressing the work-family balance. However, on the whole across the EU, care policies have tended to develop in isolation from policies for employment/equal opportunities. In the few countries (such as Finland and Denmark) that are beginning to take a more strategic approach to older people's issues, the issue of support for employed carers is beginning to be addressed, partly because of the strong similarities to the business case for older workers – indeed, many working carers of older people are also older workers.

Although there are no EU-wide data, figures from national studies indicate that up to half of all carers aged under 65 combine care with employment. There is also extensive national data on the impact of caring on employment. Withdrawal from the labour market (particularly by men, who may have access to fewer opportunities for part-time work or flexible hours), shorter working hours, early retirement, diminished career prospects, lower incomes and reduced occupational and personal pensions are widely and consistently reported. However, for some carers, continuing employment is a key condition for sustaining the role of carer.

In the US, some large corporations are providing support for working carers in order to retain skilled employees and maintain productivity. Initiatives can be categorised as:

- ◆ *policies* concerning the organisation of work and working time (eg flexi-time and flexible working location);
- ◆ services such as information, advice and referral; and some transport and workplace-based care facilities for older relatives; and
- ◆ *benefits*, for example, preferential rates for long-term care insurance that covers the older person, or cash compensation for time taken off to care.

Such developments tend to be restricted to larger corporations but even so, it is estimated that less than a quarter of companies with 100-plus employees have programmes in place to support carers. Problems in setting up and sustaining US carer-friendly employment initiatives have included:

- ◆ lack of flexibility or suitability for employees or the older person that reduces take-up (eg a company day care facility that is too far from where older person lives);
- ◆ low take-up by carers who fear they will be perceived as unable to cope or who are determined to keep their care-giving as a private matter; and
- ◆ lack of encouragement from line managers and colleagues to take advantage of available support.

There is no EU-wide data on workplace initiatives and policies to support carers in employment, particularly policies designed for carers of older people. In most member states (especially Southern Europe), difficulties in managing care-work conflicts are managed within the family, or (as in Greece) by families hiring private help/substitute care. In contrast to the US, initiatives across the EU to support working carers tend not to consist of workplace- or company-sponsored services. Instead, the emphasis has been on:

- ◆ increasing the flexibility of working time and the organisation of work;
- ◆ improving communication about available measures/entitlements; and
- ◆ explicit management support for working carers.

Within EU countries, many workplace initiatives to support working carers are the result of collective bargaining agreements that go beyond legally required minimum standards. Examples of these include agreements on family leave entitlements (some of which explicitly mention the care of older relatives). For example:

- ◆ in the Dutch insurance industry, employees are allowed up to six months unpaid leave to care for a seriously ill partner or dependent parent; and
- ◆ in the Spanish iron and steel industry, employees can take between one and five years leave of absence to care for a relative with a serious disability and their job will remain open.

National public policies on the work-care balance can also benefit working carers:

- ◆ in Sweden, employees can take up to 60 days leave to care for someone who is seriously ill;
- ◆ in Finland and Belgium, longer periods can be taken off work in the context of career break schemes that safeguard entitlements to insurance benefits during the period of leave; and
- ◆ in Ireland, a Carers Leave Bill is being discussed – this would allow carers to take unpaid leave to provide full-time care for up to 65 weeks (although even this may not be long enough to cover the average length of time for which many carers provide intensive care).

In conclusion, working carers tend to have a low profile in debates on employment, social protection, equal opportunities and the work-family balance. Their needs are usually not met within frameworks developed to reconcile employment and childcare: men are often involved; carers increasingly live some distance from the older person; the day to day timing of care needs is unpredictable; and the duration of caring is also not predictable.

Conclusions

There appears to be very little difference between the different countries of the United Kingdom in their policies and patterns of support for carers, with each country broadly following the measures set out in the English/UK Government's Carers' Strategy.

However, outside the UK, patterns of support for carers display differences that reflect the historical assumptions, values and structures that underpin the particular systems of welfare services and support within which they are embedded. Thus, depending on the dominant priorities of welfare policies in different countries, patterns of support for carers may, for example, focus on protecting labour market participation and access to employment-related benefits; on safeguarding subsistence-level income maintenance; or on providing support through social insurance. Further factors shaping patterns of support for carers include different demographic patterns, and the assumptions that have traditionally been made in different countries about the roles of working age women. Thus in the Republic of Ireland, subsistence income maintenance policies reflect the traditional roles of unmarried sons and daughters in caring for older parents; in Sweden, women's full-time labour market participation is reflected in the employment-related rights for carers and in the opportunities for carers to enter into quasi-formal employment relationships with their municipality. Conversely, in other countries such as the Netherlands and Australia, the absence of such support reflects assumptions about the role of (married) working age women within the home and family. Indeed, despite the changing patterns of women's labour market participation in many countries, the international review of policies to support working carers suggests that these policies remain fragmented and weak. The influence of assumptions about the domestic role of working age women may weaken in future, as changing demographic patterns mean that growing numbers of carers of older people are themselves elderly.

Broadly speaking, the measures to support carers that have been identified in this report fall into five main clusters:

- ◆ Traditional formal, statutory services in kind, that are primarily provided for the person receiving care and are accessed through assessments of her/his needs. These 'carer-blind' services include home care, meals services, personal care and home nursing. In Sweden, for example, relatively high levels of home care services for older people have traditionally reduced the levels of support expected from family carers.
- ◆ Respite care, both home-based and in institutions. Recent new investment to stimulate the supply of facilities for 'breaks' for carers, and publicity to encourage carers to take advantage of these new facilities, are common in many countries. However, there is considerable ambiguity about whether the provision of respite care is intended to be for the carer or the older person being cared for. Consequently, assessment and access to a respite care service purportedly for carers can actually depend on the assessment and entitlements of the person receiving care (as in Germany and Australia). There is ambiguity about the benefits of respite care too, with some countries giving much more emphasis to its role in giving carers a break, regardless of the choices of the person receiving care; in others, the person receiving care is regarded as the major beneficiary of respite care.
- ◆ Payments that are broadly intended to acknowledge the costs and reward the work of care-giving. These are normally not wage-like

payments (Sweden is an exception here); are likely to be well below the full value of the actual work involved in care-giving; and are typically accessed through an assessment of the amount of help required by the older person. They are also frequently paid to the person receiving care, on the assumption that they will then pass them on to a family care-giver of their choice. The Netherlands, with its option of paying relatives through the Personal Budget scheme, is unusual in that the level of the payment is linked to the 'market' costs of providing support to an older person through the formal home help and home nursing services; it is far more common for these payments to be much lower and provide only symbolic recognition of carers' work.

- ◆ Measures that recognise the tensions between care-giving and paid employment. These include social security benefits to replace lost income (albeit at subsistence level); quasi-employment as a paid care-giver; and protection from loss of employment-related social rights (particularly pensions). Because of the widespread assumptions about women's role in care-giving, and women's traditional position in the labour market as part-time employees and secondary earners, these policies tend to be fragmented and the benefits/protection they offer are often minimal.
- ◆ 'Soft' forms of support, such as information, advice and membership of support groups. These are often located within the voluntary sector, with grant-aided and sometimes short term funding. However, this is the most widespread form of support across all the countries included in this summary and in all these countries it has been actively promoted as part of recent policies to improve support for carers.

Despite this diversity, a number of common issues can be identified:

- ◆ In most countries, the focus of policies, on carers themselves or on the older person receiving care, remains blurred. It is often not clear whether carers are regarded as needing support in their own right, or as a resource in the care of older people. Thus in many instances, there is little acknowledgement that carers may have needs that are separate from – and in possible conflict with – those of the person receiving care. The entitlement of carers in all the countries of the UK to an assessment of their own needs, independent of the needs of the older person receiving care, is unique in this respect. Moreover, this blurring involves a wider lack of rights and entitlements by carers; in many countries, carers' receipt of services and/or payments is dependent on an assessment of the needs and circumstances of the person receiving care. This is most starkly illustrated by Germany where, despite the widespread popularity of the LTCI cash payment option, carers have no independent entitlements of their own; access to *all* forms of support is entirely dependent on first establishing the older person's eligibility for long-term care insurance. Only in relation to income replacement benefits (the Carers Allowance in the UK and Republic of Ireland) do carers have the clearest, independent entitlements – but, by definition, these can only be enjoyed by carers of working age.
- ◆ Secondly, the boundaries between services in kind and cash payments are often blurred. In the UK, direct payments are being introduced to enable carers to purchase their own respite services; the cash option in Germany has always proved popular; and Finland and California (not considered here) are experimenting with voucher schemes for carers to use to obtain their own respite care. Cash payments appear to offer

choice; but, insofar as they are widely paid at far less than the full economic value of the care being given, they are an effective method of containing costs. Moreover, it is not clear that 'supply side' markets, containing services of adequate choice, flexibility and quality, exist to be purchased with such payments. The experience of Germany, where the LCTI cash payment option was introduced partly in order to stimulate this market, suggests that this process may be slow.

- ◆ Thirdly, there is no research that has examined support for carers in the context of growing world-wide patterns of migration. The position of refugees and recent immigrants who are carers is not known. Even when asylum applications have been accepted, countries may impose additional residence tests that restrict eligibility to people who have satisfied a period of residence in the country. Moreover, even when these tests have been satisfied, apart from Australia there is little evidence of measures to inform newly immigrant carers about available support or help them access these services.

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