
Consumer Direction and Choice in Long-Term Care
for Older Persons, Including Payments for Informal
Care: How Can it Help Improve Care Outcomes,
Employment and Fiscal Sustainability?

Jens Lundsgaard

20

Unclassified

DELSA/HEA/WD/HWP(2005)1

Organisation de Coopération et de Développement Economiques
Organisation for Economic Co-operation and Development

11-May-2005

English - Or. English

DIRECTORATE FOR EMPLOYMENT, LABOUR AND SOCIAL AFFAIRS
GROUP ON HEALTH

Health Working Papers

OECD HEALTH WORKING PAPERS NO. 20

**Consumer Direction and Choice in Long-Term Care for Older Persons,
Including Payments for Informal Care**

How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability?

Jens Lundsgaard

JEL classification: D10, I38, J22, L33, M50

This paper reports the detailed results of research on choice carried out as part of the long-term care study under the OECD Health Project, which will be published shortly under the title "Long-term care policies for older people". For more information about data and analysis of health policy, see www.oecd.org/health.

Jens Lundsgaard, tel. 0033 1 45248737, e-mail: jens.lundsgaard@oecd.org.

JT00183948

Document complet disponible sur OLIS dans son format d'origine
Complete document available on OLIS in its original format

DELSA/HEA/WD/HWP(2005)1
Unclassified

English - Or. English

DIRECTORATE FOR EMPLOYMENT, LABOUR AND SOCIAL AFFAIRS

OECD HEALTH WORKING PAPERS

This series is designed to make available to a wider readership health studies prepared for use within the OECD. Authorship is usually collective, but principal writers are named. The papers are generally available only in their original language – English or French – with a summary in the other.

Comment on the series is welcome, and should be sent to the Directorate for Employment, Labour and Social Affairs, 2, rue André-Pascal, 75775 PARIS CEDEX 16, France.

The opinions expressed and arguments employed here are the responsibility of the author(s) and do not necessarily reflect those of the OECD

**Applications for permission to reproduce or translate
all or part of this material should be made to:**

**Head of Publications Service
OECD
2, rue André-Pascal
75775 Paris, CEDEX 16
France**

Copyright OECD 2005

ACKNOWLEDGEMENTS

The preparation of this paper would not have been possible without the input from the representatives of the OECD member countries in the long-term care expert group and the Ad Hoc Group on the OECD Health Project. It has also benefited from valuable comments and discussions with Manfred Huber and other members of the OECD Secretariat including Martine Durand, Mark Pearson, Peter Scherer, Herwig Immervoll, Junichi Izumi, Patrick Hennessy, Weonjong Kim and Andres Fuentes but first and foremost the project has been funded partly by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services in the United States. Thanks also to Marianne Scarborough and Victoria Braithwaite for secretarial assistance.

SUMMARY

1. As the number of older persons in need of long-term care increases, efforts to support older persons remaining in their home are intensified in most OECD countries. In this context of *ageing in place*, there is a movement towards allowing more individual choice for older persons receiving publicly funded long-term care at home. Having more *flexibility in terms of how to receive care* can increase the older person's self-determination and that of his/her informal care givers. Having a *choice among alternative care providers* can empower older persons as consumers and may help strengthen the role of households in the care-management process. Choice can also help address quality aspects that are difficult to quantify but easy to experience for users, such as the personal interaction between the older person and the care giver.

2. Arrangements to increase choice and flexibility in long-term care often overlap with arrangements to support informal care. *Personal budgets* for care or *consumer-directed employment* of care assistants sometimes allow older persons to employ a relative. To get a complete picture of how OECD countries introduce choice in practice, such arrangements therefore have to be seen in connection with cash allowances or *payments to the person needing care* as well as *income-support payments to the informal care givers*. Even where there is extensive provision of formal home care, such as in the Nordic countries, much long-term care is still provided by unpaid informal care givers being relatives, friends and others. The role of informal care is therefore important in its own right and is increasingly recognised by policymakers in OECD countries. Also, in a very direct way, the option to have a relative or friend as carer (and vice versa to provide care for a relative or friend) can be seen as a central element of choice and flexibility in long-term care – provided that both parties consent. Payments for informal care are therefore covered by this paper, although it should be stressed that paying money to informal care givers is far from being the only and, if used as the only form of support, probably not the most effective way of mobilising, supporting, and qualifying a broad carer potential enabling older persons to stay longer in the community and reduce the need for expensive institutional care.

3. The main aims of this paper are *i)* to categorise and analyse different types of arrangements allowing home-care users more choice and map the prevalence of such arrangements in OECD countries, *ii)* to review outcomes in terms of flexibility, care quality, satisfaction and conditions for care givers, and *iii)* to analyse the implications for employment and fiscal sustainability.

4. The type of schemes, the level of support they provide and the number of users varies enormously across and within OECD countries – reflecting also that long-term care provision differs to a greater extent across countries than provision of acute health care. Choice arrangements are preferred by a sometimes significant share of the elderly, who report that they feel more satisfied and less dependent when having a *say* about how, when and notably by who care is provided. Indications of shortfalls in care quality or outright neglect of frail older persons are remarkably few, but informal *care givers* – most being female – appear to carry sometimes large burdens in terms of physical pain and emotional strain from feelings of excessive responsibility, overload and isolation when working alone.

5. The implications for employment and fiscal sustainability are fairly complex. Giving older persons a budget or cash to pay informal care givers can help tap into a wider pool of human resources where there are shortages of professional care workers. On the other hand, a functioning market for formal home-care services (or public supply of such services) is essential to allow relatives of older persons in

need of care to maintain their attachment to the normal labour market. And payments for informal care can risk creating “incentive traps” attracting informal care givers away from the normal labour market, if the interaction between informal care payments, taxes, unemployment benefits and other transfer incomes is not controlled well. After having been away from a normal job for a while, it can prove difficult to come back.

6. Future ageing of populations together with demands for maintaining an active lifestyle in old age will increase the policy relevance of these issues. The large cohorts moving into old age in the coming decades may bring the fiscal sustainability of current health and long-term care systems into question. In this context, publicly funded formal home care and in particular payments for informal care will have to be carefully targeted. With more years in retirement, of which many are spent without major disabling conditions, the growing number of healthy and active senior citizens represents a potentially very valuable resource as informal care givers. Finding the best way of nurturing this potential thereby shifting the task of providing informal care away from working-age children and towards able seniors – being spouses, neighbours and others in the local community – may well prove to be key to achieving fiscal sustainability.

RESUME

7. Le nombre de personnes âgées en perte d'autonomie augmentant, les efforts à leur intention destinés à leur permettre de continuer à vivre chez elles s'intensifient, dans la plupart des pays de l'OCDE. Dans cette logique du *maintien à domicile*, la tendance est à donner une liberté de choix de plus en plus grande aux personnes âgées qui bénéficient, chez elles, d'une aide et de services financés sur fonds publics. En acceptant *plus de flexibilité dans les modalités de déploiement de la prestation* on peut renforcer la capacité de décision de la personne âgée et des aidants informels. Le fait de donner à la personne âgée *la liberté de choix entre différents prestataires* peut lui conférer un certain poids en tant que consommateur, et cela peut contribuer à renforcer le rôle des ménages dans le processus de gestion de la prise en charge. La faculté de choisir peut aussi aider à prendre en compte les aspects qualitatifs, qui sont difficiles à mesurer mais très importants pour l'utilisateur, comme la qualité des échanges entre la personne âgée et la personne qui s'occupe d'elle.

8. Les mesures prises pour élargir les possibilités de choix et accroître la souplesse en matière de soins et services de longue durée se recoupent, souvent, avec les mesures destinées à soutenir l'aide informelle. La formule du *budget personnel* ou *le choix, directement par le consommateur, de la personne qu'il emploie* permettent, parfois, aux personnes âgées de faire appel à un proche. Pour avoir une vision complète de la façon dont les pays de l'OCDE introduisent des possibilités de choix, dans la pratique, il faut donc tenir compte de ce type de mesures, parallèlement aux prestations en espèces, *prestations à la personne qui a besoin d'être aidée* et *prestations de garantie de revenu aux aidants informels*. Même dans les pays comme les pays nordiques où les services formels d'aide à domicile sont très développés, une bonne partie des soins et services d'aide de longue durée est néanmoins assurée par des aidants informels non rémunérés, membres de la famille, amis ou proches, de façon générale. Le rôle des aidants informels est donc très important, et c'est un fait de plus en plus largement admis par les responsables publics, dans les pays de l'OCDE. Par ailleurs, la possibilité de faire appel à un proche ou à un ami pour se faire aider (et, à l'inverse, d'apporter son aide à un proche ou à un ami) peut apparaître comme un facteur essentiel de choix et de flexibilité dans la prise en charge de longue durée – dès lors que les deux parties sont d'accord. La question de la rémunération des aidants informels est donc traitée dans ce document, même s'il convient de souligner que ce n'est assurément pas la seule façon – et ce ne serait probablement pas la plus efficace si on y avait recours de façon exclusive — de mobiliser, de renforcer et de qualifier un vaste potentiel d'aide au profit des personnes âgées pour leur permettre de rester le plus longtemps possible dans leur environnement habituel et réduire la nécessité de recourir à des soins en institution coûteux.

9. Dans cet ouvrage, on s'efforce *i)* de classer et d'analyser les différents types de dispositifs destinés à offrir plus de choix aux utilisateurs de services à domicile, et de voir quelle place ces différents dispositifs occupent, dans les pays de l'OCDE ; *ii)* d'examiner les résultats en termes de flexibilité, de qualité des soins, de satisfaction et de conditions de vie des aidants ; et *iii)* d'analyser les conséquences sur le plan de l'emploi et de la soutenabilité budgétaire.

10. Le type de dispositifs mis en place, le niveau d'aide apporté et le nombre d'utilisateurs varient énormément d'un pays de l'OCDE à l'autre et à l'intérieur même des pays – reflétant en cela une plus grande variabilité de l'offre de soins et services de longue durée que de l'offre de soins de santé aigus. Le fait de pouvoir choisir a la préférence d'une proportion parfois significative de la population âgée, les personnes âgées se déclarant plus satisfaites et moins dépendantes lorsqu'elles ont leur mot à dire sur la

façon dont on les aide, le moment où on le fait et, surtout, sur le choix des intervenants. Les cas de déficit dans la qualité des soins ou de véritable négligence dans l'accompagnement des personnes âgées en perte d'autonomie sont rares, mais les aidants informels – qui, le plus souvent, sont des femmes – supportent parfois un lourd fardeau sur le plan de la fatigue physique et sur le plan émotionnel, du fait d'avoir à assumer de trop lourdes responsabilités, d'une trop lourde charge de travail et d'un sentiment d'isolement.

11. Les implications en termes d'emploi et de soutenabilité budgétaire sont assez complexes. Le fait de donner aux personnes âgées un budget ou des ressources pour rémunérer les aidants informels peut aider à mobiliser un plus vaste champ de ressources humaines lorsqu'on manque de professionnels. Mais, d'un autre côté, un marché qui fonctionne bien de services formels d'aide à domicile (ou de l'offre de ce type de services par la puissance publique) est essentiel pour permettre aux proches des personnes âgées qui ont besoin d'être aidées de préserver leur attachement avec le marché normal du travail. Et le fait de rémunérer les aidants informels risque de les attirer dans un piège qui les éloignera du marché normal du travail, si l'on n'est pas suffisamment attentif à tous les phénomènes d'interaction entre les versements aux aidants informels, les impôts, les allocations chômage et d'autres revenus de transfert. Il peut se révéler difficile, pour les aidants informels, de se réinsérer dans l'emploi normal après s'en être tenus à l'écart pendant un certain temps.

12. Le vieillissement futur des populations et la volonté d'encourager un mode de vie actif durant la vieillesse ne rendront ces questions que plus pertinentes dans l'optique de l'action gouvernementale. L'entrée dans la vieillesse des cohortes nombreuses, au cours des décennies à venir, risque de mettre à mal l'équilibre financier des systèmes de santé et des systèmes de soins et services de longue durée. Dans ce contexte, le financement public des soins formels à domicile et, plus encore, la rémunération des aidants informels devront être bien ciblés. Le nombre d'années passées à la retraite augmentant, dont un bon nombre d'années sans handicap majeur, les citoyens âgés en bonne santé et actifs constitueront un effectif de plus en plus nombreux qui pourrait représenter une source très précieuse de soins informels. Trouver la meilleure formule pour mobiliser ce potentiel en déplaçant la charge des soins et services informels des enfants d'âge actif vers les seniors en bonne santé – conjoints, voisins ou autres proches – pourrait se révéler d'une importance déterminante pour les équilibres financiers.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS..... 3

SUMMARY 4

RESUME 6

1. Introduction 9

2. Overview of the context of long-term care systems in the countries studied..... 11

3. Arrangements that allow users more choice when receiving long-term care at home 14

 A. Personal budgets and consumer-directed employment of care assistants..... 14

 B. Payments to the person needing care who can spend it as she/he likes but has to acquire sufficient care 15

 C. Income support payments to informal care givers 16

 Common issues and programme design 20

4. Outcomes: What is the experience with choice and payments for informal care?..... 25

 4.1. Improving flexibility, quality and satisfaction in long-term care 26

 4.2. Getting value for money – implications for employment and fiscal sustainability 32

5. Conclusions 41

REFERENCES 42

Boxes

Box 1. Terms and concepts used in this paper 9

Box 2. Non-financial support for informal care givers in Sweden..... 24

Box 3. What do Germans do when they have the choice between cash and services in kind? 27

Box 4. Quality is roughly the same but there is less feeling of dependency when receiving care via a personal budget in the Netherlands 28

Box 5. Quality of care in Austria and Germany..... 30

Box 6. Caring for relatives can be rewarding but also emotionally demanding 31

Box 7. Numeric example of possible incentives for informal care givers not to look for work in Germany³⁶

Box 8. Balancing informal care giving and work in Australia..... 40

1. Introduction

13. As the number of older persons in need of long-term care increases in OECD countries, home care continues to be the predominant – and preferred – care setting for a vast majority of households. To achieve the goal of *ageing in place*, a complex mix of services of acute health care, rehabilitation, long-term care, and social services is often needed, and – above a certain level of dependency – support by a main carer usually becomes indispensable. Over the last ten years, care systems in many countries have made considerable progress in moving away from the restricted choice of either receiving largely unsupported care at home from a relative or to receiving formal services in a nursing home.

14. Against this background, the main aims of this paper are *i)* to categorise and analyse different types of arrangements allowing home care users more choice and map the prevalence of such arrangements in OECD countries, *ii)* to review outcomes in terms of flexibility, care quality, satisfaction and conditions for care givers, and *iii)* to analyse the implications for employment and fiscal sustainability.

15. A complete analysis of choice and flexibility in long-term care would include the provision of care both in institutions and at home. It would address arrangements facilitating choice between alternative living arrangements for those in need of formal care. In this paper, only care provided to persons living at home is covered. The emphasis is on consumer-directed employment of personal care assistants and other forms of support of informal community-based care. The terms and concepts used in this report across the very diverse national contexts of OECD member countries are defined in Box 1.

Box 1. Terms and concepts used in this paper

The terms *long-term care* and *care* are used interchangeably in this paper. Individuals need long-term care when *dependent* due to a disability, chronic condition, trauma, or illness which limits their ability to carry out basic self-care or *personal* tasks that must be performed every day, defined as *activities of daily living*, ADLs (eating, dressing, bathing, getting in and out of bed, toileting and continence), or *practical* tasks that enable a person to live independently in a house or apartment, defined as *instrumental activities of daily living*, IADLs (preparing own meals, cleaning, laundry, taking medication, getting to places beyond walking distance, shopping, managing money affairs and using the telephone). Persons of all ages can need long-term care, but this paper focuses on older persons.

To facilitate international comparisons an age limit of 65 years has been chosen to distinguish care for older persons from care for younger adults. Long-term care needs start to increase exponentially from around 75 or 85 years and this could be an argument for using an age limit higher than 65 years. Any age limit will, however, be somewhat arbitrary, and the 65 years often used in national statistics has therefore been chosen.

Long-term care should be distinguished from curative and rehabilitative health care on the one side and from other services provided to older persons on the other:

- The difference between long-term care versus curative and rehabilitative health care is that the latter two aim at changing the medical condition of the person whereas long-term care only compensates for a lasting inability. A nurse visiting an older person at home to change a bandage and inspect the healing of a wound or administer an injection, for example, provides curative health care, not long-term care. But of course, if the nurse during the same visit helps the older person to take a bath, then the nurse provides a combination of curative health care and long-term care. Similarly, an older person attending physiotherapy to regain mobility after a hip-replacement receives rehabilitative care, not long-term care.
- Apart from the ability to carry out personal and practical tasks, human wellbeing also depends on *social interaction* with other human beings. Stimulating community interactions and the participation of older persons in social life is therefore often a central element of policies to develop home and community based care. So that apart from long-term care services, public programmes may, in practice, also support the provision of *other services* aimed at older persons that are not compensating for a lack of ability to carry out personal (ADL) or practical (IADL) tasks *per se*, for example activity centres or excursions for older persons. Such other services for older persons are not part of long-term care.

In practice, it can be difficult to separate the other types of care and services from long-term care, considering the way care provision is organised and information is recorded and made available. The data analysed in this paper may therefore include elements that are not long-term care in a strict sense. But the precise definitions should be kept in mind as guidelines.

A central distinction needs to be made between informal and formal long-term care. *Informal care* is the care provided by *informal care givers* (also called *informal carers*) such as spouses/partners, other members of the household and other relatives, friends, neighbours and others with an already existing social relationship with the older person to whom they provide care. Informal care givers also include volunteers, often linked to charitable or religious communities. To be considered informal, the provision of care cannot be paid for as if purchasing a service. However, an informal care giver may receive income transfers conditioned on his/her provision of informal care and possibly, in practice, some informal payments from the person receiving care.

On the other hand, *formal care* is care provided by *care assistants* who are persons paid for providing care under some form of employment contract. Formal care includes care provided in institutions like nursing homes, as well as care provided to older persons living at home by either professionally-trained care assistants, such as nurses, or untrained care assistants. They may work for an *agency*, either a public or private organisation or firm, or be self-employed or employed directly by the older person needing care. The difference between formal and informal care is first of all not about the type of care, but who provides it.

The term *consumer direction* is commonly used in North America and refers to arrangements whereby the older persons needing care or their families act as employers of care assistants and are therefore able to hire/fire, schedule, and supervise – in other words direct – the provision of care by the *consumer-* or *client-employed* care assistant.

If a person receiving care is served by the same care assistant continuously, he/she is referred to as a *personal care assistant*. Personal care assistants can be consumer- or client-employed, self-employed or employed by a firm that allocates them to the same customers continuously.

Countries may have systems of *accreditation* or *licensing* of health and long-term care *professionals* which are open to all who have the required education, training and skills. Similar accreditation or licensing can exist for agencies requiring specific staff qualifications, quality audit etc. In some cases, government or insurance agencies may contract with a *limited set of providers* and allow persons needing care to choose among these providers. In other cases, there is a *single designated* provider, such as a municipal home care agency, to which all persons eligible for care are *referred administratively*.

The living facilities for older persons are developing into a multitude of types making it difficult to propose a precise classification. For the purpose of this paper, a simple dichotomy is used between *institutions* including nursing homes, residential care homes and old age homes in which there is a permanent presence of care assistants versus care at *home* including houses and apartments that are not built specifically for persons needing long-term care, as well as adapted housing, group living arrangements etc. where there is not a permanent presence of care assistants. *Care for persons living at home* (also called *home care*) thereby includes all long-term care received by persons living outside of institutions.

Allowances, cash allowances, benefits and cash benefits are payments; they may be liable to income taxation, or exempt.

Tax deductions are reductions in the income liable for taxation reflecting actual documented expenditure such as the purchase of care. *Tax allowances* are reductions in the income liable for taxation allowed for tax payers satisfying certain conditions, such as providing informal care for an older person. The *value* of a tax allowance is the amount saved in tax payments (that is, roughly speaking, the tax allowance times the relevant tax rate). *Tax credits* are reductions made directly to liable tax payments.

2. Overview of the context of long-term care systems in the countries studied

16. This paper covers twelve countries, namely Australia, Austria, Canada, Germany, Ireland, Japan, Luxembourg, Netherlands, Norway, Sweden, the United Kingdom and the United States.¹ This is a subset of the countries covered in OECD (2005) and includes those countries that have experience with arrangements allowing users more choice and flexibility with regards to the way care is provided, and for which sufficient information was available. A brief description of major public long-term care programmes in these countries is given in Table 1.

Table 1. Major public long-term care programmes of countries covered in this report

Australia	Residential care is mainly funded by the federal government out of general taxation. Community Aged Care Packages (CACP) is a federal government programme to provide in-kind benefit for home care. Home and Community Care (HACC) is a home care programme jointly funded by Commonwealth government and the State and Territory governments.
Austria	Cash allowance for care covers both home care and institutional care in the form of cash benefits, covering the whole population since 1993.
Canada	Both home care and institutional care are provided via provincial programmes . Support is means tested, but to a varying degree across provinces.
Germany	Social Long-Term Care Insurance covers home care (since 1995) and institutional care (since 1996) for over 90% of the population.
Ireland	Public funding exists for both home care and institutional care based on general taxation.
Japan	Long-Term Care Insurance is a social insurance scheme which provides both home and institutional care for the elderly as in-kind benefits.
Luxembourg	Public support for long-term care is mostly based on the Dependency Insurance , where users have to pay the difference between the benefit and actual costs of care.
Netherlands	Algemene Wet Bijzondere Ziektekosten (Exceptional Medical Expenses Act) is a social insurance which covers both home and institutional long-term care.
Norway	Local authorities have full responsibility over public long-term care according to the Municipal Service Act and the Social Services Act .
Sweden	Municipalities are responsible and provide most of the home and institutional long-term care services based on the Social Services Act .
United Kingdom	Social services provide both home and residential care funded by municipalities with subsidies from the central government. National Health Service provides home and institutional health care and is funded and managed by the central government.
United States	Medicare is a federal programme for persons aged 65 and over and for certain disabled groups. It covers care in nursing homes and home health services for a short period of time after an acute event, but it does not cover continuing long-term Medicaid is a joint federal and state programme, which covers both home and institutional care for persons with low income.

1. In some cases tables and figures include for comparison also other countries covered in the wider long-term care study, and in some cases Denmark is also mentioned. The latter is based on the author's own compilation of material from official sources as the Danish authorities were not formally involved in the preparation of this study.

17. In a number of OECD countries, long-term care policies have been reformed to allow users more choice among care providers and flexibility with regards to the way care is provided. The different ways countries might seek to increase flexibility and choice in long-term care depend, among other things, on the weight they put on formal care provision versus informal care. This, in turn, partly reflects cultural factors, and arrangements for care can be seen to represent different family models (Rostgaard, 2004). Countries with above-average public funding for long-term care tend to rely more on formal care than others, but this is not the full story. As illustrated by the stylised picture of long-term care systems in Figure 1, Panel A, the OECD countries analysed in this paper can be broadly subdivided into five groups:

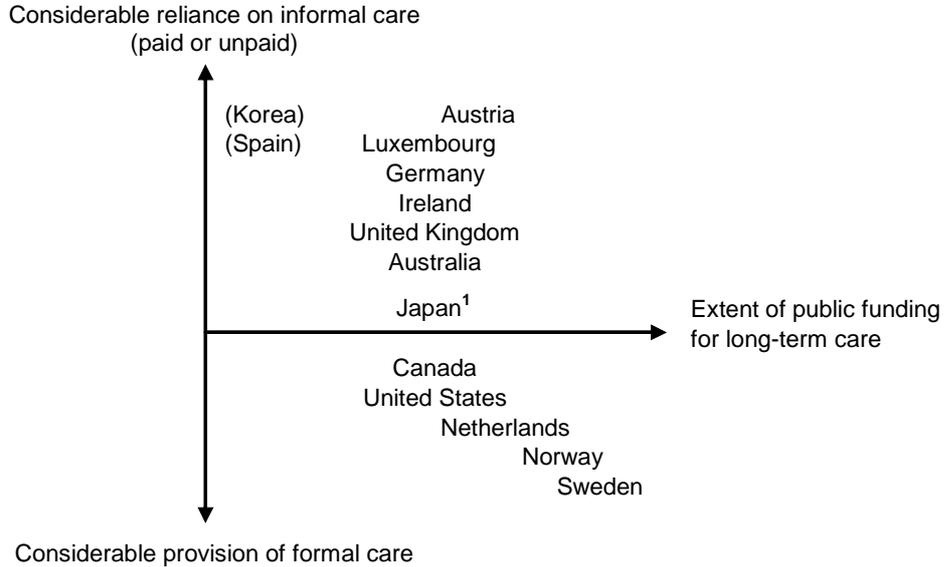
- In **Korea, Spain** and other Southern European countries long-term care is, to a large extent, provided informally within families, so that although nursing homes and other residential care institutions are predominantly funded publicly, overall long-term care provision is based on private resources to a greater extent than in other OECD countries.²
- **Austria, Luxembourg, Germany, Ireland, United Kingdom** and **Australia** have considerable levels of public funding for long-term care compared to countries like Korea and Spain. A significant share of this is in the form of payments in support of informal home care either by granting these allowances directly to care recipients, allowing them to choose whether to share them with a carer informally or to purchase other forms of care (Austria, Germany and Luxembourg), or by granting long-term care allowances to relatives providing care to older persons (Australia, Ireland, United Kingdom).
- In **Japan**, informal care within families plays a large role as well, but it is not supported financially by public programmes. Mandatory long-term care insurance now provides for substantial formal services as care alternatives.
- In the **United States** and **Canada**, informal care plays some role, but is not supported much financially by public programmes. However, the increasing orientation towards consumer direction in care has brought arrangements where in some cases relatives can be employed.
- The **Netherlands, Norway** and **Sweden** have considerable levels of public funding, but channel most of this through provision of formal services for both home care and institutional care.

18. Countries may increase flexibility by introducing choice either through support for informal care or choice among providers of formal care. As illustrated by Figure 1, Panel B, the one doesn't necessitate the other. For instance, in Sweden, where the scope of choice for persons receiving formal care is typically limited and where payments for informal care play a limited role, the introduction of choice by some local authorities currently implies moving horizontally (to the right) in the chart towards choice among a limited set of approved providers. Germany, on the other hand, moved vertically (upwards) in this chart with the introduction of the *Cash Allowance for Care (Pflegegeld)*, and also horizontally (to the right) as the long-term care insurance reform in 1995 implied more choice among formal care providers. An important point is that improving flexibility of care through choice does not necessarily imply privatisation of funding. Whether countries maintain (or expand) public funding or coverage of long-term care costs can be a separate issue from whether they channel it through formal long-term care services.

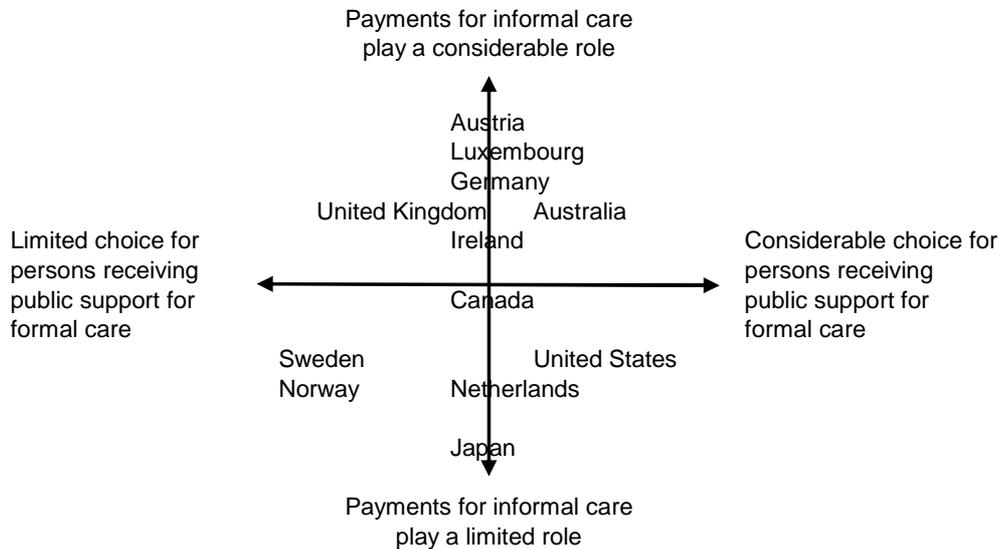
2. These countries are not covered in this study, but they are included here for comparison.

Figure 1. Stylised picture of long-term care provision in OECD countries

A. The extent to which countries rely on formal as against informal care has little relation to the extent to which care is publicly funded



B. Some countries offer choice among providers of publicly supported formal care and some countries offer payments for informal care



Note: This figure aims to give simply a rough illustration. The position of countries should not be read as reflecting an exact metric, but rather whether the country in question is at the one or the other end of the spectrum of OECD countries - or somewhere in between.

1. The system in Japan has changed considerably in recent years. With the introduction of the social insurance scheme for long-term care, Japan has moved and is moving "south-east" in the diagram towards increased public funding and development of an infrastructure of formal care.

19. With respect to choice among agencies providing home care or among *institutions*, there are very fundamental differences between countries. On the one side, the **Nordic** countries have build up provision of formal home care services almost exclusively through public agencies, and therefore introducing choice among alternative public and private providers comes in as an “additional” element which has been the matter of policy debates over the last decade or so. On the other side, the long-term care systems in most other countries are “born” with more choice among providers when older persons get publicly funded formal care services. The **United States** has considerable levels of public funding for long-term care but it is targeted at persons with low income, and the supply of care services and the market for providers of home care and assisted living are therefore in part shaped by the demand from older persons paying privately. Older persons receiving care supported by Medicaid therefore often have a choice among different agencies. In countries like **Germany** where public funding for long-term care (as for health care) is based on social insurance funds, the purchaser-provider split is a basic feature of the system. This facilitates choice among providers of formal care services as there is not one incumbent agency.

3. Arrangements that allow users more choice when receiving long-term care at home

20. A number of fairly different arrangements are used in OECD countries to allow more choice for persons receiving long-term care at home. Although they differ in many respects they can usefully be subdivided into three main groups as shown in Table 2, Panel A, B and C.³

A. Personal budgets and consumer-directed employment of care assistants

21. As an alternative to provision of formal home care by a single designated agency, different arrangements can strengthen the position of older persons as active consumers, making their individual demands clearer. Older persons needing care can be given a personal budget to purchase care from alternative competing agencies, or they and their families can be allowed to employ a personal care assistant directly and thereby be able to hire/fire, schedule, and supervise – in other words direct – care provision.

22. The *Personal Budgets* scheme in the Netherlands is the biggest of the schemes in this category. In 2003, 0.8% of the population aged 65 or over received home care through a personal budget – compared to 7.4% receiving some form of formal care at home (see columns to the right in Table 2, Panel A). Most of this amount has to be used for formal care services.

23. In all of the programmes listed in Table 2, Panel A, care assistants have a formal employment contract, even if they are relatives of the person receiving care. Therefore, care assistants are typically paid for a specified number of hours. They can provide care to several persons at the same time and their wage does not depend on what income they have from other sources, as could an income support payment. The level of care needs covered by these programmes varies from typically 3-10 hours per week for the Norwegian *Care Wage* and up to a maximum of 66 hours per week for the Californian *In-Home Supportive Services* programme. In practice however, relatives and friends employed as care assistants often provide care during more hours than they are paid for.

24. Personal budgets may also allow the person to combine care with purchase of physical aids such as a special bed or chair and can generally support very flexible solutions. In this respect, the *Cash &*

3. See Lundsgaard (2003) for a comparison of how competition and choice is introduced in long-term care versus other publicly funded services.

Counseling programme differs from other consumer directed home care programmes in the United States.⁴ In the Netherlands, no accounting is required for a limited amount of the personal budget. This can be used to compensate informal help.⁵

25. The table includes information on the level of payments. Under this category of schemes the level of payments or public spending is roughly similar to what it would be for agency-based formal home care, as the care assistants employed by consumers in many schemes get an hourly wage similar to that of care assistants employed by agencies. For the US *Cash & Counseling* programme, the table shows the average monthly payment levels per person, ranging from USD 400 in Arkansas to USD 1 400 in New Jersey. To compare across countries with different currencies, this table shows the monthly payment levels also as a share of average private consumption per person. The USD 400 corresponds to 19.6% of what an average person in the United States spends for private consumption per month (Table 2, Panel A).⁶

B. Payments to the person needing care who can spend it as she/he likes but has to acquire sufficient care

26. Some countries give older persons needing care the option of getting cash to finance (part) of their expenditure on long-term care (Table 2, Panel B). In Germany, persons receiving support from the long-term care insurance can choose between a budget for care services in kind and the *Cash Allowance for Care*, and in Luxembourg those entitled to home care support under the long-term care insurance may take part of this support as a cash benefit rather than services or everything as cash if found eligible for 7 hours weekly or less. In Austria, *all* public support for long-term care to persons living at home is given as cash. In practice, a substantial part of these cash payments is used to compensate informal care givers or simply enters the household budget when care is provided by co-habiting relatives.

27. While there are no explicit restrictions on how the German *Cash Allowance for Care* is spent, the older person and their relatives are nevertheless obliged to acquire sufficient care. The health condition and wellbeing of recipients is reviewed every 3 or 6 months by an agency. If the older person is found to be receiving insufficient care in light of her/his needs then the authorities must find some provision of ensure care services in kind are provided, in which case the cash allowance is withdrawn. For the UK Attendance Allowance, the requirements are looser, as there are no restrictions on how the money can be spent, and it can be received even if the person does not obtain care from anybody. As long as the older person is at home (not in hospital or an institution) and has had the need for care for at least six months, she/he is eligible for the Attendance Allowance which is paid independently of the person's income and assets (as for the other schemes listed in panel Panel A and B).

28. Compared to schemes listed in Panel A, eligibility for most of the schemes listed in Panel B is quite extensive. The Austrian and German schemes pay *Cash Allowance for Care* to 14.8% and 5.7% respectively of the population aged 65 or over. The payment levels vary considerably depending on need, with averages of 35% and 27% of private consumption per capita. When these payments are passed on to

4 The Cash & Counseling Demonstration and Evaluation programme was an initiative of the federal government, with operations beginning in three states in 1998-2000. The purpose was to test the limits of consumer direction via cash benefits by allowing the persons needing care to substitute between care services, modifying their homes or vehicles and the purchase of items that help them live independently. See Doty (2000), Mahoney *et al.* (2000) and Foster *et al.* (2003).

5 From April 2003, 1.5% of the assigned budget does not need to be accounted for, between a minimum of €250 and a maximum of €1250 per year.

6 Considering payment levels relative to private consumption shows their relation to the average household budget (for one person).

informal care givers, they are in practice rarely taxed as income for the care giver, as the relation remains informal, being usually within the family. The UK *Attendance Allowance* provides support to as many as the Austrian scheme but with a much lower maximum benefit paid.

C. Income support payments to informal care givers

29. A number of OECD countries offer payments to informal care givers in order to partly compensate for the loss of income while providing care, thereby enabling the care giver to reduce other work activities (Table 2, Panel C). Some of these allowances or cash benefits pay around half of the average private consumption per person while the Swedish temporary *Care Leave* pays more than that. Other allowances, however, give only a limited supplement to the income of a household, such as the Japanese *Allowance for Families Caring for Elderly*, which pays an amount equal to 5% of average private consumption per person.⁷

30. The essential difference between consumer or client employment of a care assistant (reviewed above, in Panel A) is that income support is not meant to fully compensate care givers for the value of their work. Rather they are meant to sustain a minimum level of income for persons who are unable to have a normal full-time job due to providing care for somebody who is near to them such as a relative or close friend. Therefore, some schemes are only available for low-income carers, namely the Australian *Carer Payment*, the Irish *Carer's Allowance*, the Japanese *Allowance for Families Caring for an Elderly* and the UK *Carer's Allowance*. To be eligible for support, the income and asset criteria may also take into account the income and assets of the carer's spouse or partner and thereby exclude carers from middle- or high-income families. Also, payments from these schemes is often combined with other forms of public income support.⁸ Other schemes are built into labour market institutions and provide an option for a temporary leave from work. As such they are available to persons at all income levels. The Canadian *Compassionate Care Benefit* and the Swedish *Care Leave* replace 55% and 80% of the care giver's previous or normal employment income up to a maximum, while the Irish *Carer's Benefit* pays the same amount to all recipients.

7 As several of these schemes are only available for low-income carers, however, the proportion of private consumption will be greater than the national accounts per capita average.

8 In Australia, for example, informal care givers can receive *Carer Payment* and *Carer Allowance* simultaneously if eligible for both. For example, a person aged 50 with low income who provides substantial care to, and lives with, her/his mother or father can receive both *Carer Payment* and *Carer Allowance* corresponding to 64% of average private consumption less taxes, but only *Carer Payment* if living separately (corresponding to 54% of average private consumption less taxes). In both cases, other income support payments may be added, such as Rent Assistance.

Table 2. Personal budgets, consumer-directed employment of care assistants and payments for informal care for older persons

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

Country	Programme	Description	Can relatives be employed or supported?	Monthly payment levels			Share of 65+ population receiving home care via this programme	All public home care 2 Share of 65+ Spending per user pop.	
				Lowest	Main or average	Highest			
				% of private consumption per capita 1 Monthly amount in nat. currency and USD PPP			%	% of private cons. pc.	
A. Personal budgets and consumer directed employment of care assistants 3									
Netherlands	Personal Budget for Care and Nursing <i>Persoonsgebonden budget</i>	Personal budgets can purchase agency care, directly employ a care assistant and also pay some cash for appliances and informal care.	Yes, 4 but not if living together	The size of each budget is equal to what would have been the public expenditure on formal services net of user charges less an "efficiency deduction" of 15-20%.			0.8 5	12.3	57 %
Norway	Care Wage <i>Omsorgslønn</i>	Pays relatives or others for caring when this is considered better than agency care. Typically 3-10 hrs/week.	Yes	The carer is paid for a given number of hours typically using the hourly wage of a care assistant in the public agency.			0.3	18.0	57 %
Sweden	Carer's Salary <i>Anställda anhörige</i>	The person giving care is treated as employed by the public agency. Scheme used in remote areas.	Yes, but not if older than 65 years.	Person giving care is paid a salary similar to care assistants in the public agency and has similar social security protection.			0.1	9.1	101 %
United Kingdom	Direct Payments	New scheme. Older persons eligible for care can now choose a direct payment for purchase of care.	Yes, 6 but not if living together	Same as the net costs of the services assessed as required.			0.04 7	20.3	13 %
United States	Consumer Directed home care	Consumers can hire and supervise a personal care assistant who will be paid by Medicaid for a specific number of hours.	Most prg. allow relatives but not spouses	Payment levels vary across prg.s reaching up to \$2760 a month in Kansas' HCBSFE prg. and up to 66 hrs/week in California's IHSS prg.			0.5		
United States	Cash & Counseling	Demonstration and Evaluation prg. in Arkansas, Florida and New Jersey. Budget can pay also for home adaptation etc.	Yes	20 % \$400	36 % \$723	69 % \$1400	Experimental with 1000-2000 older persons in each state	2.8	60 %

1. Percentages of private consumption are calculated based on household final consumption expenditure per capita in the national accounts statistics which is roughly equal to average disposable income per capita. Payment levels in USD at purchasing power parity (PPP) are calculated using 2003 exchange rates. For comparability across programmes, all payment levels are shown as monthly amounts even if some programmes determine the payment each person is eligible for on a weekly basis.

2. The total share of the population aged 65 and over receiving home care funded by some public programme or mandatory insurance (including the schemes shown in this table) and the average public spending per person receiving home is shown here for comparison. See Huber (2005) for details on the compilation of the underlying data.

3. The person receiving care does not pay income tax of the benefits from these schemes, but as there is a formal employment relationship, the caregiver will be taxed of the income she/he receives.

4. If the person needing care lives together with healthy adult relatives then they are obliged to do the necessary housekeeping tasks irrespective of whether they are in working age or have retired. Relatives living in the same household can therefore only be employed to provide care beyond these functions. In practice, employment of relatives living in the same household is seen mostly for adult disabled and only rarely for care

5. Personal Budgets were introduced in 1995 and grew to a total of 23,000 users in year 2000 and 54,000 in 2003. In 2003, about a third of all users were older persons which corresponds to 0.8% of the population aged 65+ as shown in the table.

6. With an adjustment of legislation from April 2002, people can use their direct payment to pay a relative who lives with them, but only in exceptional circumstances where they and their local council consider that this is the only satisfactory way of meeting their care needs.

7. Since introduced in 2000 for older persons also, the number of users in England aged 65 and over has grown from only 500 in year 2000/1 to 2,700 in 2002/3 corresponding to 0.04% of the population aged 65+.

8. The average monthly payment levels differ in the three states involved, from \$400 in Arkansas, and \$723 in Florida to \$1400 in New Jersey.

DELSA/HEA/WD/HWP(2005)1

Table 2. Personal budgets, consumer-directed employment of care assistants and payments for informal care for older persons (cont.)

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

Country	Programme	Description	Can relatives be employed or supported?	Monthly payment levels			Share of 65+ population receiving home care via this programme	All public home care 2 Share of 65+ pop. Spending per user	
				Lowest	Main or average	Highest	%	%	
				% of private consumption per capita 1 Monthly amount in nat. currency and USD PPP				% of private cons. pc.	
B. Payments to the person needing care who can spend it as she/he likes, but has to acquire sufficient care 9									
Austria 10 11	Cash Allowance for Care <i>Pflegegeld</i>	All public support for home care is through this allowance. Recipients can purchase formal care if they wish.	Yes	13 % €145 ; \$154	35 % €405 ; \$430	132 % €1532 ; \$1626	14.8	14.8	na.
Germany 10	Cash Allowance for Care <i>Pflegegeld</i>	Under the long-term care insurance, recipients can choose between care in-kind and this allowance.	Yes	18 % €205 ; \$209	27 % €311 ; \$317	57 % €665 ; \$678	5.7 12	7.1	53 %
Luxembourg	Cash Allowance for care <i>Prest. en espèces</i>	Under the long-term care insurance, recipients can choose to replace the first 7 hrs/week of care in-kind by this allowance.	Yes	15 % €267 ; \$272	39 % €679 ; \$693	63 % €1100 ; \$1122	3.9 13	4.3	32 %
Sweden	Attendance Allowance <i>Anhørig bidrag</i>	Cash payment to the person needing care who can then pay informal caregivers. Minimum care need of 17 hrs/week.	Yes		52 % Sek5000 ; \$515		0.1	9.1	101 %
United Kingdom 14	Attendance Allowance	A cash benefit to persons aged 65+ who have been needing care at home for at least six months.	Yes	16 % £170 ; \$266		24 % £255 ; \$399	19.3	20.3	13 %

9. The person receiving care does not pay income tax of these benefits. Nor does an informal caregiver living together with the person, as the payment is simply shared within the household. Presumably, informal caregivers from outside the household rarely report money they receive in this way as income when filing their tax statement, and the person receiving care has no obligation to report to whom they pass on money.

10. The middle-column "Main or average" shows a weighted average of payment levels received by beneficiaries aged 65+. "Lowest" and "Highest" show bottom and top of payment scale.

11. Because this cash allowance is also the channel for support to persons with very intensive care needs requiring institutional care, the highest level reaches 132% of average private consumption per capita. But only 1.2% of older persons receiving support are at this highest level. The lowest payment level is available for persons needing care for 12 hours or more per week.

12. This includes those choosing to have all the support they are eligible for as a cash allowance (4.7% of the 65+ population) as well as those choosing a combination of cash and services (1.0% of the 65+ population). In addition to this, 0.8% of the 65+ population receive support from the long-term care insurance while choosing to have all as services. This calculation assumes an equal propensity to choose the three options for the three quarters of long-term care insurance recipients aged 65 years or over and the one quarter younger than 65. Data for 2001.

13. This includes those choosing to have all the support they are eligible for as a cash allowance (2.1% of the 65+ population) as well as those choosing a combination of cash and services (1.8% of the 65+ population). In addition to this, 0.4% of the 65+ population receive support from the long-term care insurance while choosing to have all as services. This calculation assumes an equal propensity to choose the three options for the two thirds of long-term care insurance recipients aged 65 or over and the one third younger than 65 years. Data for the number of beneficiaries on 30 June 2003.

14. Depending on individual circumstances such as whether care is needed also at night, the payment levels vary more than indicated by the typical low- and high-level payments shown in the table.

Table 2. Personal budgets, consumer-directed employment of care assistants and payments for informal care for older persons (cont.)

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

Country	Programme	Description	Means tested on caregiver?	Can relatives be supported?	Monthly payment levels			Share of 65+ population receiving home care via this programme	All public home care 2 Share of 65+ Spending per user
					Lowest	Main or average	Highest		
					% of private consumption per capita 1 Monthly amount in nat. currency and USD PPP			%	% of private cons. pc.
C. Income support payments to informal caregivers 15									
Australia 16	Carer Payment	For people who cannot support themselves because caring.	Yes	Yes	53 % A\$934 ; \$682		0.9	14.7	28 %
Australia 16	Carer Allowance	For people who live with and care for somebody at home.	No	Yes	11 % A\$191 ; \$139		4.0	na.	na.
Canada	Compassionate Care Benefit	A short-term benefit for persons caring for somebody with a terminal condition.	No 17	Yes	Pays 55% of normal employment income. Max payment is C\$1790 ; \$1467 per month.		New scheme introduced in 2004	na.	na.
Ireland 18	Carer's Allowance	For carers with low income who live with and look after people needing full-time care.	Yes	Yes	Nil	50 % €683 ; \$683		ca. 5	61 %
Ireland 19	Carer's Benefit	A payment to insured persons leaving work temporarily for someone needing full-time care.	No	Yes	47 % €649 ; \$649		Scheme introduced in 2000	5.5	39 %
Japan	Allowance for Families Caring for Elderly 家族介護者年金	Only if low-income family, heavy care needs and not supported from long-term care insurance.	Yes	Yes	5 % ¥8333 ; \$60		New scheme playing a limited role	9.1	101 %
Sweden	Care Leave	Statutory right to take leave from work for up to 60 days when caring for a terminally ill relative.	No	Must be a relative or close friend	Pays 80% of normal employment income.			20.3	13 %
United Kingdom	Carer's Allowance	For low-income persons caring 35+ hrs/week for someone receiving Attend. Allowance. 20	Yes	Yes	18 % £192 ; \$300				

15. These income support payments are typically taxed as income for the caregiver (but not for all schemes), and the net-of-tax amount will therefore be smaller than the gross amount shown in the table. How important this difference is depends also on what other income the caregiver has since with progressive tax scales, the net-of-tax amount will be smallest for high-income caregivers. As many of the schemes are targeted at low-income caregivers, however, the actual difference between gross and net amounts may be limited.

16. Data for the number of recipients refer to June 2002 while payment levels are those that came into force by January 1, 2003. The Carer Payment will under most circumstances be liable for taxation when caring for an older person. Carer Allowance is newer taxed as income. If Carer Payment is received by both in a couple, the monthly payment level is A\$780 per recipient (45% of private consumption pc).

17. As the level of payments is a percentage of normal employment income, it will grow with income in the interval below the ceiling. But for persons with low income and children there is a Family Supplement. 18. The maximum amount shown in the table applies for a person aged 66 or over and with very little income giving care to one person. If caring for more than one person, the maximum is €1026 per month. For caregivers aged under 66 years the allowance is reduced by €79 - 118, while for each dependent child it is raised by €36 - 73 per month.

19. Amount applies if caring for one person. If caring for more than one, the benefit is €973 per month, and for each dependent child the caregiver has, the benefit is raised by €36 - 73 per month. 20. In 2002, the Carer's Allowance has been made available also for care-givers aged 65 and over. The payment is only available for persons with disposable income below £342 a month (32% of private consumption pc.) where disposable income is calculated net of spending on respite care etc. The benefit is taxable.

Source: Based on replies to the long-term care questionnaire and research into various other national sources.

31. Finally, some schemes are meant to reward or recognise the efforts of all informal care givers, also those caring for persons with less severe needs, for example the Australian *Carer Allowance*. Eligibility is therefore conditioned only on the provision of care, not on the income or assets of care givers. Giving the limited amount of the *Carer Allowance* to a wide group of persons living with, and caring for, an older person at home – equal in number to 4.0% of the population aged 65 or more – creates an extra incentive for the family not to seek institutionalisation that would entail larger public expenses.

32. In Japan, local authorities may decide if they wish to use a central government grant to support informal care, including the *Allowance for Families Caring for an Elderly Person*. This allowance has been introduced very recently and it is expected to play a minor role. The major policy direction is to expand institutional care provision through Long-Term Care Insurance (see Chapter 5 in OECD, 2005).

Common issues and programme design

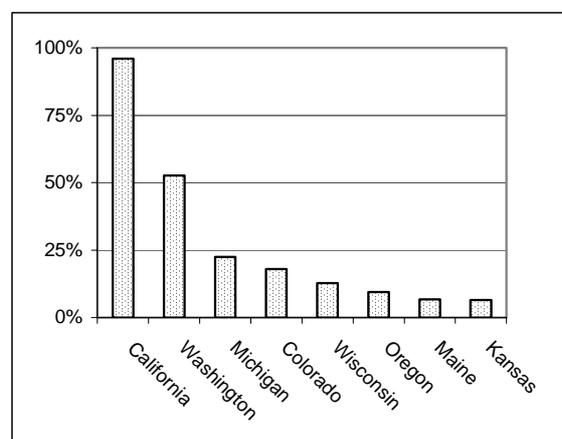
33. The review above shows how vastly different the programmes allowing choice in home care are across countries – both in terms of their structure and their size, ranging from comprehensive *Cash Allowance for Care* in Austria to small and experimental programmes in other countries. Even where seemingly similar arrangements have been put in place, the underlying policy goals for their introduction may not have been the same, taking into account different starting positions and policy context. In the following, different aspects of programme design that cut across the various schemes listed under the three categories in Table 2 are addressed.

34. In addition to the large variation in the size of the different schemes, there is also large variation across regions and local areas in the prevalence of each scheme. In the United States, the number of persons receiving consumer-directed home care based on public funding varies strongly across states reflecting differences in the organisation and provision of services even under the federally subsidised *Medicaid* programme (Figure 2, Panel A). Likewise in Norway, the number of persons receiving a *Care Wage* varies considerably across local governments even though the programme is based on national regulations. While in the average local government, the number of persons receiving *Care Wage* corresponds to 4.5% of the total number of persons receiving home care, this share is over 10% in 26 out of 404 local governments (Figure 2, Panel B).⁹

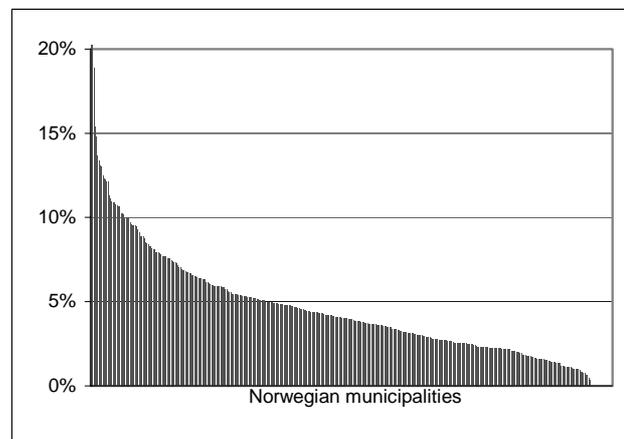
9 The scheme is most popular in the smaller municipalities and for the (unweighted) average municipality, the number of persons receiving *Care Wage* as a percentage of home care recipients is, therefore, larger than for the country considered as a whole. Norway has 435 local governments, but data are only available for 404.

Figure 2. Geographical variation in the prevalence of schemes

A. Consumer directed services as a share of all publicly funded home care in different states of the United States, 1999



B. Care Wage, *Omsorgslønn*, as a share of all publicly funded home care in different local governments in Norway, 2001



Source: OECD based on Tilly and Wiener (2001), Centre for Medicare & Medicaid Services, and the Kostra database of Statistics Norway.

Are these schemes integrated with other forms of long-term care? Is there a legal right to consumer-directed care rather than services from an agency to which users are referred administratively?

35. Some of the schemes analysed here are directly integrated with other arrangements for long-term care in the sense that there is a unique procedure for determining eligibility for support from public and social insurance programmes. A person found eligible is allocated a given level of support expressed as a particular set of services, a number of hours weekly or an amount of money. From thereon the person needing care can choose how to obtain care and how to “spend” the support for which she/he has been found eligible; either from an agency designated by the public authorities or insurance programme, from an alternative agency or self-employed care assistant, by employing a personal care assistant her/him self or possibly receive a cash allowance to support informal care. The German long-term care insurance comes close to this description.

36. Cash allowances and income support payments are typically based on clear-cut criteria and persons who satisfy these criteria have a right to benefit. Access to other schemes may be more restricted and depend on judgements made by assessment teams and local authorities. In Norway, there is no legal right to benefit from the *Care Wage*. Even if an older person agrees with a relative and prefers to rely on informal care, they can only benefit from the *Care Wage* if the local authorities consider this a better alternative than formal care provided by its own agency. The older person’s assessment of the quality of care provided by the local authority’s agency is not enough. Considerable variation in the number of care givers under the scheme could indicate that this access criterion is applied differentially in different localities. The UK *Direct Payments* scheme has only grown slowly, because local governments holding long-term care budgets have been slow to offer this option to older people (Wiener *et al.*, 2003). Central government has therefore set up a development fund to enable community organisations to receive grant aid to enable them to provide advice and assistance to potential and actual applicants for *Direct Payments*, and while the scheme was first introduced as an additional option for local governments to offer, recent legislation has given those assessed as needing home-based care a right to request a *Direct Payment* rather than in-kind services.

37. The Dutch system has evolved to become more integrated and rights-based. When the Netherlands introduced personal budgets for care and nursing in 1995,¹⁰ those eligible for at least three months of home care could apply to have a personal budget instead of care services in kind, but within an annual cap on total national spending via personal budgets. This limitation has gradually been relaxed, and from 2001 there has been an open-ended subsidy which has made the personal budget system function as if it were an entitlement for those eligible for long-term care. Following the reform of the Dutch long-term care insurance scheme in April 2003, all those who qualify for home-based long-term care can opt for a *Personal Budget* (Huijbers, 2003). At the same time, a new eligibility assessment protocol has become obligatory, specifying care needs of each individual in terms of seven functional types of service: home help, personal care, nursing, supporting supervision, activating/advising supervision, treatment, and residential care. For these types of care, those eligible for help from the public insurance scheme may make their own contracts with providers or employ an individual. For care providers this means that they now have to take individual needs as the point of departure, rather than their own supply of services. At the same time, new types of providers have been approved and existing approvals have been broadened, such as by allowing residential-care facilities to offer home-care services as well. The option of employing a relative or friend (as 21% of budget holders did in 1999) is thereby fully integrated with the options of contracting with a self-employed care assistant (as 44% did), with one of the traditional non-profit home care agencies (as 23% did) or with one of the new private firms providing home care (as 27% of budget holders did in 1999).¹¹

Fiscal agents and administrative procedures for approving the use of money

38. In the Netherlands until April 2003, payments for care under a *Personal Budget* have so far been made exclusively through the banking organisation SVB and based on prior approval of each expense by an administrative entity supervising the use of the person's budget. Since April 2003, it has been possible for individuals with a personal budget simply to have the money transferred to their own bank account and from there pay care assistants etc. themselves. However, they still have to account – now *ex post* – for how the money has been spent each month, and any amount not documented for must be paid back. Therefore the *Personal Budgets* are still a quasi-voucher system as the budget can only be spent on care-related goods and services. This is different from the cash allowances listed in Table 2, Panel B.

Character of the employment relation and conditions for informal care givers

39. Only the programmes listed in Panel A of Table 2 involve a formal employment relationship, but for some other programmes informal carers have some of the entitlements that an employed person would normally have, for example pension entitlements in the case of Germany.

40. In the United States, tax law requires that all consumer-directed care assistants are treated as employees – consumer-employed – rather than as self-employed. This implies that they are subject to federal and state laws concerning working hours and minimum wages, and many of these personal care assistants must be covered for unemployment and worker's compensation in case of on-the-job injury. Like

10 Personal budgets for nursing and care were introduced on an experimental basis in two regions of the Netherlands in 1991; from 1995, persons from all over the country who had been found eligible for long-term care were allowed to apply for budget holder status.

11 The percentages sum to more than a hundred because some budget holders apparently obtained care services from multiple sources. Note that the percentages refer to those with personal budgets in 1999. In that year majority were receiving care from the traditional non-profit home care agencies but still not via a personal budget.

self-employed persons, consumer-employed care assistants must also be covered by social security, with contributions being paid partly by the care assistant and partly by the public programme on top of the wage. The consumer-directed programmes vary across states but generally follow one of three models: *direct pay*, in which the consumer is the employer of record and has full hiring, firing, tax and payroll responsibilities; *fiscal intermediary*, where a designated agency handles payroll and taxes and the consumer selects and manages the employee; and *supportive intermediary*, in which a public agency provides supportive services such as recruitment assistance, criminal background checks and training. The Cash & Counseling demonstration project combines the direct pay and fiscal intermediary models by letting *Medicaid* beneficiaries select their personal care worker while either receiving cash to pay the worker or using an intermediary as employer. Counselling helps the consumer with tasks such as managing the cash, handling payroll and taxes and recruitment.¹²

41. In Norway, the exact type of employment relationship of care givers under the *Care Wage* scheme varies across local governments. In some places, it is a normal employment relationship similar to that of care assistants working for the municipal home-care agency. But in most places it is a looser free-lance contract under which the care giver has fewer rights than normal employees. In both cases, care givers are paid for a given number of hours per week (typically based on the hourly wages of municipal care assistants) and they have pension rights. In spite of this, the law states that the payment is not meant to reflect fully the extent of care given, and care givers typically work more hours than explicitly paid for.

42. In the Netherlands, a formal contract is required, even if the person giving care is a relative, as the care recipient is considered an employer. Care assistants are entitled (like anyone else) to national insurance schemes, such as the *State Old Age Pension* (AOW) and sickness insurance.

Respite care and other support for informal care givers

43. Periods of respite are essential to limit/avoid overburdening informal care givers, and this raises issues of eligibility for payments and of alternative care arrangements during such periods. Arrangements can differ across countries. Australia, for example, allows persons giving care to continue receiving *Carer Allowance* or *Carer Payment* during a break from their care work of up to 63 days in a calendar year, either for continuous or broken periods. Respite care is also part of the benefit package in Austria and Germany and the extent of these benefits has recently increased considerably in Germany. In addition a number of other countries provide respite care as a local service to carers, without it being given the status of a legal right to benefit (OECD, 2005, Chapter 2).

44. It should be stressed that paying money to informal care givers is far from being the only and probably not always the most effective way of mobilising, supporting, and qualifying care givers who enable older persons to stay longer in the community and reduce the need for expensive institutional care. Non-financial support for informal care can be more important, as illustrated by the developments in Sweden where the number of persons using some of the schemes listed in Table 2 has declined. The current policy direction in Sweden is to focus scarce resources on the development of non-financial support such as respite care, counselling, training and personal support for informal care givers (Box 2).

12 The Cash & Counseling demonstration projects were implemented in Arkansas, Florida and New Jersey with funding from the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services in order to test and demonstrate approaches considered promising.

Box 2. Non-financial support for informal care givers in Sweden

With the purpose of increasing the availability of non-financial support for informal care givers, the Swedish government gave an ear-marked development grant, *Anhörig 300*, to all municipalities during the years 1999 to 2001, while leaving municipalities with considerable freedom as to what types of non-financial support they would spend it on. Looking back at how municipalities chose to spend the grant and at what support services they have continued to provide after the end of *Anhörig 300* gives an indication of what types of non-financial support people in the field find to work best in practice. The table below shows the extent to which various forms of support was available to informal care givers before *Anhörig 300* was introduced in 1999 (first column), which forms of support municipalities considered they would continue based on the experience they had gained by late 2001 (second column), and what was actually provided during 2002 (third column).

The traditional form of support for informal care givers, *respite care*, was already available in more or less all municipalities before 1999, but the variety has been broadened with day care and replacement of informal care givers at home now being available in more municipalities than before. More change has taken place regarding *counselling, training and contact points*. While individual counselling and support groups for informal care givers were not uncommon before 1999, these forms of support have become more popular. Training of informal care givers was well promoted by the *Anhörig 300*, but while 70% of Swedish municipalities expected by late 2001 to continue this form of support, only 44% actually did so in 2002. And around half the Swedish municipalities have now appointed a special public officer as consultant for informal care givers and established contact points. Finally, *recreation and other support* for informal care givers has been tried in many forms as part of *Anhörig 300*, but remains at a more experimental level, and many municipalities appear to have given the broad category of other support low weight when having to prioritise scarce resources during 2002 compared to their expectation by late 2001.

The evaluation by the *Swedish National Board of Health and Welfare* concludes that municipalities have continued the efforts to develop the range of non-financial support for informal care givers, but it is difficult to know whether these support services reach the people who need them most and there is a continued need for developing their quality. Developing the appropriate form of help is a challenge, and surprisingly often informal care givers said "no thanks" to offers of support.

Non-financial support for informal care givers provided in Swedish municipalities

	Share of municipalities ...		
	... where this form of support was provided before 1999	... expecting by late 2001 to continue this form of support	... where this form of support was actually provided in 2002
	%		
Respite care			
Short-term care in institutions	99	97	95
Day care or day activity	80	92	90
Replacement of informal care-giver at home	69	87	87
Counselling, training and contact points			
Individual counselling	47	77	74
Support groups for informal care-givers	28	83	74
Training of informal care-givers	17	70	44
Appointment of a consultant for informal care-givers	5	68	52
Contact point or call-centre for informal care-givers	7	56	43
Recreation and other support			
Recreation and holiday trips	3	7	17
Health check-ups for informal care-givers	1	6	3
Other support such as financial support for purchase of an alarm, information about complaint procedures and about services available from chiropodists etc.	12	75	38

Note: Based on a questionnaire sent to all of Sweden's 258 municipalities in the third quarter of 2001 (first and second column) and the first quarter of 2003 (third column). The response rate was about 90%.

Source: Socialstyrelsen (2002) and Socialstyrelsen (2003).

4. Outcomes: What is the experience with choice and payments for informal care?

45. A review of the outcomes of giving older persons receiving long-term care more choice and of paying for informal care, should start from the objectives behind the introduction of such schemes and/or reforms moving in that direction.

- In the United Kingdom, direct payments are currently being expanded with the stated objective of empowering older persons and giving them the choice of buying care that better suits their needs.¹³ In the Netherlands, the main reasons for introducing personal budgets have been to enable the person receiving care to take responsibility for her/himself, to give the individual a larger say in how and when care should be provided, and to ensure quality by letting the person receiving care select and supervise the care assistant her/himself. In the United States, various groups and associations of older persons have actively expressed a wish to retain more independence in their lives while needing long-term care,¹⁴ and the Supreme Court's Olmstead decision from 1999 found that inappropriate institutionalisation was illegal and established a limited right to home and community-based care. Similar objectives have been expressed in other countries as well.
- In the context of ageing populations, developing home and community care has been seen as a strategy that would serve the dual purpose of sustaining independent living of older persons and avoiding costly institutionalisation, thereby mitigating the impact of ageing on public expenditures. In Austria, the introduction of a unified support for all types of long-term care needs via the *Cash Allowance for Care* scheme was aimed both at expanding choice between services on offer and at expanding home and community care rather than institutional care (Badelt *et al.*, 1997). Getting more value for money is crucial for improvements in the provision of long-term care, as all countries face scarcity of resources both in terms of public finances and in terms of labour force – scarcities that will become more pronounced as a result of population ageing over the coming decades.
- In the United States, concerns about spending increases have been a major constraint on the expansion of publicly funded home and community-based care, as noted by Wiener *et al.* (2002), and addressing the need for cost effectiveness up-front can therefore help to promote the development of long-term care systems.
- Developing a more diversified sector of formal care providers and creating care jobs has, in some cases, been an important secondary objective when expanding choice in connection with the expansion of public or insurance-based funding for long-term care (see Schneekloth and Müller, 2000, for Germany). In the United States, consumer-directed care has been seen as a way to employ a broader workforce, thereby solving the shortage of long-term care assistants.
- Finally, promoting and rewarding the work of informal care givers and reconciling work and family life for informal care givers has become an increasingly important objective as the share of women participating in the labour market and having a full-time job has increased.

13 Statement by Health Secretary Alan Milburn when presenting the Government's proposal to the British Parliament in July 2002.

14 In a national symposium on consumer-direction and self-determination for older persons and those with disabilities organised by the U.S. Department of Health and Human Services in June 2001, one paper eloquently expressed this wish for moving away from a client role towards more self-determination through its title: "I'm Not a Case and I Don't Want to Be Managed!"

46. Section 4.1 reviews outcomes in terms of flexibility, care quality, satisfaction among persons receiving long-term care and conditions for care givers, and Section 4.2 addresses the implications for employment and fiscal sustainability.

4.1. Improving flexibility, quality and satisfaction in long-term care

47. When persons needing care have several options, their actual choices can give an indication of what works well and what is considered by older persons to adequately meet their needs. The explicit choice between services in kind and a cash payment or a combination of the two which is open to persons receiving support from the German long-term care insurance is an interesting case, as older persons have a *right* to choose and do not have to go through additional administrative procedures if desiring one option rather than the other. The outcome has been that initially only 8% of the persons receiving care at home choose to have services in-kind only, the rest choose cash only or a combination of cash and services. And it is remarkable that this pattern is similar for persons with very extensive care needs and persons with fewer care needs (Box 3). Since the introduction of the German long-term care insurance in 1995, the share choosing cash only has been declining gradually, but it is still above two thirds.

48. In a number of other OECD countries, including Australia, the Netherlands, the United Kingdom and the United States, popularity among users let personal budgets, direct payments and consumer-directed home-care schemes grow. For example in Australia, the *Carer Payment* available to people who, because of their caring responsibilities, are unable to participate in the workforce, has grown rapidly over recent years from 11 740 recipients caring for persons aged 65 or more by June 1998 to 18 097 by June 2002. In Sweden, on the other hand, the option of being paid an *Attendance Allowance* for caring for a relative was in 2001 only used by 4 980 persons compared to 20 000 persons about a decade ago.

Box 3. What do Germans do when they have the choice between cash and services in kind?

When a person is found eligible for coverage by the German long-term care insurance, and her/his particular needs have been assessed, the person can choose between receiving a payment in cash, have a package of care services in kind delivered by an agency or a combination of the two.

Consequently, the development of how long-term care is provided in Germany is in a very direct way guided by the choices of the individuals needing care. This has produced fairly strong changes. From the beginning, when the long-term care insurance was introduced, 84% of all persons receiving support chose cash only – substantially more than expected prior to the introduction of the long-term care insurance in 1995. Since then there has been a gradual move towards services and combinations of cash and services so that by 2001, 73% of the persons receiving support opted for cash only – still far more than in any other OECD country, except for Austria and Luxembourg.

What is chosen differs somewhat, but not much, across the levels of care needs. Persons with extensive care needs, who are receiving higher levels of support from the insurance, tend to prefer a combination of different types of support including services in kind as well as cash. But even at the highest level of support, 64% choose to have all as cash (Table below, Panel A).

When people were asked in a survey about the motives behind their choice, most revealed a preference for receiving care from family members, as professional services seem only to be preferred when the health condition necessitates this or when informal care givers are not available (Table below, Panel B). It is remarkable, that almost none of the persons choosing cash mentioned lack of available service supply in their area or lack of information about their options as a reason for choosing cash.

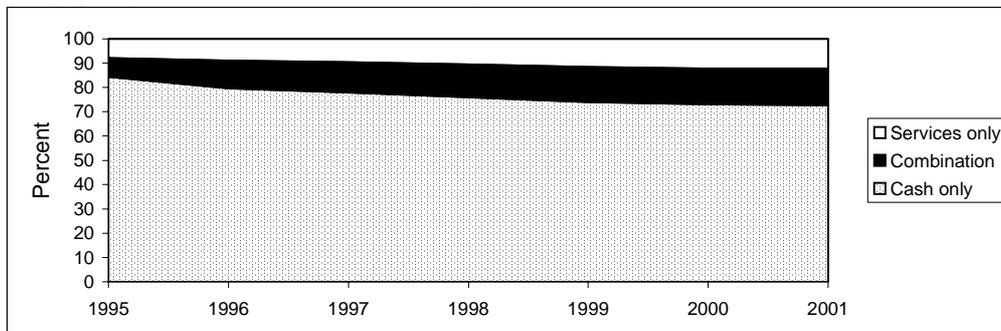
Choices made by Germans supported by the long-term care insurance, 1998

	Persons choosing			Average share of cash for persons choosing a combination of cash and services %
	Cash only	Combination of cash and services	Services only	
% of persons receiving support at each level				
A. Choice by level of care need				
1 - lowest	82	8	10	42
2 - middle	77	13	9	35
3 - highest	64	25	9	39
B. Reasons stated by persons receiving support for why they chose each form of support				
	<ul style="list-style-type: none"> • Use cash for miscellaneous care needs • Don't like to receive care from strangers 	<ul style="list-style-type: none"> • Have some cash for miscellaneous tasks • More flexibility • Can give also informal carers some payment 	<ul style="list-style-type: none"> • No informal carer, or they don't have enough time • Don't want to be a burden on relatives • State of health requires professional care • Recommend by medical service 	

Note: Information in panel B is based on detailed telephone interviews of 1001 households receiving support, including both persons aged over and under 65 years. Three quarters of the persons receiving support from the German long-term care insurance are 65 or older.

Source: Bundesministerium für Gesundheit (1999)

Changing composition of choices over time in Germany



Source: Federal Statistical Office Germany

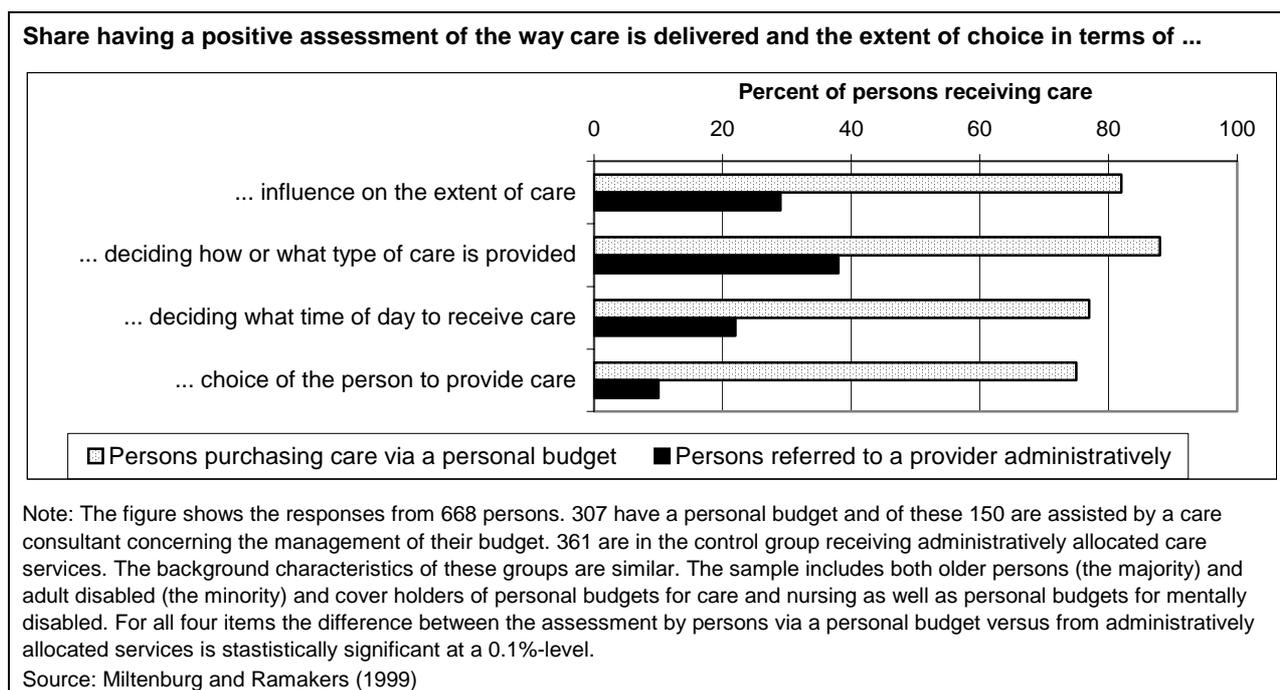
49. These trends indicate that older persons find that their care needs are well met by informal care provided by relatives and that the empowerment as consumers following from being able to choose among alternative providers is appreciated because it increases flexibility and the control older persons have over their daily lives. As mentioned earlier, flexibility and self-determination are important since long-term care involves the most intimate aspects of a person's life. This is confirmed by a study of the outcome of the *Personal Budget* scheme in the Netherlands, which found that while care quality is roughly the same as when persons needing care are referred administratively to a designated agency, persons receiving care through a personal budget feel less dependent because they have more control over when care is provided and notably by whom (Box 4). Similar outcomes have been found in the *Cash & Counselling* pilots under *Medicaid* in the United States. Foster *et al.* (2003) conclude that relative to agency-directed care, consumer-directed care greatly improved satisfaction and reduced most unmet needs.

Box 4. Quality is roughly the same but there is less feeling of dependency when receiving care via a personal budget in the Netherlands

The outcomes of personal budgets have been evaluated in a study by Miltenburg and Ramakers (1999) combining register data with interviews during the years 1996-1998 when a personal budget could be applied for in Netherlands by persons eligible for long-term care support. The main results were:

- Budget holders, as well as the control-group of persons receiving care from a provider to whom they had been referred administratively, had positive evaluations concerning the *extent* and *kind* of home care. There was no difference between the two groups regarding the users' own assessment of care quality. And budget holders had a very positive quality assessment of care provided by informal care givers whom they paid with the cash part of their budget that they need not account for.
- However, the difference was that care recipients with a personal budget felt that they could manage their own life again, and that their feeling of dependence had decreased. Budget holders felt they had a significantly larger say concerning the extent and type of care, and concerning when and notably by which person care is provided, as seen from the Figure below. This reflects that those receiving care from an agency to which they have been referred administratively, frequently experienced changes in the person who cared for them.
- Budget holders appear to be good in purchasing the care they think they need. On average they obtain a slightly larger quantity of care than the allocated budget would seem to allow them, but they succeed in purchasing it at a lower price. One third of all budget holders do *not* deplete their budgets but on average spend only 70% of it.

While the budget holders covered by the study strongly value the extra control and flexibility the personal budget gives them, the average person needing long-term care may value it less. The individuals who purchased care via a personal budget at the time covered by the study were interested and had actively applied for it. They are likely to have a higher preference for flexibility and possibly a better ability to make use of the opportunities of a personal budget than the average person needing long-term care. And a significant share of older persons may not wish to be active consumers but would simply purchase long-term care from the agency which has traditionally served their local area. Indeed, younger adults with disabilities have been more inclined to apply for a personal budget than older persons, and the average age of budget holders in 1999 was 57 years. Using personal budgets as a *universal* model for all public funding for home care would be able to accommodate this, but it means that the gains are likely to be less than proportionate to the expansion in number of budget holders.



50. To some extent, the flexibility aimed for with personal budgets can be achieved through the dialogue between the person needing care and the authorities assessing eligibility. In Norway, for example, the principle of allowing users to have influence on the care they receive is central to long-term care policy. Persons needing care can express their wishes but the final decision is made by representatives of the local government's agency.

51. It could be asked whether leaving it up to older persons to find a care assistant would not imply a risk for vulnerable older persons, particularly those with cognitive impairments, if they receive services from an untrained or possibly neglectful care assistant. How great such risks are may depend on many factors, including cultures and institutions in civil society that differ across countries. However, it is remarkable that the recent quality study of the Austrian Cash Allowance for Care – a system that goes further than in other OECD countries towards leaving it to older persons and their families to find appropriate care – did not find any cases of very poor hygiene or open neglect when surveying the condition of 700 older persons with care needs above 120 hours per month¹⁵ (Nemeth and Pochobradsky, 2002; Box 5). There may be other quality problems, but there is no indication of older persons being neglected when relying on consumer-directed rather than agency-based care. Likewise, the experience from the Cash & Counselling pilots under Medicaid in the United States shows that consumer-direction of care did not adversely affect participants' health and safety (Foster *et al.*, 2003). Apparently, the informal support and surveillance from relatives and others in the community is sufficient to avoid this. But it remains essential for public authorities to monitor the conditions of vulnerable older persons, notably those with no remaining family.

15 The survey covered 879 persons receiving support for care at levels 3-7. These levels refer to the most substantial care needs (There are seven levels, where 7 refers to the most severe care needs). Eighty percent of the persons in the sample were 65 years or older.

Box 5. Quality of care in Austria and Germany.

The introduction in Austria and Germany of comprehensive long-term care programmes covering the whole population and of cash allowances, went hand in hand with the introduction of regular assessments of the quality of care provision, including an assessment of informal care provided at home, which in both countries is mainly provided by family members.

The first assessments of informal home care in households receiving the newly introduced long-term care allowances revealed an overall positive picture of the quality of care provided in terms of satisfaction of older persons and their informal care givers. In surveys, the appropriateness of care, assessed by parameters such as general hygiene, level of attendance of care giver and health status, was generally rated as good or excellent, with a very small number of observed cases of overt problems (poor hygiene or open neglect) (Badelt *et al.*, 1997, and Nemeth and Pochobradsky, 2002, for Austria; Schneekloth and Müller, 2000, for Germany).

Part of the regular assessment in both countries is to find out whether access to formal services in support of home care has improved with the introduction of a system of care allowances providing choice between formal and informal care. A supporting infrastructure of professional home care services is essential for older persons to find the best individual mix between formal and informal services. An expressed goal of both long-term care systems was to ensure that persons in need of long-term care have a care budget that allows a tailored package of formal services such as home visiting nurses, day-care, short-term nursing home care, respite care, and services of care-management, advice and information.

Experience with progress towards better informed and educated care recipients and informal care givers has been somewhat mixed. For Austria, surveys of the situation in both 1997 and 2001 showed that households still lacked information about locally available services. Households were also unaware of what was covered by health insurance, leading to unnecessary out of pocket spending on items such as medical appliances.

52. Caring for a relative can be rewarding but also emotionally very demanding (Box 6). In strategies to promote home- and community-based care it may therefore be desirable to have sufficient flexibility to support the type of arrangement that best suits the needs and wishes of different people. There are various ways in which support can reduce the strain of informal care giving. Financial support can reduce the need to maintain full-time paid work thereby freeing up time for care giving. Likewise, some provision of formal care and home help can lift part of the burden off the informal care giver. Notably, so-called respite care, which takes over for short periods of time can allow the informal care giver a break. Education of informal care givers has been found to be another important field of support, as relatives becoming care givers are not necessarily skilled in basic tasks such as how best to lift an immobile person in and out of bed. Informal care givers can also benefit from better understanding the medical condition of the dependent. Support groups often established by voluntary organisations can contribute to this education and also provide informal care givers a forum for talking about the emotional strains arising from heavy care work. Finally, as pointed out by Lundh (1999d), allowing informal care givers to better enjoy the gains and positive aspects of caring for a relative, can reduce emotional strains. The appropriate form of support depends on the type of informal care and who provides it. In the future, the role of children and grand-children as informal care givers may decrease and the role of spouses and other senior care givers may increase, the latter group often having health problems themselves. This changing composition of the group of informal care givers calls for new forms of care and possibly more support for informal care givers.

53. Personal budgets, consumer directed employment and cash allowances are essentially arrangements for the *demand-side*. For them to work well, it is important that the *supply-side* or *infrastructure* can adjust and develop. The experience during the first years with comprehensive systems of Cash Allowances for Care in Austria and Germany during the 1990s illustrates the need for allowances to be backed up with a support system of professional home-care services to reduce the workload on family care givers. An important role which professional services can play is to serve as partners to informal carers, providing information, education and training. There is some evidence that the Austrian and German care allowance systems are developing in this direction, but more slowly than policy makers expected. In Germany, for example, three years after the introduction of long-term care insurance in 1995,

only 10% of all informal care givers reported having attended a free basic training course on care-giving (Schneekloth and Müller, 2000), although there is evidence that the situation has substantially improved since then. The need for an improved infrastructure to support informal care in parallel with the introduction of care allowance systems was recognised in both countries as one of the stated policy goals of long-term care reform. Progress in the expansion and strengthening of the market for professional home-care services (including respite care) to support informal care was achieved in both cases. In Germany, the mix between formal / informal care chosen by consumers is slowly moving towards more demand for formal services (Box 3). However, the share of professional services chosen is below what had been expected to result from the introduction of care allowance systems with free choice over the individual mix of benefits.

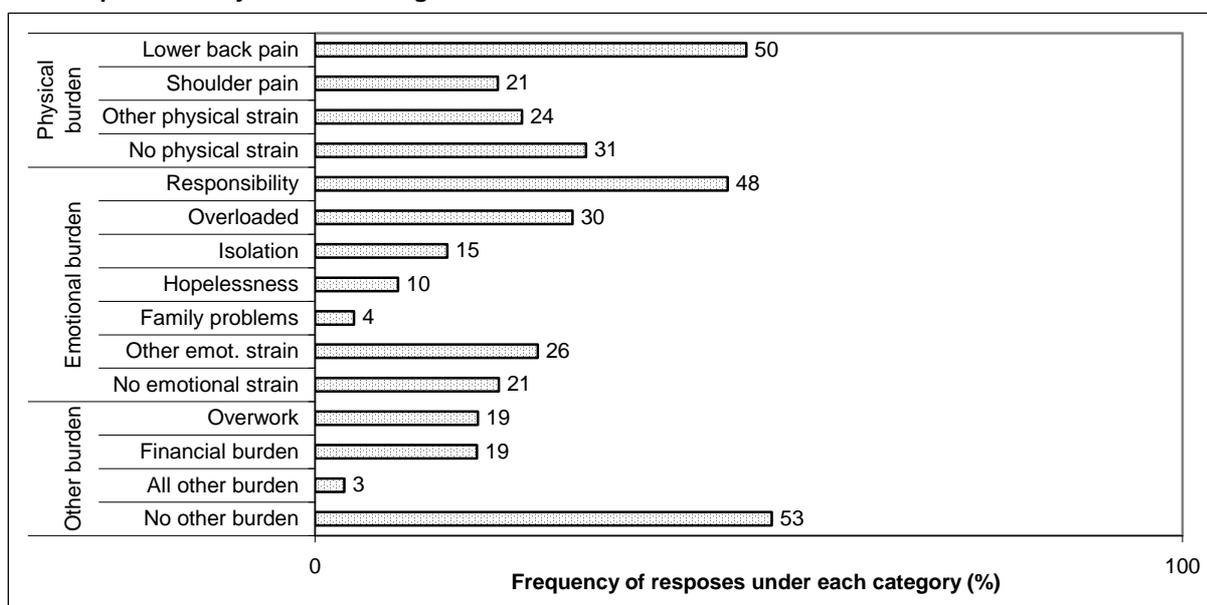
Box 6. Caring for relatives can be rewarding but also emotionally demanding

Having time to care for a relative can be a rewarding experience, and Lundh (1999b) finds that many informal carers in Sweden report benefits. Also Kramer (1997) and Noland *et al.* (1996) address the positive aspects of informal care-giving.

However, caring for a relative can also be emotionally and physically very demanding. This is documented by a number of studies from different countries including Biegel and Blum (1990), Twigg *et al.* (1990), Dooghe (1992), Hannelore (1993), Aneshensel *et al.* (1995), Healy and Yarrow (1997), Johansson and Åhlfeldt (1996), Herlitz (1999), Tinker *et al.* (1999) and Almgren *et al.* (2000). Persons with serious long-term care needs can require attention well beyond a normal full-time job for one care giver. But aside from the workload, care givers often find themselves tied to the person needing care to the extent that they are unable to live a life of their own. This can be particularly severe when living together with, and caring for, a person with cognitive impairments such as dementia. The emotional aspects of giving care to a spouse, a parent, or a parent-in-law can vary considerably depending on cultural differences. For the United Kingdom, studies find that the current generation of older persons is opposed to moving in with one of their children if they would become in need of care.

A recent survey from Austria illustrates the different types of strain experienced by informal care givers (Figure below). The most frequently reported problem is back pain, and an excessive feeling of responsibility. Only one in five (21%) state that they experience no emotional strains from informal care giving.

Strain experienced by informal care givers in Austria.



Note: Survey of households receiving the Cash Allowance for Care, *Pflegegeld*, at the upper levels 3-7, corresponding to a care need of more than 120 hours per month. The figure shows how large a share of the over 800 responding main informal care givers stated that they experienced each of the different types of strain.

Source: Nemeth and Pochobradsky (2002).

54. Finally, as the motive for allowing more choice is to increase flexibility for users, it should not be expected that one particular scheme suits all older persons needing long-term care. In particular, for older demented persons the option of employing a care assistant themselves is of little relevance unless they have relatives or friends to act on their behalf directing the work of the care assistant. And typically it is found that younger and adult disabled are more interested in managing their care themselves (Box 4). But there are many other dimensions aside from health conditions and age that matter; for example in Norway, the Care Wage, *Omsorgslønn*, is more frequently used in sparsely populated areas than in urban areas.

4.2. Getting value for money – implications for employment and fiscal sustainability

55. Arrangements to increase choice and flexibility in long-term care often take the form of arrangements to support informal care giving and thereby involve and often change the mix of long-term care over the continuum of formal and informal care. To adequately assess these schemes, it is necessary to analyse them in the context of ageing societies and overall policy strategies to put emphasis on community-based informal care.

56. The long-term trends of ageing and changes in social relationships are likely to cause what some have called an “informal care crunch” in many countries over the coming decades as the need for long-term care is likely to rise while the availability of informal care is likely to decline, as fewer older persons live together with their children, and more of these children work and therefore can hardly be expected to provide care to the same extent as daughters have done previously.¹⁶ This raises two strategic questions for the development of long-term care policies:

- ***Who should be expected to provide care in the future?*** Is it relatives and others with an existing social relationship to the person needing care or is it professionals?
- ***And should the persons doing so be paid for it?*** Whether care is provided formally via a programme or informally, it requires resources. Who should be expected to shoulder this growing bill: Informal care givers working for free, persons receiving care or governments and social insurance?

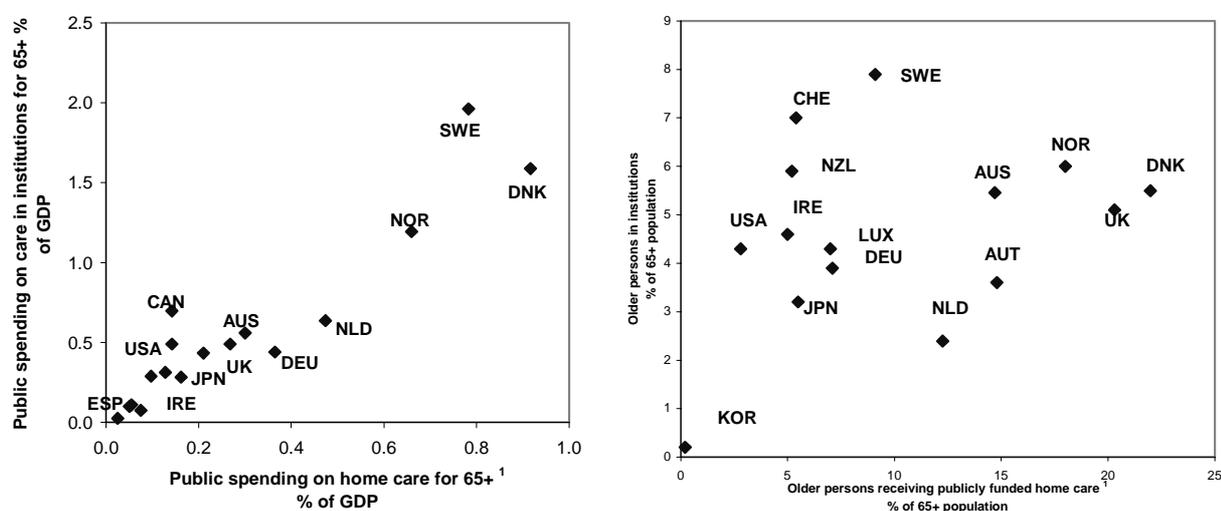
57. OECD countries follow very different strategies and represent a wide range of societal models regarding the relative role of care provided by relatives and other informal care givers versus care provided by professionals. All countries share the policy goal of promoting home- and community-based care allowing older persons to continue living in the community and avoid early institutionalisation that is costly and often limits the independence of older persons. But while some OECD countries have promoted home and community based care through agency-based formal home care (the Netherlands, Norway and Sweden) other countries have done so through financial support for informal care givers either directly (Australia) or indirectly via payments to the person needing care that may then be channelled to informal care givers (Austria and Germany). Yet other countries have been able to sustain informal community and family based care without paying carers (*e.g.* Spain and Korea).

16 In the future, the availability of informal care may or may not continue to decline depending on the country and a number of factors that are hard to predict. In *some* OECD countries the factors that have historically reduced the availability of informal care can hardly go much further. For instance in Sweden, the share of older persons living with their children is down at 4% as reported by Johansson (2000). In other OECD countries, the share is still considerably higher, but has been shrinking so far. However, other groups of informal care givers may take over. For England, Pickard *et al.* (2000) projects that while the number of older persons needing some form of care is likely to rise, a smaller share will be living alone by 2031 than what was the case in 1996 as more will still have a spouse or partner living with them.

58. For all OECD countries, however, finding cost effective ways of sustaining home and community-based care is essential in the context of high demand and cost pressures elsewhere in health and social systems. Virtually all OECD countries face substantial future expenditure increases from population ageing, seriously challenging the financial sustainability of current funding of health and long-term care. Funding growing long-term care expenditures publicly through higher taxes and mandatory contribution rates will create problems elsewhere in the economy and make it harder for governments to meet the social- and labour-policy goals of making work pay. This is especially a problem for the low-skilled. On the other hand, the costs of long-term care for an individual can in many cases reach levels where the person or family can hardly pay and insurance is needed. Balancing distortions from taxation and mandatory contributions versus needs for insurance is a key challenge for long-term care policy. It implies that insurance coverage is needed most for large costs for long-term care needs arising unpredictably. Individuals and families are able to fund foreseeable expenditure for practical help including many of the services typically provided by informal care givers in the community, as long as the dependent person is not in a condition where the needs for care are very large.¹⁷

59. A comparison of public spending on long-term care shows that the differences across countries in the level of spending on home care can only to a limited extent be explained by differences in the provision of care in institutions. Several countries seem to have increased spending on both types of care. The correlation between spending on home care and institutional care is therefore not negative, but rather positive (Figure 3). This indicates that the differences observed across countries have more to do with differences in the quantity of services provided to an older person with given needs. Differences in the availability of informal care reflect both cultural attitudes and different rates of formal employment among those who would otherwise be the likely providers of informal care (Figure 4).

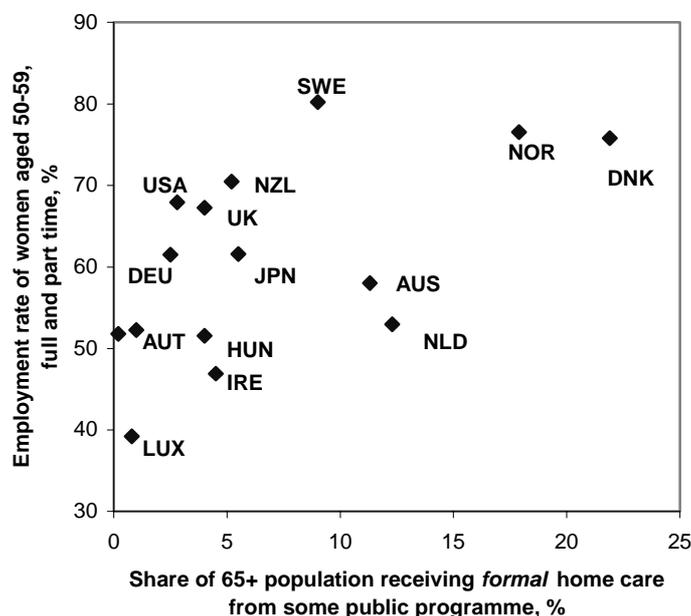
Figure 3. Home care versus institutionalisation



1. Including both formal care and payments for informal care as reviewed in table 2.
Source: OECD based on information from member countries, see OECD (2005).

17 As analysed by Scherer (1997), current pension arrangements and savings and asset accumulation have significantly reduced old-age poverty in most OECD countries. But even adequate pensions are not sufficient to finance the cost of long-term care in many situations.

Figure 4. Formal home care and employment

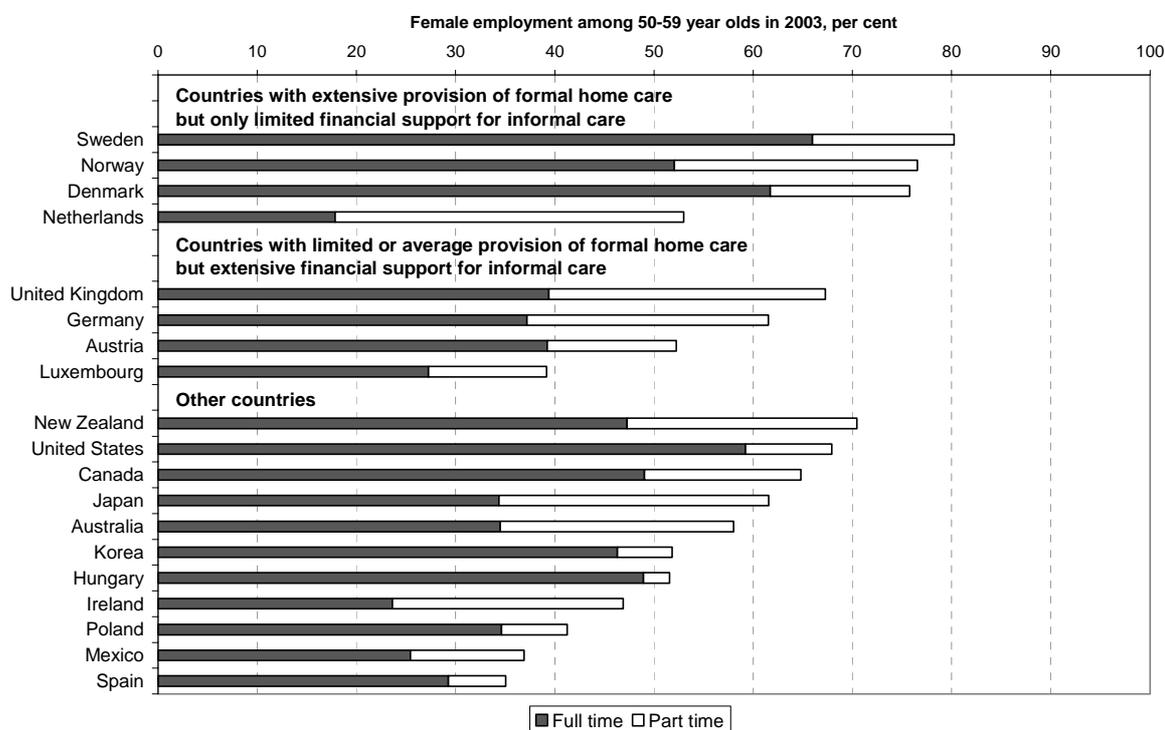


Source: OECD based on information from member countries
See OECD (2005).

60. There is a tendency for countries with extensive provision of formal home care but only limited financial support for informal care (such as the Scandinavian countries) to have higher employment rates for women aged 50-59 than the United Kingdom, Germany, Austria and Luxembourg, which are the countries in this study characterised by limited or average provision of formal home care but extensive financial support for informal care via cash allowances (Figure 5). This finding is supported by studies using micro data which show that British informal care givers earn lower wages than others (Heitmueller and Inglis, 2004; Carmichael and Charles, 1998 and 2003). That is not to say, however, that more provision of formal home-care services will automatically bring higher labour-market participation rates. It is remarkable that among the Scandinavian countries, Sweden's employment rate for women aged 50-59 is higher than that of Norway and Denmark in both part-time and full-time jobs *despite* providing publicly funded formal home care to only half as many older persons as does Norway and Denmark.

61. The question is what is cause and what is effect. The lower employment rates of women aged 50-59 in countries like Austria, Germany and Luxembourg, probably to some extent reflects cultural factors, such as a larger preference for living in single-earner couples. In this context, cash allowances may allow older persons to acquire care from these people informally in a way that is much less costly to society than if formal services were to be provided. The Netherlands clearly shows that the availability of formal home care is not the only factor determining the employment rates of females in their 50s.

Figure 5. Employment rates for women aged 50-59



Note: The numbers shown here differ slightly from a simple average of the two age groups 50-54 and 55-59 shown in Table 3 due to different size of the female population in each of these age groups.

Source: OECD based on national labour force surveys.

Table 3. Employment rates for women aged 45-64

Total employment including both dependent employment and self employment, 2003¹

	Full time				Part time			
	45-49	50-54	55-59	60-64	45-49	50-54	55-59	60-64
Countries with extensive provision of formal home care but only limited financial support for informal care								
Sweden	71.7	70.0	62.3	37.1	13.5	13.7	14.8	16.4
Norway	59.9	57.1	46.9	31.0	21.5	23.8	25.2	21.3
Denmark	67.5	66.9	57.1	21.8	15.2	14.4	13.8	5.7
Netherlands	26.0	21.6	13.9	3.9	48.3	41.1	28.8	11.0
Countries with limited or average provision of formal home care but extensive financial support for informal care								
United Kingdom	49.9	45.9	32.9	9.1	28.0	27.4	28.3	18.2
Germany	46.7	42.7	30.5	6.8	29.2	26.8	21.3	8.2
Austria	55.8	50.8	26.5	4.4	21.5	16.9	8.8	3.0
Luxembourg	33.9	34.9	18.2	4.2	20.4	14.2	9.2	3.9
Other countries								
New Zealand	55.1	51.9	41.9	24.5	25.0	23.1	23.2	18.7
United States	66.1	63.3	54.3	33.8	9.4	8.7	8.7	9.9
Canada	61.1	56.3	40.6	18.7	16.3	15.8	15.8	11.4
Japan	38.0	36.8	31.7	18.4	32.3	29.2	25.0	19.1
Australia	47.5	40.4	27.7	12.4	27.5	25.7	21.0	14.6
Korea	55.4	49.4	42.6	35.9	5.0	5.3	5.8	6.4
Hungary	71.2	63.2	32.4	4.5	2.5	2.6	2.7	2.8
Ireland	33.2	28.3	18.3	9.3	25.7	24.0	22.5	14.8
Poland	58.7	44.8	20.7	7.3	7.7	6.5	6.8	6.3
Mexico	32.5	27.0	23.5	14.8	11.5	11.6	11.2	9.5
Spain	44.4	34.1	24.2	13.9	7.6	7.0	4.5	3.2

1. Data refer to 2002 for Luxembourg.

Source: OECD based on national labour force surveys.

62. A particular concern is the adverse incentives for labour supply that can arise from programmes where persons needing care are given cash, part of which they pass on to informal care givers – in practice without it being reported to tax and benefit authorities. Indeed where the person needing care and the informal care giver are living in the same household, a cash allowance for care naturally enters the common household budget. Also, if the informal care giver is a close relative such as a daughter or son of the person needing care, the persons involved may not think of passing on the money as something that should be reported to any authorities – and there may be no requirement under tax and social security legislation to take such payments into consideration. The consequence can be that the combination of taxation, unemployment benefits, social assistance *and* cash allowances for care redirected informally to the informal care giver negates the incentives for some unemployed persons to actively search for employment while providing informal care for example 15-20 hours a week (Box 7).¹⁸

Box 7. Numeric example of possible incentives for informal care givers not to look for work in Germany²

As an example, consider a woman aged 53 who is married but with no children living at home. She and her husband both work full time in low-paid jobs each earning two thirds of the wage of the average production worker (the situation considered in Table 4 in the middle columns). Her father is no longer alive, but her mother, who is close to 80, needs home care and is eligible for support from the German long-term care insurance at level I, for which she so far has received care in kind. Now the woman aged 53 loses her job and while she is unemployed looking for a new job, she agrees to provide care for her mother who uses her right to shift from receiving care in kind to the *Cash Allowance for Care* at the rate of EUR 205 per month. As recognition of her daughter's efforts, the old lady passes on this cash allowance to her daughter on an informal basis.

The question is now: How strong are the incentives for this 53-year old woman to search actively for a new job versus continuing providing informal care for her mother while receiving unemployment benefits? The answer is that the combined effect of benefits, taxes and the care money passed on informally from her mother may be to discourage looking for a normal full-time job.

Previously, she and her husband *jointly* had *gross* earnings from employment of EUR 3 650 per month,¹ corresponding to *net* earnings of EUR 2 384 per month when social security contributions and taxes are deducted. With a net replacement rate of 90% for the household as a whole (as shown in Table 4, third column), the household's *net* income is reduced by EUR 245 per month during the initial phase of the woman's unemployment. But if her mother passes on the EUR 205 *Cash Allowance for Care*, household net income including this money is virtually the same as when she still had her old job. Presuming that she is at least not negative towards caring for her mother and presuming that she finds the extra spare time enjoyable (the difference between the 20 hours a week she spends giving care to her mother and the time needed for a full time job), there are clear short-term incentives *not* to look for a normal job.

As time passes, the amounts she can get from unemployment benefit and social assistance declines, but having been away from the normal labour market for a while, it is likely that she would have to accept a lower wage in order to get a new job. With a net replacement rate of 74% still five years after having left her old job (as shown in Table 4, fourth column), the gains in terms of household net income from going back to a normal full time job could be very limited when taking the *Cash Allowance for Care* into account. This aspect, however, is changing with the *Hartz IV* labour market reform because the duration of unemployment benefits is now being shortened considerably.

Obligations to be actively searching for a job in order to continue receiving unemployment benefits may counteract these disincentives. But the conclusion that can be drawn from the calculations above is that the economic incentives people in her situation face do not help this process, as the interaction with informal payments received in return for informal care giving may discourage active job search.

1. Each of them having two thirds of the average-production worker's gross earnings of EUR 32 900 a year in 2002.
2. The calculations of taxes and unemployment benefits in this box are based on the situation in Germany in 2002 (OECD, 2004). With the introduction of the Hartz IV labour market reforms in 2005 and 2006, the duration of unemployment benefits will be shortened. This numeric example helps to illustrate a potential problem with cash allowances, but it should be emphasised that it does not reflect the current or future situation in Germany.

18. The adverse incentives analysed here are parallel to those arising when a person receiving unemployment benefits is at the same time working on the black market.

63. Following this logic, cash allowances for care would be best suited to countries where unemployment benefits are less generous, other things being equal. If net replacement rates are low, then only large informal income could tip the balance and make unemployment more economically attractive than employment. For a country like the United Kingdom, where the net replacement rate for someone with previous gross earnings at two thirds of the average production worker's level is only 63% for a person in a two earner couple without children, a cash payment like the UK *Attendance Allowance* is less likely to create adverse labour supply incentives for informal care givers. However, the other countries with such cash payments to persons needing care have relatively high replacement rates (Figure 6 and Table 4). Germany and Luxembourg in particular, where respectively 6 and 4% of the 65+ population receive such cash allowances, may need to consider whether these cash allowances produce adverse incentives which may hold back employment for low-income women in their 50s, particularly as they are the group most frequently providing informal care to older persons.¹⁹ To tackle such disincentive problems, one option is to require a formal contract between the older person and the care giver as in the Netherlands when somebody having a personal budget uses it to employ a relative or friend. Thereby the payments received by the care giver are considered as earnings by tax and unemployment benefit authorities. This implies that care giving would be financially more attractive than a normal job for otherwise unemployed persons *only* in cases where the relative has substantial care needs requiring assistance on a full time basis. Conversely, the situation where caring 15-20 hour a week for a relative makes it financially unattractive to search for regular full time employment would be avoided. If current systems in Austria, Germany and Luxembourg were to be changed in this way, various parameters of the systems would of course have to be adjusted. In particular, the standard payment levels should be raised to maintain their net-of-tax value for an average care giver. In that way such a change can be made in a way that respects the social policy emphasis on collective responsibility and mutual help within families in countries like Austria, Germany and Luxembourg.

19. See Annex Table A.6 and A.7 in OECD (2005) for a statistical review of the typical age of older persons' informal care givers and their relationship with the older person.

Figure 6. Net replacement rates in unemployment

For two-earner couple without children having 67% of the average production worker's earnings.

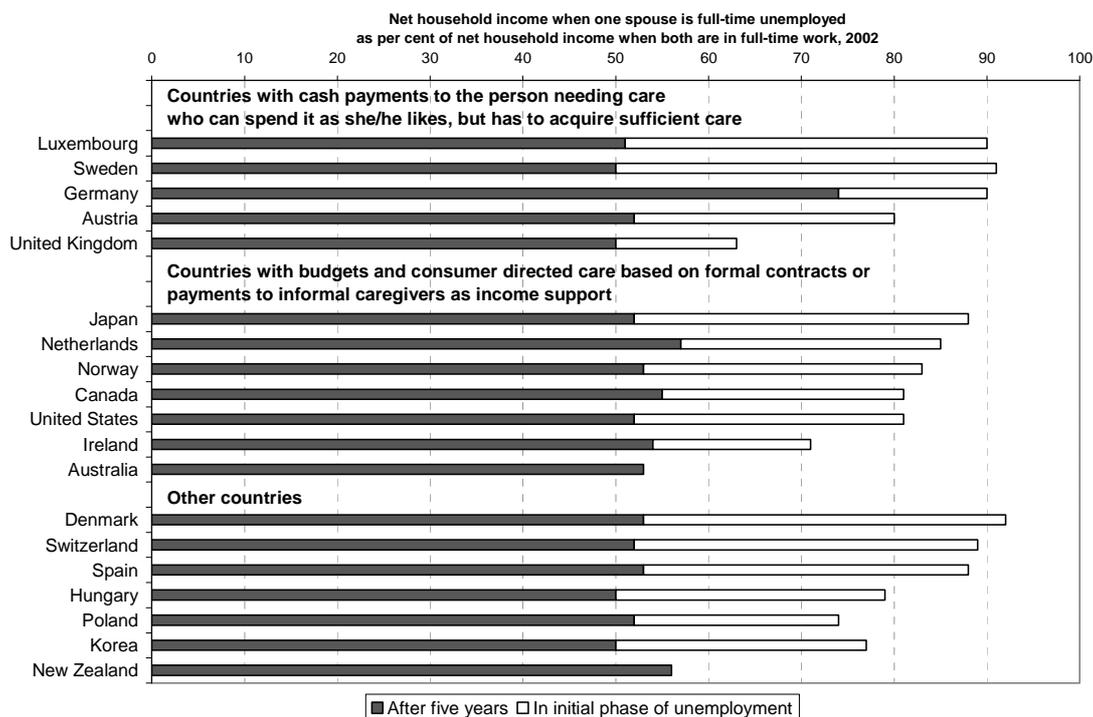


Table 4. Net replacement rates in unemployment

Net household income when the person in question is full-time unemployed as per cent of net household income in full-time work, 2002. For persons having 67 per cent of the average production worker's earnings before becoming unemployed. ¹

	Single person		Two-earner couple without children		Two-earner couple with two children	
	Initial ² phase	After five ³ years	Initial ² phase	After five ³ years	Initial ² phase	After five ³ years
Countries with cash payments to the person needing care who can spend it as she/he likes, but has to acquire sufficient care						
Luxembourg	84	70	90	51	94	56
Sweden	82	74	91	50	92	58
Germany	63	82	90	74	99	79
Austria	55	64	80	52	85	71
United Kingdom	63	63	63	50	73	71
Countries with budgets and consumer directed care based on formal contracts or payments to informal caregivers as income support						
Japan	73	50	88	52	88	63
Netherlands	79	79	85	57	85	61
Norway	66	60	83	53	86	56
Canada	63	31	81	55	87	68
United States	62	10	81	52	83	58
Ireland	40	71	71	54	79	63
Australia	46	46	53	53	65	65
Other countries						
Denmark	84	71	92	53	93	71
Switzerland	79	73	89	52	90	55
Spain	76	37	88	53	89	53
Hungary	61	33	79	50	82	58
Poland	65	45	74	52	79	64
Korea	53	25	77	50	77	50
New Zealand	54	54	56	56	63	63

1. Also the spouse who is continuously employed has earnings of 67 per cent of the average production worker.

2. Initial phase of unemployment but following any waiting period. No social assistance "top-ups" are assumed to be available in either the in-work or out-of-work situation.

3. Including unemployment benefits, social assistance, family and housing benefits in the 60th month of benefit receipt.

Source: OECD (2004), Benefits and Wages.

64. The economic rationale for paying informal care givers depends much on their labour market attachment:

- ***For persons that would otherwise be employed***, payments for informal care, such as within a leave scheme, represent an insurance against the loss of employment income they incur while providing care. Such payments allow families to choose informal care, and to the extent that such care replaces more expensive publicly funded formal care, the effect on public finances may be positive. Much, however, depends on the labour market impacts. Particularly for persons with a loose attachment to the labour market, a prolonged period of leave can lead to subsequent unemployment as the person's skills or human capital may gradually deteriorate. Women in their 50s taking leave to care for a parent or parent-in-law may frequently be at risk in this regard.²⁰ Very high payments to informal care givers is therefore a mixed blessing by producing an unemployment or low-income trap as it reduces the incentive to maintain contact with the labour market for low-skilled persons. This problem is aggravated if payments for informal care can be received on top of unemployment benefits. Cash payments to the persons needing care makes it essential to ensure that persons receiving unemployment benefits are actively searching for regular employment, in order to avoid that combined income from unemployment benefits and some informal care giving exceeds what the person could get in a regular job. In leave schemes for informal care givers, some countries confine the leave duration to a limited period of time such as during terminal illness in order to avoid care givers losing touch with the formal labour market. Active assistance to help care givers find work and a care-giver-friendly work culture are also important (Box 8). Finally, promoting a market where quality care services can be purchased can help create new jobs. It will also avoid forcing highly-skilled persons to leave their job to provide informal care, thereby reducing the return on their education to the individual and society.
- ***For persons that are outside employment and have other income, such as retired persons having a pension***, care giving does not entail an income loss and therefore there is no *insurance* argument for supporting informal care giving at home financially. However, to limit the need for costly formal long-term care services, some countries seek to mobilise and recognise informal care givers for their work with payments, disregarding their labour market attachment and other income. Other countries find it essential *not* to engage in paying pensions to care for their relatives in order not to crowd out other spending that is more essential to maintaining a welfare society. The issue of recognising and supporting informal care giving has an important gender aspect, as most care givers are women (Jenson and Jacobzone, 2000).

65. The sheer size of informal care provision within families and local communities makes it essential for all countries to consider how support for informal care can best be targeted and if alternatives such as non-financial support give more value for money for the persons receiving and giving care informally. Ageing-related projections of health and long-term care expenditure can give a sense of the magnitudes involved. Whereas the European Union countries, having the most expanded public coverage of long-term care (Denmark, the Netherlands and Sweden), currently spend 2.5 - 3% of GDP publicly on long-term care, this may rise to 4.5 – 5.5% of GDP by 2050 merely to *maintain* current public service levels in a context of ageing populations (Bains, 2003).²¹ Moreover, estimates indicate that even in a

20 Employment protection legislation may give persons on leave providing informal care a right to come back to work, but this may create another problem as employers become less inclined to employ persons that are likely to make use of leave schemes for informal long-term care, that is, women in their 50s.

21 Differences in the delimitation of long-term care versus health care and other services explain why the figures for current public long-term care spending in Bains (2003) do not correspond with those used in the

country like Sweden, the volume of unpaid informal care is twice as large as the volume of formal care (Johansson, 2000). This implies that the total volume of long-term care provided by agencies, care assistants and relatives corresponds to 7 - 9% of GDP currently in these countries but may grow to 13 - 16% of GDP by 2050 merely to maintain current service standards. This is more than *twice* the total public spending on education from nursery schools through to universities which typically accounts for 5 - 7% of GDP in OECD countries. Such a projection may seem far from today's situation in most OECD countries where less than 1% of GDP is spend publicly on long-term care. However, this simple calculation underscores that if long-term care policy aims at fully compensating the work effort of all informal care givers by public payments, then the consequences can become dramatic in the context of ageing populations. It would necessitate dramatic cut-backs in other parts of social protection and raise the burden of taxes and mandatory contributions to levels that would compromise social cohesion. Therefore, countries are well advised to carefully consider the sustainability of systems when introducing new measures today and to carefully target support for informal care to where it is most needed.

Box 8. Balancing informal care giving and work in Australia

Australia has about 2.3 million informal care givers. Some of these are seniors who have retired and provide informal care, for example to their spouse, but many are of working age. In particular, most of those informal care givers who provide the main source of unpaid, informal support for a dependent relative or friend - known as "primary care givers" - are of workforce age (348 200 out of 450 900 primary care givers or 78% are aged 18 to 64 years). Among these, 41% are attached to the workforce. 70% of primary care givers are female. 60% of young primary care givers aged 15-25 years are unemployed or not in the labour force, compared to 38% for the general population in this age group. A wider group of 1 850 100 care givers are not primary carers, but provide "some assistance". Of these 56% are female and 38% are in the 35-54 year age range.

Notably for persons that are primary care givers and for whom care-giving implies a substantial workload, getting back to work after ending care-giving (such as when a dependent person dies) can be challenging. Various active labour market programmes are available to support getting back to formal employment. Two of these, the Transition to Work Service (TTW) and the Jobs Education Training programme, provide ongoing support and advice to encourage the uptake of training and education, raise self esteem and help with practical issues such as child care, and they are especially relevant for informal care givers.

Just as importantly, flexible working arrangements are necessary to assist employees that are giving informal care, to balance their work and carer responsibilities. The Government of Western Australia has tried to promote this by stressing that it will also benefit employers and that the critical points for informal care givers are things like flexible starting and finishing times; ability to take a few hours off work, and make it up later; and flexible leave arrangements *i.e.* taking leave by the hour instead of a whole day. Employees may also need to be contactable at work during the day, especially for any emergency. In some cases, temporary part-time work or home-based work arrangements may be suitable options. On occasions employees may also need the option of taking leave with or without pay.

Source: Disability, Ageing and Carers: Summary of Findings, ABS 1998; Department of Consumer and Employment Protection, Labour Relations, Western Australia (2001).

66. Nurturing the potential of capable older persons as informal care givers is particularly relevant if the prevalence of mobility restrictions among older persons continues to decline, implying a changing composition of dependency with less physical disabilities and relatively more cognitive impairments such as dementia. Older persons keeping an eye on friends with light degrees of dementia living in the community and possibly in adapted housing may be less costly than early institutionalisation – and give a very meaningful life to older persons as informal care givers.²²

OECD (2005), but the overall conclusion would be the same had the OECD dataset been used in these ageing-related projections.

22 In a study comparing home care (Denmark), day centres (Germany), expert centres (Belgium and Spain), group living (Sweden and France) and respite hospitalisation (France), Colvez *et al.* (2002) find that group living programmes appeared to be the most efficient way of reducing informal care-giver burden, independently from the country considered. In these centres, patients are lodged in specialised housing

5. Conclusions

67. The type of choice arrangements in home care, the level of support they provide and the number of users varies enormously across and within OECD countries – reflecting also that long-term care provision varies much more across countries than acute health care systems. Choice arrangements are preferred by many elderly, who report that they feel more satisfied and less dependent when having a say about how, when and notably by whom care is provided. Indications of shortfalls in care quality or outright neglect of frail older persons are remarkably few, but informal care givers – most being female – appear to carry sometimes large burdens in terms of physical pain and emotional strain from feelings of excessive responsibility, overload and isolation when working alone.

68. The implications for employment and fiscal sustainability are fairly complex. Giving older persons a budget or cash benefits to pay informal care givers can help tap into a wider source of human resources where there are shortages of professional care workers. On the other hand, a functional market for formal home-care services (or public supply of such services) is essential to allow relatives of older persons in need of care to maintain their attachment to the normal labour market. And payments for informal care can risk creating “incentive traps” attracting informal care givers away from the normal labour market, due to the combined effect of informal care payments, taxes, unemployment benefits and other transfer incomes. After having been away from a normal job for a while, it can prove difficult to get back into paid work.

69. Future ageing of populations together with demands for *active ageing* will increase the policy relevance of these issues. The large cohorts moving into old age in the coming decades may bring the fiscal sustainability of current health and long-term care systems into question. In this context, publicly funded formal home care and in particular payments for informal care will have to be carefully targeted. With more years in retirement, many of which are spent without major disabling conditions, the growing number of healthy and active senior citizens represents a potentially very valuable resource as informal care givers. Finding the best way of nurturing this potential, and thereby shifting the task of providing informal care away from working-age children and towards able seniors (spouses, neighbours and others in the local community) may well prove to be key to achieving fiscal sustainability.

with private rooms grouped around a communal living area. Domestic activities are led by a registered nurse or housekeeper while there is no medical service attached to the structure.

REFERENCES

- ALLEN, I. and E. PERKINS (eds.) (1995), *The Future of Family Care for Older People*, HMSO, London.
- ALMBERG, B., M. GRAFSTRÖM, and B. WINBLAD (2000), "Care givers of relatives with dementia: experiences encompassing social support and bereavement", *Aging and Mental Health*, Vol. 4, 1, pp. 82-83.
- ARBER, S., and J. GINN (1995), "Gender differences in the relationship between paid employment and informal care". *Work, Employment and Society*, Vol. 9, 3, pp. 445-71.
- ANESHENSEI, C.S., L.I. PEARLIN, J.T. MULLAN, S.H. ZARIT, and C.I. WHITLATCH, (1995), *Profiles in care-giving. The unexpected career*. San Diego: Academic Press Inc.
- BADEL, C., A. HOLZMANN-JENKINS, C. MATUL and A. ÖSTERLE (1997), *Analyse der Auswirkungen des Pflegevorsorgesystems* (Analysis of the care system), Bundesministerium für Arbeit, Gesundheit und Soziales, Wien.
- BAINS, M. (2003), "Projecting Future Needs, Long-term Projections of Public Expenditure on Health and Long-term Care for EU Member States", Chapter 9 in *A Disease-based Comparison of Health Systems, What is Best and at What Cost?*, OECD.
- BIEGEL, D., and E. BLUM (1990), *Ageing and care-giving. Theory, research and policy*. Newbury Park: Sage.
- BUNDESMINISTERIUM für GESUNDHEIT (2001), *Zweiter Bericht über die Entwicklung der Pflegeversicherung* (Second report on the development of long-term care insurance), Bundestagsdrucksache, 14/5590, Berlin.
- CAMPBELL, C. and IKEGAMI, N. (2000), "Long-term care insurance comes to Japan", *Health Affairs* Vol.19, No.3, pp. 26-39.
- CARMICHAEL, F. and S. CHARLES (1998), "The Labour Market costs of community care", *Journal of Health Economics*, Vol. 17, No. 6, pp. 747-65.
- CARMICHAEL, F. and S. CHARLES (2003), "The opportunity costs of informal care: does gender matter?", *Journal of Health Economics*, Vol. 22, No. 5, pp. 781-803.
- CLARKE, J. (2004), *Consumers, Clients or Citizens? Politics, Policy and Practice in the reform of Social Care*, paper presented at the symposium "Consumerism in care for the elderly", organised by the Danish National Institute of Social Research (SFI), 30 August, Copenhagen.
- COLVEZ, A. *et al.*(2002), "Health status and work burden of Alzheimer patients' care givers: Comparisons of five different care programmes in the European Union", *Health Policy*, Vol. 60, pp. 219-233.

- DALE, S., R. BROWN, B. PHILIPS, J. SCHORE, and B.L.CARLSON (2003), "The effects of Cash and Counseling on personal care services and Medicaid costs in Arkansas", *Health Affairs*, November.
- DEPARTMENT of CONSUMER and EMPLOYMENT PROTECTION, LABOUR RELATIONS, WESTERN AUSTRALIA (2001), *Creating Carer Friendly Workplaces*, <http://www.docep.wa.gov.au/lr/publications/pdfs/carers.pdf>
- DOOGHE, G. (1992), "Informal care givers of elderly people: a European review". *Ageing & Society*, Vol. 12, pp.369-380.
- DOTY, P., A.E. BENJAMIN, R.E. MATTHIAS and T.M. FRANKE (1999), *In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery*, US Department of Health and Human Services.
- DOTY, P. (2000), "The federal role in the move toward consumer direction", *Generations*, Vol. 24, No. 3.
- DOTY, P. and S. FLANAGAN (2002), *Highlights: Inventory of Consumer-Directed Support Programmes*, www.aspe.hhs.gov/daltcp/reports/highlight.htm.
- EVANDROU, M., and J. FALKINGHAM (2000), "Looking back to look forward: lessons from four birth cohorts for aging in the 21st Century" *Population Trends*, Vol. 99, pp.27-36.
- FOSTER, L., R. BROWN, B. PHILLIPS, J. SCHORE and B.L. CARLSON (2003), "Improving the quality of Medicaid personal assistance through consumer direction", *Health Affairs*, March.
- FRANKLIN, S.T., B.D. AMES, and S. KING (1994), "Acquiring the family eldercare role: influence on employment adaptation, *Research on Aging*, Vol. 16, pp.27-42.
- GLENDINNING, C. and E. MCLAUGHLIN (1993), *Paying for care: Lessons from Europe*, HMSO, London.
- GLENDINNING, C., M. SCHUNK and E. MCLAUGHLIN (1997), "Paying for long-term domiciliary care: A comparative perspective", *Ageing and Society*, Vol. 17, No. 2, pp. 123-140.
- HALLORAN, J. (2000), *Towards a people's Europe - a report on the development of direct payments in 10 member states of the European Union*, European Social Network.
- HANNELORE, J.I.B., (1993), *Family care of dependant older people in the European community*. Dublin: Foundation for the improvement of living and working conditions.
- HEALY, J. and S. YARROW (1997), *Family Matters: Parents Living With Children In Old Age*. The Policy Press, Bristol.
- HEITMUELLER, A. and K. INGLIS (2004), *Carefree? Participation and Pay Differentials for Informal Carers in Britain*, IZA Discussion Paper, No. 1273, <ftp://ftp.iza.org/dps/dp1273.pdf>.
- HERLITZ, C. (1999), "Causes of strain affecting relatives of Swedish elderly". *Scandinavian Journal of Caring Sciences*, 13, pp.109-115.
- HUBER, M. *et al.* (2005), *Long-term care for older persons: eligibility, recipients and expenditure*, OECD Health Working Papers, OECD, Paris, forthcoming.

- HUIJBERS, P. (1999), "Elderly Care in the Netherlands: A brief overview", NIZW Kenniscentrum, Ouderen. http://www.kenniscentrum-ouderen.nl/kco/english/facts/facts_elderlycare.html (Accessed November 2003)
- HUIJBERS, P. (2003), "Care Allowances in the Netherlands", NIZW Kenniscentrum, Ouderen. http://www.kenniscentrum-ouderen.nl/kco/english/facts/facts_careallowance.html (Accessed November 2003)
- JACOBZONE, S. *et al.* (2000), "Is the health of older persons in OECD countries improving fast enough to compensate for population ageing?", *OECD Economic Studies*, No. 30, pp. 149-190.
- JENSON, J. and S. JACOBZONE (2000), *Care Allowances for the Frail Elderly and their Impact on Women Care givers*, Labour Market and Social Policy Occasional Paper 41, OECD, Paris.
- JOHANSSON, S., and J. AHLFELDT (1993), "Do public services influence patterns of informal care? On conflicting demands in everyday life". *Scandinavian Journal of Social Welfare*, 5, pp. 83-96.
- JOHANSSON, S., and J. AHLFELDT (1996), "Stress experienced by informal care givers. On conflicting demands in everyday life". *Scandinavian Journal of Social Welfare*, 5, pp. 674-681
- JOHANSSON, L. (2000), *From policy to practice: The Swedish model*, paper presented at the 2nd International Conference on Caring, Brisbane, Australia, 29-31 March 2000.
- JOHNSON, R.W., and A.T. LO SASSO (2000), *Parental Care at Midlife: Balancing Work and Family Responsibilities near Retirement*, Urban Institute, Washington DC.
- JOHNSON, R.W., and A.T. LO SASSO (2000), *The Trade-off between hours of paid employment and time, assistance to elderly parents at midlife*, Urban Institute, Washington D.C.
- KRAMER, B. (1997), "Gain in the care-giving experience: Where are we? What next?", *The Gerontologist*, Vol. 37, No. 2, pp. 218-232.
- KREMER, M. (2004), *Where are we going to when consumers are in the driver's seat? The Dutch Personal Budget (PGB) and its impact on the market, professionals and the family*, paper presented at the symposium "Consumerism in care for the elderly", organised by the Danish National Institute of Social Research (SFI), 30 August, Copenhagen.
- LAGERGREN, M. and I. BALTJAN (2000), *Will There Be a Helping Hand: Macroeconomic Scenarios of Future Needs and Costs of Health and Social Care for the Elderly in Sweden 2000-30*, report issued by the Ministry of Finance SOU 2000:007, Stockholm.
- LUNDH, U. (1999a), "Family carers 1: difficulties and levels of support in Sweden", *British Journal of Nursing*, Vol. 8, No. 9, pp. 582-8.
- LUNDH, U. (1999b), "Family carers 2: sources of satisfaction among Swedish carers", *British Journal of Nursing*, Vol. 8, No. 10, pp. 647-52.
- LUNDH, U. (1999c), "Family carers 3: coping strategies among family carers in Sweden", *British Journal of Nursing*, Vol. 8, No. 11, pp. 735-90.
- LUNDH, U. (1999d), "Family carers 4: designing services to support family carers in Sweden", *British Journal of Nursing*, Vol. 8, No. 12, pp. 787-90.

- LUNDSGAARD, J. (2003), "Competition and efficiency in publicly funded services", *OECD Economic Studies*, No. 35, OECD, Paris, <http://www.oecd.org/dataoecd/42/36/22027701.pdf>.
- MAHONEY, K.J., K. SIMONE and L. SIMON-RUSINOWITZ (2000), "Early lessons from the Cash and Counseling Demonstration and Evaluation", *Generations*, Vol. 24, No. 3.
- MIKKELSEN, P. (2002), *European experiences with greater choice of providers in the care sector*, Paper for the EU Presidency Conference on care facilities for children and other dependant people, 25-26 November 2002, Helsingør, Denmark.
- MILTENBURG, F.M. and C.C. RAMAKERS (1999), "Evaluatie-onderzoek persoonsgebonden budget in Nederland" (Evaluation of personal care budgets in the Netherlands), *Tijdschrift voor gezondheidswetenschappen*, Vol. 77, No. 7.
- NEMETH, C. and E. POCHOBRADSKY (2002), *Qualitätssicherung in der Pflege* (Quality assurance in care), Bundesministerium für Soziale Sicherheit und Generationen, Wien.
- NOLAN, M., G. GRANT, and J. KEADY (1996), *Understanding Family Care*, London Open University Press.
- OECD (1994), *Caring for frail elderly people, new directions in care*, Social Policy Studies, No. 14, Paris.
- OECD (1996), *Caring for frail elderly people: Policies in evolution*, Social Policy Studies, No. 19, Paris.
- OECD (1997), *Ageing in OECD countries: A critical policy challenge*, Paris.
- OECD (1998), *Maintaining prosperity in an ageing society*, Paris.
- OECD (1999), *A caring world: The new social policy agenda*, Paris.
- OECD (2000a), *A System of Health Accounts*, Paris.
- OECD (2000b), *Reforms for an ageing society*, Paris.
- OECD (2004), *Benefits and Wages*, OECD, Paris.
- OECD (2005), *Long-term care policies for older people*, OECD, Paris, forthcoming.
- PAVALKO, E.K., and J.E. ARTIS (1997), "Women's care-giving and paid work: causal relationships in late midlife", *Journal of Gerontology: Social Sciences*, Vol. 52B, Vol.4, pp.170-9.
- PICKARD, L., R. WITTENBERG, A. COMAS HERRERA, B. DAVIES and R. DARTON (2000), "Relying on Informal Care in the New Century? Informal Care for Elderly People in England to 2031", *Ageing and Society*, Vol. 20, pages 745-772.
- PIJL, M. (2003), *Developments in the support of carers in Finland, England and the Netherlands 1998-2002*, unpublished memo.
- RICE, D. (1996), "Yesterday, today and tomorrow", *Health Care Financing Review*, Vol. 18, No. 2, pp. 23-46.

- ROSTGAARD, T. (2004), *With due care: Social care for the young and the old across Europe*, Ph.D. thesis, The Danish National Institute of Social Research, Copenhagen.
- ROSTGAARD, T. and T. FRIDBERG (1998), *Caring for Children and Older People: A comparison of European Policies and Practices*, Social Security in Europe Report 6, Danish National Institute of Social Research, Copenhagen.
- SALVAGE, A.V. (1995), *Who will care? Future prospects for family care for older people in the European Union*, European Foundation for the Improvement of Living and Working Conditions, Dublin.
- SCHERER, P. (1997), "Socio-economic change and social policy" in *Family, market and community: Equity and efficiency in social policy*, Social Policy Studies, No. 21, Paris.
- SCHNEEKLOTH, U. and U. MÜLLER (2000) *Wirkungen der Pflegeversicherung* (Effects of long-term care insurance), *Forschungsprojekt im Auftrag des Bundesministeriums für Gesundheit*, Baden-Baden.
- SCHNEIDER, TH., S. DROBNIC, H.-P BLOSSFELD (2001), "Pflegebedürftige Personen im Haushalt und das Erwerbsverhalten verheirateten Frauen" (Home care of the elderly and the employment behaviour of married women), *Zeitschrift für Soziologie*, Vol. 30, pp. 362-83.
- SOCIALSTYRELSEN (2002), *Anhörig 300 – Slutrapport* (Dependent 300 – final report), the Swedish National Board of Health and Welfare, Stockholm.
- SOCIALSTYRELSEN (2003), *Ett år efter Anhörig 300* (One year after Dependent 300), the Swedish National Board of Health and Welfare, Stockholm.
- SPIESS C.K. and A.U. SCHNEIDER (2003), "Interactions between care-giving and paid work hours among European midlife women, 1994 and 1996" *Ageing & Society*, Vol. 23, pp. 41-68.
- STONE, R. and J. WIENER,(2001), "Who Will CARE for Us? Addressing the Long-Term Care Workforce Crisis" The Urban Institute and the American Association of Homes and Services for the Ageing.
- TENSTEDT, S., HARROW, B. and Crawford, S. (1996), "Informal care vs. formal services: changes in patterns of care over time". *Journal of Social Policy and Ageing.*, Vol. 7, pp. 71-91.
- TESTER, S. (1996), *Community care for older people: A comparative perspective*, Macmillan, Basingstoke.
- TILLY, J. and J.M. WIENER (2001), "Consumer directed home and community services: Policy issues", *Urban Institute Occasional Paper*, No. 44.
- TILLY, J, J. M. WIENER, and A. E. CUELLAR (2000), "Consumer-Directed Home- and Community-Based Services Programs in Five Countries: Policy Issues for Older People and Government", *Generations*, Vol. 24, No. 3.
- TINKER, A., F.WRIGHT, C. MCCREADY, J. ASKHAM, R. HANCOCK, and A. HOLMANS (1999), "Alternative Models of Care of Older People. *With Respect to Old Age: Long Term care*"-Right and Responsibilities, Research Vol. 2, Cm 4192-II/2, TSO, London.

- TWIGG, J., K. ATKIN, and C. PERRING (1990), *Careers and services: A review of research*, HMSO, London.
- UNGERSON, C. (1997), "Social politics and the commodification of care", *Social Politics*, Vol. 4, No. 3, pp. 362-381.
- UNGERSON, C. (2003), "Commodified care work in European labour markets", *European Societies*, Vol. 5, No. 4, pp. 377-396.
- UNGERSON, C. (2004), "Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes", *Ageing & Society*, Vol. 24, pp. 189-212.
- WANLESS, D. (2002), *Securing our future health: Taking a long-term view*, report commissioned by the Government of the United Kingdom.
- WEEKERS, S. and M. PIJL (1998), *Home Care and care allowances in the European Union*, NIZW, Utrecht.
- WIENER, J., J. TILLY and A.E. CUELLAR (2003), *Consumer-directed home care in the Netherlands, England, and Germany*, AARP Public Policy Institute paper, October, http://research.aarp.org/health/2003_12_eu_cd.html
- COLEMAN, B. (2003), *Consumer-Directed Personal Care Services for Older People in the U.S.*, AARP Issues Brief, October, http://research.aarp.org/health/ib64_cd.html. TILLY and L.M.B. ALECXIH (2002), "Home and community-based services in seven states", *Health Care Financing Review*, Vol. 23, No. 3.
- WITTENBERG, R., L. PICKARD, A. COMAS-HERRERA, *et al.* (2001), "Demand for long-term care for older people in England to 2031", *Health Statistics Quarterly*, No. 12, pp. 5-17.
- WITTENBERG, R., R. HANCOCK, A. COMAS-HERRERA and L. PICKARD (eds.) (2002), "Demand for Long-Term Care in the UK: Projections of Long-Term Care Finance for Older People to 2051", In Richard Brooks, Sue Regan and Peter Robinson, *A New Contract for Retirement. Modelling Policy Options to 2050*, Institute for Public Policy Research, London, pages 65-120. ISBN 1 86030 193 2
- WOLF, D.A., and B.J. SOLDI (1994), "Married women's allocation of time to employment and care of elderly parents", *Journal of Human Resources*, Vol. 29, pp. 1259-76.

OECD HEALTH WORKING PAPERS

Papers in this series can be found on the OECD website: www.oecd.org/els/health/workingpapers

- No. 19 *PRIVATE HEALTH INSURANCE IN THE NETHERLANDS. A CASE STUDY* (2004) Nicole Tapay and Francesca Colombo
- No. 18 *SKILL-MIX AND POLICY CHANGE IN THE HEALTH WORKFORCE: NURSES IN ADVANCED ROLES* (2004) James Buchan and Lynn Calman
- No. 17 *SKILL-MIX AND POLICY CHANGE IN THE HEALTH WORKFORCE: NURSES IN ADVANCED ROLES* (2004) James Buchan and Lynn Calman
- No. 16 *SHA-BASED NATIONAL HEALTH ACCOUNTS IN THIRTEEN OECD COUNTRIES: A COMPARATIVE ANALYSIS* (2004) Eva Orosz and David Morgan
- No. 15 *PRIVATE HEALTH INSURANCE IN OECD COUNTRIES: THE BENEFITS AND COSTS FOR INDIVIDUALS AND HEALTH SYSTEMS* (2004) Francesca Colombo and Nicole Tapay
- No. 14 *INCOME-RELATED INEQUALITY IN THE USE OF MEDICAL CARE IN 21 OECD COUNTRIES* (2004) Eddy van Doorslaer, Cristina Masseria and the OECD Health Equity Research Group
- No. 13 *DEMENTIA CARE IN 9 OECD COUNTRIES: A COMPARATIVE ANALYSIS* (2004) Pierre Moise, Michael Schwarzingler, Myung-Yong Um and the Dementia Experts' Group
- No. 12 *PRIVATE HEALTH INSURANCE IN FRANCE* (2004) Thomas C. Buchmueller and Agnes Couffinhal
- No. 11 *THE SLOVAK HEALTH INSURANCE SYSTEM AND THE POTENTIAL ROLE FOR PRIVATE HEALTH INSURANCE: POLICY CHALLENGES* (2004) Francesca Colombo and Nicole Tapay
- No. 10 *PRIVATE HEALTH INSURANCE IN IRELAND. A CASE STUDY* (2004) Francesca Colombo and Nicole Tapay
- No. 9 *HEALTH CARE SYSTEMS: LESSONS FROM THE REFORM EXPERIENCE* (2003) Elizabeth Docteur and Howard Oxley
- No. 8 *PRIVATE HEALTH INSURANCE IN AUSTRALIA. A CASE STUDY* (2003) Francesca Colombo and Nicole Tapay
- No. 7 *EXPLAINING WAITING-TIMES VARIATIONS FOR ELECTIVE SURGERY ACROSS OECD COUNTRIES* (2003) Luigi Siciliani and Jeremy Hurst
- No. 6 *TACKLING EXCESSIVE WAITING TIMES FOR ELECTIVE SURGERY: A COMPARISON OF POLICIES IN 12 OECD COUNTRIES* (2003) Jeremy Hurst and Luigi Siciliani
- No. 5 *STROKE CARE IN OECD COUNTRIES: A COMPARISON OF TREATMENT, COSTS AND OUTCOMES IN 17 COUNTRIES* (2003) Lynelle Moon, Pierre Moïse, Stéphane Jacobzone and the ARD-Stroke Experts Group
- No. 4 *SURVEY OF PHARMACOECONOMIC ASSESSMENT ACTIVITY IN ELEVEN COUNTRIES* (2003) Michael Dickson, Jeremy Hurst and Stéphane Jacobzone
- No. 3 *OECD STUDY OF CROSS-NATIONAL DIFFERENCES IN THE TREATMENT, COSTS AND OUTCOMES OF ISCHAEMIC HEART DISEASE* (2003) Pierre Moïse, Stéphane Jacobzone and the ARD-IHD Experts Group
- No. 2 *INVESTMENT IN POPULATION HEALTH IN FIVE OECD COUNTRIES* (2003) Jan Bennett
- No. 1 *PHARMACEUTICAL USE AND EXPENDITURE FOR CARDIOVASCULAR DISEASE AND STROKE: A STUDY OF 12 OECD COUNTRIES* (2003) Michael Dickson and Stéphane Jacobzone

Other health-related working papers, also available from the OECD website, include:

LABOUR MARKET AND SOCIAL POLICY OCCASIONAL PAPERS

- No. 56 *AN ASSESSMENT OF THE PERFORMANCE OF THE JAPANESE HEALTH CARE SYSTEM* (2001)
Hyoung-Sun Jeong and Jeremy Hurst
- No. 53 *TOWARDS MORE CHOICE IN SOCIAL PROTECTION? INDIVIDUAL CHOICE OF INSURER IN BASIC MANDATORY HEALTH INSURANCE IN SWITZERLAND* (2001) Francesca Colombo
- No. 47 *PERFORMANCE MEASUREMENT AND PERFORMANCE MANAGEMENT IN OECD HEALTH SYSTEMS* (2001) Jeremy Hurst and Melissa Jee-Hughes
- No. 46 *EXPLORING THE EFFECTS OF HEALTH CARE ON MORTALITY ACROSS OECD COUNTRIES* (2000) Zeynep Or
- No. 44 *AN INVENTORY OF HEALTH AND DISABILITY-RELATED SURVEYS IN OECD COUNTRIES* (2000)
Claire Gudex and Gaetan Lafortune
- No. 41 *CARE ALLOWANCES FOR THE FRAIL ELDERLY AND THEIR IMPACT ON WOMEN CARE-GIVERS* (2000) Jane Jenson and Stéphane Jacobzone
- No. 40 *PHARMACEUTICAL POLICIES IN OECD COUNTRIES: RECONCILING SOCIAL AND INDUSTRIAL GOALS* (2000) Stéphane Jacobzone

RECENT RELATED OECD PUBLICATIONS:

TOWARDS HIGH-PERFORMING HEALTH SYSTEMS (2004), *OECD Health Project series*

TOWARDS HIGH-PERFORMING HEALTH SYSTEMS: POLICY STUDIES (2004), *OECD Health Project series*

PRIVATE HEALTH INSURANCE IN OECD COUNTRIES (2004), *OECD Health Project series*

OECD HEALTH DATA 2004 (2004), available in English, French, German, Italian, Russian and Spanish on CD-ROM (Windows 98/2000/NT/Me/XP)

HEALTH AT A GLANCE – OECD INDICATORS 2003 (2003), published biennially

A DISEASE-BASED COMPARISON OF HEALTH SYSTEMS: What is Best and at What Cost? (2003)

OECD REVIEWS OF HEALTH CARE SYSTEMS – KOREA (2003)

POVERTY AND HEALTH (2003)

ASSESSING MICROBIAL SAFETY OF DRINKING WATER: IMPROVING APPROACHES AND METHODS (2003)

MEASURING UP: IMPROVING HEALTH SYSTEM PERFORMANCE IN OECD COUNTRIES (2002)

MEASURING EXPENDITURE ON HEALTH-RELATED R&D (2001)

A SYSTEM OF HEALTH ACCOUNTS (2000)

GENETIC TESTING: POLICY ISSUES FOR THE NEW MILLENIUM (2000)

For a full list, consult the OECD On-Line Bookstore at www.oecd.org, or write for a free written catalogue to the following address:

OECD Publications Service
2, rue André-Pascal, 75775 PARIS CEDEX 16
or to the OECD Distributor in your country