

Bulletin luxembourgeois des questions sociales
2005 Volume 19

Long-term Care for Older Persons

Conference organised by the Luxembourg
Presidency with the Social Protection Committee
of the European Union
Luxembourg, 12 and 13 May 2005



a l o s s
association luxembourgeoise
des organismes de sécurité sociale



a l o s s

association luxembourgeoise
des organismes de sécurité sociale

BP 1308
L-1013 Luxembourg

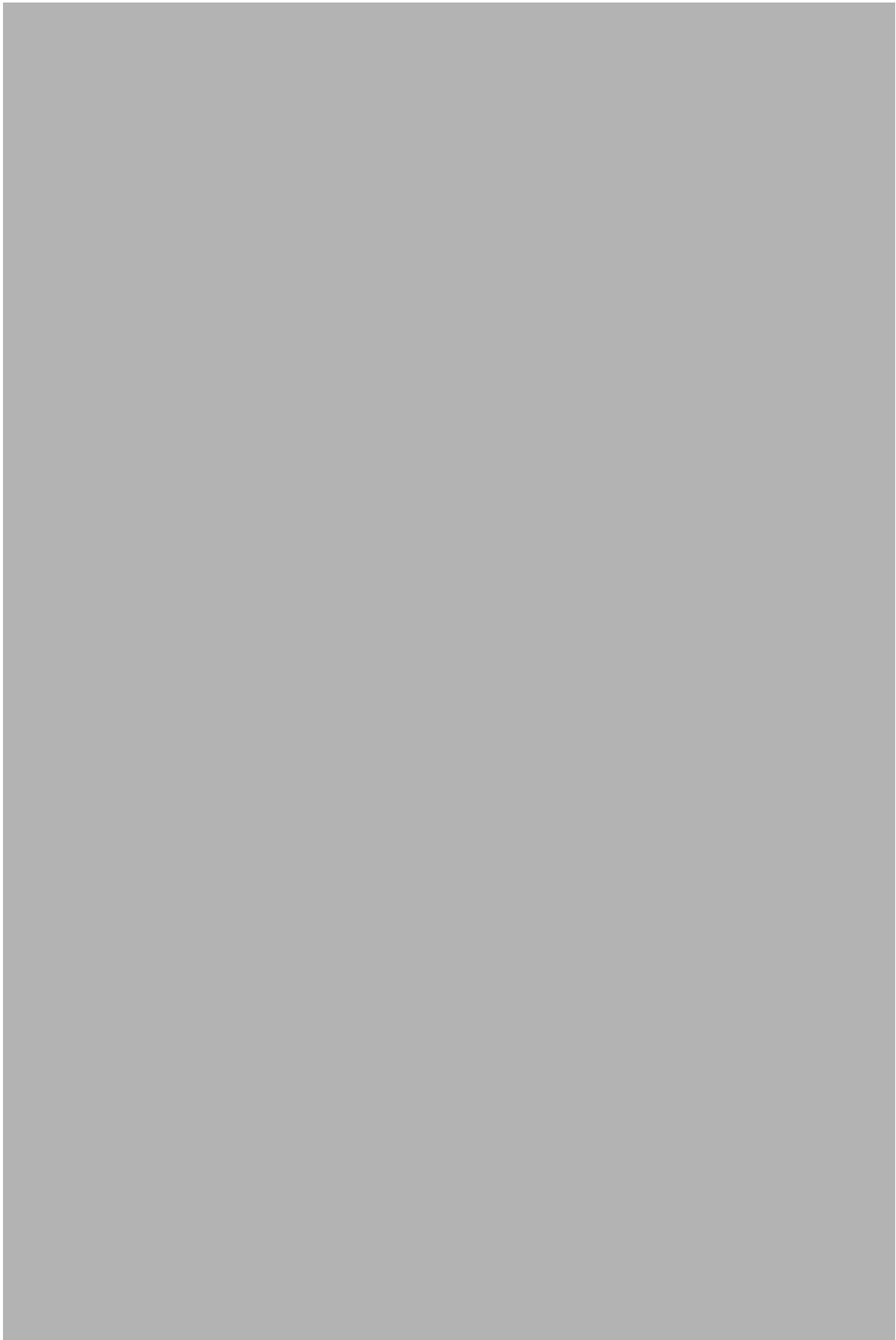
ISBN 2-495-23050-4

Les articles reproduits n'engagent que la responsabilité
de leurs auteurs et non les administrations et les
institutions dont ils relèvent

LONG-TERM CARE FOR OLDER PERSONS

**CONFERENCE ORGANISED BY THE LUXEMBOURG
PRESIDENCY WITH THE SOCIAL PROTECTION COMMITTEE
OF THE EUROPEAN UNION**

LUXEMBOURG, 12 AND 13 MAY 2005



Preface

The Luxembourg Presidency Conference on "Long-term Care for Older Persons", which took place on 12 and 13 May 2005, was organised in the context of work carried out at European level in recent years to modernise the European Social Model and to develop European social policies based on the principles of social justice, cohesion and equity. Over the next few decades, European societies must deal with the challenges resulting from an ageing European population. Social protection in particular will need to be modernised and adapted to the new demographic, economic and social conditions brought about by the ageing of the population.

The conference aimed to offer a comprehensive and contemporary assessment of long-term care for older persons within the European Union. The central topic of the conference was analysed from four different points of view trying to identify, within the different national contexts, common lines of reflection leading to a common social policy in this field. The four approaches were: the need of older people for long-term care, responsibility for long-term care, social protection with respect to long-term care and social justice and long-term care.

Key conclusions from the conference refer to the growing number of older persons and the resulting needs of support and care services in order to ensure decent living conditions. It also stressed the importance of prevention and an active life to reduce the risk of dependency later in life. The common importance in all countries of informal support and care provision, mainly by family members, and a smooth coordination of it with formal support and care services was highlighted. Informal carers, mostly women, need also to be supported in various ways, to allow them to care for a dependent person without having to give up their own life goals. A concluding presentation pointed out that public financing of long-term care, through either a social insurance or tax based system, seems to be more efficient than private financing solutions, whereas both private or public providers, or a combination of both, can provide support and care services. The conference also showed how important it is for national, regional and local authorities to learn from each other's solutions and experiences.

The conference has been a further important step in the ongoing work by the EU Member States as represented in the Social Protection Committee together with the European Commission to modernise social protection, notably in the health care and long-term care area, via the Open Method of Coordination. It was thus co-financed by the European Commission. A further conference on the subject of long-term care in September 2006 in Brussels will build on the conclusions from this conference and continue the work at the European level in this area.

Andrée KERGER and
Raymond WAGENER
*Inspection générale de la sécurité
sociale
Luxembourg*

Jérôme VIGNON
*Directorate-General for Employment,
Social Affairs and Equal
Opportunities
European Commission*

January 2006

Introduction and Acknowledgments

The conference on "Long-term Care for Older Persons" aimed to offer a comprehensive and contemporary assessment of long-term care for older people within the European Union, as stated in the opening addresses by Minister Mars Di Bartolomeo from Luxembourg and Commissioner Vladimír Špidla from the European Commission, which are reproduced here in Part 1.

The central topic of the conference was analysed from four different points of view. All four approaches tried to identify, within the different national contexts, common lines of reflection leading to a common social policy in this field. The four approaches were:

- the need of older persons for long-term care;
- responsibility for long-term care;
- social protection with respect to long-term care;
- social justice and long-term care.

The first three points of view were presented in a scientific report written by a group of researchers, Ms Nicole Kerschen, Professor Jozsef Hajdu, Professor Gerhard Igl, Professor Marie-Eve Joël, Professor Kees Knipscheer and Professor Igor Tomes. The report, which constitutes Part 2 of these proceedings, served as the background document for discussion during the conference.

The fourth point of view, on "Social justice and long-term care", was suggested by the reports and discussions of a seminar financed by WHO at the University of Chicago in 2002, on the topic of "*Ethical choices in long-term care: what does justice require?*"¹⁾, as well as by the work of the American philosopher Martha C. Nussbaum on the challenge which long-term care presents to conventional ideas on the social contract. The first two sections of the text by Professor Nussbaum are reproduced here as Part 3, with the kind permission of Professor Nussbaum and WHO. This text discusses ideas that appear in a revised and improved form in her new book "*Frontiers of Justice: Disability, Nationality, Species Membership*" (Harvard University Press, 2006).

1) WHO, *Ethical choices in long-term care: what does justice require?*, World Health Organization collection on long-term care, WHO, 2002 (http://www.who.int/mediacentre/news/notes/ethical_choices.pdf).

Prior to the conference, in December 2004, Professor Jean-François Malherbe from the University of Sherbrooke (Quebec) led a preparatory seminar in Luxembourg in which beneficiaries of long-term care, professional and non-professional carers, policy analysts and social programme managers participated. Questions of justice and solidarity in the domain of social policies for long-term care were discussed. What are our values? And in respect of which of these do we take practical action? How can we bring our values and practice closer together? Part 4 of this report presents Professor Malherbe's introductory text for this seminar.

Part 5 contains a summary of the discussions during the conference. In the final session Professor Malherbe offered his conclusions on the preparatory seminar and on the conference, especially on the values on which the social policies of the Member States of the European Union are based. Does a given value have the same meaning in different countries? What do the differences mean? What is required in order to grant the same rights to every European citizen?

This was followed by a presentation by Professor Nicholas Barr of the London School of Economics and Political Science (LSE) of his thoughts on the need for and possibility of developing convergent European social protection in the area of long-term care for older people.

The conclusions to be drawn from the conference from the point of view of the European Commission were presented by Mr Jérôme Vignon, Director of Social Protection of the European Commission's Directorate-General of Employment, Social Affairs and Equal Opportunities.

We should like to thank the European Commission for its financial support, without which it would have been impossible to organise the conference. Many thanks to the authors of the background report, to Professor Malherbe for having so kindly agreed to lead the preparatory seminar and to present its conclusions to the conference, to Professor Barr for coming to Luxembourg to express his thoughts about long-term care and social policy to conference participants, and to Mr Vignon for his conclusions. We also wish to thank the chairs of the sessions, all the discussants, and all who participated in the discussions and in the conference.

Finally, we are very grateful for the commitment of Ms Caroline Wies and of all those in the Inspection générale de la sécurité sociale and the Cellule d'évaluation et d'orientation, who helped in various ways to organise the conference and prepare these proceedings. Thank you very, very much!

Andrée KERGER and Raymond WAGENER
Inspection générale de la sécurité sociale
Luxembourg

CONTENTS

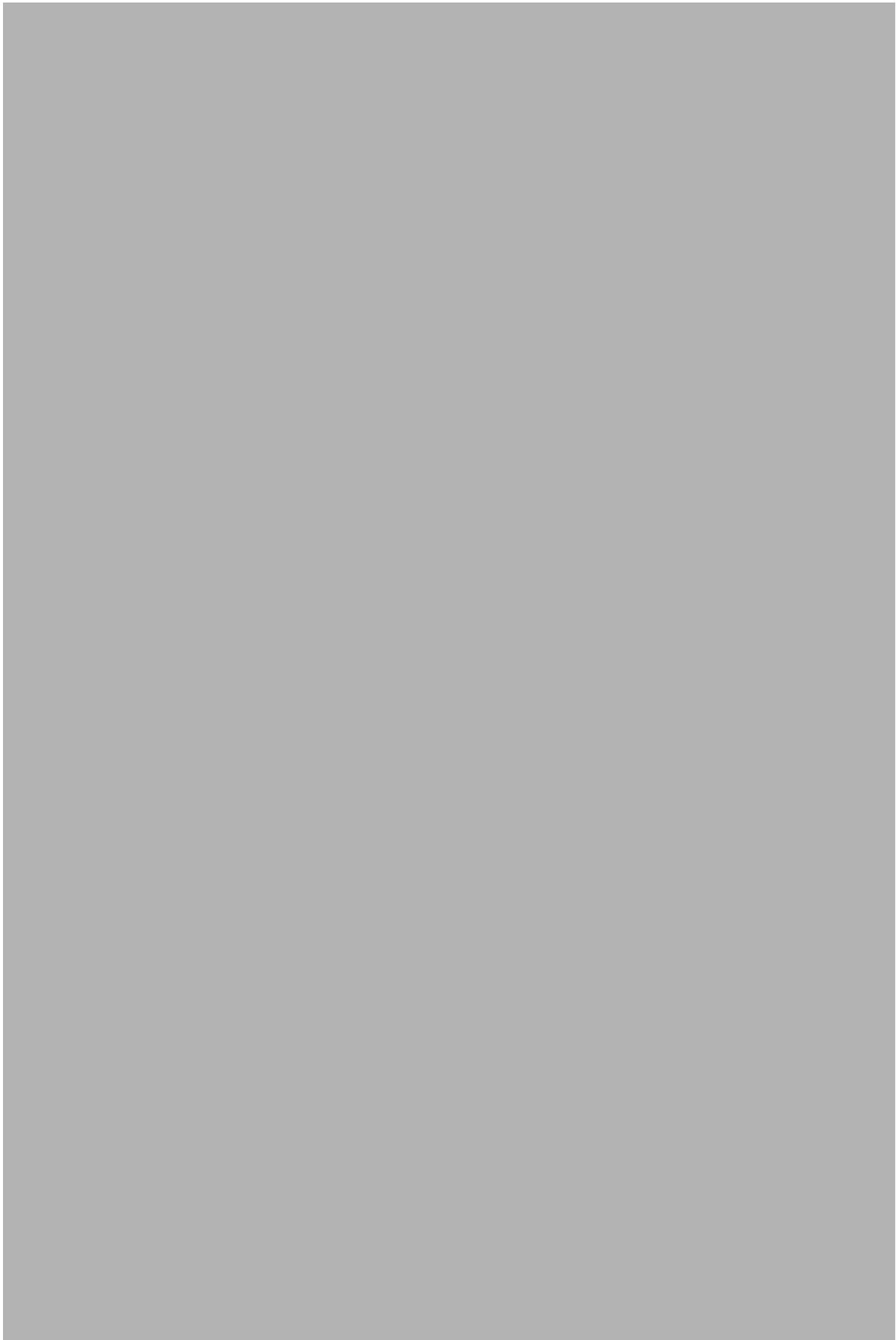
SECTION 1	Opening Addresses	
	Mr Mars DI BARTOLOMEO	3
	Mr Vladimir Spidla	5
SECTION 2	Experts' Report: Long-term Care for Older Persons	9
	Introduction	11
	Part I: Needs	13
	I. Definition of long-term care for older people	13
	II. Number and characteristics of people needing long-term care	20
	III. Projections and possible scenarios	29
	Part II: Responsibilities	41
	I. Family/private responsibility	42
	II. Public/state responsibility	50
	Part III: Protection	61
	I. Private and public protection: an appraisal	61
	II. Protection: common issues and topics	91
	Part IV: Financial issues	99
	I. Choosing a package of services for dependent older people: financial constraints and macroeconomic trade-offs	100
	II. Production constraints	101
	III. Financing agencies	102
	IV. Financial constraints and cost containment	103
	V. Changing the behaviour of long-term care beneficiaries: economic incentives?	105
	Part V: Basic Choices	109
	I. Division of responsibility between the public and the private	109
	II. Social Protection	109
	III. Support for informal care	110
	IV. Labour market, women's employment and long-term care	110
	V. Accessibility of long-term care benefits	111
	VI. User/consumer status	111
	VII. Quality of long-term care and its assessment	111
	VIII. Cost containment	112

	IX. Major challenges	112
	Annexes	113
	I. Annex 1. The main aspects of the “open method of coordination” as applied to health care and long-term care (1997 – 2005)	113
	II. Annex 2. OECD Glossary - Study on “Long-term care for older people” as one of the components of the Health Project (2005)	116
	III. Annex 3. Data from Luxembourg (2004): Beneficiaries of long-term care insurance by type of residence	118
	IV. Annex 4. Some information on maintenance obligations	119
	References	131
Section 3	Martha C. NUSSBAUM: Long-term Care and Social Justice: a Challenge to Conventional Ideas of the Social Contract (Extract)	151
	A.1 An acute problem of justice	151
	A.2 Some minimal goals	153
	Endnotes	159
Section 4	Jean-François MALHERBE: Of Solidarity between Justice and Equity	165
	What is Ethics?	165
	What are Equity and Justice?	167
	What is Solidarity?	168
	Guidelines for Decision Making	175
	The “Work of the Negative” in Ethics	175
	Corollary: What is a “Subject”?	180
	Subjectivity and “Spirituality”	182
	The Trap of Professional Idealism	183
	Sharing the Frustration Equitably	185
	On the Concept of “Scarcity”	185
	The Infinitesimal and Totality	186
	The Thirteenth Monthly Budget Method	186
	Finally, the Need for Ethics Training in Clinical Decision Making	191
	Bibliography	191

Section	Discussions	193
	Session 1: The needs of older people for long-term care	195
	Session 2: Responsibility for long-term care	203
	Session 3: Social protection for long-term care	213
	Session 4: Social justice and long-term care	227
	Final discussion	239

SECTION 1

OPENING ADDRESSES



Mr Mars DI BARTOLOMEO

*Minister of Health and Social Security
Luxembourg
Presidency of the European Council*

Dear guests and all who will be working for the next couple of days, it is a great pleasure and an honour for me to welcome you to this conference organised by the Luxembourg Presidency within the framework of the Social Protection Committee, with the support of the European Commission. I would like to wish you a very warm welcome and I would particularly like to welcome Commissioner Vladimir Špidla, who is responsible for Employment, Social Affairs and Equal Opportunities within the Commission. Commissioner Vladimir Špidla has kindly agreed to introduce the work of the conference. Thank you very much indeed, Commissioner, for coming along and, through your presence, thank you for showing the very great importance of this subject for the European Commission!

I would like to welcome every one here and I do hope that this two-day conference, all of whose aspects are of great interest, will be very fruitful. This is an interesting conference for various reasons, not only because older people are a very topical issue, but also because the consequences of ageing in the Western world are a hotly debated subject. The optimists describe ageing as being a new source of wealth for industrialised society, while others feel that the solidarity between generations is being called into question. For both, population ageing imposes a need to rethink our values and our practices. The challenge of long-term care for older people is one of the key elements in this debate.

In October 2004 the Council of the European Union, following the opinions of the Commission, decided to deal with long-term care as part of the Open Method of Coordination, which has been a very fruitful working method, and it allowed us to make progress in this field. The Council suggested that the challenges raised by long-term care for older people should be met by all the Member States together on the basis of common objectives, which will allow the coexistence of national systems which guarantee equal access to high-quality care to all citizens, and they will do this while preserving the financial viability of the system.

This is the context for our discussion today and tomorrow: we are going to look at the overall picture of the European mosaic in long-term care for older people. Part of the picture will be concerned with the need for long-term care, the various definitions, the various different needs, the expenditures involved, the descriptions and characteristics of the groups concerned. The other part of the picture will be concerned with the various ways of responding to the needs and with the sharing of responsibilities between public and private

sectors; we will be looking at the historical role played by the family in providing care and at the infrastructure for care and the existing methods of protection in the various Member States. We have experts here from various EU countries. We have some very important figures working in the field and we have representatives from the world of politics at this conference, and I think we will be able to obtain a clear and detailed picture of the situation across the EU.

This conference should allow us to exchange examples of good practice – those who have taken real steps forward can certainly give valuable advice to those who are only now building up their systems. So I think that there will be a lot of differences and contrasts in the pictures we'll see and we will have a debate about the development of social protection in Europe and will then reflect on the values of justice, independence and fairness and how these values can be applied when we are providing long-term care. This will emphasise the need for dialogue to help us to define common objectives for all countries. We would like to conclude with a round table allowing those with political responsibilities to comment on the situation in their countries with regard to the various aspects considered in this conference, and hopefully that can bring out the essential points which could be retained as the conference's conclusions.

Before I give the floor to the Commissioner, I would like to present to you the four sessions of the conference and their chairpersons. In the first session we will be looking at the needs, with Tom Mulherin; he is the joint Assistant Secretary of State in Ireland and has responsibility for social protection. That's Tom Mulherin. Mrs Agnieszka Chlon-Dominczak from Poland will chair the second session, on the responsibilities. She is the Undersecretary of State in the Ministry of Social Policy and is a member of the working group which prepared the pensions reform in Poland. The third session, dedicated to the protection of long-term care, will be chaired by Mr Marten Lagergren from Sweden. He is research director at the Stockholm Gerontology Research Center and is the national coordinator for the Swedish Study on Ageing and Care. Finally, Ms. Elise Williame from Belgium will chair the fourth session, on social justice in long-term care. Ms. Williame is from the Belgian Ministry of Social Security and she is also vice-chair of the Social Protection Committee.

I would like to thank all those whose work and commitment helped us to prepare this conference. I would also like to thank all those who agreed to participate in it, particularly the experts among us, and I hope that this work will be very useful. Thank you again and let's hope that we'll work well together for the greater good of Europe.

Mr Vladimír ŠPIDLA

*Commissioner for Employment,
Social Affairs and Equal Opportunities*

Europe is faced with considerable changes – the population is ageing, and the life expectancy of men and women continue to increase. We can see that more and more people will need long-term care; it is a very important issue. So how do we move forward? We need to protect independence and human dignity, and there is the issue of funding as well. People are becoming aware of the scale of the change which is happening and they wish to cooperate within the European Union, to identify possible specific courses of action. I would like to thank very much the Luxembourg Presidency and the Minister Mars di Bartolomeo for organizing this conference that will try to give some answers for the future.

As the recent Green Paper on Demographic Challenges shows, Europe is undergoing considerable changes. Thus some countries have managed to boost generational renewal, while others haven't. Life expectancy continues to increase, in particular life in good health following the age of 60. The baby boomers are ageing now, inexorably, and this increases the number of older workers, as well as the number of the very elderly. This is the greatest change that we have to anticipate. In 2030 we'll be talking about a figure of 35 millions of people aged over 80 compared with 19 millions today – the figure will almost double. In the Czech Republic, for example, today there are only 34 000 people aged over 80. In 2030 there will be 65 000, and this will not be an isolated case in Europe; there will be an explosion of elderly people.

Thanks to the progress of preventive care, more older people remain independent for longer, and there will be a particular focus on the end of people's lives. These people will, without a doubt, wish to remain in their own homes for as long as possible, but there will be more and more people that will need to be looked after to a considerable extent, due to the loss of their own independence. So we need to make sure that we can assure an adequate living standard for a population who will spend a quarter of a century at school and another quarter of a century in retirement. How can such long periods of inactivity be financed?

There is the question of reform; we want to increase employment levels, to increase productivity and to ensure the sustainability of our social protection systems. These reforms are essential because only they will allow us to consolidate the foundations of our European social model. But reforms alone will not be sufficient, we need to take action with regard to what families are doing today, particularly women. If we want to achieve full employment and maintain living standards, greater numbers of women will have to participate in the labour market, in order to compensate for the programmed reduction

in the working population. In order to have a younger generation growing up, there needs to be greater sharing of domestic and familial tasks between men and women. Care for older people, employment, the birth rate, this is a sort of magic triangle with which Europe needs to deal, and it can't do this without mobilising all the social actors, without inventing new formulas and without strong public intervention. Families or women alone cannot solve the issue of looking after these people, whether they are dependent or independent – they need to receive greater support, starting today.

First of all, this means strengthening our policies of reconciling jobs and family in private life. As the best European practice shows, such a policy has to be a global one. First of all, employees need to have easier access to flexible working time systems, such as variable working hours, flexitime, part-time and so on. Provision for childcare and care for dependent people needs to be strengthened. We need to make sure that quality jobs are provided in this sector. The institution of care leave can also be considered, so that people can look after their ageing parents, on the model of parental leave. We need to change attitudes and behaviour, and men need to have access to parental leave or care leave as women do.

The second major issue at stake is the development of the social services, the care networks, in particular at local level. Should we separate provision for older people from the classic risks covered by social protection for illness and retirement? Should it be an autonomous branch with its own sources of finance to give older people equal access to quality care? Some countries have already moved down this road.

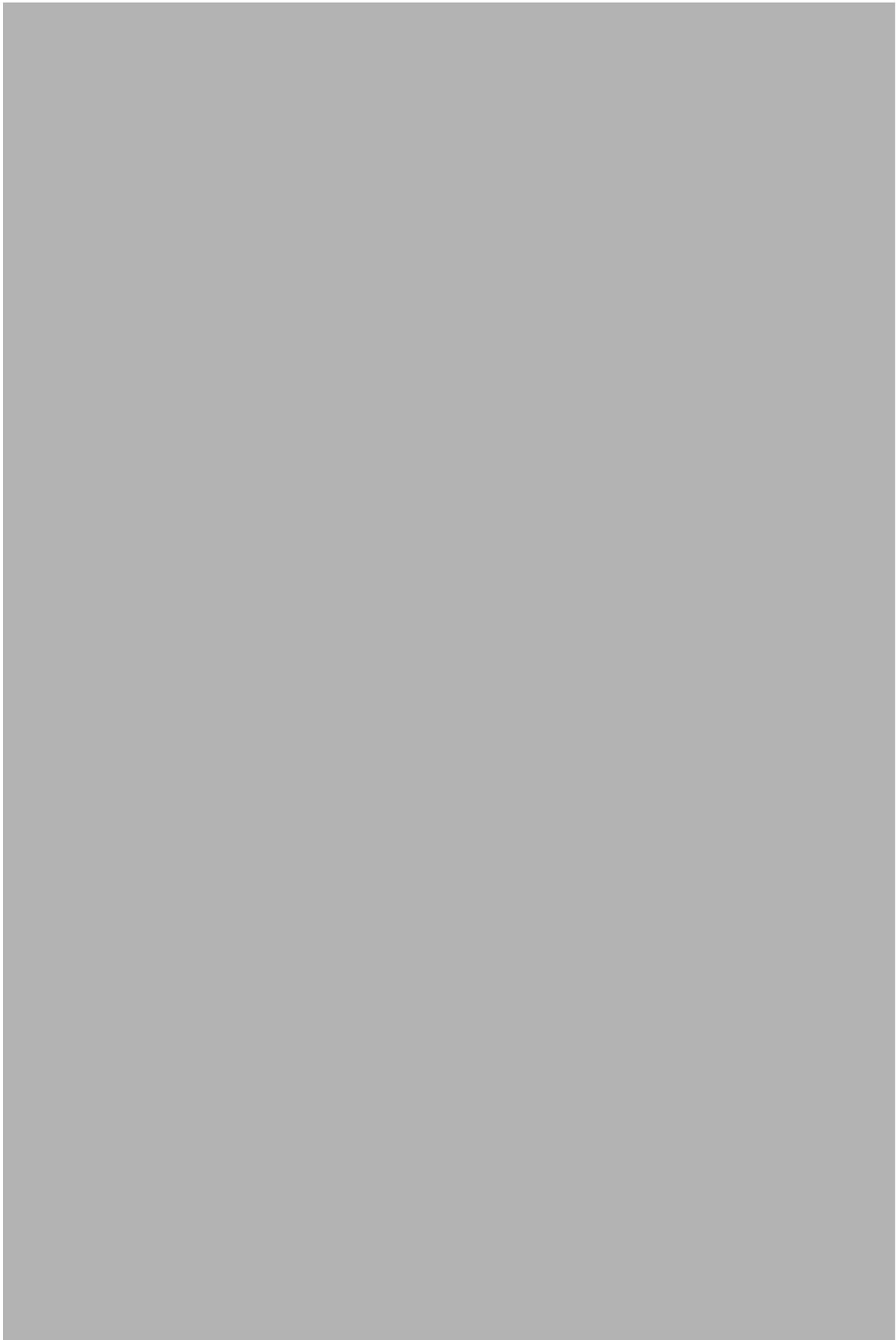
The public consultation launched by the Green Paper will mean that many contributions will be made on these vital subjects, which are so important for the future of our model of society. I also hope that the definition of the common objectives for modernisation of the health system and the long-term care system, planned for next year, will allow us to move towards common approaches. We have a lot to learn from each other through the diversity of national situations, which is why this conference represents a major contribution to the coordination of our national policies. I do hope that this conference and your work will be enriching and fruitful.

Thank you very much indeed for your attention!

SECTION 2

**Nicole KERSCHEN
Jozsef HAJDU
Gerhard IGL
Marie-Eve JOËL
Kees KNIPSCHEER
Igor TOMES:**

LONG-TERM CARE FOR OLDER PERSONS



Long-term Care for Older Persons

Nicole KERSCHEN (coordinator),
Jozsef HAJDU,
Gerhard IGL,
Marie-Eve JOËL,
Kees KNIPSCHIEER
and Igor TOMES

This report has been coordinated by *Nicole Kerschen*¹⁾, researcher in Social Policy and Law at the CNRS, IRERP UMR CNRS N°7029, University of Paris X, France. She was an adviser to the Minister of Social Security in Luxembourg between 1989 and 1999. Team members were *Jozsef Hajdu*, *Gerhard Igl*, *Marie-Eve Joël*, *Kees Knipscheer* and *Igor Tomes*. Final redaction by *Gerhard Igl* and *Nicole Kerschen*. *Jozsef Hajdu*²⁾ is a lawyer and a Professor at the University of Szeged, Hungary. He is also Director of the Institute of Industrial Relations and Social Insurance.

*Gerhard Igl*³⁾ is a lawyer and Professor of Social Security Law and Public Law at the University of Kiel, Germany. He is also Director of the Institute of Social Security Law and Social Policy in Europe.

*Marie-Eve Joël*⁴⁾ is an economist and a Professor at the University of Paris Dauphine (Paris IX), France. She is also Director of the Research Institute on Economy and Management of Health Organisations (LEGOS).

*Kees Knipscheer*⁵⁾ is a sociologist and Professor in Social Gerontology at the Vrije Universiteit, Amsterdam, the Netherlands.

*Igor Tomes*⁶⁾ is a lawyer and sociologist, and Professor in Social Policy, Law and Administration at the Charles University and the Superior School of Applied Law, a private law University in Prague, Czech Republic.

1) kerschen@noos.fr; kersche@u-paris10.fr

2) hajdu@lib.juris.u-szeged.hu

3) gigl@instsociallaw.uni-kiel.de; www.uni-kiel.de/instsociallaw

4) joel@dauphine.fr

5) CPM.Knipscheer@fsw.vu.nl

6) igor.tomes@personnel-consulting.cz

Ten years ago, Gerhard Igl, Marie-Eve Joël, Nicole Kerschen and Kees Knipscheer worked together on a report for the Luxembourg Government on “Dependency of elderly people: social protection systems in France, Germany, Luxembourg and the Netherlands”⁷⁾. The report provided a basis for work to set up Luxembourg’s long-term care insurance scheme which was introduced in 1999.

7) IGL G., JOEL M.-E., KERSCHEN N., KNIPSCHER C.P.M. (1993), *La dépendance des personnes âgées. Volume I. Prise en charge et financement en Allemagne, en France et aux Pays-Bas. Volume II. Bilan du système luxembourgeois de prise en charge des personnes âgées dépendantes et propositions de réforme. Report commissioned and financed by the Luxembourg Government.*

Introduction

Long-term care for older people is a topic of growing importance in the Member States of the European Union and consequently also within the EU institutions. The reasons are well known. Long-term care is primarily a contingency that increases in significance with old age. Increasing life expectancy statistically implies an increasing need for long-term care. In Central and Eastern Europe, for example, the oldest section of the population (typically defined as people aged 80 and over) is growing at the fastest pace, expanding in many countries at rates of 3-4% per year. The demand for care among older people, including the demand for long-term care, is growing rapidly. This trend is being accentuated, among other things, by the fact that more and more older people are living alone.

Most of the EU Member States faced with this trend have introduced a range of measures in the field of social protection and health policy. Families, communities and public institutions have been adapting to the developing situation and further progress has been made towards meeting the demand for care for older people. However, progress is uneven as it requires what are often complex adjustments to existing legislation and financial and labour-market regulations. It is particularly slow in countries that lack resources and experience in this new area of policy. This report aims to provide a structured overview of measures that have been taken and to highlight both general tendencies and points of difference. To facilitate productive discussion, the focus is on key issues for debate and future policy decisions.

The various measures reflect the huge diversity of social systems in the Europe of 25. These differences are historical and rooted in the specific approaches that each Member State has taken to achieve solidarity and social cohesion. Beyond these differences, one of Europe's general features is that states play the role of guarantors of economic solidarity as regards social contingencies.

All the Member States currently face demographic changes and all need to find ways of adapting their social systems. The political will exists at Community level to adapt social systems without renouncing the European social model. But how is that model – enshrined in Article 2 of the EC Treaty as the promotion of a high level of employment and of social protection – to be sustained in the long term while, at the same time, essential changes are carried out?

In the late 1990s, the Europe of 15 adopted a fresh approach to social protection which was initially known as the “concerted strategy” and was later termed the “Open Method of Coordination”. It involved jointly identifying the challenges at Community level and setting shared goals with a view to adapting and developing social systems in a harmonious manner while

allowing different national systems to coexist. The process of convergence has been ongoing since 1997 (see Annex 1).

Since December 2001, long-term care has been one of the areas covered by the Open Method of Coordination as applied to health care and care for older people. The Member States have set themselves a number of shared objectives to be achieved simultaneously: namely, universal access to care, a high quality of care and financial viability in care systems. The spring 2005 conference, under Luxembourg's Presidency, comes at a time when Member States are required to submit reports describing the challenges that confront their systems at national level, ongoing reforms and policy directions in the medium term.

This report deals with needs (Part I), responsibilities (Part II), protection (Part III) and financial issues (Part IV) in the field of long-term care. It attempts to situate the topic of long-term care in the context of possible political action, reactions and solutions.

One of the main themes of discussion is the shift of responsibility for action and solutions between the public and private spheres. No EU Member State provides full protection for people who require long-term care. Taking needs as the starting point, it is essential to find a balance between public social protection and private intervention by family and volunteers, in order to provide adequate protection when long-term care is required. At the same time, the question of the public/private sharing of responsibilities cannot be divorced from that of the minimum level of long-term care that society believes it owes its members.

The subject is a difficult one because it concerns the links between public and private solidarity. The extent of research into private solidarity varies from country to country and most of the research that has been conducted concerns public solidarity.

Part I: Needs

In the first part of the report, the needs for long-term care of older persons are identified by three different approaches:

- what is meant by long-term care?
- who are people in need for long-term care?
- how will needs for long-term care evolve in the short, medium and long term?

I. Definition of long-term care for older people

A. Benefits and terminology

Up to the end of the 1970s there was no comprehensive conceptual grasp, either in Europe or internationally, of what is nowadays understood as the need of care and assistance or “long-term care”.⁸⁾ In those days some countries, including France and what are now the Czech and Slovak Republics, recognised what was termed the “need of assistance by third persons”, and special allowances for this were provided. In some cases, as in France, they were payable solely as an adjunct to invalidity benefit; and under some systems, too, disability benefits were not discontinued when their recipients reached pensionable age (the pensioner could opt for a higher level of allowance). Under Czech and Slovak legislation, entitlement to the allowance for “need of assistance by third persons” extended to people on old-age pensions – as a special benefit – and social services were offered to people with such a need regardless of whether they drew old-age or disability pensions. The English-speaking area also had difficulties in finding an adequate term at that time, and being “in need of nursing care” is a variant which is still quite commonly used.

Early elements of long-term care provision can be found in legislation on invalidity and old-age pensions, as well as pensions payable under industrial accident schemes. The areas covered by such legislation are social security provision and benefits under different pension schemes. Other provisions for people needing long-term care were more or less hidden (and in the Czech Republic currently remain so) in the system of social services provision for people with disabilities, under social assistance schemes. This was especially true with regard to nursing institutions (for example the French hospices). Other provisions are to be found in disability schemes. Forms of protection for people in need of what we nowadays call long-term care therefore

8) See IGL G. (1998), *Pflegeversicherung als neuer Gegenstand sozialrechtlicher Regulierung*. in SIEVEKING K. (Ed.) (1998), *Soziale Sicherung bei Pflegebedürftigkeit in der Europäischen Union, Nomos, Baden-Baden*, p. 19-34.

emerged at an early stage. Up to that point, however, long-term care needs were not regarded as a distinct phenomenon or a special risk.

In the meantime, better descriptions of the need have been developed. In France one speaks, in the context of long-term care, of “dépendance” (dependence) and “perte d’autonomie” (loss of independence). A new care benefit was therefore called “prestation spécifique dépendance” (special dependence benefit). This benefit has since been renamed “allocation personnalisée d’autonomie” (personal independence benefit). In the English-speaking world, the primary term used is “long-term care”, in some cases associated – as in the German usage – with the concept of “dependence”. In the Netherlands, the need for care and assistance was recognised in the 1960s in the category of “exceptional medical expenses” (AWBZ 1968). More recently, Sweden – after the major Adel Reform of 1992 making municipalities comprehensively responsible for long-term care and services for older people – decided to discontinue using the term “long-term care”. The stress is now on the “individual’s right to independent living in an ordinary house or in special housing regardless of her/his need for health and medical services and for social services”⁹⁾.

In international and European documents, there was no mention of long-term care and the underlying social situation that it reflected for many years. This has since changed, but it is quite strange that the draft European Constitution, instead of referring to “long-term care”, used the term “dependence”¹⁰⁾. An earlier, slightly modified, use of this term occurs in the Recommendation of the Council of Europe No R (98) 9 of the Committee of Ministers to Member States on Dependence¹¹⁾. In the otherwise very progressive European Social Charter, even in its amended version, there is no mention of long-term care.

Long-term care as a human contingency has thus found its name only relatively late. It would be wrong, however, to conclude from this that it is a social risk which has emerged recently or is “new”. What constitutes a need for long-term care can and could be deduced independently from perception of the social security issue that it represents. As with any other social risk, it depends on the care structures available to the person concerned. When immediate care structures, such as family, are lacking and/or residential care

9) VERWEY-JONKER INSTITUUT (Holland), EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH (Austria), DUTCH MINISTRY OF HEALTH, WELFARE AND SPORT (2004), *Integrated care systems: country profiles – responses to questionnaire*. Dutch EU Presidency, Hague Conference, 18-19 November 2004, p. 68.

10) Article II-34: “The Union recognises and respects the entitlement to social security benefits and social services providing protection in cases such as maternity, illness, industrial accidents, dependence or old age, and in the case of loss of employment, in accordance with the rules laid down by Union law and national laws and practices”.

11) Recommendation of the Council of Europe No R (98) 9 on dependence adopted by the Committee of Ministers on 18 September 1998 at the 641st meeting of the Ministers’ Deputies.

becomes increasingly expensive, society's perception of the risk evolves until it is deemed a social risk.

B. International terminology and understanding of long-term care: ICF

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was first published by the World Health Organisation for trial purposes in 1980 and has since been developed. Revised as the International Classification of Functioning, Disability and Health, known as ICF, it was endorsed for international use by the 54th World Health Assembly on 22 May 2001 (Resolution WHA 54.21).

The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states. It does this with reference to a series of health domains and health-related domains that are described from the perspective of the body, the individual and society in two basic lists: (1) Body Functions and Structures and (2) Activities and Participation. These terms replace those formerly used in the ICIDH, namely "impairment", "disability" and "handicap".

As a classification, the ICF systematically groups different domains for a person in a given health condition (thus indicating what a person with a disease or disorder does or is capable of doing). Functioning is an umbrella term encompassing all body functions, activities and participation; similarly, disability is an umbrella term for impairments, activity limitations or participation restrictions. ICF also lists environmental factors that interact with all these concepts.

The ICF belongs to the "family" of international classifications developed by the World Health Organisation (WHO) for application to various aspects of health. The WHO family of international classifications uses a standardised common language enabling communication about health and health care throughout the world in various disciplines and sciences. It thus aims to improve communication between different users, such as health-care workers, researchers, policy-makers and the public, including people with disabilities¹²⁾. It may be used as a social policy tool – in social security planning, compensation systems and policy design and implementation¹³⁾. This particular international classification can be used to improve understanding of what long-term care comprises.

12) *ICF Introduction*, p. 5.

13) *ICF Introduction*, p. 5.

		Health condition (disorder of disease)		
Body functions and structures	↔	Activities	↔	Participation
	Environmental factors		Personal factors	

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in respect of body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Activity limitations are difficulties an individual may experience in executing activities.

Participation is involvement in a life situation.

Participation restrictions are problems an individual may experience in involvement in life situations.

Matrix of Activities and Participation¹⁴⁾ - Domains:

Learning and applying knowledge

General tasks and demands

Communication

Mobility

Self-care

Domestic life

Interpersonal interactions and relationships

Major life areas

Community, social and civic life.

This matrix covers the main aspects encompassed by the different meanings of long-term care, dependence, etc. The most significant activity limitations are those in the domains of self-care, mobility and domestic life.

14) ICF Introduction, p. 18.

C. International and European definitions

Some of the official definitions which have been used during the last ten years at both international and European levels are given below.

1. Definition of dependence by the Council of Europe

On 18 September 1998, the Committee of Ministers of the Council of Europe adopted Recommendation No R (98) 9 on dependence¹⁵⁾ which contains the following definition:

Dependence is a state in which persons, by reason of lack or loss of physical, psychological or intellectual autonomy, require significant assistance or help in carrying out their usual day-to-day activities.

Dependence may affect any section of the population and not only older people. Even though dependence tends to increase with age and is frequently due in old age to associated multiple health problems, age is not the only criterion for this state. The recommendation does not deal with financial or economic dependence.

The concept of dependence developed by the Council of Europe contains *four main elements*¹⁶⁾:

An element of cause:

This is the requirement that dependence is due to disability, sickness or injury. In order to be classed as dependent, a person must be suffering from sickness or disability.

This element is of crucial importance because it makes the concept of dependence operational. Knowledge of the causes of dependence makes it possible to envisage preventive measures under public health policy. Similarly, this element makes it possible to design individual rehabilitation measures and to plan special care facilities to cope with the evolution of some diseases. Finally, it makes it possible to forecast the duration of dependence (see the fourth element).

An element of effect:

This element relates to the assistance required. As commonly formulated, it refers to the need for assistance in carrying out day-to-day tasks. A potentially more restrictive formula may refer to essential tasks. Day-to-day

15) *Recommendation of the Council of Europe No R (98) 9 on dependence adopted by the Committee of Ministers on 18 September 1998 at the 641st meeting of the Ministers' Deputies.*

16) *COUNCIL OF EUROPE (1995), The situation of dependence in relation to the protection afforded by social security, 6th Conference of European Ministers responsible for social security, Lisbon, 29-30 May 1995, p. 14.*

tasks mean assistance with mobility, personal hygiene, meal preparation, getting into and out of bed, dressing and washing are obviously included. Communication, leisure, participation in social and cultural life may or may not be included. The need for a home-help may be excluded from the definition of dependence, but may be recognised through a specific benefit.

This element represents a “gateway to benefits”. Dependence has to be more than nominal, in other words it must exist to a “significant” or “considerable” degree. Some dependent people, who have only a “light” degree of dependence, will thus be excluded from grants.

The threshold of dependence is expressed in terms of a minimum number of hours of care needed per week or per month. It is a more political element. Governments decide either to grant care to a large population, with low to high degrees of dependence (in which case the minimum threshold will be low) or to a small population with high care needs (in which case the minimum threshold will be higher).

An element of duration of dependence:

Dependence has to last a specified length of time for entitlement to benefit. This should not be confused with the condition of a qualifying period, according to which the dependent person has to have spent a specified period in a state of dependence. What is at issue here is the projected duration of dependence.

2. Definition of long-term care by the OECD

The OECD¹⁷⁾ recently published a study on “Long-term care for older people” as one of the components of its Health Project, which was carried out during 2001-2004 in order to explore key issues in improving the performance of health and long-term care systems. The project was conducted with the voluntary participation of a network of national experts from 19 OECD countries¹⁸⁾.

In the course of the study, definitions and a glossary of terms were compiled because “terminology in long-term care policy and statistics varies widely between countries”. To quote from the study report: “The Secretariat hopes that the following set of definitions represents a helpful interim step on the way to a more comprehensive and widely useable set of common definitions that apply to OECD countries with different institutional and financing settings for long-term care. Major sources of terms and definitions in this glossary are the International Classification for Health Accounts (ICHA) of the OECD

17) OECD (2005), *Long-term care for older people*, OECD, Paris.

18) The countries were Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Spain, Sweden, Switzerland, the United Kingdom and the United States.

manual "A System of Health Accounts" (SHA) and definitions suggested in previous OECD reviews of long-term care policies (see OECD 1996, 1998)".

Long-term care: The terms long-term care and care are often used interchangeably in this study. Individuals need long-term care when dependent for an extended period of time 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 or ADLs.

OECD Report, 2005

There are three key components in the OECD definition:

- dependence for an extended period of time;
- a link between the causes – disability, chronic condition, trauma, illness – and dependence;
- limitation of the ability to carry out activities of daily living.

3. Definition of long-term care by the European Union (OMC documents)

The official documents relating to the Open Method of Coordination on health care and care for the elderly do not really define long-term care, except perhaps the 2003 joint report.

The Communication from the European Commission on "The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability"¹⁹⁾, of 5 December 2001, mentions "*old people's greater morbidity (often as a result of a combination of illnesses) and the seriousness and more chronic nature of age-related diseases, which can lead to dependence on others*"²⁰⁾. Dependence and its causes are thus considered very much together. It is not age that makes people dependent, but certain pathologies or diseases.

Two years later, in the joint report from the European Commission and the Council on "supporting national strategies for the future of health care and care for the elderly"²¹⁾, of 10 March 2003, long-term care was described as traditional in-family care²²⁾. The terminology used here is more diverse, probably because the joint report, drawing conclusions from an analysis of the Member States' responses to a questionnaire on health care and care for the elderly, reflects the different notions used by the 15 Member States. The following notions appear in the joint report: age-related diseases, disability

19) COM (2001) 723 final.

20) COM (2001) 723 final, p. 4-5.

21) No 7166/03, SOC 116, ECOFIN 77, SAN 41.

22) COM (2001) 723 final, p. 4.

rates, very old persons, frail elderly, people who have lost their autonomy and people suffering from chronic diseases. From that time, health care and care for the elderly have been treated as two very separate items.

The joint report supplies a definition of long-term care, in the context of recognising need for such care as a major social risk that needs to be covered by social protection systems.

Long-term care consists of assistance to persons who are unable to live autonomously and are therefore dependent on the help of others in their everyday lives. Their needs for assistance can range from facilitating mobility, shopping and household tasks to washing and feeding in the most extreme cases. Providing such long-term care does not necessarily require medical skills. This type of care is therefore often left to relatives, usually spouses and descendants who continue to be the main providers of long-term care (Joint Report, 2003, p. 13).

In the recent Communication from the European Commission on “Modernising social protection for the development of high quality, accessible and sustainable health care and long-term care: support for the national strategies using the Open Method of Coordination”²³⁾, of 20 April 2004, the vocabulary used in the title has changed. “Long-term care” is referred to, rather than “care for the elderly”, although it is not clear whether long-term care at any age is included. The term continues to embrace the concepts of age-related diseases and very old age.

This report takes up the common understanding of the term, as set out in the OECD report and glossary (see Annex 2).

II. Number and characteristics of people needing long-term care

How many older people in the European Union today are partly or severely dependent? Who are these people needing long-term care?

A. Information from the PACOLET report (1998)

The PACOLET report on “Social protection for dependency in old age in the 15 EU Member States and Norway” (1998), commissioned by the European Commission DGV/E and the Belgian Minister of Social Affairs²⁴⁾, suggests that 3-5% of people in the over-65 age group are severely dependent, and up to 15% are partially dependent. Among the over-75s, the proportion highly

23) COM (2004) 304 final.

24) PACOLET J. et al. (1998), *Social Protection for dependency in old age in the 15 EU Member States and Norway. Main results of a comparative study. Draft synopsis report. National reports. Report for the European Commission DGV/E and the Belgian Minister of Social Affairs, UCL, HIVA, Belgium. See also: PACOLET J. et al. (1998), La protection sociale des personnes âgées dépendantes dans les 15 Etats membres de l'Union Européenne et en Norvège, Rapport de synthèse. Commission européenne, Série Emploi & Affaires sociales, Sécurité sociale et Insertion sociale.*

dependent increases to 10% and the proportion partially dependent to 25%. The population of highly dependent people is therefore, on average, 3% of the total population, or about 9 million people in Europe. On the basis of national reports, the report identified at least 7.6 million persons in the Member States receiving some type of allowance for dependence. No parallel figures for the ten new Member States are available.

B. Results of the French INSEE study on “Handicaps, Incapacités, Dépendance” (HID) [*Disability, incapacity and dependence*] (1998/2002)

In France, one of the main features of the debate about dependence was for many years – in sharp contrast to the approach taken by many other European countries and the Council of Europe – its failure to take account of the causes of dependence and the multiple pathologies associated with it. This changed with the publication of the study entitled *Handicaps, incapacités, dépendance (HID)*, carried out between 1998 and 2002 by INSEE in cooperation with a number of other bodies. The study concerned a sample of people aged over 60, living both in institutions and at home²⁵). Some of the findings in relation to older people living at home are discussed below.

1. Over-60s at home

The number of over-60s living at home is 11 586 000, i.e. 95.9% of the total population in that age group (12 081 335).

2. Physical dependence

In the 60-plus age group living at home, 8 592 742 people (i.e. 74 %) report at least some form of impairment or difficulty in everyday life as the result of a health problem. On the basis of the COLVEZ classification system (see Table 1b), a total of 1 053 000 over-60s are dependent (see Table 1a). This figure represents 9% of the population in the 60-plus age group living at home. Again under the COLVEZ classification, 405 000 people – i.e. 3.5% of the older population living at home – are severely dependent (level 1 and level 2). The number of bed-bound or chair-bound people in the same population group is 105 000 (or 0.9%) and this is the group with the heaviest degree of dependence. Two thirds of dependent over-60s, most of them women, live at home.

25) *For further information see: INSEE (1998/2002), Enquête « Handicaps, Incapacités, Dépendance » (HID), France. <http://rfr-handicap.inserm.fr>. The HID study helps to identify the users of medical/social services, their needs, types of incapacity, income levels and financial means. It presents a clearer profile of those who receive long-term care. The study also provides more information about those who assist people thus incapacitated, the nature of the assistance provided and the responsibility that remains with families (based on information about older people's incomes and arrangements for financing care).*

Table 1: Numbers of older people living at home (France)

	Living at home
Total population of over 60s	11 586 000
Number of over-60s reporting no impairment or difficulty in everyday life	2.994.000
Number of over-60s reporting at least some form of impairment or difficulty in everyday life as the result of a health problem	8 592 000
Dependent population of over 60s (COLVEZ classification)	1 053 000

Table 2: Numbers of people living at home – dependent according to the COLVEZ classification system (France)

	Living at home
Level 1 (bed-bound or chair-bound)	105 000
Level 2 (needing help to wash and dress)	300 000
Level 3 (needing help to get out of the house)	648 000
Total: Dependent population of over 60s	1 053 000

3. Psychological dependence

Among the people who are bed-bound or chair-bound, half (i.e. 50 000) also suffer from psychological dependence. This compares with just 30% of those classified under Level 2 in the COLVEZ system. In the HID study, psychological dependence is perceived as an incapacity resulting from problems of behaviour and orientation and is not based on any clinical, diagnosis-based approach.

Table 3: Severe physical dependence and psychological dependence (HID study - France)

	Living at home
Colvez Level 1	
Bed-bound or chair-bound and psychologically dependent	50 000
Bed-bound or chair-bound and not psychologically dependent	55 000
Colvez Level 2	
Needing help to wash and dress and psychologically dependent	73 000
Needing help to wash and dress and not psychologically dependent	227 000

4. Over-80s at home

The HID study is interesting in its characterisation of the over-80s. Of the 2 339 000 people in that age group (figures for 1999), 81% live at home and 30% of that group are dependent. Of the 502 000 over-90s, 64% live at home, 53% of whom are dependent.

The house-bound population – i.e. those obliged to remain permanently indoors – numbers 421 000, the majority (75%) of them women, with an average age of 82. 40% of house-bound people need no assistance with the six activities of daily living listed in the Katz classification system. In other words, the state of being house-bound cannot be equated with dependence and need of assistance. Two sub-groups are identified: house-bound people dependent on assistance with the basic activities of daily living and in need of help on a very regular basis, and people who although house-bound have no incapacity for the activities of daily living but do experience certain difficulties with instrumental activities. In the house-bound but non-dependent group, the incidence of motor and sensory deficiencies (including impaired sight and hearing) is higher, and that of psycho-intellectual and early-stage psychological problems appears to be lower.

The HID study provides information about respondents' social backgrounds and income levels as well as their family and social networks and all the formal and informal assistance they receive.

There are more people (8.7 on average) in the family networks of those respondents living at home than of those living in institutions (the average here being 4.6).

The risk of being institutionalised can thus be appreciated more precisely: age, physical dependence, a relatively inactive family network and social disadvantage are the predisposing factors. By contrast, the facts of being a woman and living as part of a couple reduce the risk – a reflection of the protective effect of marriage and the importance of the care that older dependent people receive at home from spouses.

5. Carers

Among the over-60s living at home, nearly 28% (or 3 230 000 people) receive regular help because they have a health problem; the corresponding figure among the over-75s is 50%.

The HID study provides an initial indication of the burden that carers bear, i.e. the physical, psychological, emotional, social and economic effects that the situation has on them. 40% of informal carers cannot take holidays, 11% have had to change their working arrangements, 75% experience mental tiredness and stress and 50% are physically tired.

The nature of the tasks that carers perform varies little with older people's age once they are over 60. In order of increasing incidence they are housework, shopping, managing finances and accompaniment on visits to the doctor and hospital.

Table 4: Older people receiving help at home: breakdown by type of carers (from HID study carried out in France)

	Group 1	Group 2	Group 3	Group 4	Group 5	Total
	Single non-professional carer	More than one non-professional carer	One non-professional carer and one or more professional carers	More than one non-professional carer and more than one professional carer	Professional carers only	
Number of older people concerned	1 080 000	510 000	590 000	360 000	690 000	3 230 000
Gender of person receiving help	53% women	69% women	75% women	79% women	75% women	57% women
Average age of person receiving help	73	75	80	81	78	77
Household composition	People living alone: 22% Couples: 63%	People living alone: 35% Couples: 44% Lone people living with their children: 16%	People living alone: 47% Couples: 42%	People living alone: 59% Couples: 30%	People living alone: 53% Couples: 41%	People living alone: 39% Couples: 48% Lone people living with their children: 9%

C. Some findings from the assessment of individual needs of dependent people: data from Luxembourg (2004)

The findings of an assessment of the individual needs of dependent people in countries with a long-term care insurance system are interesting because in principle they cover everyone classed as dependent under the definition of the term in national law.

Luxembourg²⁶⁾ is a particularly interesting case for two reasons. On the one hand, its dependent population is very small – on 30 June 2004 only 7 134 people were in receipt of dependence insurance benefits – and this makes it possible to carry out exhaustive studies. The results of such studies are of potential interest to other EU Member States.

On the other hand, the Assessment and Orientation Unit responsible for assessing both the causes of dependence and dependent people's individual needs is now able to produce statistics relating the causes of dependence to people's age, gender and place of residence as well as the benefits they receive and the average length of time over which they need long-term care. When dependence insurance was being introduced in Luxembourg, the dimension of cause was deemed to be essential in the definition of what constituted dependence. Identifying causes was seen as a way of stimulating a policy of preventive health care and rehabilitation. Likewise, awareness of the main types of pathology and the nature of different forms of physical and psychological dependence should make it easier to organise the provision of services.

1. Beneficiaries of long-term care insurance

On 30 June 2004, 7 134 dependent people (1.6% of Luxembourg's resident population) were in receipt of benefits. Two-thirds of them – i.e. 69% of all the beneficiaries of long-term care insurance – were women. Age is a decisive factor: 70.7% of people needing long-term care were aged 70 or more.

26) *In Luxembourg, an Act passed in June 1998 recognised dependence as a new risk to be covered by social security schemes and introduced long-term care insurance. The provisions took effect on 1 January 1999. Dependence is defined as the state of a person who, as a result of a physical or mental illness or a deficiency of a similar nature, has a major and regular need for assistance from a third person in order to carry out the activities of daily living. The activities of daily living include personal hygiene, nutrition and mobility. Instrumental activities such as household chores are excluded. The assistance needed must amount to at least three-and-a-half hours per week and the duration of the need must be at least six months or permanent.*

A new public service called the Assessment and Orientation Unit was created under the responsibility of the Minister of Social Security, with the task of assessing dependent people's individual needs. Every year, as part of the general report on social security, the unit publishes statistics on long-term care insurance : IGSS (2004), Rapport général de la Sécurité Sociale au Grand-Duché de Luxembourg 2003, Ministère de la Sécurité Sociale, Luxembourg. Chapter 2 deals with long-term care insurance. The latest statistics date from 30 June 2004.

Table 5: Beneficiaries of long-term care insurance by age and gender (LTC insurance - Luxembourg)

	Women	Men	Total
Age	%	%	%
90-109	14.4	5.5	11.6
80-89	40.2	20.6	34.1
70-79	24.1	27.1	25.0
60-69	7.9	13.3	9.6
40-59	7.0	14.4	9.4
19-39	3.1	8.2	4.6
0-18	3.3	10.9	5.7
Total	100	100	100

Dependent over-70s needing long-term care account for 11.2% of the total population in that age group; the corresponding figure in the 80-plus age group is 23.1%.

Table 6: Comparison between the populations of dependent over-70s (and over-80s) and the total populations in those age groups (LTC insurance - Luxembourg)

Gender	70 and older		80 and older	
	General population	Dependent population	General population	Dependent population
Women	61.7 %	76.4%	71.4%	82.1%
Men	38.3%	23.6%	28.6%	17.9%
Total	100%	100%	100%	100%

The Assessment and Orientation Unit concludes that “more women than men reach very old age, but are more exposed to the risk of dependence than men; far fewer men than women reach very old age, but those who reach very old age are less exposed to the risk of dependence than women”²⁷⁾.

Dependent women live predominantly in residential care, while men needing long-term care more often live at home. Age is also a decisive factor here. In the 80-plus age group, the majority of dependent people live in residential care; at 90-plus, two-thirds are in residential care (see Annex 3).

27) IGSS (2004), Report 2003, p. 160.

2. Causes of dependence

Table 7: Main causes of dependence: breakdown of beneficiaries of long-term care insurance by age and diagnosis²⁸⁾ (LTC insurance - Luxembourg)

Pathology leading to dependence	Age groups							All age groups
	0-18	19-39	40-59	60-69	70-79	80-89	90-109	
Group 1 Dementia and other cognitive disorders		0.9	2.7	8.7	22.6	34.0	38.8	22.9
Group 2 Psychiatric disorders	0.5	2.5	6.0	10.0	6.4	2.9	2.0	4.4
Group 3 Cardiovascular diseases	0.2		1.9	3.1	5.0	4.3	4.0	3.7
Group 4 Diseases of the nervous system	30.9	33.4	34.1	28.1	21.1	11.2	6.2	19.0
Group 5 Congenital malformations and mental and motor disorders (children and adolescents)	44.1	28.3	19.9	5.2	2.0	0.7	0.1	6.9
Group 6 Diseases of the osteoarticular system	1.5	3.6	11.5	19.5	24.4	32.6	32.9	24.2
Group 7 Disorders of a sensory organ	4.0	15.7	6.6	4.2	4.1	4.8	5.8	5.3
Group 8 Malignant tumour	1.0	0.6	3.1	2.8	1.6	0.7	0.4	1.3
Group 9 Miscellaneous	3.2	7.8	8.8	13.3	9.2	6.3	6.9	7.9
Group 10 Unclassified	14.6	7.2	5.4	5.1	3.6	2.5	2.9	4.3
TOTAL	100	100	100	100	100	100	100	100

The following table presents the 70-plus age group in order to show the main pathologies that lead to dependence in old age.

²⁸⁾ This classification was drawn up by doctors employed by the Assessment and Orientation Unit. It is based on the international classification of diseases and allied health problems (ICD10).

Table 8: Main causes of dependence: breakdown of beneficiaries aged 70-plus by age and diagnosis (LTC insurance - Luxembourg)

Pathology leading to dependence	70-79 %	80-89 %	90-109 %	All age groups 90-109 %
Group 1 Dementia and other cognitive disorders	22.6	34.0	38.8	22.9
Group 4 Diseases of the nervous system	21.1	11.2	6.2	19.0
Group 6 Diseases of the osteoarticular system	24.4	32.6	32.9	24.2
7 other groups	31.9	22.2	22.1	33.9
TOTAL	100	100	100	100

Three types of pathology are responsible for more than two thirds of dependence in all age groups. In the over-80 age group, these three pathologies account for close on 80% of dependence.

In the over-70 age group, diseases of the nervous system are decreasing while dementia and, to a lesser extent, diseases of the osteoarticular system are increasing.

Dementia is a factor in one third of all cases of dependence in the over-80 age group. Luxembourg has addressed this situation by developing day-care centres and nursing homes that specialise in dealing with dementia.

The statistics on distribution between home and residential care show that, in Luxembourg, dependent people with dementia are mainly in residential care. Two thirds of all dependent people with dementia live in nursing homes. It should be noted that these people belong to the oldest group of dependent people, the majority of whom are in residential care (see also Annex 3).

III. Projections and possible scenarios

Several European studies have produced estimates of spending on long-term care, with various projections and scenarios on the cost of dependence. What follows is based, in particular, on a recent OECD study²⁹⁾ and on a study for the European Commission coordinated by Adelina COMAS-HERRERA

29) OECD (2005), *Long-term care for older people*, OECD, Paris.

and Raphael WITTENBERG³⁰).

A. The cost of long-term care

The OECD study examines the response of 19 countries to the phenomenon of an ageing population and looks at the ways in which long-term care provision has been developed and adapted. Information on 10 EU countries (Austria, Germany, Ireland, Hungary, Luxembourg, the Netherlands, Poland, Spain, Sweden and the United Kingdom) can be extracted.

Throughout the OECD countries, spending on long-term care accounts for 0.2-3% of GDP, although in most of them it is under 1.5%. The balance between public and private spending differs considerably from country to country. Austria, Germany, Luxembourg, the Netherlands, Sweden and Norway provide extensive coverage of long-term care needs. Long-term care, like acute care, comes under the social protection system and the countries in question are among those with high levels of public spending. The proportion of private spending also varies considerably in the different countries. In GDP points, it is seven times less in Sweden than in Germany.

Table 9: Public and private spending on long-term care as percentages of GDP (2000) (source OECD)

	Public spending/ GDP	Private spending/ GDP	Total spending on long-term care/GDP
Austria	1.32%		
Germany	0.95%	0.40%	1.35%
Ireland	0.52%	0.10%	0.62%
Spain	0.16%	0.44%	0.61%
Hungary	<0.20%	<0.10%	<0.30%
Luxembourg	0.52%	not available	not available
Netherlands	1.31%	0.13%	1.44%
Poland	0.37%	0.01%	0.38%
United Kingdom	0.89%	0.48%	1.37%
Sweden	2.74%	0.14%	2.88%

The extent and quality of services offered, the age profile of the population and the prevalence of dependence are the factors that explain the differences in levels of expenditure. Spending on long-term care increases in line with the proportion of over-80s in the population. The link between spending on long-

30) COMAS-HERRERA A., WITTENBERG R. (2003), *European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs. Report to the European Commission, Employment and Social Affairs DG, Grant number VS/2001/0272, Personal Social Service Research Unit (PSSRU) Discussion Paper 1840, London School of Economics, London.*

term care and the prevalence of dependence in the population is far from straightforward, however. According to the OECD report, the proportion of older people in the population explains only half the degree of variation recorded in rates of spending as a proportion of GDP. The other part of the explanation is that spending on long-term care depends greatly on the type of public coverage of dependence that is available. Where there is universal coverage and a more generous system (particularly as regards the level of comfort in retirement homes), spending accounts for a higher proportion of GDP (between 0.8% and 2.9%). Where the system is less generous and especially where many benefits are means-tested, spending on long-term care as a percentage of GDP is lower (between 0.2% and 1.5%) and may be restricted to the part-funding of residential care.

Table 10: Breakdown of spending on long-term care between institutional and home care (2000) (source OECD)

	Public spending in institutions as a percentage of the total	Public spending on home care as a percentage of the total	Total public spending on long-term care as a percentage of GDP
Austria	not available	not available	1.32%
Germany	55%	45%	0.95%
Ireland	63%	37%	0.52%
Spain	69%	31%	0.16%
Hungary	not available	not available	<0.20%
Luxembourg	71%	29%	0.52%
Netherlands	57%	43%	1.31%
Poland	8%	92%	0.37%
United Kingdom	65%	35%	0.89%
Sweden	71%	29%	2.74%

Except in Poland, the lion's share of public spending – between 55% and 71% of the total – goes on institutional care. Long-term home care for people with a relatively low level of dependence is provided, as a rule, by informal carers. The above figures provide enough information to suggest the general thrust of a policy for controlling spending on long-term care (leaving aside any considerations of inter-generational solidarity), namely by:

- stabilising the public contribution to the financing of institutional care (by stabilising or reducing the number of places available, making quality policy subject to financial scrutiny and increasing the amount that individuals and their families contribute to the cost of institutional care);
- promoting a policy of keeping people in their own homes, relying chiefly on informal carers.

In most countries, tax revenue is the main source of financing for long-term care. On the other hand, a number of countries (notably Germany,

Luxembourg and the Netherlands) have opted for systems of dependence insurance.

B. Projections

It is generally agreed that the need for long-term care will grow, that the demand for long-term care services will increase as the baby-boom generation ages and that, at the same time, the number of potential providers of informal care will fall.

All the projections are based on the same demographic mechanism. According to the probable prevalence of incapacity, each age group is deemed likely to consume a certain quantity of long-term care and is thus allocated a corresponding volume of spending. The projections involve modelling the ageing process for each group, as well as likely increases in the cost of services and rates of economic growth. In all the models, the growth of long-term care is not primarily due to population ageing or changes in the age structure, but to other variables that are introduced. As a rule, the projections make a distinction between two types of help: informal help paid for from private sources and publicly funded formal help.

1. OECD Studies on Long-Term Care (1999, 2005)

Research by JACOBZONE S.³¹⁾ (OECD, 1999) provides an initial estimate of how spending on long-term care might evolve, assuming that needs were met in identical ways. In a scenario where the prevalence of incapacity declines over the long term, spending would increase less rapidly than in a scenario of stable incapacity rates. In the years since this research was done, the OECD has tried to address the major difficulties raised by any international comparison of spending on long-term care (e.g. the fact that national statistics differ and the conceptual problems raised by the use of the ADLs and IADLs), and a great deal of methodological work has been devoted to pinning these issues down³²⁾.

31) JACOBZONE S. et al. (1999), *The health of older persons in OECD countries: Is it improving fast enough to compensate for population ageing*, Labour Market and Social Policy, Occasional Paper No 37, OECD, Paris.

32) *Meetings of experts on 27-28 October 2003 and 30 September and 1 October 2004. Documents may be downloaded from DELSA/ELSA/WP1/HS/M(2003)3 and DELSA/ELSA/WP1/HS(2004)9.*

In the 2005 OECD report, the OECD countries' social response to the need for long-term care is analysed on the basis of various sets of statistics

- on the demand side: traditional epidemiological and socio-economic data on age, life expectancy, the proportions of older and very old people (over 65 and over 80 respectively), the prevalence of incapacity by age group and the degree of isolation of older people;
- on the supply side: projected levels of dependence between 2000 and 2004, the profile (gender, age and family link) of informal carers and trends in public spending between 1990 and 2002.

For those countries with systems of universal coverage, the report also looks in depth at the way in which reforms have been carried out and what approach is currently being used to contain spending on long-term care.

Table 11: Proportion of older people in the population as a whole in 2000 and 2040 (OECD - Long-term care policies for older people)

	% of over-65s		% of over-80s	
	2000	2040	2000	2040
Germany	16.4	29.7	3.7	8.7
Austria	15.5	29.6	3.5	8.2
Belgium	16.8	27.4	3.6	8.6
Denmark	14.8	24.1	4.0	6.9
Spain	16.9	30.7	3.8	8.5
Finland	14.9	26.2	3.4	9.0
France	16.1	26.6	3.7	9.1
Greece	17.3	28.2	3.5	7.9
Hungary	15.1	25.7	2.6	7.1
Ireland	11.2	20.5	2.6	5.5
Italy	18.1	33.7	4.0	10.0
Luxembourg	14.2	24.0	3.0	7.4
Netherlands	13.6	25.5	3.2	7.6
Poland	12.2	24.1	2.0	7.5
Portugal	16.3	24.0	3.4	6.2
Slovak Republic	11.4	23.2	1.9	6.3
Czech Republic	13.8	28.8	2.4	8.5
United Kingdom	15.9	25.4	4.0	7.3
Sweden	17.3	25.2	5.0	7.9
OECD average	13.8	25.6	3.1	7.7

The level of age-related dependence (i.e. the number of over-65s in proportion to the number in the 20-64 age group) is commonly regarded as an indicator of the burden of care on the total population of potential informal carers.

Table 12: Number of over-65s in proportion to numbers aged 20-64, expressed as a percentage (OECD - Long-term care policies for older people)

	1960	2000	2040
Germany	not significant	26.4	54.5
Austria	21.1	25.1	59
Belgium	20.4	28.2	51.2
Denmark	19	24.1	44.4
Spain	14.5	27.2	55.7
Finland	13.4	24.6	49.8
France	20.8	27.5	50
Greece	14	28.3	57.9
Hungary	15.5	24.5	38.4
Ireland	22.4	19.2	37.7
Italy	15.9	29.1	63.9
Luxembourg	17.6	23	36.9
Netherlands	16.9	21.9	48.1
Poland	11.1	20.3	41.1
Portugal	14.5	26.7	46.3
Slovak Republic	12.8	18.8	39.4
Czech Republic	15.2	21.9	47.8
United Kingdom	20.1	26.9	46.3
Sweden	20.2	29.5	46.7
OECD average	15.9	22.7	46

Spending on long-term care as a proportion of total spending on care (both acute and long-term) in the period 1990-2002 was calculated at 10-20%. Over the last ten years it would seem that beyond the initial phase of organising long-term care, public expenditure on this form of care has not grown faster than total spending on care. It is interesting to note that the OECD report does not raise the issue of how to contain the overall growth of spending on care.

To date, the governments of the OECD countries have contained the growth of the public contribution to long-term care costs by concentrating increased spending on older people and on informal care arrangements. Qualitative analysis by the OECD of recent reforms in long-term care coverage indicates that where universal coverage is in place individuals are protected against any disastrous rise in the cost of employing carers and that less use is made

of social services care. Rising costs can be contained if people on higher incomes are required to pay proportionately more (through a mechanism of means-tested allowances), if benefits are targeted on the most dependent people and if the number of people receiving care in institutions is stable or falling³³).

The OECD report does not offer any quantitative projections but rather presents a diagnosis in which several tables of general figures are presented alongside much more qualitative analyses of long-term care policies, drawing on replies to a very detailed questionnaire. Research by HUBER M., to be published shortly³⁴, is expected to provide much more detailed estimates of how long-term care will evolve in different European countries. The European Community will find it highly instructive to study his conclusions in depth.

Projections carried out for Sweden³⁵) appear to bear out the idea that the rate of growth of long-term care spending will depend essentially on variations in the prevalence of incapacity.

2. The COMAS-HERRERA Report to the European Commission (2003)

The COMAS-HERRERA report³⁶), covering Germany, Spain, Italy and the United Kingdom, looks at how future spending on long-term care might be affected by different hypotheses in relation to demography, dependence and incapacity, formal and informal care and the cost of care. Four distinct models are used for each of the countries studied. Older people are grouped by age, gender, level of dependence and other characteristics, in order to project likely numbers of older dependent people. In the second part of the study dependent people are accorded a probability of receiving services (both informal and professional, at home and in institutions). Projected spending figures are obtained by applying unit costs to these services.

A number of hypotheses underpin the projections, the main ones being that demographic trends will follow EUROSTAT projections, that neither the prevalence of incapacity nor household composition will change, that the demand for services will remain constant in the different groups, and that there will be no supply-side constraints to prevent demand from being met.

33) *See Part IV for more details.*

34) HUBER M. (2005), *Estimating expenditure on long term care. OECD Health Technical Papers.*

35) LAGERGREN M., BATLJAN I. (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, Annex 8, Long-Term Survey 1999/2000, Fritzes Offentliga Publikationer, Stockholm.*

36) *See above annotation 30.*

The following findings emerge from the base scenario:

**Table 13: Spending on long-term care as a percentage of GDP in 2050
(Source COMAS-HERRERA study)**

	Spending on long-term care as a percentage of GDP in 2050
Germany	3.32
Spain	1.62
Italy	2.36
United Kingdom	2.89

In the main scenario, the percentage spent on long-term care doubles in each of the four countries, as do numbers of recipients and actual spending on long-term care, assuming no variation in costs in real terms. The projections are sensitive to demographic hypotheses: depending on the variant applied, long-term care expenditure as a proportion of GDP can vary between 0.5 and 1%. They are also sensitive to variations in the prevalence of dependence. If dependence sets in six months or a year later for every year of increased life expectancy, the cost of long-term care will decline significantly (by more than half if dependence sets in a year later). Two factors remain highly uncertain in these projections: variations in the supply of informal care and the degree of comparability in the consumption of long-term care. The financial impact of a reduction in the supply of informal care may be considerable. Likewise, if all older people received an average level of professional long-term care, this too would have significant financial consequences.

Clearly, preventing dependence should thus be a key aim of long-term care policies, as should supporting informal carers. There is likely to be a major increase in the provision of formal home services and it will become essential to measure their cost effectiveness. A last important finding from the study concerns the high level of uncertainty that public authorities will face in addressing the issue of long-term care in the future, and the need for a much more detailed information system, particularly with regard to informal care.

3. The DUTCH SOCIAL AND CULTURAL PLANNING OFFICE report (2004)

A recent report from the DUTCH SOCIAL AND CULTURAL PLANNING OFFICE³⁷⁾ takes a slightly different approach, tackling the particularly interesting question of the potential demand for care and changes in the use of services.

37) DUTCH SOCIAL AND CULTURAL PLANNING OFFICE (2004), *The elderly now and in the future: health, nursing and caring, 2000-2020 (Ouderen nu en in de toekomst: gezondheid, verpleging, en verzorging, 2000-2020)*, The Hague.

The Dutch report addresses the following five questions (of which only the last two are relevant here).

1. What is the actual health situation of over-65s in the Netherlands?
2. Which factors determine the health situation of over-65s?
3. What will be the health situation of future generations of over-65s?
4. Which factors determine the actual use of caring and nursing services financed by long-term care insurance, and how will these factors change in future decades?
5. How will potential demand for and actual use of caring and nursing services change?

The focus will be on answering the last question but, in order to do so, information is needed on the earlier questions. Firstly, the five types of factor that determine the use of nursing and caring services (question 4) are as follows:

1. health characteristics, i.e. prevalence of chronic diseases, subjective health and limitations of physical health;
2. demographic characteristics, i.e. age, gender, household composition, marital status and degree of urbanisation;
3. socio-economic characteristics, i.e. level of education and net income;
4. environmental adaptations in and around the home, i.e. special housing for older people, special mobility resources, accessibility facilities, etc;
5. availability of personal resources, i.e. informal care and privately hired care or support.

Information on trends in each of these determinants was available from other studies and was used in the calculations. Extended epidemiological studies in the Netherlands provide precise information on the prevalence of chronic diseases among the over-65s. Trends with regard to decreasing or increasing prevalence and its determinants are also known. The chronic diseases and conditions included are diabetes mellitus, cardiovascular diseases, stroke, chronic obstructive pulmonary disease (asthma, chronic bronchitis) and impairments of movement and mobility.

The next step is to calculate the potential demand for nursing and caring services (in institutions and at home). Potential demand is defined by including all those people over 65 who are affected by health limitations in their activities of daily living (personal care, household and mobility) and, in one way or another, make use of either informal care or care financed privately or by long-term insurance. The main criteria here were those of the standard assessment system that has been used for a number of years with people applying for caring/nursing services covered by long-term care insurance.

Potential demand is, in fact, higher than actual demand or use. On the one hand, the supply is limited, and, on the other hand, some people hire (privately paid-for) care services independently, prefer to be cared for by their partner or children, or postpone their application for care until their need is greater (thus setting themselves a higher self-sufficiency standard).

The next step was to calculate potential demand and actual demand/use for 2000. The first calculation was based on epidemiological data and the second on actual assessments and populations both in institutions and receiving home care. Taking these data as a starting point, and using demographic trends and trends in determinants, a 20-year forecast was arrived at. Table 13 shows potential expected demand and Table 14 actual expected demand over the next 20 years.

Table 14: Estimation of potential demand for caring and nursing services among the over-65s, broken down into home care and institutional care, between 2000 and 2020
(absolute figures x 1 000)

Year	No of over-65s	Potential demand	Home care	Institutional care
2000	2 160	736	509	227
2005	2 289	797	548	248
2010	2 499	867	597	270
2015	2 899	972	680	292
2020	3 220	1 099	778	321

Table 15: Estimation of actual demand for caring and nursing services among the over-65s, broken down into home care and institutional care, between 2000 and 2020
(absolute figures x 1 000)

Year	No of over-65s	Actual demand/use	Home care	Institutional care
2000	2 160	426	274	125
2005	2 289	447	283	164
2010	2 499	467	288	179
2015	2 899	492	300	192
2020	3 220	529	324	205

The considerable discrepancy between potential demand and actual demand has much to do with supply limitations over the last 20 years. In 1980, the proportion of over-65s being cared for in an institution was about 13%, nowadays it is about 7% (still quite a high figure by comparison with other countries). The further the Netherlands goes in the direction of demand-

oriented supply, the more the discrepancy between potential and actual demand is likely to decrease while, at the same time, costs may rise proportionately.

Over the years the discrepancy between potential demand and actual demand increases. The main underlying factor here is the expected increase in income among over-65s, given improved private pension provision based on rising earnings.

C. The limitations of statistics and modelling

All the European reports on long-term care refer to the shortage of economic data from which to reliable comparative projections at Community level can be drawn up.

There is little information about the life histories of dependent people or about trends in their behaviour. It would be extremely helpful if, having first identified the main causes of dependence, the dependent older population could be categorised more closely with a view to obtaining a better picture of life histories and of the types of long-term care provided. Anticipating changes in demand solely on the basis of demographic information is difficult. Longitudinal statistics are needed to relate the use of long-term care services to factors causing the onset of dependence and to the socio-economic profile of the population concerned. The current lifestyle of the baby-boom generation differs from that of their parents and it would be useful to predict the impact of this difference on the long-term care system when that generation reaches old age.

There are similar gaps in the statistics with regard to the supply of professional services. It is essential to have accurate information on the different types of provider (public, private and community- or charity-based), i.e. on the volume, quality and likely development of services as well as providers' ability to cope with rising demand. In the absence of such data, the authorities are dealing with a production system that is, to some extent, a "black hole" with the result that they find it hard to measure the impact that injections of funding will have.

Information about the contribution of carers is even more fragmentary. Data available about carers is primarily epidemiological. It allows to estimate the extent of the burden on the carer and may tell us something about the carer's state of health. Little is known about the contribution (in cash or kind) that carers make or about their economic role, even though the current debate hinges on finding the correct match between private and public systems of social protection, and the potential of social protection systems and informal carers to absorb the coming demographic shock and its consequences in terms of dependence. The demand from carers for help or services for ageing relatives is not always well identified.

The main reason for this lack of economic information is the fact that, in some countries (including Italy and Spain), long-term care provision for dependent older people is highly decentralised, fragmented and diverse. In all the countries that have introduced a universal system of long-term care, coherent data on spending – albeit it for relatively few years so far – have been compiled as part of the process of controlling the system's expansion. These data provide a basis from which public spending can be projected.

As matters stand, quantitative comparison of the long-term care systems in different European countries remains rudimentary and modelling is limited, despite the availability of more extensive qualitative information. Sound statistical bases are needed to facilitate regular monitoring of the supply, demand and financing of long-term care.

Part II: Responsibilities

Throughout history the Western World has dealt with the problem of dependent people in many different ways. From the 16th century onwards and especially during the 19th and 20th centuries public authorities gradually started to play a more significant role. Since the Second World War many Welfare States have taken the lead in the care of dependent people, and dependent older people in particular. In other welfare states the primary role in care for dependent older people (sometimes organised jointly with care for severely disabled people) is left to the family, volunteer organisations and other support groups, in some cases with public authority co-financing.

There is an evident differentiation of responsibilities for dependent older people among the 25 EU Member States. Some countries argue straightforwardly for state (or municipal) responsibility while others use historical, legal and/or moral arguments to leave the care of dependent older people to the family. From the outset the issue appears to be characterised by a real bi-polarity – primary responsibility lying either with the public sector or the private sector.

In practice, however, this bi-polarity is much less clear-cut. In countries where public responsibility is the starting point, a substantial amount of private care is given, while in countries where the primary responsibility rests with the private sector, the public sector has often taken an important role by facilitating and/or financing private-sector care, and/or supporting carers in the private sector.

Recent developments and studies also point to a certain rapprochement of the extremes. In comparison with the first decades after the Second World War – in the golden days of growing Welfare States – there has in recent years been less stress on the principle of primary state responsibility for care for dependent people. The public authorities have learned to appreciate the contribution of the private sector and sometimes prefer to restrict their responsibility to dependent people with the highest level of need. On the other hand, countries that have left primary responsibility with the private sector appear to be introducing more and more publicly initiated or publicly supported contributions, in the form of social insurance schemes, general assistance regulations and/or support for carers.

The issue of bi-polarity and the public-private mix in long-term care for older people is a key area of European debate. This bi-polarity is viewed from a historical perspective. Part II then goes on to discuss family responsibility and public responsibility.

I. Family/private responsibility

For centuries, and without being legally obliged to do so, the family undoubtedly played a crucial role in caring for dependent older people. However, older people with no relatives or at odds with their families were left to charitable associations or taken care of in almshouses. Most such institutions were set up at a local level by local authorities or church-related associations. The first relevant national legislation was introduced in most European countries in the early 19th century. We shall begin by looking briefly at earlier legislation on family responsibility, before describing the main developments in the role of family carers and related policy since the Second World War.

A. Legitimising family responsibilities

Nowadays, the family's responsibility for dependent older people has a legal basis in about two thirds of the 25 EU Member States. In some countries legal responsibility rests explicitly with the public authorities while in other countries legal responsibility for care is not explicitly defined (MESTHENEOS E., TRIANTOFILLOU J. 2005). In most cases the family's legal responsibility dates back to the 19th century Napoleonic or Austrian Civil Codes, although some countries (for instance Hungary) have more recently introduced a specific Family Responsibility Act. In about half the countries where families have a statutory responsibility, the law can be enforced through court decisions ((MESTHENEOS E., TRIANTOFILLOU J. 2005). (See also Part III).

B. Developing Welfare States and responsibility for dependent older people

In the first decades after the Second World War, most of the EU Member States started to develop a modern Welfare State and to deal with the problem of caring for dependent older people. While most countries did not do away with families' legal responsibilities, public authorities began at the same time to be concerned about the problem and to introduce home care and institutional care facilities. On the one hand, these initiatives were entirely in keeping with the core role of the Welfare State which legitimised its authority by assuming responsibility for ensuring citizens' social rights to education, income, housing and care. On the other hand, public involvement became essential because of a number of changes in European societies – demographic shifts, changes in family structures and in relationships between the generations, and the large-scale development of professional expertise in many areas (not just among medical staff, but also among nursing and caring staff and social workers) – as well as emerging gender and labour-market issues.

C. Demographic changes

EU countries have experienced certain common changes in the demographic composition and structure of populations, which have been more pronounced or have occurred earlier in some countries than in others. As regards care for dependent older people, the two most important demographic changes are the extension of life expectancy and reduced fertility. More people live longer. More people will need long-term care, while fewer younger people will be available as carers (see Part I).

D. Changing families

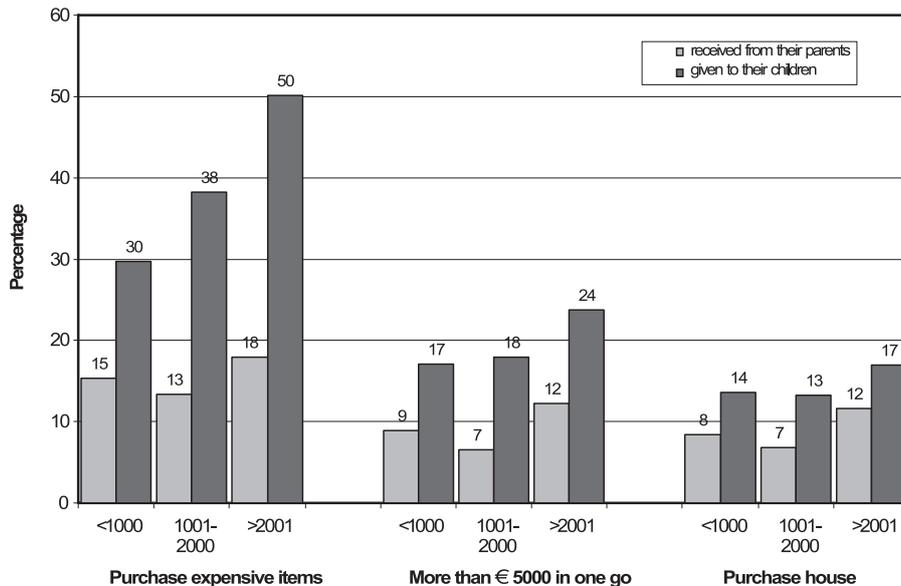
Demographic changes have “verticalised” family structures, with more generations alive at the same time, and fewer people in the younger generations. As a result of these structural changes and in a context of increasing industrialisation and mobility, it was anticipated that the nuclear family would become an isolated unit and grow apart from other generations. In the 1960s and 1970s, family sociologists worldwide tried to demonstrate that the nuclear family was the ideal unit for the industrialised world and that it would inevitably become isolated from older generations. The traditional kinship system seemed to be all but dead and a growing generation gap appeared to be unavoidable. However, over the last 20 years many studies have demonstrated that by the end of the 20th century the growing independence of the nuclear family did not destroy the intergenerational kinship system at all. COLEMAN P.G. (1984) demonstrated repeatedly that older parents are of great value for the majority of adult children and contribute to a meaningful life. Older parents appear to refer very often to the relationship with their children as an enduring source of subjective well-being in later life. In 2000, ARBER S. and ATTIAS-DONFUT C. published an overview of European studies in “The myth of generational conflict: the family and the state in ageing societies”. The second chapter reports about the three generation study by ATTIAS-DONFUT C. in France. In this study about 2000 men and women between 49 and 53 were interviewed about their life courses, their family relationships and about the material and immaterial exchange between the older, the middle and the younger generation. Representatives of the older and the younger generations were interviewed too. One of the major findings, reported here, is that family transfers are going especially to the neediest family members. Second, the authors show that the transfers in cash money are mostly going from the oldest generation to the younger generations (ATTIAS-DONFUT C. and WOLFF F.C. 2000). Another chapter on the situation in Norway (GULBRANDSEN L. and LANGSETH A. 2000) confirms these findings on cash flow between generations in France. KOHLI et al. (2000) report about the family transfers in East and West Germany. Family relationships appear to be stronger in East Germany than in West Germany, East German retired people donate more often to their

children and relatively also a higher amount than West Germans. This last finding may be related to the German public pension scheme, which offers the same amount of retirement benefits for East and West German retired people. In another chapter BERNARD M. et al. (2000), who studied in the nineties family relationships in London suburbs – selecting the same areas as WILLMOTT P. and YOUNG M. (1960) and YOUNG M. and WILLMOTT P. (1957) in the forties and the fifties - confirmed on the one hand a number of changes since the sixties, however they also confirmed the actual strength of family relationships despite a number of disintegrating developments such as decline in proximity and the loosening of the neighbourhood network. They conclude that “household size is substantially reduced, more older people live alone, family networks are smaller in size, the geographical dispersion of family members is greater, but intergenerational ties are still strong” (p. 18). LE GALL D. and MARTIN C. (1996) stress that family networks have become more wide spread and more extensive because of a widening car ownership among parents and children, the universal use of telephone options, but also because in many cases of the addition of step-children and step-grandchildren. If family relationships have become in such a way more separated from communal networks in the neighbourhood, paradoxically they may have become more vital family exchange networks.

Most of these findings fit very well with a few more recent results in the Netherlands. The Netherlands Kinship Panel Study (DYKSTRA P.A. et al. 2000) studied family transfers between three generations among over 2000 families. They asked especially parents of over 55 whether they received ever cash donations from their parents and whether they ever offered cash contributions to their children. The following figure shows the results, differentiated for three income classes and specified for the purchase of expensive goods, as a direct donation and as a support for the purchase of a house. It shows clearly that parents nowadays offer more often cash to their children than these parents received cash from their parents, that among higher income classes the proportion of those parents who contribute is higher than among the lower income classes and similar for the amount of money contributed (in relation to income differentiation this may disappear). By and large this shows that cash contributions from parents to children substantially increased in the second half of the 20th century.

Financial transfers 55-plus people with children differentiated by household income: Ever received from parents and given to children (N=2152)

Source: www.NKPS.nl



Based on data from the Dutch Longitudinal Ageing Study Amsterdam (LASA) a recent cohort comparative analysis by VAN DER PAS S. et al (in press) compared exchange patterns between older parents and their children among a cohort of parents between 55-65 in 2002 the same age cohort from 1992. This study provides evidence of an increase between cohorts in the exchange of support over the nineties. The late cohort can be characterized as providing high levels of support and receiving less than they are giving. In this respect, BENGTON V.L. (2001) notes that parents are the donors, not the net recipients of cross-generational support. This also agrees with previous research (BENGTON V.L., HAROOTYAN R. 1994) showing intergenerational patterns of support flowing mostly from older generations to younger generations in the family, which may reflect the intergenerational stake phenomenon (GIARRUSSO R., STALLINGS M., BENGTON V.L. 1995). Moreover, in this respect, we find that the emotional support given by parents is distinct for the late cohort. Not only do we find an increase between cohorts in the support flow downwards but also an increase in emotional closeness.

A specific perspective which can not be left out from this overview is concerned with the norms and values related to family care issues. One of the reasons why family sociologists and Welfare State ideologists in the seventies and eighties of last century were so pessimistic about future of family relationships was because family norms and values were on drift. Not only the enforcement of family obligation was getting more difficult, however there seemed to be a lot of ambiguity and confusion about the reach of norms itself. Family rules which had been maintained as legitimate for centuries were brought into discussion and challenged. KNIPSCHEER C.P.M. (1986) wrote in these days about the anomy in fa-mily care and suggested a kind of alienation in family care norms. In 1989, FINCH J. published an in depth study on family norms in care for older parents. She analysed families giving a high amount of family care, interviewed family carers about their motivation and norms and questioned related issues in connection to the Welfare State. One of her main conclusions was that the norms about family care "keep sleeping" as long as there is no need for family care. When the need comes up they have to be negotiated among the children, and between children and parents, and that the outcome of this negotiation is not clear from the beginning. Whether and to what extent family care by children will be given depends to a large extend from such a negotiation.

A recent Dutch study asked about 900 family carers about their motivations to care for by offering them a number of statements. After analysis these motivations could be reduced to 4 factors. More than 60 % of the family carers considered the family care giving as a matter of course, 25 % was giving family care because the person cared for preferred to stay at home, 8 % saw no alternative and 5 % cared in order to keep the relationship good (DUTCH SOCIAL AND CULTURAL PLANNING OFFICE 2004). On the one hand these outcomes show quite a high support for family care among family caregivers, however on the other hand we know from other studies that quite a large proportion of the population prefers the state to take first responsibility. Nowadays the retrenchment tendencies in the European Welfare States will keep the discussion about family and state responsibilities alive.

For the moment we conclude, despite the geographical dispersion of family members, the growing independence of nuclear family units and the differentiation in family care norms, the generations within the kinship system have kept in close contact and intensive and mutually supportive exchange patterns have been maintained. Mobility seems to be compensated for by new transport options, and visiting patterns appear to have been replaced by new communication systems. Despite these changes in the kinship system, many unmarried women in both Eastern and Western Europe continue to stay at home to care for their dependent parents without any support from public authorities or care institutions.

At the same time, however, other developments within the nuclear family began to be seen as threats to its continuity: the marked rise in divorce rates, a growing preference for cohabitation instead of marriage, and the tendency to postpone or reject parenthood. These phenomena were part of the strong emancipation movement among women in the 1970s and 1980s and have to be seen as reflections of a much broader ambition on their part for greater economic independence and individualisation. The male-female dichotomies of work versus household responsibilities and breadwinning versus bringing up children had to be rethought and various models for a more balanced division of tasks between the sexes were developed.

While the trends are similar throughout Europe, the extent to which policy-makers are willing – and can afford – to accommodate them continues to vary greatly.

“Enormous behavioural change in the second half of the 20th century has resulted in more family breakdown, more fluidity in intimate relationships, and a large increase in single-person households. In addition, increasing numbers of women have entered the labour market. Indeed this has become one point of convergence between EU Member States”. However, “there has been a shift towards individualisation that is more evident at the level of prescription than behaviour. Adults are more economically autonomous and intimate relationships have become more elective. But care work, which is by definition relational, is inevitably characterised by interconnectedness, and is still marked by relations of dependence as well as inter-dependence. The changing nature of the contributions men and women make to families requires an effort on the part of policymakers to promote new forms of social solidarity, both at the level of collective provision via policies to promote cash payments for care and care services (so-called de-familialisation), and within the family, by encouraging a more equal distribution of money and labour between men and women”³⁸⁾ (LEWIS J. 2004, p. 51-52).

The family of the 21st century clearly has two ambitions: to achieve a more balanced distribution of family care work between men and women and to share the care responsibility for dependent older people with public authorities in such a way that family carers can remain economically independent and socially integrated. These two ambitions will soon come to the fore in Central European countries as well. Coming from a regime which pushed most women into employment, women in these countries may be more accustomed than their counterparts in the West to sharing care activities. Economic independence seems to be their main goal.

38) LEWIS J. (2004), *Individualization and the need for new forms of family solidarity*. in KNIJN T. and KOMTER A. (2004), *Solidarity between the Sexes and the Generations*. Cheltenham, UK, Edward Elgar Publishing Limited, p. 51-67.

E. Differences in family inputs into care for dependent older people

A just finished draft version of the final report of a EU-wide study on family care concludes: "Despite the fact that many countries in Europe still do not acknowledge the role of the family carers in the social and health support of older people, it should be evident from this report that politicians and policy makers at local, national and EU levels ignore the changing demographic structure of Europe at their peril!"

The frequently mentioned 'burden' and spiralling costs for the care of dependent older people can only be confronted by utilising all available resources in a partnership approach to care. The four sectors of the welfare diamond (public, voluntary, family and private) concerned with the provision of care for older dependent people need to find a new balance in ways of working together, based on clearly agreed areas of responsibility. The policy in the EU to encourage the labour market participation of women, including older women, will reduce the already diminishing pool of family carers able to devote adequate time to hands on care and many ad hoc forms of care currently utilised to fill this gap may not be the best solutions. The public sector, already responsible in large part for the health care of its population, needs to take a proactive role in the allocation of responsibility and the development of support for family carers.

Policy implications and recommendations are derived from the NABARES reports and what the national experts initially considered to be critical in their country for the support of family carers. These and other issues emerge as areas where action might effectively be taken at the EU or at the national and local levels for the support of family carers. This section covers issues concerned with types of support for family carers, service organization and provision and, critically, the way in which family care can be an integral and acknowledged element in the care for dependent older people within the wider context of labour market policies" (MESTHENEOS E., TRIANTOFILLOU J. 2005 p. 49).

Despite families' formal responsibilities for caring for dependent older people, public authorities, even in countries where families have a legal responsibility, have introduced a huge variety of compensatory measures to support family carers in carrying out their duties. An important question is the extent to which these measures afford relief from the often heavy burden borne by families caring for a dependent partner or parent.

A recent comparative study among the 25 EU Member States (MESTHENEOS E., TRIANTOFILLOU J. 2005) readily shows the enormous diversity of measures taken to enforce or promote family involvement and/or to compensate families for their investment in time and concern. Mechanisms include:

- personal budgets, allocated in most cases to dependent people so that they can employ professional carers or to compensate a family carer or carers;
- care allowances or care wages, paid either to the person in need or to the family carer;
- care benefits, paid mostly to the family carer, either in cash or in the form of tax relief;
- remuneration of care costs;
- payment of a pension to the carer;
- care leave, paid or unpaid, from the work place (normally part-paid in practice), with varying entitlements in terms of length and frequency of leave and, in some cases, protection from dismissal;
- respite care, to provide temporary relief for carers.

Payments may be funded through long-term care insurance or health insurance schemes, or from general taxation.

Most countries have taken a combination of measures to address the family care burden. In a number of countries means-testing plays a part. However, in order to understand the compensatory effect of these provisions and to evaluate the level of relief afforded, it is crucial to take into account the amount of money allocated to individuals, the question of eligibility (depending on the level of need of the person receiving care) and the proportion of needy older people cared for in institutions. The latter ranges in the EU countries between 1% and 8% of over-65s, with institutions normally caring for those most in need (for instance, in Luxembourg, persons with dementia; see Annex 2). All this makes comparison between the EU Member States extremely complicated, if not impossible. Moreover, all these measures can easily be manipulated to suit national budget considerations at the expense of families providing care.

F. Support for family carers

Recently, OECD warned policy makers in Europe by saying: "Informal carers can not be taken for granted as a resource, but require support in a number of ways, for example, with specialised home-visiting services and respite care, and help to combine work and caring rather than leave the labour market on a long-term basis" (OECD 2005).

It is clear from many studies in the EU Member States that millions of people are involved in caring for dependent older people within families. A considerable proportion of them have been caring for years, often for people with a high level of need. Many of these carers are themselves threatened by health problems or mental disorders. A recent study in the Netherlands tried to identify the major burdening factors among family carers. The question

was whether the main burden was the caring task itself or aspects of the carer's situation, the characteristics of the person needing care, or discussions and disagreements among family carers. The findings were that providing personal care (with ADLs) represented a heavy burden and that conflicts among carers also played an important role³⁹. It should thus be the task of public policy to prevent family carers from being overburdened.

It is also for these reasons that, in several EU Member States, family carers have set up "caring for carers" groups, while in other countries NGOs have begun to provide voluntary support for carers. NGOs aim to raise public awareness of the burden of care and to give carers a stronger position in negotiations with the state or insurance companies. They are setting up support groups for carers to help them cope better with the distressing aspects of their task, and are promoting their interests through collective approaches to political parties. Some countries have set up professional organisations to support individual family carers or the NGOs that represent them (MESTHENEOS E., TRIANTOFILLOU J. 2005).

II. Public/state responsibility

A. Principles

Social Europe is based on human rights to dignity, freedom, equality and sustainable solidarity. There is no doubt that human rights include the right to a decent life (respecting dignity) for the entire population, including long-term dependent older people, and that solidarity is the means by which that right can be ensured.

The concept of Social Europe is developing since 1961, since the adoption of the European Social Charter, as revised. Among other principles the Charter declares under point 25 the right of older persons to full social protection. This principle is then defined in detail:

- Articles 11 and 12 declare the right to protection of health and to social security at the level defined by the European Social Security Code.
- In Article 13 the right to social and health assistance is declared and defined.
- Article 14 declares the right to access adequate social services.
- Article 15 defines the rights of handicapped persons to independency, social integration and full participation in social life.

The rights of older persons to support when in need of long-term care are thus evident.

39) KNIPSCHEER K., BROESE van GROENOU M. (2004), *Determinanten van zorgbelasting bij partners en kinderen van hulpbehoevende ouderen met fysieke gezondheidsproblemen (Determinants of the care burden among partners and adult children of physically impaired older persons in need of care)*, *Tijdschrift voor Gerontologie en Geriatrie*, 35, 3, p. 96-106.

The European Union in the Preamble to the Treaty declared full acceptance of the European Social Charter and its applicability in the European Union. Accordingly the European Council, the Parliament and the Commission have treated the problem of long-term care at various occasions. The latest legal act to deal with the matter is the Charter of Fundamental Rights of the European Union.

In the Charter of Fundamental Rights of the European Union (2000), in Article 25, entitled "The Rights of the Elderly", it is explicitly stated that "*The Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life*". In Article 26, relating to the integration of persons with disabilities, it is explicitly stated that "*The Union recognizes and respects the rights of persons with disabilities to benefit from measures designated to ensure their independence, social and occupational integration and participation in the life of the community*". These articles identify public responsibility for support to senior people in need of long-term care.

The Charter also identifies the measures to be adopted. In Article 34, under the title Social Security and Social Assistance, in paragraph 1 it states "*The Union recognizes and respects the entitlement to social security benefits and social services providing protection in cases such as ... dependency or old age, ...*". In Paragraph 3 it states that "*In order to combat social exclusion and poverty, the Union recognizes and respects the right to social and housing assistance so as to ensure decent existence for all those who lack sufficient resources ...*".

These articles identify the international principles to be applied to long-term care in the member states of the European Union.

Long-term care is evidently in the competence of Member States. Thus the principle of subsidiarity fully applies. Nevertheless the bodies of the European Union attempt to coordinate efforts of Member States to implementation of afore mentioned European principles through the Open Method of Coordination. One of the documents relates to old age, including need for long-term care.

These principles imply some degree of public responsibility for the long-term care of older people in all EU Member States. In some countries, the responsibility is shared between the health and social welfare administrations, in others it is treated as a separate social risk. The various ways in which public responsibility meets its constitutional obligation are examined below (see Part III for a discussion of social protection systems).

In the interests of economic, political and social sustainability, solidarity is generally diversified and fairly shared between all stakeholders and recipients. Diversification and sharing of solidarity is a further issue which is discussed in this part of the report.

B. The role of public intervention

The first question is whether public responsibility is

- a) a comprehensive response to citizens' rights (implying a primary role for the public sector) or
- b) whether it is expected only when all other (non-governmental) resources have been exhausted (implying a subsidiary role for the public sector).

Both approaches are to be found among the Member States. Both approaches are in line with European social values identified above.

In the first case it is argued that a citizen, when in need, has the right to be supported by society. This approach is based on the fact that in the modern and especially post-modern societies the nuclear family is no longer economically capable to support both its children and parents. Families may add, possibly in a subsidiary way, to what the universal public services provide but can no longer support the full cost of support when the elderly are in need of long term care.

In the second case it is argued that responsibility and accountability are crucial elements of democratic societies, in which individuals' freedoms are based on respect for the human rights of all other individuals. There is therefore no doubt that in a democratic society all adults are fully responsible, morally, economically and legally, for their decisions and accountable for the measures they take to cover future social risks. All people should be educated to be capable of rational conduct and are consequently morally and economically accountable for any action they take to meet future needs. This makes democratic societies trustworthy and reliable. The public sector should intervene only if the person and his/her family (or other private entities) fail to act.

If the first argument is accepted the burden of long-term care cost is to be shared by the tax payers, which in the light of the present demographic developments increasingly hampers public finances and overburdens the tax payer. To tune down the increasing insustainability of public long-term care the care is being gradually reduced to a decent minimum living level and people are offered possibilities (e.g. social insurance) to make improved arrangements to cover the risk of eventual need of long-term care.

If the second argument is accepted, there is also responsibility for the needs of the family. In the European social context, therefore, responsibility requires positive and active responses by the family to the needs of its older members. Consequently, families are called upon by the public sector to cater for dependent older people. Yet families find it hard, in the current economic and social circumstances, to shoulder the full burden of their responsibilities.

In response to population ageing⁴⁰⁾ and the increasing need for and cost of long-term care, these two extreme positions are gradually shifting towards a public-private sharing of responsibility. Given the current demographic, social and financial problems of long-term care for dependent older people, public involvement seems to be unavoidable; on the other hand, individuals and families cannot be discharged of their share of responsibility. It is increasingly evident that there is a need to share and to diversify the burden among all the stakeholders⁴¹⁾.

C. The nature of public involvement

As discussed earlier, national practices differ with regard to the extent and nature of public involvement in the provision of long-term care for older people. Discussion of the extent to which personal responsibility should be nationalised has taken place in all the EU Member States, with very different outcomes ranging from liberal to public-welfare solutions. States either:

- a) assume full responsibility and provide social assistance as a right, either at
 - a. central or
 - b. local level; or
- b) make other (physical or legal) persons responsible, and reserve public social assistance as a universal subsidiary instrument for those cases where the physical or legal person fails to provide, or the recipient fails to make, the necessary arrangements.

Those countries with full public responsibility can, in principle, be divided into two groups depending on the level of involvement of public systems:

- a) those with local-level provision and
 - a) sole and universal public responsibility (e.g. Denmark and the Nordic countries) or
 - b) local-level provision only for the needy (e.g. the UK and Ireland), with or without a fixed amount of financial support from central government;
- b) those where provision is organised centrally (chiefly former Communist countries which inherited a highly centralised system of management and provision that is in the process of being decentralised) and where applicants are generally
 - a) income-tested or
 - b) means-tested.

40) See DUTCH EU PRESIDENCY (2004), *Background Paper on "Health Care in an Ageing Society" based on the OECD study (2004) "Towards High-Performing Health Systems"*.

41) See also OECD (2005), *Long-term care for older people*, OECD, Paris; OECD (2005), *Ensuring quality long-term care for older people. Policy brief*, March 2005, OECD, Paris.

Those countries where public responsibility is subsidiary in nature differ as to whether they:

- a) regard long-term care for older people as an insurable risk and use social insurance techniques, involving the social partners, to cover it (e.g. Austria, Germany, Luxembourg and the Netherlands); or
- b) use a different type of public-private mix, setting family responsibilities under
 - a) civil (family) laws (as in France) and/or
 - b) involving recipients in the financing of subsidiary social welfare arrangements (via various types of cost-sharing or co-financing arrangements).

In both cases a distinction is made between responsibility and provision. Responsibility does not necessarily involve provision. Responsibility means making long-term care available in terms of

- physical accessibility – the support and/or services to be available when and where there is a need for long-term care,
- acceptable quality of accessible services – the services provided shall be of a quality fully respecting dignity and freedom of the person concerned,
- financial accessibility – respecting equality in access by supporting those who could not otherwise utilize the offered services.

The public authorities do not necessarily have to provide the long-term care services. These may be provided by non-public entities. However such provision does not relieve the public authorities of their responsibility to make such support and services accessible. They are therefore expected to effectively regulate and supervise such provision through systems of regular monitoring and accreditation.

There is evidence that approaches are gradually converging towards a public-private mix, involving non-governmental organisations (NGOs) in provision, and increasing public responsibility for financing long-term care. NGOs are being called upon to provide services, but in some cases public authorities also work with profit-making organisations (care enterprises). Their role in the field of care provision therefore needs to be redefined.

On the other hand, there is pressure on public authorities or the social partners to play a greater role in financing – the argument being that the risk is a universal one. The idea here is that countries can either base their systems on the principle of universality (in the Beveridge tradition) and consider the state budget as the broadest base for implementing solidarity, or define the need as a social insurance risk (in the Bismarck tradition) and call upon the social partners to meet its cost.

Some countries are discussing the provision of care by commercial bodies, while in others non-profit-making arrangements are required. The roles of

- NGOs – the so-called third sector of private non-profit-making organizations and
- the private profit-making commercial sector

as providers are defined by legislation and supervised by public authorities (via licensing, accreditation, monitoring and auditing where the bodies concerned receive public subsidies).

D. Level of management of public intervention

A distinction is generally made, with regard to long-term care for older people, between managing the provision of cash and services and managing financial flows.

In the first case the public authorities are called upon to organize services that provide long-term care, be they general for all people in need of long-term care or special nursing homes for senior population in need of long term care. In the second case they finance or co-finance long-term care services provided by non-public entities or organized by the family itself.

Long-term care provision differs depending on the nature of the services:

- Cash benefits may be provided centrally (e.g. in some of the former Communist countries or countries with social insurance schemes for long-term care) or locally, with various degrees of central budget backing.
- Public residential homes may be managed either centrally by the state or regional authorities (this is often the case with specialised institutions) or locally (as in the case of nursing homes), while day centres and home care are mostly managed on a decentralised basis.

There is also evidence in most countries of a tendency to de-centre-lise management of specialised residential care. Public responsibility is being increasingly outsourced to NGOs operating under government supervision. The argument in favour of decentralisation and outsourcing goes hand-in-hand with the requirement of individualised provision, i.e. local providers and recipients know best who is in need and how needs can be efficiently met.

The way in which public responsibility is funded differs from country to country. It ranges from direct financing from central budgets to social insurance financing administered by the social partners, with no central budget responsibility. In most countries there is a central-local budget mix, either through a system of regular transfers or budget grants from central to local level (as in the Czech Republic), or through systems based on local taxes or matching transfers from the central budget with local budget contributions (as in Denmark and the Nordic countries).

In all the countries there is growing local authority involvement, either directly or through private-public partnerships with NGOs, and an increasing trend towards cost-sharing to make the system of long-term care financially sustainable.

E. Availability and accessibility of public long-term care

Another issue that is being widely discussed in connection with public responsibility is the availability, accessibility and quality of service provision. This was highlighted in the Joint Report of the Commission and Council (March 2003)⁴²⁾ and in the Open Method of Coordination documents on health care and long-term care for the elderly (October 2004)⁴³⁾.

The latest trend in many European countries (for instance, Germany) is to make public authorities responsible for the availability and quality control of long-term care, without necessarily providing the services themselves. This issue will be discussed in more detail in Part III.

F. The stakeholders – the state, municipalities, employers

Historically, during the 16th to 18th centuries, when poverty could not be alleviated by private endeavour (whether by family or church), it became the responsibility of local authorities to provide care for disabled people within their territory, regardless of age.

The oldest intervention are the poor laws of Elizabeth I in the United Kingdom that evidently gave priority to making people work and supporting the incapable to work as a subsidiary measure. Similar approaches and corresponding legislations were developed in France, Prussian Kingdom and the Austrian-Hungarian Empire. It was necessary to define which local authority was liable. While in the early days it was the municipality where the person was domicile, later e.g. in the Austrian-Hungarian Empire the concept of “Domicile rights” was developed, whereby the municipality where the incapacitated person in need was born was liable to provide support. This was intended to relieve the large cities which were over-burdened by the concentration of the incapable poor in need of long-term care.

Today, in all the countries studied, this responsibility is shared between families, corporate bodies and local and central governments. The apportionment of responsibility differs from country to country and is largely the product of past developments and present economic possibilities. This

42) EUROPEAN COMMISSION, COUNCIL (2003), *Joint report on “Supporting national strategies for the future of health care and care for the elderly”*. No 7166/03, SOC 116, ECOFIN 77, SAN 41 (10 March 2003).

43) COUNCIL OF THE EUROPEAN UNION on *Employment, Social Policies, Health and Consumer Affairs* (2004), *Launch of the “Open Method of Coordination”*, 4 October 2004, 12400/04 (Press 264).

aspect will probably remain specific to countries, because changes will be questioned on grounds of political sustainability.

The general issue of “who is responsible for what” does not seem to be one of major concern. Discussion is focusing instead on:

- whether the stakeholders are able to meet their responsibilities, including, in the case of public stakeholders, that of supporting family carers at risk;
- to what extent the social partners should be involved;
- whether taxation or social insurance should be the main source of financing for long-term care transfers; and
- to what extent the public authorities are responsible for the performance of non-public stakeholders.

There is a growing demand everywhere for the performance of stakeholders in the field of long-term care for older people to be subject to public supervision, because older people needing such long-term care are extremely vulnerable.

Public opinion is split about the role of the social partners in long-term care for older people. More liberal commentators reject the idea of increasing employers' social costs on the grounds that their involvement is questionable, while the more socially minded see the need for long-term care as a chronic situation in which employment has played a part. Liberals therefore support universal approaches with universal cost-sharing, while the socially minded prefer social insurance with the social partners playing a predominant role.

There is a growing consensus that the public authorities are responsible for the performance of non-public stakeholders, because the recipients or clients of services are vulnerable and incapable of asserting their rights against providers and under the European social model they have the human right to an acceptable decent living. As a result, licensing, accreditation, reporting, monitoring and supervision are needed, because public authorities are responsible for protecting everyone's human rights, especially those of vulnerable sections of the population.

G. The range of public responsibility

The final issue connected with public responsibility – and one more frequently discussed – is that of what public responsibility should entail, i.e. the contingencies covered and the benefits and services to be provided.

The first issue that is being discussed in this regard is the nature of the contingency. What is the scope of the contingency that should legally be covered? Is it need of long-term care in general, regardless of age, or is it nursing for aged senior population in need of long term care. The answer may have important legal consequences.

In the first case the issues are quality and the nature of cost sharing. Common services to young and old, unless individualised, may not treat differences in need adequately. Moreover, young people in need of long-term care do not have the same chances to make “provision for the eventual future risk” as the older ones for lack of time. The problem of equal chances arises. Treatment will be equal in quality of provided services, but not in possible financial participation. The younger will need more tax-payers support.

Similar problems arise in the second case as different services may treat need more adequately, but may also give rise to natural but undesirable inequalities in the quality. They may enable more targeted and effective financial arrangements.

The other issues discussed include those of eligibility for publicly supported protection. Countries differ insofar as they may offer public care:

- as of right to all legally resident inhabitants;
- as of right to insured persons; or
- as of right to those legally resident inhabitants satisfying an income test or means test, the latter being more restrictive.

The question is whether there should be subsidiary public support for those who do not qualify for social insurance benefits (as in Germany) and, if so, whether there are any grounds for introducing social insurance if everyone will in any case be protected. Even in this case, there is a rationale for social insurance, as subsidiary public support would probably have to be income-related or means-tested.

Another key issue is the definition of the need for public long-term care. Most countries include the key words “need for assistance by a third person” in this definition (see above Part I). The question is whether such a requirement excludes borderline categories of need. This criterion is also accepted in EU and OECD documents (see the EU Open Method of Coordination documents 2001-2004 and the OECD Report 2005) where long-term care is defined as help from a third person as a result of disability.

The last issue is the form of public support. Should it be services to be provided as in-patient or out-patient-ambulatory care, should it be collective or individualised, targeted to the actual needs of the beneficiary? Should it be a service or rather cash to finance a service the beneficiary chooses?

The general trend in many of the EU members is towards individualization, thus fully respecting the participation of the person in need or his/her family in the decision taking on what services should be most adequate to the need.

This trend is evident also in the post-communist member states. The Czech government has recently proposed to the Parliament a new bill on social services, which prefers ambulatory to in-patient services and cash

compensation to co-finance services the eligible person selects. Similar tendencies are evident in some of the other new member states.

There seems to be no doubt that public responsibility reflects the human right to a decent life (which ties in with the definition of needs discussed in Part I). That being so, public authorities are clearly responsible for creating the conditions in which constitutional human rights can be exercised. A decent life for people requiring long-term care obviously (see Part I) includes access to food appropriate to their state of health, to the health care that they need, including drugs and appliances, to adequate accommodation and to assistance by third persons. The issue is whether these needs should be categorically identified by the public authorities or whether the emphasis should be on taking account of individual needs and providing appropriately tailored services.

The needs to be satisfied require services because, by definition, people needing long-term public care are incapable. The issues are to what extent such services should be provided by public or private authorities, and to what extent recipients should have a right to decide how their needs are to be satisfied, once they have been recognised by the public authorities. This question of the personalisation of needs and services is discussed in Part III.

Part III: Protection

The different types of protection for people needing long-term care vary greatly in the EU Member States. In particular, the kind of typology normally drawn up for comparative purposes at an international or EU level is difficult or even impossible to draw up for protection schemes. This is due to the fact that protection in the long-term care field has become a general social policy issue only in the last three decades (see AWBZ in the Netherlands in 1968). Even now there is no common understanding of types of protection in the EU Member States. The first major difference is the balance between private and public responsibility for the protection of people needing long-term care (as described in Part II).

Part III returns to this issue, but in a different way. We will look first at private and public protection through legal maintenance obligations and at the issue of women's employment in the European employment strategy. We will then look at the way in which the social protection systems of the 25 Member States have evolved over the last 15 years.

Part III also looks at a range of topics and issues that crop up in many or even most countries when the protection of people needing long-term care is being discussed. These issues, about which concerns vary, include:

- problems of service availability (in terms of place, time and quality);
- quality assurance as a general issue, and as a particular issue in the field of informal care;
- user/consumer status of people needing long-term care; freedom to choose between different providers – creating consumer control by granting a personal budget;
- inclusion in allied fields such as disability policies, health protection, old-age policies and housing.

I. Private and public protection: an appraisal

There is still a strong link in most of the EU Member States between maintenance obligations met by the family and what is expected of public policies for people needing long-term care. Modernisation of the European social model and social demands from older people may nevertheless be bringing about some changes.

A. Private protection and its limits

In the EU Member States, long-term care costs which are not or are not sufficiently covered by social protection and/or means-tested social protection schemes are offset to different extents by maintenance obligations. In some countries, only the resources of people in need (and possibly of their spouse) are means-tested. In other countries, the resources

of other family members are also taken into account. Older people's dependence may therefore have serious financial consequences for the family as a whole.

Maintenance obligations are also a kind of mirror of the place of the family (and women in particular) in society and the burdens on families. In some countries, women are expected to care for older people needing long-term care. In other countries, this is not at all the case. Another factor here is that maintenance obligations have traditionally been met in kind by women within the family. However, the European social model calls for major employment growth, especially for women. This raises the issue of reconciling care and employment.

People may also look for private protection on the private long-term care insurance market. However this kind of protection seems to be not well developed inside the European Union, subject to France.

1. Impoverishment of the family through extended maintenance obligations

Being in need of long-term care is considered to be a catastrophic risk which contains the risk of impoverishment⁴⁴⁾ even of the family.⁴⁵⁾ At first the different approaches and major trends in Europe are highlighted. The EU Member States can be divided into two groups in which the extent of family obligations is approached in a similar way⁴⁶⁾.

Group 1 – Extended family

Most of the 25 Member States of the European Union come within the “extended family” model. This does not just mean that spouses and parents are responsible for their minor children, but also that maintenance obligations are incumbent on other members of the family.

In some of the Constitutions, adopted after 1989 in the Central and Eastern European countries, there are explicit maintenance obligations on children. For instance, Article 38 of the Lithuanian Constitution (adopted on 25 October 1992) states “that the family shall be the basis of society” and that “the duty of children is to respect their parents, to care for them in old age and to preserve their heritage”. Similarly, in Estonia, the family has a duty to care for family members requiring care (Article 27 of the Constitution). In other

44) “Social protection is a way of distributing, at the level of an entire society, costs which often exceed the means of an individual or his/her family, ensuring that paying for health care does not lead to impoverishment....” EUROPEAN COMMISSION (2004), *Communication on “Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the ‘Open Method of Coordination’”*. COM (2004) 304 final (20 April 2004), p. 2.

45) *See also Annex IV.*

46) *See: MILLAR J., WARMAN A. (1996), Family obligations in Europe. Family Policy Studies Centre and Joseph Rowntree Foundation.*

countries, maintenance obligations are covered by various laws. For instance, the recently amended Family Act of the Czech Republic states that “children who are able to earn their own living have a duty to provide their parents with reasonable maintenance if their parents are in need thereof” (Article 87) and that “forebears and descendants have a mutual duty of maintenance” (Article 88). In Latvia, the Act on “Protection of the rights of the child”, adopted on 19 June 1998, defines the rights and freedoms of the child as well as the child’s obligations towards his/her family.

The “extended family model” is not uniform. It has two, possibly more, components.

“Filial duty” exists in all the countries belonging to this model. This means that adult children have obligations to their parents. In some countries, this also includes sons- and daughters-in-law (France). Sons-in-law and daughters-in-law have an equal duty, under the same circumstances, to maintain their fathers-in-law and mothers-in-law. This legal obligation ceases when the spouse through whom the relationship existed and any children born in wedlock are dead (French Civil Code – Article 206). The obligations under this provision are mutual. In Germany, sons-in-law and daughters-in-law are not legally required to maintain their fathers-in-law or mothers-in-law. If, however, the married couple has entered into an agreement under which they have decided to own their property jointly, the whole property is taken into account for the purposes of the maintenance obligation of one spouse (BGB – Article 1604). If, however, they have agreed that each spouse retains ownership of his/her property, the property of the other spouse is not taken into account for the purposes of the maintenance obligation incumbent on one spouse.

Moreover, there are mutual obligations between ascendants and descendants in a wider sense in most of these countries. This means that grandparents have to maintain minor and even adult grandchildren and that adult grandchildren have to maintain their grandparents.

In the Mediterranean countries and in Portugal, there are mutual obligations within a wider community. Families are expected to support one another across a broad range of relationships and people in need are expected to look first to their family for support.

For instance, in Spain and in Italy, brothers and sisters must provide maintenance, but they come at the bottom of the list of preference, after the spouse, descendants and forebears. In such cases, maintenance obligations are limited to what is “absolutely necessary”. In Greece, courts may impose a legal maintenance obligation on brothers and sisters, if the person in need can prove his/her need by particular legally defined conditions, such as age, serious illness or infirmity.

Group 2 – Nuclear family

The UK and Ireland have always defined maintenance obligations within the family in a narrow way. There are obligations on members of the nuclear family. Spouses have a mutual duty of maintenance and parents have obligations towards their minor children. In these countries, legal maintenance obligations play only a limited role, but that does not mean that families do not support their older members.

Some of the Nordic countries defined obligations in a narrow way along the same lines as the UK, while others used the Napoleonic Code with its extended definition (see Group 1). In these latter countries, expansion of the Welfare State led to the repeal of this extended definition during the sixties. Today, family obligations are minimal in the Nordic countries and state provisions are geared mainly to individuals.

A reappraisal of the nuclear family nevertheless seems to be taking place, at least in theory⁴⁷⁾.

There is also some debate about the real nature of legal maintenance obligations. Some argue that it is only in a very few countries that maintenance obligations are enforced by court decisions when family members need long-term care and therefore that their role is becoming increasingly less important. This would not seem to be the case. For instance, in France, residential care institutions are entitled, under social law, to take court action to force family members to meet their maintenance obligations and to pay accommodation expenses including part of the dependency costs (because of the low level of the new “personal independence allowance”, called APA⁴⁸⁾).

A recent French research on “Private contributions to finance dependency within the scope of legal maintenance obligations: judicial practices and macro-economic implications” shows an interesting picture⁴⁹⁾. A short summary of the results of this research will be presented here.

47) *In The Third Way. A renewal of Social Democracy* (Polity Press, 1998), A. GIDDENS, attempting to reshape the relationship between the state and civil society, proposes a democratic family, where adult children have responsibilities to their parents: “The family doesn’t only refer to parents bringing up children. Children should have responsibilities to their parents, not just the other way round. It is worth at least considering whether this should be legally binding. The federal Government in the US in 1983, in fact, sought to require children to help support ageing parents, as part of the Medicaid programme. The proposal was never implemented, although some 26 states now have statutes requiring children to provide support for needy parents. While these have rarely been enforced, perhaps this is a notion whose time has come. For example, such obligations could be meshed with life-long parenting contracts” (p. 97).

48) See below section Part III.

49) GRAMAIN A., WITTMER J., REBILLARD C., DUEE M. (2004), *Les contributions privées au financement de la dépendance dans le cadre de l’obligation alimentaire: pratiques judiciaires et implications macroéconomiques*. LEGOS, Université de Paris-Dauphine et INSEE, Paris.

In a first study, a sample of judicial decisions on maintenance obligations related to 305 persons has been analysed. What kinds of criteria have been used by the judges, when they determine the amount of the financial contribution of each family member? The results suggest that the determination of these contributions is very simple: each contribution depends on the financial needs of the creditor (the dependent person) and on the means of the obliged family member. Also the contribution rate of the obliged person is all the more important since the debt is high and it is all the less important since the means of all the obliged persons are high. There is "intra-family solidarity" between the family members who earn high means and those who have fewer means.

These results have, then, been applied to a second sample of legally obliged family members of persons aged 75 and more and, in a second study, simulations have been done on the whole population.

First, the question was raised on how risks are shared between the different income classes: risk that a parent would become dependent and risk that he/she could not cover the supplementary costs linked to dependency. Results show that the distribution of these risks reinforces the anti-redistributive character of the legal maintenance obligation. There is a strong probability for people with low income to become a debtor and to have to pay high contributions. Contribution rate of the classes with a low income (0,51% of stand of living) is four times as much as contribution rate of the classes with a high income (0,13%).

Secondly, the perspective of the distribution of accommodation expenses over the whole population was analysed. The average contribution rate for the children of dependent elderly people would be around 0,3% of the average standard of living. But the perspective of a better coverage of institutional costs might increase the number of dependent persons living in institutions. Therefore, a better solution would be a new financial mechanism covering both costs at home and in institutions. In that case, the average contribution rate must be doubled and fixed at 0,63% of the average standard of living, which seems to be affordable.

In other countries only the person needing long-term care can take family members to court to enforce their maintenance obligations. This difference may explain why there is a large body of case law connected with long-term care issues in some countries while there is no such case law in others because families meet their maintenance obligations without court decisions. Maintenance obligations are therefore very often a private issue.

Family members may be impoverished by cash payments for long-term care needs. This is not the only issue, however. It has always been possible to choose between maintenance in cash and maintenance in kind. In the past, under some Civil Codes, people in need could make their own choice and choose their informal carer. Today, people subject to maintenance

obligations are free to provide maintenance in cash or in kind. In order to avoid impoverishment, family members, especially women, may choose maintenance in kind and act as informal carers.

2. Long-term care, informal care and women's employment

At the Lisbon European Council in March 2000, the EU Member States set an objective of "full employment" reflected by the following numerical targets: increasing the total employment rate of the population of working age (15 to 64) to 70% and the women's employment rate to 60%⁵⁰). These numerical targets are a mean for the European Union. Every country is nevertheless expected to play its part in achieving this common objective.

Table 1: Overall and women's employment rates in the 25 Member States (% population aged 15-64)

	Overall employment rate		Women's employment rate	
	2000	2003	2000	2003
European Union (25)	62.4	62.9	53.6	55.0
EU 15	63.4	64.3	54.1	56.0
Belgium	60.5	59.6	51.5	51.8
Czech Republic	65.0	64.7	56.9	56.3
Denmark	76.3	75.1	71.6	70.5
Germany	65.6	64.8	58.1	58.8
Estonia	60.4	62.9	56.9	59.0
Greece	55.7	57.9	41.2	43.9
Spain	56.2	59.7	41.2	46.0
France	62.1	62.8	55.2	56.7
Ireland	65.2	65.4	54.1	55.8
Italy	53.7	56.1	39.6	42.7
Cyprus	65.7	69.2	53.5	60.4
Latvia	57.5	61.8	53.8	57.9
Lithuania	59.1	61.1	57.7	58.4
Luxembourg	62.7	-----	50.1	-----
Hungary	56.3	57.0	49.7	50.9
Malta	54.2	-----	33.1	-----
Netherlands	72.9	73.5	63.5	65.8
Austria	68.5	69.2	59.6	62.8
Poland	55.0	51.2	48.9	46.0

50) EUROPEAN COUNCIL (2000), *Presidency Conclusions, Lisbon 23-24 March 2000*, paragraph 30.

See Internet:

http://ue.eu.int/ueDocs/cms_Data/docs/pressData/en/ec/00100-r1.en0.htm.

Portugal	68.4	67.2	60.5	60.6
Slovenia	62.8	62.6	58.4	57.6
Slovak Republic	56.8	57.7	51.5	52.2
Finland	67.2	67.7	64.2	65.7
Sweden	73.0	72.9	70.9	71.5
UK	71.5	71.8	64.8	65.3

Source: Employment in Europe 2004, Statistical Annex.

Long-term care raises the problem of women's availability as it is mostly women who provide such care either as informal carers within the family or as workers in home-care and institutional services.

To enable women (and men) to reconcile work and family life, keep a foothold in the labour market and take on their family responsibilities, the European Employment Strategy, through its fourth pillar on equal opportunities, has since 1998 encouraged Member States to introduce policies on working time (career breaks, parental leave, part-time working) and on the development of high-quality child-minding services and care for dependent people⁵¹). In adopting this twofold strategy, the European Union has taken a multicultural approach encompassing different attitudes to care (and, to some extent, women's free choice). At the same time, it considers that the development of services could create new jobs, chiefly for women, and thus help to raise the women's employment rate.

Are the priority objectives of the European Employment Strategy likely to be at odds with the traditional family-based approach, at least for the population of working age? By recognising informal care through financial support and the award of social rights, are social protection systems not curbing the expansion of an occupational sector in which jobs could potentially be created?

51) *Reconciling work and family life forms Guideline N°16 of the 1998 Employment Guidelines, Council Resolution of 15 December 1997.*

See Internet:

http://www.europa.eu.int/comm/employment_social/employment_strategy/98_guidelines_en.htm

Since 2003, it has been included in Specific Guideline N°6 Gender Equality, Council Decision of 22 July 2003 on Guidelines for the Employment Policies of Member States, OJ EC L 197, 5 August 2003, p. 13.

3. Private long-term care insurance market

There is only little information available about private long-term care insurance products⁵².

France and the United States of America have developed the most important markets of private non compulsory long-term care insurance. On the other hand, experts tend to think that, in the future, there will be important developments in European countries. What will be the reasons? Private insurance does not exist in countries with public universal long-term care coverage (Scandinavian countries) or with long-term care social insurance (Austria, Germany, Luxembourg and the Netherlands). It is able to develop in countries with low social coverage or in countries where social protection is cut back. But the creation of a public protection is often seen as “a catalyst” for the development of a private insurance market.

The French private long-term care insurance exists for more than 20 years and it has more than 2.5 Mio. of insured persons. Its long experience gives insurance companies better knowledge about the risk they have to cover (the need for long-term care) and allows them to improve the definition of the guarantees.

French insurance companies offer “lump sum” guarantees in form of monthly annuities. When the insured person becomes in need for long-term care, he/she will get a life annuity as determined at the subscription of the insurance product. Since the eighties, three different generations of products have followed one another. The last generation of products offers guarantees increasing according to the level of the need of long-term care (from 300 to 2.300 Euros per month) and covers partial and total dependence. These guarantees are completed by a range of services for the dependent person and his/her family.

In 2005, more than 30 companies offer contracts of long-term care insurance. This market is very concentrated. Only three companies realize 80% of the turnover. Insurance companies offer individual and collective contracts. Compulsory collective contracts within the scope of a firm are a French specialty. More than 700.000 persons are covered by a collective contract.

Experts think that, besides France, there are numerous emergent markets inside the European Union.

In UK, a small part of long-term care costs is covered by the public system. But private insurance is not much developed. The first insurance contracts have been signed in 1991. Today, more than 15 companies offer products.

52) TALEYSON L. (2004), *L'assurance dépendance privée. Comparaisons internationales*, SCOR Division Vie, Paris ; TALEYSON L. (2005), *Survol des expériences européennes de la prise en charge de la dépendance*, Centre International de Recherche et Développement sur l'Assurance Dépendance de SCOR Vie (CIRDAD), Présentation à la Conférence de l'AEIP à Bruxelles, le 21 avril 2005.

But only 40.000 persons are covered and the private market remains embryonic. It is characterized by an offer in form of savings.

In Germany, persons with a private health insurance contract are obliged to sign a private long-term care insurance contract. This obligation is part of the Long-term Care Insurance Act. Besides, private supplementary non compulsory long-term care insurance does not exist in a significant manner, because of the statutory long-term care social insurance. But the latter is facing important financing problems that mean that, in the future, private insurance might have more space. Today, there is only an offer of complementary products in form of savings for customers at the top of the range.

In other European countries, the private insurance market seems to be emergent.

Italian insurance companies have recently imported the French approach of annuity products. There are numerous companies, but only few clients interested by these products.

Spanish insurance companies are waiting for the creation by the State of tax benefits in order to develop a private insurance market.

In Belgium, there are complex products, which have had no real success.

B. Social protection: trends over the last 15 years

In the late nineties, a report, coordinated by Professor J. PACOLET and financed by the European Commission and the Belgian Ministry of Social Affairs, looked at "social protection for dependence in old age in the 15 EU Member States and Norway"⁵³.

This report concluded that there was growing debate about social protection for dependent older people. Throughout the European Union of 15, older people are voicing "personal feelings of insecurity" as regards health care and long-term care.

At first sight, the European Union gives the impression that it has a diversified and highly sophisticated system of assistance and long-term care, and good public coverage of dependence. Detailed examination by researchers from the various Member States has shown, however, that some aspects of dependence are not covered at all or are inadequately covered by social protection. These gaps explain, according to the report, why long-term care, in terms of both infrastructure and financing, has been on the agenda in a number of countries, especially in the run-up to elections.

53) PACOLET J. et al. (1998), *Social Protection for dependency in old age in the 15 EU Member States and Norway. Main results of a comparative study. Draft synopsis report. National reports. Report for the European Commission DGVIE and the Belgian Minister of Social Affairs, UCL, HIVA, Belgium.*

In the 1990s, the creation of German long-term care insurance as a new pillar of social insurance opened up a real debate on dependence as a new social risk. The PACOLET report (1998) examined whether the German model could be taken as an example and what effects this would have on the rest of the European Union of 15.

For that purpose, it divided the countries into three groups:

- the Nordic countries
- the Mediterranean countries
- the Central countries.

These three groups are used to illustrate various aspects of debates and reforms in recent years. The 10 new Member States are added to these groups.

1. The Nordic countries, the United Kingdom and Ireland

In the *Nordic countries* the introduction of long-term care insurance has never been a topic of debate – for an evident reason. The dependence of older people has long been covered by these countries' welfare states. In keeping with BEVERIDGE's model of universal non-means-tested rights financed from taxation, long-term care is well covered by public health and social service systems.

In the *United Kingdom and Ireland*, countries which also use the BEVERIDGE model, a distinction is made between free health care and responsibility for the costs of long-term care of dependent older people. In 1998, the Labour Government, in response to protests from older people forced to sell their assets to pay for long-term care, set up a ROYAL COMMISSION on long-term care⁵⁴). This Commission proposed that personal care should be free⁵⁵) and financed from taxation, arguing that a distinction could not logically be made between health care and long-term care or between services which would be free of charge for dependent people and services which would require means-testing for public funding and would therefore be limited to the poorest people⁵⁶).

54) SUTHERLAND S. (1999) (Ed.), *With respect to old age: Long-term care – rights and responsibility; A report by the ROYAL COMMISSION on long-term care, Cm. 4192-I, Stationery Office, London.*

55) *Personal care is defined as care connected with personal toilet, eating and drinking, managing urinary and bowel functions, managing problems associated with immobility, managing prescribed treatments, and behavioural management and personal safety. It also includes assistance with cognitive functions. The definition of personal care is based on the notion of "touching a person's body" (ROYAL COMMISSION Report, p. 67) and thus excludes cleaning and housework, shopping, transport services and sitting services whose purpose is company or companionship (ROYAL COMMISSION Report, p. 68).*

56) *Elderly people need care not just because they are old, but because their health has been undermined by disabling illnesses such as Alzheimer's disease, other forms of dementia or strokes. These illnesses cannot as yet be cured by medical treatment. People suffering from these conditions need various types of treatment or ongoing personal care so they can live with their illnesses. In this respect, the limits of medicine are the only difference between cancer and Alzheimer's disease (ROYAL COMMISSION Report, p. 67)*

The British Government has taken up this proposal only very partially by deciding to make personal care provided by a registered nurse free in care homes. The distinction between health care and long-term care has therefore been retained, but for reasons of public expenditure rather than ideological reasons⁵⁷⁾.

However, the newly created *Scottish Parliament* decided in 2001 to take up the ROYAL COMMISSION's proposal and make personal care for older people free⁵⁸⁾.

EUROBAROMETER has also shown that the *Irish* are very much in favour of public coverage of long-term care.

In the Nordic countries, the monopoly of the public sector as a service provider has been called into question in a debate which has been continuing for some years. *Denmark* has recently introduced a major reform in this respect. From 1 January 2003, dependent older people have been free to choose their service provider. They are now free to choose whether the services decided by municipalities following individual needs assessment are provided by the municipality or by another service provider. The Danish Government is hoping in this way to give older people a chance to influence the quality of care. The system by which services are allocated nevertheless continues to be driven by need, via procedures to assess dependent people's individual needs, and not by demand.

2. The Mediterranean countries and Portugal

In these countries, the PACOLET report (1998) notes a lack of any real debate, attributing this to two causes, one cultural and the other economic and financial. These countries continue in practice to set great store by family models of informal care provided by women. Over the years, there have been few large-scale protests about public service deficits. Moreover, their social protection system for long-term care continues to be based on assistance and the principle of subsidiarity. In the 1990s, these countries had to cope with major budgetary constraints in order to comply with the convergence criteria for Economic and Monetary Union which prevented them from extending their social protection systems.

In *Spain*, the Madrid and Barcelona regions have implemented a forward-looking policy for older people, within a decentralised system which is not at all comparable. Since autumn 2003, there has been wide-ranging public debate in Spain about ways of coping with dependence. A White Paper on

57) MEANS R., RICHARDS S., SMITH R. (2003), *Community Care. Policy and Practice*, Palgrave Macmillan UK, Third Edition, p. 117.

58) *Community Care and Health Act* adopted by the Scottish Parliament on 6 February 2002. See also the Regulation of Care (Scotland) Act adopted by the Scottish Parliament on 31 May 2001.

“the protection of dependence in Spain”⁵⁹⁾, tabled before Parliament in December 2004, recommends as a priority that informal carers should be assisted by financial benefits and in particular by social and health services. It is now felt in Spain that care from the family nucleus should be fostered, but that family members agreeing to provide such care should receive some return. Carers should therefore be eligible for specialist training in long-term care and in the treatments that carers can administer.

Cyprus and Malta⁶⁰⁾, became members of the European Union on 1 May 2004. In *Cyprus*, care for older people has traditionally been the responsibility of the family. The political events and family displacements of the seventies created a need for residential care for older people. There has been a gradual shift away from residential care to community services which have grown apace over the last 10 years. Community councils and NGOs have developed local support services. Grants are provided by Social Welfare Services. Public assistance legislation ensures that low-income families have access to these services. A significant development has been the introduction in 2000 of measures to support informal family carers. People who are unable to work because they care for older family members, receive a monthly public assistance allowance and a grant for a week’s annual holiday.

In *Malta*, informal care given by the family still occupies a major place, but seems to be declining rapidly as women enter the labour market. There are, moreover, two main strands to long-term care: residential facilities and social care and home support. 50% of residential facilities are publicly funded and operate on a co-payment basis, beneficiaries contributing according to their pensions and/or their earnings. 25% are private non-profit-making facilities run by the Catholic Church and charging a daily fee which is subsidised by the Catholic Church in case of poor people. The remaining 25% are private profit-making facilities for which a full fee has to be paid. Social and home care support – a wide range of services and cash assistance – are mostly publicly funded, partly by the Ministry of Health, the Elderly and Community Care and partly by the Ministry for the Family and Social Solidarity.

3. The Central countries: Austria, Belgium, France, Germany, Luxembourg, the Netherlands

In these countries in which the Welfare or Social State is based more on the BISMARCKIAN model, there has been very lively debate about the

59) www.seg-social.es/imserso/mayores/may_libroblanco.html.

See also: GONZALEZ ORTEGA S., QUINTERO LIMA G. (2004), (coord.), Protección social de las personas dependientes. Laley, Madrid.

60) VERWEY-JONKER INSTITUUT (Holland), EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH (Austria), DUTCH MINISTRY OF HEALTH, WELFARE AND SPORT (2004), *Integrated care systems: country profiles – responses to questionnaire. Dutch EU Presidency, Hague Conference, 18-19 November 2004, p. 12 (Cyprus) and p.43 (Malta).*

recognition of dependence as a fifth social risk. This debate led to the introduction of dependence insurance in Austria, Germany and Luxembourg in the nineties.

In *the Netherlands*, since 1968, insurance for exceptional medical expenses, called "AWBZ", has been covering long term care expenditure. This social insurance has been the first one, in Europe, covering expenses linked to dependency. Recently, the Netherlands seem to have been influenced by U.K, because they decided to limit long term care to personal care. This means that, for dependent people living at home, instrumental activities of daily living will no more be covered, except for those living without a circle of acquaintances.

In the *Federal Republic of Germany* a better social protection for people in need of long-term care was under discussion since the seventies⁶¹). To begin with, pensioners were highly critical of the cost of care and accommodation in institutions, in comparison with average pensions. As the dependence risk was not covered by social insurance, they had to resort to social assistance, a social protection technique for the "poor", which they were not keen to do as it took account not just of their own resources, but also of the resources of their spouse, children and grandchildren. In parallel, the burden of aid for dependent people was felt to be too high by social assistance (as it was absorbing two thirds of its resources) leading to calls for the introduction of a separate system geared specifically to dependence.

Reform proposals were drawn up in the eighties. There was a political divide between those advocating a general tax-financed solution and universal schemes and those supporting solutions within existing insurance schemes (sickness insurance) or new insurance schemes along the lines of the BISMARCKIAN tradition of social insurance. The political decision ultimately took this approach: after long and highly controversial debate, a new branch of social insurance, long-term care insurance, financed by contributions and not by general taxation, administered by the sickness insurance funds and covering more or less the whole of the population was introduced. The focus of this debate was not the issue of private versus public insurance (partisans of private insurance models did not have the support of private insurance enterprises, which were not very interested in covering a contingency about which little was yet known) but rather that of wage costs, as the contribution to long-term care insurance was a percentage of wages (1.7% under a ceiling).

Cost containment was therefore one of the goals of the legislator: (1) the contribution rate is set by law (and not as is conventional by the insurance fund) and, up to the end of 2004, had not been increased from its original

61) See : IGL G. (2003), *La prise en charge de la dépendance des personnes âgées: quelques observations à partir du cas allemand.* in MARTIN C. (sous la direction de) (2003), *La dépendance des personnes âgées. Quelles politiques en Europe ?*, Rennes, p. 217-225.

level (which is one of the reasons for financing problems in the near future); (2) all benefits are capped and have not been cost- or price-indexed since the outset (with the result that the benefit increases that are now needed will also be difficult to finance). In order to contain costs, legislators pinned their hopes on rehabilitative measures to prevent people from needing long-term care, but these measures have not as yet been introduced in any proper way.

In *Luxembourg*, discussions of the introduction of dependence insurance for the whole of the population, whatever their age, drew on German experience⁶²). This kind of insurance was discussed between 1993 and 1998. An expert report⁶³) examining three systems by which dependence could be covered (Germany, France, the Netherlands) and the situation in Luxembourg came out in favour of the “grand solution”, i.e. creating a new branch of social insurance, rather than the “simple solution” of one-off reforms to put an end to the problems recorded in care allocation and organisation. Dependence insurance, introduced on 1 January 1999, was intended to be a way of restructuring the care supply and in particular of developing home care networks. As well as an evaluation and guidance body, new tools were also introduced for dependent people such as the care plan drawn up after needs assessment. The law also affirmed the principle of free choice for dependent people. They can opt for whatever care they want: home care or institutional care; in the case of home care, they can also opt for a mixed, professional and informal, package, or even employ an informal carer if they are not highly dependent. There has been much discussion of the extent of social coverage. The government had proposed flat-rate coverage by degrees of dependence along the lines of the German model. Employees’ unions, which administer social insurance in Luxembourg together with employers and the state, felt that needs should be fully covered in the same way as under sickness insurance in Luxembourg. The government’s decision was to abolish the degrees of dependence while retaining a ceiling on benefits, albeit set at a very high level. In institutional homes, board and lodging costs have to be met by dependent people themselves and, if they lack resources, social assistance may be involved after any maintenance obligations have been enforced.

In order to finance dependence insurance, the reform introduced, alongside a state contribution accounting for 45% of resources, a “dependence levy”, i.e. a tax of a particular nature, levied on all income of all the population. This

62) KERSCHEN N. (1997), *La reconnaissance de la dépendance comme un nouveau risque de la sécurité sociale: le modèle allemand et le projet luxembourgeois*. *Revue française des affaires sociales*, N° spécial “Le vieillissement comme processus”, Octobre 1997, p. 205.

63) IGL G., JOEL M.-E., KERSCHEN N., KNIPSCHEER C.P.M. (1993), *La dépendance des personnes âgées. Volume I. Prise en charge et financement en Allemagne, en France et aux Pays-Bas. Volume II. Bilan du système luxembourgeois de prise en charge des personnes âgées dépendantes et propositions de réforme*. Report commissioned and financed by the Luxembourg Government..

levy is proportional to income and is not progressive. Its rate, set by law at 1%, has not changed since 1999.

In *Belgium and France*, other initiatives have been taken and discussions are continuing.

In *France*, the allocation personnalisée d'autonomie called "APA" (*personal independence allowance*) was introduced on 1 January 2002⁶⁴), after much uncertainty about the type of long-term care system to support. Policy choices about long-term care norms and ways of supporting their financial consequences have been measured and progressive. Politicians were not sure at what level long-term care should be organised: by municipalities, with the advantages of proximity, or by départements, offering an opportunity for more extensive and structural policy. Women and older people took little part in the public debate. Recent developments in long-term care have nevertheless been much more positive.

Under the Solidarity Plan of 6 November 2003, it is planned:

- to create 17 000 places in home nursing care (+20%),
- to create 4 500 temporary beds in institutions and 8 500 places in day care services,
- to increase the ratio of employees to dependent older people living in nursing homes by 20% (creating 15 000 jobs),
- to create 10 000 beds in nursing homes.

Up to 2008, this will cost a total of around EUR 9 billion.

These measures are being supplemented by the Alzheimer Plan under which the government is taking a fresh interest in a condition which has long been neglected. The main strands of the plan cover early diagnosis and support for sufferers and their families from the onset of the condition, the creation of a large number of temporary accommodation and day care places (+13 000 by 2007), and the development of training for professionals and assistance for volunteers.

A major legislative overhaul is also worth mentioning: the law on social responsibility for the independence of older and disabled people (enacted on 30 June 2004)⁶⁵).

The APA, for which people aged 60 or more are eligible, may now be awarded without means-testing.

Similarly, children and grandchildren no longer have a duty of maintenance and costs cannot be recovered from beneficiaries' estates when they die. However, the amount of the allowance depends on household resources, i.e.

64) Law N° 2001-647 of 20 July 2001 on care for older people who have lost their independence and the personal independence allowance, J.O. N° 167 of 21 July 2001.

65) Law N°2004-626 of 30 June 2004, J.O. N°151 of 1 June 2004.

the resources of the spouse (or other) are also taken into account. The average amount is € 755 for high-level dependence and € 308 for low-level dependence. The ceiling on this allowance makes it necessary for many families to supplement social coverage, either by looking after their dependent members themselves, or by paying for professional services. The APA has been a major success since it was being paid to 605 000 beneficiaries by the end of 2002, to 758 000 beneficiaries by the end of 2003 and to 827 000 beneficiaries in April 2004. At the end of 2001, only 150 000 people were in receipt of the specific dependence allowance which the APA replaced.

The debate surrounding dependence as a fifth risk re-emerged after the heat wave of August 2003 which led to 14 802 deaths, mostly of frail older people⁶⁶). To increase the financing of existing benefits, it was decided to set up a national independence fund, financed from two contributions:

- a solidarity day: in return for the cancellation of a day of holiday, employers pay a social security contribution of some 0.3%⁶⁷;
- a national tax corresponding to 0.5 of the CSG (general social security contribution).

This fund is to be used to finance measures to promote disabled people's independence, to develop home care and care homes for dependent people and to contribute to the funding of the APA. While this supplementary funding is undoubtedly a step in the direction of an insurance system, it is not as yet possible to speak of a dependence branch of social security.

In *Belgium*, in February 2005, a team of researchers led by J. PACOLET published a major report on "ageing, aid and health care in Belgium" commissioned by the Federal Public Social Security Service⁶⁸).

4. Central and Eastern European countries (CEECs)

Eight of the 10 new Member States of the European Union have a common Communist heritage. They can be divided into three groups: 1) the Visegrad countries (Poland, Czech Republic, Slovakia and Hungary), 2) the Baltic

66) ASSEMBLEE NATIONALE (2003), *Rapport JACQUAT D., Rapport d'information sur la crise sanitaire et sociale déclenchée par la canicule [Information report on the health and social crisis triggered by the heat wave]*, Document No 1091, France; ASSEMBLEE NATIONALE (2004), *Rapport ÉVIN C. et D'AUBERT F., Rapport de la Commission d'enquête sur les conséquences sanitaires et sociales de la canicule [Report of the Commission of Inquiry report on the health and social repercussions of the heat wave]*, Document No 1455, France. These documents can be downloaded from the website <http://www.assemblee-nationale.fr>.

67) ASSEMBLEE NATIONALE (2004), *Rapport JACQUAT D., Rapport sur le projet de loi No 1350 relatif à la solidarité pour l'autonomie des personnes âgées et des personnes handicapées [Report on Draft Law 1350 on social responsibility for the independence of older and disabled people]*, Document No 1540, France.

68) PACOLET J. (2005), *Vieillesse, aide et soins de santé en Belgique*. UCL, Ecole de Santé publique et HIVA. This document can be downloaded from <http://www.sesa.ucl.ac.be>.

states (Estonia, Latvia, Lithuania) and 3) Slovenia (former Yugoslavia). While there are many similarities among these three groups from the point of view of financing principles, type of benefits, etc., each country has its own particular features which make it unique.

a) Some background information relating to CEE countries

These countries have experienced massive economic, political, social and societal changes. They have experienced a shift away from different kinds of communism to a similar kind of capitalism. However, the point from which the transition started differed significantly among these groups. The Visegrad countries were not wholly occupied by the Soviet Union. They were able to decide on their own economic policy. There was also political resistance to the ruling Soviet order in these countries. Their social security systems are based largely on the BISMARCKIAN model of social insurance. The Baltic states were wholly occupied, controlled and influenced by the former Soviet regime. Slovenia was part of the former Yugoslavia and drew on a different concept of socialism: "LASSALLE's idea" based on the cooperative principle. In a sense, Slovenia was the freest of the new Member States examined here.

Economic and political transformation has been no easy task. It has raised economic difficulties connected with liberalisation and privatisation and brought about social exclusion, poverty, unemployment, etc. These were new problems that the Communist regime did not officially recognise. They nevertheless existed to a certain extent. More or less the whole of the social security system has had to be reformed and new schemes introduced for unemployment, social assistance, social care, etc.

As mentioned above, in Central Europe, BISMARCKIAN social policy had a key influence on the Austro-Hungarian Empire at the turn of the 19th and 20th centuries. Poland, the Czech Republic, Slovakia and Hungary consequently have a common tradition of social services, based on Christian principles and offered by free private providers and local authorities which are responsible for running social services.

Another aspect common to all these countries was shaped by the Communist governments of the second half of the 20th century. In line with the prevailing Communist doctrine, the former socialist countries (except Slovenia) had to adopt the soviet paternalistic model of social security which long influenced the whole of the social services system as well. All services had to be centralised. The entire social services system was run by the state, social services could not be provided by private providers (although the church was active in some countries) and the prevailing form of social services was residential care.

In the CEECs, social services are one of the instruments of social assistance. Providing social services in practice enhances the application of basic human rights. The right to social assistance in cases of material or other needs is one of the social rights enshrined in all the Constitutions of the countries

examined here⁶⁹). The Constitutions of all the countries examined here (and the Visegrad countries in particular) enshrine the right to social welfare. They have not, however, implemented this right with the same vigour⁷⁰).

The oldest-old, typically defined as persons aged 80 and over, are the fastest rising population group in the CEE region, growing in many countries at rates ranging between three and four per cent per annum. As the incidence of disability, frailty or debilitating diseases is the highest among the oldest-old, the demand for care among older persons, including the demand for long-term care is growing rapidly. This trend is being reinforced, among other things, by the rise in prevalence of living alone among older people. Families, communities and public institutions have been adapting to this development and further progress has been achieved toward meeting the demand for care for older persons. However, the progress is uneven as it presupposes often complex adjustments to existing legislative, financial and labour market regulations. It is particularly slow in countries lacking means and experience in this new area. In the years ahead, the challenge will increasingly be to find a sustainable mix of the various forms of care, including formal and informal care for older persons. Civil society as well as public and private institutions will be called upon to provide adequate infrastructure and services for aged persons who cannot rely on their immediate family.

The activity of the NGO's in the field of social care was under the previous regimes severely suppressed, almost completely eradicated. After nationalisation in the late forties existed only some exemptions – the retirement houses, in fact cloisters, for the elderly monks and nuns. These institutions survived the socialist period as so-called charity houses.

Long-term care, in CEE as well as in any other EU countries, is becoming a critical component in judging the actual performance of health systems. As populations continue to age, issues of chronic care continue to grow in both financial and social importance for policy-making. Long term care policies face numerous challenges where they overlap with other health and social services, as well as with informal care provided at home by family and friends.

b) Ongoing debates

Only a limited amount of up-to-date information is available about these countries. Only a few countries – *Czech Republic, Hungary and Slovenia* –

69) *The Hungarian Constitution, for instance, enshrines a number of social rights, and in particular the right to social security and the subsistence needed to live. The right to social benefits is met by the state through its social security system and its welfare institutions. According to Article 67 of the Polish Constitution, citizens are entitled to social security if they are unable to work as a result of disease or disability or because they have reached retirement age. Under the Slovak Constitution, (legally resident) citizens are entitled to claim benefits to cover essential living needs, defined by the 1998 Act as "one hot meal per day, necessary garments and shelter". All social rights in the Czech Republic are defined in the Bill of Fundamental Rights and Freedoms.*

70) KOLDINSKA K., TOMES I. (2004), *Social services in accession countries, Social Work & Society, Volume 2, Issue 1, p. 110-112.*

have published any information about their ongoing social service reforms. Only reforms in these three countries will therefore be briefly reviewed below.

The *Czech Republic* is preparing a special act on social services. There have been major changes in social service provision in the Czech Republic over the last 10 years. These changes were prompted and implemented in a bottom-up way, primarily through individual providers from both the non-governmental and governmental sectors. Social services have developed rapidly but have not been coordinated and regulated by law. Users of social services have become more outspoken and are keen to play their part in decisions about where, by whom and how services are to be provided. Providers are introducing new social work methods and are therefore better able to respond to individual users' needs. Further development of social services is hindered, however, by outdated legislation, the division of powers, the methods by which funds are distributed and the professional abilities of social workers in the public administration. Changes to the existing social services system cannot continue to be merely cosmetic. A radical overhaul of the system is now needed.

The existing legal standards governing the social sphere and social services in particular are outdated and do not in practice reflect current developments or the general changes that have taken place in recent years. Effective instruments have not been developed to implement state social policies, and the responsibilities and powers of individual bodies have not been clearly defined. A coherent set of tools to implement the social policies of municipalities and regions is completely lacking in the current system. Individual regions are unable to meet requirements (in terms of types of social services and in terms of capacity) and their ability to meet demand varies greatly. The expertise and skills of social workers in the public administration are inadequate in some areas as there is no system of lifelong training to help them to respond to new trends and tackle problem areas in this field. An ongoing and very unfortunate feature of the current system is that governmental and non-governmental bodies providing social services are financed separately and providers do not have equal access to funding. Financing social services on the basis of capacity rather than demand is equally wrong. Moreover, the quality of the services provided is not adequately monitored and there is no control at all of the effectiveness of spending. Comprehensive data on social services are not at present available and there is no evaluation of quality. Users play a very small role in decision-making about the methods and types of social services to be provided and play almost no part in auditing, which runs counter to European trends to step up the role of users in social services systems. Institutional/closed services still continue to prevail over community/open services, and there has been no de-institutionalisation; moreover, the approach taken by social services is too often medical. Citizens – potential users – are not very aware of the services available because there is no coherent system of information on social

services. The system's lack of transparency is further exacerbated by the terminology used, which is outdated and inconsistent; there is also no professional or social debate about new concepts.

The aim of the *Hungarian reforms* is to overhaul the social assistance and social service system as a whole. The health and social problems of an ageing population are becoming increasingly prominent in advanced countries as well as in Hungary. The increase in life expectancy of recent decades combined with a drop in the birth rate has led to the gradual ageing of the population, a trend that has become more pointed in the past ten years. Although life expectancies for the various age groups in Hungary have not changed as significantly as in the advanced countries, the ageing of the population is nevertheless noteworthy. In 1990, about 13,2% of the population (1,374,000 people) were 65 or over, while in 2002 the ratio had gone up to 15,3% (1,552,000 people). The ageing index of the population - that is, the ratio of elderly compared to the 0-14-age-group - was 61,9% in 1980, 64,9% in 1990, and 93,5% in 2002.

Social services for the elderly and the disabled have a relatively well developed institutional network in Hungary. However, they do not meet growing needs either in terms of number of places or quality of the services. Development of special institutions for long-term care within the health sector (home care, nursing homes and hospices) started only in the 1990s and still needs considerable extension. The 2002 election programme of the government suggested considering the introduction of public long-term care insurance. It has not yet been launched.

Provision of long-term care services within the health care system: The health insurance system offers no special services for the elderly as such, although long-term care in hospitals, services in nursing homes and home-care services are provided and received mainly by older persons. Moreover, drugs for the treatment of certain geriatric conditions are subsidised at high rates, reducing the user charge to a comparatively low amount or to zero in the case of low-income recipients. In rural areas particularly, General Practitioners (GPs) and primary care nurses tend to spend considerable time visiting patients (many of them elderly) at home, with a significant part of these visits serving a social and mental health function. In addition, there are a growing number of specialised home-nursing care organisations, which provide post-operative and pre-operative care as well as limited ongoing treatments. Both GPs and home care organisations are mainly private providers, but their services are financed by compulsory health insurance.

Hungary meets some functional problems within its health care system relating to long-term care: (1) There are not enough capacities for long-term care and rehabilitation, so chronic patients often use acute beds. (2) Nursing time needs to be reduced in many areas of patient care.

Hospice services: The Hungarian health care administration, working in cooperation with charities, recognised the need for this type of service. Act 154 of 1997 legislatively established the need to care for terminal patients. The conditions for financing this new form of care, the minimum professional conditions (personnel, facilities), the qualifications, the extension training requirements, and the data content of hospice care documentation have been defined. They follow the same logic as the nursing process. In 2003, there were 26 hospice organisations operating in health care. They had 56 beds in inpatient facilities and offered assistance to 4,787 patients. Otherwise, nursing homes, social facilities, and home care services offering hospice care worked with 6,536 patients up to 2003.⁷¹⁾

The tasks in reshaping health-care services are:

- expanding specialised home nursing
- establishing specialised geriatric units
- improving the hospice services
- providing geriatric services in day hospitals
- evolving geriatric rehabilitation schemes
- introducing a patient follow-up system
- building a home care and nursing system as a part of primary health care.⁷²⁾

Provision of long-term care services within the social services: When it comes to long-term care, the social aspects of personal care appear alongside the health care aspects. The rules for long-term care are in Act 3 of 1993 on social administration and social benefit. This social system includes both benefits in cash and/or in kind as well as social services. The two major groups of social services are basic services, and specialised services, which fall within the category of personal care. Assistance in both cash and kind is means-tested, and determined by the per capita income in a given household. Assistance in cash and kind may be granted on a regular or ad hoc basis (a few types of assistance can be offered in both ways). The goals of the assistance are to prevent the elderly from becoming completely indigent (non-contributory old age allowance – idskorúak járadéka), to alleviate excessive home maintenance costs (such as support for home maintenance – lakásfenntartási támogatás), to prevent complete deterioration of a health status (through public health care aid - közgyógyellátás), and to mitigate the effects of unexpected crises (such as funeral grant – temetési segély).

Personal social services include services for the elderly and for mentally and physically disabled persons. Services provided in their own homes or on a

71) *National Health Insurance Fund, European Welfare Fund (2005).*

72) *MINISTRY OF HEALTH (2005), Preliminary Report on Hungary's Health Care and Long-term Care Systems, Draft paper.*

daily basis include meal-delivery, home help, day-care facilities, clubs for elderly people and day care for the disabled. Residential care includes the following types of facilities: homes for the elderly; homes for psychiatric patients, disabled children, disabled adults, and for alcohol and drug addicts. These residential facilities can be permanent care homes or temporary care homes.

Moreover, Act 3 of 1993 on social benefit contains the rules regulating long-term care, as follows: The local governments of all settlements are required to provide home help for all persons who are in need of it and request it to maintain their independent living. All local governments where the population exceeds 10,000 people are required to provide community care for psychiatric patients and people with addictions, to treat them in the community and to promote the restoration of their health and their rehabilitation. All local governments where the population exceeds 10,000 people are required to provide support services as basic social services so that persons with disabilities may access satisfactory care in their living environments.

Skilled nursing care at home - specialist home care was declared a part of outpatient care under Government Decree 43/1993 (March 3), offering specialist home nursing when ordered by a physician, either in the home of the patient or wherever the patient happened to be staying. Since 1996, the National Health Insurance Fund has covered operation of the system. From the point of view of regional access, as of 1999, the network of home nursing services has been accessible to 98% of the population. The health care policy goal of specialised home nursing is to have it replace one portion of hospital care, which is much more expensive. Under separate statute, specialised home nursing is qualified as an alternative to hospital care or as a way of reducing periods of hospitalisation. Any physician treating a patient may order specialist home nursing. In 2002, there were 359 such services operating in Hungary. One specialist nurse is limited to performing five specialist therapeutic services a day during four home visits. A part-time nurse may perform proportionately fewer services and visits. The number of home visits made nationwide in 2002 was 901,103, of which the number of specialist nursing visits was 544,385, the number of physical therapy visits was 265,078, the number of physiotherapy visits was 85,724, and the number of speech therapy visits was 5,916. The number of visits per service was 2,510. As far as the breakdown of total visits is concerned, some 69% of all visits were to people over the age of 65.⁷³⁾

The reform project ("SZOLID Project"): The Hungarian Ministry of Health, Social and Family Affairs launched an independent project in summer 2003 entitled "Towards a renewal of the Social Act and the democratic, long-term

73) RESEARCH INSTITUTE FOR HEALTH STRATEGY (2004), *Hungary's health and social system 2004, National Statistical Survey Programme Report, 2002.*

development of social administration". The project's Hungarian acronym ("SZOLID Project") suggests that the aim of the programme is to overhaul the Social Assistance Act which regulates service provision under the principle of solidarity. The Social Assistance Act (Act III of 1993 on Social Administration and Social Provisions) was enacted 10 years ago and can be considered to have been a fundamental law during the first few years of transition. Bearing in mind, however, the very rapid and significant social changes of the past decade, the act is, in many respects, no longer in keeping with the current situation. It is planned to change the present Social Act into a fundamental solidarity law overarching more detailed laws regulating the sub-fields of social protection and defining their basic principles. The act will not regulate the different social provisions in detail but will provide general guidelines on means-testing, eligibility and legal redress. In addition to this fundamental law, at least two further laws are to be enacted, one regulating cash benefits and the other regulating personal social services.⁷⁴⁾

Tasks involving the transformation of the social system: The social system will undergo a gradual transformation in the years to come. Currently, the legislative backing is being prepared for "service packages" in which all persons accessing social services will be able to find a scheme that suits them best. The goal of the transformation is to increase the accessibility of benefits within the residential environment and to achieve a targeted increase in live-in accommodations. Through these features the system will evolve a complex network that offers services to satisfy needs based on the given individual's social situation and health status, and are affordable at the same time.

The advance of the home help and home-assistance-on-request systems is taking place with state support in an amount commensurate with the task. The goal is to allow elderly people to maintain independent living within their own homes for as long as possible. If it becomes necessary for an individual to switch to live-in institutional care, plans are underway to establish special care units using priority funds - such as special units that care for and offer nursing to dementia patients - that provide services which are satisfactory in quality.

Social services: The idea underpinning the reorganisation of social services is that they should be integrated and community-based. The new law intends to promote participation by non-public agencies (from the lay or religious civil sector, or from the profit-making sector). A full range of community services is to be included: 1. permanent information service; 2. organisation of social

74) *The Solidarity Act is to be supplemented by the following laws: 1. Basic law on provision; 2. Basic law on cash benefits and benefits in kind (based on solidarity); 3. Basic law on personal social services (based on solidarity); 4. Laws on social occupations; 5. Child protection act (Act XXXI of 1997 on Child Protection and Guardianship); 6. Law on equal opportunities for the disabled (Act XXVI of 1998 on the Rights and Equal Opportunities of the Disabled); 7. Law on family provisions (Act LXXXIV of 1998 on Support for Families).*

assistance for families; 3. case coordination; 4. integrated day services; 5. clubs, play centres, daytime child care; 6. development of voluntary (neighbourhood) help networks; 7. organisation of self-help groups.

Reform of the public administration. In addition to general modernisation, the main objective of the reform of the public administration is to reduce the current extremely fragmented nature of the administration (3200 autonomous and very powerful local authorities for 10 million inhabitants). For this purpose, the administrative system is to adopt the system of regions, sub-regions and micro-regions. A further main objective is to create a monitoring and supervisory system for agencies, which is completely lacking at present. The success of this reform will depend on the outcome of the overall reform of local self-government and administration for which preparations are also underway.

Slovenian reforms involve the health care (integrated care) reform, which touches on social care as well.

For the time being the services and benefits related to elderly long term care are in different laws and insurances and other schemes:

- pensioners are entitled to pensions and to assistance and attendance allowance and physical impairment allowance;
- institutional care is covered from the income of the institutionalized person; if the income is not sufficient the difference is paid by the local community of the persons residence;
- help at home is organized by local centers for social work.

In Slovenia there is a plan to introduce a law on long-term care insurance. In 2002, the Slovenian Ministry of Health developed a 10-year reform strategy in consultation with the parties concerned, including insurers, care providers, and professional clinical associations. The reform process is now underway and initial progress has been encouraging. A study on long-term care was prepared. The activities related to preparing a draft law should start in autumn of 2005. A key aspect of the reform is to redefine the products to be financed and delivered. Ten main types of service have been defined for the basic structure: acute inpatient, non-acute inpatient, rehabilitation, palliative care, intensive care, primary medical care, specialist medical outpatient care, other outpatient care, home care, research, clinical staff education and tertiary severity. Expert clinical panels have been set up for each type of service and asked to advise on all relevant matters including methods of clinical practice, classification, costing, pricing and data.

c) Financing

Expenditure on social services during the Communist regime was covered by the central governments of all these countries. However, this approach made citizens passive – they simply expected all (or most) social services to be paid for by the state from public funds.

In most CEECs studied the main source of public financing is general taxation. Public funding for long-term care is still relatively low, often being restricted to a limited amount of care provided in institutions (e.g. Hungary).⁷⁵⁾ In many studied countries the main health insurance programme finances a limited amount of care in hospitals in the absence of other programmes, but the total involved is quite small (e.g., Hungary, and Poland).⁷⁶⁾ A number of countries (e.g., Hungary and Poland) have reported recent problems arising from the boundaries between health and social service financing. These have included different assessment criteria for similar services but paid for from different budgets. This can lead to difficulties in arranging a package of services, difficulties in transferring patients from one to another service, and consequently to a lack of equity in outcomes for patients in similar circumstances.⁷⁷⁾

However, as public resources are lacking in all these countries, new resources need to be found, in particular by motivating clients to make financial contributions to the costs of the social service that they receive, when they can afford it.

NGOs are playing an increasingly key role in social service provision. Most NGOs usually ask their clients to pay for services or charge a token sum at least. When a non-profit-making NGO provides services, its activities should be financed partly from the central budget, as the state should fund anyone caring for its citizens. This principle is, however, not entirely respected, especially in the Visegrad countries. Many NGOs have to apply for state subsidies every year, and are not automatically entitled to them⁷⁸⁾.

Publicly run long-term care institutions in the CEECs are financed in various ways which can be summarised as follows:

1. financing chiefly from the state and local government budget (for instance, the Czech Republic, Slovakia and Hungary);
2. financing solely from the local government budget (for instance, Estonia);
3. financing partly from social insurance (invalidity) contributions from employers and employees, and from national and municipal budgets (special child care, home care, institutional care, supplement for care and assistance, etc.) (for instance, Slovenia).

d) Co-payment rules

Beneficiaries and/or (in certain types of system) their families may be asked for co-payments. For example, in Hungary health care services are mainly

75) OECD (2005), *Long-term care for older people*, OECD, Paris.

76) OECD (2005), *Long-term care for older people*, OECD, Paris.

77) OECD (2005), *Long-term care for older people*, OECD, Paris.

78) KOLDINSKA K., TOMES I. (2004), *Social services in accession countries*, *Social Work & Society*, Volume 2, Issue 1, p.115-116.

financed by mandatory health insurance and services of “basic quality” are free of charge. However, for services of “higher quality” and services provided for patients from outside the official catchments area of the hospital, the hospital can require fees (in addition to the payment by the health insurance) from the patients. These fees are set by the institutions. Services can also be provided and financed totally in the private sector.

Local governments are responsible for social care. Social care is co-financed by central government and local governments. For social services, user payment is required and it is set by the institution within the range defined by the local governments in their decrees on social care. However, fees for social services cannot exceed a certain proportion of the income of the client.⁷⁹⁾

Co-payment systems can be grouped under four headings:

1. The percentage of the public subsidy is fixed. In *Estonia*, for instance, beneficiaries or their families must contribute towards certain services. The state covers 50-90% of the cost, the rest being paid by the beneficiary.
2. All of the beneficiary’s income (usually social security benefits) is used to cover the costs of social care institutions, the beneficiary receiving only a small amount of pocket money. In *Latvia*, for instance, all of the needy person’s social security income is used to cover the cost of their stay in a long-term care institution, except for 15% of their income from pensions or state social security benefit.
3. The maximum rate of the beneficiary’s co-payment is set by law according to the type of care and the beneficiary’s income. In *Lithuania*, for instance, residents in permanent social care institutions pay no more than 80% of their income (usually a pension), and no more than twice the social insurance basic pension. In day care centres, disabled people pay 50% of their pension. People receiving home care services pay depending on family income.
4. The amount of the co-payment is set by means-testing and differs for various institutions. In *Hungary*, for instance, services are provided free of charge if the beneficiary does not have an income, lives in a long-term residential home and does not have any relative able to assume responsibility and fulfil his/her obligation to support and care for the beneficiary. Another example is *Poland*, where, in the case of benefits in kind, beneficiaries are expected to pay part of the costs of goods or services if their income is above a threshold (i.e. the threshold for cash benefits from social assistance). In *Slovakia* and the *Czech Republic* beneficiaries’ contributions depend on their income and assets. In *Slovenia* beneficiaries are obliged to cover the costs of social services (home care, institutional care) as far as they are financially able. People

79) OECD (2005), *Long-term care for older people*, OECD, Paris.

living on financial assistance as their sole source of subsistence and recipients of disability benefits are exempted from paying for any services, with the exception of institutional care services.

e) Benefits

The aim of new legislation from the early 1990s onwards in the Visegrad countries was, among other things, to introduce new types of social services. The *Czech Republic*, for instance, has introduced municipally-run services delivering goods to the homes of pensioners unable to shop and cook, and a medical home nursing service. The social services inherited from the past almost exclusively took the form of residential care, and were provided chiefly in large institutions built for hundreds of residents. The aim of the reforms, in the Visegrad countries at least, was to provide people in need with an individual service, possibly at home or at a day centre when the service aims to activate clients and include them in their assistance (care) process.

Placing older people to residential care facilities is a highly unpopular solution in the CEECs. New family and working patterns mean that more and more families are being forced by their busy lifestyles to place their dependent parents in elderly care facilities.

CEECs' Governments have tried various ways over the past 10-15 years to allow dependent persons receiving care at home- and their families – more choice among care options. The benefits come in various ways: personal budget, income support, etc.

Thus far, *Poland* has continued to rely for long-term care mainly on the traditional provision of informal care by families, but this may be difficult to sustain at the current level in the future. The most recent health service reforms, in 1999, did not specifically address the situation of older people or long-term care and there was no separate system of long-term care, as of 2004. Health services are funded by a combination of general taxation and contributions to national health insurance schemes

In most cases, the majority of services are provided by NGOs, and services provided by local public authorities are often restricted to residential care, counselling and perhaps some home care⁸⁰.

It should be stressed that the CEECs have no separate long-term care scheme. They have a mixed scheme. Various types of benefit and care are available under various branches of social protection schemes. People needing long-term care and/or their carers can apply for various social benefits and care. These countries' systems are mixed in a multiple way: there is both an institutional mix of providers (state, municipality and private agencies, persons, NGOs, etc.) and a mix of benefits (benefits and services

80) KOLDINSKA K., TOMES I. (2004), *Social services in accession countries, Social Work & Society, Volume 2, Issue 1, p. 112.*

being provided by different social security and social welfare systems, for example health care, social assistance, etc.).

The new Member States do not, in our view, fit neatly into the three groups used in the PACOLET report (see above). However, most long-term care systems in the CEECs are similar to the group based chiefly on assistance, the principle of subsidiarity and means-testing.

- Universal rights for individuals “from the cradle to the grave”, without means-testing: No CEEC belongs to the group using this model of social care.
- Long-term care insurance: No CEEC belongs in principle to the group using this model of social care. According, however, to unconfirmed information, *Slovenia* is planning to join the Central (Continental) European long-term care insurance model (Austria, Germany, Luxembourg).
- Assistance, principle of subsidiarity, means-tested in one way or another: According to the information available, the overwhelming majority of the CEECs belong to this group of social services. A qualifying period is not normally required to receive long-term care in the CEECs (Czech Republic, Hungary, Poland, Slovakia, etc.).

The CEECs offer, as types of benefit, benefits in kind and cash benefits.

In the case of *benefits in kind*, every country has a) home care, b) semi-stationary care and c) nursing-home care. Most countries provide mental health care services as well, but under separate systems. The home care, semi-stationary care and nursing-home care systems include a wide range of special social care services. In many countries, there are integrated care solutions enabling long-term care recipients to stay in special care hospitals financed by health insurance funds. In some countries, such as Lithuania, this is limited to no longer than four months on each occasion.

Home and community care: Home help services are the responsibility of local government. These services are means-tested. Services are provided free of charge in cases where the per capita income of family members does not exceed the minimum state pension. Referrals can be made by the community health team, consisting of a doctor, community nurse and social worker, or by family carers, neighbours or friends. Older people are entitled to apply for help from the Fund for the Rehabilitation of Disabled People, which provides a limited range of disability equipment and adaptation to the home. The recipient is required to make a contribution to the cost of these services. Other services, such as the provision of meals etc., exist on a more ad hoc basis, through agencies such as Red Cross nurses who may purchase and deliver a meal to an older person’s home.

Cash benefits come in many forms. They vary according to the social services systems of the various countries. There are four main types of cash benefit:

- Benefits paid to a family member or other person caring for someone in need (who is fully or significantly disabled) (for example, the *Czech* care allowance, the *Estonian* carer's benefit and the *Hungarian* nursing fee paid only for close relatives).
- Benefits paid to persons in need, normally with the proviso that they are not receiving home care services (for example, *Estonia*, or personal assistance benefit in *Slovakia*).
- Benefits paid to persons in need (recipients) to enable them to buy social care for themselves from a carer, a professional NGO offering care services or any other source. Lastly, this kind of benefit may be paid to the professional or non-professional person or service providing social care (countries with this type of system include *Lithuania* where, if municipalities are unable to provide the social services needed, they may pay "money for care" so that recipients can buy these services; *Poland*; *Slovakia* with its attendance service benefit; and *Slovenia* where a supplement for care and assistance is available).
- Various utility costs (heating, hot water, cold water, electricity, etc.) (for example, *Lithuania*, housing allowance in the *Czech Republic* and *Hungary*).

Cash benefits have a number of features in common. The first question is whether cash benefits are available for semi-stationary care and nursing-home care. In most of the CEECs, no cash benefits are available for this purpose (in, for instance, the *Czech Republic*, *Estonia*, *Latvia* and *Poland*).

Another question is: who pays for institutional care, if the person in need does not have enough resources to cover the whole cost? In *Slovakia*, if recipients of nursing-home care are on low incomes, the state pays the difference between the full cost of the service and the contribution made by the recipient. In *Slovenia*, the local community covers the cost of nursing-home care for people who do not have resources or have insufficient resources to cover these costs by themselves. In the *Czech Republic*, this applies to the institution (state, local government) that sets up and runs the facility.

Cumulation, i.e. simultaneous payment of cash benefits for social care and other social security benefits, is a further question. The purpose of cumulation is to guarantee sufficient resources for recipients and/or their carers. In a slightly smaller group of the CEECs, such cumulation is prohibited by law. In the *Czech Republic*, for instance, the care allowance (Rodinné pídavky, pídavky na dti) cannot be cumulated with recipients' (carers') old-age, full invalidity, widow's or widower's pensions. Pensions are not reduced, but there is no eligibility for the care allowance. In *Lithuania* long-term care is not cumulated with pensions or with income from work. This cumulation is possible in another group of countries. For example, in *Latvia*, cumulation with pensions is possible. In *Hungary*, the contribution-based pension system is supplemented by a system of specially designed and enhanced social

benefits for those in need. In *Poland*, long-term care benefits can be cumulated with all kinds of pensions; if, however, recipients are receiving care at home, they are not entitled to the medical care supplement (Dodatek pielgnacyjny). While cumulation is possible in *Slovakia*, in some cases recipients must contribute financially to the costs of care from their income. In *Slovenia*, the assistance and attendance allowance (dodatek za pomo in postrežbo) can be combined with old-age, early retirement, invalidity, widow's/widower's and survivors' pensions.

The last question is whether recipients (carers) are allowed to work or not, and if so, to what extent. In the *Czech Republic*, for instance, recipients can work up to an earnings ceiling (1.5 times the amount required for their personal needs). In *Hungary*, the nursing fee (Ápolási díj) can be combined with income from part-time work (up to a maximum of four hours per day) or from work at home (with no time restriction). In *Poland*, long-term care benefits can be combined with income from work.

There is no precise and widely used definition of long-term care in the CEECs. Under *Czech legislation*, for instance, need of long-term care is defined as the "inability to perform the following tasks: dressing, washing, shopping" and, in *Slovenia*, it is defined as a need for permanent assistance and attendance for basic human needs.

f) No special legislation on long-term care in the CEECs

There is no special legislation on long-term care. This is perhaps the feature most common to the CEECs. In the Central and Eastern European Member States long-term care is an integral part of existing health care and personal social services. None of the CEECs have long-term care insurance. The current trend seems to be along the lines of the means-tested Beveridge model.

Long-term care institutions and services are allied with health care and social assistance (social care) systems. It is very difficult to draw a line between health care, social care, institutional care and community care. Health care systems play an important role in long-term care. They provide treatment for people who are seriously ill and dependent. More care-intensive systems or services focusing on housing and domestic aspects are provided at local authority level.

The prevailing trend seems to be towards mixed provision with different social security schemes responsible for long-term care (in *Slovenia*, for example, long-term care benefits are included in the Pension and Disability Insurance Act, the Social Protection Act, the Parental Protection and Family Benefits Act, the Social Security of Mentally and Physically Handicapped Persons Act and the Health Care and Health Insurance Act).

More care-intensive services continue to be largely publicly financed (by central state and/or local government). NGOs are nevertheless starting to

play a much larger role and are now important partners in the system alongside the state, municipalities and churches. In these countries, families can be legally obliged to fulfil their obligations.

g) Age limits

In most of these countries, long-term care systems are not limited to older people alone. There is no age limit, for example, in *Lithuania*, *Hungary* and *Poland*. In *Slovakia*, however, there is an age limit in the case, for instance, of personal assistance benefit – payable to people aged between 6 and 65. There are also age limits on some benefits in *Slovenia*: benefits in kind (home care, institutional care) are available for people aged over 65, for disabled adults and for disabled children and infants.

h) Financing and organisation

From the point of view of financing, benefits are service-oriented, although cash support is available for dependent people or their main carers, thereby providing some form of support or payment for informal care.

From the point of view of organisation, long-term care services are usually organised and regulated centrally and supplemented at a regional level (for example, Hungary, Slovenia). Local authority legislation can go only so far, however (for example, Hungary, Slovenia). Municipalities run a network of public services providing institutional care (for example, Hungary, Slovenia).

i) Quality of services

Regulating and improving the quality of long-term care provided at home. The regulation and regular quality assessment of the home-care market is a relatively new development. Specific policies for quality assessment and improvement are being considered in others, e.g., Hungary. In general, these focus on setting standards of structure of care provider organisations, and process of care provided. The use of outcome measures in standard setting is much less common, and continuous research efforts are needed to clarify and improve underlying measurement concepts.⁸¹⁾

II. Protection: common issues and topics

A. Availability of infrastructure

The European Commission set out an initial general framework to guarantee accessibility, quality and financial viability in its Communication on the future of health care and care for the elderly (December 2001)⁸²⁾. Availability is also one of the key issues noted in the Joint Report of the Commission and the

81) OECD (2005), *Long-term care for older people*, OECD, Paris.

82) EUROPEAN COMMISSION (2001), *Communication on "The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability"*, COM (2001) 723 final (5 December 2001).

Council (March 2003)⁸³⁾ and in the open method of coordination on health care and long-term care for the elderly (April and October 2004)⁸⁴⁾.

Long-term care services should be made available at the place where and time at which they are needed, and should meet the specific needs of the client at a cost the client can afford. To achieve this goal, public institutions in some countries pay cash benefits and leave recipients to choose the services that they need. In other countries, recipients can make their own arrangements to meet recognised needs and pay the provider's bill, thereby avoiding misuse of resources by irresponsible recipients. It has often been pointed out in the debate surrounding this issue that practices of this kind are in keeping with the principle of personalisation, but should not relieve the public authorities of their responsibility to make the necessary services available at the place and time that they are needed.

Providing an infrastructure for long-term care services can actually be managed in two completely different ways: as a state responsibility or as a market supply and demand system. If the state takes full responsibility, it removes an economic sector, i.e. the long-term care sector, from the market, and plans a supply of long-term care services which are sufficient in number, available in a timely way and of adequate quality. The market system has different rules: demand and profitability play a part in the provision of long-term care services. A market system may not in practice provide enough long-term care services which are available in a timely way and of adequate quality.

These two fundamentally different solutions are in practice being supplemented by a myriad of transitional solutions. The state can, for instance, assume its responsibilities by surveying what is available in the market and, after pinpointing potential shortcomings in the supply of care services, become a promoter of services or a service provider itself. If the state promotes services by awarding aids, it may well be that European regulations prohibit such aids (see Article 87 of the Treaty). The issue in this case is whether the services provided by the state can be deemed to be "services of general economic interest" (Article 16 of the Treaty).

If the state is responsible for the provision of long-term care infrastructure, a further question is the level at which the state should organise it: the central/national level, the regional level or the municipal level? This tends to be

83) EUROPEAN COMMISSION, COUNCIL (2003), *Joint report on "Supporting national strategies for the future of health care and care for the elderly"*. No 7166/03, SOC 116, ECOFIN 77, SAN 41 (10 March 2003).

84) EUROPEAN COMMISSION (2004), *Communication on "Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the "Open Method of Coordination"*. COM (2004) 304 final (20 April 2004); COUNCIL OF THE EUROPEAN UNION on *Employment, Social Policies, Health and Consumer Affairs* (2004), *Launch of the "Open Method of Coordination"*, 4 October 2004, 12400/04 (Press 264).

shaped by the way in which each Member State organises its administration, which is a constitutional matter for each state.

B. Quality of long-term care services

Some countries have been stepping up their endeavours to promote quality assurance in the field of long-term care, whereas this issue is of little or no importance in other countries. In countries in which the quality of care is a major concern, the main feature of quality assurance strategies is their multiplicity and experimental nature. Such strategies may take account of state-regulated quality requirements, concepts of quality management and regulation by the professions involved. Some countries include consumers, relatives and volunteers in their quality strategies. In all countries, quality strategies in the health (medical) sector are separate from those in the long-term care sector. Despite the many features specific to individual countries, there are international trends:

- introducing quality management systems;
- combining state inspections with internal quality management;
- drawing up quality standards based on professional consensus and a scientific approach;
- comprehensive concepts of quality assurance.

Quality assurance and quality development strategies will in future have to take account of the following issues:

- combining reliability with an open mind for innovation,
- fostering self-regulation under state supervision,
- passing on common quality knowledge,
- integrating the various groups of civil society,
- gaining the acceptance of carers.

Quality rules are usually decided in the country in which the service is provided. These quality rules are primarily structural quality rules (training standards for medical staff, technical standards for goods, *lex artis* rules).

Under the freedom to provide services in Europe, guidelines have been drawn up to allow medical and nursing staff to use the skills obtained in one Member State in another Member State. The quality requirements that such persons must satisfy in their professional activities are nevertheless the quality requirements of the Member States where the activity takes place. Making the quality of service provision subject to the prevailing standards of the location where the service is performed is no longer necessary according to the Proposal for a Directive from the European Commission in relation to services in the internal market (COM (2004) 2 final of 13 January 2004). According to this draft Directive, in order to reduce barriers to the freedom to provide services, the country of origin principle applies when providers are

subject to the law of the country in which they are resident (Article 16(1) of the Directive). The draft Directive sets out general derogations to this principle. Derogations are possible only as regards the authorisation system applicable to the reimbursement of hospital care (Article 17(18)) and, in exceptional circumstances only and on a case-by-case basis, to specific providers exercising a health profession (Article 19(1)(a)). This raises the question of whether long-term care services are regarded as health care services (or services to sick people). This can be assumed from the judgment of the European Court of Justice in the *Molenaar* case, where care services were deemed to be services provided in the case of sickness as regulated by Regulation No 1408/71.

In the long-term care field, service quality also depends on the prevailing quality rules of the location where the service is provided. However, in contrast to health care, people without specific qualifications may work in long-term care. In all the European countries, especially as regards home care, lay persons (family members, neighbours, friends, volunteers) with no specific qualifications and very little training work in long-term care. In these care fields where no or very few skills are required – de facto at least – the issue of potential restrictions of the freedom to provide services because people do not possess the required qualifications becomes irrelevant. It is only in those fields where the legislation of a Member State requires a provider to possess particular qualifications, primarily the case for care in nursing homes, that the freedom to provide services can be considered to be respected by adequate European rules.

Other factors can be taken into account in quality requirements, such as process quality and results. In contrast to medical action, the main feature of long-term care is that it is a continuum of identical activities. The quality of these activities, as well as their results, may differ in different countries for traditional, cultural and social reasons. Local and regional, as well as national, quality standards can therefore be the valid standard. There may be problems if the process quality and the result of a care service is being measured by the standards of the country of origin of the person providing the care and assistance and not of the country in which the person needing care is being provided with the service. As a rule, the prevailing standards of the location where the service is provided need to be respected, especially for care complying with process quality and results. The draft Directive on services does not take account of these particular features of long-term care services.

C. User/consumer status of people needing long-term care: free choice/right to have a say and a choice

Nowadays the rights of users to have a say in and to choose how social benefits are to be provided are accepted in most countries. This is a result of the user's right of self-determination. They are subject, however, to certain

limitations. These limitations may be financial in nature in the case of benefits in kind or cash benefits. In the case of benefits in kind, the limitations may be administrative in nature, especially if they are provided within a planned system.

The choice of providers is not an issue in the case of the supply-and-demand solution. In this case, all providers – public, private, commercial, those pursuing a general interest, voluntary – are entitled to provide services. It may be different when the state or social service providers designate which providers are to provide services. Here, there may be competition between different kinds of providers, not only in terms of service prices but for other reasons as well (cultural, religious, traditional). German long-term care insurance has solved this potential conflict by allowing every service provider fulfilling certain quality standards to provide services for long-term care insurance, with private providers (whether profit-making or non-profit-making) taking priority over public service providers.

People needing long-term care have a need for care and other services which may be decided individually. In contrast to the medical field, where needs are defined by diagnosis and medical practice rules determine how needs are to be met (diagnosis-oriented determination of needs), the service needs of people needing care do not depend solely on diagnosis of the reason for their care need (in terms of the degree of care that they need), but on other factors as well, such as the equipment and location of their home, the willingness of family members or other volunteers to provide care and their financial situation.

Continuing on from the trend towards independence and self-determination in the field of policy for disabled persons (“independent living”), a kind of benefit that takes up the concept of self-determination is being tested in the long-term care field: personal budgets place people needing care in a position where they can themselves decide how the services that they need are to be provided. In Germany, personal budgets of this kind are being piloted among disabled people. Similar pilot projects are planned for people needing long-term care.

D. Inclusion of long-term care strategies in broader themes

1. Long-term care and disability

Many countries have additional benefits for long-term care, which can be added to invalidity pensions and disability benefits. However, disability and long-term care are not necessarily linked in social security schemes despite the fact that, in most cases, needing long-term care can be understood as a disability in the ICF sense. One of the main differences between long-term care strategies and disability policies is the fact that the latter focus primarily on labour-market participation issues. Such issues are irrelevant for most

people needing long-term care – i.e. mainly older people who no longer work. Older disabled people needing long-term care continue to be left out of disability policies. Recent developments (in Germany for instance) nevertheless show that some disability policy objectives, such as preventive measures to avoid disability, are just as useful in the field of long-term care strategies.

2. Long-term care and health

While disability and long-term care needs are primarily health issues⁸⁵, this does not mean that social and environmental factors should be neglected. The preventive measures discussed above are being implemented by players in the health policy field. There are very close links between long-term care needs and needs which are generally covered by sickness insurance schemes such as orthopaedic devices and wheelchairs. The care field includes a wide range of interventions: bodily care, direct care, personal care, nursing care, paramedical and medical care. These terms and the boundaries between them are not clearly and consistently defined in the different countries, which may lead to problems if there is more than one body financing or providing the different kinds of care.

The close links between long-term care needs and health policies/sickness protection, combined with the fact that long-term care among the older population is mostly due to multi-morbidity and chronic illness, may persuade legislators to assimilate long-term care protection with sickness protection and not to set up separate provision bodies and financing schemes. In Europe, however, there is no social security or social services scheme in which long-term care is merged completely with health care. Even in the Netherlands, where long-term care is considered to be a specific sickness need, a distinction is made between general and specific sickness costs. In Germany, where long-term care and health care are strictly separated as regards financing and service provision, it has been proposed to integrate long-term care insurance into sickness insurance.

The European Court of Justice ruled in the Molenaar case with respect to Regulation No 1408/71 that Germany's long-term care insurance benefits in cash (care allowance) are to be considered as sickness cash benefits and can thus be exported. In the new Regulation No 883/2004 long-term care benefits are still not separated from sickness benefits.

The issue is one of whether it is useful in terms of social policy-making to separate long-term care schemes from or integrate them into health care

85) For Integrated care issues, see: VERWEY-JONKER INSTITUUT (Holland), EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH (Austria), DUTCH MINISTRY OF HEALTH, WELFARE AND SPORT (2004), *Integrated care systems: country profiles – responses to questionnaire*. Dutch EU Presidency, Hague Conference, 18-19 November 2004.

schemes. International and European developments show that different solutions are possible. In some cases (United Kingdom, Netherlands) there is partial integration into health care, but nowhere is there complete integration.

3. Long-term care and old age

At first sight, there may be a temptation to equate old age with need of long-term care, given that the risk of long-term care is statistically very high for older people, and the very old in particular. The reason for this is the multi-morbidity from which older people suffer. Long-term care becomes more probable if these people have several interacting conditions at the same time. Nevertheless (very) old age does not automatically mean that people need long-term care.

The link between old age and long-term care is not one which should have an impact on the design of social security schemes (in the same way as on health/sickness and long-term care), but it should have more of an impact on old age policies such as housing, service provision, family recovery, volunteer resources and so on.

4. Long-term care and housing

One of the most important issues raised by long-term care (and disability), over and above care per se, is housing. Housing conditions, fitting out of dwellings and accessibility are more technical aspects of this problem. More social aspects include the integration of appropriate housing in neighbourhoods, service availability and access to emergency-call systems. Some housing concepts, such as sheltered housing, are designed to avoid institutional care. Further development of facilities of this type could well lead to innovative styles of housing where several generations can live together and support one another's care needs.

Part IV: Financial issues

This part looks at the discussions surrounding ways of financing dependence which are taking place in all the European countries: the package of services that should be provided for dependent people, financing agencies, financial constraints and production constraints, financing and decentralisation, and economic tools able to make the players more responsible.

The globalisation of population ageing is providing a backcloth for these discussions. Growing awareness of population ageing led initially to studies of the specific target group of dependent older people or of dependent people of all ages, depending on the country. The retired population as a whole and in particular people taking early retirement were then included. By extension, everyone affected indirectly by ageing, i.e. informal carers, started to be included, which immediately raised the question of the link between women's work and long-term care provided first for children and later for dependent relatives. The lively discussion of this latter issue was largely due to a militant feminist current in public opinion. Discussions have now moved on to an analysis of solidarity between the generations in terms of short-term financial transfers and long-term analyses of these transfers and the links between retirement and dependence.

Solidarity between the generations is perceived as follows by the European Commission⁸⁶):

- giving priority to the integration of young people which is currently becoming problematic,
- promoting active ageing⁸⁷,
- fostering greater solidarity with the very elderly, especially women living alone.

As a result, the financing of long-term care cannot really be separated from employment in the medical and social sector. How can the quality of care be improved if wages and qualifications are low and if the medical and social sector is not sufficiently attractive in terms of jobs to produce enough long-term care to meet demand? It is also becoming difficult to deal with the question of public funding of long-term care without dealing with the question of the split between formal and informal care and the assistance and training to be provided for different types of carers. It is significant, in this context of

86) EUROPEAN COMMISSION (2005), *Green Paper on "Confronting demographic change: a new solidarity between the generations"*. COM (2005) 94 final (16 March 2005).

87) *The European objective is for 50% of the over-55s to be in work; in 2003 only 40.2% of them were actually in work; 5.6% of the 65-74 age-group work in Europe in comparison with 18.5% in the United States.*

globalisation, that the question of the link between retirement pensions and dependence allowances has been raised by the European Commission⁸⁸).

I. Choosing a package of services for dependent older people: financial constraints and macroeconomic trade-offs

There may be three situations depending on the stage reached in public discussion:

- The package of services has been explicitly chosen, and politically endorsed. There is a standard of care for dependent people to which the community adheres because that standard reflects prevailing values.
- Dependent people's needs can then be objectively decided in relation to this standard. If needs can be objectively decided, the package of services to be offered can be defined and the corresponding budgets evaluated. Changes in financing involve actual changes to the package of services. For instance, domestic help is no longer funded in the Netherlands unless dependent people live alone.
- Discussions of the choice of package have not yet come to an end. There is in some ways a democratic deficit. Implicit choices have been made, but their extent and economic repercussions have not really been assessed. Politicians are likely to review some options. Trade-offs are not made as regards the composition of the package and the choice of services financed by the community, but are made for economic reasons. This is true of France. Politicians' uncertainties about the type of services to be provided for dependent people have been reflected by successive changes of benefits⁸⁹) in a debate restricted to a very small number of partners (the General Councils, the National Old-Age Fund and state representatives) and focusing on financing issues. Fortunately, this situation has changed since 2002.
- The Budget Minister or another authority competent in this field has set the amount to be channelled into dependence depending on the financing agency's budgetary constraints and other political considerations in some cases having little to do with an assessment of older people's needs. The budget is broken down into expenditure on possible services either without any direct link to needs assessment or with a subsequently constructed link.

The choice by the community of a package of services is the first stage. Political consensus makes it possible to introduce a long-term care production system and an overall financing system.

88) EUROPEAN COMMISSION (2005), *Green Paper on "Confronting demographic change: a new solidarity between the generations"*. COM (2005) 94 final (16 March 2005), p. 10.

89) *The experimental dependency benefit was replaced by the PSD (specific dependency benefit) and then by the APA (personal independence allowance).*

II. Production constraints

Constraints connected with the production of services are being greatly underestimated and logistical problems disregarded even though they are extensive. Long-term care production requires enough staff with suitable qualifications, whether for care of people suffering from mental disorders, for the organisation of the mobility of people suffering from multiple disabilities, for efficient coordination of the organisation of home care or for the structuring of care strands. The current demand for long-term care is an increasingly personal and individual demand.

From the point of view of organising long-term care production, the corollary to this is readily evident. The adaptability expected of home carers is very substantial: they must be able to adapt to different visiting times, the different types of disorders that they encounter and different types of relationships with older people and their families involved in the care relationship. There is a need for staff who are trained appropriately to deal with these relationships, which may prove very difficult when older people are mentally deteriorating. There is a further need, however, for staff trained to coordinate carers and to match the care system with current requirements.

Qualification takes time and depends on an existing body of trainers. If enough staff are to be available, the occupation has to be attractive (adequate wages, status and social protection). These requirements are set to become major constraints if the anticipated growth in the volume of long-term care mirrors demographic developments. In other words, the demography of health and social occupations does not necessarily mirror (far from it) general demographic trends and the tendency towards population ageing. Unless the gap between these two trends is closed by the market or the Welfare State, it is highly likely that the supply will be inadequate. The introduction of the 35-hour week in France highlighted the severe shortage of nursing staff and care workers in both hospitals and care homes for the elderly in comparison with the current, and future, demand for care.

Production constraints are to be found at another level: public mass production. In practice, the long-term care produced in the public sector reflects the choices of the community. The public authorities have to set minimum standards which may prove financially untenable if production grows substantially. As a result, the trend is towards a levelling off or even a decline in the proportion of care produced in the public sector.

Shifting a proportion of long-term care production into the open market goes some way towards resolving this situation. It also helps to diversify the supply of long-term care. Families currently want to have greater margins of manoeuvre in terms both of the choice of service providers and the types of services available (day care, respite for carers, etc.). From the point of view of service providers, the whole issue is about the emergence of a demand

backed by purchasing power, i.e. the market offers services that individuals want to buy as such. Older people may be provided with this purchasing power if they receive cash benefits enabling them to buy their services themselves; however, they may also find services in the market for which there is a direct demand irrespective of any benefits for which they may be eligible.

III. Financing agencies

A. Estimating the various contributions

In some countries an overall estimate of the contribution of the various financing agencies to short- and long-term care is generally available, but does not always separate out long-term care. In the Netherlands, for instance, 42% of health and social care is funded by basic social protection (AWBZ), 36% by complementary public social protection, 15% by private insurers and 7% by individuals⁹⁰).

While, as discussed in Part I of this report, there are comparable estimates of public contributions at European level, there are no detailed comparative studies of private contributions.

B. Public funding methods

There are two linked questions here: is it better for the central state or local authorities to fund dependence; and is it better for funding to come from social security or social welfare?

In all the Member States, long-term care is financed from a public source. This may be the central state, local authorities (region, département or municipality) or any combination of the two. The municipality has been chosen by many European countries because often it is the institution to which groups of people with problems naturally turn.

Discussions have generally focused on the alternative of a fifth risk administered by social security or social welfare managed by the state and/or local authorities. Partisans of the fifth risk point out that coverage can be wider, more equitable from region to region and that the system can be more readily regulated by a single overall system. Partisans of a social-welfare type solution stress the proximity of populations and administrative players. This debate has evolved over the last 15 years. The Welfare State in European countries is based more on individual social protection, from two points of view. The aim is both to tune benefits more finely to people's situations (on a

90) VISSER-JANSEN G., KNIPSCHEER C.P.M. (2004), *Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage*. EUROFAMCARE, National Background Report for the Netherlands, Vrije Universiteit Amsterdam, p. 58. This report is available from: <http://www.uke.uni-hamburg.de/extern/eurofamcare/nabares/>

case-by-case basis) and at the same time to bring contributions closer to benefits, taking a more insurance-based approach. The less social protection is developed, the less public opinion knows about costs and risks, since citizens contribute to collective solidarity in an overall way and, to some extent, "blind". However, when compulsory levies reach high levels (in particular the notorious barrier of 50% of GDP), and when there is greater awareness of these risks and their financial implications, citizens call for their contributions to be brought into line with the benefits that they receive. Social protection models are then geared more to the individual, from the point of view of both services and contributions.

C. Trends in the various contributions

The trend is towards a relative decrease in the state contribution, although it is not envisaged that this contribution will be entirely eliminated and replaced by a fully private system. There are few historical data on this contribution in the various countries. This leads to larger direct payments and to transfers of a proportion of long-term care to local authorities with a view to finding a better match between supply and demand. In the *Netherlands*, the provinces are currently responsible for supporting family carers, a situation that might rapidly lead to regional differences in this type of support, which is no longer compulsory. In *France*, the introduction of the specific dependence benefit revealed that the départements' generosity varied on a scale of 1 to 10, causing the government to return to the idea of a national tariff.

The "completely private" solution has not been taken up in Europe because little is known about the way in which this risk may evolve in the long term and because there are uncertainties about numbers of dependent older people. Private insurers are taking a cautious approach to coverage of this risk.

IV. Financial constraints and cost containment

Is the financing of dependence connected with the macroeconomic situation? Expenditure by the EU Member States on dependence as a proportion of GDP varies from 0.5% to 3%. Those countries which have spent the most have done so thus far without major macroeconomic problems, making this into a relative financial constraint.

However, all the countries are now faced with the question of cost containment. The issue is one of finding out how to produce long-term care at the lowest cost and the highest quality. Which system is likely to enable the resources that the municipality has committed to cope with the problem of dependence to be allocated in the best possible way? This raises various questions: is it public or private providers which produce at the lowest cost and the highest quality? Is competition between providers desirable? If it is, how should it be implemented: by giving older people the option to choose

freely between service providers or by making a care manager or an administrative officer responsible for purchasing services on behalf of older people at the best price/quality ratio? Care managers⁹¹⁾ may have a number of functions: assessing and choosing between services and setting up packages of services to meet the needs of older people, purchasing services at the best price, and managing the care relationship in the long term. The economic dimension of their work cannot be disregarded.

Major privatisation has taken place in the Swedish system since the 1980s. Some services, produced up to then by the public sector, have been transferred to the private sector, i.e. to companies, cooperatives or non-profit-making organisations. Financing and administrative supervision are still a public responsibility. The picture that G.-B. TRYDEGARD⁹²⁾ gives of this privatisation is mixed. Growth is chiefly due to profit-making companies, with non-profit-making bodies playing little part and occupying a static position. There is nothing to say that competition brings about a reduction of prices in the private sector. Consumers can in theory choose between a number of producers, but in practice they do not always make a real choice based on clear information. Purchases of private services paid for directly by older people have increased. In other words, this privatisation suits municipalities and politicians as they are no longer directly responsible for managing a proportion of long-term care production and merely have financing and supervisory tasks. Whether or not the market is a better option remains to be seen, however, as too little information is available for a full and satisfactory evaluation.

Cost containment can take place at two levels: direct management by institutions and services and monitoring by a supervisory authority (whether municipalities or départements). In the case of supervisory control, there is currently a lack of balance, as the most sophisticated checks are on institutions, while most of the population lives at home. Moreover, medical and social institutions and services have not always, for cultural and historic reasons, managed their facilities in a sound way because managers have had

91) For an overview of the British-style care manager, *see*: MEANS R., RICHARDS S., SMITH R. (2003), *Community Care. Policy and Practice*, Palgrave Macmillan UK, Third Edition, p. 48. For an overview of the Japanese-style care manager and Japanese dependency insurance, *see*: HIRAOKA K., *Long-term care insurance in Japan*. in YOON H., HENDRICKS J. (Coord.), *Handbook of Asians Ageing*, Baywood Publishing; IGUCHI N., *Establishment of long-term care insurance schemes in Japan*. Ministry of Health and Welfare, Health and Welfare Bureau for the Elderly, Japan; KERSCHEN N. (2005), *L'assurance soins de longue durée au Japon. Comparaison avec des systèmes européens*. Actes du Colloque franco-japonais sur "Longévité et politiques publiques", Université Nancy II, 18 et 19 octobre 2004. TOKYO METROPOLITAN GOVERNMENT (2000), *Long-term care insurance system. Supporting nursing care through society*. *See also* Website: <http://www.kaigohoken.metro.tokyo.jp>; VOLLMER R.J. (2003), *Die "nahtlose" Pflege als Leitmotiv der japanischen Pflegeversicherung in Im Dienste der Sache. Liber amicorum für Joachim Gaertner*. Peter Lang (Ed.), p. 695.

92) TRYDEGARD G.-B. (2005), *Elderly care in Sweden - a public or private affair*, Presentation at the AFSR Social Science Workshop on the Ageing Society, 7-8 April 2005, Stockholm.

little financial training and have often been doctors or social workers charged with managing facilities. Management tools that are in keeping with the particular nature of this sector are also needed. Economic management tools cannot be directly imported as they have to be adapted. The importance that long-term care is assuming and the financial issues that it raises are now exerting major pressures on this sector which is being forced to find rigorous and apposite management tools.

V. Changing the behaviour of long-term care beneficiaries: economic incentives?

From the point of view of a diagnosis of dependence care systems, the EU Member States are well aware of the need to allocate scarce resources in the best possible way, especially when needs are increasing. The purpose of the regulatory mechanisms that have been introduced is to economise on resources and promote quality. Regulation may take place in a macroeconomic and budgetary way. The amount of the budget is set by the public authorities, and the players in the field work with this amount and make the necessary trade-offs.

Regulation may take place at a macroeconomic level, in the form of trying to change the behaviour of the players by introducing economic incentives likely to make them adopt different and more economic practices. These direct tools, intended to change practices among older people, their families or carers, include means-testing, the choice between benefits in cash or in kind, recovery from estates and maintenance obligations. Situations differ substantially.

It is currently very difficult to assess the long-term effect of these incentives, as statistics are not available, or to evaluate the implementation of these various economic incentives. The OECD report nevertheless shows that where public contributions are low, means-tested benefits predominate.

**Table 1: Means-testing in the main public programmes covering long-term care in Europe – 2003
(OECD - Long-term care for older people, OECD 2005)**

	Type of care		Type of benefits	Means-tested	Private cost-sharing
Germany	Institutional care	Social long-term care insurance	In kind	No	Board and lodging is not covered
	Home care	Social long-term care insurance	In kind and cash	No	No cost-sharing required but beneficiaries must pay for additional services or services that are more expensive than those covered by public insurance
Austria	Institutional care	Long term allowance	Cash	No	Users are expected to pay the difference between the allowance and the actual cost
	Home care	Long term allowance	Cash	No	Users are expected to pay the difference between the allowance and the actual cost
Spain	Institutional and home care	Social care programmes at Autonomous Community level	In kind	Yes	73% of the total cost of long-term care was met privately in 1998 according to an estimate
Hungary	Home and institutional care	Social protection and social care provision programme	In kind and cash	Yes	Users' payments are set by the institution within the range set by local authorities
	Home and institutional care	Services financed by the health care insurance fund	In kind	No	"Basic quality" services are free of charge. Beneficiaries have to pay for "higher quality" services.

	Type of care		Type of benefits	Means-tested	Private cost-sharing
Ireland	Institutional care	Nursing Home Subvention Scheme and public long-term care	In kind	Yes	Maximum of 26000 per year on average in nursing homes; maximum of 80% of the non-contributory old-age pension in public long-term care
	Home care	Community-based Care	In kind	Yes, partly	Only entitlement to a home help is means-tested
Luxembourg	Institutional and home care	Dependence Insurance	In kind and cash	No	Users are expected to pay the difference between benefits and actual cost
Netherlands	Institutional care	AWBZ	In kind	No	Income-related co-payments are required
	Home care	AWBZ	In cash	No	Income-related co-payments are required
Poland	Institutional and home care	Social services	Cash and in kind	Yes	
United Kingdom	Institutional and home care	NHS	In kind	No	Free of charge
	Institutional and home care	Social services	In kind	Yes	Users are charged according to their ability to pay
	Home care (cash)	Social Security Benefits	In cash	Yes	
Sweden	Institutional and home care	Public long-term care	In kind	No	Users pay a moderate amount of fees set by local authorities

Part V: Basic Choices

If adequate responses are to be found to the problem of protection for older people needing long-term care, some *basic choices* have to be made:

I. Division of responsibility between the public and the private

Is the task of providing long-term care protection chiefly a public or chiefly a private task or is it a joint task? This question has to be seen in the context of the further development and structuring of the Welfare State in the various Member States.

If there is a private/public division, can public responsibility for long-term care be organised within existing social protection schemes or should there be new schemes (as, for instance, in Luxembourg or Germany)? Should there be a uniform public protection scheme or is public responsibility split between different bodies at different levels (for instance, local authorities, national social security bodies)?

What does private responsibility mean with respect to:

- the own resources of the person needing care,
- the financial resources of that person's family,
- the working resources of that family,
- the work of volunteers?

The public/private division plays a key role in all the other issues raised by long-term care: who is eligible for public care and to what extent, and where can the line be drawn between public and private provision as regards:

- level of need,
- type of care, i.e. home or nursing care,
- the income/assets of the person needing care,
- the duration of the need?

II. Social Protection

How can older people be provided with a high and sustainable level of long-term care protection? How can they be given adequate purchasing power while containing costs? Should social protection not be reviewed to include coverage of care? Is voluntary private insurance the answer or should compulsory social insurance be systematically developed? Which social protection systems help dependent older people to become more independent? How can the free choice and preferences of dependent older people – and their carers – be ensured, and in which areas (home versus institutional care, benefits in kind versus benefits in cash)?

III. Support for informal care

There is currently a gap between what is being said about support for informal carers in many European countries and the support that they actually receive.

Support for informal carers raises a number of questions:

- Would the demand for support for carers not tend to disappear if long-term care were sufficiently developed?
- Should assistance not be given as a priority to dependent older people?
- To which types of carer should priority be given for assistance: people caring for relatives suffering from mental disorders, people caring for highly dependent older people or all carers?
- When is an informal carer eligible for public support?

To what type of measures for carers should priority be given:

- recognising their situation as carers, i.e. anything which helps to give them a status (for instance giving them an opportunity to take a holiday or providing them with pension rights);
- psychological support for carers in distress (support groups within institutions, support for family and carers' associations);
- logistical support for the organisation of long-term care at home and crisis management throughout the care period;
- organisation of respite care (temporary accommodation or day care for dependent people);
- immediate financial support (payment of an allowance by dependent people to their main informal carers, informal carers paid a wage or an allowance by the municipality).

This also raises the question of whether action for carers should come from the community or via associations, institutions and services.

IV. Labour market, women's employment and long-term care

Long-term care can be perceived in two ways: as a brake on any increase in the employment rate among women acting as "informal carers" within the family; or as a prime mover of new (high-quality) job creation as care becomes more professional.

Can we achieve the European objective of increasing the female employment rate (Lisbon target of a European Union average of 60% in 2010) and, at the same time, meet the growing need for long-term care within the family? Can public equal opportunity policies be designed with a view to sharing long-term care more equitably between women and men?

How can long-term care be taken into account in policies at enterprise level? Does long-term care for older people differ from care for children? Does its

unpredictable and changing nature require more flexible working conditions so that women and men can reconcile work and family life and retain a foothold in the labour market (implementation of the European Employment Guidelines)?

How can professional services be developed in this potentially job-creating sector? How can equality between men and women be ensured in formal care? How can high-quality jobs be ensured?

V. Accessibility of long-term care benefits

Under what conditions can equal access to long-term care benefits be ensured in terms of local and timely availability and decent quality?

VI. User/consumer status

Users find it difficult to make their voices heard in many European countries, partly as a result of ageism in public opinion. Qualitative studies show that dependent older people, their families and professionals have different perceptions of the quality of care, and rank needs in different ways. Users are especially unlikely to make their views known if they are in a precarious situation where their relationship of dependence with their carers could deteriorate and end in maltreatment.

How can users make their voices heard? Which social systems promote the autonomy of older people needing long-term care and improve their quality of life? Is this chiefly by giving them the freedom to finance their own long-term care?

How can the free movement of dependent older people within the European Union be promoted? How can they be provided with high-quality coverage wherever they are?

VII. Quality of long-term care and its assessment

Quality can be measured by resource indicators or result indicators. Quality may also be improved, however, through a procedure in which the actors of care construct their own concept of quality and their own measurement of quality.

How can the quality of long-term care be increased? By actively promoting quality measurement methods at governmental level, among care producers or among care consumers/users?

Evaluation is a very important issue, as it has been very inadequately developed at European level. The ease with which public opinion considers that informal long-term care can be replaced by formal care, and that this is therefore a simple task, goes some way towards explaining the lack of evaluation of long-term care.

Should independent private evaluation agencies be promoted in the medical and social sector? Should institutions and services (public, voluntary or private) be supervised by the authorities? What factors need to be taken into account in the evaluation of long-term care at home, bearing in mind the frailty of the people involved (evaluation in care institutions being more sophisticated than evaluation of home care services).

VIII. Cost containment

Costs can be contained in a number of ways:

Is it advisable to draw up national packages or set an annual rate of growth of the costs of long-term care and then to pass on any shortfall in resources to the local budget level? Do local authorities need to be made more responsible? Do limits need to be set on collective action (restriction of the number of accommodation places and definition of a minimum service package for care at home) and any further demand left to the market or informal care? Should a public insurance system be made responsible for the costs of cost containment?

IX. Major challenges

Long-term care policies face two main challenges:

- do preventive and rehabilitative measures play a part in preventing or delaying the need for long-term care and what are their effects?
- how can we provide care for the growing proportion of people with dementia?

Annexes

I. Annex 1. The main aspects of the “open method of coordination” as applied to health care and long-term care (1997 – 2005)

In the late 1990s, the Europe of 15 introduced a new method in the social protection field, initially called the “concerted strategy” and then the “open method of coordination”. The aim is to meet challenges together, at Community level, by setting common objectives in order to adapt social systems and enable them to progress “harmoniously” while allowing different national systems to coexist. This convergence process started in 1997 and is still continuing today.

Since 1997, the Commission has been fostering overall thinking about the future of social protection in order to “modernise and improve social protection in the European Union”⁹³). One of the focuses of this thinking has been the question of adapting social protection to demographic ageing by meeting the care needs of older people through the development of professional services and social protection systems likely to promote their independence. Adapting social protection to the new balance between the sexes brought about by the massive influx of women into the labour market has been another focus. A further aim here has been to help women having to work as “informal carers” in the family to retain a foothold in the labour market through measures to reconcile work and family life.

1999 saw the introduction of the concerted strategy to modernise social protection, whose objective was to encourage and support, through Community action, the reform efforts being made by states within the framework of their national priorities⁹⁴). The issue of long-term care for older people was briefly addressed under the objective entitled “ensuring high quality and sustainability of health protection” from two points of view: providing appropriate care facilities and reviewing social protection cover of care and carers. Since then, long-term care for older people has been included in a specific “care” strategy, i.e. health care and care for older people. This specific strategy was launched in 2000/01.

In March 2000, the Lisbon European Council introduced the “open method of coordination” in the social protection field and, in June 2001, the Gothenburg European Council asked the Council to draw up an initial report on policy on health care and care for older people for the European Council in spring 2002. The Commission set the European debate in motion in December 2001 by

93) *Communication from the Commission of 12 March 1997, “Modernising and improving social protection in the European Union”, COM (1997) 102 final.*

94) *EUROPEAN COMMISSION (1999), Communication on “A concerted strategy to modernise social protection”, COM (1999) 347 final (14 July 1999).*

proposing common objectives to be simultaneously achieved in the 15 Member States and the candidate countries: universal access to care, high-quality care provision and the financial viability of systems. To achieve these objectives, cooperation by all the players of the health system – public authorities, health care professionals, social protection bodies, supplementary insurance companies, consumers and their representatives – is felt to be essential.

In this Communication⁹⁵⁾, the Commission sets out two main principles:

- “organising and funding social security systems is the responsibility of the Member States” (p. 9);
- “access to health care is a fundamental right” guaranteed by the European Union’s Charter of Fundamental Rights (p. 10).

Thereafter, the Council submitted a preliminary guidance report to the Barcelona European Council in March 2003. The Commission and the Council were invited to look in depth at the issues of accessibility, quality and financial viability, taking account of the principles of solidarity, fairness and universal access. A questionnaire, drawn up by the Social Protection Committee together with the Economic Policy Committee, was sent to the Member States for that purpose. This questionnaire dealt separately with health care and care for the elderly, objective by objective.

The replies from the Member States were analysed in a joint report by the Commission and Council. This report, published in March 2003, reviews the systems in place and identifies common challenges and changes to be made in the future⁹⁶⁾. It also states that a “process of mutual learning and cooperative exchange should be continued on the basis of the issues identified in the joint report” (p. 30).

On the basis of this joint report, the Commission proposed common objectives in April 2004 to support the development of systems in the enlarged union through the application of the “open method of coordination”⁹⁷⁾.

95) EUROPEAN COMMISSION (2001), *Communication on “The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability”*, COM (2001) 723 final (5 December 2001).

96) EUROPEAN COMMISSION, COUNCIL (2003), *Joint report on “Supporting national strategies for the future of health care and care for the elderly”*. No 7166/03, SOC 116, ECOFIN 77, SAN 41 (10 March 2003).

97) EUROPEAN COMMISSION (2004), *Communication on “Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the ‘Open Method of Coordination’”*. COM (2004) 304 final (20 April 2004).

There are three objectives:

- Objective 1 – Ensuring access to high-quality care based on the principles of universal access, fairness and solidarity. Providing a safety net against poverty or social exclusion associated with ill health, accident, disability or old age for both the beneficiaries of care and their families.
- Objective 2 – Promoting high-quality care in order to improve people's state of health and quality of life.
- Objective 3 – Ensuring the long-term financial sustainability of high-quality care accessible to all.

On 4 October 2004 the Council followed the Commission and decided to introduce, in a progressive and flexible way, the open method of coordination in health care and long-term care⁹⁸⁾. The coordination of national policies in this field is thus to complement the Community processes underway in the area of pensions, social inclusion and "making work pay". The Member States are to present national reports covering the challenges facing their health care systems, current reforms and medium-term policy by spring 2005⁹⁹⁾. The Conference (organised by the Luxembourg Presidency) for which this report has been prepared is taking place at this important juncture when the open method of coordination is to be implemented.

98) COUNCIL OF THE EUROPEAN UNION on Employment, Social Policies, Health and Consumer Affairs (2004), Launch of the "Open Method of Coordination", 4 October 2004, 12400/04 (Press 264).

99) *These national reports are to be analysed by the Commission. Member States' opinions and contributions will be taken into account when setting "common objectives" for the "streamlined" social protection process. This streamlining will lead in 2006 to a first set of "development and reform strategies" for health care and long-term care for the period 2006-2009. The conclusions of the review of these strategies are to be presented in the 2007 joint report on social protection and social inclusion.*

II. Annex 2. OECD Glossary - Study on “Long-term care for older people” as one of the components of the Health Project¹⁰⁰ (2005)

Activities of daily living, ADLs *Activities of daily living* refers to the Katz ADL Scale, which describes self-care activities that a person must perform every day, such as eating, dressing, bathing, transferring between the bed and a chair, using the toilet, controlling bladder and bowel.

Allowances *Allowances, cash allowances and cash benefits* are all payments that may be either liable for income taxation or exempt from income taxation.

Care Frequently used in the study as synonym for long-term care

Consumer direction The term *consumer direction* refers to arrangements whereby public programmes enable persons needing care or their families to act as employers of care assistants.

Dependent See: Disabled, or dependent person

Disabled, or dependent older persons Older persons whose overall level of functioning is substantially reduced, such that they are likely to require help from a third party, or substantial help from aids and adaptations, in order to fulfil the normal activities of daily life.

Formal long-term care services Long-term care services supplied by the employees of any organisation, in either the public or private sector, including care provided in institutions like nursing homes, as well as care provided to persons living at home by either professionally trained care assistants, such as nurses, or untrained care assistants.

Home care Used here as synonym for long-term care provided to patients at home. This includes day-care and respite services and the like. Includes long-term care received in home-like settings, like assisted living facilities, although statistical systems are in many cases not able to identify these.

IADLs Instrumental activities of daily living (Lawton IADL Scale). Activities that enable a person to live independently in a house or apartment, such as preparing meals, performing housework, taking drugs, going on errands, managing finances, using a telephone.

Informal 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, usually but not

¹⁰⁰ OECD (2005), *Long-term care for older people*, OECD, Paris.

necessarily with an already existing social relationship with the person to whom they provide care. Informal care is usually provided in the community and is typically unpaid.

Informal carer (informal care-giver) See: informal care. A synonym in the study is *informal care-giver*.

Institutional care Long-term care provided in an institution which at the same time serves as residence to the care recipient.

Note: institutional care should be distinguished from short-term care received in institutions such as *respite care*.

Long-term care The terms *long-term care* and *care* are often used interchangeably in this study. Individuals need long-term care when dependent for an extended period of time 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 (see above for definition).

Long-term care institutions *Long-term care institutions* are places of collective living where care and accommodation are provided as a package by a public agency, non-profit or private company. Residents may or may not be charged separately for care services and accommodation.

Long-term care services See: Long-term care

Older persons All those aged 65 or over

Nursing home/Nursing-home care Used in this study as synonym for long-term care institution providing nursing and personal care to persons with ADL restrictions.

Private home Personal residence not intended specifically for people with care needs

Respite care Persons who live outside an institution may at times go to an institution for short-term respite care. Respite care is a short-term care arrangement with the primary purpose of giving the carer a short-term break from their usual care commitments.

Social care Assistance with the normal activities of daily life, including personal functioning, domestic maintenance and social activities given on a continuing basis to individuals with chronic impairments and/or a reduced degree of independence in instrumental activities of daily living (IADL).

Social services See: Social care

III. Annex 3. Data from Luxembourg (2004): Beneficiaries of long-term care insurance by type of¹⁰¹⁾ residence

Beneficiaries by gender and type of residence

	Home care	Residential care	Total
Gender	%	%	%
Women	62.3	79.1	68.7
Men	37.7	20.9	31.3
Total	100	100	100

Beneficiaries aged 70 and over by type of residence

	Home care	Residential care	Total
	%	%	%
90-109	33.0	67.0	100
80-89	48.5	51.5	100
70-79	65.5	34.5	100
Population aged 70 and over	52.0	48.0	100

Main causes of dependence – Distribution of beneficiaries by type of residence and diagnosis - All beneficiaries

Pathology causing dependence	Residential care	Home care	Total
	%	%	%
Group 1. Dementia and other cognitive disorders	67	33	100
Group 4. Diseases of the nervous system	28	72	100
Group 6. Diseases of the osteoarticular system	33	67	100
TOTAL of the 10 Groups	38	62	100

101) IGSS (2004), Rapport général de la Sécurité Sociale au Grand-Duché de Luxembourg 2003. Chapitre 2. Assurance-dépendance. Ministère de la Sécurité sociale, Luxembourg.

IV. Annex 4. Some information on maintenance obligations

This Annex presents some information on maintenance obligations in a historical and comparative view:

1. French Civil Code, called also « Code Napoléon » from 1804
2. Austrian Civil Code from 1811
3. Maintenance of relatives in the Hungarian family act
4. Other examples of legislation on maintenance obligations in CEEC

1. French Civil Code, called also « Code Napoléon » from 1804

The French Civil Code may be considered as a “Code for Europe”¹⁰². On account of the matured legislative situation and its advanced content, it had been widespread in Western Europe. It had an influence on law in France, Germany, Northern Italy (at the time called Italian Kingdom), temporarily in the Western provinces of Austria (East Tyrol, Upper Carinthia and Carniola), and also in the Netherlands, Belgium, Luxembourg and several other states such as Spain, Romania, etc.

Today, rules of French Civil Code continue to play a certain role in legislations in different countries in Europe (for instance, Belgium, Luxembourg, the Netherlands). Maintenance obligations are among these rules.

French Civil Code - Maintenance Obligations

(official English translation - <http://www.legifrance.gouv.fr>)

Book 1. Of persons. - Title 5. Of Marriage

Chapter V. Of the obligations arising from marriage.

Article 203. The spouses contract together, by the sole fact of marriage, the obligation of feeding, supporting and educating their children.

Article 204. A child has no claim against his father and mother for a settlement in view of marriage or otherwise.

Article 205. Children owe maintenance to their father and mother or other ascendants who are in need (amended in 1972).

Article 206. Sons – and daughters in law owe likewise and under the same circumstances, maintenance to their father- and mother in law, but this obligation ceases where the spouse owing to whom the affinity existed and the children born of his or her union with the other spouse are dead (amended in 1919).

¹⁰²) http://www.thucydide.com/realisations/comprendre/code_napoleon/code0.htm;
<http://www.herodote.net/histoire03212.htm>

Article 207. The obligations resulting from these provisions are reciprocal. Nevertheless, where the creditor has failed seriously to fulfill his obligation towards the debtor, the judge may discharge the latter from all or part of the maintenance obligations (amended in 1972)

Article 208. Maintenance shall be granted only in proportion to the needs of the one who claims it and to the wealth of the one who owes it.

The judge may, even of his own motion and according to the circumstances of the case, couple the periodical payments with a revision clause permitted by the law in force (amended in 1972).

Article 209. Where the one who provides or the one who receives maintenance is placed again in such a condition that the one can no longer give it, or the other is no longer in need of it, a discharge or reduction of it may be applied for.

Article 210. Where the person who must provide maintenance establishes that he cannot make periodical payments, the family causes judge may, with full knowledge of the facts, order that he shall receive in his home, feed and maintain the one to whom he owes maintenance.

Article 211. The family causes judge may also decide whether the father or the mother who will offer to receive, feed and maintain in his or her home the child to which he or she owes maintenance should in that case be exempted from periodical payments.

2. Austrian Civil Code from 1811

The Austrian Civil Code from 1811 was called „Allgemeines Bürgerliches Gesetzbuch für die Gesamten Deutschen Erbländer der Österreichischen Monarchie (ABGB)“.

The aim of the codification of private law was to create uniform private law within the entire Austrian-Hungarian Monarchy. The ultimate aim was to apply the same law in the entire territory of the Monarchy.

The ABGB was created between 1753 and 1811. A separate Marriage patent (act) was passed on matrimonial issues in 1783, which replaced the previous ecclesiastical marriage law with state marriage law. This act was integrated by the Austrian ABGB. At the time of creation, Austria and France were at war; therefore the French Code Civil had hardly any effect on ABGB. The ABGB exerted considerable influence on the states of the Monarchy and also on the Moldavian Principality, Montenegro, Liechtenstein and on the German-speaking cantons of Switzerland.

Obligation of spouses

Section 89 of ABGB states that the rights and obligations of spouses ensue

1. from the act
2. from the marriage contract.

The personal rights of spouses are regulated by the act, while the property rights are provided for in the marriage contract.

The mutual obligations of spouses include (Section 90) that both parties are under the obligation of proper treatment.

The ABGB states that the husband is the head of the family. The husband's obligation is to maintain his wife properly in accordance with his wealth (Section 91).

In judicial practice it ensues from the nature of maintenance that it is usually provided in kind (care).

Pursuant to Section 91 of ABGB only the husband is under the obligation of maintenance and there is no statutory regulation according to which the maintenance obligation would devolve upon the father-in-law due to the husband's lack of property.

In spite of the husband knowing that he is marrying a sick woman, he will be under the obligation of maintenance until the marriage is annulled.

Obligation of parents

The parents are obliged to rear and properly maintain their legitimate children. They are obliged to provide for their life and health, to give them moral strength and to develop their physical and mental talents (Section 139 of ABGB). This maintenance obligation does not apply to stepfathers and foster-fathers.

Judicial practice states that the parent is obliged to maintain a child of age only in the case of the child's loss of earning capacity. With respect to ascertaining maintenance it is of no importance whether the child of age has earnings.

It is primarily the father's obligation to provide for the children until they are able to provide for themselves. The mother is mostly responsible for physical care and for care related to health (Section 141 of ABGB). This obligation will devolve upon the mother only if the father dies or is unable to provide maintenance.

If the father has no property, the maintenance obligation devolves upon the mother. If neither of them has property, the maintenance obligation devolves first upon the paternal, then upon the maternal grandparents.

The maintenance obligation of the parent and grandparent depends on the ability or inability to maintain. At the same time the maintenance obligation for

each other is an independent legal obligation. The maintenance obligation of both the parent and the grandparent is based on blood relationship and mutual obligation. The child or the grandchild is obliged to maintain their parents and their grandparents if they are in need of maintenance and if the child or grandchild is capable of this.

It is a general legal practice that no compensation is due to the grandfather for maintenance as the given maintenance can be considered as a gift based on blood relationship with the grandchild.

The sum spent on rearing the child cannot be deducted from the child(ren)'s wealth acquired later. However, if the parents live in destitution, the children are obliged to maintain them properly (Section 154 of ABGB). The maintenance obligation does not apply to children born out of wedlock.

The maintenance obligation imposed on the child – usually – lasts only until the end of his or her life. After their death maintenance can be claimed only from another living person (relative) and not from the child's bequest.

If the needy parent has two or more children, both or all of them are under the maintenance obligation. The parent can choose which child should provide maintenance in kind (care). The maintenance obligation has to be shared so that each child will be responsible for the corresponding part of the sum of maintenance, but the obligation of several children can also be shared in such a way that the children take turns in providing maintenance. If only one child provides maintenance, he or she can claim that the others pay their share from maintenance.

If more children are obliged to provide maintenance but maintenance can be provided only at one of them, the other sibling's maintenance shall be paid in kind (care) to the sibling who actually provides maintenance.

The parent's maintenance claim means maintenance in kind (care) and medical treatment under the same consideration.

Children are obliged to maintain only parents actually living in destitution.

The child is obliged to provide primarily maintenance in kind (care). If the parent refuses maintenance in kind (care), maintenance in cash cannot be claimed from the child.

3. Maintenance of relatives in the Hungarian family act (Act N° IV. 52)

Pursuant to modern civil codes, the maintenance obligation applied for the most part only to lineal relatives (for example, the sibling or the step-parent did not have a maintenance obligation).

In Hungary Saint Stephen's laws prescribed the maintenance obligation of parents with respect to their underage children, while Werboczy's Tripartitum

(law-book) mentioned the mutual maintenance obligation of blood-relations in several places.

Underlying principles of the maintenance of relatives

The effective Hungarian family law recognizes multiple maintenance obligations:

- a) the maintenance obligation of parents with respect to their children, including adopted children (maintenance of children);
- b) the maintenance obligation of grandparents with respect to their grandchildren (maintenance of grandchildren);
- c) maintenance of parents and grandparents;
- d) maintenance of the spouse;
- e) in exceptional cases, maintenance of a sibling or step-child.

Exactly the same mutual maintenance obligation applies to a child born out of wedlock and his or her ancestors as to cases of maintenance based on family relationships.

There is no maintenance obligation in the case of relations by marriage and between partners in co-habitation.

Conditions of the maintenance of relatives

The person who cannot maintain himself or herself and who has no spouse under maintenance obligation is entitled to maintenance by relatives. The person of age whose conduct is unworthy is not entitled to maintenance. The child usually cannot refer to the parent's unworthiness if the parent has fulfilled his or her obligations of maintenance, care and education (Section 60 of the Family Act).

Based on the system of the Family Act, the maintenance of relatives invariably has four conditions:

- a) the need of the entitled person,
- b) the entitled person has no spouse who could be obliged to provide maintenance,
- c) the entitled person is not unworthy of maintenance,
- d) he or she has a relative who is capable of maintenance and can be obliged to provide it. Those persons can be obliged to provide maintenance whose own maintenance is not endangered by having to maintain another person. The maintenance of a child is an exception as in this case the parent's own maintenance can be endangered.

Order of the maintenance of relatives

Underlying principles

It is primarily the spouse, who is obliged to provide maintenance for the person entitled to maintenance. In the absence of a spouse, the descendants are obliged to provide maintenance. If there are no descendants who could be obliged, the maintenance obligation applies to the relatives in the ascending line. The relative who is closer to the person entitled to maintenance – with respect to the maintenance obligation – precedes more distant relatives. If the person has no lineal relatives who could be obliged to provide maintenance, his or her brother or sister of age is obliged to provide maintenance if this does not endanger his or her own maintenance or the maintenance of his or her family (Section 61 of the Family Act).

The following cases may be encountered as to the relationship between the persons entitled to maintenance and persons obliged to provide maintenance:

a) there is one obliged and more entitled persons

If there are more persons entitled to maintenance and the person obliged is unable to provide maintenance for all of them, the following order is specified by law:

- the child and the parent precede the other relatives
- the descendant precedes the ancestor
- the closer relative precedes the more distant relative
- the child precedes the spouse (divorced spouse)
- the spouse (divorced spouse) precedes the other relatives.

b) there are several obliged and one (or more) entitled persons

The maintenance obligation is shared by several, simultaneously obliged persons in proportion to their earnings, income, assets and ability to perform. The personal care provided to the entitled person has to be taken into account.

Extent and manner of the maintenance of relatives

The maintenance obligation has an upper and a lower limit:

- upper limit: needs of the entitled person
- lower limit: the maintenance must not endanger other maintenance provided by the obliged person (with the exception of the maintenance of children).

Manners of providing maintenance:

- in the obliged person's household (in kind)
- monthly maintenance in cash paid in advance.

The obliged person can choose between the above manners.

Individual cases of the maintenance of relatives

Maintenance of parents

The child has an obligation to provide maintenance for the parent if the parent is needy. Blood, adopted and step-children are obliged to provide maintenance for the parent. A step-child is obliged only if the step-parent provided maintenance for him or her for a longer period [(2) of Section 62 of the Family Act].

The maintenance of parents is usually provided in their own household, in kind. If this is not possible, monthly maintenance in cash is considered.

Maintenance of grandparents, grandchildren and siblings

The maintenance of grandparents, grandchildren and siblings is usually encountered in exceptional cases.

The maintenance of a grandchild is usually provided if the parent obliged to maintain has died. The general rules of maintenance of the Family Act apply in this case, too. The Family Act does not specify the maintenance of grandparents and grandchildren, this obligation ensues from the general rules.

Strict restrictions apply to the maintenance of siblings: this obligation is imposed on the sibling of age with respect to the underage sibling but only if maintenance can be provided without endangering the maintenance of his or her own spouse and lineal relatives in need of maintenance [(4) of Section 61 of the Family Act]. There is no obligation to provide maintenance for a sibling of age.

4. Other examples of legislation on maintenance obligations in CEEC

Lithuania

Lithuanian Constitution (adopted 25 October 1992)¹⁰³⁾

The Constitution expressis verbis contents the maintenance obligation of the children. It states the following:

Chapter 3. Society and the State.

Article 38.

(1) Family shall be the basis of society and the State.

¹⁰³⁾ http://www.oefre.unibe.ch/law/icl/Ih00000_.html

- (2) Family, motherhood, fatherhood, and childhood shall be under the care and protection of the State.
- (3) Marriage shall be entered into upon the free consent of man and woman.
- (4) The State shall register marriages, births, and deaths. The State shall also recognize marriages registered in church.
- (5) In the family, spouses shall have equal rights.
- (6) The right and duty of parents is to bring up their children to be honest individuals and loyal citizens, as well as to support them until they come of age.
- (7) **The duty of children is to respect their parents, to care for them in old age**, and to preserve their heritage.

Estonia

Estonian Constitution (adopted 28 June 1992)¹⁰⁴⁾

The Constitution states:

Chapter II. Fundamental Rights, Liberties and Duties.

Article 27

- (1) (1) The family, being fundamental to the preservation and growth of the nation and as the basis of society, shall be protected by the state.
- (2) (2) Spouses have equal rights.
- (3) (3) Parents have the right and the duty to raise and care for their children. The protection of parents and children shall be provided by law.
- (4) **The family shall be responsible for the care of dependent members.**

Latvia

Latvian Constitution (adopted 15 February 1922 and amended in 1933, 1994, 1996, 1997, 1998, 2002, 2003)¹⁰⁵⁾

The Constitution states:

Chapter VIII. Fundamental Human Rights.

Article 109 (Social Security, Disability, Unemployment)

Everyone has the right to social security in old age, for work disability, for unemployment and in other cases as provided by law.

Article 110 (Marriage, Family, Parents, Children)

The State shall protect and support marriage, the family, the rights of parents and rights of the child. State shall provide special support to disabled

¹⁰⁴⁾ http://www.oefre.unibe.ch/law/icl/en00000_.html

¹⁰⁵⁾ http://www.oefre.unibe.ch/law/icl/lg00000_.html

children, children left without parental care or who have suffered from violence.

Article 111 (Health)

The State shall protect human health and guarantee a basic level of medical assistance for everyone.

Act on the Protection of the Rights of child

The Law on "the Protection of the Rights of child" was adopted on 19 June 1998. It is based on the principles of the UN Convention on Child Protection and the purpose of the Law is to define the rights and freedoms of the child, **the obligations of the child towards his/her family** as well as the rights and obligations of the parents, legal guardians and other persons towards the child.¹⁰⁶⁾

Czech Republic

The Act of the Czech Republic No. 94/1963 Sb. on family

The Act of the Czech Republic No. 94/1963 Sb. on family as amended by the Acts No. 132/1982 Sb., No. 234/1992 Sb., by the decision of the Constitutional Court No. 72/1995 Sb., by the Acts No. 91/1998 Sb. (full wording promulgated in No. 210/1998 Sb.), by the Acts No. 360/1999 Sb., No. 301/2000 Sb. and No. 109/2002 Sb.

Part II. Relationships between parents and children

Chapter I. Parental Responsibility

Article 31

- (1) The parental responsibility is an aggregate of rights and duties concerning
 - a) care of a minor including in particular care of his or her health, physical, emotional, intellectual and moral growth; and
 - b) representation of the minor; and
 - c) management of his or her property.
- (2) In exercising the rights and duties mentioned in paragraph 1, the parents must rigorously protect the child's interests, manage his or her behavior and exercise a surveillance over him or her in accordance with the level of his or her development. They may use adequate upbringing measures so that the child's dignity is not violated and his or her health, emotional, intellectual and moral development are not endangered.

106) <http://www.hri.ca/fortherecord2001/documentation/tbodies/crc-c-11-add22.htm>

- (3) If the child is able to have his or her own opinion and to consider consequences of measures concerning him or her, the child has the right to obtain necessary information and express his or her opinion about all decisions of the parents concerning essential affairs of his or her person and to be heard in every proceedings in that such affairs are decided on.
- (4) A child living in common household with parents must help them according to his or her abilities and possibilities. He or she must contribute to coverage of common needs of the family if it has his or her own income or a property that can be used for common needs of the family.

Article 32

- (1) The parents have a decisive function in the child's upbringing.
- (2) The parents should be an example to their child through their personal life and behavior.

Article 33

Also the spouse who is not parent of the child takes part in the child's upbringing provided that he or she lives with the child in a common household.

Article 34

- (1) The parental responsibility shall be born by both parents.
- (2) If one of the parents does not live, is not known, has not a full capacity to legal acts, the parental responsibility shall be exercised by the other parent. The same rule shall apply if one of the parents was deprived of his or her parental responsibility or if exercise of his or her parental responsibility was suspended.
- (3) The court may grant the parental responsibility concerning care of the child even to his or her minor parent who has achieved sixteen years if he or she has the necessary makings of exercise of rights and duties following from the parental responsibility.

Article 35

The child must honor and respect his or her parents.

Part III. Maintenance

Chapter I. Mutual maintenance duty between parents and children

Article 85

- (1) The parent's duty to maintain their children exists unless the children are able to earn their living in their own.

- (2) Both parents contribute to their children's maintenance according to their abilities, possibilities and property condition. The child is entitled to take part in his or her parents' life standard.
- (3) In determining the extent of their maintenance duty, there must be taken account of which of the parents personally cares of the child and in what extent. If the parents live together, there must be also taken account of the parents' care of the common household.

Article 85a

- (1) A parent having income from another than dependent activity that is subject to income tax must prove his or her income before court, submit documents necessary for evaluation of his or her property condition and enable the court to find out also other facts necessary for decision by making the data protected according to special acts accessible. If the parent fails to fulfill this duty, his or her average monthly earning shall be presumed to amount to a fifteen times of life minimum necessary for assurance of maintenance and other fundamental personal needs of this parent according to the Act on Life Minimum.¹⁰⁷⁾
- (2) If property condition of the liable parent admits so, also creation of savings assuring in particular preparation to future profession may be also considered the child's justified needs.

Article 87

- (1) Children who are able to earn their own living have a duty to provide their parents with a reasonable maintenance if their parents are in need thereof.
- (2) Each of the children shall fulfill this maintenance duty in a share according to proportion of his or her abilities, possibilities and property condition to the abilities, possibilities and property condition of the other children.

Chapter II. Maintenance duty between other relatives

Article 88

- (1) Forebears and descendants have a mutual duty of maintenance.
- (2) Unless the descendants are able to fulfill their maintenance duty, this duty shall pass to ancestors. More distant relatives have maintenance duty only if it can not be fulfilled by closer relatives.
- (3) If the court determines maintenance for a minor, the provision of § 85a shall apply analogously.

Article 89

¹⁰⁷⁾ § 3 para. 2 letter e) of the Act No. 463/1991 Sb. on life minimum.

If more liable persons are relatives in the same level, each of them shall fulfill his or her maintenance duty in a share corresponding the proportion of his or her abilities, possibilities and property condition to abilities, possibilities and property condition of the other liable persons.

Article 90

The entitled persons have the right to maintenance only if they necessarily need it.

Chapter III. Maintenance duty between spouses

Article 91

- (1) Spouses have a mutual maintenance duty.
- (2) Unless one of the spouses fulfills this duty, the court shall determine of its extent on the basis of a petition of any of them; in doing so, the court shall take account of care of the common household. The extent of maintenance duty shall be determined so that material and cultural level of both parents is principally the same.
- (3) This maintenance duty must be preferred to maintenance duty of the children.

References

AARTSEN M.J, van TILBURG T., SMITS C.M.S., KNIPSCHEER C.P.M. (2004), A longitudinal study of the impact of physical and cognitive decline on the personal network in old age. *Journal of Social and Personal Relationships* 2004, 21,2; p. 249-266.

ALBER J., KOEHLER U. (2004), Health and care in an enlarged Europe. Social Science Research Centre (WZB), Berlin. European Foundation for the improvement of Living and Working Conditions project: Quality of life in central and eastern European candidate countries.

ALBER J. (1995), A framework for the comparative study of social services, *Journal of European Social Policy* 1995 5 (2), p. 131-149.

ANHEIER H. (2000), (Dir. Pub.), Social Services in Europe: Annotated Bibliography, Observatory for the Development of Social Services in Europe, Frankfurt.

ANTTONEN A., SIPILÄ J. (1996), European Social Care Services. Is it possible to identify models? *Journal of European Social Policy* 1996, 6 (2), p. 87-100.

ARBER S., ATTIAS-DONFUT C. (2000), The myth of generational conflict: the family and the state in ageing societies. London, Routledge, ESA Studies in European Societies.

ASSEMBLEE NATIONALE (2004), Rapport JACQUAT D., Rapport sur le projet de loi No 1350 relatif à la solidarité pour l'autonomie des personnes âgées et des personnes handicapées [*Report on Draft Law 1350 on social responsibility for the independence of older and disabled people*], Document No 1540, France. This document can be downloaded from the website <http://www.assemblee-nationale.fr>

ASSEMBLEE NATIONALE (2004), Rapport EVIN C. et D'AUBERT F., Rapport de la Commission d'enquête sur les conséquences sanitaires et sociales de la canicule [*Report of the Commission of Inquiry report on the health and social repercussions of the heat wave*]. Document No 1455, France. This document can be downloaded from the website <http://www.assemblee-nationale.fr>

ASSEMBLEE NATIONALE (2003), Rapport JACQUAT D., Rapport d'information sur la crise sanitaire et sociale déclenchée par la canicule [*Information report on the health and social crisis triggered by the heat wave*]. Document No 1091, France. This document can be downloaded from the website <http://www.assemblee-nationale.fr>

ATTIAS-DONFUT C., WOLFF F.C. (2000), The redistributive effects of generational transfers. *in* ARBER S., ATTIAS-DONFUT C. (2000), *The myth of generational conflict: the family and the state in ageing societies*. London. Routledge, p. 22-46

BAINS M., OXLEY H. (2004), Ageing-related spending projections on health and long-term care. *in* OECD (2004) *Towards High-Performing Health Systems: Policy Studies*, OECD Health Project Series, Paris.

BERG K. et al. (2001), Identification and Evaluation of Existing Quality Indicators that are Appropriate for Use in Long-Term Care Settings, Centers for Medicare & Medicaid Services, Baltimore.

BENGTSON V. L. (2001), Beyond the nuclear family: The increasing importance of multigenerational bonds. *Journal of Marriage and the Family* 2001, 63, p. 1-16.

BENGTSON V. L., HAROOTYAN R. (1994), (Eds.). *Intergenerational linkages: Hidden connections in American society*. New York. Springer.

BERNARD M., PHILIPS J., PHILLIPSON Chr., OGG J. (2000), Continuity and change. *in* ARBER S., ATTIAS-DONFUT C. (2000), *The myth of generational conflict: the family and the state in ageing societies*. London. Routledge, p. 209-227.

BLINKERT B., KLIE Th. (2005), *Solidarität in Gefahr? Pflegebereitschaft und Pflegebedarfentwicklung im demografischen und sozialen Wandel*. Vincentz Network Hannover.

BRAAM A.W., BEEKMAN A.T.F., EEDEN P., van den DEEG D.J.H., KNIPSCHEER C.P.M., van TILBURG W. (1999), Religious climate and geographical distribution of depressive symptoms. *in* *Older Dutch citizens. J. Affective Disorders*, 54, p. 149-159.

BRAVO G. et al. (2002), Relationship between Regulatory Status, Quality of Care and Three-Year Mortality in Canadian Residential Care Facilities: A Longitudinal Study. *Health Services Research*, Vol. 37(5), p. 1181-1196.

BULLETIN LUXEMBOURGEOIS DES QUESTIONS SOCIALES (1999), *L'assurance dépendance, No spécial*, Volume 7.

CBP NETHERLANDS BUREAU FOR ECONOMIC POLICY ANALYSIS (2004), *Ageing in the Netherlands*. The Hague.

See Website: <http://www.cpb.nl/eng/pub/bijzonder/25/bijz25.pdf>

COLEMAN B. (2003), Consumer-Directed Personal Care Services for Older people in the US. AARP, Washington, DC.

COLEMAN P.G. (1984), Assessing self-esteem and its sources in elderly people. *Ageing and Society*, 4, p. 117-135.

COMAS-HERRERA A., WITTENBERG R. (2003), European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs. Report to the European Commission, Employment and Social Affairs DG, Grant number VS/2001/0272, Personal Social Service Research Unit (PSSRU) Discussion Paper 1840, London School of Economics, London.

See Website:

http://www.europa.eu.int/comm/employment_social/social_protection/docs/ltc_study_en.pdf.

COLOMBO F., TAPAY N. (2004), Private Health Insurance in OECD Countries: The Benefits and Costs for Individuals and Health Systems, OECD Health Working Papers, OECD, Paris.

DALY M., LEWIS J. (2000), The concept of social care and the analysis of contemporary welfare states, *British Journal of Sociology*, 51, 2, p. 281-298.

DEUTSCHER BUNDESTAG (2004), Dritter Bericht über die Entwicklung der Pflegeversicherung, Drucksache 15/4125.

See Website: <http://dip.bundestag.de/btd/15/041/1504125.pdf>

DOTY P. (2000), Cost-Effectiveness of Home and Community-Based Long-Term Care Services, United States Department of Health and Human Services, Washington, D.C.

DUTCH EU PRESIDENCY (2004), Background Paper on "Health Care in an Ageing Society" based on the OECD study (2004) "Towards High-Performing Health Systems".

DUTCH SOCIAL AND CULTURAL PLANNING OFFICE (2004), The elderly now and in the future: health, nursing and caring, 2000-2020 (*Ouderen nu en in de toekomst: gezondheid, verpleging en verzorging, 2000-2020*), The Hague.

DYKSTRA P.A., KALMIJN M., KNIJN T.C.M., KOMTER A. E., LIEFBROER A. C., MULDER C. H. (2000), Family relationships: The ties that bind. A

sociological and demographic research programme 2000-2006. The Hague, Tilburg, Utrecht, Amsterdam.

EVANS CUELLAR A., WIENER J.M. (2000), Can social insurance for long-term care work? The experience of Germany. *Health Affairs*, Vol. 19(3), Project HOPE, Congers, New York, p. 8-25.

EVERS A. (2003), Report on "Current strands in debating user involvement in social services". Council of Europe.

EVERS A., RAUCH U., STITZ U. (2002), Von öffentlichen Einrichtungen zu sozialen Unternehmen . *Hybride Organisationsformen im Bereich sozialer Dienstleistungen*. Sigma, Berlin.

FINCH J. (1989), *Family obligations and social change*. Polity Press, Cambridge.

GAVIRA L., GANZALES F. (2003), Report on "The role of new information technology as regards user involvement in social services". Council of Europe.

GIARRUSSO R., STALLINGS M., BENGTON V. L. (1995), The "intergenerational stake" hypothesis revisited: Parent-child differences in perception of relationships 20 years later. *in* BENGTON V. L., SCHAIK K. W., BURTON L. M.(1995), (Eds.), *Adult intergenerational relations: Effects of societal change*. Springer. New York, p. 227-263.

GIDDENS A. (1998), *The Third Way. A renewal of Social Democracy*. Polity Press, UK.

GONZALEZ ORTEGA S., QUINTERO LIMA G. (2004), (coord.), *Protección social de las personas dependientes*. Laley, Madrid.

GRAMAIN A., WITTMER J., REBILLARD C., DUEE M. (2004), *Les contributions privées au financement de la dépendance dans le cadre de l'obligation alimentaire: pratiques judiciaires et implications macroéconomiques*. LEGOS, Université de Paris-Dauphine et INSEE, Paris.

GULBRANDSEN L., LANGSETH A. (2000), Wealth distribution between generations. *in* ARBER S., ATTIAS-DONFUT C. (2000), *The myth of generational conflict: the family and the state in ageing societies*. London. Routledge, p. 69-87.

GVG (2003), *Social Protection in the candidate countries*, *Schriftenreihe der GVG*, Band 40-43,

HAJDU J. (2000 and 2002), Social Protection in the Czech Republic, Estonia, Hungary, Poland and Slovenia: A brief description. *in* PIETERS D. (2000 and 2002) (Ed.), A publication by the European Institute of Social Security for STAKES National Research and Development Centre for Welfare and Health.. HEIKKILA M. (2003), Report on "Obstacles to an increased user involvement in social services". Council of Europe.

HIRAOKA K. (2005), Long-term care insurance in Japan. *in* YOON H., HENDRICKS J. (Coord.), Handbook of Asians Ageing, Baywood Publishing.

HUBER M. (2005), Estimating expenditure on long-term care. OECD Health Technical Papers.

HUNGARIAN MINISTRY OF HEALTH (2005), Preliminary Report on Hungary's Health Care and Long-term Care Systems, Draft paper.

IGL G., WELTI F. (2005), Integration von behinderten Menschen. *in* LINZBACH Chr., LÜBKING U., SCHOLZ St., SCHULTE B. (2005), (Eds.), Die Zukunft der sozialen Dienste vor der Europäischen Herausforderung, Nomos, Baden-Baden.

IGL G. (2003), La prise en charge de la dépendance des personnes âgées: quelques observations à partir du cas allemand. *in* MARTIN C. (2003) (Ed.), La dépendance des personnes âgées. Quelles politiques en Europe ? Presses Universitaires de Rennes, Ed. ENSP. Rennes, p. 217-225.

IGL G., SCHIEMANN D., GERSTE B., KLOSE J. (2002), (Eds.), Qualität in der Pflege. Betreuung und Versorgung von pflegebedürftigen alten Menschen in der stationären und ambulanten Altenhilfe. Schattauer Verlag Stuttgart.

IGL G. (1998), Pflegeversicherung als neuer Gegenstand sozialrechtlicher Regulierung. *in* SIEVEKING K. (Ed.) (1998), Soziale Sicherung bei Pflegebedürftigkeit in der Europäischen Union, Nomos, Baden-Baden, p. 19-34.

IGL G., JOEL M.-E., KERSCHEN N., KNIPSCHEER C.P.M. (1993), La dépendance des personnes âgées. Volume I. Prise en charge et financement en Allemagne, en France et aux Pays-Bas. Volume II. Bilan du système luxembourgeois de prise en charge des personnes âgées dépendantes et propositions de réforme. Report commissioned and financed by the Luxembourg Government.

IGL G. (1987), Pflegebedürftigkeit und Behinderung im Recht der sozialen Sicherheit. Eine rechtsvergleichende Untersuchung für die Bundesrepublik Deutschland und Frankreich. Nomos. Baden-Baden

IGSS (2004), Rapport général de la Sécurité Sociale au Grand-Duché de Luxembourg 2003. Chapitre 2. Assurance-dépendance. Ministère de la Sécurité sociale, Luxembourg.

IGUCHI N., Establishment of long-term care insurance schemes in Japan. Ministry of Health and Welfare, Health and Welfare Bureau for the Elderly, Japan.

IKEGAMI N., HIRDES J.P., CARPENTER I. (2002), Measuring the quality of long-term care in institutional and community settings, Chapter 13 in OECD (2002), Measuring Up: Improving health system performance in OECD countries, OECD, Paris.

INSEE (1998/2002), Enquête « Handicaps, Incapacités, Dépendance » (HID), France.

See Website : <http://rfr-handicap.inserm.fr>.

JACOBZONE S. et al. (1999), The health of older persons in OECD countries: Is it improving fast enough to compensate for population ageing. Labour Market and Social Policy, Occasional Paper No 37, OECD, Paris.

JENSON J., JACOBZONE S. (2000), Care allowances for the frail elderly and their impact on women care-givers. Labour Market and Social Policy, Occasional Papers No.41, OECD, Paris.

JOBBAGYI G. (2002), Személyi és Családi Jog (Personal and Family Law), 3rd edition, Szent István Társulat, Budapest.

JOEL M.-E., COLVEZ A. (2002), (Eds.), La maladie d'Alzheimer, quelle place pour les aidants? Expériences innovantes et perspectives en Europe. Editions Masson, Paris.

JOEL M.-E., COZETTE E. (2002), (Eds.), Prise en charge de la maladie d'Alzheimer en Europe. Editions de l'INSERM, Paris.

JOHANSSON L., SUNDSTRÖM G., HASSING L.B. (2003), State provision down, offspring's up: the reverse substitution of old-age care in Sweden, Ageing and Society, Vol. 23, Cambridge University Press.

KALLIOMAA-PUHA L. (2004), From independence and individual choice back to family? Some remarks on organising elderly care in Finland. Discussion paper, KELA, Helsinki.

KARPATI Z., SZEMAN Z. (2002), Nonprofit Organizations and Social Welfare in Hungary. Research Center on Societal and Social Policy (RCSSP), Research Paper Series No. 5, Hong Kong.

KAUTTO M. (2002), Investing in services in West European welfare states, *Journal of European Social Policy*, 2002, 12, 1, p. 53-65.

KERSCHEN N. (2005), L'assurance soins de longue durée au Japon. Comparaison avec des systèmes européens. Actes du Colloque franco-japonais sur "Longévité et politiques publiques", Université Nancy II, 18 et 19 octobre 2004.

KERSCHEN N. (2005), Evolution démographique en Europe et politiques sociales : l'exemple de la dépendance des personnes âgées. Actes du Colloque sur « L'élargissement de l'Union Européenne : enjeux et implications socio-démographiques », Université catholique de Louvain – Chaire Quételet 2003 – Institut de démographie - 21 au 24 octobre 2003

KERSCHEN N. (2004), La dependencia como nuevo riesgo de la Seguridad Social: el ejemplo de la creacion del seguro de dependencia en Luxemburgo *in* GONZALEZ ORTEGA S., QUINTERO LIMA G. (2004), (Coord.), *Proteccion social de las personas dependientes*. Laley, Coleccion relaciones laborales, Madrid.

KERSCHEN N. (2000), (Coord.), LAWNET project. Comparative analysis of legislation in Europe relating to the rights of people with dementia. Final report and national reports, Alzheimer Europe (<http://www.alzheimer-europe.org> – see under "legal rights").

KERSCHEN N. (1999), L'assurance-dépendance au Luxembourg. *Gérontologie* 1999 – 4 N° 112.

KERSCHEN N. (1997), La reconnaissance de la dépendance comme un nouveau risque de la sécurité sociale: le modèle allemande et le projet luxembourgeois. *Revue française des affaires sociales*, N° spécial "Le vieillissement comme processus", Octobre 1997, p. 205.

KESSLER F. (1997), (Ed.), *La dépendance des personnes âgées*. Sirey. Série Actions, Droit sanitaire et social, 2nd Edition, Paris.

KNICKMAN J.R., SNELL E.K. (2002), The 2030 problem: Caring for aging baby boomers, *Health Services Research*, Vol. 37, 4, p. 849-884, Blackwell Publishers Inc., Boston.

KNIJN T., KOMTER A. (2004), (Eds.), *Solidarity Between the Sexes and the Generations, Transformation in Europe*. Cheltenham (UK), Edward Elgar Publishing Limited.

KNIPSCHIEER C.P.M., BROESE van GROENOU M. (2004), *Determinanten van zorgbelasting bij partners en kinderen van hulpbehoevende ouderen met*

fysieke gezondheidsproblemen. (Determinants of care burden among partners and adult children of physically impaired older persons in need of care). *Tijdschrift voor Gerontologie en Geriatrie*, 35, 3, p. 96-106.

KNIPSCHEER C.P.M., van TILBURG T.G. (2003), Family characteristics and loneliness among older parents. *in* BENGTON V.L., LOWENSTEIN A., (2003), (Eds.), *Global ageing and challenges to families*. Hawthorne, NY, Aldine de Gruyter, p. 143-158. .

KNIPSCHEER C.P.M., DYKSTRA P.A., UTASI A., CSEH SZOMBATHY L. (2000), Family in an ageing society. *in* BEETS G., MILTENY K. (2000), (Eds.), *Population Ageing in Hungary and the Netherlands: a European perspective*. Thela-Thesis, Amsterdam.

KNIPSCHEER C.P.M. (2000), Biographical and Strategic Issues in Research about Ageing. *in* ÖBERG B.M., NÄRVÄNEN A.L., NÄSMAN, OLSSON E. (2000), *Changing Worlds and the Ageing Subject, Dimensions in the Study of Ageing and Later Life*. Ashgate: Hants, England.

KNIPSCHEER C.P.M. (1989), Familiäre Pflege, Reife und erfolgreiches Altern. *in* BALTES M., KOHLI M., SAMES K. (1989) (Hrg.) , *Erfolgreiches Altern. Bedingungen und Variationen*. Verlag Hans Huber, Bern, p. 142-148.

KNIPSCHEER C.P.M. (1986), Anomie in der Mehrgenerationen Familie: Kinder und die Versorgung ihrer altern Eltern. *Zeitschrift für Gerontologie*, 19, p. 40-46.

KODNER D.L. (2003), The quest for integrated systems of care for frail older persons, *Aging: Clinical and Experimental Research*, Vol. 14, 4, p. 307-313.

KOHLI M., KUNEMUND H., MOTEL A., SZYDLIK M. (2000), Families apart? Intergenerational transfers in East and West Germany. *in* ARBER S., ATTIAS-DONFUT C. (2000), *The myth of generational conflict: the family and the state in ageing societies*. London. Routledge, p. 88-113.

KOLDINSKA K., TOMES I. (2004), Social services in accession countries, *Social Work & Society*, Volume 2, Issue 1.

KREMER B., SZIKLAI I., TAUSZ K. (2002), The Impact of Decentralization on Social Policy in Hungary.

See Website: <http://lgi.osi.hu/publications/2002/101/Tausz-Hungary.pdf>

LAGERGREN, M. (2002), The systems of care for frail elderly persons: the case of Sweden, *in* *Aging: Clinical and Experimental Research*, Vol. 14, Editrice Kurtis, Milano.

- LAGERGREN M., BATLJAN I. (2000), Will be a helping hand? Macroeconomic scenarios of future needs and costs of health and social care for elderly in Sweden, 2000-2030, Annex 8, Long-Term Survey 1999/2000, Fritzes Offentliga Publikationer, Stockholm.
- LAMURA G. (2003), Supporting carers of older people in Europe: a comparative report on six European countries. Paper presented at the 11th European Social Services Conference, Venice, 2nd to 4th July 2003.
- LE GALL D., MARTIN C. (1996), Familles et politiques sociales. L'Harmattan, Paris.
- LEICHSENRING K. (2005), Soziale Dienste für pflegebedürftige alte Menschen. *in* LINZBACH Chr., LÜBKING U., SCHOLZ St., SCHULTE B. (2005), (Eds.), Die Zukunft der sozialen Dienste vor der Europäischen Herausforderung, Nomos, Baden-Baden.
- LEWIS J. (2004), Individualization and the need for new forms of family solidarity. *in* KNIJN T. and KOMTER A. (2004), Solidarity between the Sexes and the Generations. Cheltenham, UK, Edward Elgar Publishing Limited, p. 51-67.
- LINZBACH Chr., LÜBKING U., SCHOLZ St., SCHULTE B. (2005), (Eds.), Die Zukunft der sozialen Dienste vor der Europäischen Herausforderung, Nomos, Baden-Baden.
- LUNDSGAARD J. (2005), Consumer Direction and Choice for Long-term Care for Older Persons, including Payments for Informal Care. How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability, OECD Health Working Papers, n°20.
- MARTIN C. (2003), (Ed.), La dépendance des personnes âgées. Quelles politiques en Europe ? Presses Universitaires de Rennes, Ed. ENSP. Rennes.
- MEANS R., RICHARDS S., SMITH R. (2003), Community care. Policy and practice. Palgrave Macmillan UK, 3rd Edition.
- MERCER LIMITED (2003), Study to Examine the Future Financing of Long-Term Care in Ireland, The Stationary Office, Dublin.
- MESTHENEOS E., TRIANTOFILLOU J. (2005), Pan-European Background Report "PEUBARE". Hamburg: Univ. Medic. Centre Hamburg-Eppendorf, EUROFAMCARE Consortium.
- MILLAR J., WARMAN A. (1996), Family obligations in Europe. Family Policy Studies Centre, Joseph Rowntree Foundation.

MOISE P., SCHWARZINGER M., UM M.-Y. (2004), Dementia Care in 9 OECD Countries, a Comparative Analysis, OECD Health Working Papers n° 13.

MONTGOMERY A., FEINBERG L.F. (2003), The Road to Recognition: International review of public policies to support family and informal care giving. Family Caregiver Alliance, San Francisco.

MUNDAY B. (2003), Report on "European social services: a map of characteristics and trends". Council of Europe.

MUNDAY B. (2001), Key Issues in European Social Services. Paper presented for a Conference on "The Role of Social Services in Sustainable Social Development". Berlin, 25-26 October 2001.

MUNDAY B., LANE G. (1998), (Eds.), The Old and the New: Changes in Social Care in Central and Eastern Europe, European Institute of Social Services, University of Kent, Canterbury.

PACOLET J. (2005), Vieillesse, aide et soins de santé en Belgique. UCL Ecole de Santé publique et HIVA. This document can be downloaded from <http://www.sesa.ucl.ac.be>.

PACOLET J. et al. (1998), Social Protection for dependency in old age in the 15 EU Member States and Norway. Main results of a comparative study. Draft synopsis report. National reports. Report for the European Commission DGV/E and the Belgian Minister of Social Affairs, UCL, HIVA, Belgium.

PACOLET J. et al. (1998), La protection sociale des personnes âgées dépendantes dans les 15 Etats membres de l'Union Européenne et en Norvège. Rapport de synthèse. Commission européenne, Série Emploi & Affaires sociales, Sécurité sociale et Insertion sociale.

PACOLET J. et al. (1998), La protection sociale des personnes âgées dépendantes en Belgique : vers une assurance-dépendance. Recherche commanditée par le Ministre belge des Affaires sociales et la Commission des Communautés européennes, UCL, HIVA, Belgium.

PEETERS A., BOUWMAN B., KNIPSCHIEER C.P.M. (2005), The Netherlands: quality of life in old age (I) and (II). *in* WALKER A. (Ed.), Growing Older in Europe. Berkshire Open University Press.

PICKARD L., WITTENBERG R., COMAS-HERRERA A., DAVIS B., DARTON R. (2000), Relying on Informal Care in the New Century? Informal Care for Elderly People in England to 2031. Ageing and Society 20, Cambridge University Press, the United Kingdom, p.745-772.

POT A.M., DEEG D.J.H, KNIPSCHEER C.P.M, (2001), Institutionalization of demented elderly: the role of the caregiver characteristics. *International Journal of Geriatric Psychiatry*, 16, p. 273-280.

RESEARCH INSTITUTE FOR HEALTH STRATEGY (2004), Hungary's health and social system 2004, National Statistical Survey Programme Report, 2002.

ROSTGAARD T. (2003), *Social Care Regimes. The Configuration of Care for Children and Older People in Europe.*

SCHULZ E., LEIDL R., KÖNIG H.H. (2004), The impact of ageing on hospital care and long-term care. The example of Germany. *Health Policy*, Vol. 67:1, p. 57-74, Elsevier, Amsterdam.

SCHUYT-LUCASSEN N.Y, KNIPSCHEER C.P.M. (1999), La proteccion social a las personas mayores dependientes en los Países Bajos. *in* Observatorio de personas mayores, Vejez y proteccion social a la dependencia en Europa. Ministerio de Trabajo y asuntos sociales, Madrid.

SIEVEKING K. (1998), (Ed.), *Soziale Sicherung bei Pflegebedürftigkeit in der Europäischen Union*, Nomos, Baden-Baden.

SUTHERLAND S. (1999) (Ed.), *With respect to old age: Long-term care – rights and responsibility; A report by the ROYAL COMMISSION on long-term care*, Cm. 4192-I, Stationery Office, London.

TALEYSON L. (2005), *Surviv des expériences européennes de la prise en charge de la dépendance*, Centre International de Recherche et de Développement sur l'Assurance Dépendance de SCOR Vie (CIRDAD), Présentation à la Conférence de l'AEIP à Bruxelles, le 21 avril 2005.

TALEYSON L. (2004), *L'assurance dépendance privée. Comparaisons internationales*, SCOR Division Vie, France.

THOMESE G.C.F., van TILBURG T.G, KNIPSCHEER C.P.M. (2003), Continuation of exchange with neighbours in later life: The importance of the neighbourhood context. *Personal Relationships*, 10, 4, p. 535-550.

TOKYO METROPOLITAN GOVERNMENT (2000), *Long-term care insurance system. Supporting nursing care through society.*

See Website: <http://www.kaigohoken.metro.tokyo.jp;>

TOMEŠI. (2003), *The role of social services in sustainable social development with special reference to the development of social services in the*

transformation of central and east Europe. *in* The role of social services in sustainable social development, Berlin.

TOMEŠ I., KOLDINSKA K. (2003), Sociální právo EU (Social Law of the EU), Praha CH.Beck.

TOMEŠ I. (2002), Sociální správa (Social administration), Praha Portál.

TRYDEGARD G.-B. (2005), Elderly care in Sweden - a public or private affair, Presentation at the AFSR Social Science Workshop on the Ageing Society, 7-8 April 2005, Stockholm.

VAN DER PAS S., VAN TILBURG T., KNIPSCHEER C.P.M. (in press), Changes in contact and support within intergenerational relationships.

VERWEY-JONKER INSTITUUT (Holland), EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH (Austria), DUTCH MINISTRY OF HEALTH, WELFARE AND SPORT (2004), Integrated care systems: country profiles – responses to questionnaire. Dutch EU Presidency, Hague Conference, 18-19 November 2004.

VISSER G., KLINKENBERG M., BROESE van GROENOU M.I., WILLEMS D.L., KNIPSCHEER C.P.M., DEEG D.J.H. (2004). The end of life: informal care for dying older people and its relationship to place of death. *in* Palliative Medicine; 18, p. 468-477.

VISSER-JANSEN G., KNIPSCHEER C.P.M. (2004), Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage. EUROFAMCARE, National Background Report for the Netherlands, Vrije Universiteit Amsterdam.

This report and all the reports of the 23 EU Member States are available from: <http://www.uke.uni-hamburg.de/extern/eurofamcare/nabares/>

VOLLMER R.J. (2003), Die “nahtlose” Pflege als Leitmotiv der japanischen Pflegeversicherung *in* Im Dienste der Sache. Liber amicorum für Joachim Gaertner. Peter Lang (Ed.), p. 695.

WIENER J.M., TILLY J., EVANS CUELLAR A. (2003), Consumer-Directed Home Care in the Netherlands, England and Germany, Public Policy Institute, Washington D.C..

WIENER J.M., TILLY J., ALECXIH L.M.B. (2002), Home and community-based services in seven states, Health Care Financing Review, Vol. 23(3), Centres for Medicare and Medicaid Services, Baltimore.

WENDT W. R. (2001), Case Management im Sozial- und Gesundheitswesen. Eine Einführung, 3rd Edition, Lambertus, Freiburg.

WILD F. (2004), Die Bewältigung des Pflegerisikos in Skandinavien, Duncker & Humblot, Berlin.

WILLMOTT P., YOUNG M. (1960), Family and class in a London Sururb. Routledge and Keagan Paul, London.

YOUNG M., WILLMOTT P. (1957), Family and kinship in East London. Routledge and Keagan Paul, London.

Council of Europe

Council of Europe Internet site:

<http://www.coe.int>

See also Council of Europe Internet site on Social Services:

http://www.coe.int/T/E/Social_cohesion/Social_Policies/04.Activities/1._Access_to_social_rights/4._Social_Services/default.asp#TopOfPage

COUNCIL OF EUROPE (1998), Recommendation No R (98) 9 on dependence adopted by the Committee of Ministers on 18 September 1998 at the 641st meeting of the Ministers' Deputies.

COUNCIL OF EUROPE (1995), The situation of dependence in relation to the protection afforded by social security, 6th Conference of European Ministers responsible for social security, Lisbon, May 1995, Strasbourg 1995.

EVERS A. (2003), Report on "Current strands in debating user involvement in social services". Council of Europe.

GAVIRA L., GANZALES F. (2003), Report on "The role of new information technology as regards user involvement in social services". Council of Europe.

HEIKKILA M. (2003), Report on "Obstacles to an increased user involvement in social services". Council of Europe.

MUNDAY B. (2003), Report on "European social services: a map of characteristics and trends". Council of Europe.

European Union:

EU Internet site on long-term care policies: http://www.europa.eu.int/comm/employment_social/social_protection/health_en.htm

COMAS-HERRERA A., WITTENBERG R. (2003), European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs. Report to the European Commission, Employment and Social Affairs DG, Grant number VS/2001/0272, Personal Social Service Research Unit (PSSRU) Discussion Paper 1840, London School of Economics, London.

COUNCIL OF THE EUROPEAN UNION on Employment, Social Policies, Health and Consumer Affairs (2004), Launch of the "Open Method of Coordination", 4 October 2004, 12400/04 (Press 264).

DUTCH EU PRESIDENCY (2004), Background Paper on "Health Care in an Ageing Society" based on the OECD study "Towards High-Performing Health Systems".

EUROPEAN COMMISSION (2005), Green Paper on "Confronting demographic change: a new solidarity between the generations". COM (2005) 94 final (16 March 2005).

EUROPEAN COMMISSION (2004), Communication on "Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the 'Open Method of Coordination'". COM (2004) 304 final (20 April 2004).

EUROPEAN COMMISSION, COUNCIL (2003), Joint report on "Supporting national strategies for the future of health care and care for the elderly". No 7166/03, SOC 116, ECOFIN 77, SAN 41 (10 March 2003).

EUROPEAN COMMISSION (2001), Communication on "The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability", COM (2001) 723 final (5 December 2001).

EUROPEAN COMMISSION (1999), Communication on "A concerted strategy to modernise social protection", COM (1999) 347 final (14 July 1999).

EUROPEAN COMMISSION (1999), Communication on "Towards a Europe for all ages – promoting prosperity and intergenerational solidarity", COM (1999) 221 final (21 May 1999).

EUROPEAN COMMISSION (1997), Communication on “Modernising and improving social protection in the European Union”, COM (1997) 102 final (12 March 1997).

PACOLET J. et al. (1998), Social Protection for dependency in old age in the 15 EU Member States and Norway. Main results of a comparative study. Draft synopsis report. National reports. Report for the European Commission DGV/E and the Belgian Minister of Social Affairs, UCL, HIVA, Belgium.

PACOLET J. et al. (1998), La protection sociale des personnes âgées dépendantes dans les 15 Etats membres de l’Union Européenne et en Norvège. Rapport de synthèse. Commission européenne, Série Emploi & Affaires sociales, Sécurité sociale et Insertion sociale.

PACOLET J. et al. (1998), La protection sociale des personnes âgées dépendantes en Belgique : vers une assurance-dépendance. Recherche commanditée par le Ministre belge des Affaires sociales et la Commission des Communautés européennes, UCL, HIVA, Belgium.

VERWEY-JONKER INSTITUUT (Holland), EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH (Austria), DUTCH MINISTRY OF HEALTH, WELFARE AND SPORT (2004), Integrated care systems: country profiles – responses to questionnaire. Dutch EU Presidency, Hague Conference, 18-19 November 2004.

Organisation for economic cooperation and development (OECD):

OECD Internet site on long-term care policies: <http://www.oecd.org/health/>

BAINS M., OXLEY H. (2004), Ageing-related spending projections on health and long-term care. *in* OECD (2004) Towards High-Performing Health Systems: Policy Studies, OECD Health Project Series, Paris.

COLOMBO F., TAPAY N. (2004), Private Health Insurance in OECD Countries: The Benefits and Costs for Individuals and Health Systems, OECD Health Working Papers, OECD, Paris.

HUBER M. (2005), Estimating expenditure on long term care. OECD Health Technical Papers.

IKEGAMI N., HIRDES J.P., CARPENTER I. (2002), Measuring the quality of long-term care in institutional and community settings, Chapter 13 *in* OECD (2002), Measuring Up: Improving health system performance in OECD countries, OECD, Paris.

JACOBZONE S. et al. (1999), The health of older persons in OECD countries: Is it improving fast enough to compensate for population ageing. Labour Market and Social Policy, Occasional Paper No 37, OECD, Paris.

JENSON J., JACOBZONE S. (2000), Care allowances for the frail elderly and their impact on women care-givers. Labour Market and Social Policy, Occasional Papers No.41, OECD, Paris.

LUNDGAARD J. (2005), Consumer Direction and Choice for Long-term Care for Older Persons, including Payments for Informal Care. How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability, OECD Health Working Papers, n°20.

MOISE P., SCHWARZINGER M., UM M.-Y. (2004), Dementia Care in 9 OECD Countries, a Comparative Analysis, OECD Health Working Papers n° 13.

OCDE (2005), Les soins de longue durée pour les personnes âgées, OCDE, Paris.

OCDE (2005), Pour des soins de longue durée de qualité aux personnes âgées. Synthèses, mars 2005, OCDE, Paris.

OECD (2005), Long-term care for older people, OECD, Paris.

OECD (2005), Ensuring quality long-term care for older people. Policy brief, March 2005, OECD, Paris.

OECD (2004), OECD Countries: A comparative analysis, OECD Health Working Papers, OECD, Paris.

World Health Organization (WHO):

WHO Internet site: <http://www.who.int/en/>

WHO (2001), International Classification of Functioning, Disability and Health (ICF), 54th World Health Assembly, 22 May 2001, Resolution WHA 54.21, Geneva.

Central and eastern european countries – Internet Sites:

In Central and Eastern European Countries, the issue of long-term care is relatively under-represented in social protection literature. The main sources of information can be researched in the websites of CEEC governments and other relevant Internet pages :

http://www.oefre.unibe.ch/law/icl/lh00000_.html

<http://www.hri.ca/fortherecord2001/documentation/bodies/crc-c-11-add22.htm>

<http://www.sigov.si/mddsz>

The programme of Combating Poverty and Social Exclusion, 2000: 42

<http://www.gzs.si>

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/SP107.asp>

Social Policy Research 107 - November 1996

<http://free.ngo.pl/temida/family.htm>

http://europa.eu.int/comm/justice_home/ejn/maintenance_claim/maintenance_claim_int_en.htm

<http://www.uem-rs.si/eng/cedaw2/22.html>

www.euro.who.int/observatory

www.euro.who.int/observatory

<http://www.lm.gov.lv/?sadala=306>

<http://www.lm.gov.lv/index.php?sadala=319&id=909>

<http://www.sdrc.lt/eswin/itswfs.htm#sserv>

<http://www.socmin.lt/index.php?1545971650>

MISSOC Long term care tables

<http://www.icnl.org/JOURNAL/vol3iss4/prelimstudy1.htm>

<http://www.sigov.si/irssv/essocpe.html>

http://lgi.osi.hu/resources/elderly/Slovakia_3.html

<http://www.moznostvolby.sk/ihf2000.htm>

www.observatory.dk

www.ose.be/files/slovenia%20Country%20Report.doc

<http://www.stat.si>

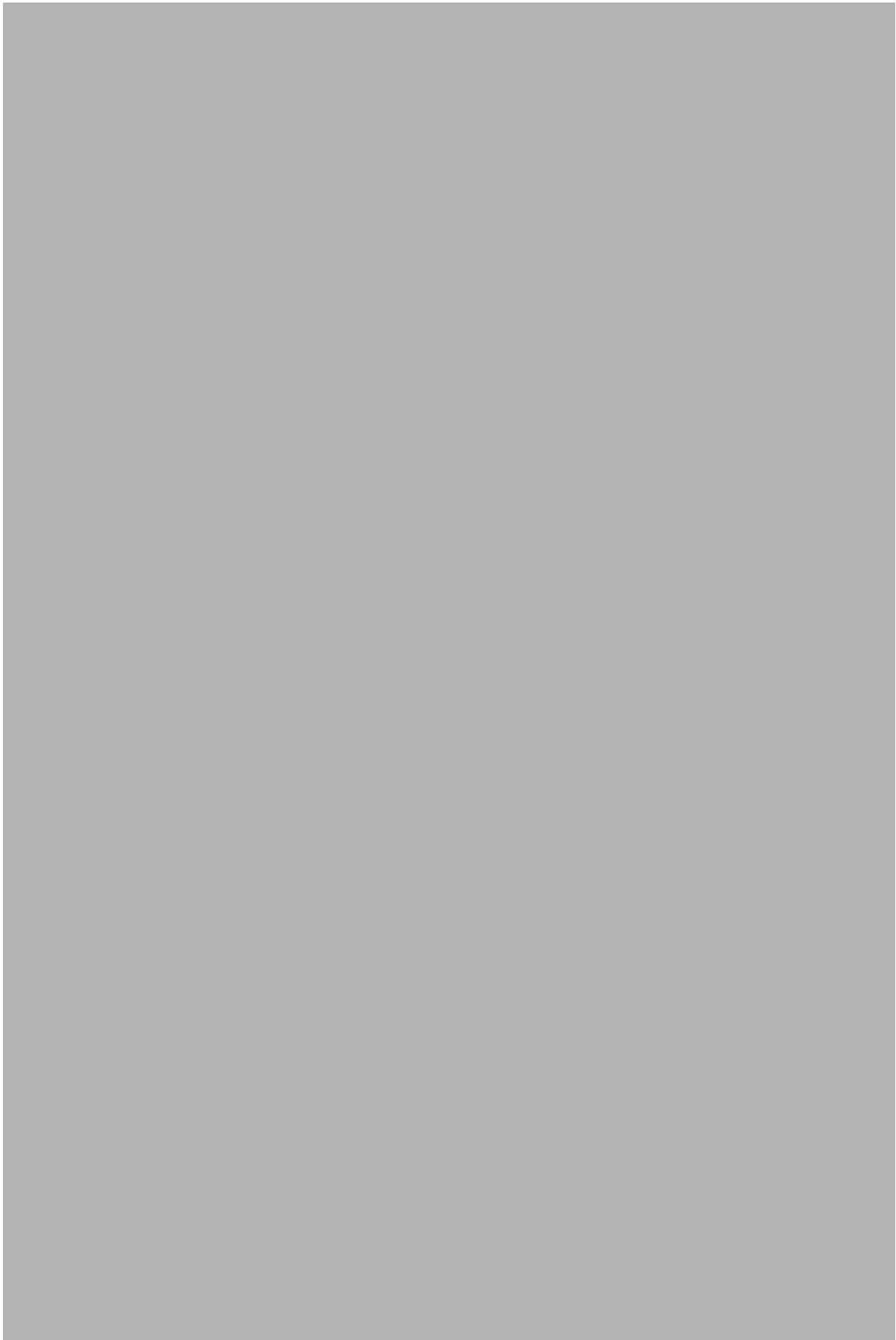
<http://www.otthonapolas.hu/mtt.html>

<http://www.un.org/ageing/coverage/hungaryE.htm>

SECTION 3

Martha C. NUSSBAUM:

**LONG TERM CARE AND SOCIAL JUSTICE:
A CHALLENGE TO CONVENTIONAL IDEAS
OF THE SOCIAL CONTRACT
(EXTRACT)**



Long-term Care and Social Justice: a Challenge to Conventional Ideas of the Social Contract (Extract)^{*)}

This text discusses ideas that appear in a revised and improved form in the book *“Frontiers of Justice: Disability, Nationality, Species Membership”* (Harvard University Press, 2006).

Martha C. NUSSBAUM

*Ernest Freund Distinguishes Service
of Law and Ethics
University of Chicago Law School*

It will be seen how in place of the wealth and poverty of political economy come the rich human being and rich human need. The rich human being is...the human being in need of a totality of human life-activities.

Marx, Economic and Philosophical Manuscripts of 1844

A.1 An acute problem of justice¹⁾

All societies contain people in need of care. Indeed, all people in all societies are in need of care. Even so-called “normal” and “able-bodied” adults rely constantly on care provided by others in the fabric of their lives: people who cook meals and tend the home, providers of regular health care, people who prepare the external environment so that it is safe and conducive to ordinary functioning. At times during their lives the “normal” have more acute needs for care: during an illness, after an accident, etc. But of course “normal” adulthood is itself a temporary phase of a human life. It is preceded by a very long period of childhood, much longer than in most animal species, during which basic needs for food, comfort, shelter, cognitive development, and social interaction must be met by the constant involvement of adult givers of care. This period can last for over twenty years in many cases, though of course the nature of the needs in question shifts over time.

^{*)} Reprinted, with permission from appendix A of WHO: *Ethical choices in long-term care: What does justice require?*, WHO 2002 (http://www.who.int/mediacentre/news/notes/ethical_choices.pdf).

The phase of “self-sufficient” adulthood is usually followed, in turn, by a period of increasing dependency, as aging gives rise to new physical and mental needs. The increasing life expectancy in many nations of the world is giving rise to a new, or newly numerous, set of dependencies, as children who have just raised their own children, or are still doing so, must care for their own parents in their physical and/or mental decline.

There are many citizens in every society, moreover, who are asymmetrically dependent upon others throughout their lives. In some cases these dependencies result from unusual physical disabilities. All human beings are disabled beings, with many imperfections in judgment, understanding, perception, and bodily functioning. But society is typically arranged to cater for the most typical disabilities, so they do not become handicaps.²⁾ Thus we do not find staircases so high that only the giants of Brobdingnag can climb them, nor do our symphony orchestras play at frequencies inaudible to the human ear and audible only to dog ears. When a person is blind, or deaf, or has to go around in a wheelchair, societies are not so well adjusted to make such persons fully mobile, fully able to occupy public space on a basis of equality. What blind law professor Jacobus Ten Broek called “the right to be in the world” is unevenly extended to its citizens, and people who could perfectly well get around if the streets were maintained in a particular way, for example, are put by social contingency in a position of dependency - on a dog, other humans, a network of support.³⁾

Other citizens have disabilities that make dependency on others a virtually inevitable fact of their daily lives. People with severe mental disabilities, for example, may never be able to live on their own, and some rely on caregivers for their most basic bodily needs.

Who does all the work that care requires? In a vast majority of the cases, women⁴⁾. Indeed, the most ubiquitous and long-lasting conception of the woman, in virtually all countries and traditions of the world, is as a giver of care: homemaker, mother, wife, tender of the needs of the elderly - in general a supporter of the needs and ends of others. Often this conception of the woman sees her as a mere means to the ends of others, rather than as a source of entitlements in her own right, a being who ought to be treated as an end in herself. Thus, women’s care giving function has often been understood to remove them from candidacy for full citizenship and for many aspects of employment, especially wage-earning work outside the home.⁵⁾ Even when women are legally entitled to work and participate in citizenship, their heavy responsibilities in the home often make it difficult for them to do so.

Nancy Folbré uses a vivid image for this situation:⁶⁾ it is as if society, in trying to get ahead, allows some people to run in the race without any handicap. Others have to run carrying other people (children, the sick, the elderly). Obviously enough, those in the second group will lag behind from the point of view of their personal goals and their contribution to society outside the

home, even though the work they are doing is obviously essential to the survival and well-being of society. This will be true of all who bear a disproportionate burden of housework and care in addition to other work they do. Even in societies where women are heavily involved in family agriculture (for example, much of sub-Saharan Africa), women typically face extra burdens, insofar as they are expected to do most of the housework and child care in addition to their other work. (Women in Sub-Saharan Africa, however, typically do somewhat better than poor women in economies that do not encourage women to work outside the home, because at least the non-care work that they do is perceived as work and enhances their bargaining position in the family.⁷⁾

The problem of care is a complicated logistical problem for any society. It is also, most emphatically, an ethical problem, a problem that must be addressed not only with resourceful policy thinking but also with the best normative thinking that we can muster. All too often, economic thought addressing this problem proceeds as if it is only a matter of efficiency, and not, as well, a matter of justice and equity. The first step in addressing this problem well is to recognize that it is an ethical problem, a problem of justice. We will only work out good strategies to solve it if we first map out clearly the goals toward which we want policy to work, and offer sound normative reasoning supporting our choice of goals. Here as elsewhere in the international development world, the simple language of economic efficiency must give way to a more complex, more reflective language of full human development, and to a debate in which we reflectively identify some especially central goals for a process of human development. As the late Mahbub UI Haq wrote in the first of the Human Development Reports of the United Nations Development Programme, "The real wealth of a nation is its people. And the purpose of development is to create an enabling environment for people to enjoy long, healthy, and creative lives. This simple but powerful truth is too often forgotten in the pursuit of material and financial wealth."

A.2 Some minimal goals

What shall those more complex goals be? In this paper there is of course no space to offer a full account of this difficult matter, and it would be inappropriate in any case to attempt such an account, given that the appropriate goal for this project would be to propose a set of normative guidelines that will command wide agreement among people who otherwise differ about what goals societies should be promoting. In the context of such an enterprise, it would be inappropriate to rest the argument on a particular kind of controversial theory of development, however attractive. So, following the procedure of the Human Development Reports, let me simply mention some matters that seem uncontroversially central in thinking about a society's quality of life, in areas that are pertinent to care. First of all, as the

Reports repeatedly insist with their constant focus on inequalities in basic life chances, a just society would minimally be one that offered to all its citizens, regardless of birth or race or sex or disability, decent life chances in areas including, though hardly limited to, health, education, employment, and political participation. Both the caregivers and those for whom they care, then, should have decent life chances in these areas. And (as the Human Development Reports imply by their constant focus on the measurement of inequalities), they should be given these opportunities on a basis of equality with other citizens: no group should be turned into second-class citizens by accidents of birth or race or sex or disability. Implicit within these twin emphases on equality and basic life chances is another goal, more elusive but extremely important: that of giving all citizens the social bases of self-respect. John Rawls called this the most important of the “primary goods,” goods that all people can be assumed to want whatever else they want, as crucial to the formation and execution of any life plan.⁸⁾ Both the cared-for and the caregivers, then, should have their self-respect protected, so far as it is within the power of social institutions to do so.

These are highly general goals: but they have teeth, particularly when we consider the area of care. On the side of the cared-for, most societies are very far from providing the long-term disabled with opportunities for adequate health care, education, employment, and political participation. As Ten Broek so trenchantly put it, social institutions frequently deny the disabled “the right to be in the world,” to occupy public space on a basis of equality with others.⁹⁾ The mentally disabled, especially, lack support for their educational development and for the political participation of which they are often quite capable.¹⁰⁾ When we add to the issue of decent life chances that of equality, these problems become larger. The denial of suitable education to mentally disabled children, including the “mainstreaming” of the disabled in classrooms for “normal” children where feasible and appropriate, has been found by U.S. courts to be a violation of the equal protection clause of the U.S. Constitution, much in the way that schools segregated by race were found to be an equal protection violation.¹¹⁾ On the side of the caregiver, once again there are decent life-chances issues. Women who must shoulder the burden of care for a dependent are frequently greatly hindered in education, employment, and political participation, and their health frequently suffers as well. These issues, once again, become larger when we raise the question of equality: if women face an undue burden, it is all the more inappropriate for being one that is given to them unequally, in a way that unequally limits their life chances.

Finally, the issue of self-respect is obviously of crucial importance, both on the side of the cared-for and on that of the caregiver. Care for elderly and disabled people is frequently offered in ways that subvert dignity and self-respect. At one extreme here are citizens like Ten Broek, who plausibly insist that it is a terrible insult to their equal competence to be made to accept

limitations on their use of public space on account of their disability; what they seek is recognition for their equal capacity to participate fully in society. At the other extreme are elderly and disabled persons who are not capable of autonomy or full social participation; for these people, too, respect for human dignity needs to be a central goal of the caregiving process. It is important to recognize that the Ten Broek group is larger than we think: disabilities such as Down Syndrome, reared appropriately in the early years, can yield a life of very full inclusion and participation.¹²⁾ Elderly people, too, are far more capable of many types of functioning, given appropriate support, than they have typically been thought to be. Many problems that have been regarded as inevitable consequences of aging are actually due to treatable diseases, such as depression. Protection of the self-respect of the disabled thus requires complex thought about many different types of disability.

On the side of the caregiver, self-respect again poses urgent problems: work in the home is typically not respected as work and is not considered to be work in the way nations typically keep economic accounts. The category of the “productive” worker has usually been distinguished from that of workers in the home, as if work in the home is not productive and does not contribute to society’s productivity.¹³⁾ More informally, women who care for children, disabled people, and elderly people in their own home are usually treated as if they have no occupation. Even when this work is paid work, it is given low respect. Thus, in a 1975 U.S. government survey in which people were asked to rank types of employment by the amount of skill involved, the jobs of (paid) foster parent and nursery school teacher ranked right at the bottom, next to people who shovel wastes and the job called “mud mixer helper.”¹⁴⁾ Moreover, the self-respect of caregivers is often seriously undermined by the sheer difficulty of pursuing life-plans of one’s own while doing the work required to care for others. Especially in modern societies in which people’s sense of worth is frequently tied to a career and success in it,¹⁵⁾ people who stay at home, or who work part-time because of burdens of care at home, are at high risk for depression and a sense of low worth.

Addressing the problems of care has at least three distinct aspects, on the side of the caregiver: the allocation of caregiving responsibilities within the household, the support (or lack of support) for caregiving on the part of the public sector, and the structure of jobs and careers. Women are disabled by caregiving responsibilities, to the extent that they are, in part because men do not do anywhere near half of the housework, child care, disability/illness care, and elder care, even in two-career or two-job households. Raising women’s awareness of their worth and their (at least nominal) opportunities is surely one task of human development. But to have any hope of changing real life this task needs to be accompanied by the task of educating men to see worth and manliness in ways that are not incompatible with doing more care than men typically do. The recognition of this issue is not restricted to “developed” countries but is a prominent part of the development process. To cite just one

example, Adithi, a prominent NGO in Bihar, India, which focuses on the empowerment of women through labor organization and education, also runs a training program for male teachers who teach boys in the public schools. Here these male teachers reflect about how they can get young boys to see that housework and child care are not shameful. When I visited the Adithi project in the Sitamarhi district in northern Bihar, they boasted proudly of their success: "In every household in this district," I was told, "you will see boys sweeping, caring for the body, even cooking." Although it is hard to know how exaggerated such rosy claims may be, the very awareness of the issue is itself progress.

Public sectors in different countries vary greatly in the extent to which they subsidize parental leave, public child care, elder care, and care for people with disabilities. Women who care for a dependent or dependents without having any choice in the matter will have new freedom to choose to care for a loved one if the state makes alternative modes of care (in-home nursing, for example) available as part of a basic health care scheme. Such policies may also remunerate the caregiving work of family members. Eva Kittay, among others, has recommended a cash payment to the household for purposes of care, which can be used either by the members of that household for their own purposes, or to hire outside help. In this way, she argues, care will be clearly recognized as paid work, and given dignity, even when, as will often happen, a member or members of the household prefer to care for an elderly or disabled or young relative themselves.¹⁶⁾ State policies decisively influence the fortunes of physically and mentally disabled people in other ways, influencing what types of specialized health care and education they are entitled to claim. State policies also influence the issue of allocation within the home; for example, parental leave that can be shared between men and women strongly encourages males to do more caregiving. One obvious need is for a centralized pooling of experiences with these different types of policies, and a study of the extent to which state action actually makes a difference in the choices women are able to make.

But state action is limited in its effects by the policies of private employers. In all countries of the world, jobs and careers differ greatly as to whether they provide the flexibility that many caregiving adults, male and female, need if they are to fulfill both work responsibilities and caregiving responsibilities. The lives of poor women in India are typically shaped, generation after generation, by employer inflexibility. For example, poor sharecroppers in Bihar, whose employers insist on a long day without breaks for housework or child care, often have no choice but to turn over household tasks (including care for family-owned animals) to their female children, keeping them out of school for this purpose. If the household contains an elderly or disabled relative, girls are even more likely to be kept home. Such decisions do not necessarily reflect sexist thinking; they may only reflect economic reality, since educated boys have greater job opportunities than educated girls. Thus

inequality perpetuates itself from generation to generation. In “developed countries” with successful schemes of compulsory education for children, the likely outcome of this type of tension is for the adult woman to “elect” part-time work or work on a “track” that does not promise much job advancement. Unfortunately, most careers still define the successful worker as the full-time worker and define part-time workers, or workers who take extensive leave, as second-class workers. A macho ethos still prevails in the workplace, according to which the good worker is the one who puts in long hours and takes little time off. Such policies (especially common in the U. S., with its tradition of valuing overwork and devaluing leisure) discourage ambitious men from doing care in the home or taking parental leave, even when it is available. Young lawyers in the U.S., for example, have no chance of advancement to partner if they choose the flexible part-time “mommy track.” Although some firms provide on-site child care, there are few who do not subtly frown on workers, male or female, who seem to need it.

The workplace problem has, of course, another face: that of the recipient of care. Workers who are disabled in various ways need accommodation if they are to be able to work productively. Employers often fail to provide such accommodation. In almost all nations, blind and deaf employees, people with a wide range of physical disabilities, and even the mentally disabled can do valuable work if the environment supports them; to the extent that they can do such work, they are more independent and less likely to need full-time care. But such accommodations are often costly, and employers are reluctant to hire such employees. Some nations have made virtually no progress in integrating people with disabilities into the labor force; stigma remains prohibitive. In the many nations that have made serious efforts to alter the workplace to suit the needs of disabled workers, litigation continues over what a disability is, what obligations it imposes, and what a reasonable accommodation would be.¹⁷⁾

So: care must be supplied to those who need it, without exploiting the givers of care. All must have decent life opportunities and self-respect, on a basis of equality with others. At present, in all nations of the world, this difficult social problem has not been solved.

These problems need to be approached from many angles. We need better data about their extent, and more comprehensive accounts of how different nations and local governments are addressing them. We need more comprehensive studies of different career structures, in order to be able to imagine models that promise good solutions for caregiving adults.¹⁸⁾ But we also need to ask whether there are deeply entrenched ways of thinking in many societies that militate against the full and fair solution of these problems. The present paper will pose that question, and offer an affirmative answer.

This paper, then, will be a conceptual and theoretical essay, intended to complement the more empirical treatments of the problem of care. The paper criticizes dominant models of society as a social contract and recommends a new theoretical perspective based on the idea of “human development” and that of fostering human capabilities. I shall argue that the general way of thinking about society, its citizens, and its goals fostered by the social contract tradition and by now widely disseminated around the world is one large part of our problem. It has created a blinkered way of thinking about need, dependency, and dignity that make it hard to place care in a sufficiently prominent place on the agenda of society, and to give it the support it deserves. By contrast, I shall argue that a perspective based on ideas of human capability and functioning can more adequately deal with issues of social justice raised by the need to provide care for the elderly, the lifelong disabled, and others in a state of extreme and asymmetrical dependency.

Abstract images of human interactions may seem very far away from the daily stuff of political problem-solving. And yet we all think of ourselves in ways influenced by abstract pictures of what a human being is, and these ways shift over time. The importance of such abstract concepts is well known in the history of feminist thinking about law and social justice. Concepts such as those of rape within marriage and sexual harassment in the workplace are not self-evident. For many centuries it was supposed that marriage on its own gave a man a title to intercourse whenever he wanted, without waiting for the wife’s consent. And in the workplace it was assumed that to ask for sexual favors was perfectly unproblematic. Feminist theory, building on people’s experience of indignity and inequality, created these theoretical concepts and helped prepare the way for legal and political change. Theory needs to be securely anchored in experience if it is to be adequate, but the dominant theories are often theories that respond to the dominant voices. We need critical theories, which listen to the experiences of the oppressed and take their orientation from these facts of inequality. The type of conceptual criticism carried out by the feminist movement and its methods of “consciousness raising” have turned out to be profoundly practical.

This is just one example of the way in which pervasive images of the person shape social and political thought; the reflective critique of such images can reshape thought. I shall argue that the social contract tradition has shaped widespread ways of thinking about care, in ways that have deformed our conceptualization of the problem and its solution. I shall offer a critique of the image of the citizen proposed in that tradition and argue for a way of reshaping it that retains many of its best insights concerning the importance of dignity, agency, and reciprocity, but lacks its most troubling defects.

Endnotes

- 1) *My own version of the Capabilities Approach, as an approach to a minimal theory of social justice, is given in "Frontiers of Justice: Disability, Nationality, Species Membership", Harvard University Press, 2006, in "Women and Human Development: The Capabilities Approach, Cambridge and New York", Cambridge University Press, 2000, and in "Capabilities as Fundamental Entitlements", Feminist Economics, 2003.*
- 2) *In the literature on disability, the terms "impairment" and "disability" are typically used of a limitation in function that is, so to speak, internal to the person; the term "handicap" is used to refer to the burdens and difficulties the person faces in the world, many of which are social in origin.*
- 3) *See Broek T. "The Right to Be in the World: The Disabled in the Law of Torts," California Law Review, 1996, 54:841-919. He points out that the tort law of his time allowed a blind person like himself to bring a damage suit for negligence against, say, a municipality that maintained its streets in an unsafe way, only if that person was escorted by either a sighted person or a guide dog. He proposes, instead, that the streets ought to be maintained in a way that would make them safe for sighted people at night and blind people during the day, and that departure from this norm defines a standard of negligence. He movingly indicts the legal situation of his day as one that is demeaning to the blind person's desire for independence and full participation in public space "No courts have held or even darkly hinted that a blind man may rise in the morning, help get the children off to school, bid his wife goodbye, and proceed along the streets and bus lines to his daily work, without dog, cane, or guide, if such is his habit or preference, now and then brushing a tree or kicking a curb, but, notwithstanding, proceeding with firm step and sure air, knowing that he is part of the public for whom the streets are built and maintained in reasonable safety, by the help of his taxes, and that he shares with othersthis part of the world in which he, too, has a right to live."*
- 4) *To take just one example: According to the U.S. Department of Labor, Women's Bureau (May 1998), an estimated 22.4 million households - nearly one in four - are providing home care for family members or friends over the age of fifty. For these and other data I am grateful to Harrington M. Care and Equality, New York, Knopf, 1999. This is a major theme in recent feminist work: see especially Kittay EF. Love's Labor: Essays on Women, Equality and Dependency, New York, Routledge, 1998; Folbré N. "Care and the Global Economy," background paper prepared for the Human Development Report 1999, United Nations Development Programme, New York, Oxford University Press, 1999, and, based largely on Folbré, chapter 3 of Human Development Report 1999; see now Folbré N. The Invisible Heart: Economics and Family Values, New York,*

The New Press, 2001; Williams J. Unbending Gender: Why Family and Work Conflict and What to Do About It, New York, Oxford University Press, 2000; Harrington M. Care and Equality. Earlier influential work in this area includes: Fineman MA. The Illusion of Equality, Chicago, University of Chicago Press, 1991, and The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies, New York, Routledge, 1995; Ruddick S. Maternal Thinking, New York, Beacon Press, 1989; Tronto J. Moral Boundaries: A Political Argument for an Ethic of Care, New York, Routledge, 1993; Held V. Feminist Morality: Transforming Culture, Society, and Politics, Chicago, University of Chicago Press, 1993; West R. Caring for Justice, New York, New York University Press, 1997. For an excellent collection of articles from diverse feminist perspectives, see Held V, ed. Justice and Care: Essential Readings in Feminist Ethics, Boulder, CO, Westview Press, 1995.

- 5) *For just one typical example, see Bradwell v. Illinois, 83 U.S. (16 Wall.) 130 (1873), in which the U.S. Supreme Court, upholding an Illinois law that made it illegal for a woman to practice law, declared that woman's role in the family "evidently unfits" her for "many of the occupations of civil life."*
- 6) *See "Care and the Global Economy," cited above.*
- 7) *See Sen A and Drèze J. Hunger and Public Action, Oxford, Clarendon Press, 1989, arguing that women in Africa thus command a more adequate share of food and basic necessities. For the fundamental analysis of different work patterns in agriculture, see Boserup E. Women's Role in Economic Development, New York, St. Martin's Press, 1970.*
- 8) *Rawls J. A Theory of Justice, Cambridge, MA, Harvard University Press, 1971. Rawls's concept of primary goods will be discussed further below.*
- 9) *For more discussion, see the essays in Francis LP and Silvers A, eds. Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions, New York and London, Routledge, 2000; and Silvers A, Wasserman D, and Mahowald, M. Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy. Lanham, MD, Rowman and Littlefield, 1998.*
- 10) *See Levitz M and Kingsley J. Count Us In: Growing Up With Down Syndrome, New York, Harcourt Brace, 1994; and Bérubé M. Life As We Know It: A Father, A Family, and An Exceptional Child, New York, Pantheon, 1996.*
- 11) *Pennsylvania Association for Retarded Children v. Pennsylvania, 343 F. Supp. 279 (1972); Mills v. Board of Education (District of Columbia, 1972). I discuss these cases and the issues they raise at length in Hiding From Humanity: Disgust, Shame, and the Law, Princeton, forthcoming from Princeton University Press in 2003. The allocations of funds under the Individuals with Disabilities Education Act (IDEA), which responded to*

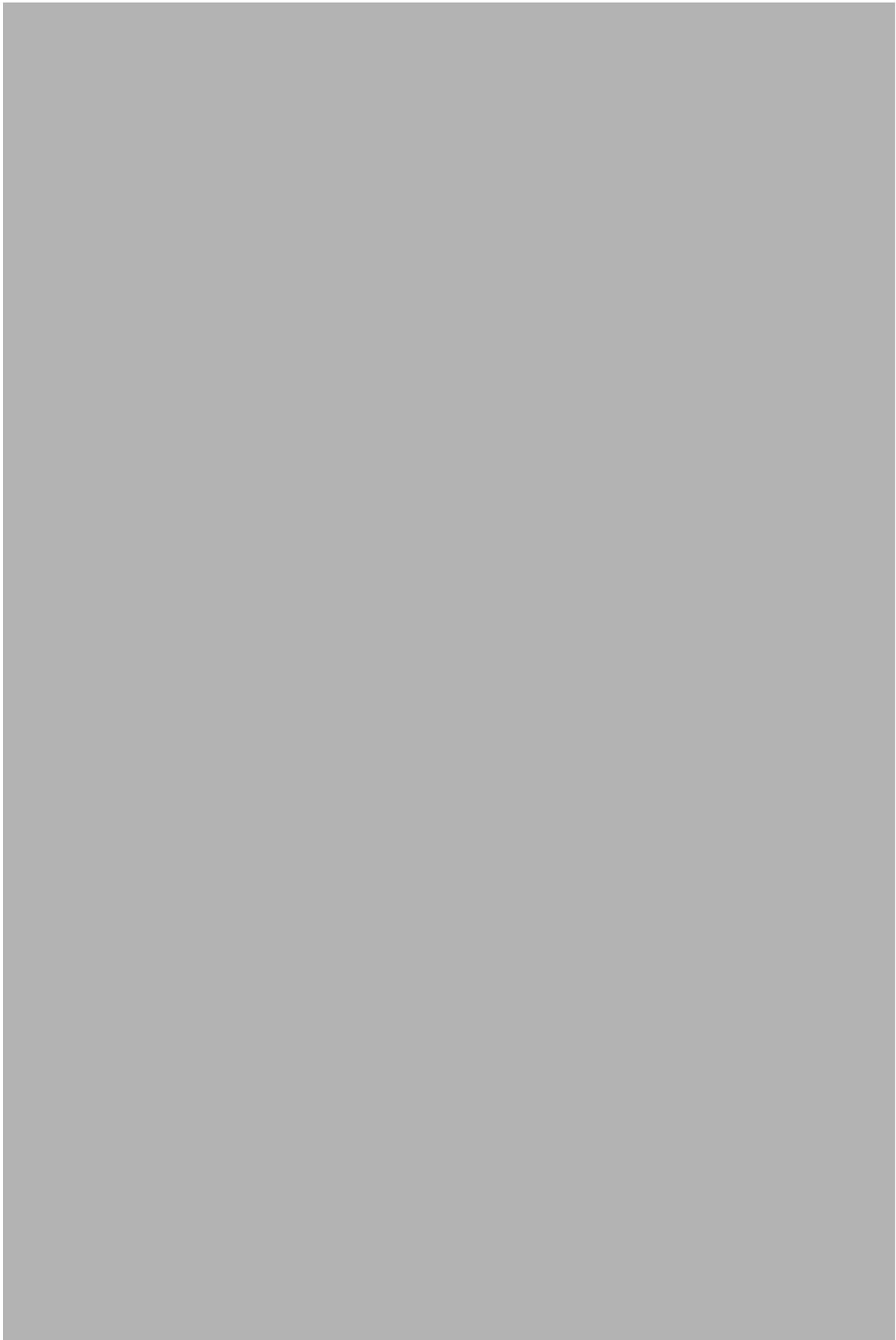
these cases, have been much criticized on the grounds that the definition of "learning disability" is vague and open-ended, and encourages states to classify normal-slow children as disabled, in order to get access to federal funds: see Kelman M and Lester G. Jumping the Queue: An Inquiry into the Legal Treatment of Students with Learning Disabilities, Cambridge, MA and London, Harvard University Press, 1997. But even Kelman and Lester grant that the law works well for children who have severe disabilities that have a precise medical definition, such as Down Syndrome, autism, etc., and that, given the emphasis on "mainstreaming," the law does not impose impossible financial burdens.

- 12) See Levitz and Kingsley; see Bérubé.
- 13) A formative example of this way of speaking is in Adam Smith's *The Wealth of Nations*.
- 14) From Ruddick S. *Maternal Thinking*, Boston, Beacon Press, 1989, quoting Howe LK, *Pink Collar Workers*, New York, Avon, 1977, p. 237.
- 15) I mean here not "developed" as contrasted with "developing" countries, but all societies influenced by the idea that work is integral to one's self-definition and worth. Ancient Western societies were very different: ancient Greece, for example, understood work to be a baneful necessity, and a diminution of one's worth. The modern Western version of this idea probably has Protestant origins; but, whatever its origins (and they are probably multiple, in different traditions), it is by now very widespread.
- 16) Kittay EF. *Love's Labor*.
- 17) See Francis and Silvers, cited above.
- 18) See Williams, cited above.

SECTION 4

Jean-François MALHERBE:

**OF SOLIDARITY BETWEEN JUSTICE
AND EQUITY**



Of Solidarity between Justice and Equity¹⁾

Jean-François MALHERBE

*Professor and Holder of the
Applied Ethics Chair
Université de Sherbrooke
(Canada)*

Honorable Minister,

Ladies and gentlemen,

In regard to the allocation of scant resources for the long term care of geriatric patients, I would like to put forward a few conceptual tools within the realm of what I refer to as the *ethics of finiteness*. By this I mean a practice of ethics that is two fold. On the one hand, it is a lucid approach, because it accepts the fact that ideals are not of this world; while on the other hand it is a courageous approach, because it radically demands a daily battle against evil, suffering and pain. It is an ethics which recognizes that none of us are all-powerful, nor are we totally helpless. It is also an ethics which claims that there are things we are empowered to do, and yet, that we cannot do everything.

What is *Ethics*?

Since the concept of ethics takes so many forms in our culture and the meaning I attach to it is rather unusual, I must, before I go proceed, clearly define what my understanding of *ethics* is. In my view, ***ethics is the labor I am willing to perform in the groundwork, with other people, in order to reduce as much as possible the inevitable gap between the values I display and those I actually practice.*** I think it would be useful that I comment on this statement, since each part of it bears special significance.

Ethics is the labor ...

The word “labor” is used in the very powerful sense of parturition, as in the expression “to be in labor” used to describe a woman delivering a child. It is

1) *This was the inaugural speech at a seminar held in Luxembourg on December 10 and 11, 2004 by the Inspection générale de la Sécurité sociale, which was attended by Monsieur Mars di Bartolomeo, Minister of Health and Social Security of the Grand Duchy of Luxembourg. The seminar theme was: Values underlying social justice their application to the long-term care of older persons.*

an act which gives life to a human being, therefore a personal act of origination. It is not simply a commanded work performed mechanically and relatively devoid of creativeness.

... that one is willing to perform

Everyone is called upon to participate in this labor, but each person is free to reject the involvement it requires. There will always be hard core individualists who will value their subjectivity above the law. And there will always be legalists who will hide their frailty behind the letter of the law. But these extremes cannot be justifications to refuse to participate in the search for a third way between subjectivism and legalism.

... *that one performs with others*

Of course, anyone can strive to refine one's judgment. But the most fruitful way to evolve one's common sense into "refined common sense" remains a critical discussion between peers, which is characterized by what philosopher Karl Popper called "critical inter-subjectiveness".

... to reduce the inevitable gap

There is always a gap between ideals and reality. There is no reason to be scandalized by this, since the human condition is such that we can never live up to our ambitions, even the most legitimate ones. But our challenge is not so much to become perfect, as to follow the path that leads to a greater good.

... *the gap between the values I display and those I actually practice*

Some people deny the very existence of this gap. For example *Idealists* can only see displayed values and hold them as so sacred that they become a screen which creates the illusion of being protected from reality; cynics, on the other hand, only consider practices while deny the existence of values or use these practices in "machivellian" ways to turn other people's eyes away from their own dubious behavior. To deny the gap by making one pole the absolute truth is to deny the work of ethics, even if one makes an impressive display of values. To positively deal with the pressure inherent to the gap, by working at reducing it, such is the work of ethics.

... *"as much as feasible"*

The labor is endless, and for this simple reason we cannot have a grip on everything. Many realities remain beyond our ability to change them. This is what Aristotle called *necessity*, namely that which cannot be other than what it is. To this concept Aristotle opposed the idea of *contingency*, namely that which *could* be other than what it is. Aristotle indeed advises us to avoid trying to modify *necessity* and to accept what we cannot change, while concentrating our efforts on modifying that which is in our power to change, contingency. This humble determination amounts to dealing with the finiteness of our human condition. This may cause some people to become discouraged, especially those who, much like spoiled teenagers, want to have everything right then and there. But as adults let us remember that one

cannot have his cake and eat it too. We are called to use our ability to distinguish between what is feasible and what is not, a sign of true maturity.

Our discussion workshops will be centered on this operational definition of ethics so we will have opportunities to put it to the test. In a first series of workshops we will try to measure the gap between our displayed and practiced values, and in a follow-up series we will try to devise concrete measures to reduce this gap.

What are Equity and Justice?

My answer to this question is a classical one since it is, in my understanding, that of Aristotle. In his *Nicomachean Ethics* he wrote:

What creates the problem is that the equitable is just but not the legally just but a correction of legal justice. The reason is that all law is universal but about some things it is not possible to make a universal statement which shall be correct. In those cases, then, in which it is necessary to speak universally, but not possible to do so correctly, the law takes the usual case, though it is not ignorant of the possibility of error. And it is nonetheless correct; for the error is neither in the law nor in the legislator but in the nature of the thing, since the matter of practical affairs is of this kind from the start. When the law speaks universally, then, and a case arises on it which is not covered by the universal statement, then it is right, where the legislator fails us and has erred by over simplicity, to correct the omission – to say what the legislator himself would have said had he been present, and would have put into his law if he had known. Hence the equitable is just, and better than one kind of justice – not better than absolute justice but better than the error that arises from the absoluteness of the statement. And this is the nature of the equitable, a correction of law where it is defective owing to its universality.

Here is an illustration of this remarkable definition of equity as a corrective for justice, when the latter fails us by being²⁾ excessively universal. A mother wishing to share a sugar pie with her husband and four children first thinks of dividing the pie justly, thus in six equal shares. But she is hesitant because her husband is diabetic and she is trying to lose weight. They have two boys aged 2 and 11, and two twin daughters aged 17. So she reconsiders and decides to serve the pie equitably. Not equally, but not unjustly either. And so, she cuts “symbolic” sized helpings for her husband, the younger boy and herself; the older boy gets a “normal” piece and the twins, whose birthday

2) *Aristotle : The Nicomachean Ethics, 1137 b 10, Translation by William David Ross. Clarendon Press, 1908.*

they are celebrating, get double shares. Such is equity: a corrective for justice where error can be encountered due to the absoluteness of the law. Sharing in accordance with the principle of equality is justice “in principle” but such “to the letter” application of equality in field situations may prove to be inequitable. In such cases, as Aristotle teaches us, is it preferable to transgress the letter of the law in the name of its *raison d’être* which is equity. It is thus necessary to have precise guidelines (rules or laws) to control our decisions, but equally important to exercise judgment in their application. Our guideline systems are essential but “intrinsically imperfect” as our philosophers tell us. This is why laws are only applicable through the exercise of judgment.

Equitable distribution would then take into account the whole which is to be distributed and the actual needs of each one of the recipients. I will come back to this later.

What is Solidarity?

In order to define solidarity, I will use a roundabout way which may appear long but which will prove its absolute usefulness later on. In my view, solidarity is one of the “ingredients” of human autonomy. I must immediately put forward that autonomy is not a matter of either-or, an attribute which we either possess or are completely devoid of. Autonomy is a matter of more or less, a matter of degree. And the biography of a human being could be described in terms of a curve that records the variations in one’s autonomy during the course of one’s life.

I will define autonomy on the basis of a very ancient observation (since ancient Greek philosophers had already made it) that a human being is a “speaking animal”– therefore “political” as Aristotle would say. If a human being is a speaking animal, it follows that his greater or lesser autonomy will manifest in the order of speech and dialogue. As Hannah Arendt would put it, a human life becomes successful when a person, aside from being the actor of his/her own life, also becomes the author of the scenario which decides how that life will be acted. This implies that I, in true dialogue with my fellow human beings, should become autonomous with respect to what they can expect of me. Thus, the conditions that make a true dialogue possible are also the “ingredients” of autonomy.

From a “critical” standpoint, what does the expression “to cultivate the autonomy of others” actually mean? In the title of the chart below, (*critical concept of autonomy*) the adjective “critical” which qualifies the noun “concept” indicates that we are dealing with a concept which is defined following a discernment effort (the Greek word *krinein* means to discern) rather than a usual concept. Therefore, the definition of the concept put forward here is a technical one, which is not necessarily in accordance with current uses of the word.

Autonomy stems from the Greek word *auto-nomos*. *Nomos* means rule or law while *auto* conveys the idea of reflection, in the sense of a reflexive pronoun. Etymologically then, one would say of a person or an institution that they are autonomous if they make their own rules, if they are their own legislators. Likewise, a democratic government is autonomous by definition, since it makes its own laws.

"One who makes his own rules". This does not necessarily mean that one can elevate one's own arbitrary pleasure to the status of rule or law. This would be false autonomy. Reality is different: a truly autonomous person learns to read the law engraved deep within self, which defines one's belonging to the human race. This law is the same for all human beings since it defines our common humanity. Of course, one may read it differently from another person. But then, what is this law which philosophical thinking allows us to read in the depths of our identity and renders us united to one another?

Critical concepts of the autonomy matrix

" <u>Matter</u> "	" <u>Form</u> "	" <u>Labor</u> "	" <u>Finality</u> "
Acknowledging, between others and myself:	Complying with the prohibitions of :	Dealing with my human condition i.e. :	Fostering the values of :
The presence	Homicide	My solitude	Solidarity
The difference	Incest	My finiteness	Dignity
The equivalence	Untruthfulness	My uncertainty	Liberty

To answer this question I shall start from the basic truth that in the course of human history there has been at least one act of communication between two human beings which was, at least in part, successful. There can be no doubt about this. When one asks a question he/she automatically demonstrates its validity simply by communicating a different opinion to others. Anyone issuing a statement to demonstrate that communication is impossible would, by the very fact of making a statement, demonstrate that it is invalid since it would be in fact... communicated. So this starting point cannot be questioned, under any philosophical or religious pretension, since objectors would have no standpoint to speak from.

Our unquestionable starting point leads us to the dialogue that can exist between two people, even if less than a perfect one. Our work thence will consist in stating the conditions that must be met to make this starting point possible. First we observe a fact and then ask ourselves under which conditions this fact can exist. For reasons that would take too long to explain in detail, we will now lay down twelve conditions in the form of a chart with two sets of entries: three vertically, four horizontally.

There are three vertical entries because every human act has a three-dimensional aspect: organic, physical and symbolic. The chart is set in four columns, in accordance with the classical Aristotelian approach (theory of the four causes) which states that human existence can be exhaustively analyzed from four successive standpoints: the material cause, the formal cause, the efficient cause and the final cause. This chart represents what is called the *critical concept of autonomy matrix*.

What are the conditions that must be fulfilled for a dialogue to exist, at least half successfully?

First condition: For a dialogue to originate between two people, first they must be present to one another. This presence may be via a medium such a telephone, a fax, paper mail or any other medium of communication, but each interlocutor must make sure that the other is present. Mutual presence is then an *a priori* condition for a dialogue. In a derived sense, this is also a condition for soliloquy – presence to oneself.

Second condition: It is because at one point in my life, someone else other than myself addressed me that I was able to enter into the realm of social conversation. Difference between interlocutors is a necessary condition for dialogue to occur. Indeed, no dialogue is possible without being altered by it. A thousand and one differences in fact have made us distinct entities and everyone a unique being. Now the question is to acknowledge as differences in *right* those differences in *fact*, meaning that the other person does not belong to me, is not my thing or my tool to use as I please. I cannot communicate with a slave, that is, with someone I consider inferior to myself; neither can I communicate with a machine that is slightly more sophisticated than an inanimate object.

Third condition: Difference is not enough. There must also be a certain equivalence between interlocutors. To avoid any misunderstanding, let me specify that the difference I am referring to here is factual; such as when a man is talking to woman or an older person is talking to a younger person, etc. Equivalence, on the other hand, is in the order of values. By this I mean that whatever the “factual” differences are between two people, my moral values are the same for everyone. For example, in an extreme case, if I had to choose between someone else’s life and mine, the choice could only be an arbitrary one since, in principle, because as members of the human race we have the right to the same dignity and consequently the right to the same respect.

Another way of stipulating this would be to highlight the fact that I cannot really communicate with someone I do not take seriously, someone I think I can lie to as I wish, or whom I suspect of lying to me. I must consider the person I address as being on the same moral level as I, in spite of the factual differences that distinguish, or even separate us.

Presence, difference and equivalence are thus the first conditions for the possibility of a dialogue.

Now then, how could I acknowledge the presence of others if I allowed myself to do away with them as I please? When I acknowledge the presence of others I am required not to separate people in the two categories, those I choose to keep relating to, and those I choose to get rid of. Thus, without complying with the prohibition of homicide, it is impossible to acknowledge the presence of others or consequently of a dialogue with them.

Further, if I allowed myself to exploit others as mere extensions of myself; if I claimed the right to engulf others within me, to “eat them up” and merge them into my bosom, how could I claim to acknowledge the difference between them and I (myself)? This being is the necessary difference for a dialogue to occur.

The compliance with the prohibition of incest, which we will call later the prohibition of domination, is yet another condition for a dialogue to occur. Incest is not understood here in the sense of social misconduct but in the archetypal sense used by psychoanalysts and anthropologists to convey the idea that in any community there is at least one potential sexual partner whom it is strictly forbidden to access sexually. Usually, it is one’s mother or wet nurse, and by extension one’s sisters and some cousins. Not that the intercourse would necessarily be a fusion, an engulfment of someone else into myself, or the enslaving of the person. But rather because there must be a prohibition designed to limit our desire to engulf others in order that communication – even of a sexual nature – may occur. Therefore, it is the prohibition of this fusion with the object of my desire which opens the way for a sound relationship, under the auspices of autonomy. There is no exception to this rule, in any known culture.³⁾

Furthermore, if I did not comply with the prohibition of idolatry, which we could also call the prohibition of alienation or untruthfulness, how could I claim that I respect moral equivalence, without which I could never initiate a dialogue with others? How could it be possible to have a true dialogue with someone I despise to the point of being untruthful with, or who despises me in the same way? In any idolatry, as in any alienation there is a lie.

3) *It is worthy of noting that this prohibition has other positive effects. It implies that a sexual partner must be sought after in another family or clan, which consequently reinforces social cohesion and genetic diversity through family alliances.*

A psalmist said:

The idols of nations

Are of silver and gold:

They have a mouth that does not speak,

Ears that cannot hear;

There is no breath in their chest;

As they be, so be those who make them

From this last sentence, Hegel, Feuerbach and Marx derived their theory of human alienation. It perfectly demonstrates the pernicious mechanics of idolatry: to take a man-made object and to invest one's humanity into it and to do so, to the point of forsaking one's own status of subject and turning oneself into an object. Idolatry and alienation are specific cases of untruthfulness. You cannot dialogue with someone with whom you are lying. You may dialogue with someone you have lied to, on the condition that you acknowledge it and ask for forgiveness. Let us put aside the cases of moral deadlock where it could be viewed that lying is acceptable in order to avoid greater evil.

When we define true autonomy as the capability to access within the depths of the self, or as the rule or law, which instigates humanity, while not elevating free will to that status, we are in actual fact anticipating the more detailed statement of the three prohibitions which we have just described. Humanity would not be what it is, if it were not structured by these three prohibitions, which actually define it. These prohibitions are not forced upon us by some greater authority. They are intrinsic (to our nature) and express the very conditions under which it becomes possible for us to (co-) exist as human beings, as distinct individuals and as a community as well.

Some philosophers hold that these three prohibitions are summed up in the first one, namely the prohibition of homicide. It is in fact plausible that to lie to others or to try to engulf them are two ways of killing them. I personally prefer to account for the three levels separately.

However, this task of complying with the three prohibitions that define humanity does not come easily. Indeed, a long path of personal evolution and maturing is required from each and every one of us, which challenges us to deal with our own unique human condition. Let me explain.

We are all required to deal with our solitude. Each one of us is alone, and most definitively alone. No one can take the place of another. Everyone carries his place with himself, so to speak. One can sympathize with someone else but no one else can take our place. When one gets a power of attorney to conduct banking transactions, how does he or she sign the legal forms? One signs with his or her own signature of course. One signs his or her own name on behalf of the person he or she has power of attorney for. Signing the other person's name would be considered counterfeit. Each one of us is the only

one who can say “I”, in his or her own name. If you say to someone: “I love you”, you are speaking on your behalf. Only for you are these words truthful and only you are bound by these words. Theatrical conventions allow for an actor to take the place of someone else, or rather to *play* a character. And yet, the actor is still playing a character, he or she is not the person he or she is depicting. Each one of us is so unique that we all have unique fingerprints. I call this the *inherent solitude* in all human existence.

We are not only solitary, we are also finite. We are the bearers of infinite dreams and desires and yet we are still limited in our possibilities to fulfill them. This means that we must choose, and to choose is to relinquish. Such is the kingdom of our finiteness. One cannot be the professor and the student at the same time. One cannot be a master of all trades. Sometimes we wrongly perceive our limits which lay beyond, or beneath what we believe them to be. But the fact remains that we are limited, by essence. If we refuse to accept the principle that we are limited, we are denying our differences and indulging in an engulfment; precisely because our limits are never exactly akin to those of others. It is only by coming to terms, day by day, with the fact that we are not God (nor the devil, for that matter) that we may in the long term give birth to ourselves. And this labor – in the sense of parturition – is always labor performed facing another person who either fosters or impedes it, but without whom the labor could not even take place. Thus we must always read the imprints of others within ourselves.

To add to this, we are also called upon to deal with our uncertainty. From the moment we accept to wage war against untruthfulness, we come to realize that there are very few things that we can hold as certain, and many of our certainties begin to appear as illusions that we were holding on to. Sometimes we hold on to them so tightly that we fail to – or just won’t – see them for what they really are. To let them go requires courage because too often our illusions are much like an immaterial and unconscious skeleton, wrapping our life and holding it together. And yet, it is on the path of uncertainty and detachment from our illusions that we can end up finding, deep within our being, the traces of others and the laws that make us human. It resounds like a call from within requesting us to cultivate the autonomy of the whole human being, in all human beings.

The fact remains that we are always in a state of uncertainty. Especially in difficult times when we are never sure that the lesser evil is really what we think it is. Inasmuch as we can assert, in truth, that we did all in our power to make the best decision in a given situation, we can also plead *not guilty* for that decision, even we were not sure that it was absolutely the best decision. In these matters as in many others, decisions that are said to be *objective* are more often than not, dictated by those who wield the biggest stick. We should certainly not feel guilty for being uncertain. But should be found guilty for believing that we were certain of our decision, or for not having critically considered the situation from all angles before rendering our final decision.

Rest assured, our human condition is not only characterized by negative aspects. Fortunately, it also comprises positive aspects which can be expressed in terms of values that we are called upon to cultivate. Only I can stand in my own space, and yet, I would not have a place to stand on, had I not been put there by others. The fact that we each occupy a pronominal position implies that other pronominal positions are also occupied, which readily demonstrates that there are others. We could not say “I” if there was not also a “you” and a “she” or a “he”. Our very solitude implies that there is solidarity between us. We would not be alone if we were not wanting for solidarity and we would not be capable of solidarity if we were not alone.

On the other hand, our finiteness is also that which bestows dignity upon us. Admittedly, we are not God. But neither are we nothing. We are ourselves and as such we are worthy. We all know people who are so dignified that they have become completely impervious to any call for solidarity; or others who are so lost in solidarity that they have relinquished their dignity. We have a calling for solidarity, but not at the price of our dignity. We are called upon to demand respect for our dignity but not at the price of our liberty.

Here at last is the twelfth condition for dialogue to exist – liberty. Is it not our uncertainty that is the condition for our liberty? How could we actually be free if we were not uncertain? If it were not for uncertainty, there would be neither choice nor responsibility. “*Responsibility*”: the moral obligation to answer for our choices and for the exercise of our liberty. It must be emphasized here that liberty is not autonomy but a mere component of autonomy. The arbitrary exercise of liberty is contrary to autonomy. Liberty becomes autonomy when it is adequately balanced by dignity and solidarity.

In the end, the law which instigates our humanity, the moral law said to be “natural law” according to certain schools of thought; that law which we can read in the depths of Self, in true dialogue with others who walk with us the path that leads deep within; that law is precisely the acknowledgement of the presence, the difference and the equivalence between us and others; the compliance with the prohibitions of homicide, incest and untruthfulness, the dealing with our solitude, finiteness and uncertainty and the cultivation of solidarity, dignity and liberty. Autonomy is all of this. An autonomous being is one who, day after day, endeavors to live according to this natural law which is to be found at the very depths of our humanity. Thus autonomy is not a question of either-or but rather of more or less, of progression and regression. This law does not confine us to heteronomy. It does not originate elsewhere. It is the raw expression of our humanity, which we can read in the traces of other beings within ourselves.

Finally our individual autonomy grows to the extent that we increasingly keep on acknowledging the presence, the difference and the equivalence between ourselves and others; that we also comply with the prohibitions of homicide, incest and untruthfulness; that we harmoniously integrate in our daily lives our

own solitude, finiteness and uncertainty; and that we resolutely cultivate the values of solidarity, dignity and liberty. Such is the foundation of “solidarity”: it is the fruition between human beings of the imperatively reciprocal fostering of each other’s growth in autonomy.

Guidelines for Decision Making

The critical concept of autonomy matrix is also a very useful tool to facilitate decision making in difficult situations. Let us consider a situation where it is difficult to choose between solutions A and B to a problem. Let us also consider that the key persons concerned by these solutions are X, Y and Z. The best way to decide between A and B (or to let a C solution transpire that would be preferable for all) would be to ask which one of these solutions would best cultivate the autonomy of the persons involved. Which one, A or B (or even a C solution) would the most adequate to further the acknowledgement of the presence, the difference and the equivalence between self and others; the compliance with the prohibitions of homicide, incest and untruthfulness; the harmonious integration of their solitude, finiteness and uncertainty in their daily lives; and the resolute cultivation of solidarity, dignity and liberty between them? There are twelve questions that call for answers that will highlight the dimensions of reality which in turn will likely become the foundations on which to base the best decision – or the least harmful one. Thus the best decision will be the one that will allow the people involved to better grow in autonomy – or at least to regress as little as possible.

Experience shows that this matrix is much more pertinent by virtue of the questions it raises than by the answers it induces. It is not uncommon to see that the reflection brought about by this tool to lead to the creation of new solutions, which are better for everyone than the solutions considered at the beginning.

The “Work of the Negative” in Ethics

Ethics, as defined above as “labor” implies a triple quest: the quest for truth, good, and beauty.

According to Ludwig Wittgenstein, the quest for “*truth*” is the quest for coherence between a “language set” and the life form which sustains it; that is to say the search for the “shortest distance” between the practices and the displays, or between what we do and what we say. Strangely enough, in our culture the quest for truth is always considered a “positive” conquest. The Cartesian approach to the quest for truth, which is to say, the progressive and

methodical extension of the “true” from a core considered “indubitable”, continues to dominate our culture even though, since the work of Claude Bernard⁴⁾ which was formalized by Karl Popper⁵⁾, we should have accepted the fact *that the quest for truth is in fact a fallacy chase*. The logic of scientific research endeavors can be construed as the multiplication of audacious conjectures and the merciless attempts to refute them, hitherto concealed under deceptive appearances. Therefore, in my opinion, it is quite erroneous, that since Descartes, we have conceived of the truth as the result of an unveiled knowledge. As suggested by the Greek word, which expresses it more accurately – *aletheia* – truth is in fact the act of unveiling. However, what is achieved by the operation is not the unveiling of the truth but rather that of a past mistake hitherto unnoticed. Oddly enough, this past mistake was to hope to discover the ultimate truth under a veil. Thus, the most authentic quest for truth is actually the quest for the lesser fallacy. So it is in fact the “work of the negative”.

The quest for “Good” is also a byproduct of the work of the negative. Is it not in fact the search for the greatest distance from the suffering generated by the contradiction between our practices and our displays? In his 1952 essay on “possession” at Loudun⁶⁾, Aldous Huxley wrote this :

The effects of an intense and prolonged concentration on evil are always disastrous. **Those who do not campaign for God⁷⁾ within themselves but against the devil⁸⁾ within others never succeed in making the world a better place; they only leave it as it is, or even obviously worse than it was before they began their crusade.⁹⁾** By primarily focusing on evil, whatever one’s intentions are, one invites evil itself into manifestation.”

“No one can concentrate on evil, or on the idea of evil and get away unscathed. It is extremely dangerous to be against the devil more than we are for God. All crusaders are at risk of losing their mind. They are haunted by the malice they ascribe to their enemies, which becomes in a way part of themselves.

Cultivating the “Sovereign Good” (Plato) seems in fact to stimulate the manifestations of the “Radical Evil” (Kant). The reason for this is that human beings do not readily agree on what the “Sovereign Good” is, and many have a tendency to impose their own interpretation of “Sovereign Good” upon

4) *Claude Bernard : Introduction à l'étude de la médecine expérimentale, Paris 1867.*

5) *Karl R. Popper, Logik der Forschung, Springer, Vienna, 1934. See also : Jean-François Malherbe: La philosophie de Karl Popper et le positivisme logique, PUF, Paris, 1976, 1979².*

6) *Aldous Huxley : The Devils of Loudun, « Perennial Library », Harper and Row, 1952.*

7) *One could also say : « oneness».*

8) *One could also say : « division ».*

9) *Highlighting is by the author of this address.*

others. Diverging dogmas ensue, which create rivalries and disagreements, which in turn give rise to clashes that end up impeding the quest for Good. As a result, the quest for the “Sovereign Good” transmutes into a reinforcement of Evil. It could even be said of the *radical evil* that it is the evil upon which rests the very root of our being, day after day. Things seem to happen as though the *radical evil* was feeding upon the “triteness of evil” (Arendt) that is, in the lack of common sense which drives people to see the “Sovereign Good” in the illusion of a so-called knowledge of it. That illusion is in fact a denial of our finiteness brought about by our technical control over our daily lives. So the quest for Good is actually the work of the negative: the quest for the **lesser evil** rather than that of the Greater Good¹⁰). In fact, it would be worthwhile to look at things from this point of view when we examine the awesome question of what happens to “dialogic ethics” when the conditions for dialogue are not met¹¹). Beyond this borderline, is ethics thwarted by an intrinsic limit or does it on the contrary find fulfillment methods other than dialogue?

In ethics, the individual’s quest for “beauty” takes the form of the creation of his own life as a “work of art¹²)”. The question becomes: “What is my identity, when I experience who I am, in synergy with others, as an unlimited creator of harmony?” To this very difficult question Hannah Arendt, in the wake of Thomas Hobbes, gave the following answer: “Not only am I the actor in the scenario of my own life but also the author of it¹³).” The labor of “becoming oneself” is then more than an effort to conform to a predetermined “idea of self”. This labor begins to produce its own “work of art” from the moment the subject transcends his subjection and evolves, even though little by little, from the state of “plaything” in a scenario written by others to that of writer of his own scenario. Here again, as brilliantly professed by Meister Eckhart¹⁴), the question is “to not become what we are not”. It is a question of detachment, or as theologians would put it, of “kenosis”, which tantamount to the quest for the **lesser influence** from our repetitious identity scenarios. Once again, this is the work of the negative.

The three quests described above can be summed up by three negative self commands: “Do not claim to know what you do not” (Popper – uncertainty); “Do not want what you cannot manifest” (Machiavelli – finiteness); “do not

10) *In fact, one could construct a complete « ethics of the lesser evil » on the basis of Nicolo Machiavelli’s work.*

11) *See particularly Socrate’s meta-discursive comments in Plato’s Gorgias which I referred to in: La corde pour me pendre. Remarques sur la possible naïveté d’une éthique dialogique, Novalis, Ottawa, 2005 (sous presse).*

12) *See Jean Bédard et Jean-François Malherbe: Telle un œuvre d’art, la vie ..., Éditions GGC, Sherbrooke, 2003.*

13) *Hannah Arendt : The human condition, French translation : La condition de l’homme moderne, Pocket Books, Agora, 1983.*

14) *Jean-François Malherbe: Maître Eckhart : « Souffrir Dieu », Éd. Du Cerf, Paris, 1992, 2002.*

become what you are not” (Eckhart – solitude). They are in fact the work of the negative. They are not endeavors conducted haphazardly, because the synergy that exists between them makes them a battle against dispersion, multiplicity and disharmony. Thus it is an orderly endeavor towards a sort of watermarked integrating finality. Oneness is not a given, it weaves itself through the progressive synergy of one’s battle against fallacy, suffering and subjection. In a sense it is utopia: a representation of reality which nowhere is to be found in its fulfilled form. On the other hand, it has the potency of an “eschatological restraint” relentlessly reminding us that in spite of the real progress we are making, “we are not there yet”.

Thus, applied ethics patiently devises humble answers to Kant’s three famous questions: “What may I have?” “What must I do?” “What may I hope for?” These watermarked finalities, these “utopias” are but “falsely true” names for “unreal realities”. Truth, Good, Beauty and Oneness do not exist. They have not survived the blow of William of Occam’s¹⁵⁾ awesome razor blade. Everything seems to point to the fact that to try to pursue them is to chase after a mirage and to fall into the trap of “contingent substance”. Thus the watermarks with which it is advisable to draw the utopian teleology of applied ethics urge us to proceed with modesty¹⁶⁾.

The “modesty” in question consists not in “*idealizing*” the object of the quest, since experience shows that *Ideals* are so seldom commonly shared and that the differences between them generate most of the violence we experience. Is it not in their name that are committed most of the murders, manipulations and lies which shatter the very foundations of our social pact and therefore allow the law of the strongest to prevail over the law of the State? Not to “idealize” probably means to “*de-substantialize*” (“not to be of substance”) as Hegel suggested in his preface to *Phenomenology of the Mind*, when he wrote: “*To grasp and express the true not only as substance but as subject as well*¹⁷⁾.”

That the True be subject as well as substance seems to imply that it is a process as well as a result. Doesn’t this focus we have on results, to which we have been addicted ever since Descartes, prevents us from thinking that the Truth is the unveiling of a fallacy; a *disillusionment* rather than the effective discovery of pre-existing realities? That Good is the absence of any suffering; analgesia rather than life conformed to a moral ideal? That Beauty is the progressive “*dis-enthralment*” (not enthrall) from subjection? And ultimately

15) « *Entia non multiplicanda praeter necessitatem* » : « *Beings should only be multiplied by necessity* » said philosopher and nominalist theologian William of Occam who urged his colleagues not to mistake the labels they stuck on their jars for new jars.

16) This outlook is presented by Jean Bédard as the concept of « *informal idealism* » in his doctorate thesis on Jan Amos Komenski (Université de Sherbrooke, 2004).

17) « *Das Wahre nicht als Substanz, sondern eben so sehr als Subjekt aufzufassen und auszudrücken.* » Hegel : *Préface à la Phénoménologie de l’Esprit, II-1. Bilingual edition (German/French). Translation by Jean Hyppolite, Aubier, Paris, 1966, pp. 46-47.*

that Oneness is the “super-enthralment” resulting from the synergy between disillusion, “*an-alesia*” and “*dis-enthralment*”. Oneness is never a given. Of course, we can talk about it, but as an asymptote which remains out of reach as long as we ride the curve of which it is no more than the projection into the infinitely distant.

From the very beginnings of philosophy, the ancient Greek language has echoed this suspicion. It had two words to evoke the idea of substance: *hypostasis*, meaning “what lies beneath” and *epithesis*, for “what is beneath and ready to erupt”. But this hypostasis, which is actually the *substance* (what subsists under phenomena, what is hidden under appearances) or *reality* (what exists in spite of the perception I have of it) also refers to the *deposit* (by sedimentation, that is: what remains after the evaporation of subtle elements), or further, the *trap*, the *ambush* meaning “what we fall into when we rely on appearances”. The *hypostasis* of the True, the Good, the Beautiful and Oneness is the thousand year old trap of philosophy against which applied ethics can protect us, precisely because it is the work of our battle against fallacy, suffering and illusion. On the condition of course that philosophy does not challenge this evidence through the *hypocritical arrogance* of those who, under the cover of technical “competence” claim to know the True, The Good and the Beautiful.

As a prophylactic against this, we are actually in need of a genuine “*ontology of lack*”. What is being said here can hardly sketch it, let alone draw it entirely.

To claim to know the True, the Good and the Beautiful is to attempt to raise my subjectivity to the level of a universal rule. It is an attempt to subject others to my arbitrary will: to assassinate others, not in the sense of killing living organisms, but in the sense of destroying subjects: to turn others into objects or even playthings that I can manipulate at will: to tell beautiful but false tales that enthrall them but still enslave them.

Applied ethics, which I consider to be “socio-political clinical ethics” begins in my view, with the “cry of a subject” suffering from subjection. Of course, his or her search, stemming from deep within, for the dignity and nobility of his subjective being, can only be drawn with watermarks. In applied ethics, we do not really know who the “subject” is, but on the other hand, we have an extensive experience of who the “object” protesting for not being respected as a “subject” is. However, we are allowed to risk a few hypotheses on who the “subject” is.

Corollary: What is a “Subject”?

The least erroneous approach I can suggest to define a subject (and particularly an “ageing subject”) is to try to characterize one by defining him (or her) as a “*bewildering creator of harmony* evolving on the basis of past mistakes, suffering and subjections.”¹⁸⁾ I use the word “*bewildering*” because he is transcendent. I shall explain this later on. I call him a “creator” firstly because he is the “field” of resistance to the work of the negative within him; secondly because he is a “consenting victim” of this work imposed upon him and of which he can but faintly feel the enjoyment it provides; and thirdly, because he is himself the artisan behind this work which, in synergy with other creators, creates his own existence as an original work of art. Lastly, I use the word “harmony” as the result of this labor; it is by virtue of this peculiar obstetric that he gives birth to an “*autopoietic*” (self unifying) subject, forged from the raw material of his own errors, suffering and subjections.

The roadblocks on the path to “becoming a subject”

This labor of auto-therapy, consists of an untying, widening and liberating “analysis” with respect to three serious illnesses: “*chrematite, chronite and hypocritite*”. One of the most rigid presets that our culture tends to force upon both our behavior and the understanding we claim to have of it, lies in the belief that it is our duty to “make our money work”. This is what I refer to as “*chrematite*”, the ailment inflicted upon our lives by this rather strange belief. Behind the doctrine of economic liberalism, which advocates free enterprise, unrestricted competition and the free interaction between individualistic initiatives, lurks the illusion that “*money actually works*”. This ideology is in fact a founding myth of the doctrine. But it is also founded on another myth which is the belief that “*time is money*”¹⁹⁾, and this is what I refer to as “*chronite*”, the ailment inflicted upon our lives by this fallacious maxim. The concrete practice of economic activity as a “*subject*” seems to stumble not only upon the road blocks of “*chrematite*” and “*chronite*” but also upon a powerful “*prohibition of thinking*” which diverts our critical judgment²⁰⁾

18) *This proposition is inspired by a whole philosophical tradition including Socrates, Hannah Arendt, Johannes Eckhart, Thomas Hobbes and Carl Jung, which makes a distinction between the Self and the Persona, also referred to as the mask, in human beings.*

19) *It seems that we owe this awesome formulation to Benjamin Franklin.*

20) *In order to illustrate this state of fact, I shall resort to current affairs situations. How is it for example that the Irak War – albeit dramatic – does not readily appear to us as a manoeuvre to divert us and turn our attention away from the incredible infringements upon civil liberties which were instituted – particularly in the land of freedom – under the false pretence of a war on terrorism. The disguised abolition by the American Government of the habeas corpus principle (a fundamental principle American and English law which advocates that any suspect is considered innocent until proven guilty beyond any reasonable doubt). This government now claims the absolutely unconstitutional right to arrest and to « preventively » detain, without judgment and for a period in time not limited by law, anyone suspected of having anything to do with the 9-11 events. This does not seem to have worried American citizens whose attention is diverted towards the deployment of military forces to « destroy the Axis of Evil ».*

towards totally fabricated questions. This thinking impairment is yet another ailment inflicted upon our lives, which I call “hypocritite”.

The “subject” is then afflicted with three ailments. What then is the etiology of this pathology? In my view, it is because human beings choose, on their own, to deny their “transcendence”.

What is the difference between an *object* and a *subject*? From my point of view, self-transcendence is the quality only the latter has. Where the object absolutely remains within itself, the subject always escapes himself. He is so to speak un-conceptualized (*unbegrifflich* : un-seized; from *begreifen*: to grasp with (imaginary) claws, to comprehend, to perceive). It must be underlined here that this notion of transcendence is purely secular and does not imply any religious reference²¹⁾. In order to base this statement I must resort to a little detour via mathematics.

Arithmeticians – mathematicians specializing in the study of numbers – have noticed that there are whole numbers (multiples of a unit considered undividable) and decimal numbers (comprising fractions of the unit). Thus, for example 347 is a whole number whereas 3.47 is a decimal number. Specialists have noticed that there are two kinds of decimal numbers, those which repeat themselves and those which are always original. The former are called “periodical decimal numbers”. The numbers $1/3$ or 0.333333... and 0.34734734734... for example are categorized by an indefinitely recurring period – 3 in the first case and 347 in the second. These numbers are “easy” in the sense that if one asks what is the 642nd decimal of 0.333... one will know in advance, without calculations, that it will be a 3. As for the 642nd decimal of 0.3473473, I also know without calculating that it will be a 7, since 7 occupies all the third positions in the sequence and all the positions that are multiples of 3.

Such is not the case however with other decimal numbers which are not periodicals and are characterized by the fact that each next decimal is unpredictable. For example, the ratio between the perimeter of a circle and its diameter referred to as “ π ” equates (approximately!) 3.14159... In this case it has been shown that no decimal sequence is ever a repetition of the previous one. Such is also the case with other numbers, such as “ ϕ ”, which symbolizes the “Golden Number”.²²⁾ Mathematicians refer to these numbers as “transcendent numbers”. They are “unpredictable” and “inexhaustibly different from themselves”. They generate feelings of uncertainty, inaccuracy and perplexity. They are utterly “bewildering”.

21) *On the other hand, it could serve as an « anthropological » basis for « revealed » interpretations of transcendence. It could even help define God as The Transcendent Entity. However, let us point out that this « definition » would be in effect « Voltairian » since François Marie Arouet had quite correctly pointed out that: « If God has created Mankind to the likes of Himself, Mankind did return the compliment fairly well ».*

22) *The Golden Number being the ratio of two magnitudes, such that the greater number is to the smaller number, what the sum of the two is to the greater one.*

Strangely enough, human beings are much like these numbers: they are (at least in some aspects) “unpredictable”, “inexhaustibly different from themselves” and utterly “bewildering”. It is in that sense that I consider humans as “transcendent”, without pledging myself to any spiritual school of thought. Humans are, for themselves and for each other, genuine sources of bewilderment.

Subjectivity and “Spirituality”

Here, I am putting forward this very “secularized” definition of “*spirituality*” which I see as “*the relationship that a subject allows himself with his own transcendence*”. To be a never ending puzzle for oneself is a source of fear for human beings who, rather than let themselves enjoy their bewilderment, will most often pretend to be in control of a situation when they truly are not. Of course the subject may fear, ignore or even deny his own transcendence. But he can also deal with it, tame it and try to harness it. All these attitudes can be found in social life. However, my experience of clinical ethics has convinced me that a subject only becomes an effective “subject” to the extent that he relinquishes any desire to possessively take over his own transcendence; and to the extent that he freely accepts that for ever, his transcendence is a bewildering ally, letting himself be driven by it in his endeavor to become his true Self.

Transcendence induces giddiness. By trying to maintain our relationship with our transcendence we truly can become ourselves. There is more. It is the maintenance of a harmonious relationship with our transcendence which yields the happiness of living our human condition, even though the attainment of happiness through this relationship shall not be the ultimate goal. This is why I would say that to live a spiritual life is to maintain a harmonious relationship with our fully accepted solitude, finiteness and uncertainty. Or, in a more positive sense, spiritual life is a “playful” relationship with our own “bewilderment”.

It is through a relationship to self that a subject may come to acknowledge, and accept, that others assist him in his auto-parturition, as he will, most likely, assist them in their own. Taking turns as obstetrician and parturient²³, subjects may then unfold in reciprocal creativity.

23) *Obstetrician or (female) parturient; midwife or (female parturient); obstetrician and (male) parturient; midwife and (male) parturient; such would be the possible permutations of this essential image of « reciprocally becoming subject ».*

The Trap of Professional Idealism

Health and social service professionals are not there to make people happy but rather to help them live in the least pain, in spite of the trials and tribulations of their individual stories. Such is the conclusion to be drawn from the work of the negative in the field of helping relationships. One is forced to acknowledge that this completely shatters professional idealism.

Professional idealism often stems from a culture of perfection which paradoxically causes professionals to adopt attitudes and behaviors that are incompatible with the deontology governing their professions. What is the nature of this trap? What is it rooted in? And above all, how can we hope to get out of it?

Any culture of perfection is a denial of real life. It stifles the manifestation of the universal force which, when it filters through human beings, becomes ambivalent and swerves their power of speech towards either the most noxious perversity (diabolic violence) or the most beneficial creativity (symbolic violence). This denial turns against perfection and induces the very same perverse effects it claims to keep away from the practice.

Professional idealism consists in focusing on a stringent ideal from which it becomes forbidden to deviate. This ideal is deeply rooted in values of service, honesty and professional objectivity. However, the prohibition to deviate paradoxically induces:

1. *Heavy tensions when professionals are forced to realize that there is a gap between their ideal and their actual practices.* When such tensions become unbearable, for example when the practices are questioned from without, they tend to be resolved through a concealment of the breaches of the ideal. This tendency is reinforced by the fear of denunciations for “lack of professionalism” and the possible penalties that may result. In order to protect his image, the professional begins to walk the path of untruthfulness. But untruthfulness being a professional misdemeanor, he will be forced to walk the path further and further, each lie giving rise to another in order to cover the previous one. In the long term, it will no longer be his professional ideal that guides his actions, but a constant and rigid concern for the “political correctness” of his practices, in spite of the fact that sometimes – or perhaps often – these practices will radically belie his ideals. His ethics will become what is referred to in Québec as “cosmetics”: he will be content with simply “looking good”, in other words, “to keep up appearances”.
2. *The reduction of others (colleagues, clients) to the status of “living evidence”, for the purpose of justifying the above-mentioned lies.* Colleagues then cease to be team members, they become potential informers, so in order to prevent any attempt to denounce, one must charge them with one’s own faults before they take the initiative. The first

one to denounce someone else will be the one with the best chances to “save face”. The same attitude will be adopted, *mutatis mutandis* towards clients, the recipients of the professional activity: if something does not conform to the ideal, it will be their fault. *They are so difficult, unstable, irrational and stupid*. In short, “others” (colleagues and clients) are “instrumentalized” (used as instruments) by the lying process and they become certification objects on which to base the “beautiful false tales” which conceal the gaps between their practices and their professional code of ethics. This “instrumentalization” is a negation of their status of persons which actually kills them symbolically. Thus the lies required to support professional idealism actually lead to the violation – at least symbolically – of the prohibition of homicide.

3. *The dividing line between personal and professional interests is a fuzzy one*. Ideally speaking, a good professional makes sure that there is no interference between personal matters and professional activities. This agreement creates the condition for objectivity and impartiality to be possible. Unfortunately, this ideal is unattainable because no one can undo his subjectivism, short of becoming completely dehumanized – and deontology demands humaneness. Our personal being is in constant interaction with everything we experience, professional activities included. Our subjectivity cannot be by-passed and must not be confused with arbitrariness. On the pretense of doing away with subjectivity, we open the door for the dehumanization of relationships. Under the cover of a theoretical separation of professional and personal interests lie concrete confusions which lead to incestuous behaviors.

In short, professional idealism injects professional practice with a lethal paradox which could be exemplified by the following command: “Be perfect; and I forbid you to be so.” The second part of the sentence is usually left out, which actually reinforces its efficiency. It puts on it an inconspicuous pressure via the mandatory economic success of professionals.

When confronted with this paradox – whether consciously or not – professionals are left with three avenues:

- a) to end up having a burnout, or various more or less work-related illnesses;
- b) to indulge in explosive violence (crime, acting out, suicide...);
- c) to display a type of apraxia consisting in a lack of creativity, initiative and responsibility caused by a shy withdrawal behind the shield of regulations.

“*Keep up appearances*” and above all “*do not make yourself conspicuous*”; these have become the slogans of idealistic professionals. Needless to say that they do not have a great opinion of themselves since, in the end, they know very well that “vice has taken the appearance of virtue” and, unless they become completely cynical, they do not take pride in it.

Sharing the Frustration Equitably

At this point I would like to come back to the question of equity. As I said earlier, equity consists in distributing something according to two parameters: the matter to be distributed and the needs of the recipients. Taking for granted my explanations of the *work of the negative*, an equitable distribution is not a distribution of happiness but an *equitable sharing of frustration*. Certainly, we will be able to do something to soothe part of the mistakes, illnesses and subjections everybody suffers from, but nobody will receive total happiness; everyone will have to contend with and hopefully with a little less misfortune. This corollary with what was said earlier and it is often taken as a slap in the face by idealistic professionals. Nevertheless, human beings cannot account for the total happiness of others. They can only help each other live their lives with the least possible pain. This modest approach is the essential key to tackle the extremely delicate question of how to distribute scant resources in a situation of scarcity. The problem is not so much to equitably distribute the little we have but to make everyone understand that we are all afflicted with a finiteness we cannot transcend, and therefore what must be done is to equitably share the frustration.

On the Concept of “Scarcity”

The question must be asked, is there really scarcity? I for one, have my doubts, and for two reasons; the first one being essential, while the second one is circumstantial. The “essential” reason is that human beings are bearers of infinite dreams and desires but endowed with very limited means of fulfilling them. Could scarcity then be just another name for finiteness? Are we not always in a situation of scarcity? Are we not always lacking something to make our wishes come true? Situations of economic slumps are not the only times we feel the pressure of scarcity. It is also felt in situations of economic growth and peaks as well. Of course, during growth periods our lacks are not felt so much because it is less difficult for leaders to keep their promises to give everyone a little more each year. During economic recessions, the “pie” becomes smaller – or at least ceases to grow as much as we hoped. Essentially then, human beings are always in a situation of scarcity. However, scarcity is more or less felt depending on whether the general economic situation is promising or deceptive.

As stated earlier, my second doubt is dictated by more circumstantial considerations. In many countries, citizens are confronted with budget restrictions which affect the social, health and educational sectors. We hear about the scarcity of financial resources due to the “pressures of globalization”. Yet, there has never been so much money circulating in developed countries as there is now. Major enterprises (pharmaceutical, petrochemical and telecom industries, insurance companies, banks ...) have

never yielded so much profit and never before have “successful” managers been granted such high salaries and bonuses.

It is my understanding that these facts indicate that the problem is one of resource distribution rather than a lack of means. This shows me that the “frustration of taxation” is not shared equitably. We are not in a situation of lack of resources, but rather in a situation of inequity in the distribution of the tax burden. This is a major cause of the budget restrictions which affects – in very tangible ways – the social, health and educational sectors in our communities. It is in this difficult context that we must endeavor in the least damaging ways. These are human decisions that heavily weigh on our social security, health and education services and they are not immutable laws such as the law of gravity.

The new task is to equitably share both the frustration of taxation and that of the limited social, health and educational services, which we are entitled to; while remembering that we can not hop to have all of our desires fulfilled.

The Infinitesimal and Totality

This “negative” outlook could appear as grim and un-motivating, but fortunately, such is not the case because any action, no matter how small it is, is a contribution in reducing the amount of errors, dependencies and suffering that affect us. However small may be the impact of an action (infinitesimal a mathematician would say; that is, as small as one wishes but not zero), it participates in altering the course of history – the totality. Is it not that totality is precisely the total sum of an infinite number of infinitesimal variations? What makes the cup overflow is not the last drop poured into it. Had the last one not been poured, the one before that would have been the last, and so on back to the very first drop. All of the drops that were poured into the cup – from the first to the very last one – bear equal responsibility for causing the overflow.

The Thirteenth Monthly Budget Method

Before we go on to the workshops – which consist firstly in measuring the gaps between our displayed and practiced values, and secondly in developing concrete strategies to reduce this gap – I would like to submit a practical case for your discussion.

We all know the *budget package* method of managing funds. Each ministry is given an overall annual budget, which is divided into departmental budgets and so on down to the smallest expenditures “in the field”. Such expenditures, which are deducted from the departmental budgets, are more or less regulated and civil servants tend to strictly follow the rules and regulations that apply in order to avoid arbitrary spending. And yet, as I explained when I quoted Aristotle, rules and regulations are intrinsically

imperfect because the regulation authority could never predict in an absolute detail all of the cases in which these regulations are bound to apply. Rules cannot be applied without the exercise of judgment. Field decisions are made between two “arbitrary powers”, so to speak. First the bureaucratic power of applying the regulations to the letter, without any consideration for specific contexts; and second, the power of subjective judgment. It is between these arbitrary powers that a just decision must find its own selection path in order to sort out demands which are greater than the means available, so that the rules and regulations are as accurate as possible. But accuracy only postpones the problem. A provision must always be made for cases where the rule would produce exactly the effect that the regulators wished to avoid, should the rule – however accurately worded – be applied as written. If there is no resource available when such a case arises, the frustration will be immense. This is why I advocate the creation of a thirteenth monthly budget segment for annual budgets (or a fifth weekly for each month; or an eighth daily for each week), which can be kept aside for exceptional cases.

In order to tackle this question with maximum clarity, let us rely on a fictitious but plausible situation.²⁴⁾ Let’s imagine that we are responsible for an Orthopedics Department which has just suffered a budget cut compared to previous years. Let us now consider a sub-budget, that of hip prosthesis. Over the past three years the department has yearly installed 92, 98 and 95 prostheses, for an average of 95 per year. Now let us suppose that the departmental budget has been cut down to 76 operations per year and the demand has remained the same. It is clear that 19 patients will be denied an operation this year. The question is now; which patients should be accepted or denied? The usual tendency is to try to establish objective criteria. For example, it could be stated that, based on statistics compiled by similar departments, the exclusion of patients aged over 82 would solve the problem. Other statistics could show that by combining age and sex one could arrive at finer result: men over 80 and women over 85 could be excluded. Still others could be based on the life expectancy of patients, etc. The advantage of such criteria is that they can be applied bureaucratically without requiring the personal commitment of the professional staffs; the other side of the coin is that they always end up creating absurd and radically unjust situations. Let us just consider the age criterion, for example: it is inevitable that one day or another a choice will have to be made between an 83 year old patient in great health and a 77 year old in bad shape, whose life

24) *So much has been written on the question of the allocation of scant resources that documents could fill an entire library. None of these studies are mentioned in this brief document because most of them are highly technical and my objective is to simplify the matter. Furthermore, most of these studies are conducted from a legal point of view whereas the one adopted here is rather anthropological. For more details, the reader may refer to the work of P. Boitte (Éthique, justice et santé. Allocation des ressources de soins dans une population vieillissante, “Catalyses”, Fides-Artel, Montréal-Namur, 1995, 272 pages) and that of P. Van Parijs (Qu’est-ce qu’une société juste?, “La couleur des idées”, Éditions du Seuil, Paris, 1991, 316 pages).*

expectancy will be much less than that of the older patient. But rules are rules, and applied to the letter they generate what some would call shameful wastes. The same goes for all “objective criteria”: they all lead to deadlocks.

The right to make exceptions

Of course, a conscience clause could be attached to the “objective” regulations, thereby allowing exceptions to be made – upon proper justification of course. Some patients under age 82 could then be denied the operation and some older patients could be granted priority even though their case would not comply with the rule. These exceptions could be decided upon, in a non arbitrary manner, according to a well defined dialogic process such as the discussion of the cases at a departmental meeting, perhaps attended by an ethics consultant. This kind of suggestion has been made fairly often and such procedures exist in many institutions. They are very interesting because on the one hand, they are certainly more subtle than the application of rigid “objective” rules, and on the other hand they open the way to a more comprehensive solution to a question.

Indeed, if a team of professionals is capable of the kind of moral judgment required to legitimize an exception to an “objective” rule, then surely they should be capable of deciding upon each case. Are human beings not all exceptional (at least in some ways) and for this reason deserving of an exceptionally humane treatment?

Suggestions to regain control

In concrete terms, things could be organized as follows: First of all, the care team should plan a calendar budget, that is to say a division of the overall budget (which we will take as annual) into monthly, weekly or even daily sub-budgets, according to specialized fields and operational activities. The purpose of this fragmentation is to preserve the chances of late arriving patients with respect to those who require care at the beginning of the year. It also gives the care team a better management grip on the overall budget. Now, it would be wise to plan what could be called a “thirteenth month” for *unexpected cases* not accounted for by statistics.

So let us imagine our Orthopedics Department with a budget for 76 operations – rather than the statistical average of 95. The department could divide the annual budget into twelve monthly segments of six operations plus a thirteenth budget for four “*unexpected operations*”, for a total of 76. Thus fragmented, the ethical problem is reduced to more human dimensions and the team members can get a better hold over their work. The next problem is to make the inevitable patient selections. Based on previous statistics, it is to be expected that about seven or eight persons will show up each month for hip prosthesis operations. So each month, two will be denied access and six will be selected.

Finiteness and endless desires

Before we discuss the possible selection criteria, an essential comment must be made. Let us remember that the human condition – that of the patients and the staff members as well – is governed by finiteness. We all bear endless desires and are given limited means of fulfilling them. This is true of societies and of individuals and it is therefore inevitable that we should have to make difficult choices. Frustration is inherent in the human condition and happiness is not to fulfill all our desires but to fulfill a few that appear most essential. Therefore, my answer to the second major question of clinical ethics in situations of scarcity may be considered frustrating in many respects; there is a risk that some people may reject it, especially those who, like spoiled teenagers, want “everything right now”. Such rejection would be understandable but nevertheless childish. These decisions must be made by mature adults, not by spoiled brats.

Cultivating the autonomy of people involved

The answer I wish to put forward is derived – as one would expect – from the considerations set forth in the first chapter above and particularly from the ethics of reciprocal autonomy. We will simply apply the principles of reciprocal autonomy to the question we are analyzing.

The basic principle is clear: in any problematic situation, the most ethical decision is the one which maximizes the autonomy of all people involved. Let us agree from the start that autonomy, as we understand it here, is not quantifiable. Such considerations as *the maximization of everyone’s autonomy or the sum total of the autonomies of all concerned* would be totally inappropriate. In order to develop and grow, individual autonomy relies on the autonomy of others. This is why, as far as autonomy is concerned, what is given to someone is not taken from someone else. In this respect, autonomy has nothing to do with a hip prosthesis. But let’s get back to our decision.

Pertinent questions to ask before deciding

The patients are referred to the department as the needs arise, therefore the team cannot hold meetings to discuss and compare all the cases. The patients come in randomly and the decisions concerning each case must be made at relatively short notice.

Aside from urgent treatments, the first concern of the team must then be to get acquainted with the person who has been prescribed a hip prosthesis. Who is this person? What is he/she going through personally? What impact will the operation have on his/her life? What does that person hope for, in the short and long term? And so on.

The second concern should be to get to know at least a little about the person's social network, especially people close to that him or her, including the family doctor, if one is assigned.

The third concern should be to talk to that patient – or if that is impossible, to someone close – so as to analyze the patient's current situation, get a glimpse of his/her future and provide details on the scarcity problem affecting the department, which could also affect the person.

The fourth concern should be to work towards a reasonable decision which takes into account all people involved and therefore to hold discussions which allow everyone to have a say, whether directly or indirectly.

Care for others which does not lose sight of care for the individual

During this debate, held according to the rules of ethical discussion, a reasonable option should filter through, while focusing on the possible ways to comply with the three prohibitions, to deal with individual conditions of solitude, finiteness and uncertainty and to foster everyone's solidarity, dignity and freedom. All members will have to strive to come up with a sort of balance of arguments which will be the sign of the desired reasonable option, a focused option but with an eye on universality. Indeed, in every decision we make we should seriously ask ourselves what type of humanity may result in the future from the approach we are taking to this problem: will it lead to greater solidarity, dignity and freedom of mankind, or rather a global village filled with outcasts?

What this all comes down to is the creation of meaning where there is a lack thereof. Of course, such debates are difficult because they do not allow people – not even professionals – to take refuge behind their knowledge. All participate at their own risk. But the discussions also provide opportunities for self help and for the improvement of one's own autonomy. The debates are difficult but they are also paths to the reciprocal humanization of human beings, to the development of their autonomy.

The ethics of reciprocal autonomy outlined here derives from a double *a priori* assumption: trust in humanity and in the human ability to self-humanize. It implements an anthropological optimism which some people may find naïve. But this path shown by the ethics of reciprocal autonomy is not the path of utopia. It is currently walked by people in hospital and social service departments and in schools as well. The optimism expressed here is that of those who actually practice this ethics.

Finally, the Need for Ethics Training in Clinical Decision Making

The *13th budget* method in a way allows us to reduce the uncertainty margin in the decision making process, but not to eliminate it either. It is thus a refinement of the decision making guideline system which implies – as should always be the case – the exercise of ethical judgment in a given situation. It should therefore be stressed out that ethical training is essential to this practice. Ethics is neither a bureaucratic application of flawless “objective” rules and regulations nor the rationalization of noble feelings nurtured by decision makers. It is a true discipline of a university level which should be studied and practiced by those who wish to engage and endow their field decisions, with the potential of reducing, as much a possibly can be done, the inevitable gap between our displayed values and those we actually practice.

Bibliography

Cadoré B. [1997] : L'éthique clinique comme philosophie contextuelle, Fides, Montréal, 1997.

Malherbe J.-F. [2003] : Les ruses de la violence dans les arts du soin, Liber, Montréal, 2003.

Malherbe J.-F. [1997a] (éd.): Compromis, dilemmes et paradoxes en éthique clinique, “Catalyses ”, Fides, Montréal, 1997. (Épuisé).

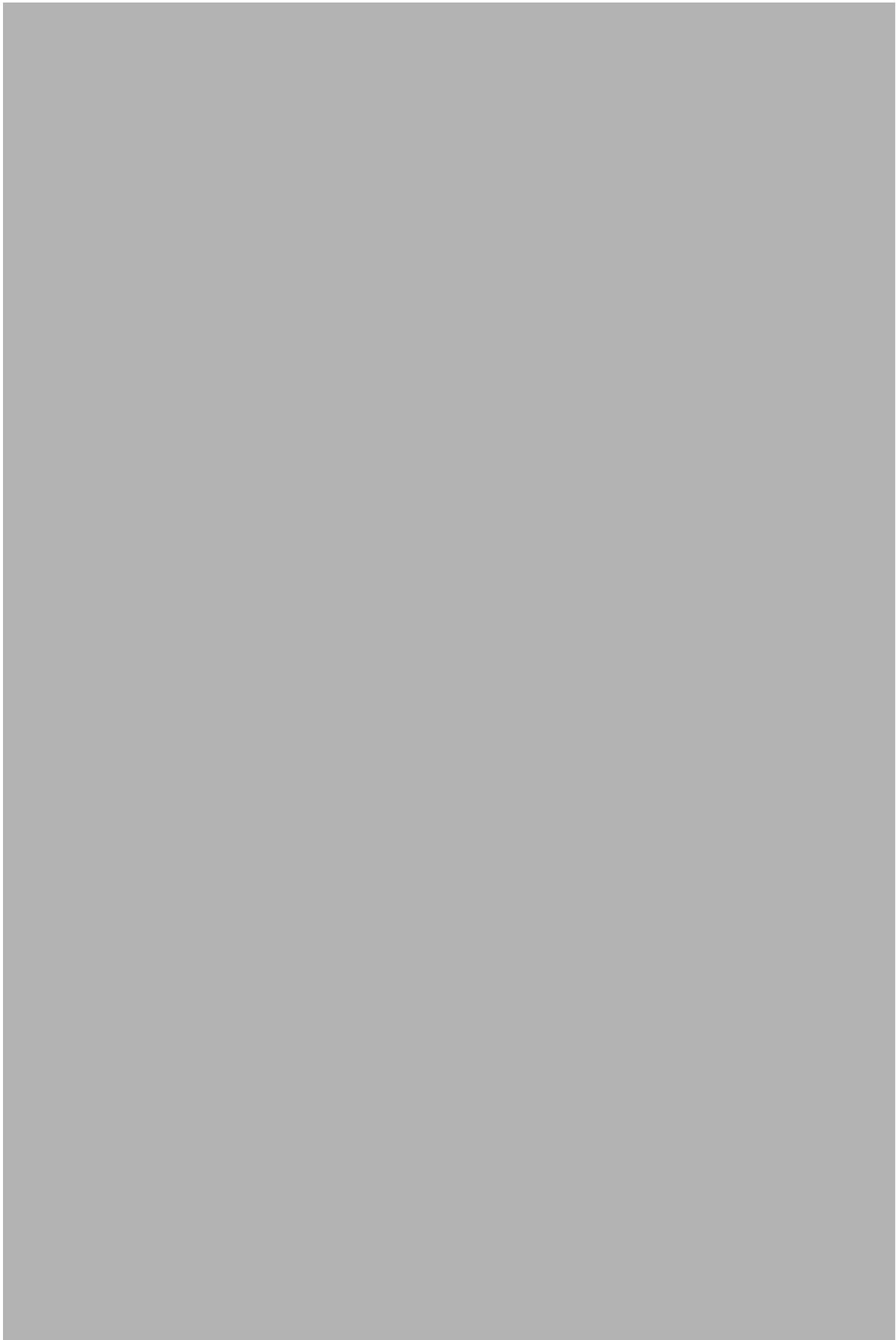
Malherbe J.-F. [1997b] : Pour une éthique de la médecine, 3^e édition revue et corrigée, “Catalyses ”, Fides, Montréal, 1997. 1^{re} édition : Larousse, Paris, 1987. Traductions allemande, italienne et espagnole.

Malherbe J.-F. [1996] : Homicide et compassion, L'euthanasie en éthique clinique, Médiaspaul, Montréal, 1996. Traduction espagnole.

Voyer G. [1998] : Qu'est-ce que l'éthique clinique?, “Catalyses ”, Fides, Montréal, 1998.

SECTION 5

DISCUSSIONS



**Session 1:
The needs of older people for long-term care**

Chairperson: *Mr Tom Mulherin, Chairman of the Social Protection Committee, Ireland*

Rapporteur: *Ms Marie-Eve Joël, Université de Paris Dauphine, France*

The first session tried to identify persons in later life in Europe who are in need of long-term care. The European legislation applicable to this population was analysed.

The concept of need for long-term care has different meanings at European level and within the national context of Member States. The first session attempted to take stock of these different interpretations at European and Member State level, as well as of the relevant aspects of European law.

In addition, the session presented lessons learned from the procedures used to evaluate individual requirements for care. Finally, possible scenarios and perspectives were examined concerning the future evolution of long-term care needs.

Discussants:

Dr Josée André, doctor of medicine, Luxembourg

Often in the media, you see the image of older people looking absolutely at ease enjoying their leisure activities and facing serenely a future that will be less active but nevertheless satisfying and happy. Future users of long-term care are described as people who are well prepared and ready to make lucid choices between the various options offered by the long-term care system in their particular country.

However, practical experience shows us that this is actually an extremely rare situation - in fact, most people are not ready for that rather upsetting phase in their life which happens to be a painful process making them lose gradually their independence and leading them invariably closer to death.

Finally people are taken by surprise, nobody really is prepared: neither the old people who hope that somehow things will sort out, nor their families who do not want to be proactive and thus risk upsetting their older ones or taking moves without their consent.

Speaking today of needs of a person in long-term care I would like to have a closer look at how people concerned experience what happens. It is a more subjective approach compared with what we have seen before.

Older people getting dependent of long-term treatment first of all need to be taken in charge by someone who really respects their particular identity, their

family background, their cultural context, someone who tries to understand where they live, how they have lived, someone who tries to grasp their real needs, not only physical but also psychosocial ones.

This relationship between two persons from a different generation who often don't share the same value system turns out to be far from being easy.

Furthermore, we are often talking of someone who is very lonely, family links may have been lost completely, often relatives, mostly daughters or daughter's in-law, are simply overburdened and exhausted by their task and ask urgently for relief. Sometimes the partner is still alive, maybe equally fragile and afraid of a separation. Fact is that people wait until very late to ask for help and it is necessary to offer a very complete assistance including their family circle.

It is important to start a dialogue, a minimum level of communication in case of cognitive deficiencies, with the recipients of care and their families, in order to find together the best ways of improving the present situation. It is necessary to develop a tailor-made programme, which may need, according to each person's personality, life history and family situation, educational level etc., to be very different for the same level of loss of independence.

So even if the request of assistance is not made spontaneously by the person concerned, it seems to be essential to encourage team-building with the professionals, trying to put tools in place to enable them to regain more autonomy and if possible to be able to continue to live in the same place. (This is the dearest wish of most of them, not considering the fact that moving in an institution may be a considerable relief, offering new opportunities....)

At this stage in people's lives, there is not much room for manoeuvre. Balance is very precarious, the frequent co-existence of several pathologies from a medical point of view, the growing fragility, leads to a situation where the slightest shift can bring a whole system crashing down. In these cases, a great deal of flexibility is required of the team of long-term carers wanting to organise support.

Members of such a team should be very well trained and well equipped for the tasks in hand. The number of experts necessary to assess the problem should be as low as possible. Ideally, there is always only one interlocutor of reference, whatever the size of the team, in order to keep procedures as transparent as possible to the care-receiver and/or his family. Given that, quite benign events can endanger the equilibrium and completely change the situation. The ideal team should be able to react fast, in order to reassess the changes and adapt the solutions. Actually, there remains always a risk that the response to the current situation comes too late. (One example of my practice: several times necessary equipment and devices to help arrived after the needing persons had died.)

To conclude, considering the previously enumerated facts such as:

- the fragility of old people,
- the need a lot of empathy to assess their needs,
- the necessity of transparent procedures avoiding too much intermediate stages,
- the need of flexibility in order to move quickly ...,

some basic measures required appear to be:

- specifically trained health care professionals,
- simplified administrative requirements and
- small intervention teams with some degree of autonomy vis-à-vis the administration.

The challenge is to create a system that is adapted to the dependent person, rather than the other way around.

Mr Manfred Huber, OECD Paris, France

The report that we have before us today is very rich in insights and provides an excellent starting point for a very broad discussion that illustrates the complexities and the multiple challenges of long-term care policies. In my comments I would like to focus on one main point, one question addressed in the conference report, which is 'what will drive future costs of long-term care and social services?' My comments will mainly be based on findings from a recent OECD study, incidentally one which has the same title as the report that you have before you. The report on which we base our discussions today has elaborated on a number of cost drivers, such as demographic dynamics facing populations, changes in living arrangements and family structure.

It is important to consider at least two additional factors on which I would like to elaborate. One of the significant drivers are raising public expectations for better-quality care and a second is the need to address staff shortages and staff qualifications, and these two points are closely interrelated.

The quality of long-term care services varies widely across countries. Comparative information is still scarce, but what we know so far clearly points in this direction. Consequently, the quality of services offered does not meet the expectations of the public, users of services and their families. To give only one example where we have some data: countries differ widely in the degree of privacy and amenities available to residents in long-term care. For example, the number of persons residing in single or double rooms can range from under 25% to almost 100%. The latter is the case, in countries where independent living in old age is now considered as a social right. Improving the situation in many other countries will mean that substantial additional investments, for example in new facilities, will have to be made.

Secondly, staffing - this is another issue which governments need to address in the years to come. Is it likely that better-quality care will be sustainable in the future with current staffing levels? One way of researching this question is to ask administrations and policy-makers in countries about their most important concerns regarding quality of care, and this is what the OECD study has done. From a survey of 19 countries we have found that staffing strategies and staff qualifications have come up as the number one concern of long-term care policy-makers. It is therefore important to address these issues now, in order to avoid further worsening of the situation in the future. Many countries are already facing staff shortages now, in both health and social services. Difficult working conditions can generate a high turnover of nursing staff, and early retirement from the profession, a situation most of you may be familiar with. Improved working conditions and better pay may be needed in many cases in order for qualified jobs in the care sector to remain competitive.

Finally, let me emphasise that I fully support the conclusions in Part One of the report, on the need to step up investment, at national and international level, in data and evidence to support analysis for policy-making in long-term care, and I'm sure that nobody is surprised to hear me saying this. I think the report illustrates this point well, with a number of impressive national examples, but comparative data in this field are still scarce. However, there is considerably more activity now at international level, and the OECD Secretariat and the European Commission have recently intensified cooperation, not only on basic data, such as on expenditure, but also in the quest to improve ways of modelling and projecting future long-term care needs and their implications for financial sustainability.

These are two examples from what I see, is now a new dynamic and a new level of international cooperation in long-term care, and I don't think that we have seen this in this way before. So let me conclude with a rather optimistic view: I believe there is much room for substantive progress in the near future regarding the evidence for long-term policies which our policy-makers and the researchers and others need in order to make progress in this crucial field of social policy.

Ms Sabine Henry, Alzheimer Europe

I would like to start by thanking the organisers for inviting Alzheimer Europe to participate in this conference on long-term care, which is a vital subject as far as our organisation is concerned. The subject is very close to my heart, as I have a family connection with it. The specific nature of Alzheimer's disease means that it requires long-term care, lasting for as much as 15 years from the time the diagnosis is given, and it is a real burden not only for the person him/herself, but also for families and carers.

Alzheimer Europe has 28 national associations from 24 European countries, originally set up to defend the interests of the families concerned and of people close to those affected by Alzheimer's and other forms of dementia. Recently, Alzheimer Europe has been particularly concerned with the persons themselves. We have a labour philosophy implemented through a business plan, and we want to promote the dignity, respect, self-determination and independence of the persons with dementia and also want to help the families throughout the illness.

As the experts' report has shown, Alzheimer's and other forms of dementia constitute one of the most important causes of dependency and the need for long-term care on the part of older people. A 1991 study on the prevalence of dementia shows that there has been a constant increase in the percentage of people affected with increasing age: 0.09% between 30-59; 0.47% between 60-64, and then you see an increase to 3.86% for 70-74 and 6.67% for 70-79. Alzheimer Europe has used the prevalence rates in order to establish estimates for people currently living in the EU, across the 25 Member States, and suffering from Alzheimer's or other forms of dementia. Applying the prevalence rates to the population statistics published by EUROSTAT, Alzheimer Europe estimated a figure of approximate 5.4 million. Alzheimer's and dementia in general affect more women than men, due not only to the admittedly higher prevalence rates for women, but also to the fact that women live longer, perhaps a rather miserable privilege – 3.5 million women are affected in Europe compared with 2 million men.

We have the same situation if you look at the gender of the carers; there is the EPOCH study from 2002, carried out by Alzheimer Europe on 600 carers from Belgium, Iceland, Denmark, Ireland, Germany, Italy, Luxembourg and Norway, which allowed us to have a better idea on this issue. The study showed that care for an Alzheimer's patient mainly remains within the family: in 85% of cases a man is looked after by his wife, in 8% of cases by his family and in 2% of cases by the sons. But for women, the situation is different. Husbands are the main carers in only 43% of cases, while in 37% of cases daughters help out and in 7% of cases, sons. So Alzheimer's is affecting women to a greater extent, both as patients and as people who have to shoulder the greater part of the burden of caring for the person with Alzheimer's.

Now these figures are really striking when we look at the future and look at the prospects. With the ageing population, there will be a major increase in the number of dependent people, dependency due to Alzheimer's or to other forms of dementia. In parallel, there will be a change in the proportion of older dependent people to the working population. EUROSTAT estimates that this proportion will grow from 25% in 2005 to 50% in 2050. Thus there will be two persons of working age for each dependent older person. This involves major challenges for our society. On the other hand, recent societal and family

trends mean that we can no longer rely only on women to care for these people.

Nonetheless, I think it is difficult, even impossible, to make specific predictions about the evolution of Alzheimer's up to 2050, because we cannot predict the possibility of greatly to be welcomed progress in medical treatment, in delaying the illness and even curing it, or in preventing this illness. But from this perspective, we run the risk of forgetting the current situation.

Alzheimer Europe wants to promote the dignity and independence of the person affected by dementia, and this shouldn't just be vague promises, but should concern all of us – carers, medical staff, nursing staff, and the political decision-makers. This requires greater involvement of these people in major decision-making. People should at least have the right to choose to know their diagnosis, we need guidelines for the staff, other mechanisms should be instituted, like living wills for example, or clearer guidelines when people agree to participate in medical research and so on. These are the new challenges in the European Union, with very different situations from one country to another. But we want an upscaling of the systems, a general upgrading, both in terms of treatment, prescription rules and funding, and in terms of the availability of different services and the way they are funded. The information, support and services offered to the persons concerned, the patients and the carers, need to be improved, in accordance with what was set out in the report.

We want to have quality services accessible to all and financially viable, with a particular focus on the subjective burden borne by the carers, which is very much linked to the length of time of the care for persons with dementia. For the most part, the quality criteria for services aren't very well developed at present; these criteria are non-existent when it comes to care in their homes, and to palliative care adapted to the specific needs of the individual with Alzheimer's, and has remained only at the level of pilot projects.

The national associations of Alzheimer Europe have an important role to play as service providers. And there are also various support groups, telephone help lines, Alzheimer's cafés, day and night support, training for professionals, for families and so on. Alzheimer's requires a multidisciplinary approach, with the participation of various different actors from the medical profession and the psychosocial field.

The legal and ethical dimension is very important as well. Unfortunately, the cooperation between these areas' social actors is limited or even non-existent. In order to insure continuity of care throughout the course of the disease, cooperation does need to be improved, and we can make proposals. We could put in place a case manager, a reference person. This case manager would be able to monitor the patients and their families and guide them towards adequate services in the event of need. The Alzheimer's

associations will have a role to play in this field, and to a large extent they are already doing so. This role should be better known and supported by government bodies. Furthermore, these associations need to be at the very heart of the development of a partnership between all the actors involved in the diagnosis, treatment and care of and support for Alzheimer's patients.

The key demand is for recognition of the role of these associations. At the point of diagnosis, the family and the patient should be pointed in the direction of an Alzheimer's organisation. For example, in Belgium we have launched a poster campaign, aimed at GPs, saying "NO DIAGNOSIS WITHOUT INFO", giving a free phone number, and all this information is provided in three languages.

Ms Luigina De Santis, EFREP

The European Federation of Retired and Elderly Persons was created in 1993 by trade unions of pensioners, and the aim of the organisation is to ensure that workers and pensioners can contribute to the creation of a democratic society in every area and at all levels, including the European one.

Today it has about 10 million members in 25 European countries through 43 national organisations. Its culture is characterised by great solidarity between generations, and its organisation is very much based on trade union principles. The complexity of contributions from different cultures and different age groups within the organisation enables us to find a common framework of objectives, aimed at improving the daily life of pensioners and of older people in Europe. Together we will all work to make sure that their rights are respected at national and European level.

EFREP has established six fundamental rights for the quality of life of older people: the right to participate in society, the right to have access to health, the right to a pension, to a minimum income in order to combat poverty and to ensure a dignified life, the right to be cared for when you become dependent, to make sure that the social system helps you, and the right to lifelong learning. Today, there are about 2 million people who are dependent in Europe and that number is going to increase. Policies of preventing dependence are needed. They should focus on improving living conditions, among other things, and especially health and safety in the workplace.

Social Europe is based on respect for human rights and solidarity. The right to a dignified life for everyone, including dependent people, is a human right. We need solidarity to ensure that policies prevent dependence from automatically leading to a loss of or decrease in the rights of dependent persons. Once we recognise this fundamental right, we have to make sure that the funds needed are available from taxes or from local contributions, and, if necessary, we can create an ad-hoc tax for this purpose.

It is essential that we are all fully aware of what we can expect in the future in this area. Demographic trends are clear in this area, also there are changes in family size, women's role is increasing in the workplace, divorces are increasing, there is an increase in work-related mobility, and so family members are not available to provide care. Therefore society needs to take charge of this, it has to be a public service and we need to find the necessary resources to make it available. But this will also create a number of jobs, qualified jobs.

The needs of dependent people are not homogeneous, are not uniform, there are distinctions to be drawn between people who are physically dependent on others, who need assistance to carry out daily tasks. And then we have people who have mental disorders, for example Alzheimer's. We need to identify what their needs are. These needs have to be treated differently in terms of the services that are provided. Those who are physically dependent need people to go to their homes and help them; governmental services need to provide for people who have mental disorders. Quality of accommodation is essential too, and those who are affected, i.e. patients or family members who are carers, should be able to participate in the organisation of these services. It is not the case that the professionals should organise things and then the family should accept what they've done.

Now we need to create a situation in which dependent persons have rights and can participate in organising these services. The Second UN Assembly in Madrid and the Conference in Berlin in 2002 stated quite clearly that people who are dependent on others should have a voice, either a direct voice or through an organisation, on the quality and quantity of services, and they should be able to cooperate in ensuring that services are more effective. Some countries already do this. Social services that meet the needs of dependent people, as has already happened in some European countries, and establishment of all these services, are an enormous step forward. When politicians become aware of this, it will be a very important step forward.

But we need to make even more progress, and there are three things to bear in mind. First, we need to valorise the work of professionals in this field, and their jobs have to be recognised and valued, valued socially and financially. We need to value the work of family members who are carers, especially women. We can't hide from reality, it is still mainly women we are talking about, and their work needs to be valued and appreciated. And, thirdly, we need to value and appreciate those who do voluntary work, because they are taking the place of public services that do not exist, which that happened in some countries, with people relying on charities to help them.

**Session 2:
Responsibility for long-term care**

Chairperson: *Mrs Agnieszka Cholin-Dominczak, Undersecretary of State, Poland*

Rapporteurs: *Mr Igor Tomes, Univerzita Karlova Prague, Czech Republic*
Mr Kees Knipscheer, Vrije Universiteit Amsterdam, Netherlands

The second session addressed the diverse responsibilities of the family and the state in the field of long-term care.

In recent years, both the definition and the role of the family have changed significantly in Europe. Nevertheless, the family is still, in practical terms, the first social group within which long-term care is provided, either without any external help or together with health-care and long-term-care professionals. Therefore one of the important questions today is how to help the persons – usually women – who provide long-term care to some members of their family under conditions which are sometimes extremely difficult. How are the Member States of the European Union responding to these issues?

Who is responsible for providing an infrastructure? What policies are implemented? Across the European Union, home care is a live issue. What is the role of municipalities in providing services? What is the role of non-governmental organisations and of the private sector?

Do older persons have a free choice between staying at home and entering an institution, between benefits in cash and benefits in kind? And what is the role of “care managers”?

Discussants:

Ms Audrone Morkuniene, Counsellor to the President, Lithuania

Long-term care has only recently been recognised as a contingency, and it was even proposed to recognise it as a 5th insurable risk. So my question is: why and how did it happen that now we are talking about long-term care as a new contingency?

The main task of our social welfare system is to deal with dependence from its very beginning. In fact, those people who are no longer able to live in an autonomous way should be a focus point for every social welfare system from the very beginning. What people need in their very old age is mostly services, and in most countries service provision is left to families and municipalities.

So it is time to rethink this approach. Lithuania is an example of this situation and of this mix between public and private provision and sharing of responsibilities between state and family. The former Soviet system of highly centralised state provision of services, while ignoring the family burden, has disappeared. Now in our society we talk about family and all the disabled people. All our countries are now in a process of transformation which is due to demographic changes, changes in family patterns and changes in civil society. We have an increasing share of older people in our society and a decreasing share of children.

Very important changes took place in our society after we regained our independence. Actually, we experienced a boom in new care institutions, provided above all by religious organisations. First of all, we can see that municipalities or NGOs created most of the newly created facilities. In most of these facilities the number of residents has increased. We started to develop home care services, but only 3% of the population over 70 received them. Who is responsible for long-term care? Lithuania's Constitution proclaims very clearly the duty of children to take care of their parents. On the other hand, it is not so clear what the state guarantees in this situation. The state already guarantees retirement and disability pensions, and possibly social assistance in cases provided for by law.

So this mix of private and public in Lithuania, and in other countries like the Baltic States and all the Central European countries, has yet to be defined. It is not clear which institutions are responsible for what functions, or what services or what combination of services should be provided by the institutions or residential homes or in home care, and what the distinction is between social care and home care. At the financing level, Lithuania has introduced allowances for disabled people, for totally dependent people, but services are only partly provided free. It is not very clear if we should apply means tests in all cases or if we should provide free services. Under the recent changes no special disability supplements are granted to retired people, but there are reform plans for introducing a special needs allowance to be used for purchasing services or for providing services in kind.

The burden of maternity and paternity is much more widely recognised and supported than is long-term care. This statement is unfortunately true for all European countries, and brings some problems in its wake. In fact, when we talk about pension provision, and if we still leave responsibility here within the family, we should be asking for whom the insurance is intended – for recipients of care or for care providers, because both of them really need support.

The real burning issue here, which has been mentioned in other presentations as well, is that this burden of care for the family not only requires financial resources but is also a very intensive psychological burden. What is really needed is, for example, temporary respite for families, for holidays, for

weekends, because family members who are carers are on duty 24 hours a day and 7 days a week. So if we go further along this path, one can suggest that if we take persons who are caregivers today, they will very soon be dependent themselves. They will become recipients of care. In order to find solutions to the contingency of long-term care, do we need to rethink our welfare state model, or leave it as it is?

Mr Jozef Pacolet, Katholieke Universiteit Leuven, Belgium

I would like to add some comments from Belgium and this is an example where you can also assess the strengths and weaknesses of this kind of social protection for dependent persons or dependent older people. It happens that I have been finishing a report for the Belgian Federal Government. The report is on social protection and the relationship between ageing, healthcare and care for older people, and this is using the two terms together. It is completely part of the welfare system, and it is perhaps not even a new contingency, but a risk that has been there from the beginning of the creation of this kind of social protection.

What can we learn from our Belgian experience in relation to this choice between responsibilities – should responsibility lie at the family level or with the state? The market was not mentioned, but there are three potential distributions and of these insurance is the most important. Who can provide decent risk insurance for this new kind of risk? Families, can they provide it? Well, they do so and there is no opposition, and it may even be a competition between policy-makers and families, because the state wants to do more than people are perhaps expecting. I have never heard politicians say that the family is not accepting its responsibilities. When there is a family, a spouse, children, they pick up the responsibility for care. It is a 40 hours a week job caring for very old persons, perhaps 60 hours a week if they are with a person with Alzheimer's. When the main carer is a very old friend or a spouse or partner, it is a 24 hours a day job, 7 days a week. So the family accepts its responsibilities and it benefits from them.

The Belgian report emphasises that you cannot create an informal carer or family where there isn't one. So there is a less urgent need to provide support or to create a new system of parental leave. It is not care leave, or compensation, or allowances for the main carers, because they are using and consuming and benefiting from the system, and there are all those additional supports you cannot create when they are not available. But you do have to support this informal care, and that comes down to the role of the state or the market.

We are not looking too closely at the role of the market for the moment, certainly not at the financing issue involved. We have to make a distinction between financing and providing this care for the elderly. So I'm very much in

favour of giving a very large role to state insurance, I call it social insurance. I think that it should be a social insurance with social assistance characteristics, applying a lot of proofs of selectivity, asking that you spend your wealth when you become at risk or when you are rich enough to pay for the care needed yourself. This is not an insurance system, or a market insurance system, because it is a real risk, so the reaction should be to create appropriate insurance. The market doesn't provide too much insurance at the moment, even in the United States. The state should take up that role, and finance professional care. How important is professional care? Just consider again the case of the person at home. It is a 40 hours a week job for informal care, while for professional care it is an 8 hours a week job. So five times more informal care than professional care should be the reality, and we should not make economic evaluations of these differences in the time involved, the facts are really enough – five times more informal care than professional care.

It should therefore be the state that should take the responsibility, and it could do so via the fifth pillar, as many Bismarck-oriented welfare states in the 15 old Member State regimes have done. What did we do in Belgium? There was also a long debate on organising such a fifth pillar. The risk became obvious only when it was in front of us, and then we started a debate on organising an insurance system. Finally, a small long-term care insurance system at the Flemish level was introduced in Belgium. We succeeded in creating it, and within three years it reached a large population – almost all the people in residential institutions and the greater part of the people at home are currently benefiting from a reasonable amount of funds; it is only 1.08% of our national income. So with little money we are providing only a small allowance, but nevertheless for lower incomes it is a reasonable allowance, reaching a large part of the population.

But on top of this Flemish miracle observed in Belgium was what I call “the silent power”, in Dutch “de stille kracht”¹⁾. Dutch-speaking people will certainly recognise the poetry in that title – in French it was translated in our report by “la force tranquille”, “calm power” and it is a reassuring translation, because, indeed, it is what is meant. In the past ten years, we have had better financing of retirement homes and nursing homes, better financing and expansion of the provision of district nursing, community care, better financing of a system similar to what exists in Flanders, but more selective depending on income, a kind of allowance for third-party help. So in ten years it succeeded in adding 0.405% of the national income to the long-term care services. 0.5% brings Belgium into line with some 1.6%-1.7% public spending on long-term care, and some 0.89%, in total 2.3% of our national income, is now going to long-term care in a broadly defined way, including care for people with disabilities.

1) *Title of a novel by Louis Couperus.*

Belgium succeeded without a revolution, but as a silent power, in including long-term-care insurance in health insurance, and that is where it should be. It is part of the total risk of getting old, even if getting old does not necessarily mean becoming ill or dependent. Thus this system of protection for the state is included in the very traditional pillar of social security.

Ms Enid Kassner, AARP Washington, USA

AARP is a membership organisation of people aged 60 and over, advocating for the needs and rights of older people, and one part of that is to do research, which is my role at the AARP. Within the European Community has been a shifting focus in terms of where the responsibility should be, because in the US system, traditionally the role of the public programme has been much less emphasised than it has been in the European countries.

Why are we seeing long-term care come so late to the discussion? The experience in the US has been that some 50 years ago there really was no long-term care system, because people did not have high longevity and people who got older were cared for in the family pretty much exclusively, because women were not in the workforce, so that was part of the family system. But with the growing lifespan and greater longevity and medical advances that are keeping people with greater levels of disability alive, we have suddenly been confronted with enormously greater numbers of people who need these types of services.

However, in part what we have seen is that long-term care comes as an outgrowth from the health care system, and this creates some strange bedfellows, so to speak, in terms of what the expectations are. Because when you are looking at healthcare, you expect a trained professional to provide you with services. You do not want your parents to perform brain surgery on you. However, long-term care services are very often different in nature, they are predominantly personal care, so the medical model of having trained professionals does not often translate so easily. However, we have had in the US more of an emphasis on the family providing care or on people taking responsibility, by saving their own money, hiring people, buying long-term-care insurance and so forth. But the problem is that the cost of long-term care is becoming overwhelming, especially for people who do need institutional care and therefore, even though there is an intention that people should take responsibility, often it is not affordable to do so.

The irony is that in the US, like many of the European nations, there is predominantly a focus on institutional care, even though today most people will prefer to be cared for at home, to remain independent as long as possible. Yet our social services delivery systems have not kept up with what people want. There is a predominance of spending in institutional settings, even though that is no longer the preference, nor is it the most cost-effective

setting for delivering services. So the way the situation has played out in the United States, we really do not have any form of national programme that provides long-term care to all people who need it. What we do have is a welfare-based programme, a means-tested programme, for which people need to become impoverished in order to receive services. Under that programme, 70% of the spending goes to institutional care. Like people mentioned here, despite the fact that this is the programme that is out there, some 80% of long-term care is still provided informally by family members, neighbours, helpers and so forth.

But even with the great amount of informal care that is provided by family members and the fact that the system in the US is a welfare-based system, by the time people finally enter nursing homes, 2/3 of the costs end up being paid for by the public programmes. In other words, people have spent down their assets. They impoverish themselves and then come to rely on the system. So it is not really a good fit to have a welfare-based system when people can't afford to pay for services on their own, and then they end up with the indignity of having to impoverish themselves and rely on a programme that was basically developed only for the poor. The issue that is facing us in the US now is that the cost of the Medicaid Program, which is what our social programme for the poor is called, has been growing enormously, and so there are a lot of calls for reductions in the programme.

And the other thing is that long-term-care services are not only for older people, but also for younger persons with disabilities. In our system a very high percentage of the funding is currently going, for example, to persons with developmental disabilities or mental retardation. It really takes up a lot of the costs of programmes, even though it is a smaller number of people. With some of the advances in neonatal and intensive care we are actually seeing a very great increase in the number of children with developmental disabilities because the medical advances are keeping them alive, but at the cost of a need for long-term-care services throughout their lifetime.

So in particular, what we are looking at right now is a concern that people who have substantial long-term-care needs but have resources are artificially transferring these resources in order to get care through the public programme and so on. There are a lot of discussions and debates about how to stop this and how to make sure that people spend their own money before they come to rely on a government programme.

First of all, we are looking at the question of whether people should impoverish themselves and then leave the spouse impoverished, or whether they should be able to protect assets so that, if there is a spouse or dependent children, they can still retain a decent standard of living. Is it all right to protect the home? Currently, our programme allows people to retain their homes, but there is some talk that people should sell their home before they are allowed to get care, and this is something that is very controversial,

because the concept that a man's home is his castle is very prominent in the US. Should there be a right for people to protect assets to pass on to their heirs and still get services? In countries where there is more of an acceptance of public responsibility that issue doesn't come up so much, but in the US that is a big issue.

Despite all the problems with our system, there are some positive developments in the long-term-care system in the United States and the system has been developed in many of the European nations as well. Even it is slower than we would like to see, there is a greater move to provide home care services instead of institutional services. This is something that we would certainly like to see develop more, especially given that it can be more cost-effective.

Secondly, this issue of consumer-directed services is growing in the US and in a number of the European nations. The idea of giving people a cash allowance rather than requiring them to go to a specialised agency, and letting them perhaps hire a family member to provide the services, has the double effect of helping family caregivers to continue to provide care services, whether or not there are public programmes available. So, there is recognition of the importance of the role, and of family caregivers.

And then finally, it is certainly my hope that this baby boomer generation, which is known for being much more vocal about its own concerns, will, first of all, realise that baby boomers are now seeing their parents needing long-term-care services, which will hopefully bring them into this debate at a younger age, where they will recognise that not only do we need a better system for our parents, but that one day perhaps it will be us.

Mr Marten Lagergren, Stockholm Gerontology Research Center, Sweden

I'm going into two issues: one is the family and the other is the division of responsibilities within the public sector, which is also an issue to be considered. First, concerning the family: does it exist? I'm not so sure, actually. What we are looking at is definitely a different type of family from the one we used to have. I'm taking examples from Sweden – you may look at Sweden as the kind of future model for the Nordic countries in general or you can look at it as a blind alley if you like, but maybe our experience is not so uncommon. We are subject to the same basic forces. What's happening is that the family is changing, from extended family to nuclear family and then to what we have called the social family. It is more or less no longer a biological unit but a social unit.

And to make this clear, I'll take myself as an example – I've been married twice and divorced twice. I have four biological children and one adopted child. All five call me Dad. I have four grandchildren, all adopted. Now will they or won't they call me Granddad, one might when he starts talking, I don't

know. So, the point is, is this a family or not? From some points of view this can be seen as a family, but not from others. The question is one of responsibility. Who feels responsible?

Growing old and becoming dependent is a process, it is a long process, it doesn't just happen, it is not an accident that occurs. For example, I remember my grandma, who died at the age of 94, she started becoming dependent at 86. First we could help, we could manage, then we couldn't manage, we had to have home care, and then in the end she had to go into a home at the age of 92.

So it is a process, there are a diversity of approaches that we have to approve. There is not one approach, there is not a black and white problem, and it's a very complicated and diverse problem. And the problem of responsibility is how to face this process, starting at the beginning with informal care and maybe ending with very highly professional care because nobody else can do the job. So let's look at it as a process, not as something that suddenly happens.

The second summarised answer will be that we consider ourselves in Europe as having responsibilities for solidarity and human dignity as human rights, and this has been put into many constitutions. Now, when you put a human right into the Constitution, legally what happens? Somebody becomes responsible for implementation of that human right. So always, the moment we put that in the Constitution we impose responsibility on the state, because someone has to implement that human right, it doesn't just happen, does it? Now, the responsibility can be different. Again, there are many varieties of responsibilities and again, it is a process. For example, responsibility starts with being responsible, with ensuring that informal care doesn't hurt your human rights. So there must be some supervision. You must have the chance to go somewhere to complain, to discuss.

Coordination, what is coordination? Somebody must organise coordination. Who is responsible for organising it? It is the state, because it is written into the Constitution as a human right. So again, coordination doesn't just happen, it has to be organised. So when we talk about responsibility, we aren't thinking only of giving money, we aren't thinking only of organising residential care, we are also thinking about responsibility for supervising that care. People are vulnerable; maybe they can't defend their own rights properly. There is an unequal relationship between the care provider and the recipient of care, because she is completely dependent on what the provider offers, so somebody has to supervise this. The same applies to the private market. But again, there must be supervision, somebody must be sure that you are not robbed of your money when you take out insurance. Again, who is responsible? The state. This is what I meant by sharing responsibilities between private individuals, the family, the market and the state, but the state cannot deny its responsibility and the Constitutional Courts should look very

carefully into whether the state is keeping its promises in accordance with the Constitution.

And that's where the choice comes. My third remark is as follows – you remember that I was asking when the Government should step in with active tools: money, services? When the family cannot take care of itself. Well, that's a problem of choice. Again, if you want to have a choice, somebody must offer you that choice, choice doesn't just happen, so it must be a choice between something and something else. And something else is what the Government is offering, so you have a choice in between, otherwise there is no choice; otherwise you just have one alternative and full stop.

**Session 3:
Social protection for long-term care**

Chairperson: **Mr Marten Lagergren**, Stockholm Gerontology Research Center, Sweden

Rapporteurs: **Mr Gerhard Igl**, Universität Kiel, Germany
Mr Jozsef Hajdu, University Szeged, Hungary

The third session described and assessed how social protection of persons in need has evolved through a typology of the systems of social protection and the role played by the persons themselves and their families in financing the protection.

Is social protection for long-term care increasing or decreasing within the European Union? What is the place of private insurance?

What are the advantages of social protection in this area? It aims to foster the financial independence of older persons and to reduce the burden on families, and particularly on women, of providing long-term care. To what extent has social protection succeeded in doing this?

Discussants:

Mrs María Amparo Valcarce García, Secretary of State for Social Services, Families and Disability, Spain

Caring for the needs of people who are dependent in Spain has become a very significant social demand and a challenge for the political authorities. There are many Spanish families who are affected by the problem of dependence. In 1.6 million Spanish homes elderly people are looked after, and in 200 000 of these homes disabled people under the age of 60 are helped. The number of people in the situation of dependence, the care that they receive, the way in which the care is provided, which is almost exclusively by families, particularly women, and the imbalance in access to social resources, mean that a law for the promotion of personal independence and for care for dependent people is necessary. It needs to strengthen the rights of the citizen, social protection and carers through benefits and social cohesion. Thus the commitment of the Spanish Government is to present a bill that will create the national system of dependence.

The idea is to reach a basic agreement involving all the parties involved: the business world, the trade unions, the entire public administration, central government, the autonomous communities, and local government. The intention is also to involve the private sector, the healthcare and insurance private sector, because they have significant resources and can set up a

network of care that is of high enough quality. There also needs to be a dialogue with civil society, with organisations that represent dependent people, older people, as well as people who are disabled, scientific organisations, etc.

The government has put forward a White Paper on dependence using a participatory method. We have already introduced the document to you; it is very thorough, very honest. It contains a photograph, a picture of the situation in Spain concerning dependence.

The White Paper is organised in such a way as to take account of demographic factors and also of the characteristics and the profile of the dependent people. There is a legal angle to protecting dependent people. It includes informal support, the way that the network, including health, social resources, etc., covers the people involved. In Spain a significant amount of money is being channelled into caring for dependent people.

There is a very important issue here, namely the criteria that are used to assess dependent people. Logically, we need to work out what the costs of the system are going to be, how they are going to be funded in the medium to long term, but also the employment issue.

There has also been a comparison of different dependence systems within OECD countries. The research focused on the German, Austrian and Luxembourg model because we feel that this is a very important, significant model. We want our Spanish law to have a system based on four fundamental principles: firstly, the conditions and requirements with which people who are dependent need to comply so that they can have access to benefits; secondly, what those benefits will be, the basic benefits that will be available; then the mechanisms to ensure that there is equality, equal access, throughout Spain, regardless of where people live. Of course, the regional and local administrations with a bigger budget can improve the benefits that they provide if they choose to. And then finally, there's how the system of services is going to be financed and managed.

A national scale in accordance with which dependent people are categorised is needed, and it has to be equal across the board. We also want to have a system of co-payment, so that the beneficiary would pay according to what income he or she has, from capital, work, whatever it is, the pension, benefits, etc. So there needs to be a scale of how much the user needs to contribute.

We also want to encourage employment through this system, to help families. According to the White Paper we can create about 300 000 new jobs. And not only new jobs, it would also lower the unemployment rate in what is known as structural unemployment and would also increase the employment rate and combat the seasonal nature of jobs. We also need to talk about the returns, the financial returns. So what is the benefit of investing in the social sector? We know that developing infrastructures and service networks will make it specifically possible to achieve a substantial financial return – we are

talking about almost 2 billion euros a year. It will generate new jobs, and then that will make it possible to stimulate the economy in general.

In conclusion, there are very significant social reasons, there is a political consensus in Spain for this reform, financially it is a viable project and it will have a favourable impact on the economy, these are the factors that have encouraged the Spanish Government to help people who are dependent.

Mr Georg Fischer, *Head of Unit, Social protection: Pensions and Health, Directorate-General for Employment, Social Affairs and Equal Opportunities, European Commission*

Why is it that the EU emphasises long-term care together with social protection policies? The EU looks at long-term care, at least in the context of the OMC, as an important element of social protection policies. This will become even more clear from 2006 with the streamlining of the OMC, when policies about social inclusion, pensions, healthcare and long-term care will be incorporated into a broader integrated strategy for social protection and social inclusion. There are essentially three reasons why one would look at long-term care as a task for social protection policies.

The first reason is that there are serious and growing needs on the part of people for long-term care. And secondly, there are major inequalities in these needs. Recently, the European Commission has financed a very large research project on the health of older people, the SHARE project. One of the most striking results is that in the limitation of daily activities among older people there is a strong bias towards people with low incomes and low education. And these are the people who are least able to provide for themselves. One can of course say this should all be left to the family, but in the SHARE study there is some evidence that isolation may be more marked in these groups of people with a low income and low education, and thus there is a clear need for action based on the solidarity principle. This is one of the reasons for including long-term care as an aspect of social protection policies. There is no way to expect society to work in a structure in which those who are probably most in need are also able to afford this themselves. As a result - public intervention seems to be needed.

Thirdly, and you know this better than me, that even for middle income groups, at certain stages care costs are so substantial that they may have a catastrophic impact on finances. So even if one moves a bit higher up the social scale, one will see a need for an overall solidarity-based approach to these care costs.

There is another basic reason why there is a strong link between long-term care policies and social protection policies. I think Mr Igl has touched on it by asking the question about the links between different EU strategies. And of course the various EU strategies are no different from the rest of the world,

they are policy issues which everybody, all the Member States, have to address - these are the questions of prevention, rehabilitation and employment. I know I don't have the time to go through all these elements, but I will just give you some ideas.

In the SHARE study, for example, one of the most interesting results is that there is a bidirectional relationship between voluntary work and limitation of daily activities. If it is true, it is a very strong argument for a broader perspective, certainly on the prevention side of long-term care policies. There is a need to look at how to break down the borders between different policy areas, and certainly a social protection approach is more likely to do this than if we put things in different boxes and then communicate between the boxes.

We need higher employment to afford social protection policies, also long-term care policies. Secondly, obviously long-term care needs generate employment, and we need qualified personnel. Do we move to a society in which work is more evenly shared between men and women, between older people and younger people, household work, paid work, care work, childcare work? So, if we manage to have a society in which people work longer, and if we manage to have a society in which men and women work, wouldn't we also move to a society in which in the longer perspective we also had less long-term care needs, because people would be more active also at later ages? Then long-term care might still be a big problem, but not such a predominant issue as it seems at the moment. It might also be easier to approach that problem, because we would have an employment system geared towards providing these services.

Mr Kai Leichsenring, European Centre for Social Welfare Policy and Research, Austria

No country in Europe or in the world has a long-term care system, but we researchers, you as politicians or in the public administration, we are all trying to construct something that we can then call long-term care. Now the time has also come to discuss it as the fifth pillar, or something that should be added to the social protection system, as something distinct.

So what we actually need here is more differentiation. The types of services we rely on in different countries are home care, home help, and perhaps respite care or day care. But the individual needs are so differentiated that we also need more differentiated services and more differentiated social protection. It is not a discussion only about more money or more services, but also about which kind of services.

The issue is not only about focusing on older people. A long-term care system would include not only older persons, but also younger persons in need of care.

There is a tendency aside from the construction of long-term care systems to move from 'poor law' to 'social rights'. There are additional schemes coming in, in the different countries, be it in the social insurance systems or in hybrid systems as in Austria, France or parts of Italy. And there is one important and interesting question that could also be tackled in the discussions – whether Central and Eastern European countries will now have to follow the same path as Western European countries, or whether they could skip part of this exercise and, instead of building huge nursing homes or retirement homes, could push on immediately towards differentiated integrated services.

Another topic is linked to mapping. With respect to the Open Method of Coordination processes, we have to evaluate and compare the different systems. But not in such a way as to see whether Sweden is better than Italy, for example, but from the perspective of development and a quality-management perspective, in terms of what our objectives are for the next year and how we can reach them, and in such a way as to start social discussions about these kinds of objectives. We would subsequently need to decide, and this would be a genuine political task, what the priorities are and how far we can go in Spain, in the Netherlands, etc.

So if we look at evaluating policies, then first of all we should evaluate policies against what is claimed – it is said that you can go wherever you want in Europe. Politicians will tell you that what we want is more care at home, people should stay at home as long as possible. Expenditure, at least public spending, is mainly on institutions!

So this would be one of the first things to do; another is coverage. If you look at people receiving a long-term-care allowance as a percentage of the total population, in Austria it is 4.3%, in Germany 2.1%, in Luxembourg 1.6%. Does this mean that Austrians are twice as dependent on care as Germans? No, it means that underlying this is a specific political decision about how to define and how to assess long-term-care needs. So ask yourself, ask your Government how they see it, and discuss it.

Third thing: entitlements. What are the maximum and the minimum? In terms of long-term-care allowances the question is fairly easy, but it becomes more tricky in terms of services and so on, I know. We at least need some easy indicators in order to set to work on evaluation.

The next thing to discuss is the whole issue of 'choice'. Because if we talk about choice, there are different kinds of choices: money versus services; care at home versus nursing home care; choice of whether or not to provide care. So we need to support family carers – do I act as a carer? Do I have the choice of whether to care or not? This is an important decision I have to make, and it depends on what kinds of incentives are given. Many people are cared for by spouses and people who are already on pensions. But we know from evaluation of the long-term-care allowance in Austria that it was an incentive for women to leave the labour market. There, about 20% of the carers had

decided to leave the labour market because of the long-term-care allowance, because it made it possible for them to leave. So hopefully they will then come back – or not? That's another question for the labour market.

One of the most important issues involved in long-term care is the integration of social and healthcare services in Europe. If you want to evaluate it, look at access and assessment procedures or just ask the simple question: what happens to a person that is released from hospital on a Friday afternoon when he or she lives in a remote village and is in need of long-term care? If you can answer this question, then you have a long-term-care system. Then you are able to compare that system, to show it in the Open Method of Coordination to all the others, and to invite them to your country and show them how you manage the system. Hopefully you also do that by involving carers and service users, of course.

Ms Anne-Sophie Parent, AGE, Belgium

Dependence is for us a life risk and, like any other life risk, it has to be covered by the solidarity system. Because like any other life risk, it depends on a variety of factors over which individuals have very little control – it has to do with the genes that you inherit from your parents, it has to do with the working conditions that you have experienced, and it has to do with the society and the community in which you live. So it is the responsibility of the public authorities to ensure that the most vulnerable are protected against that risk. Member States should feel free to organise protection against the risks of old age in the way they prefer. Not the way they want, as governments or finance ministers, but the way their citizens want this to be organised.

We hear about private insurance, and it may work, but we have very major concerns about this. Because we see a huge risk of discrimination against those who incur higher risks, which is exactly the opposite of a system based on solidarity.

We have also heard a lot about the role of the family. It is a puzzle how we can go back to such a system and at the same time set very high targets for employment, for social cohesion, and in terms of gender equality. Just look at the examples of the countries that have high employment rates among older workers and high employment rates among women: I don't know if this is a coincidence, but all of them have high levels of services for child- and eldercare.

So we need to remind our decision-makers that they can't have their cake and eat it. They have to decide what the priorities really are. And they have to ensure that they coordinate those priorities together. So this is why the OMC on health should not just be a light, soft, 'nouvelle cuisine' type of OMC, it should be a real OMC, a strong one, one which will ensure synergy between the other policy developments. If we are really serious about gender equality,

we have to tackle the issue of long-term care very, very seriously. And especially this system which puts such a focus on family, for me this is going back to what happened once upon a time when we left our old people in the bush or on the top of a mountain. The only difference is that we propose to send a carer with that old person, that's the only difference.

The EU objective is above all else one of greater social cohesion, and Mr Barroso should keep that in mind!

Discussants

Ms Lucie Taleyson, SCORVIE, France

SCORVIE is a life insurance company that provides private insurance for people who need care. I am going to focus on Europe, but the major centres are France and the US. You can see that France is the only country in Europe where the private insurance market has really developed – 2.5 million people are insured by a private insurance company against the risk of becoming dependent. This type of insurance was launched about 20 years ago. If you compare this with other countries such as Germany, or if you look for example at the UK, it appears that in 14 years they have only sold 40 000 policies.

So what explains France's success? How do we explain the fact that this development has really taken off in France, but nowhere else in Europe? There are a number of factors. First of all there's a favourable environment in France, in the sense that in France people are much more aware of the risk of dependence, communities are much more aware of these problems and these issues, there have been public debates on this, and the state has a number of benefits available to people who have become dependent. But the state cannot take care of all needs and so there is a need for complementary funding from the private sector. And private insurers took an interest and managed to come up with a product that was attractive to people. People can have a monthly income if the insurance policy kicks in, and this gives them independence, autonomy, because financial independence is a major element.

Now over the 20 years, there have been a number of generations of these products, and there are products where guarantees increase, the funding increases according to how heavily dependent a person is. There is also partial cover; there are also products where the person who has become dependent can choose to divert those funds, that income, to the care institution. If a person chooses to have private care exclusively from a particular institution, the insurance pays the care institution to provide the care. There are cases where the insurance policy can kick in to prevent the person from becoming dependent, so before the disaster strikes, so to speak.

Some of these contracts are individual, some of them are collective, they can be compulsory or optional, and are offered by companies, big companies, such as the Post Office or France Telecom.

With regard to the profile of the people who are insured, usually it is people with a very low income, who want to ensure that their income is subsidised. Women are the people who are most affected. And they live longer, so these diseases affect them more, and they are affected as carers as well. Two out of three insured persons are actually women. If you ask them why they insure, it is because they want to ensure their financial independence, without eating away their savings and so that they don't have to rely on their children. Women take out insurance out of selflessness, in fact, because they don't want to put the burden of care on their family. It is selflessness in women that has actually stimulated the development of the private market for this insurance.

Long-term care insurance is a developing market, where the private sector has a role to play as a complementary factor – you have the state on the one hand and then the private sector on the other. It is a form of cooperation, and as members of the private sector we would like to see public and private partnerships in the area of research as well, so that we continue to improve our awareness of the risks, where the public and private sectors need to come together to attempt to solve the problems.

Mrs Agnieszka Chlon-Dominczak, *Undersecretary of State, Ministry of Social Policy, Poland*

In Poland the family is very important in caring for people. This is why institutional care is treated by the family as a solution of last resort. About 86 000 people are covered by various forms of institutional care.

With regard to the financing issue, if you take the total expenditure in Poland divided between cash benefits and institutional care, then cash benefits are definitely prevailing as far as Polish expenditure goes. With regard to institutional care, there is a difference between access to institutional care, which is more or less free to everybody, and financing of the relevant institutional care, because public financing only kicks in when the family really cannot afford to pay for the care. This is why the overall financing looks like that.

Poland is not very supportive of institutional care as something that should be developed at the very early stage of a person's need for care. Rather, other services should be provided first, before starting on institutional care.

Mr Henri Lourdelle, European Trade Union Confederation, Belgium

Are we talking about needs or are we talking about our capacity to fund these needs? And that's a whole issue relating to social protection, it is a key problem. Social protection in general and paying for long-term care are a social issue with economic implications, or is your starting point to say that these are economic questions with social consequences? The answer in each case would be very different.

The OMC is very important. We are not just talking about the initial model of the OMC, with the exchange of examples of best practice. The idea is to make commitments to implementation.

Then there is the question of funding. It is always the same party, the people that are paying, yes indeed. But the arrangements are different if you have socialised funding as it is called, as opposed to individual funding. Because if you have individualised funding, you are moving towards risk selection, exclusion, a two-track system, a duality, a splitting-up of society.

In the context of private insurance paying for care for the dependent, people were saying that through private insurance we would solve a problem that was very fundamental. And gradually, as time went by, the bodies adopting this position shifted towards supplementary funding, so that there is another source of funding, which is really socialised cover.

Ms Muriel Rabau, Permanent Representative at the EU, Belgium

In a society whose aim is to seek social cohesion we should talk more in terms of life risks than in terms of individual responsibility. We need to talk more in terms of solidarity and social protection rather than private insurance. A society seeking social cohesion should manage to come up with the means to fund this adequately, so that there is accessibility, geographical accessibility and financial accessibility to quality services. Good-quality services should be accessible to the most vulnerable and to those excluded from society.

It is a matter not only of social protection, but also of the responsibility of the state, which is the final guarantor of this financial accessibility. Of course, the state shares the burden and shares the tasks with other players, local authorities, NGOs and families. And on this note we simply have to think about enhancing the role of and really valuing the informal carers. But the lion's share should be the responsibility of the state, so that there is full coverage and insurance for all, in the spirit of solidarity, which is after all, one of our most fundamental values.

Mr Victor Bayarri, *Foundation Koiné-Aequalitas for social development, Spain*

The Foundation is trying to promote quality of life and equal opportunities for dependent older people. We should not create a separate classification for older people who are dependent compared with those who have a disability. Just because they are elderly, people are not to be considered automatically ill or dependent. So we have to tackle incapacity, and the ICF classification (International Classification of Functioning, Disability and Health) is very helpful. Why don't we set up a European classification allowing us to tackle systematically the detection of elements boosting activity, restricting activity, elements which will facilitate participation, elements limiting this, from the point of view of the person and of the environment and surroundings? Why don't we come up with some sort of European classification which would allow us to pinpoint the support services and benefits which would be appropriate for each one of these areas – from the point of people's health and housing and social provision? This will not be too difficult, but if we don't take this initial step, we are moving towards patchwork care, and I don't think this would be very desirable for European social policy. Long-term care should be more than patchwork, it should be a right linked to citizenship, equality of opportunities vis-à-vis public services when it comes to incapacity. We need to think about rehabilitation of the person, not just caring for them, helping them to participate. We are talking about help from neighbours, from the family environment.

Mr Davor Dominkus, *Ministry of Labour, Family and Social Affairs, Slovenia*

Three years ago Slovenia began preparing new legislation on long-term care insurance, and in fact this year a group of experts has been set up, from the Health Care Institute of Slovenia, from the Ministry of Labour and the Ministry of Health, to prepare the new legislation on long-term care. We see the need for long-term care as a new risk which should be covered through social insurance systems, and our idea of long-term care is integrated care. So within one framework we should provide both social care and healthcare services.

Although we started three years ago, I have to say that the awareness in a broader public of the importance of this issue is not very high. So we would like to start a campaign in Slovenia to promote this idea, and within that framework we would very much appreciate help from experts in countries which have already introduced this type of system, of services or insurance.

Ms Angela Blanco Moreno, *Institute of Fiscal Studies, Spain*

I would like to make a brief comment to stress the need for coordination between social services and health services. I think in many countries, as is the case in Spain, access to social services is means-tested. But the same doesn't happen with the healthcare services. And often we have a lack of resources for social services.

I think this is something that needs to be borne in mind, because it has an impact on the quality of the services provided.

Mr Kai Leichsenring, *European Centre for Social Welfare Policy and Research, Austria*

With regard to the debate on whether or not to start from needs, the thing is that often the assessment processes, as we see them in the existing systems, are designed as a kind of gatekeeping instrument. So this is one thing that we should not do.

In view of shared responsibilities, we should assess what the needs are, and then discuss, together with all the different stakeholders, what we can do about them. Of course the relevant German law says, as does the relevant Austrian law (every long-term-care law has to say this at the outset), we are not covering everything, because it is simply impossible. So what you have to do is to say now, you as a citizen, what you can do for yourself or together with others, and what the State or the provider can do for you. And this is the approach that we should use for the assessment process, rather than gatekeeping processes.

Ms María Amparo Valcarce García, *Secretary of State for Social Services, Families and Disability, Spain*

Informal carers have to be included in a system, but the system shouldn't hinge on informal carers. There should be a network of services.

Informal carers should receive support, i.e. a reasonable financial benefit or subsidy and then appreciation for the care that they are providing. But they need to be supervised by the local authorities to make sure that there is a guarantee of quality in the service that is being provided to the person who needs care.

But the informal carers also need a breather; they also need to be able to get away. With regard to the inclusion of informal carers, and women are the most affected, we need to be very careful in case they disappear from the system if we handle it wrongly.

In terms of access to services, we must make sure that an increase in access to these services doesn't lead to a reduction in their quality.

Mr Gerhard Igl, Universität Kiel, Germany

Taking stock of the situation, when it comes to insurance for long-term care in the Member States, the issues are settled at national level. But it is important to have the information. And then secondly, there is a European level. What are the European institutions doing with regard to the need for care? Are we talking about social security risk or not?

The European Court of Justice doesn't care about the label; the Court of Justice has dealt with the need for care as an illness and with benefits as provisions, benefits when suffering from an illness. What matters isn't the label but the content. When it comes to payment going to informal carers, all of us are aware that the Court of Justice's approach is not actually correct, but we are quite glad that their case-law is as it is. We are moving towards a social union, though we are far from a social framework for Europe. There are positive European strategies, but there are also more dangerous ones when it comes to quality of care. If you look at the European Services Directive, there's the discussion about removing healthcare from the scope of the Directive. But the whole issue hasn't really been clarified; it hasn't been clarified whether long-term care is to be understood as healthcare. Because there is a major difference between healthcare and long-term care. And in many Member States, some people are labouring under the delusion that healthcare is likely to be excluded, so that long-term care can be included.

Mr Jozsef Hajdu, University Szeged, Hungary

Legislation on social security is like a picture, you might say, of insects, of small insects. If you put the first one in, it is OK, it is moving. When you put the second one in, it is already moving the first one, do you see? This is similar to legislation, which is why it is very difficult to collect the correct information every time. So thank you very much for correcting me.

In answer to the question about the Services Directive, the Commission proposal did not say that services in the public interest would necessarily be covered. In the Commission's draft there were certain provisions about how certain public services might be excluded, and that's independent of the whole issue of healthcare and long-term care. But at the moment the European Parliament, in its most recent opinion, has said that all social services should be considered together, so long-term care will not be considered on its own, it will be part of healthcare. We need to keep a close eye on developments. We need to talk to the people in the European Parliament, people who you think can represent your interests.

On the issue of social and health services, the Commission is planning a communication in which it aims to set out how the specific features of social services can be taken into account in implementing – we were talking about that – provisions on competition, public procurement, all the services legislation.

With regard to the OMC, I would like to express my thanks, not only on behalf of the Commission, but also on behalf of the many members of the Social Protection Committee. I would like to thank the Luxembourg Presidency for putting the subject on the table, we have had many different positions put forward as to what the OMC should be doing in terms of long-term care and I think this will really enliven our work, but I would ask you to bear with us, you need a bit of patience for things to happen, I think a major step forward will be taken in the Social Protection Committee in July. I think in the course of 2005 documents will be produced which will serve as a focus for discussion.

Ms Anne-Sophie Parent, AGE, Belgium

Older people don't really care how you label their needs, it doesn't really matter to them whether it is social security or not. What matters is that their needs are really met and taken on board. They want their needs to be met, giving a choice both to the recipients of care and to the carers. However, keeping in mind, of course, that we have to live with limited resources, for them the only solution is for the risk of dependence to be shared through a solidarity system.

How this system is to be organised, that's for every Member State to decide, but the principle of solidarity and of non-exclusion, that means universal access, must be promoted. Because we do have a huge problem – just remember, in the summer of 2003 more than 3000 older people died alone. They may have had relatives, they may even have had enough money to buy care, but they died alone.

So obviously the problem is maybe not so much the money, because we know it is limited, but the way we use the money. We should use it in a much more efficient way, which means not only in a much more financially sustainable way, but also in a way that really meets people's needs. All older people will tell you they want to stay at home as long as possible, but they don't want to rely solely on their families because they want to give their children a chance in life. So we have to see if we can develop innovative approaches and organise their needs in a better way. The starting point would be to make our societies more age-friendly, because this is one of the biggest barriers that makes people dependent at a much earlier age than necessary.

The level of civilisation of a society is proportional to the level of protection it offers to its citizens, and especially to the most vulnerable ones. We all know

that the EU aims to become the most competitive economy. Let's hope that we will also try to become the most civilised society.

Ms Marie-Eve Joël, Université de Paris Dauphine, France

First of all, when we started looking at dependence, it was from the financial angle, because we had realised that there is a need for this, an increasing body of people who will need care. However, we are in sort of a counter-phase. We are approaching the matter in an orderly way – there is a risk of dependence, in the face of this risk we need to define clear objectives, and once we have clear objectives and a political consensus, we do not really have a problem in tackling the issue of providing care from the financial angle, because society takes its decisions under financial constraints.

Then another point on private insurance in France – the Government has taken a while to become aware of the need for care for dependent people and then to come up with specific ways of tackling this and of providing benefits to enable people to keep their independence. Even so, I would point out that the first specific benefit for dependence was with an appeal on an estate. It wasn't that French people demanded these benefits to make sure that their children could inherit whatever they had to leave them, that was not the case.

This example is mentioned to illustrate that we need to understand fully what people's financial needs and incentives are, because otherwise we may tackle the whole issue from the wrong angle.

The last point concerns indicators and the need to work on the indicators which we have available. We have indicators that reflect political choices, but do not reflect the efficacy of the long-term care system and how it is organised. In fact, how many older people enter a care home and lie down and never get up again? This is one indicator. And a suggestion for the second indicator is: how many elderly people die in the ambulance going from the care home to the hospital?

Session 4: Social justice and long-term care

Chairperson: Ms Elise Williame, Ministry of Social Security, Belgium

The topics of the final session were suggested by the reports and discussions of a seminar financed by WHO in 2002 at the University of Chicago, on the topic "Ethical choices in long term-care: what does justice require?"²⁾, as well as by the work of the American philosopher Martha C. Nussbaum on the challenge which long-term care presents to conventional ideas on the social contract.

Last December, Professor Jean-François Malherbe from the University of Sherbrooke (Quebec) led a preparatory seminar in Luxembourg in which beneficiaries of long-term care, professional and non-professional carers, policy analysts and social programme managers participated. Questions of justice and solidarity in the domain of social policies for long-term care were discussed. What are our values? And on which of these do we take practical action? How can we bring our values and practice closer together?

Professor Malherbe started the final session by presenting the conclusions of the preparatory seminar. He will discuss the values on which the social policies of the Member States of the European Union are based. Does a given value have the same meaning in different countries? What is implied by the differences? What is required in order to grant the same rights to every global citizen?

This was followed by a presentation from Professor Nicholas Barr of the London School of Economics and Political Science (LSE). Based on the scientific report, the work of the preparatory seminar and the discussions during the preceding sessions, Professor Barr presented his thoughts on the necessities and possibilities for developing convergent European social protection in the area of long-term care for older people.

During the last part of the session high-ranking officials from the European Commission and from various Member States presented their points of view on the reports and discussions of the conference, as well as on the reflections of Professors Malherbe and Barr on how to guarantee access to adequate long-term care to all older people in Europe.

2) WHO, *Ethical choices in long-term care: what does justice require?* World Health Organization collection on long-term care, WHO, 2002.

Prof. Jean-François Malherbe, *University of Sherbrooke, Canada*

How can we go further in terms of our values: do we have complementary values, do we have common values? Are they very culture-specific and very difficult to share? These are the things we need to look at.

There are a number of different definitions of dependence, from WHO, the OECD and other organisations as well. At the same time there are many definitions of the three basic values that all the nations of the EU will refer to when we discuss what is at hand here: justice, solidarity and independence.

But beyond the recognition of these three basic values, we don't see that there are differences, divergences.

Justice, for example – is it equality or equity that we are looking at? The difference is sizeable. Equality means everyone gets the same size slice of the cake. Equity, however, means that each gets what they need, depending on what is available as well. So there are subtle differences between these two concepts of justice. Justice is a task, it is not an acquired quality, and it is a task that we are working on. We have been working on it for some time, attempting to reduce the differences between us, to get rid of the disparities that can divide us, and sometimes pit us against each other.

The next value is the price that we are prepared to pay in order to achieve justice – that's solidarity. But how do you express solidarity?

Is solidarity expressed by proximity, meaning in a universe of closeness that we construct such as families, friends, our immediate surroundings? We need to think about this idea of closeness/proximity and its links to the idea of family.

You have a family when there are human intergenerational relations, biological or otherwise, as long as there is an affective connection there and there is at least an alliance, between people of the same gender or of different genders. So when we have these two aspects of relationships (intergenerational and alliance) we could use the term family in the broadest possible sense. At least from a philosophical stance. That's one of the hypotheses that we could consider.

This is one way of seeing solidarity, but solidarity can be institutional – local, regional, national institutions. Our systems in different countries combine these two concepts of solidarity, of proximity and institutional solidarity.

I live in a small village in Quebec. And the villagers of that village decided to build accommodation which was suitable for people who were losing their independence. This allowed dependent people to stay in the village, to receive the visits of children from schools with which they had very good affective relationships. Thus they could stay within the community; they were still part of the community. The state subsidised the building of this

accommodation and there again, that is a source of inspiration. Or if you already have something similar in Europe, this might be looked at further.

Now independence, which is defined as the ability to set for oneself personal projects and to achieve them. Namely independence, psychological and relational independence, a type of independence which allows participation in convivial life.

Another form of independence is ethical and spiritual independence, which is the ability of each one of us to give meaning to our lives. Anna Arendt, who is an American philosopher of German extraction, was asked by a journalist what a successful life would be for her. She said life begins to be a success when a person is no longer satisfied with simply being an actor in the scenario of his or her own life as written by others, but decides to write the plot for that life themselves. This is one way of conceiving independence, as something that can always be worked on and developed.

The issues we are talking about here are so important in their economic impacts that in discussions such as the present one, we spontaneously talk in an economic language or an administrative language, most of the time.

We ask that dependent people should be more active, should participate more, for example should wash themselves and not be washed by someone else. Although it has been said that what counts is what can be counted, money isn't the be-all and end-all. And so people need to hold all the cards, as has been said, and those people who are dependent still need to have a voice and to be able to make decisions.

So consider the following question: how do you treat someone as being the star of their own life, the key player? How do we treat each other as actors in the building of Europe?

Our relations with people who are dependent are very similar to the relationships we have amongst ourselves, but their problem is very dramatic because they are gradually losing their independence.

In order to answer the question of how do we treat a person as being the important key player in their own life, three main points have to be highlighted. First of all, we have to have it very clear in our minds and we have to be brave enough to say quite openly that frustration is part of the condition of becoming dependent. When it comes to promoting justice, we cannot please everyone and we should all share that burden of frustration fairly amongst everyone. So we accept the concept of things as being finite, and our own finite quality, as we say in philosophy.

The second point is that we have before us a person who is going to pieces, their downfall, their dramatic decline, and it is a tragic thing to witness. We have to see that clearly and be brave. And take responsibility and accept again your own finiteness, which is what that represents to us.

The third point is that there is a difference between the values that we would claim to uphold and the practice, the way we actually behave in practice. That is part of the human condition. There's no point in feeling guilty about it, but we have to be brave and attempt to reduce that gap. So share out the frustration fairly, accept our own human condition and work at reducing the distance between what we say we want and what we actually do.

These are the three cornerstones of a framework of our differences. We cannot suppress all these differences, but there are differences between us as individuals, as citizens, differences between Member States, and differences between ourselves and those people who are becoming gradually dependent.

It is not up to philosophers to redefine our collective values, but up to everyone, all individuals. As philosophers, we can suggest a method, a word that is of Greek origin, which means to accompany someone along the way.

In the light of this, it seems that if we want to go further with these discussions in terms of the ethical angle, then we need to want and to try and set up international workshops on justice and solidarity and independence. Research workshops, but not in terms of concepts, there's plenty of that, but rather international meetings of delegates of different Member States who will come and explain when they have implemented effective practices of solidarity and justice and independence, so that we can use what is done in the field to identify the individuality of our different approaches and see the merits in others. For example, if you talk about the role of the family, the institutions, etc., we can see how that is perceived in all the countries, and that is how we can develop this ethical clarity, lucidity and bravery, courage. Because although nothing about this human Earth is ideal, we can throw ourselves into pursuing this idea wholeheartedly, in order to achieve as much as we can and always treat each other with respect, as the protagonists of our own lives.

The route we should take is to reduce the gap between our alleged values and practice in terms of long-term care for older people.

Prof. Nicholas Barr, *London School of Economics and Political Science, UK*

In talking about these things, it is important to distinguish funding from delivery - who pays for long-term care and how it is delivered. I am going to talk almost entirely about the funding side and about broad principles, not about the specifics of EU convergence.

Why is insurance for long-term care important? There are two sets of arguments: economic arguments and moral arguments. The economic argument is that there is a huge welfare gain from insurance. Suppose, to keep the arithmetic simple, that high-quality long-term care costs 50 000

euros a year. If you can't buy insurance, you need to save enough to pay for the maximum duration you are likely to need care, which could be 20 years, so you have to save 20 times 50 000, that is, a million euros, which is completely unrealistic.

Alternatively, if you can insure, you have to set aside only enough for the average duration of long-term care. If that, on average, is half a year, your total insurance contributions over the years need to be 25 000 euros. So the argument is that if you can't insure, you face an appalling risk; thus insurance, if it is possible, improves people's well-being enormously by largely removing that risk.

The moral argument supports that conclusion. The philosopher John Rawls talked about what he called 'the veil of ignorance'. His argument is the following: you can't design a fair society if you know who you are going to be in that society. So, he said, you should design the rules for a just society behind the veil of ignorance. In other words, you know you are going to be a member of that society, but you do not know who you are going to be in it. So, for example, we know that some of us will need long-term care, but none of us know which one of us, or for how long. So insurance, if we could buy it, is an example, in Rawls's terms, of making policy behind the veil of ignorance, which gives it a moral claim, which supports the economic argument.

We can then argue whether that insurance should be organised explicitly as insurance, or whether it should be financed through the tax system, which is another way of organising insurance. But the key point is that the moral argument and the economic argument both point in the same direction - in an efficient and humane society people should be able to insure against the need to pay for long-term care. So, proposition one: insurance matters.

The question then is: why not private insurance?

To answer, it is important to explain briefly how insurance works. Suppose that there are a hundred of us in this room, and that we get on a bus to go to the airport to fly to a football match in Brazil. And we know from long experience that when we get there two of us will have lost our luggage (or rather, the airline will have lost our luggage). Suppose too that each of us has a suitcase worth one thousand euros. In those circumstances I could go among you and say, I know about insurance, I want each of you to give me twenty euros (i.e. two per cent of the thousand euros that your luggage is worth). Thus I collect twenty euros from each of you, and so have two thousand euros. We get to Brazil, two of you have lost your luggage; I have two thousand euros, exactly enough to pay each of you the value of the luggage you have lost.

And now a warning for the timid among you, I am about to put up an equation - equation alert! The way private insurance operates is that the premium you pay depends on (a) the size of the loss you are insuring against (the thousand euros your suitcase is worth) and (b) the probability that you will lose it (two

per cent in my example). And that is a perfectly simple, intuitive economic variable - if you live in a large house with lots of old paintings, the loss you insure against is large and you will pay a high premium; if you are a student and you don't own very much, your burglary insurance will be a lot cheaper. This mechanism works well in many areas, but it is important to be clear about the circumstances in which competitive insurance will be efficient and those in which it won't work well.

First of all, probabilities should be independent, in other words, insurance works for something that happens to you, but not to everyone else. If something happens to all of us, insurance can't work.

The probability must be less than 1 - insurance can deal with risk, but not with certainty. You can't buy an insurance policy to protect you against the need to buy food, because it is not a probability, it is a certainty.

And number three, critically, the probability has to be known. In other words, the insurance company needs to know the probability that you will experience a loss. If they don't know, it is not a risk but an uncertainty. And uncertainty is something that private insurers can't deal with very well.

Let's apply those conditions to long-term care insurance. The key thing with private insurance for long-term care is uncertainty about what the probability is going to be. In Britain today, one in six people needs long-term care, and the average person who needs long-term care needs it for two years. That is true for today's elderly. But we have no idea what the situation is going to be in 30 or 40 years' time; the probability might be higher or might be lower. So this is a situation of uncertainty and not of risk, and private, actuarial insurance, doesn't cope very well with uncertainty.

Equally, there's uncertainty about the size of the loss - how expensive is it going to be for someone who does need care in the future? It may be cheaper because robots can do the job cheaply and effectively, it may be more expensive because people live longer in a dependent state. So there is uncertainty both about the probability and about the size of the loss.

Looking at the policies that private insurers offer, what happens is that insurers design policies which reduce their exposure to risk. Premiums tend to be on the high side to address uncertainty. If, as an insurer, you are not sure how big the risk is, you are going to charge a somewhat higher premium to protect yourself. There may be a cap on the maximum paid out in any one year. Full disclosure of all relevant facts - anybody who doesn't give the insurance company full information can be prevented from receiving benefits. And very often contracts offer assistance only on the basis of tightly specified criteria rather than a more general 'need for care'. In other words, there is a lot of specific detail in the policies. Thus uncertainty causes problems for private insurers, and so causes problems for us, ordinary people, who buy insurance policies. Because they are insurance policies that are long-term,

we pay contributions now for something that may not happen for 50 years, and they are rather complicated.

To sketch out the problems that arise - what type of care is covered? Is it only residential care, or also care in the person's home? Is care offered on the basis of general infirmity or only for specific ailments? In other words, I might be able to get cover if I get a specific medical condition, but will the policy cover me if I don't have anything specifically wrong with me, but am elderly and fragile and need to be looked after? And how do the answers to these two questions change as medical technology advances?

On what financial basis is care covered? Can the insurer increase premiums if maintenance of the policy becomes more risky? Will there be a maximum on the monthly amount that the insurer will pay? Will there be a maximum duration over which the insurer will pay, and will the answers to these questions change over time as economic events unfold? In other words, can you buy a policy today which gives you certainty about what might happen to you in 30 years' time, or does the company's wording contain quite a lot of discretion for the insurance company to adjust things as events unfold?

On the basis of arguments like that a Royal Commission was appointed in the UK. Its Report, published in 1999, concluded was that, left to grow without intervention, there is little reason to think that private insurance will become more important in the UK than it has become in America.

The fact that private actuarial insurance works well for some risks, like automobile insurance or burglary insurance, does not mean that the mechanism can be applied uncritically in other areas. It works brilliantly in some areas and much less well in others, healthcare and long-term care among them. The technical arguments give considerable understanding about which risks private insurance can deal with and which ones it finds it harder to address.

In the context of policy directions, there are powerful arguments in favour of social insurance of long-term care. Yes, people's preferences differ, but the scope for differences is limited, so that a single well-designed social insurance policy might come close to meeting the needs of most people.

The second point is that these are not risks that fit the actuarial mechanism very well. In contrast, with social insurance, the contract doesn't have to be fully specified: it is easier to adapt social insurance arrangements to an uncertain future as medical and social circumstances change.

A further argument for social insurance is that the costs of long-term care tend to be lower than for pensions, because on average people require care for a much shorter period of time than they require a pension. So there has been some discussion about long-term care as linked to healthcare, and in very important respects that is right; but other aspects of it, the financing aspects, also have quite strong resonances with the financing of pensions. So

the advantages of social insurance are that it can adjust to changing reality and that where you do need to change the terms of a social insurance arrangement, those changes are the outcomes of democratic politics and therefore have some legitimacy. You could argue that they have more legitimacy than changes in the terms of private contracts, mandated to consider the interests of the insurance company's shareholders. So the key advantage of social insurance is that it can respond to uncertainty.

Thus the strategy is the following - if one can make a distinction between two aspects of care:

- The clinical aspect is mainly technical, largely beyond the person's control, it is clinical, it is technical, it is medical.
- On the other hand there are the hotel aspects of care, the type of food, the size of room, whether or not there is a garden, etc. Those are more matters involving individual choice.

So the strategy is that social insurance would cover the cost of meeting clinical needs, however severe those needs are and whatever the duration of the resulting care. Social insurance should also cover the cost of good-quality hotel care, but it does not follow, and it should not follow, that a person should be entitled to 100% funding through social insurance of enormously expensive hotel care. If I would like my mother to live in a stately home and have gourmet food and fine wines, that's wonderful, but it is not clear that the taxpayer should pay for them. So the strategy is that social insurance pays for all clinical needs and a good quality of hotel care, but beyond that it is up to individuals and their families.

I now turn briefly to the German system, because it is the one that I had come across before, and I was listening and learning rapidly about social insurance arrangements in other countries.

Its key features are: it offers benefits financed by social insurance contributions; it offers benefits for home care services or a cash allowance, so that you can buy your own care in your own home, or in the form of institutional care; and it covers the entire population, because that's something social insurance can do. It is based on ability to pay; it provides help for informal carers; it has been argued that it widens and deepens the market for care; restrictions on benefits, which may change over the next 25 years, have democratic legitimacy; and, an important point in practical terms, social insurance is based on an existing administrative mechanism.

So social insurance is one practical way of providing insurance. It is of course possible to finance long-term care through the taxpayer. And some countries finance at least part of long-term care through general taxation. My own country does so, though very parsimoniously, Scotland does so slightly more generously; and some of the countries in Scandinavia also use tax finance.

So my concluding slide: either social insurance or taxation is, in principle, a feasible solution for long-term care, just as either is, in principle, a solution for financing healthcare. And both approaches are used in different countries, as I have indicated.

Social insurance may, however, offer a better vehicle for EU convergence, for several reasons. Firstly, virtually all the new Member States are fiscally highly constrained by the Stability and Growth Pact, so the capacity to finance things out of taxation may be limited.

Secondly, we have been hearing a lot about things being different in different countries - family structures differ, social attitudes differ, so it is clear that there shouldn't be a single EU-wide template, but scope for countries to vary their arrangements in the light of national differences, and social insurance makes that possible.

So, to wind up, the delivery of long-term care can be private, public or mixed, and there are good arguments for saying that a mixed system has advantages. On the funding side, economic theory answers strongly that, as with healthcare, there is a strong case for relying mainly on public funding, either social insurance or taxation. In contrast, private actuarial insurance has only a limited role, a complementary role in paying for long-term care.

A final point is that in some areas efficiency and social justice compete with each other. Long-term care is a case where they go together. You can argue for social insurance, as I have, very strongly, in efficiency terms, but there is also an enormously strong moral case in terms of social solidarity. The two cases go hand in hand and reinforce each other.

Mr Jérôme Vignon, *Director, Social protection & social integration, Directorate-General for Employment, Social Affairs and Equal Opportunities, European Commission*

Following such high-level presentations, it is rather difficult to take the floor now as a European official and to commit my institution by my words. So I will start on a rather cautious note. But I speak most sincerely when I thank the Luxembourg Presidency for organising this conference. We have covered all aspects of the subject in our sessions, with a lot of in-depth work and expertise. And I think what has been said has engaged people's interest and intelligence and has touched their hearts as well. So this conference will have made a difference. And let me tell you what the European Commission has learned from this.

It is important to try and draw conclusions at European or Community level from this in-depth deliberation on the situation of older people. For more than 10 years now the work with the European Council, the Social Protection Committee and the European Parliament has gradually elaborated a common

language relating to long-term care. The Social Protection Committee and the European Commission drafted a joint report in March 2003, defining care as being assistance to people who are not able to live in a fully independent way and hence find themselves dependent on the help of others in their everyday life. The need for assistance covers many areas: shopping, mobility in doing household tasks, getting dressed, eating. This sort of care is often entrusted to close friends and relatives, particularly the family, which continues to be the main provider of this permanent care. This may sound a bit commonplace, but this common language has enabled us to go into such depth in our sessions in the course of this conference.

Furthermore, if the Constitutional Treaty of the European Union is ratified, amongst our fundamental rights and principles the Union will acknowledge and respect the right of older people to lead a life of dignity and independence, and to participate in social and cultural life. So we will be living a long way ahead from a purely economic union dedicated to the market. Obviously we do need that in the EU, it is a driving force, but it should be at the service of a community of values.

We will only move forward in solving our difficulties and exchanging experiences if we are better informed, not just about financial needs, but also about the qualitative social and personal side. At European level, we can give our full support to this attempt to be clear-sighted and lucid about real needs. What remains to be done - we need to work together. And that will actually save us time.

Secondly, when we talked about the sharing out of private responsibility and public responsibility - that is a sort of coded term, and underlying it is a whole debate about culture and values. But we have seen that more and more countries are really moving towards a mixed system where, in the case of care provision, we have the public sector, the non-profit-making sector and the private sector as well, which seeks to boost its profitability. This association, this combination - to be able to respect our values, the Member States, which are responsible at the end of the day, do need to have a more important role to play when laying down tasks of general interest that will be carried out by the various different types of service providers. We in the Commission see an augmented task for us, in combining adequately the liberalisation of services and the consideration of specific aspects of social services, healthcare services and long-term care. The question is one of compatibility, or rather of harmony, between the internal market framework and the specific nature of long-term care. So that's the question we really need to address.

When we talk about the respective tasks of social protection, the state, private insurance, and so on, how this care is to be funded, we can see a trend emerging, namely one of giving priority to social protection systems when it comes to long-term care. But if that's the case, the Community

legislation ensuring coordination of social security, particularly compulsory social security schemes, will have to be modernised with the help of all the administrations represented, to open the way for this common trend and to cover that.

The European Commission has a modest role to play as far as long-term care and social protection are concerned. What do we mean when we talk of convergence? It is based on reciprocal and free commitments; the Open Method of Coordination is not based on legislation. What do we mean when we talk about this convergence in the fight against poverty and in social protection? It is a dialogue of national subjectivity, and subjective not in so far as individuals are concerned, but in so far as nations are concerned. The nations around the table are subjects in their own right, and national cultures are irreducible.

The idea is to work to see what one might have in common with the others. We are seeking common objectives; this is what we now are doing also in the area of healthcare and long-term care. We need common foundations which preserve and encourage the development of specific forums for cohesion of national societies. All are faced with threats, as Professor Malherbe said, all are faced with shortcomings, deficiencies, which are similar and which we will never be able to solve entirely. But we can reduce these deficiencies and fill the gaps to some extent. In the context of this work, facing national autonomies, within the Social Protection Committee we do have the OMC, and this puts the notion of solidarity into context. Often we talk about solidarity without reflecting sufficiently on it. We tend to be idealistic and this leads to disappointment, when we do not manage to achieve what we have set out to do. And in order to have a place in a world of competitiveness and efficiency, we risk placing solidarity at the service of competitiveness and efficiency.

Society is constantly renewed through the ageing process. Solidarity is a value to be cultivated, as you cultivate your garden. It is an interaction of subjects, free citizens who are getting older and now run the risk of losing their dignity. So solidarity is a dynamic value which needs to be developed, and it is up to society to develop it, it is society's responsibility.

We are so different, we will stay different, and we don't have the same vision of solidarity. Yet we still use solidarity as a word which helps us to move forward together. And the OMC perhaps is less important in terms of the objectives that we revise from time to time, but much more so by virtue of the process of exchanges itself, which we call peer review, examples of good practice, social indicators, joint reports which are nothing less than an effort by all sides to come together in a viable, authentic and true manner, lucid in our actions.

To some extent it seems to me that Prof. Barr has just illustrated what Prof. Malherbe was saying. Prof. Malherbe is encouraging solidarity as the fruit of society, which does respect the coming together of subjectivities, particularly those at risk of disappearing. And Professor Barr sets out a way forward for cultivating this solidarity. It is an opportunity, perhaps it is a reality described to us by the economists with regard to the funding of long-term care. Social insurance seems to be the safest way forward, the best way of overcoming shortcomings and deficiencies in comparison with individual insurance. There seem to be solid arguments speaking in favour of this.

We feel that we have been strengthened and reinforced by the messages given to us. Within the months to come, through various instruments, the Commission will endeavour to collect and compile the fruits of these two days of discussion. Under the aegis of balance between the generations, the Green Paper on the demographic challenge will set out to obtain the alternatives on the issue.

The OMC is going to be developed in the coming period, for health- and long-term care, and this will strengthen the presence of social protection and solidarity on the ground, when it comes to the new Lisbon strategy and major Community policies. There is no doubt that the discussion over the past couple of days will feed into the Commission's proposals, with a view to the debate in the Social Protection Committee, and especially the link made between strengthening and deepening social protection and the quest for dignity and independence for older people.

By means of these two processes, the Green Paper and the OMC, which is basically a dialogue between autonomous bodies organised at Community level, the Community hopes to make a contribution to this prospect of lucidity and clear-sightedness to which we are committed. Lucidity on our shortcomings, we need to be clear-sighted about the gaps between what we would like and the reality, we have the indicators, but we would also like to be clear-sighted in a way that encourages us to go as far as possible, to do as much as we can.

Final discussion

Chairperson: Ms Anne-Sophie Parent, AGE, Belgium

What are the priorities of the Spanish Government in order to guarantee long-term care?

Mrs Maria Amparo Valcarce Garcia, Secretary of State for Social Services, Families and Disability, Spain

The model chosen in Spain is that public authorities will provide the benefits for users. Both benefits and services will be available where the infrastructure is available. In the event that the infrastructure is available, preference will be given to services. Otherwise there will be a financial contribution so that the person can purchase the necessary services.

The national dependence system will have services which will be guaranteed to all persons in Spain who need them. So people can receive services and benefits regardless of their age, of the cause of their dependence or of their social status. There will be one benefit across the board, everyone will be entitled to it, it will not be income-related, it will be a public-service system.

What are the reactions of the new Member States to the discussion during this conference, in particular with respect to social justice?

Mrs Agnieszka Chlon-Dominczak, Undersecretary of State, Ministry of Social Policy, Poland

Firstly, I would like to say that on becoming a member of the European Union we basically entered the debates which were there, for example through participation in the Social Protection Committee, so I don't believe that there's still discussion on Old and New Europe, but that instead we are discussing Europe together. During this conference we have had many examples of the fact that indeed the discussion is not only about the old Member States, but also about the new Member States as well. During these discussions, I believe that it is more and more apparent that the values of Old Europe are also shared by New Europe. Certain common values, like the European Social Model, all the values that come from the times of the Enlightenment, as Igor Tomes mentioned during his presentation, they are indeed shared, between the Old and New Europe, so it is the same Europe. These values are indeed the same.

However, there are certain problems and certain differences that have to be mentioned, which are important. Poland faces three problems – first, the problem of values versus reality and practice and the gaps and frustrations. I would say that the social policy that was conducted in Poland especially after the Marshall Law, during the transition period, focused on providing cash benefits to various people that could not find employment on the labour market. As a result we have developed a lot of cash payments to relatively

young people through early retirement schemes. We find that as a result, we have ended up in a situation where we spend a lot on cash benefits, on early retirement pensions and on disability pensions. Thus our share of expenditure on family benefits for example, or indeed on long-term care, is lower, though the overall level of social expenditure is similar to other EU countries. There is a frustrating gap between the values that we have and the financial constraints that we face. These are very difficult to manage. So indeed, for the future, we are considering ways in which we could increase our expenditure on family policies and long-term-care policy, and we are considering introducing social insurance that would be devoted to helping persons in need of long-term care.

Fortunately, there is one element that helps us a little bit, and that is demography – our population in Poland is still a little bit younger still than the population of ‘Old Europe’, so to say. Though the demographic processes are indeed very intense in Poland and we are catching up with the ageing, it gives us some time and space to design policies so that when long-term care really becomes very necessary, it will be there thanks to an earlier intervention trying to scale down social expenditure on retirement pensions and disability pensions. The latter seemed to be very important at the point when the transition process took place, and right now they are really sort of hindering possible social developments.

What is Luxembourg’s evaluation of the effect of the long-term-care insurance system that it has had for the last six years on the issue of the family looking after the dependent person and on cash benefits?

Mr Mars Di Bartolomeo, Minister of Health and Social Security, Luxembourg

Well, that’s a whole programme in itself! The upshot is that the result is positive. However, we have a few question marks and we need to closely monitor this new element, which has become a pillar of social security. To avoid traditional problems with social security, it is in our interest to monitor right from the beginning and very closely developments which may seem less normal, or less to be expected. We need to monitor things very closely if we don’t want to run any risks and be taken by surprise by unforeseen events.

With regard to the various guidelines for social insurance for dependence, the first objective is to try and keep people in their own homes, to help them maintain their own independence rather than going into an institution. The efforts made have borne fruit, we should note that the evolution of care and services provided at home to those who have benefited from dependence insurance since it came in has been very dynamic. If you go back to 2001, dependence insurance was in its infancy. But if you compare those figures with those for 2004, the number of beneficiaries of home help benefit has almost doubled and the number of those going into institutions has remained

almost stable. There is constant progression. We are talking about 30 to 35% overall, so we are talking about maintaining people's independence rather than putting them into homes. We can also say that this has contributed to less dependent people remaining with their families and the major infrastructure has been reserved for people who are severely dependent. In fact, the real aim of such a measure (institutional care) should be to care for severely dependent persons.

The second question, with regard to the structures, we have had an unprecedented development of structures to help people stay at home, of networks. We haven't created new networks, but we have really seen dynamic development of those that already existed, with massive recruitment of staff.

The area of services of general interest, and of services as a whole, is actually one of the most dynamic sectors in employment terms. So if you are focusing on jobs and job stability, we shouldn't forget services of general interest. We shouldn't act as though they weren't part of the whole dynamic employment process. We should have a social pillar in Lisbon, we shouldn't compare services of general interest with commercial services, because different objectives are followed, and there are different constraints, different expectations in terms of quality and freedom of access. So when we are talking about unemployment and competitiveness, we should not forget that this sector, which people tend to put in opposition to the economic side, is actually almost the most dynamic. In Luxembourg one can see this clearly, for the health sector, with services of general interest, has developed in a very dynamic way.

Just to touch briefly on the problem of the informal sector – the informal carer has a long-established role in long-term care. If we look at care at home, the informal carer, acting complementarily to the networks, has a key role to play in keeping people at home. We need to look at the role and the economic position of the informal carer, and how carers can be acknowledged. Obviously gender equality is an issue here, because this is an area which seems to be dominated by women.

There is one unsatisfactory strand of dependence insurance or dependence prevention strategy, the whole area of primary prevention of dependence. There is a lot of scope for action here, in respect not just of our dependence insurance but also of the whole range of players, the whole sector of action.

Thus we have established a separate system, partially copied from social security. It is a system which is in its infancy really, and if we want to avoid this going the way of more established pillars, we need to see how things develop and to react to any anomalies occurring, and it would be better to be proactive than reactive, so that we can adapt the system in good time.

Open discussion

Ms Luigina De Santis, EFREP – European Federation of Retired and Elderly Persons, Belgium

It is a great mistake to underestimate, the importance of people. We should not talk about the object of the services, but rather the protagonists, the people, and you should see them as people. This is very important to the quality of European democracy.

EFREP sees citizenship as a human right, and dignity and participation are a crucial part of that. If you are going to transform a dependent person into a citizen who is merely more limited in their abilities and in what they can do, that is something that we consider very, very important. And these people need to participate in these processes, in the system that they should be part of creating. If they participate in the care system, we are very sure that it will mean lower costs and improvement of the system.

Ms Anne-Sophie Parent, AGE, Belgium

Well I will take advantage of having the floor here and will answer that immediately. When we are talking about users, we do so because we do not want to reduce that dependent person to merely a dependent person. As far as we are concerned, they are citizens, full citizens, but we need to provide services to them, because they are dependents and they are the users of those services.

Mr Mars Di Bartolomeo, Minister of Health and Social Security, Luxembourg

It is very important for politicians and those who have the political power to cooperate with those who work in the field. We need excellent cooperation between Ministers and those who work in the field. I have just been sent a note saying that a survey of the satisfaction of those who benefit from our dependence system is going to take place in 2005. So if you want to have a good system, you need to ensure that there is good cooperation between politicians and those in the field.

Prof. Jean François Malherbe, Sherbrooke University, Canada

With regard to participation, well, I am not here to defend Mr Vignon, of course, who is no longer here anyway, but I think when he stressed the point about inter-subjectivity, I think basically he was putting his finger on what you call 'participation'. I think he meant the same thing, really. Because if you are in a relationship of helping someone who can't do things for themselves,

whose independence is jeopardised, and if you treat the person as a subject in their own right, research has shown that with the required technical backup, this is the best way of slowing down people's loss of autonomy, and often you can actually reverse the trend for a certain amount of time because often loss of autonomy arises from the fact that people have just felt that they are objects. They may be treated quite well, they may be kept clean and fed and so on, but they cannot express their own values, their own subjectivity and their own preferences. So in my philosophical jargon, I talk not just about 'objectivation', but also about 'objectification'. So you are making the other person a mere object. And if you say that everything that counts can be counted, it is easier to count objects than subjects.

Prof. Nicholas Barr, *London School of Economics and Political Science, UK*

First, we have heard the word solidarity used quite a lot. Just to make the point that the moral appeal of insurance is that it is exactly that, it is solidarity behind the veil of ignorance. We, who contribute to social insurance, agree that the contributions of those of us who do not need long-term care will pay for those of us who do. And to me that's very much a form of solidarity.

Second point. This is not now an analytical point, but a very practical one - a discussion of surveys of satisfaction, etc. I have recently been involved with one of those as a relative of somebody in a nursing home. One of the problems is that we are imperfectly informed consumers when we buy complex insurance products. And imperfect information is something to which economics these days pays increasing attention. But the problem gets much worse for some dependent people who do not have the capacity to remember very well, and for whom questionnaires, etc., therefore do not cater, even if someone fills it in for them. And therefore it becomes difficult, because if you can't ask the people themselves, then maybe you should be asking their relatives. But however much people go and visit our elderly relatives, they have got to be around a lot before they can really assess a place. So yes, of course you need to try to monitor how well things are going.

One final point is about England. Its regulation is one-size-fits-all. So every long-term-care institution has to go through the same regulatory process, and the process is designed to protect the frail elderly from the cowboys. There are a lot of institutions that are well run, by long term reputable non-profit organisations, who of course need to be regulated, and of course need some sort of an inspection regime, but it should be a much less heavy-handed one. Nurses spend huge amounts of time on paperwork, purely because the regulations require it. That does nothing to contribute to the residents' care, and indeed takes carers away from looking after residents. So questionnaires and surveys, yes, regulations, yes, but please make sure

that the regulation has as much of a light touch as possible for those institutions that have a proven track record.

Ms Anne-Sophie Parent, AGE, Belgium

The NGOs' experience is that we have actually developed systems which can help express the opinion even of people who are unable to speak. Yes, just ask Alzheimer Europe, which would be able to tell you how you assess whether a person with Alzheimer's is pleased with the service that they get or not.

The same applies to other very dependent people. Because I used to work for Autism Europe, we developed easy but sophisticated systems to evaluate the needs of people who, you would say, were not even able to express themselves. So it does exist. We can work together with policy-makers to improve the lives of the people we care for. What we should be aiming at is comprehensive participation of older citizens and the full right for them to lead a dignified life.

How do you see Spain contributing towards a converging social policy in Europe?

Mrs Maria Amparo Valcarce Garcia, Secretary of State for Social Services, Families and Disability, Spain

The differences in care systems and models for dependent people in Europe are being reduced. The problem is resources. The differences are reducing, or they should be reducing. We need to do something about financing with regard to the proportion of GDP. We can see major differences in Europe. If you compare Spain, Italy and Ireland with Sweden and the Netherlands, for example, there are massive differences, of up to 50%. We are setting up our national dependence system because we think this is a way of reducing the current differences in terms of the proportion of GDP spent on care, compared with the figure across the EU. In Spain in 2002 it was 20.2%, while in the EU as a whole the average was 28% of spending on social protection. So we are going to be investing more with regard to care for dependent people and people with infirmities or disabilities. So we are improving our social protection. We know that major economic efforts are required, but we feel that if we don't make this effort things will be more expensive in the long run in terms of the social economy.

From the point of view of a new Member State, how do you think we can achieve a certain level of harmonisation when it comes to long-term-care policy and the rights of the people concerned to benefits and funding?

Mrs Agnieszka Chlon-Dominczak, Undersecretary of State, Ministry of Social Policy, Poland

The method which is already applied in the case of social inclusion and in the case of pensions, which is the OMC, is a good tool for setting common objectives and setting certain indicators and is a way of sharing certain good practices between the countries. It is not possible to harmonise the benefits, the financing systems across 25 or even more countries in the future, because there are certain specificities and certain differences in how society observes what the values are, and what are the best ways of providing care to those who need it.

For example, the highest values in Poland are 'family' and 'friendship'. In Poland, even if we had a very well-developed, very well-organised, very good-quality institutional care, people would still prefer to care for their family members at home. And they would rather see ways of supporting families in providing that care at home than ways of developing institutional care. Well, in other countries the situation might be different and other ways of providing care might be preferred by society. So it is not a question of how we should do it. The officials, the politicians are not the ones who can tell society what they want. They are there to listen to society, to what society wants, and to try to develop systems that meet the needs of society. And these needs can vary between European countries, because we are all slightly different.

It is not that the attitudes or the expectations are different in the new Member States, but sometimes family values and certain ways of providing care in the family, in Poland for example, results from the way we treat religion, Catholicism, and the way this is embedded in our society. And the way we treat elderly people. While in other societies, institutional care is treated as something that is also something good. So it is simply the way society sees certain things. Institutional care is not bad, but in Poland institutional care is seen as the solution of last possible resort for providing help to persons that need long-term care. This should be respected, and this is why it is not possible to harmonise everything. And in the same way you cannot harmonise pension systems, you cannot harmonise disability schemes, you cannot harmonise family policies. Because the expectations of the societies are different as regards the way in which those benefits and services can be provided. It is not that the values are different; the values may be the same. But the way these values are met can be different.

In Europe we are still far from having the same benefits or services. So how do you see convergence in this area, what's your reply to what the previous two speakers have said?

Mr Mars Di Bartolomeo, *Minister of Health and Social Security, Luxembourg*

How do we contribute? We organise conferences, giving the people in the field and specialists from different countries the opportunity to exchange best practices, to see what everyone else is doing. That's one very good practice. We do need discussion, and we need to get those politicians who are responsible for social affairs (even though this field may not, strictly speaking, be a Community issue) involved, because our communities are all affected and involved.

Now, in terms of long-term care, there is not one European model. Obviously there are many different models which are suited to different contexts in the different countries. This does not mean that we should be dogmatic about care in the home or external services, but we should tend towards the formal or informal sector. We need to make a choice, and it is often a difficult choice. But if you are forced to look after your parents at home, and at the same time be an active part of the labour force, as the European Community wants people to be, there is no choice, the choice is no longer there.

Even though it is not an absolute priority in Community plans, the different EU countries should agree to make it a priority and to offer people possibilities. Just as there are health cover, sickness insurance, pensions, disability pensions, there is not one type of disability or sickness model but several, and we are entitled to have these different models.

Mr Jens Bruder, *Deutsche Expertengruppe Dementenbetreuung (DED), Germany*

I am from the German expert group looking after people with dementia. For 25 years now I have been dealing with dementia patients and their carers. And I think it would be rather a shame to end this conference by speaking out against homes. If someone has dementia, they can't really structure their own time to carry out activities. In the last five to ten years, people have benefited from small communities, from living in small communities like families, and we have some experience in Germany and throughout Europe suggesting that in many cases this actually improves relationships with relatives, if they are in such homes. We have thousands of outpatient set-ups, perhaps 50% of dementia patients, I mean not everything is perfect, we are in a state of transition, but I think we have seen in the last few years that a proportion of people with dementia, you can't generalise, but a proportion which is greater than we had initially assumed, finds that life in such communities actually does them good and maybe that their need for drugs is actually less as a

result. And it means that they can have better relationships with partners and children as a result, so my message is that you shouldn't really be so negative about the care institutions.

Ms Tsiakatoura Nashashibi Charikleia, *Ministry of Health and Social Solidarity, Greece*

Since we all agree here that family plays a huge role in dealing with people who need long-term care, shouldn't we focus on the implementation of laws that financially support families that face this kind of problem, and on following a common policy inside the European Community, separately from the other measures that must be taken in this area? If we had the support of the European Community in a small country like my own, then things would be easier.

Ms Anne-Sophie Parent, *AGE, Belgium*

I will take this opportunity of referring to EUROFAMCARE study, which studies the situation of family carers in Greece as well. One of the major recommendations is that it should be left to the people themselves and the families how they want to provide the care. But the families would need support. And especially, as we said earlier, and as we all know from the Commission's papers and others, it is an objective of the EU to increase the employment rate of women and to increase the employment rate of older workers. That's the way we are trying at EU level to lobby as NGOs, to make sure that those recommendations are at least considered at national level by your governments.

Mr Jean-Pierre Baeyens, EUGMS – Benelux University/Luxembourg University, Belgium

There is primary prevention and secondary prevention, and throughout Europe we see that in hospitals very elderly patients become even more dependent once they are there, and it would limit long-term care costs if that were to be borne in mind.

Mr Mars Di Bartolomeo, *Minister of Health and Social Security, Luxembourg*

We should not be talking in terms of either/or, total opposition between care at home and structures on the other. I think it should be both/and, not only one, but also the other. There should be a real choice, and if a family really makes a choice to keep their relative at home as long as this is possible, this should be supported, but there are some cases, as you mentioned, where it simply isn't possible. If it is not necessarily in the interests of the dependent

person to stay with the family, then you do need to have other provision on offer.

At European and national level, we should be talking about the best possible right to care. We should not be thinking just of ourselves, but also of the interests of the person affected. It is very important, because obviously you have to respect the feelings of each family, and the traditions of individual countries, but above and beyond that, you shouldn't neglect the interests of the person affected. You can't forget about the dependent person's interests. It would be very difficult to produce a directive or regulation at European level to make sure that everyone who looks after elderly relatives has support, but this is a key point which is enshrined in what we are doing.

Prof. Jean François Malherbe, *Sherbrooke University, Canada*

We should work on the basis of pre-established concepts, which have worked based on people's life experience. We could say, for example, we give priority to the family, but in some situations we still need an institution, or in some situations the institution would be the priority option, but the family may benefit. This is a very interesting subject, and we could try and get some joined-up thinking on this. And there is the whole issue of solidarity and autonomy as well.

Prof. Nicholas Barr, *London School of Economics and Political Science, UK*

As our colleague from Greece mentioned, financial support for families who care for elderly or young dependents is part of the flexibility that we have heard about. It should not be financial support only for people in residential care; it should be for family support as well.

With regard to residential accommodation, none of us likes the thought of an elderly relative living away from home. Of course most of us would like to look after them, but our choice may be constrained. It may be constrained because we have other family commitments, like young family members. The ultimate constraint is that you say, fine, we will help an elderly relative by making sure he or she has a live-in carer. But once you reach the point where a live-in carer cannot cope on their own, you end up turning your parents' house into a railway station. Even if you can afford the money, 24 hour care in a person's home is usually impractical. So eventually, however much you want to keep an elderly person at home, as a practical matter you run out of road. That's the bad news.

But the good news is that very often, when an elderly person does move, residential care improves the quality of life for him or her: there are more people around, there's more stimulation, etc. It improves the quality of life for

the family, and partly because of that, improves the quality of the relationship between children and those caring for their dependent. So this idea that residential care is a last resort undervalues it. When it is done well it can be a very affirmative part of a dependent person's life.

The delivery of care can and should be mixed, but there is a very strong case for relying mainly on public finance, either social insurance or taxation. That conclusion isn't just a moral or an ideological statement, it is also a technical statement, and this is an area, as far as I am concerned, where arguments of economic efficiency and of social justice arguments go along together.

Ms Anne-Sophie Parent, AGE, Belgium

Before giving the floor to Minister Di Bartolomeo to close the conference, I would like just to stress again, it has been said several times, but that obviously is not an end in itself, we heard from Mr Vignon that the Commission is really planning to follow up this conference, to follow up all the ideas that have emerged during these two days, and we certainly look forward to another initiative, either from a later Presidency or from the Commission itself, in organising similar events where you bring all the stakeholders together in order to debate and see how we could develop a better system, better measures, better institutions, but also services for home care in order to meet the needs, especially the future needs of our population.

I think primary prevention is a very important issue. Because as always with prevention, you solve something today and you expect to grab the results in several years or sometimes even in decades, but it doesn't mean that it is not worth devoting money or efforts specifically to it, because a lot can be done, starting with the way we organise ourselves, how people live, and helping people to live a healthy life, and quite a lot has already been started. There is a new programme by DG SANCO which will look at the issue of prevention. It should help us maybe improve our reflections and come up with good ideas in that direction.

Mr Mars Di Bartolomeo, Minister of Health and Social Security, Luxembourg

Thank you very much for that discussion! I think it ended on a very committed note, because, like you, I am convinced that we are really at the very start of the discussion and it is a very passionate, a very interesting discussion. We are not talking about an exact science here when we talk about long-term care, but I can say that this conference has really been a brainstorming session, a laboratory of ideas, which has been very helpful, so thank you very much. I am very interested in this debate myself and I do remember when I was young and involved in a peace movement, we were faced with an American strategy known as 'flexible response'. I wasn't totally keen on that

at the time, but I think in this area we do actually need flexible reform, which is adapted to different situations, there isn't just one system, I think we have various different parts of the mechanism which make up a system where you need the family, you need structures, you need intermediate structures between the two, you need informal carers, and you need professionals. And I think the system benefits if all the parts of the mechanism work together. So I don't think there is one single answer here. Our aim is to make sure that the different parts of the mechanism are integrated, so that the wheels move smoothly and don't try to go in different directions.

So please excuse me for that rather personal aside. But now I would like to thank all those who in one way or another have contributed to the very smooth running of this conference. I would particularly like to thank my colleagues, Mrs Amparo Valcarce Garcia, Mrs Chlon-Dominczak, Commissioner Špidla and Georges Schroeder. I would like to thank Mr Erny Gillen and Mr Paul Schmit for supporting us right from the very early stages of preparing the conference and thank you to the rapporteurs as well, Mrs Joël, Mrs Kerschen, Mr Tomes, Mr Knipscheer, Mr Igl and Mr Hajdu and to all those who have worked so hard and made such interesting contributions.

Thank you also to Professor Barr, Professor Malherbe and Mr Jérôme Vignon. Thank you for your very valuable contributions to this conference and the various debates we have had. I am also very grateful to you, the participants in this room; you have been a very active and committed audience and participants. Thank you very much to the interpreters as well.

And to all those working in the Ministry of Social Security, the General Inspectorate of Social Security and the Evaluation Unit, I would like to thank you. I would like to thank Andrée Kerger and Raymond Wagener. I think if you ever leave the IGSS I know a job for you where you would have a great future. Thank you for working in such a professional way.

Thank you very much, Caroline Wies! I think we owe you sincere thanks and a round of applause.

So, ladies and gentlemen, dear colleagues, I hope we will meet again, during other presidencies, I hope our institutional partners will carry the torch for us so that we can move forward. I would like to wish you all a safe trip home!

Please help us move forward with these ideas, we have planted some seeds in the ground, I hope they will bear fruit, I hope you will enjoy your holidays, thank you very much indeed to everyone!

