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FAMILY CARE IN EUROPE

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From the American point of view Europe may look like a small homogeneous continent with a very dense population and a luxury Welfare State. However, talking about Europe is talking about diversity. Europe has an enormous wealth in its diversity of cultures, histories and policy approaches. More then any other continent, Europe is blessed with large cultural, historical and political differences even within small distances.
Comparing countries and regions to simply observe how these differences have shaped the behaviour of the European citizens is a fascinating task. In this contribution I will try to show some of these differences in ageing and family care for the elderly, it is talking about the European mosaic in long-term care for older people.

A Historical diversity and common background

Throughout history the Western World has dealt with the problem of dependent people in many different ways. 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. From the 16th century onwards and especially during the 19th and 20th centuries public authorities gradually started to play a more significant role. 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. In most cases the family's legal responsibility dates back to the 19th century Napoleontic or Austrian Civil Codes, although some countries (for instance Hungary) have more recently introduced a specific Family Responsibility Act. In about half the countries families still have a statutory responsibility, the law can be enforced through court decisions ((MESTHENEOS and TRIANTOFILLOU, 2005).

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.
Actually, there is an evident differentiation in formal responsibilities for dependent older people among

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. 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 and TRIANTOFILLOU, 2005).

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.

B Common changes in diverse contexts

- *demographic changes*

EU countries have experienced a number of 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.

Pictures (see pp-presentation)

- *family changes*

Demographic changes have "verticalised" family structures all over Europe, 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 30 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 (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 and ATTIAS-DONFUT 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 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 and WOLFF, 2000). Another chapter on the situation in Norway (GULBRANDSEN and LANGSETHER, 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 et al. (2000), who studied in the nineties family relationships in London suburbs – selecting the same areas as WILLMOTT and YOUNG (1960) and YOUNG and WILLMOTT (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 and MARTIN (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.

Based on data from the Dutch Longitudinal Ageing Study Amsterdam (LASA) a recent cohort comparative analysis by VAN DER PAS, et al (2007) compared exchange patterns between older parents and their children among a cohort of parents between 55-65 in 2002 with 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, BENGTSON (2001) notes that parents are the donors, not the net recipients of cross-generational support. This also agrees with previous research (BENGTSON and HAROOTYAN, 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, STALLINGS and BENGTSON, 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.

- *changes in norms and values*

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 where 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 (1986) wrote in these days about the anomy in family care and suggested a kind of alienation in family care norms. In 1989, FINCH 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 national Dutch study in 2002 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 acre 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.

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" (LEWIS, 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.

- *changes in the Welfare State*

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.

Up to the eighties these various Welfare States in Europe evolved according national traditions, fitting regulations and provisions into their own national political, economic and social protection systems, creating comparable provisions as there are special housing and social care, home care and home nursing, residential care, however implying a huge diversity in the implementation in the national systems and in the level of ambitions they were willing and able to afford. At the same time the EU countries developed the notion of Social Europe and adopted the European Social Charter (1961) declaring the rights of older people to full social protection, including support when in need of long-term care. The renewed Charter of Fundamental Rights of the European Union (2000) did confirm "The Rights of the Elderly" explicitly.

Since the nineties 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. 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? How to keep the EU Welfare State affordable and sustainable?

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. 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.

In the context of the EU efforts to cope with demographic changes and family developments a number of comparative studies among the EU member states have been executed in order to understand the differences and the commonalities between the Sates. Several of them focussed on the construction of a limited number of prototypes of

Welfare State frameworks, based on the division between public and private responsibility an/or provision in elder care, on universal or subsidiary principles in the distribution of elder care, and on tax paid or social insurance funded elder care. One of the first frameworks is the one developed by Esping-Anderson in "Three Worlds of Welfare Capitalism" (Esping-Anderson 1990). Since then both a Southern European (Ferrera, 1996) and a Central Eastern/Eastern European framework have been added. The original Esping-Anderson model has been criticized for focussing on the labour market and ignoring important gender and family issues (especially important in elderly care). These issues led to differentiated regime models more focussing on care regimes in Europe.

PICTURE

C Actual Family Care: continuity and diversity.

SHARE is the Survey of Health, Ageing and Retirement in Europe, initiated and greatly financed by the EU Commission and several other national bodies in Europe. It has gathered data on the individual life circumstances of about 22.000 citizens aged 50 and over in 11 European countries, ranging from Scandinavian to the Mediterranean. One of the key issues in this study was family structure, family networks and exchanges within the family network.

Research on changes in the family and intergenerational contexts is "like fighting against windmills: raising empirical arguments against myths that seem to remain untouched by them. It is widely assumed that the modern welfare state has undermined family solidarity and the family itself. Increasing childlessness and fewer births, decreasing marriage and increasing divorce rates, increasing number of singles and the decrease of multigenerational co-residence – to name just a few widely known facts - may indeed indicate a weakening of the family and its functions. But despite the high intuitive plausibility of such interpretations in which large parts of the social sciences meet with common sense, it may turn out that the family has in fact changed but not diminished its role (cf Künemund and Rein, 1999)" (Kohli, Künemund and Lüdicke, 2005, p.164)

The following data are taken from the first report of the SHARE study (report: Health, Ageing and Retirement in Europe, First Results from the Survey of Health, Ageing and Retirement in Europe, ed. A. Börsch-Supan et al., 2005, www.straussbuch.net):

PICTURES (see pp)

- Proximity to nearest living child
- Frequency of contact to most contacted child
- Frequency of contact to most contacted parent
- Percentage of grandmothers who looked after their grandchildren at least weakly and percentage of mothers who are in paid employment (grandmothers aged < 65)
- Percentage of grandmothers who looked after their grandchildren at least weakly and percentage of mothers who are in paid employment, grandmothers aged < 65) Coresidence of older parents and adult children

- Proprotions of respondents living alone who receive non-family help with
- Network of people who help with personal care within the household
- Proportions of respondents living alone who receive non-family help with personal care or practical tasks
- Percentages of respondents who give help

D. Support services for family carers

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 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. In the meanwhile national governments in Europe have instituted reforms that shift the focus of welfare systems from acute to long term care, with the common policy objective of ageing in place (OECD, 2005). Recognizing the strategic role of the family and the key role of the family carers in achieving this aim, some countries have introduced enhanced carer support initiatives (Kröger, 2003).

With the aim of providing comparative evidence on the availability, use and acceptability of family care support throughout Europe - a necessary, preliminary step for the possible development of harmonised directives and initiatives at EU level - in 2004 the EUROFAMCARE project was funded by the EU to collect detailed and in depth information on the situation of carer support in six countries: Germany, Greece, Italy, Poland, Sweden and the United Kingdom and to complement this with limited information from all the other EU countries (25 in total, EUROFAMCARE Consortium, 2006). Due to existing cross-national differences in terms of family care roles, female employment, public/private mix of care expenditure and residential/home/monetary share of care provision, the six core countries represent heterogeneous European care regimes (Alber & Köhler, 2004; Anttonen & Sipila, 1996; Kautto, 2002; Rostgaard, 2002), schematically identified as:

- the **Scandinavian** model (represented by Sweden), characterised by high public investments in home/residential care and a residual family role, in connection with high female employment rates;
- the **liberal**, "means-tested" model (United Kingdom), focussing public provision of care to the economically more dependent population, thus implying a broader role for private care providers for remaining users;
- the **subsidiarity** model (Germany), allocating primary responsibility to families, backed up however by a long term care insurance scheme funding care services provided by religious and non governmental organisations;
- the **family-based** model (Greece and Italy), with limited public responsibilities and formal service provision, a central role being played by kinship networks, in connection with low female employment;
- the **transition** model of post-socialist societies (Poland), resembling in many aspects that of family-based countries, however with much more severe

financial constraints following recent economic restructuring and care decentralisation/pluralisation processes (Munday, 2003).

PICTURES (see pp)

- Elder care country clusters
- Over 65 year old people receiving home care (%)
- Over 65 year old people in residential care (%)
- Households with three or more adults (%)
- Provision mix in domestic care

EUROFAMCARE shows the enormous diversity of measures taken to compensate families for their investment in time and concern (MESTHENEOS and TRIANTOFILLOU, 2005). 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.

PICTURE

- **Support services in 6 EUROFAMCARE countries**

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.

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).

E. Sustainability of the Welfare State in Elderly Care in EU countries

The focus of EU policy on the future of the Welfare State, and more specifically on Elderly Care, is on two issues:

- promotion of participation in the labour force, in combination with
- developing a sustainable elderly care in a cooperation between informal and formal services and the promotion of support systems for family carers.

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

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

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