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Institut für Sozialforschung
Dr. Marianne Egger de Campo
8020 Graz, Floßlendstraße 18
Tel. (0316) 68 71 41 DW 12
Fax: (0316) 68 71 41 DW 41
carma@compass-org.at

Green Paper on Demographic Change
DG EMPL/E/1
J-27 01/122
European Commission
B-1049 Brussels

Graz, 30th August 2005

Green Paper Demographic Change

Dear Ladies and Gentlemen,

On behalf of the social policy research project CARMA - Care for the Aged at Risk of Marginalization I enclose the following statement related to the questions in the Greenpaper on Demographic Change to.

Unfortunately we have to send the statement as a paper copy, because posting our statement on the interactive website was impossible since our recommendations clearly exceed the limit of 4.000 characters incl. spaces. Considering the fact that a simple text message on a mobile phone is restricted to 160 characters, **this limit of 4.000 seems to be far too low to allow a serious consultation process**.
In addition the usability of the online IPM- Interactive Policy Making leaves a lot to be desired: Why is the user only informed of the 4.000 character limit *after* pressing the SUBMIT button and not on the top of each box?

Should you have any questions please do not hesitate to contact me: Tel. ++ 43 316 68 71 41 12 or carma@compass-org.at.

Kind regards,

Marianne Egger de Campo

Statement to Green Paper on Demographic Change by the RTD Project CARMA (Care for the Aged at Risk of Marginalization, co-funded by the EU, DG Research (QLK6-CT-2002-02341)

Introductory Remark:

The social policy research project CARMA - Care for the Aged at Risk of Marginalization funded by the GD Research within the Fifth Framework Programme wants to bring the following statement related to the questions in the Greenpaper on Demographic Change to your attention.

(Unfortunately posting our statement on the interactive website was not possible since our recommendations clearly exceed the limit of 4.000 characters incl. spaces. Considering the fact that a simple text message on a mobile phone is restricted to 160 characters, **this limit of 4.000 seems to be far too low to allow a serious consultation process**.
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Project co-ordinator:
Dr. Marianne Egger de Campo
Compass, Sozial- und Gesundheitsverein
Flosslendstrasse 18, A-8020 Graz (Austria)
0043 316 68 71 41 12 (office); 0043 699 1713 7720 (mobile)
Telefax: 0043 316 68 71 41 41
e-mail: carma@compass-org.at
World wide web address: **www.cooss.marche.it/carma**;

List of participants:

P2: Dr. Guido Cuyvers
Katholieke Hogeschool Kempen
Kleinhoefstraat 4; B-2440 Geel (Belgium)
Telephone: (32 – 14) 562310
Fax: (32 –14) 584859
E-mail: guido.cuyvers@khk.be

P3: Kai Saks M.D.
Department of Internal Medicine at the University Tartu,
Puusepa 6; 50406 Tartu, Estonia
Telephone: (372-7) 318627
Fax.: (372-7) 318607
E-mail: Kai.Saks@kliinikum.ee

P4: Annely Soots M.D.
Estonian Association of Gerontology and Geriatrics,
Kooli 34-13; 50409 Tartu, Estonia
Telephone: (372-7) 441340
Fax: --
E-mail: annelysoots@hot.ee

P5: Dr. Claudio Sdogati
Cooperativa Sociale Marchigiana di Servizi Sociali e Sanitari,
Via Saffi 4; 60121 Ancona, Italy
Telephone: (39-071) 50103211

Fax: (39-071) 501 03206
E-mail: ricerca1@cooss.marche.it

P6: Hans Inge Saevareid
University of Bergen, Dept. of Public Health and Primary Health Care, Section for Geriatric Medicine
Serviceboks 604, N-4809 Arendal, Norway
Telephone: (47-)37 00 4040
Fax:(47-)37 00 40 01
E-mail: Hans.I.Savareid@hia.no

P7: Dr. Hagen Kühn
Social Science Research Center Berlin, Working Group Public Health
Reichpietschufer 50; 10785 Berlin, Germany
Telephone: (49-30) 254 91 548
F.: (49-30) 254 91 556
E-mail: theobald@wz-berlin.de

P8: William Morrow,
Jill Harpur (European Office)
South and East Belfast Trust
Knockbracken Healthcare Park
Saintfield Road, Belfast, BT8 8BH; Northern Ireland, UK
Telephone: (44-28) 9056 5267
Fax: (44-28) 9056 5806
E-mail: jill.harpur@sebt.n-i.nhs.uk

Our project has started in January 2003 and will conclude this year.

Our objectives:

- prevent marginalization of the aged
- comprehensive collection of practical guidelines on services that help old people to stay in their spontaneous social networks (prevent institutionalisation!)
- address policy makers, social service providers, and both professional and informal caregivers

Our research tasks:

1. Literature Review on Origins of Marginalization and Welfare State Response
    - Description of the results of socio-gerontological research about the process of marginalization, in particular the multidimensionality of exclusion processes
    - Description of the various welfare state measures taken against the exclusion processes of elderly people
    - Comparison of the various care systems (which also include countries that are not participating in the CARMA project like Sweden and the Netherlands)
    - Conclusion about successful strategies of welfare states to combat marginalization of the aged and insight into hidden built-in exclusion processes in the care systems (social costs of various care systems)

2. Research on the State of the Art – Documentation of Services for the Aged at Risk Of Marginalization in all CARMA countries (A, B., EE, Ger, I, N, N.-I.)
    - Description of the various service systems for older people in need of care in the countries of the CARMA consortium (Austria, Belgium, Estonia, Germany, Italy, Norway and U.K. respectively Northern Ireland) representing various models of welfare states; focus on older people living at home using community based domiciliary services (resulting in 7 national reports)
    - Comparison of the various care systems from the individual point of view of each partner, thus avoiding a summary written with an implicit bias of one cultural background (resulting in 7 internal comparison papers)

- Discussion of comparison papers on the internet shared workspace;
- Compilation of comparisons and agreement on a concluding report integrating all points of view
- Feeding back results to national experts who were interview partners during the research and data collection phase (And who showed great interest in the documentations which in most cases represent the first scientific documentation of health and social care services, number of users, conditions of provision and analysis of problematic consequences of the organisation of care for older people)
- Local conference in Fano/I on Nov 4, 2004 where partners presented and discussed findings about national care service systems with policy makers of the region Marche/I. and with practitioners of care work.

3. Case Study on Instructive Deviance – Interaction between Users and Service Providers (A, B, I, N.-I.)

- Detection of hidden preconditions of care services for elderly by collecting data about "deviant" users in a comparative qualitative study in Austria, Belgium, Italy and Northern Ireland
- Description of exclusion processes within service provision for older people in need of care
- International conference in Graz/A on April 22 and 23, 2005 presented and discussed results with practitioners of social work and care work

4. Panel Survey about Coping Skills and Resources of the Aged (in A, I, N)

- Finding salutogenic potentials in individual coping strategies of older home nursing patients in a comparative quantitative study with standardised questionnaires in Austria and Italy

5. Quantitative and Qualitative Study exploring Care Arrangement Patterns and Negotiation of Care arrangements (in A, B, Ger, I and N.-I.)

- Exploration of the way how informal care provided by the family members (which is still the lion share of all care work in Europe) is interconnected with professional care services in a two step study with standardized questionnaire for the first step and further in depth interviews with a sub sample of the respondents. The comparative study is carried out in Austria, Belgium, Germany, Italy and Northern Ireland.
- Findings will be presented and discussed to researchers and policy makers in Berlin on October 17 and 18, 2005.

6. Guidelines and Protocols for Policy Makers

- Practical guidelines for decision makers on three levels will be developed based on the research results of the project:

  on the macro level: European and national level politicians in charge of social and care services for older persons

  on the meso level: educational institutions, provider organisations, occupational representations of care and social workers
  on the micro level: individual care givers (both professional and private/informal) will be addressed via established channels of information of providers

Statement to Greenpaper

Introduction

Do you take the view that the discussion of demographic trends and managing their impact should take place at European level?
If so, what should be the objectives, and which policy areas are concerned?

Yes, ageing of the population is a common phenomenon in all modern societies and because of that it will need to be addressed with structural measures in the future.

The most important objective are unified European minimum standards of accessibility and quality of services. Especially the level of social service provision needs to be raised in many Southern and Central European countries and particularly in the new member states.
Questions of ageing will concern every aspect of policy but especially economics, health, immigration, education and employment policies as well as questions of housing and infrastructure.
Solidarity between generations should be strengthened and there should be a guarantee that resources are distributed equally between different groups in society. Both the prevention of social exclusion and the promotion of social inclusion are the main objectives in this area.

The introduction of universal social rights on a European level would be a guiding principle for the national governments to introduce an equal distribution of care services for all persons in need of care. A universal (European) citizenship based entitlement for care in old age would most probably also foster the people's belief in Europe and enhance identification with European integration.

Whether an individual may use the publicly funded services or has access to different types of benefits depends on the eligibility criteria for the service allocation, the covered level and the covered range of services. While with regard to health care services "need" is the basic allocation principle and the idea of public responsibility is well established, with regard to long-term care the societal responsibility and public economic liability is less clear. Different allocation principles are used in different countries and in the same country for different types of services. The underlying principles define whether the establishment of a comprehensive care arrangement is possible for certain groups of care recipients and which costs for the users and care burdens for informal carers are left.

The newly introduced tax-or insurance funded care systems on the national levels are typically universalistic, i.e. include all residents in a country, and use the criteria "care need" for the allocation of benefits. The allocation principle "need" grants the care dependent persons access to benefits according to their care needs and is the most comprehensive criterion.

Further criteria, which are used, are the income of the elderly and the family members and the living-, respectively family situation. Typically, the income is taken into account by a means-testing procedure, i.e. only the elderly below a certain income threshold receive services. Research shows that services oriented only towards the lower socio-economic classes are at risk to be very poor. The orientation

towards the living situation respectively the family status may burden the families with a responsibility they are not able or not ready to take on and leave the care-dependent elderly in a situation of dependency.

1. The challenges of European demography

1.1. The challenge of a low birth rate

Over many years, the Union has been making considerable efforts to achieve equality between men and women and has coordinated national social protection policies.
How can a better work/life balance help to tackle the problems associated with demographic ageing?

Since demographic change will lead to a situation where fewer young adults have the obligation to care for a larger share of elders, the informal care work needs to be facilitated by the economic system. According to the Lisbon Strategy more women will be entering the labour market in the near future. This requires a better work/life balance which could improve the provision of informal care to older relatives, in particular giving more responsibility of care to men than women. While currently women have more responsibility of elderly care and consequently reduced opportunities to satisfy their expectations in terms of participation in the civil life, labour market, etc. This puts them at risk of marginalization as well as the risk of health damages or psychological strain like burn-out.
The bulk of care is done by female informal carers which calls for international recognition of their effort. If the welfare systems fail to support the informal carers, they will collapse under the burden of care and more financial means will have to be deployed to cover the care needs. Programmes which effectively (strongly and widely) support informal carers should offer a perspective to the informal carer, that relief is available and affordable.

How can the availability of child care structures (crèches, nursery schools, etc.) and elderly care structures be improved by the public and private sectors?

Empirical research shows that the combination of formal and informal care-giving is often not accompanied by a retreat to family help or a simple substitution of help. Usually, formal and informal care-giving complement each other and the larger share of care services even promote family help. In addition in more service-oriented systems less elderly are left without care than in the more family-oriented systems. The results recommend the development and expansion of professional care services.

The vast majority of carers are still women, mainly spouses or daughters (in-law). Men take over more traditional caring duties in partner relationships only, while in non-partner relationships, they tend to be active in the area of logistics or care management. There is evidence in some countries, such as the United Kingdom, The Netherlands and Germany that people with a lower educational attainment level are more likely to be active as informal carers. This may negatively affect their labour-market position and their income situation even in the long run. Efforts should

be undertaken to secure that there are alternatives and the involvement is voluntary, the caring work is adequately economically supported and that on the basis of regulations, i.e. employment or pension regulations, the negative consequences in the future are minimised.

The establishment of a co-operation between the informal and formal carer in daily care work should be accepted as a task of its own. It requires on the one hand the acknowledgement of the professional competence of the professional carers. On the other hand, the professional carers should develop insight into the competencies of the informal carer, based on the latter's day-to-day experience with the care recipient, as well as into the psychological and social consequences of their care task. A change in the system is essential if the attention is to be directed not only towards the care recipient but towards the individual situation of the carer, thus including the entire care system.

Three exemplary suggestions address the question to reconcile paid occupation with informal care for older relatives:
1. The provision of services that support informal carers such as day centres for older persons, free respite care, counselling or sitting services and more flexible home care services needs to be increased. These services should be accessible and affordable.
2. Informal carers should have the right for paid leave from the job to help them carry their care duty. E.g. a full time employee who cares for her dependent mother should get e.g. 4-8 hours a week off. This would prevent that – mostly female - informal carers have to invest all of their leisure time for the socially valuable work of care for older persons.
3. In addition, insurance based pension systems should pay social security contributions (covering health, unemployment and pension insurance) to informal carers who temporarily have to withdraw from paid employment in order to work as informal carers for their relatives.
Tax based pension systems should offer a carer allowance for informal carers who have to give up their paid occupation in order to take care of their elders.

The findings in CARMA show that the best support of informal carers is the assistance with daily caring activities or even the sharing of daily caring activities. Two patterns of a successful support can be found within the findings: An adequate relief can be provided either by the use of professional service at all levels of care-dependency or by a common support of family members and professional care services related to a more frequent use of professional care services with an increasing level of care-dependency. Thus, an adequate unburdening of informal carers requires the development of adequate and accessible professional care services and the support of the assistance by the relatives and wider networks. Especially in country samples where the informal carers are heavily burdened they complain about the quality, lack of flexibility and the high costs of professional services. The development of an adequate, accessible care service infrastructure is the first step to support informal carers.

Some practical examples to support informal carers are:

- *Day centres*

Day centres are important measures to strengthen and relieve the informal carer. The day centres have to be improved by a more flexible time schedule in accordance with the working time of the employed informal carer.

- *Right to paid respite care*

The provision of financial support for carers and the establishment of a social right to respite care for informal carers were major topics of the social policy agenda in the 1990s in Germany, leading to the provision of extra funding for these services and creating appropriate forms of funding.
Despite the positive development, obstacles can be revealed which necessitates further efforts. The access to respite care is still underdeveloped. Figures in The Netherlands and Germany show insufficient take-up rates of such services. This is explained by the costs, the lack of flexibility and adaptation to the situation of the individual carer as well as the criticism of informal carers on the quality of such care facilities. Efforts have to be made to adapt the services and the funding to the needs of the individual informal carers.
Relief can be provided on the basis of different types of accessible and affordable respite care, which should become available and affordable. Respite care should also be available within the home of the elderly to provide those of the elderly with daily assistance who do not want or are not able to leave their own homes.

- *Sitting service*

Informal carers are at high risk of social marginalization because of their care role. To allow them to get a break of some hours or to attend e.g. a self-help group a service which is replacing them in their care responsibility is necessary.

- *Insurance covering accidents*

A statutory right for an insurance which covers accidents of informal carers while performing care in the home of the care dependent would be another measure of improvement.

- *Adaptation of working-time arrangements*

The combination of care work and employment requires adequate support with high-quality care services but also an adaptation of the arrangements at the working-place. Adaptations of working-time arrangements, such as flexible working time, free hours to accompany the care-dependent elderly to the medical doctor etc., a reduction of working-hours or even an employment break are absolutely necessary. To secure such arrangements/regulations laws are necessary that give the individual informal carers the right to claim the adaptations and thus be less dependent on the good will of an employer or direct boss.

- *Information for informal carers*

In most western European countries, the increasing awareness of the importance of informal care and at the same time its fragility within changing family structures has led to a debate on the role of carers in society and on the efforts being made to create new forms of support. Information, advocacy and counselling as well as emotional support is provided by a wide range of actors on the local level, i.e. by the carers' organisations, parishes, municipalities, self-help groups or insurances, but the availability and accessibility of such services has to be increased.

- *Counselling for Family Care Arrangements*

Since in the family based care systems informal carers report to be confronted with a sudden need to provide many hours of care – in basic nursing, housework and care management – which consequently did not give them time to reflect for alternative

care arrangements, it would be necessary to support informal carers with counselling well before or at latest at the beginning of care dependency. I.e. a social worker should explore all family and professional resources and then support the relatives to assign duties among each other. Very often, care arrangements mirror gender specific division of labour, male children are usually less involved in instrumental help than female. This situation not only protracts gender injustice of society in general it also may lead to severe family conflicts among siblings. Therefore a written agreement could be made – similar to the often recommended marriage contracts – that would demand equal share of assistance of all available children or relatives. E.g. should some relatives live further away their share could be financial support for the many aids and adaptations necessary in the case of care dependency – because, after all we have learned that being a relative within easy reach plays a central role for becoming an informal carer (cf. CARMA Del. 16, p.44; and Prelim. Report on Interview Analysis, p. 80).)

For elderly care, research from the project CARMA proves also that benefits in kind are preferable to benefits in cash, i.e. the availability of elderly care structures should be improved by more public funding for care structures such as day centres and respite care. To guarantee a basic European quality and quantity of such care provision it may be discussed to make care for older persons a European policy responsibility (we know that this would affect the Treaty and the Constitution etc.). After all, the demographic composition of *European* societies is a common challenge; why not tackle it on an European level?!

The private sector could be encouraged to regard care for the older relatives of a company's employees just as much a company's responsibility as child care. Day centres for older persons should be sponsored by bank foundations and private industries analogous to child care facilities connected to the parents' workplace. The day centres have to be improved by a more flexible time schedule in accordance with the working time of the employed informal carer.

Can a reduced rate of VAT contribute to the development of care services?

Concerning the VAT on services our research (on the impact of social services on elderly's social exclusion) has compared a care system of the NHS with free services, with a system where co-payments are required without VAT (Austria) and a system which adds VAT on the service charge (Germany): According to our findings IN CARMA service use is not increased by the elimination of VAT but by elimination of the complete co-payment or costs.
As said above, benefits in kind are preferable since – given sufficient supply – they guarantee easy and equal access to all care dependent regardless of their financial background. Our research has shown that there are marked distribution effects in care service use when it is connected with costs: basically poorer people will be cost conscious and spend less on care services (and aids etc.) at the expense of quality of care and quality of life in general. Wealthier people are willing to bear the costs of high quality care and expensive equipment which improves their quality of life significantly. Therefore, costs for care services have a detrimental effect on social equality.

1.2. The possible contribution of immigration

The Thessaloniki European Council in June 2003 declared that an EU integration policy for immigrants should help to meet the new demographic and economic challenges currently facing the EU. This is the debate initiated by the Green Paper adopted last January.

To what extent can immigration mitigate certain negative effects of demographic ageing?

What policies should be developed for better integrating these migrants, in particular young people?

At the moment the population of older persons in the different countries is relatively homogeneous but an increase in the migrant population among elderly can be anticipated. Increasing and ageing migrant populations in Europe call for a higher sensitivity of care systems for the particular needs of ethnic minorities. Services like meals on wheels have to include religious diets just as much as medical ones. Providers should be encouraged to hire employees representing ethnic minority groups, too, so multi-ethnic clients will feel treated with the utmost cultural sensitivity applied.

The comparison of care systems across the CARMA countries revealed that some states create incentives to black market care work of migrants with all its consequences (precarious working conditions for migrant care workers, insecurity of the clients in the care relation, unclear educational and quality standards): cash benefits for care dependent or their family carers.
This calls at least for an effective monitoring board checking the use of these benefits, that after all are paid out of tax revenue and should not be flowing into a grey or black market (that does neither pay taxes nor social security contributions). The clear advantage of the NHS in this context is, that the professional services are offered for free and thus discourage informal work and that the standards of this professional care are constantly monitored. Therefore it would be preferable to substitute systems of cash benefits by benefits in kind: official care offers a certain standard of quality which can be claimed by each citizen who contributes to the tax revenue paying for the benefits. The jobs in an official care system have to comply with educational and labour law standards and would help finance social security and tax systems. Furthermore, benefits in kind instead of cash benefits would relieve older persons of the burden of having to submit new applications again and again (e.g. when the client's condition has suffered a decrease and now he/she needs more aid), since the professional caregiver would permanently assess the client's situation and help him/her get the support needed.

2.3. A new place for "elderly people"

The European coordination of retirement scheme reforms is promoting more flexible bridges between work and retirement.

> How can elderly people participate in economic and social life, e.g. through a combination of wages and pensions, new forms of employment (part-time, temporary) or other forms of financial incentive?

Elderly people could participate in the economic and social life in different ways: the opportunity to have a (temporary) job "of public/social interest" could be an interesting way. Another opportunity should be considered as well: to give older persons the possibility to organize themselves in self-managed free associations recognized within the local communities and with a specific role of public interest. An example from Fano, Italy: The community gave the older persons a plot of land in the countryside where they could cultivate fruit-trees and then sell the fruits, plants and flowers to local markets, devoting incomes to their future activities. Another example are self-managed associations of mutual help, organized and managed by older persons and devoted to help people of the same age dealing with some difficulties of mobility, health or social isolation.

> How can activities employing elderly people in the voluntary sector and the social economy be developed?

The healthy seniors can play an important role by taking on a role as volunteer. They can visit care-dependent elderly, listen to them, give them information or perform minor tasks. Therefore, they can help with the prevention of loneliness and marginalization. At the same time, the experience also enriches the volunteer's feeling of being needed and having a meaningful role in society. Their commitment prevents them from loneliness, too.
Local service centres can play a central role in recruitment, training and placement of volunteers. It has to be underlined that volunteers need training, guidance and coaching. Volunteer work should be guided by professionals in order to ensure quality. A social security insurance for volunteers should offer them basic medical care in case of accidents.
There is a need for a global policy for volunteer work. Governments can develop a blueprint for volunteers that can be customized and implemented on the local level.

> What should be the response to pensioner mobility between Member States, in particular with regard to social protection and health care?

The response to higher mobility of pensioners in Europe clearly must be a uniform basic level of care supply both in terms of quantity and quality:
Research in CARMA has shown that although we can identify converging tendencies in policies for older persons such as a convergence between insurance and tax based pension systems (cf. Kern/Theobald forthcoming in European Journal of Social Policy) and also convergence within the various care service offers for older persons, the levels and accessibility of services differ significantly between North and South in Europe, and particularly in the new EU member states. E.g. while care

dependent older persons in the UK have a very good chance to get more than one house call of care workers or nurses a day (54,8 %), and this is rather similar in Germany (with 42,9 %), this does only apply to 21,1 % of the Belgian and 9,5 % of the Austrian care dependent. However, in Italy none of the interviewed 90 care dependent in the Marche Region reported to get one or more house calls a day, the Italian care dependent have to manage with a couple of visits a week or one visit a week (!).

The current practice of the EU to deal with social policy matters by OMC (Open Method of Coordination), the exchange of Best Practice Models etc. is a rather weak instrument if we want to attain universal entitlements for benefits and services of all older persons in Europe. As a matter of fact "Europeanization is clearly not as advanced in the area of social policy as it is in other policy areas." (Kern/Theobald forthcoming, 7). A universal (in terms of European universal) citizenship based entitlement for care in old age would most probably also foster the people's belief in Europe and enhance identification with European integration.

For the future we recommend to promote ideas of best practice in care for older persons by European or National awards for care service providers for innovative and inclusive models of care.

In addition, a step towards basic service standards needs to be made across Europe by demanding minimum standards of publicly funded services for older care dependent, such as the extensive availability of affordable night time service in home based care in all European countries. This is not the case yet. While Scandinavian countries and the NHS in the UK are rather advanced in these terms, the family based systems in Central, Southern and Eastern Europe lag behind.

Research in the project OASIS has revealed that there is no danger of crowding out family care by increased public professional care supply since care needs are not final but negotiable. The OASIS study could not detect a substitution of family care by professional care services by the NHS but better support for informal carers and fewer threats of social exclusion in old age.

2.4 Solidarity with the very elderly

The coordination of national social protection policies is due to be extended to long-term care for the elderly in 2006. How can this help to manage demographic change?

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by professional care services by the NHS but better support for informal carers and fewer threats of social exclusion in old age.

> In particular, should a distinction be drawn between retirement pensions and dependency allowances?

First and foremost, every European citizen should have the right to receive a minimum pension / basic level of income in order to guarantee a decent life. A measure to define these minimum pensions should be found by experts in this field. With respect to the distinction between pensions and dependency allowances we recommend that dependency allowances should be paid regardless of income – while, of course, pensions are related to work life and thus income. In general dependency benefits in kind are preferable to those in cash since they prevent black market employment which attracts thousands of women from Eastern Europe who are being exploited by the welfare states and the families of more affluent countries and since it would create more jobs in the social and health sector.

> How do we train the human resources needed and provide them with good quality jobs in a sector which is often characterised by low salaries and low qualifications?

Training of staff – soft skills

Educators should put particular emphasis on training 'soft skills' like emotion management in care personnel; we have seen that persuasion skills and empathy are key competencies when handling aggressive clients or clients unwilling to cooperate or even rejecting help. There are two major goals in this kind of training: to better understand the care dependent's situation; and to better understand one's own feelings as a carer.

Too often carers suppose that the old persons know themselves what their problem is. The elderly often accept problems as normal, as a part of growing older, as something they have to accept because they cannot be resolved. Furthermore, the elderly do not dare to express some of their questions, because they still are taboo. This target group often does not know very much about opportunities to develop as person, about the positive dimensions of the old age. For all that reasons there is a need of training in constructive communication between carers and the elderly.

We have seen good examples of applied knowledge in the practice of care when senior care personnel assigned aggression of a client to his/her inner rebellion against dependency and sickness. This rationalisation enables the single care worker to treat a patient with professional composure which calms tensions and conflicts (cf. CARMA Del 13, p. 16f, 23f., p. 30).

An increase of elderly people affected by dementia calls for both special training of the staff working with this group and support for the informal carer in this challenging situation (cf. CARMA Del 10, p. 35).

Our findings also reveal that older persons experience considerable psychological problems, i.e. feeling downhearted or lonely. This applies especially to persons living alone and with rare social contacts; and persons with low incomes and an economic burden due to the use of professional care services. Apart from the fact that the use of a social service promoting social integration or lowering the economic burden can improve the situation, psychological support or even treatment might be necessary as well. Social and emotional support should become a task in daily care delivery, which requires of course time and special training of the carers.

Training coping with sexual harassment

The question of sexual harassment needs to be covered explicitly in the training of care personnel; it is such a common feature of everyday life in care that its structural reasons (patriarchy) may not be ignored. At the moment coping is left to the individual care worker and her experience and self esteem, this creates unnecessary troubles for young staff. Therefore care teams should be encouraged to openly reflect and discuss events of harassment and support the – mostly young – care workers affected. Sexual harassment ought not be treated as a taboo within care but openly reported, and it may not be the individual problem of a single nurse or care worker but a difficulty the whole team (including the management) should try to solve (cf. CARMA Del 13, p. 17f.).

Balanced education

In the medical education there is a need for a holistic view on care and on the developmental process of ageing.

The education must consider the training of competencies; often education is too much oriented to theoretical knowledge. That is of course important, but the work field experiences a lack of practical skills and self-reflection by the students.

The training of medical skills does not necessarily imply that a care worker is qualified for the task of caring for a person.

One-sidedness of the carers' education has to be avoided, at the moment there seems to be not enough space for practical training in education. A new balance in the distribution of practical skills and theoretical knowledge in the curricula must be found.

Another CARMA research result was that geriatric care is to a large extent based on "common sense" instead of evidence based knowledge. Both in the general staff and within the groups of specialists there seems to be a need for more research and evidence based education.

Continuous education

We recommend that the knowledge and skills of the care workers be constantly updated in order to make their work more and more effective and coherent with the

users' needs. Both service providers and the states/NHS should invest in continuous vocational training.

Networking and cooperation of social and health staff

Concerning vocational (educational) training, specific training networks should be designed in order to enhance the cooperation between social and health staff. Professional and vocational training might as well be integrated. Professional boundaries need to be overcome without confusing the tasks of different groups of care workers.

European minimum level of training for care personnel

Research in CARMA has shown that education of care personnel is very heterogeneous within member countries let alone across Europe. Uniform educational standards and curricula should be developed in all European countries which would by the way also enhance mobility of employees and combat black market and low quality care.

The working conditions of care staff also need to be improved.

Bad working conditions and a low income of professional carers leads to the fact that there is a shortage of staff (cf. Del 11, p. 17). In one of the CARMA studies we learned that in systems where care provision involves both care staff in the status of civil servants and care staff of private organisations, the public employees in general have more and better training to deal with *difficulties* which they regard as *challenges*. Moreover, the private organisations try to pass 'difficult' clients on to other services to minimize their efforts, while the statutory services feel responsible to care also and particularly for those who are at risk of marginalization. Therefore care work should be performed under equal standards (working conditions as well as pay and education) regardless of the status of an employee (meaning civil servants or private employees).

Integrated care, as recommended elsewhere in the CARMA results, will also have a positive impact on the working conditions of professional carers.

Supervision, Coaching and Support of professional care workers

For the professional carers coaching and supervision should be included in the work scheme. Communication with peers could lead to recognition of the same needs and feelings. Some organisations offer their employees round-the-clock telephone support. Care workers who experience troubles or conflicts with clients can get advice and support from experts. Most of the institutions and organisations must put greater efforts into the implementation of a communication and employee development policy.

Whenever conflicts arise – be they with the client her/himself or his/her family – the single care worker will need back up from management. Thus it should be standard procedure that employees do not have to fear to report difficulties to their superiors. Particularly when the care workers advocate for the care dependent against his/her environment a clear policy of the provider will provide invaluable support. Courageous behaviour should get the support of the management to maximise the

potential of professional care in preventing abuse and exploitation of older persons (cf. CARMA Del 13, p. 16 and 172).

Some providers believe in staff rotation as a means of preventing burn-out. From the perspective of care workers, however, it might mean a less predictable career and unnecessary stress with having to adapt to the new clients' peculiarities, apartments and living circumstances all the time. Thus, job rotation should be related to career development rather than routine as an end in itself.

Continuous training

High-quality vocational training is not offered by every provider. The right to receive continuous training during one's whole career should be part of any employment contract. Paid leave must be granted to care workers attending further training.

> How do we arrive at a balanced distribution of care for the very old between families, social services and institutions? What can be done to help families? What can be done to support local care networks?

With regard to a balanced distribution of care between families, social services and institutions we recommend the development and provision of tailored services, that consider the individual needs of the care dependent and their families, based on a holistic assessment:

Improve access to a variety of services and housing facilities

The changed policy goals with regard to elderly and health care have led to the establishment of a wide range of services and facilities suited to different care needs. The availability of a wide range of different services and housing opportunities (e.g. apartment sharing) according to individual care needs offers freedom of choice and the possibility of independent living. The boundaries between residential and home based care as well as intermediate services were opened up. Since the 1980s most western European countries began to establish a continuum of social and home-based care services, semi-residential and residential facilities, and a variety of housing opportunities, i.e. sheltered housing in different forms.

As our results in CARMA and other research projects show different types have become established in most European Union member states. In principle, the different facilities and services provide the elderly with a wide range of opportunities according to their care needs but the difficulties concern the availability and accessibility. Even if a variety of facilities can be found in every country, the availability may be reduced, e.g. there is often only one model project in a town, the facilities are established in one area only or the use presupposes private means etc. The goal must be to expand the facilities and services to all regions and towns and to make them accessible for the elderly according to their need.

Especially for women, living alone constitutes a risk of marginalization. Different forms of sheltered housing or apartment sharing facilities are a possibility to enhance the social integration of this risk group.

Flexible care services offer the opportunity to integrate different services to a comprehensive care arrangement. Care services which allow older people with a high level of care dependency to live at home and which substitute 24/7 black market care work have to be established to prevent them from institutionalisation (cf. CARMA Del 2, p. 31; Del 3, p. 6; Del 4, p. 33; Del 16, p. 11 and 69; Del 17, p. 18ff.).

Promote access to rehabilitation-measures

In all country samples of CARMA the respondents report about institutional and ambulant rehabilitation measures, which very often successfully improve mobility and the health status in general. Five to eight out of ten patients consider rehabilitation measures as significant for their ability to remain at home. Functional decline is the most important reason for getting care assistance.

In the findings some problem areas could be stated: While access to institutionalised measures, e.g. during or after a hospital stay seem to be quite easy, it is more difficult for the elderly to receive ambulant measures afterwards as a part of a regular care package. Furthermore, institutionalised measures after a hospital stay are often not well enough adapted to the individual situation of the elderly. In some country samples, it is obvious that access to measures require considerable efforts of the care-dependent elderly respectively their informal carers. Thus, the elderly who are not able to fight for their interests are put at a disadvantage. Here the GPs should encourage more disadvantaged elderly to use rehabilitation measures. Furthermore mobile Physiotherapist/Occupational Therapist services must be offered and funded.

Adaptation of services to specific cultural needs

At the moment the population of older persons in the different countries is relatively homogeneous but an increase in the migrant population among elderly can be anticipated. Increasing and ageing migrant populations in Europe call for a higher sensitivity of care systems for the particular needs of ethnic minorities. Services like meals on wheels have to include religious diets just as much as medical ones. Providers should be encouraged to hire employees representing ethnic minority groups, too, so multi-ethnic clients will feel treated with the utmost cultural sensitivity applied.

Some examples for new services

Special services and specialised staff for people with dementia

Dementia is one of the main reasons for admission to a nursing home. This disease puts a challenge to the informal carer who often feels heavily burdened. Day centres, respite care, home-based services, relief services, training and supervision for the informal carer have to be established.

The necessity of specialised staff intervening when the care workers are on the limit of their capacity to treat a client has been shown in many cases. This specialisation ensures competent treatment of persons with mental problems and relieves the care workers who may feel at a loss when they are attacked by clients. The Viennese

"INDIBET" service can be named as a best practice model (cf. CARMA Del 10, p. 35, p. 42; Del 13, p. 16f., p. 23f., p. 29).

Organised activities, self-help groups, day centres

Organised activities proved to be important for both the social integration of care-dependent elderly and of informal carers. Social activities can provide a buffer against feelings of loneliness and social exclusion and involve carers and care-dependent elderly in activities outside their homes. Considerable adaptations are required in order to offer such an opportunity to different groups among the elderly or informal carers. Often such activities are not oriented towards the interests of the members of the lower socio-economic classes and migrants. It is important to find out which type of offer may be adequate for different social groups and migrants. Furthermore, the elderly sometimes describe the groups as not ready to integrate new members. Care-dependency is also reported as an obstacle. Especially, elderly with mobility problems often feel excluded from the activities.

Assistance with overcoming gendered division of labour by services

Older men living alone after divorce or widowhood are at a significant disadvantage in terms of their involvement in formal organizations, social networks and they display a higher level of health risk. There is a need to establish clubs, day centres and services that are specially addressing older men (cf. CARMA Del 1, p. 32, 42).

We found evidence in our research that elderly who had lived in a partnership with traditional, gendered division of labour are a special group at risk of marginalization. Cases were reported where widowed men have not been eligible for services helping them with household tasks because they did not have physical or mental impairments. Their only impairment was the fact that they did not know how to cook a meal or to do the laundry because their wives had performed these tasks for them. In other cases women who never had a driving license or who had no experience in handling their personal financial issues were particularly vulnerable and at risk of social exclusion. A society that actively promotes the division of labour between men and women should actually be ready to bear the consequences for the individuals in old age rather than expect an immediate change of habits.

Elderly in such cases should be eligible for home-based services for a certain time span which aim at activating and supporting them. To offer them day centres could be another opportunity to cope with this situation of loss of the partner. Women who never held a driving license should be eligible for transport services.

Use of traditional services for innovative aims

The wheel need not always be reinvented. An adaptation of previously known services to new care needs is sometimes sufficient. Sydenham Court (of South and East Belfast Health and Social Care Trust in Northern Ireland) could be an example for a best practise model where a traditional sheltered house was adapted to the special needs of people with dementia and supported by assistive technology. This combination ensures independent and autonomous living for elderly with severe care dependency.

Support more severe care-dependent elderly by a professional care manager/ care

The findings in CARMA reveal the necessity of an individual care management with an increasing help provision and the inclusion of different types of services etc. This task is often performed by the informal carers or the care dependent elderly on their own. It requires competences in organisation, time management, organisation of information, writing of applications and organisation of different types of services, medical aids etc. A professional management of care in case of severe care-dependency should be offered to the care-dependent elderly and their informal carers to secure an adequate care arrangement. An adequate care management in combination with affordable services provides the elderly and their informal carers with the necessary security that in case of an increasing care-dependency there will be solutions. As research in CARMA shows, the insecurity about the future development of care-dependency and care resources causes considerable psychological strain for the elderly and the informal carers.

Information to establish appropriate care arrangements

The western societies of today are knowledge based societies. The increasing number of services and information is often provided through new information and communication technologies or automated services. When older people lack the skills of handling these technologies they are put at risk of marginalization. To act as a consumer, one must have access to relevant information, negotiation competences and means to cover the additional costs. Many older people are overwhelmed with the task of finding the appropriate care arrangement.

The development of intensive case management services is devised to support the elderly in the establishment and adaptation of their individual care arrangement. A case manager is the neutral advocate of the care dependent and establishes the most suitable and cost-effective care arrangement.

Various channels should be used to spread information about care, benefits and also activating social activities for the elderly. People should e.g. receive with their entry in retirement a brochure with all necessary information about help in case of care dependency, different types of benefits, of reductions for seniors and about cultural and social activities. Additionally, at key crossroads when care needs occur, professionals should be ready to deliver specific information which is continuously updated.

A free European telephone hotline – ECHO EuropeanCareHOtline (cf. "112" for emergency calls) - operating with national/regional call centres should be set up where people can receive thorough information on care services in their country/area.

Also the establishment of a EUROCARE website is an information channel for the future generations of older persons who are more familiar with new media.

Further, the use of interactive TV-information services or the formation of a CareNewsNetwork-CNN should be promoted (cf. CARMA Del 1, p. 17; Del 3, p. 7; Del 10, p. 43).

Counselling for Family Care Arrangements

Since in the family based care systems informal carers report to be confronted with a sudden need to provide many hours of care – in basic nursing, housework and care management – which consequently did not give them time to reflect for alternative care arrangements, it would be necessary to support informal carers with counselling well before or at latest at the beginning of care dependency. I.e. a social worker should explore all family and professional resources and then support the relatives to assign duties among each other. Very often, care arrangements mirror gender specific division of labour, male children are usually less involved in instrumental help than female. This situation not only protracts gender injustice of society in general it also may lead to severe family conflicts among siblings. Therefore a written agreement could be made – similar to the often recommended marriage contracts – that would demand equal share of assistance of all available children or relatives. E.g. should some relatives live further away their share could be financial support for the many aids and adaptations necessary in the case of care dependency – because, after all we have learned that being a relative within easy reach plays a central role for becoming an informal carer (cf. CARMA Del 16, p.44; and Prelim. Report on Interview Analysis, p. 80).

In addition, we recommend including informal carers in the arrangement by case management:
Providers have the power to take the wind out the sails of conflicts with family carers; if they were willing to include informal carers in the care arrangement they establish with the client, the informal carers would feel respected and have an assigned role. As a result of the professional training of the formal care worker, many of them are oriented towards the needs of the care dependent person and tend to neglect the experience and competence of the informal carers. The formal care giver has to learn to take into account the entire care system. Clear – written – agreements will be necessary to ensure a reliable partnership, but this is worth the effort since it helps trace deviation from agreed goals or detect actions that contradict the interest of the care dependent. Such an integration of informal care is part and parcel of case management which would always follow a contextual conception and include informal resources under equal terms as professional services (CARMA Del. 13, p. 18, p. 21).

Improve the combination of formal and informal care-giving

If the welfare systems fail to support the informal carers, they will collapse under the burden of care and more financial means will have to be deployed to cover the care needs. Programmes which effectively (strongly and widely) support informal carers should offer a perspective to the informal carer, that relief is available and affordable. Empirical research shows that the combination of formal and informal care-giving is often not accompanied by a retreat to family help or a simple substitution of help. Usually, formal and informal care-giving complement each other and the expansion of care services even promote family help. In addition, in more service-oriented elderly approach less elderly are left without care than in the more family-oriented

systems. The results recommend the development and expansion of professional care services.

The vast majority of carers are still women, mainly spouses or daughters (in-law). Men take over more traditional caring duties in partner relationships only, while in non-partner relationships, they tend to be active in the area of logistics or care management. There is evidence in some countries, such as the United Kingdom, The Netherlands and Germany that people with a lower educational attainment level are more likely to be active as informal carers. This may negatively affect their labour-market position and their income situation even in the long run. Efforts should be undertaken to secure that there are alternatives and the involvement is voluntary, the caring work is adequately economically supported and that on the basis of regulations, i.e. employment or pension regulations, the negative consequences in the future are minimised.

The establishment of a co-operation between the informal and formal carer in daily care work should be accepted as a task of its own. It requires on one hand the acknowledgement of the professional competence of the professional carers. On the other hand, the professional carers should develop insight into the competencies of the informal carer, based on the latter's day-to-day experience with the care recipient as well as into the psychological and social consequences of their care task. A change in the system is essential if the attention is to be directed not only towards the care recipient but towards the individual situation of the carer, thus including the entire care system.

Support of informal carers (family, neighbours, friends)

The findings in CARMA show that the best support of informal carers is the assistance with daily caring activities or even the sharing of daily caring activities. Two patterns of a successful support can be found within the findings: An adequate relief can be provided either by the use of professional service at all levels of care-dependency or by a common support of family members and professional care services related to a more frequent use of professional care services with an increasing level of care-dependency. Thus, an adequate unburdening of informal carers requires the development of adequate and accessible professional care services and the support of the assistance by the relatives and wider networks. Especially in country samples where the informal carers are heavily burdened they complain about the quality, lack of flexibility and the high costs of professional services. The development of an adequate, accessible care service infrastructure is the first step to support informal carers.

As a next step unburdening measures directed towards informal carers are important. This applies to professional social or emotional support, e.g. self-help groups. Relief can be provided on the basis of different types of accessible and affordable respite care, which should become available and affordable. Respite care should also be available within the home of the elderly to provide those of the elderly with daily assistance who do not want or are not able to leave their own homes.

Some practical examples to support informal carers are:

Day centres

Day centres are important measures to strengthen and relive the informal carer. The day centres have to be improved by a more flexible time schedule in accordance with the working time of the employed informal carer.

Right to paid respite care

The provision of financial support for carers and the establishment of a social right to respite care for informal carers were major topics of the social policy agenda in the 1990s in Germany, leading to the provision of extra funding for these services and creating appropriate forms of funding.

Despite the positive development obstacles can be revealed which necessitates further efforts. The opportunity to respite care is still underdeveloped. Figures in The Netherlands and Germany show insufficient take-up rates of such services. This is explained by the costs, the lack of flexibility and adaptation to the situation of the individual carer as well as the criticism of informal carers on the quality of such care facilities. Efforts have to be made to adapt the services and the funding to the needs of the individual informal carers.

Sitting service

Informal carers are at high risk of social marginalization because of their care role. To allow them to get a break of some hours or to attend e.g. a self-help group a service which is replacing them in their care responsibility is necessary.

Insurance covering accidents

A statutory right for an insurance which covers accidents of informal carers while performing care in the home of the care dependent would be another measure of improvement.

Adaptation of working-time arrangements

The combination of care work and employment requires adequate support with high-quality care services but also an adaptation of the arrangements at the working-place. Necessary are especially adaptations of working-time arrangements, such as flexible working time, free hours to accompany the care-dependent elderly to the medical doctor etc., a reduction of working-hours or even an employment break. To secure such arrangements/regulations laws are necessary who give the individual informal cares the right to claim the adaptations and thus be less dependent on the good will of an employer or direct boss.

Information for informal carers

In most western European countries, the increasing awareness of the importance of informal care and at the same time its fragility within changing family structures has led to a debate on the role of carers in society and on the efforts being made to create new forms of support. Information, advocacy and counselling as well as emotional support is provided by a wide range of actors on the local level, i.e. by the carer's organisations, parishes, municipalities or insurances but the availability and accessibility of such services has to be increased.

Support the caregivers

Caregivers, professionals and informal, are in close contact with the care-dependent elderly and they experience the burden of their role, conflicts with the old persons and others members of the family. However professional carers often undervalue the contribution of the informal carers. On the other hand, informal carers often do not know what to expect from the professional carers. A roundtable combining all carers involved would help to exchange information, negotiate the different tasks and thus promote integration of informal and professional care. Such a roundtable would also offer an opportunity to talk about their own feelings of frustration and anger and could offer a kind of relief which may also act as a preventive measure against abuse of the elderly.

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the many aids and adaptations necessary in the case of care dependency – because, after all we have learned that being a relative within easy reach plays a central role for becoming an informal carer (cf. CARMA Del 16, p.44; and Prelim. Report on Interview Analysis, p. 80).

Preventive Measures for the Development of Wider Informal Networks (neighbours, friends)

Wider networks, especially neighbours and friends are an important resource in daily care provision. They are available in case of an emergency, take over small tasks, e.g. shopping, carrying heavy things or are resources in regard to social/leisure activities, e.g. visits, go for a walk. Preconditions for this type of support are existing social contacts and good relationships to the neighbours and friends even before the entrance of care dependency. Here efforts to develop a good neighbourhood by the city councils are an important preventive measure. Efforts for a good neighbourhood should also include activities for healthy and disabled residents together. In addition, transport- or mobility services which facilitate social contacts within a neighbourhood should be established. Furthermore, the findings show clearly that the elderly who moves to another flat, e.g. to an assistant living facility etc. should stay in their neighbourhood. Consequently, such facilities should be located in different areas of a town.

How can new technologies support older people?

The project CARMA has studied the risks of care dependent older persons to be become marginalized and socially excluded and one of our findings proves that inadequate environments can cause significant threats to the social integration of older persons once they are more frail. We therefore recommend to improve access to assistive technology.

The role of assistive technology and the relevance of its availability has been shown by the comparative study – care systems offering medical aids and equipment for free lower the barrier to autonomous living at old age and they may significantly stimulate the market for assistive technology and care aids thus contributing to more development and better products (cf. CARMA Del 13, P. 18, 19).

Further, health and social service providers should promote the use of assistive technology.

Providers and educators will have to include the application of medical aids, assistive technology and housing adaptations to a larger extent than today. We have seen too many cases where the physical environment was limiting freedom and access to quality of life. This seems almost anachronistic in the 21st century where spaceships explore the universe. Intensifying use of aids and assistive technology is a question of information, too. Many a care worker or family carer is simply not aware of what is available and accepts a restriction too willingly. Thus, companies in this realm need

to enhance their marketing and information strategies. After all, clever technical solutions can help save personnel resources and make an important contribution to occupational health (CARMA Del. 13, p. 18f.).

Various channels should be used to spread information about care, benefits and also activating social activities for the elderly. People should e.g. receive with their entry in retirement a brochure with all necessary information about help in case of care dependency, different types of benefits, of reductions for seniors and about cultural and social activities. Additionally, at key crossroads when care needs occur, professionals should be ready to deliver specific information which is continuously updated.

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Further, the use of interactive TV-information services or the formation of a CareNewsNetwork-CNN should be promoted (cf. CARMA Del 1, p. 17; Del 3, p. 7; Del 10, p. 43).

3. Conclusion: what should the European Union's role be?

> Should the Union's financial instruments – particularly the structural funds – take better account of these changes? If so, how?

Yes, more resources will definitely be needed in the future to provide adequate social and health care for older persons in Europe.

In particular, we think that better account should be taken of the social dimension in every policy area and strategy. A new structural fund directly devoted to demographic change / social policy could be introduced, being wider than and different from the ESF that is limited to employment policies only. Alternatively, as a first step, accessibility to the current ESF could be improved.