

To: Green Paper on Demographic Change
DG EMPL/E/1
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European Commission
B-1049 Brussels
Belgium



EUROCARERS

EUROPEAN ASSOCIATION
WORKING FOR CARERS

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Date:	18 -10- 2005
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Utrecht, 12-10-2005

Dear sir/madam,

Eurocarers, the European Association Working for Carers, would like to present you the response to the Green Paper on Demography.

With kind regards on behalf of the editorial committee,

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EUROCARERS' Response to the Green Paper "Confronting Demographic Change: a New Solidarity between the Generations"



Eurocarers, a European Association Working for Carers

Editorial Committee: Brigid Barron (Caring for Carers, Ireland), Imelda Redmond (Carers UK), Giovanni Lamura (INRCA - Italian National Research Centres on Ageing, Italy), Geraldine Visser (Expertise Centre on Informal Care / The Netherlands Institute for Care and Welfare / NIZW, The Netherlands)

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, we take the view that the discussion of demographic trends and managing their impact should take place at European level. Currently many welfare policies are predicated on the basis that family and friends will continue to provide informal care. This will become increasingly important as demographic change means that there will be more people needing care at the same time that the pool of potential carers is shrinking. Eurocarers, thereby, is focussing on family care or informal care in answering the questions in the Green paper on Demography, with informal care being defined as care provided

- outside a professional framework but within some form of emotional relationship, e.g. by family members, loved ones, friends or neighbours, but not through formalised volunteering;
- by people of any age;
- to people irrespective of their age or type of health need;
- over a longer period of time.

Informal carers shall hereinafter be referred to as 'carers'.

Informal care will become increasingly important over coming decades, as demographic changes mean that there will be more older people, who are likely to need care, and more carers who will need to retain their links with the job market if economic targets on labour participation are to be met. These carers will need to be actively supported to care whilst also retaining their own rights and aspirations.

With demographic changes, the need for informal care will increase in the coming decades. The level of awareness of carers' interests and concerns is very variable across EU member states; in some member states there is an urgent need to make the work that carers do more visible and to promote carers interests. Against this background of demographic changes and challenges to health and social care services throughout Europe, the role of informal carers is more crucial than ever. At the same time, The importance of carers being able to combine caring and paid work, if that is what they choose to do, is becoming clearer. In response to these trends, representatives from carers' organisations and research and development organisations are establishing an EU-wide organisation – Eurocarers - that will represent and provide a voice for carers. By exchanging knowledge about different aspects of these demographic developments between European countries, EU member states and the EU herself are able to develop well-informed policy.

Objectives of a discussion on EU level are:

- To improve the situation of carers, to ensure the sustainability of this improvement, and to safeguard the rights of carers across the EU;
- To promote recognition of carers and carers' interests, irrespective of their age or the particular health needs of the person they are caring for.
- To promote empowerment of carers
- To promote the social inclusion of carers

- To promote equality for carers
- To promote the development of services that can support carers
- To promote the development of employment policies that allow for flexible arrangements enabling people to combine caring responsibilities with paid work.
- To promote adequate social security policies to financially compensate carers
- To promote collaboration and co-ordination between formal and informal care

Policy areas

These objectives concern the following policy areas:

- Carers should have the right to choose freely whether or not to be a carer
- Recognition and support of carers
- Access to health and social care services
- Employment policy -Combining of paid work and care
- Voluntary work
- Intergenerational solidarity
- Income and poverty (both during and after caring) / social security
- Gender and care
- Education and lifelong learning
- Social inclusion
- Equality

Recognition and support of carers

In all member states the pressure on informal care has increased in recent years due to different demographic changes (such as the ageing of the population, the increase of smaller families, increase in divorce, increase of female labour participation), epidemiological and political developments. It is expected that the demand for informal care will rise, but the supply of caregivers will decline. Research throughout Europe shows that Carers want to care for their dependant members at home (Eurofamcare). Carers have the same rights as others to participation, employment and social inclusion. Many carers find it difficult to speak up for themselves; therefore it is vital to recognise and support carers and their organisations that raise awareness of carers' issues and represent their interest on a local, regional, national as well as EU level.

Combining work and care

Policy makers have to be aware that different demographic and political developments, such as aging of the population, social-economic measures concerning professional care and increased participation in the labor market, generate more pressure on carers. Caring can adversely affect the health and well-being of carers. It is also true that carers may want to work, and this right must be respected by policy makers. Carers are likely to have a range of responsibilities (taking care of their own family, paid jobs, taking care of parents). To support them in making those choices, and to enable them to have the option of economic activity alongside providing essential care, a good system of health and care services and measures for combining work and care are necessary.

Objectives of a discussion on this policy area are:

- To raise awareness of the barriers carers face while combining work and care, and to support them.
- To raise awareness of the barriers facing carers who wish to work, and to study and promote ways of supporting them.
- To develop adequate supports to enable the carer to care full-time in the home
- To facilitate choice for carers to enable them to work full-time caring in the home or to combine work outside the home with caring.
- To develop policies which will ensure good quality services for the cared for person
- To inform employers about the needs of carers combining work and care
- To develop (European) policies for more efficient and effective process of volunteering (to support carers)
- To find new possibilities for voluntary work (e.g. encouraging working people to perform voluntary work; supporting vulnerable citizens who work as volunteers; encouraging people in social security/benefit to take on volunteer work; encouraging pensioners to volunteer)

Income / poverty

Working carers are facing different problems: these may result in reduced earnings if they have to reduce their working hours or (temporarily) quit working in order to provide informal care. Many carers are not able to work as flexibly as they would like to. There are a range of personal and systems barriers to combining work and care. Giving up work, because for example self esteem has been undermined or alternative care is not available or of good enough quality, will mean the economy loses important skills, and will mean the carer is more likely to be in poverty in later life, as well as immediately losing earnings

Not only working carers, but also non-working carers are facing financial problems due to informal care (e.g. co-payments for health care, increasing costs for health care, expenses for travelling, telephone, (medical) device, medicine), as well as the impact on their working lives. To prevent them from financial burden / poverty, financial compensations for carers are needed to support them. One of the purposes of Eurocarers is to promote adequate social security policies to financially compensate carers.

It will be necessary to:

- Examine the options available to recompense carers more adequately to reflect the value of the work they do and the employment-related income they may forego whilst caring
- Ensure that Carers have an income considered as earnings not as social assistance
- To examine the costs of care and to recompense carers adequately
- To ensure that carers do not suffer social insurance or state pension disadvantages because of periods of caring

Voluntary work

Volunteering plays an important role in finding solutions to societal issues (*European Roadmap to 2010. Volunteering and participation in the EU*). It strengthens social cohesion, increases social involvement, stimulates active citizenship, improves quantity and quality of services and helps individuals develop new competencies. Volunteers take an important part in the support of carers in many countries. However, people have less time for volunteer work.

Older people remain active and healthy for longer, have a relatively large amount of time on their hands and represent a considerable potential in human capital. The engagement of their life and work experience, talents and competencies is of great value to society, and not least for the elderly people themselves. But the ageing process among volunteers may create a shortage of volunteers in the future.

Intergenerational solidarity

Due to all the demographic, social, cultural and political changes and developments the question is whether there still is solidarity between generations. Are children still able and willing to take care of their parents and other relatives or friends who are in need for care? What are the moral obligations to care?

We know that there are families and friends across the EU who do care. They save government a huge amount of money each year – in the UK £57 billion, the equivalent of a second national health service. It is vital to support carers in continuing to care.

Gender

In all countries, the majority of carers are women. Women report more time spent caring than men, and people of working age – particularly women, appear most likely to take on the care of older relatives, with the peak among those in the second half of working life. Male carers may be more likely to be sharing caregiving with others and may define their role more in management of caregiving than direct personal care. The financial disadvantages of being a carer are only one amongst a range of problems that carers experience, their health may suffer with stress-related conditions as well as widespread fatigue and tiredness.

Women often have less resources to provide care (e.g. due to increasing labour participation). Demographic change also means an increase in "sandwiching" – people who are caring for parents/older relatives and children at the same time, or in quick succession). Informal care and volunteer work in care is performed mainly by women over the age of 45/55. With regard to volunteering, they constitute what are known as traditional volunteers, who devote themselves to their fellow people constantly and almost as a matter of course. In contrast to this group are the 'new' volunteers, who critically weigh up how they will spend their leisure time, and in the process might look at what volunteer work has to offer them. Consequently, the need felt by volunteers to belong

to an organisation for a sustained period is declining. Short tasks with a clear start and end, and if possible also a clear result, are preferred.

Education/lifelong learning

Lifelong learning is important for the continual enhancement of skills and abilities and for the carers own general development, employment and career prospects. Data from the 2002 Irish Census suggest that those carers who would benefit most from lifelong learning may be ones that are most constrained by caring. This is because carers with lower levels of education are proportionately more likely to be caring for longer hours. Young carers are more likely to have difficulties with school attendance and academic achievement. They are also likely to miss out-of-school educational activities such as after school clubs, visits and holiday programmes.

Education and lifelong learning are necessary to inform carers about providing care. Particularly, since new technologies are developed in supporting care work (alarm systems, video-telephones, tele-medicine devices etc.), their use should be properly disseminated among carers in order to promote their widespread usage.

Not only carers have to be trained in providing care, but formal care workers need to be educated and trained to be able to support, cooperate and collaborate with carers. The topic 'Informal care' should be part of their initial training and further education programs.

Life long learning is also vital in equipping carers to retain and update skills and confidence, so that they have the option of working or volunteering during or after a period of caring responsibility.

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 co-ordinated national social protection policies.

- How can a better work/life balance help to tackle the problems associated with demographic ageing?

Flexible working: many carers can resolve short term care if they are given the flexibility to reorganise their working time. Carers need the opportunity to have flexible working hours, to have the opportunity to take time off during working hours, to deal with emergencies or to take someone for a hospital appointment. Care leave arrangements (paid or unpaid) as well as facilitated part-time work options may be feasible solutions for working carers. Another option may be to work from home.

Employers' recognition and understanding of informal care are necessary. Therefore, not only employers have the responsibility to create policy and good conditions for working carers, but also **social and health care services** have to adjust their organisation to the needs of working carers (e.g. home care workers have to be able to visit the cared for person before and/or after working hours).

A range of evidence demonstrates that good work life balance and flexible working policies are also good for business, with increased productivity and loyalty.

- How can a more balanced distribution of household and family tasks between men and women be encouraged?
 - Women are more often working part-time than men do. Moreover mens' average earnings exceed those of women. As a result the choice for couples who is going to work part-time is easy: women do. So, one way to develop a more balanced distribution of household and family tasks between men and women would be more equally balanced wages between men and women.
 - Employers should allow both women and men to work part-time.
 - Another way could be to start a discourse about a more balanced distribution of household and family tasks between men and women through TV-commercials, talk shows etc.
- How can the availability of child care structures (crèches, nursery schools, etc.) and elderly care structures be improved by the public and private sectors?

Services need to be flexible, suitable and of high quality, and need to be designed with the carers needs in mind as well as those of the user of they are going to be effective and to allow the carer to work.

- How can parents, in particular young parents, be encouraged to enter the labour market, have the career that they want and the number of children they want?

Parents of disabled children often find it more difficult to work because childcare or education provision for disabled children is not adequate.

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?

Immigration offers no simple solutions for demographic changes c.q. ageing of the population. As Eurofamcare shows, migrant workers have their own problems: they are rarely trained in care work per se and may have language problems. Furthermore, by attracting migrant workers – mostly qualified nurses or other care workers - and putting them to work as professional carers leaves those countries without qualified care personnel. This may decrease the quality of health and social care in those countries. It is also clear that increased immigration will not significantly increase the number or the experience of family carers.

We should be very careful in presenting only negative aspects of such a phenomenon. The experience of Mediterranean countries (Italy, Greece, Spain etc.) shows that in many cases the support provided by migrant care workers has been very highly appreciated by both the cared for older person as well as by the caregiving family members, especially in the light of insufficient “formal” care services and increasing female labour market participation.

On the other hand, the savings which many migrant care workers could achieve through this activity have provided a remarkable source of income for their families in the sending countries, most of which have been lately facing huge economic crises (especially in the case of Eastern European countries after the fall of the Soviet Union).

What is most important, is the need of providing an appropriate system of monitoring that no exploitation takes place at a “micro-level” (for instance by families paying too little the hired migrant workers), and that international cooperation takes place more actively at a “macro-level”, promoting initiatives aimed at preventing the “care labour drain”, but at the same time recognizing the dynamic role of international labour migration movements in adjusting for cross-national (economic, social etc.) differentials.

In the Netherlands a new problem is rising, the **migrant family carers** of the ageing migrant population (mostly the daughters and daughters-in-law):

Using immigration to mitigate certain negative effects of demographic ageing could be useful for the short term. However, the immigration in the Netherlands which started in the sixties of the last century may give some thoughts for consideration. The migrant population in the Netherlands is now also ageing. Ethnic minority elderly people are less healthy than Dutch older persons. This may be because of their lower socio-economic status, heavier working conditions, or the stress of migration.

In more than one respect with regard to health care attention has to be paid to this ethnic minority group. First, they are unfamiliar with the Dutch health care system. Second, their attitudes towards care differ from native people. Third, the health care system and policy are saturated with native values. And finally, there may be a lack of understanding due to barriers of language. Additionally, it has to be noted that among the different ethnic cultures there are many differences with regard to care attitudes and values.

Although, ethnic minority families usually find a solution for care within their own circles, there are signs that these informal carers are under even more pressure than their Dutch national counterparts. They make little use of existing forms of support for carers. They are even more reluctant to ask for help for themselves. This does not always mean that they do not need help. There are also barriers to calling in help, or making use of existing forms of help because of a lack of awareness of care and welfare facilities, culturally-determined attitudes to care, the language barrier and a different communication style.

Informal carers of ethnic minority groups may perceive extra burdens:

- They have additional tasks in translating for older persons, who usually do not understand and speak Dutch very well:

- Long-term care is not common in ethnic cultures. Due to the medical system older people continue to live longer in the Netherlands than is the case in their country of origin.
- Older people from ethnic background are less preparing themselves for their older age than native older persons. Parents expect their children to take care of them. They, generally, do not prefer living in residential or nursing homes.
- For children is not easy to say that can only take care of their parents (in-law) to a certain degree. This may be perceived as a lack of respect for their parents.
- What policies should be developed for better integrating these migrants, in particular young people?

Example from the Netherlands:

In the Netherlands, there are a number of projects particularly developed for migrant family carers, such as projects focussed at providing information & advice, support with organising and arranging care, to guide carers through the Dutch social and health care system, and respite care ('granny sitting'). The Dutch Expertise Centre on Informal Care (EIZ) has gathered information about these projects (www.eiz.nl; in Dutch).

Example from Italy:

Several Italian Municipalities, but also some regional authorities, have introduced in the last few years ad hoc programmes for the training and accreditation of migrant care workers. These programmes aimed at reducing illegal forms of undeclared work, provide a better quality of care provided by migrants, and a better integration of their role within the existing health and social care system.

2. A new solidarity between the generations

2.1. Better integration of young people

European objectives have been laid down for the prevention of long-term youth unemployment, combating early school leaving and raising the level of initial training. The structural funds help to attain them at grass roots level.

- What forms of solidarity can be fostered between young people and elderly people?

With regard to this last question, we would like to remark that young carers are still a relatively unrecognised group. Only in a few countries there is research on this topic, but it is shown that young carers face different problems which can hinder them in their further development. For example, children who take care of parents with psychiatric illnesses or an addiction (alcohol, drugs) run higher risks to develop psychological or psychiatric problems themselves. Policy makers need to pay attention to this group. And not only schools, but also general practitioners, voluntary organisations and health and social care need to develop good support services for these young carers. Furthermore, young people could be stimulated to support the elderly (carers) as volunteers, but also young carers within their peer groups: solidarity within and between generations.

2.2. A global approach to the "working life cycle"

In order to foster the transition to a knowledge society, EU policies promote the modernisation of work organisation, the definition of lifelong learning strategies, the quality of the working environment and "active ageing", in particular raising the average retirement age. Demographic changes reinforce the importance of these policies, whilst raising new questions:

- How can the organisation of work be modernised, to take into account the specific needs of each age group?

With regards to the needs of working carers (having caring responsibilities can happen to anyone, at any age) there are several conditions in order to reconcile working and caring life. It is expected that the demand for informal care will rise, but the supply of carers will decline. In addition, governments stimulate (female) labour participation for example by reducing unemployment benefits as well as disability allowances and limiting early pension. This makes it even more important to focus attention on good conditions to combine work and care, such as flexible working hours, care leave arrangements, education and training, participation in pension schemes etc.

What **conditions** do working carers need?

First of all they need flexibility from their employers: in working hours, the option to work from home, the possibility to take a break, and the option to make changes to work responsibilities. Next to that, they may need mentoring and personal support, access to information and advice and they also need understanding from managers.

Employers also have to recognise that caring can happen to anyone; they have to value the experience, awareness and resourcefulness which carers can bring to their organisation. Employers also value the increased productivity and increased loyalty that flexible working brings.

Carers who want to enter the labour market (after a long period of absence on the labour market) need support and measures to enable them to apply for a job, such as accessible training, advocacy services, and fair treatment with application, interview and training.

- How can the various stakeholders in the Union contribute, in particular by way of social dialogue and civil society?

Eurocarers aims to become an important stakeholder in the field of informal care. Eurocarers purpose is to:

- Promote recognition of carers and carers' interests, irrespective of their age or the particular health needs of the person they are caring for;
- Promote the social inclusion of carers;
- Promote the development of services that can support carers;
- Promote the development of employment policies that allow for flexible arrangements enabling people to combine caring responsibilities with paid work;
- Promote adequate social security policies to financially compensate carers;
- Promote collaboration / coordination between formal and informal care.

Eurocarers aims to do this by

- Bringing together organisations representing carers and those involved in research and development;
- Stimulating and supporting the development of carers organisations in countries and regions where these do not exist;
- Supporting carers and their organisations through the collection, exchange and dissemination of information, experience, expertise and good practice;
- Contributing to policy development at regional, national and EU levels, supported wherever possible by evidence-based research;
- Providing opportunities for co-operation on cross-national research, policy and practice, particularly the exchange of information about innovations and best practice;
- Interpreting relevant EU policy developments for member organisations working at national and regional levels;
- Collaborating with other interest and lobbying groups at national and supra-national (EU) levels, including organisations representing disabled people, women's organisations, organisations campaigning against social exclusion and poverty – in order to promote recognition of carers and carers' interests.

2.3. A new place for “elderly people”

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

- Should there be a statutory retirement age, or should flexible, gradual retirement be permitted?

In their fifties and sixties people are facing a higher chance to become a carer for their partner and parent. A flexible retirement age / flexible pensions would enable people to combine work and care.

- 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?

A pension for carers or other income measures (care allowances, benefits etc.) are necessary for those carers who face financial problems caused by their caring responsibilities. Care responsibilities and voluntary work could be reasons for part-time pensions and retirement and formally recognised as such.

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

To help strengthen volunteer work in welfare and care the following activities/conditions are necessary:

- Information, advice and mediation (through the volunteer centre or job bank, which have a greater outreach capability);
- Physical support (space);
- Finance (administration charges, costs for events, grant);
- Collective insurance,
- Policy, related to welfare policy, local health policy and so on;
- Consultation opportunities and promotional activities (presence at meetings, invitation to discussions, space on the municipal web page and in the local newspaper, organisation of events);
- Agreements on sound volunteer policy and management within welfare, voluntary and care organisations;
- Training and support by professional organisations

Some discussion has been sparked off recently on *compulsory measures*, such as compulsory social service by young people, welfare recipients and elderly people. If the people concerned fail to comply, a punitive cut will be made in their social benefits.

On the other hand rewarding people who do voluntary work may also be a solution, through income tax measures or providing small amounts of compensation for volunteering.

Another idea focuses at early pensioners who may be rewarded for voluntary work for older people in need for care and who are living alone.

An alternative way of turning the tide of the limited willingness to perform voluntary care is by building up a sound relationship between, on the one hand, professional care, social work and municipalities and, on the other hand, the carers and volunteers. So far, carers' efforts have been taken for granted. However, the easy assumption that they would do 'their work' has contributed nothing to their willingness to take on the task.

Acknowledgement and appreciation on the one hand and the offer of support and assistance on the other lead to greater satisfaction and motivation on the part of carers (NIZW, Fact sheet Aging and Informal care, 2004).

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

There is a trend that older people move for example to Spain when they reach the retirement age. They leave their social environment to enjoy the better climate. However, when they become dependent, most of them return to their countries of origin. There is little research about the consequences of this kind of migration. More focused studies should be carried out in order to develop a proper set of measures to properly "accompany" this phenomenon.

- How should we be investing in health promotion and prevention so that the people of Europe continue to benefit from longer healthy life expectancy?

By informing older people at an early stage about health care, healthy life styles, problems of informal care and also inform them about the services that are available when necessary, older people are better prepared for the time they will become dependent or have to take care of a relative who is in need for care. Comparative studies in this respect are particularly crucial and needed, since they are able to highlight the best practices and solutions existing in some areas in ways that facilitate their transferability to other areas or groups of people

More information and support for carers would also increase early preventative work that they could do informally and at home. Proper provision for carers, ensuring their health needs are met, would also reduce the numbers of carers who need health provision at a later stage in their lives, due to the pressures of caring.

Example from the Netherlands:

In the Netherlands there are several experiments with periodical consultation for older people (55-85 years). Not only are people tested for heart failure, diabetes, life style, functional ability, but are also asked about quality of life, wellbeing, depression, cognition and burden by informal care. People receive different advices and are followed up whether they actually do something with these advices and whether they are healthier. General practitioners in the Netherlands have too many patients and too little time to carry out these prevention tasks.

Example from Ireland:

- Carers Clinics assess carers needs including establishing their own health status and their ability to continue to care.
- A positive attitude towards maintaining their own health and wellbeing is encouraged including health eating, exercise, relaxation, promotion of health checks and promotion of respite care to address the high levels of stress experienced by Family Carers.

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?

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

Yes, since this distinction is crucial to understand the reasons behind monetary transfers occurring in later age, an information which is necessary to operate appropriate adjustments to existing policies, if needed, including considerations on support measures to be provided to dependent persons and their caregivers.

- 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?
- 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?

Older carers and particularly older female carers are a risk group:

- They frequently provide care alone, without the support of other carers.
- They are less inclined to engage formal help, and will go to great lengths to keep the invalid partner at home, partly because of their wedding vows.
- They often supply more intensive personal care tasks than younger carers.
- It is hard for them to withdraw from caring tasks, because they live in the same house as the care recipient.
- They themselves are more likely to have health problems, especially if their socio-economic status is relatively low.
- For all the above reasons, they are more often at risk of isolation and social exclusion.

The group of older carers therefore demands additional attention and support, especially in the preventive sphere.

Support for carers:

Carers need different kinds of support to continue to provide informal care, categorised into the following themes:

Information, advice and emotional support

Examples:

- Carer support centres provide information and advice about different aspects of caregiving (e.g. on the availability of services, training courses, about financial schemes, technical aids etc.), but they also provide social and emotional support (e.g. through support groups).
- Many patients' or clients' organisations focus not only on patients but also on their carers and are often an important source of information especially about specific diseases.
- Advice service (by telephone or email/website) gives information on many issues. Questions about rules and regulations e.g. on the combination of work and care, financial compensation and the personal budget for care are most frequently asked.
- Advice for working carers. Care Brokers, who help carers in paid employment, obtain the services, allowances and other facilities, which enable them to stay in paid employment.
- Carers' newsletter
- Nurse led Carers Clinic gives one to one advice, information and on-going support in the provision of home care.
- Information about life long learning, re-skilling and rebuilding confidence is invaluable in terms of giving carers social networks and supporting them back to work.
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Practical help

Examples:

- Home Help, help with personal care and nursing care
- Sitting service, twilight and night time care
- Home adaptation, provision of aids and appliances
- Use of ICT and Telecare support systems
- Meals- on-wheels and delivery services
- Handyman services

Material support

Carers can be compensated for the costs of caring through:

- Income tax measures
- Cost of care allowance
- Income support (Carers Allowance, Carers Benefit, Carers Respite Grants)
- care leave
- Insurers (e.g. compensation for respite care)
- Measures by local authorities
- Payment by the care recipient who has opted for a personal budget and can use it to pay his carer a wage.

Advocacy

Carers' association who represent the interests of carers at local, regional and national level (e.g. Carers UK, Caring for Carers Ireland, LOT Xzorg (Dutch carers' association), The Workgroup Home carers in Flanders, Belgium, Aidants in France, The Association of Care Giving Relatives and Friends in Finland (Omaishoitajat), AHR Swedish National Carers Association). Examples:

- Carers' charter
- Carers Forum enables carers to voice their concerns regarding all aspects of care.
- Make submissions to Government departments.
- Host to conferences at local, national and European levels in relation to caring issues.

Respite Care

Respite care can be provided by different formal and/or voluntary organisations. It can be provided at home or in institutions. It can be for as short as a few hours or it can last several weeks.

Vacation/holidays for carers: organisations which arrange holidays for carers and cared for. During these holidays professional and voluntary workers will take over the care

Training and Health Promotion

Training programmes for carers:

- Caring in the Home (e.g. how to lift patients, how to handle with medical technology, how to communicate with the patient and health providers, etc.)
- Basic Life Support
- Healthy Living
- Personal Development
- Back to work and life long learning.

Training programmes empower carers, develop personal skills and increase individual's self-worth.

Social Inclusion

- A national network of Carers Groups has been established
- Community development programmes are designed to include carers.
- Carers Consumer Panels
- Administration of grand aid to improve the security of older people and their carers in their homes.

• **How can new technologies support older people?**

New technologies may support carers. Using telecommunications to carry out more routine tasks, such as running errands through the internet, telebanking services, may provide them with more free time, relieving the "burden" of care. Access to information advice and counselling is also important.

Smart house technology can also improve the quality of life of carers through ensuring careful monitoring of activities and alerting the carer only when necessary, e.g. allowing a carer to sleep secure in the knowledge that they will be woken if the person gets up and needs attention or reassurance. Another possibility may be to consult a nurse by television or web cam.

The increasing medical technology enables more people to stay at home. But we have to look carefully at the potential problems for carers. Who is responsible when something goes wrong? Carers have to be trained in handling the equipment. It may become more difficult to hand over the care to someone else. This may put extra pressure on the carer. New technology should, therefore, not lead to replacement of professional care by informal care.

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?**

The overarching policy challenge that emerges from the examination of the National Action Plans is the need for Member States to ensure that there is a strong integration of economic, employment, lifelong learning, cultural and social policies and that a concern with preventing and eradicating poverty and social exclusion is mainstreamed across all these policy areas. This is essential if an integrated and co-ordinated approach to eradicating poverty and social exclusion is to be achieved.

It is clear that countries that combine high levels of social protection with highly productive economies and continuously high levels of employment are most able to sustain socially inclusive societies. Effective policies in areas such as social protection, lifelong learning, health, housing, transport and culture, sport and recreation that result in accessible services for all are vital. However, for more vulnerable persons such universal provision often needs to be complemented by targeted and tailored supports which will help them to overcome particular barriers to participation in society.

In the first round of the National Plans there tended to be a lack of integration of the social inclusion process with the employment process. There was also little attention given to how Structural Funds can be used to support the implementation of the National Action Plans.

- **How could European coordination of employment and social protection policies better take on board demographic change?**

Carers must be named in policies specifically targeted at their specific needs. Targeting carers is a valuable equality strategy. Caring should be "mainstreamed" by a systematic linking into other relevant public services. What would be involved here is an institutionalised (as direct from ad hoc local arrangements) system of community-oriented services which would constitute a network of support.

- How can demographic change be made an integral part of all the Union's internal and external policies?

The European Union should be promoting exchanges and regular analysis of demographic change and its impact on societies and all the policies concerned. Structural funds could enable European organisations who represent the interest of older people, patients and / or carers to gather, disseminate, exchange, and develop knowledge.

What is needed?:

- The European Union should stimulate exchanging knowledge about informal care, good practices, research between different European countries
- Ensuring balance between generations: by providing good conditions to combine both work and care (meaning care for your children, but also for older parents and other relatives/friends who are in need for care)
- Support advocacy for carers on a European level (e.g. carers' charter, carers' day)
- Promote European (comparative) research about effectiveness of policy measures and services for the support of carers
- Promote and stimulate employment in the care and welfare sector among young people who still have to choose a professional career, to prevent shortage of professional care in the (nearby) future
- Stimulate intergenerational solidarity by community development, housing policy and social services (there will be a need for a different approach of urban and rural areas)
- Extend current attention on employment policies in a way which ensures their development towards a more equilibrated work-care balance, through increased opportunities for a flexible time management by working carers, facilitated access to the labour market for unemployed carers (also in a perspective aiming at seeing work as a respite opportunity) as well as promoting the implementation of services and measures specifically addressing the need of the increasing number of working carers.

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