CARMA – Care for the Aged at Risk of Marginalization (QLK6-CT-2002-03421)

Recommendations and Guidelines to Policy Makers

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1. Enhance the System itself – Paradigm Shift in Caring

1. Introduce universal social rights covering a wide range of care related areas

Whether an individual may use publicly funded care/health/social 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, in long-term care the societal responsibility and public economic liability is less clear.

Different allocation principles are used in different countries and within one country for different types of services. The underlying principle of service allocation defines whether the establishment of a comprehensive care arrangement is possible for certain groups of care recipients. Furthermore, it determines the costs for the users and the amount of care burdens left to informal carers.

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" enables the care dependent elderly to 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 arrangements or family situation. Typically, 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 may be very poor. The orientation towards the living situation and 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.

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. Such an entitlement should not be limited to services meeting basic (physical) needs but follow an holistic view and include social and emotional needs,

too.

2. Extended services for elderly living at home

To be able to take care of an increasing number of elderly in Europe, the capacity of home care must be given priority. This includes that home services must be accessible every day, and also at night. Home living of older care dependent persons can promote coping capacity and diminishes the need for institutionalization.

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.

3. Basic European quality standards

To guarantee a sufficient quality level of the services, it is necessary that the governments prescribe uniform basic scientifically informed quality standards for provider organisations and institutions. It is important that those standards not only contain norms for housing conditions, physical treatment and material equipment. In addition, the psychosocial and spiritual needs must be considered in the assessment of the elderly.

The activities that are deployed in institutions must guarantee the rights of the users/inhabitants and must stimulate social inclusion. In order to realize these basic quality standards every organization and institution must - at least - develop a system of quality management and a kind of quality handbook. Financing by governments will require monitoring of the quality system. Self-evaluation reports and audits are useful tools to reach these quality objectives.

In addition, policy makers are encouraged to develop a central social care register for all care workers in Europe. The register should have a positive aim of establishing a unified quality standard in care and have the same aim as similar registers of nurses and medical professions - with all necessary transparency and the possibility of appeal for the care workers.

The central social care register would prevent care workers who have committed a care related offence entering a new job, without the employer having knowledge of the offence. The register would protect the vulnerable care dependent persons. It could also promote job mobility of care workers within Europe.

Each government should negotiate with the professional representation of care workers to develop a code of conduct, violation would lead to being removed from

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the register of care workers. The procedure would also need to consider de-registration, appeal etc. in order to be fair.

4. Scientific Support for Planning and Monitoring of Policies against Social Exclusion of Older Persons

Researchers should be commissioned to study needs of the elderly considering all aspects of life. A dialogue between scientists and politicians would provide scientific support and valid empirical data to aid social planning. This would lead to evidence based policy, e.g. aggregating data of needs assessments to gain a realistic view on what policy issues have to be dealt with. Furthermore, policy planning also should be based on scientific monitoring of needs and whether or not they are covered by any service.

Following the scientific results local governments will be empowered to develop plans against social exclusion of older persons, and to improve the adequacy of policy measures in terms of meeting real needs.

Researchers should also be encouraged to provide new scientific models to facilitate social inclusion of the elderly, models that go beyond the planning of service provision. This research will very often consist of a scientific analysis of best practice models on an international level.

5. Promotion of social participation

Measures or efforts to support social integration should become an integral part of the care arrangement. According to the findings of the investigation the improvement of mobility with adequate medical aids or transport services form the basis of social participation.

Social integration provides a buffer against feelings of loneliness and depression. Support for social participation should become a part of the regular care package and should be covered by care benefits. However, the measures should also be accessible for elderly who do not receive care benefits yet, because this type of services is also important for less care dependent elderly. Access should not be impeded by high prices or a lack of information on available offers and opportunities, which is often the case.

Different practice oriented strategies to promote social participation of the elderly

should be developed, which enable an adaptation to the situation of the individual elderly, the family and wider network.

A practical example are mobility or transport services which make it easier for the elderly who are still socially integrated to maintain their social network/contacts.

In addition to contacts with family members, friends or neighbours, the elderly often participate in different types of organised activities, e.g. self-help groups, events in the neighbourhood and organised care activities, e.g. day centres. These activities should be further developed and made accessible to the elderly, because they provide a starting point for social integration. However, older persons should not be patronized by these offers for enhanced social participation; provided that they are aware and fully capable they should make their own decisions. Some clients may need more assistance in deciding their social involvement.

For elderly who report a lack of social contacts the involvement in different types of social activities can promote their re-integration.

For the elderly who can not leave their home any longer, visiting services or the support of the use of the internet help to overcome social isolation.

Often friends of care dependent elderly are also disabled, thus transport or mobility services may improve their opportunities to visit their friends confined to bed.

In general, offers to support older persons' social participation should follow a bottom-up approach, taking the older persons' genuine needs as a basic reference and encourage self managed associations and clubs.

6. Efforts to Eliminate the Medicalization of Care

Care dependent elderly have most contacts with medical and paramedical carers. That holds the risk of a one-sided approach, because care dependency is not only a medical problem but a societal responsibility. Medical professions focus on the physical treatment and physical care at the expense of a holistic view of humans, in which also psychological, social, existential and spiritual (also in a non religious sense) dimensions of humankind should be part e.g. of the assessment. Another aspect of one-sidedness is the fact that the carers exclusively focus on the curative dimension of care, and neglect the preventive and salutogenic dimensions.

It is necessary that the psychosocial dimension of care and the attention for the spiritual development are integrated in basic quality standards.

7. Improve cooperation versus isolation and competition

The WP3 case study about "Instructive Deviance – Interaction between users and service providers" has revealed that care systems offering a number of competing providers may contribute significantly to social exclusion of "difficult" clients because they are passed around like hot potatoes. This leads to the following conclusions:

Either care systems are organised in monopolies that have to face effective monitoring and should be controlled by clients' advocates.

Or competing providers are bound by contracts that ensure that their staff has to undergo a fixed number of hours of additional training per year and may have a fixed number of unproductive hours (i.e. sick leave which may increase with the age of staff). This would limit the tendency of private providers to increase hours worked with the client at the expense of further education of the staff (which can actually improve the quality of care of particularly difficult clients). It would also guard against laying off older employees in private services that want to keep personnel costs low (cf. CARMA Del 13, p. 23, p. 31f., 47f.).

Furthermore, there is evidence that competition between care providers can inhibit the exchange of best practice models of care which could improve the situation of the users. National or European awards could be established to honour the most innovative solutions (cf. CARMA Del 11, p. 17) in order to promote sharing of best practice models.

Apart from competition between service providers there is a similar situation between regional authorities in charge of care services; communication and networking between regional authorities and cities concerning care services for older persons needs to be encouraged.

8. Creation of Local Networks among Social Cooperatives and Other Providers

In most welfare system care is provided by public as well as private for or non profit organisations such as social cooperatives. These organisations should be regularly consulted in the planning process by the public authorities since their experience in the daily practice can constitute a valid contribution to both the development and the provision of care services. In addition, a networking effort among these organisations would promote the exchange of best practice among them and promote the quality of services. A best practice example can be seen in the NHS' cooperation with "Engage with Age".

9. Promote access to rehabilitation measures

In all country samples of the WP5 study "Exploration of care arrangement patterns and negotiation of care arrangements" the respondents report about institutional and ambulant rehabilitation measures, which very often successfully improve mobility and the health status in general. 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 insufficiently adapted to the individual situation of the elderly. In some country samples, it is obvious that access to measures requires considerable efforts of the care dependent elderly or their informal carers respectively. Thus, the elderly who are not able to fight for their interests are put at a disadvantage. Here the general practitioner should encourage more disadvantaged elderly to use rehabilitation measures.

Also WP4 "Coping skills and resources of the aged" has found evidence that rather few patients reported to have been using "training-/rehabilitation"- stays within the previous six months, but of those that had been admitted to such treatment, five to eight out of ten considered them as significant for their ability to remain at home. Furthermore, the knowledge about, and the utilization of physiotherapy in their own homes, was very low.

It is striking, that while functional decline is the most important reason for getting care assistance, very little effort seems to be put into enhancing mobility.

It is necessary to increase the use of rehabilitation measures among older persons and to ensure that rehabilitation is seen as a continuous process by the care professionals (except in particular cases where medical conditions only require a limited period of rehabilitation).

10. More psychological support or treatment

The findings of WP5 "Exploration of care arrangement patterns and negotiation of care arrangements" reveal that elderly experience considerable psychological problems, i.e. feeling downhearted or lonely. This applies especially to the elderly living alone and with rare social contacts and elderly with low income carrying a significant economic burden due to the use of professional care services. Efforts to

promote social integration or lower the economic burden caused by the use of services can improve the situation. In addition, psychological support or even treatment is necessary.

As a first step, social and emotional support should become a task in daily care delivery, which requires time as a resource and training of the carers.

As a next step professional support and treatment should be available for the elderly.

The absence of (specialist) treatment of psychogeriatric conditions and the lack of such knowledge is considered to be a prominent problem in European geriatric care, since psychogeriatric conditions undoubtedly have a negative influence on the quality of life both in the patient, and in the network.

Particularly persons with higher care dependency have more psychological problems which need to be addressed in the daily care provision.

In addition, professional psychological support should be available for the informal carers, too. The caring situation may be characterised by conflicts between informal carers and care dependent elderly. An adequate support with professional care services improves the situation. Further, assistance with conflict management is necessary to create a more advantageous situation for the elderly and informal carers.

2. Cultural Change

1. Promotion of a positive view of age in attitudes, beliefs and behaviour

It is necessary that the vision on elderly care is widened. Service providers should use a view of humans which not only considers the physical dimension but also the psychosocial and spiritual dimensions. At the moment the curative aspects of care are predominant. Less attention is given to prevention and almost none to the salutogenic aspect or the promotion of health. Curative care is oriented towards the negative dimensions of old age, the loss of competencies and skills. By promoting the salutogenic dimension, we stress the opportunities for development. Older people can compensate the losses of physical abilities by investing in the inner, spiritual (not necessarily religious) development: intellectual, moral, artistic, and social gains are possible by accumulating and sharing experience. In this case the physical-material decline on the one hand is at the same time outweighed by a psychic and spiritual rise on the other hand.

It is also very important that the elderly learn to handle losses and finiteness. Too often, these experiences are stashed away by the old people themselves and by the carers.

Many experts stress that there is a need for becoming conscious of a constructive way of getting older. For too many older persons old age is associated with a feeling of aimlessness and the absence of a perspective for the future. They miss a view of man in which old age offers a fruitful perspective on life. There is a need for information and training about that topic. The development of such a constructive approach to old age is the responsibility of both the government, organisations and institutions for the elderly. Awareness raising may be enhanced by media campaigns.

Further, support and stimulation of the autonomy of older persons must be an important objective of each interaction with them. The experience to be independent/self-supportive gives the elderly a sense of identity and self esteem.

The promotion of autonomy may of course not be abused as a justification for neglect which is caused by a lack of time, space, professionalism or respect, because this might put the old person at risks and undermine his/her self-respect. In

practice such neglect could affect old people with early stage dementia who forget to eat and who need special attention; in this particular case promoting the person's autonomy requires a sensitive approach as to ignore the situation would be irresponsible.

Too few institutions pay explicit attention to the autonomy of their inhabitants. Seldom do they take actions to re-activate people who became passive due to a disease.

The main reason for this neglect of self-support is the education of the caregivers. The education of carers and nurses stress the helplessness of the patient on the one side and the helping attitude of the carer on the other side. Implicitly they stimulate patronization of the elderly. The education also stresses the physical care and neglects the psychological dimension.

Some logics of the care system also enhance the care dependency of the elderly because institutions get more subsidies with rising level of care dependency of users/inhabitants. This can be counter-productive for the promotion of autonomy.

2. A Change of attitudes on care for elderly

A new understanding of the interplay between medical, social and psychological needs of older care dependent persons is important. This implies a change of attitudes: Care in general and particularly geriatric care is BOTH medical care AND social/human care. A holistic view of care will counteract the tendency of "medicalizing" the care of elderly.

3. A Change on the Political Level

Social Policy for questions on ageing has to act in a threefold way: solve existing problems of social exclusion of older persons, prevent social exclusion, and promote positive contributions of civil society supporting social inclusion of older persons. All responsible agents should bear in mind that the older population is not a homogenous social group.

This requires serious efforts for valid national plans on social inclusion, as well as a policy preventing risks of social exclusion. On the local level efforts for social inclusion will require a more active view on old age: e.g. by more public funding for associations of older persons that may later become mutual help associations. In this

context it has to be stressed that such activities of civil society are not to be understood as a substitute for professional services but in close collaboration and integration. A practical example for these activities is where volunteers exchange help in organisations. The emphasis of public funding of such associations, however, should be put on the leisure aspect as an end in itself instead of demanding yet another contribution of the older persons.

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3. Assessment Procedures

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1. Improve the procedure of the assessments of needs

Since the 1990s assessment procedures have been introduced to secure a fair and equal access to care benefits. The establishment of a formalised assessment procedure linked to strict eligibility criteria forms a decisive step towards fair access to social care services. In some countries, however, the introduction of assessment procedures has been used to introduce a stricter targeting of services and some of the elderly with minor needs even have been left without any support, which causes problems especially for the elderly with a low or medium income.

The findings show that assessments which are done in close contact between the care dependent elderly/informal carers and a care manager are most efficient. If the assessment procedure requires an application of the care dependent, this gives the elderly or informal carers an opportunity for initiative in their own interest. Thus it opens up the system for individual applications and complaints, but it also requires a lot of competences. Here the professionals, e.g. general practitioner, case manager, social workers, are important supporters of the care dependent elderly or informal carers. The findings show how important it is that they encourage the writing of an application, they help with the application/write it on their own or write certificates. This should become an important and acknowledged task of these professional groups. Otherwise there is a risk to some social groups who are unable to apply on their own.

Criticism was voiced by care dependent and/or their informal carers in the WP5 study "Exploration of care arrangement patterns and negotiation of care arrangements" about assessment procedures. In case of a rejection of the application the decision is often regarded as unfair. Especially the lack of competence of the assessors was pointed out, who often are not able to assess care needs which are not directly related to the performance of daily activities. Furthermore, the individual decisions are often regarded as inconsistent, i.e. the same level of need is assessed very differently.

Literature research revealed that the level of need is decisive for the inconsistency of the assessments. While high levels of needs are assessed more consistently, there are marked variations in the same cases for elderly people with low and moderate

needs. The definition of more clear criteria and better trained assessors can improve the quality of assessments. This reveals a necessity to improve the training and education of the assessors.

In addition, the emphasis on the performance of daily activities is also related to the care (insurance) laws with their orientation towards daily activities. Further, the regulations should be changed to include social needs and more caring activities, such as the need for a sitting service.

In the daily practice of the assessments, a difficult balance emerges between formally defined procedures and day-to-day flexibility to respond to individual needs. However, as a general rule assessments have to ensure fairness of distribution of resources, and they must be transparent to users as well as additional assessors who might be involved to get a second opinion (see also chapter 5, recommendation 2).

In practice, improved assessments will be based on a combination of validated objective criteria and <u>interactive</u> methods that take into consideration the opinion of the user. This requires the development of new instruments to assess social and cultural as well as psychological conditions and the family setting.

Not only the needs of the clients should be assessed but also the clients' quality of life, because this may enable the service provider to prioritize the various care tasks. In addition, the assessment of quality of life will enhance the general validity of the assessment of needs and will reveal whether a need acknowledged by the assessor is necessarily a central need of the user.

When developing improved assessments it should be kept in mind that not just deficits and needs should be observed but also capabilities, and the potential for rehabilitation. This would encourage independence of the users and at the same time help prevent risks. The capacities and willingness of informal carers should explicitly be considered in the assessment.

The medical assessment needs to consider both the problems that can be cured and the problems that require care. For this, geriatric competence is needed.

2. Improve the assessment of psychological health conditions

The connection between ageing, diminished functional capacity and/or diminished

social relationships and various psychological disorders is well analysed. The WP4 study "Coping skills and resources of the aged" revealed that factors like "life satisfaction/quality of life" and psychological conditions influenced the need for institutionalization. Commonly, psychological health is poorly examined and documented in the community health care. While physical conditions appear as an obvious reason for care assistance, psychological conditions are frequently ignored, and this either becomes a source of isolation/marginalization or may be ignored as a reason for care assistance with regard to prevention and empowerment.

3. Improve the assessment of social and cultural conditions

Most of the persons included in the WP4 study "Coping skills and resources of the aged" were frequently meeting with family members or neighbours and friends. The amount and the quality of the collaboration with these social sources have shown to influence the perception of social support. Furthermore, having (a) close friend(s) has shown to be of special importance for good psychological health. This implies that assessing detailed knowledge about the frequency and quality ("social support") of social relations – also resulting from preventive measures such as day centres - is imperative.

In addition, an increasing migrant population calls for the consideration of cultural needs that may be specific to migrants and ethnic minorities such as e.g. particular religious diets etc.

4. Improve the assessment of family network conditions

A large proportion of the respondents in the WP4 study "Coping skills and resources of the aged" were clearly dependent on persons in the family. Although the family in many cases is the main source of assistance, in general little documentation has been gathered a) on the content and extent of this work, b) on the quality of the collaboration, and c) on the social/emotional and health condition of the relatives involved in care.

Since the informal network clearly is one of the main coping resources, more knowledge about these conditions is required.

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4. Integration of care & case management

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1. Improve the integration of services

The integration of services has become a major topic in the debate on the further development of home-based and health care services in general. Further, the establishment of the variety of services and facilities poses the question how the collaboration between the institutions can be improved.

One approach is the establishment of centres or care co-ordinators, which offer home-based, semi-residential and residential care. In addition, the emphasis on care provision within the client's home particularly in case of severe care dependency requires a 24 hours service and close cooperation between health care, specialised and basic nursing care, home help, social services etc. Integration efforts are impeded by the process of privatisation, which leads to an even more fragmented care infrastructure.

The development of integrated care systems is a process where institutional structures, forms of co-operation, social relationships as well as status and power and the income relations of different professional groups are involved. In consequence, processes of integration cannot simply be planned and implemented, but demand time and opportunity to develop new forms of co-operation in the day-to-day activities. In most countries, however, there is a lack of time and space for experiments and for the development of new forms of co-operation.

Furthermore, the integration should be done under the premise of a social model, i.e. including the assistance with social activities or home help. However, cross-country comparisons reveal the retraction of many low-level services, such as assistance with housekeeping or leisure/social activities and thus the loss of their preventive potential.

As a general rule, the integration of care should follow a client centred approach, where the client's complex needs are the final goal of integration.

From the perspective of the practitioner this means that there is a need for improved interdisciplinary collaboration, flexibility and "multidimensional working" within geriatric care, especially in difficult and complex cases, care workers often have a need to combine various professions. It is imperative to tear down the existing barriers between medical specialists/hospitals, community health care, informal

carers/family and the patient. Flexibility of the service, i.e. more flexible structures able to suit (and adapt to) the single cases is a central requirement in community care.

On the practical level it has also often been observed that when many parties are involved in care provision confusion may occur about responsibilities. Thus, care tasks have to be correctly and reliably defined and assigned, otherwise no one of the involved professionals feels responsible. This division of work needs to be monitored by e.g. the case manager.

2. Integration on a regional level

The devolution of the executive power and responsibility to the municipalities or regions in some countries is aimed at integrating services and adapting the care services to the individual needs and to the risk structure in the local area. Despite the advantages, this emphasis on local level responsibility in the co-ordination and the planning of care raises the question of equity and citizenship, i.e. the issue of regional inequality. In addition, national frameworks should be constructed, which guarantee equal access to services within one country across different regions and which can at the same time be combined with opportunities for decision-making at the local level.

The integration at a regional level sometimes calls for cooperation within government bodies of one country in order to eliminate bureaucratic hurdles for care dependent persons. Many bureaucracies seem to be completely unaware of the necessity to support vulnerable people such as care dependent older people, e.g. when clients are required to negotiate with local authorities to get refunds for services they have consumed in a different operating area this clearly asks too much of a vulnerable person. Co-payment schemes have to consider that clients living outside the operation area should not be at a disadvantage, communities and authorities have to agree on reimbursements instead of making clients fight with authorities. After all, the regulation of operating areas is an invention of the policy system and not a natural boundary, thus the political system is responsible for the elimination of this obstacle when it prevents social integration of vulnerable people (cf. CARMA Del 13, p. 24).

It is necessary to systematize the cooperation between local government networks, social cooperatives and non profit organisations involved in the provision of care.

3. Co-ordination of informal and formal carers

The informal carer is a very important partner within the care process. However, because of the professional training of formal care workers, many of them only learn about the needs of a care dependent person and tend to neglect the experience and competence of the informal carers. Therefore, the formal caregiver has to learn to take into account the entire care system. In some countries, respite care opportunities for informal carers should be extended, because they enable them to take some time off and therefore have some more time for themselves.

A practical measure for the integration of informal and formal care is a round table combining all carers involved: this would help to exchange information, negotiate and assign the different tasks and thus promote integration of informal and professional care.

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 (cf. CARMA Del 13, p. 18-21).

5. Information and Empowerment

1. Information

Western societies of today are knowledge based. An increasing number of services and information is now provided through new 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 any additional costs. Many older people are overwhelmed with the task of finding the appropriate care arrangement. At the moment the responsibility for getting information lies with the user but it should rather be the system's duty to provide the information.

Research in CARMA revealed that many times the elderly lacked the right information of what they could expect from the service providers, leading to wrong expectations and frictions. It is clear that good communication is necessary, and that providing information in itself is not enough.

It is important to distinguish between various types and particularly purposes of information: There is on the one hand basic general information about what benefits and services are available and who is in charge. This base needs to be spread widely in order to empower older people.

Various channels should be used to spread information about care, benefits and activating social activities for the elderly. People should e.g. receive at 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. Most service providers have clear pamphlets, and sometimes a website but these appear to be insufficient. The target group is often not able to find the right information. Due to time pressure and workload, the care workers often do not have the time to explain the information and to talk about it with the elderly.

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).

The accessibility of information is often a problem for the elderly. The information most of the time is very dispersed in offices that do not co-operate. There is mostly no overview of the whole range of help that is offered by many parties. The information is provided at different places that use different terminology for the same service.

A solution could be a central office where the elderly can gather the information about all possible services at first hand. Those central offices must of course co-ordinate the information and refer the elderly to specific service providers. It is also very important that there is also a place where the older person can tell her/his story and where he can find help to elaborate and clarify her/his questions and problems. Often the initial question conceals further questions. Therefore, it is necessary that such offices have a low threshold.

In general, there is a need of a care co-ordinator, an expert in elderly affairs, who co-ordinates the care process and who also monitors the problem at large. Every aspect of the situation of the elderly must receive attention.

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.

Too often care workers suppose that the older people 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 of personal development namely about the positive dimensions of old age. For all these reasons there is a need for training in constructive communication between carers and the elderly.

2. Empowerment

The support and stimulation of autonomy must be important objectives of every involvement with older people. Autonomy can be supported by offering and developing a broad range of housing situations.

An important dimension of autonomy is the right of self-determination, the right to make one's own choices. Too often, really important decisions are made without the consent of the person affected by them; often they are not even informed. It is therefore necessary that the elderly get accurate information about the practical and financial consequences of their choices.

The social and health care areas are key agencies in the construction of dependency of older people. Empowerment and grassroots pressure from service users and informal carers is needed in these areas. Integration of service users in the decision-making process of these institutions should be established in order to build up a greater choice and participation voice. Older people should have the chance to participate more actively in decisions affecting them and their care arrangements. There may be a need to teach the older clients to participate in the decisions that concern themselves. (An example of best practice is Sydenham Court in the South and East Belfast Health and Social Services Trust.) Besides that, a kind of mediation at the beginning of the care process and also during the process can assist the elderly to make the right choices.

A culture of empowerment and an encouragement of professionals to operate in a more participative way is needed at all levels. Service providers should actively create an atmosphere where critical feedback by the user is encouraged, regarded as acceptable and even welcome. Too often older persons are too timid to raise their voices towards the care workers or the provider organisations.

Patient organisations or the individual care receiver should get rights to influence policy approaches and service providers. The establishment of ombudsman offices for care service users could be a first step in this direction. Health and social care service providers should encourage regular meetings of their users.

Governments should also encourage older citizens' activities to form associations and representations that can speak out for the elderly. The current seniors' organisations represent only part of the relevant population and it should be kept in mind that these organisations need to be complemented continuously by interest

groups and lobbies in a society that becomes more and more diverse and pluralized (cf. CARMA Del 1, p. 13, 30; Del 3, p. 7; Del 4, p. 34; Del 13, p. 20f. and p.48).

In practice empowerment can be achieved by:

(1) Active involvement of the care dependent in the development of the care arrangement and an understanding of the care provision as an interactive process where the professionals are actively seeking feedback from the client.

(2) A mandatory right to appeal against crucial decisions such as assessments:

Our study has shown that assessment procedures are decisive for access to care services and that the personnel performing these assessments have almost no sensitivity for the potentially excluding effects of their judgement. The welfare state entrusts vulnerable persons with generally little abilities to fight for their rights to a group of social workers and head nurses, who in the worst case only see their assessment criteria but never question the impact their decisions may have on the social integration of the older person.

Assessment criteria are currently dominated by medical and care needs and almost completely ignore social, emotional and psychological needs. Nevertheless psychological needs cause feelings of loneliness and a sense of marginalization, it is essential therefore, that these needs are not ignored. An emphasis on medical needs can undermine the holistic approach of social integration which will consider social needs to the same extent as health needs.

The care system needs to become more aware of the violation of citizen rights that may occur in the process of allocating scarce resources of care, and the individual assessors must be trained to empower older persons and encourage their dissent when they feel treated unjustly.

In addition, from a scientific point of view the validity of the assessment procedures is an important objective. Service providers mostly use their own procedures where validity and reliability are not evaluated. A formalised ombudsman or clients' advocate should be established who monitors the quality of assessments and care provision in the interest of older care dependent citizens. The institution of care ombudsmen is a rather recent achievement in many countries and in most cases they are in charge of institutional care only; however, this means that they ignore the problems of the majority of care dependent older persons (cf. CARMA Del 13, p. 20f and p. 28).

3. Public Responsibility to monitor informal care

Particularly in family based systems (e.g. Austria, Germany, Italy) where the majority of home based care is exclusively provided by informal carers, it is necessary that the public authorities observe their responsibility to monitor informal care.

If ageing is seen as a risk that affects each and every citizen we may not close our eyes in front of the risks some older persons have to face when they depend on their families. Therefore social policy has to develop measures to preserve the individual rights of older persons and defend them instead of entrusting them to the families.

Informal carers need to be supported with professional services, counselling and training to prevent abusive practice, which might range from using cash benefits to supplement family income to severe physical or emotional abuse of the care dependent.

It is irresponsible for the welfare state to burden families with the care of their elders and not offer relief and supervision. If care standards should be a valid criterion, they may not just be applied to professional and institutional care, but also to informal care. Of course, this touches a taboo area of social policy, because it seems to be consensus that the state ought not to interfere in families. However, in the interest of vulnerable individuals this seems to be legitimate (cf. CARMA Del 13, p.18, 22f.).

The practice of the German long term care insurance to monitor informal carers who use the cash benefits instead of the benefits in kind (i.e. the professional services) could serve as a model here.

Further, societal awareness must be created to prevent abuse of older care dependent persons.

Another best practice example was found in Northern Ireland where teams of specialist social workers investigate incidents of elder abuse. The teams also provide long term support and monitoring and work closely with service providers (cf. CARMA Del 8, p. 41).

6. Financial Aspects of the Care System

1. Improve the economic conditions of the pensioners

The economic conditions of pensioners studied in WP4 "Coping skills and resources of the aged" varied in the different welfare state models. Although basic needs seem to be supported, the ability to "buy something extra" enhances freedom of action. Especially, if lack of economic resources inhibits the ability to participate in social relations/hobbies/leisure time activities, or even in public services, this could cause marginalization. Consequently, first and foremost every European citizen should have the right to receive a minimum pension/basic level of income which guarantees a decent life. A measure to define these minimum pensions should be found by experts in this field. Apart from this minimum level of income, it is necessary to facilitate the access to retirement pensions in insurance systems.

Guaranteeing a decent minimum income will positively affect the proper use of further benefits related to care dependency; our research shows that cash benefits related to care are abused to increase the household income of poorer people instead of helping them to pay for expenses related to care.

2. Access to affordable services

The access to affordable services with the principle of universalism has proved to be a basic criterion for inclusive care.

Since the 1990s the way and range of funding of long-term care have undergone significant changes in most western European countries. In some continental European countries separate tax, or insurance based systems have been introduced to finance long term care. Especially in the Northern countries the already existing funding systems have been re-regulated. In addition, in all countries collective and individual economic responsibilities for different types of care have become re-defined.

Despite an improved collective funding, especially in continental European countries, the level and way of funding left gaps which cause obstacles for service use due to high user costs. In general, services related to specialised or basic nursing care are more often collectively covered than household services or social services. The neglect of social services aimed at supporting the elderly with social or leisure

activities impedes the social participation of care dependent elderly people. In order to promote social participation these services should be covered by systems of collective funding. The same applies to housing benefits for sheltered housing.

Furthermore, the adaptation of the prices of the services to the income situation of the elderly, which is currently not the case in every country, provides a further necessary step for the establishment of a comprehensive care arrangement for the elderly with a medium or lower income.

The costs of services that are not covered by care allowances or the care insurance can be so high that some groups of care dependent elderly cannot afford certain services and run the risk of marginalization.

High costs are not only an obstacle for service use, but lead to considerable psychological problems when the use of services is inevitable and the users are in a bad economic situation. Thus, the consequences of care provision at an adequate price are twofold especially for the members of the lower socio-economic classes. It enables them to use the necessary professional care services and thus to unburden the informal carers and it prevents the development of considerable psychological impairments, e.g. depression.

Offering the services free of charge could prevent marginalization (cf. CARMA Del 3, p. 6; Del 10, p. 47; Del 13, p. 21f. and 46f.; Del 16, p. 96; Del 17, p.10ff.). With regard to budgetary constraints it may be necessary to find a compromise, which would mean that at least benefits are being raised for some groups or that the costs for services are adapted to the individual situation of the users.

A practical recommendation based on research findings of WP5 "Exploration of care arrangement patterns and negotiation of care arrangements" could provide a solution: The findings indicate that a mixture between different types of financing of services seems to be adequate. Firstly, the costs should be related to the individual income of the care receivers. This also enables the members of lower socio-economic classes to use services and unburden the informal carers.

Furthermore, there should be an income threshold below which the elderly should not pay for services, medical aids etc. at all. However, one has to be aware that such means tested benefits may be putting better educated persons at advantage to access them. In addition, means tested benefits may be stigmatizing the recipients.

All costs should be adapted to the increasing level of care needs, either by an increase of care benefits or a reduction of costs of the services. This can also be

achieved by maximum bills, e.g. a system which only allows charging a certain percentage of the income for care services regardless of the number of hours of service.

3. Increase number of personnel

The macro level of social policy makers who have the power to create the structures, within which care can be delivered, will have to provide higher budgets for more personnel. A study of the demand and an inventory of the offer of the organizations could reveal where the deficits in the system are. It is clear that both residential and home care suffer from a shortage of staff. However, it is the most pressing problem which lays the foundation for qualified care and thus better chances for a maximum of social integration. Certainly personnel resources have to be applied in an efficient manner, but reorganisation of the service process will not release a sufficient number of staff to cover the needs. Waiting lists and maxima of service hours are signs of a malfunctioning social policy that has lost touch with the noble goal of well-being for all citizens who need help. Older people are often obliged to go to an institution because there is no one to take care of them (cf. CARMA Del 13, p. 19, p. 21).

4. Benefits in kind or adequate cash benefits where use is monitored

Cash payments may encourage the provision of care in an informal setting, which may result in an insecure labour-market situation of the privately paid helpers and an insecure care situation without any quality control for the care receivers. Research shows that employing friends or family members may lead to vulnerability on both sides. It is difficult to distinguish between paid work and unpaid support where paid carers feel obliged to work beyond the working contract. The empowerment of the care user, the right to hire and fire, leaves the care giver in a dependent situation. However, due to the often limited amount of money, the freedom of choice of the care receivers is limited and they often depend on family members ready to carry out the caring tasks for a symbolic payment only.

Benefits in cash may also create incentives to black market care work with all its consequences (precarious working conditions for migrant care workers, insecurity of the clients receiving care, unclear educational and quality standards).

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.

If cash benefits are to be a meaningful solution two preconditions should be fulfilled: The benefits should enable payment at regular prices for care work and this should be monitored in order to control the situation of the carers and the quality of care work.

In general, however, it would be preferable to substitute systems of cash benefits by benefits in kind: this would create new jobs and offer 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 employment 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 continuously assess the client's situation and help him/her get the support needed (cf. CARMA Del 4, p. 34; Del 13, p.18, 22f. incl. footnote 8, and 46f.; Prelim. Report WP5 Interview Analysis, p. 148).

7. Support of Informal Carers (family, neighbours, friends)

1. 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 promotes family help. In addition, in a more service-oriented system fewer 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 informal 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.

2. Support of informal carers

The findings in WP5 "Exploration of care arrangement patterns and negotiation of care arrangements" 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 results: An adequate relief can be provided either by the use of professional service at all levels of care dependency or by a combined 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 also support of the assistance provided by 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 daily assistance for those 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 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.

In spite of this positive development obstacles can be revealed which necessitates further efforts. The opportunity to have 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 needs of the individual carer as well as the criticism by informal carers on the quality of the 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 replaces them in their care responsibility is necessary.

- *Insurance covering accidents*

A statutory right for an insurance which covers accidents by 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 work-place. Especially adaptations of working-time arrangements are necessary, such as flexible working time, free hours to accompany the care dependent elderly to a medical doctor etc., a reduction of working-hours or even an employment break. To secure such arrangements/regulations laws are necessary which 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 older people and other 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 round table 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.

- *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 on 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).

3. 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 with the neighbours and friends even before the outset 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 move 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.

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8. Provider Policy

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1. Complaint Management and Feedback

"Every complaint is a present/gift for us!" is the slogan of the manager of a service provider. Too often, a complaint is interpreted negatively, as something typical for difficult, ungrateful people. On the contrary, complaints can also be seen as opportunities to ameliorate the quality of the care (in terms of quality management).

Our research made clear that conflicts are often the consequence of unclear arrangements between service provider and carer on the one hand and the dependent person and the family on the other hand. Open and constructive communication is necessary to make use of conflicts as an opportunity to save the relationships and to avoid marginalization. To avoid conflicts clear and written agreements between provider and care dependent need to be developed and made clear to the elderly, whose consent is necessary.

Apart from critical feedback which may be captured in standardized complaint procedures, positive feedback should also be shared and considered in quality management.

2. Fluctuation of Staff

Many cases of friction are obviously caused by the providers' policy of moving staff above the extent necessary for compliance with employment laws etc. Providers have to develop more sensitivity for the delicacy of the care relationship, not just the invasion of personal territories and privacy but also the practical consequences of ever changing staff that has to get familiar with the whereabouts of a household and locate items needed within a household.

To a certain extent rotation of staff in challenging settings may prevent burnout. However, better training of staff will reduce the need to increase fluctuation.

To some extent we got the impression that management even strives to establish the customer relation in a way where they can exchange their staff arbitrarily, because this diminishes the power of the single employee in the work relation. Yet, care dependent elderly and their informal carers report the wish of stability in staff to build up a confidential relationship and to avoid unnecessary stress with changing employees.

If we interpret the protest of clients against fluctuation of staff as an expression of loyalty, penalising this loyalty will deprive the provider of the most quality sensitive clients in the end. After all we may interpret this demand to have a minimum number of care workers as a demand for integrated care, and since care as a profession is a rather young phenomenon and is mostly provided informally, it seems almost natural that clients have little understanding for strict regulations dividing care into different work tasks (cf. CARMA Del 13, p. 17, 48f.; Del 14, p. 24, 33).

3. Encouragement of Providers to include Volunteer Work

Volunteers can be of great value in the support of elderly at risk of marginalization. They have the time and the motivation to identify and contact peers who are at risk of social isolation. They can explore their neighbourhood looking for old people who need contact and support. Volunteers can be a channel of information, they can provide social contact, and can help with minor tasks.

There is a need for a global policy of volunteer work. Governments can develop a blueprint for volunteers that can be customized and implemented on the local level.

Providers should be encouraged to include volunteer work; however, this calls for a clear definition of the roles of volunteers and professional care givers. There is a need for tools for the recruitment, training and coaching of volunteers. Professional assistance for the volunteers is essential to recognize – appreciate the volunteers' contribution – and monitor the quality of the volunteer work.

4. Experts should be included in the team providing care

In meeting the daily psychosocial needs of the elderly, there is often no need for experts. The common aspects of the ageing process require the attention of every caregiver and can in general be covered by the basic competencies of the care givers. Even volunteers can do a very good job.

However, highly complex care tasks are the responsibility of experts such as a psychologist. Situations where experts are needed are:

• pathological phenomena such as depression or losses people cannot cope with;

• the coaching of teams of carers;

• education of carers in specific subjects; e.g. constructive communication, psychogerontological subjects;

• specialized diagnosis.

Most single providers cannot afford a full time expert, but providers could develop a network of providers and institutions that share an expert who commutes between them.

9. Service Diversity and New Services

1. 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, however difficulties exist concerning their 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 into 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 avoid institutionalisation (cf. CARMA 2, p. 31; Del 3, p. 6; Del 4, p. 33; Del 16, p. 11 and 69; Del 17, p. 18ff.).

2. 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 them 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 seems 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 requires considerable efforts of the care dependent elderly or their informal carers respectively. Thus, the elderly who are not able to fight for their interests are put at a disadvantage. Here the general practitioner should encourage more disadvantaged elderly to use rehabilitation measures. Also mobile physiotherapist/occupational therapist services must be offered and funded.

3. Adaptation of services to specific cultural needs

At the moment the population of older people in the different countries is relatively homogeneous, but an increase in the migrant population among the 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.

4. Some examples for new/improved services to be established:

4.1 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).

4.2 Organised activities, self-help groups, day centres

Organised activities proved to be important for both the social integration of care dependent elderly and for 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 changes 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 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. The elderly sometimes describe the groups as not welcoming to new members. Care dependency is reported as an obstacle, particularly for the elderly with mobility problems who often feel excluded from activities.

4.3 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 and social networks; also they display a higher level of health risk. There is a need to establish clubs, day centres and services that are specifically addressing older men (cf. CARMA Del 1, p. 32, 42). We found evidence in our research that elderly people 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 to help 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.

4.4 Use of traditional services for innovative aims

Sometimes a traditional model of care can be reinvented for a new generation of older people. Sydenham Court (of SEBT in Northern Ireland) could be an example for a best practice model where a traditional sheltered housing model was adapted in a newly built facility 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.

4.5 Support more severe care dependent elderly by a professional care manager/ care coordinator

The findings in CARMA reveal the necessity of an individual care manager with an increasing provision of support 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 cases of severe care dependency should be offered to the care dependent elderly and their informal carers to secure an adequate care arrangement. 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 WP5 "Exploration of care arrangement patterns and negotiation of care arrangements" shows, insecurity about the future development of care dependency and care resources causes considerable psychological strain for the elderly and the informal carers.

4.6 Information to establish appropriate care arrangements

Western societies of today are knowledge based. An increasing number of services

and information is now provided through new 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 any 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 receive at 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 people 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).

4.7 Counselling for Family Care Arrangements

Since in the family based care systems informal carers report they are often 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 on 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).

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10. Physical Environment:

Contribution from Domotics[1] and assistive technology

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1. Extend the supply of "handyman"-functions and technical aids

As research in CARMA showed, living in their own home was clearly the most prominent choice of the vast majority of the care dependent respondents, even if their health condition had deteriorated. Older people are often obliged to go to an institution because their physical environment is limiting their mobility. For those who want to stay in their home, support is necessary. Sometimes minor adjustments of the house can help keep older persons at home.

In the WP5 study "Exploration of care arrangement patterns and negotiation of care arrangements" the respondents of all country samples report difficulties with their physical environment, i.e. to move freely around the flat, to leave it as well as with mobility outside. Most efforts are undertaken to promote free movement within the flat. The findings show that programmes within this area should be diversified and support different types of solutions adapted to the individual living/housing situation, i.e. adaptations of the house/flat, to move within the house downstairs including the necessary housing adaptations, the use of medical aids and if necessary the provision of personal help.

Efforts to make it easier for the care dependent elderly to leave the flat are often a neglected area. Here programs should be developed to adapt the surroundings of the house/the flat to the needs of the elderly, e.g. ramps, hand rails, stair lifts. Further, the elderly should get more support and information, when they apply to their landlords etc. Rather simple home adaptations can sometimes significantly improve the quality of life of a care dependent, but are not very well known. Compass' free Apartment Adaptation Advisory Service could be a best practice model here; that is an occupational therapy project for care workers who cannot perform care tasks any more due to e.g. back conditions, and who counsel older persons in their private homes with adaptation of living arrangements and use of medical aids.

Many elderly at risk of marginalization cannot afford those adjustments. Financial

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1-Domotics is applied information and communication technologies for more comfort and convenience in and around the home (www.domotics.com).

support from the government for the adaptation of the housing conditions can be sufficient to maintain their autonomy.

Public buildings that are not built accessibly constitute an obstacle for older people with physical impairments. This can affect the autonomy and social participation of older people (cf. CARMA Del 1, p. 15).

2. Training of Architects, Engineers and Designers

Some architects/engineers/urban planning experts do not have sufficient knowledge about the needs of those who are care dependent, because this is not included in their curriculum. Training for architects, engineers, and designers should be enhanced in order to increase their expertise about the special needs of people with disabilities and of older people. Also, explicitly considering the needs of persons with impaired mobility should put architects at an advantage when bidding for a public project.

3. Impact assessment

The impact of the design and layout of public buildings and of urban planning (particularly infrastructure) on the older population with limitations in mobility etc. should be studied, analogous to the ecological impact assessment of large projects. The requirement to consider the impact of buildings and urban planning on older people should be established on a European level. In the future criteria may be developed to measure planning and design that affects the environment of older people in their daily life.

4. Promotion of assistive technology

The role of assistive technology and the relevance of its availability has been shown by the comparative study in CARMA – care systems offering medical aids and equipment free lower the barrier to autonomous living in 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; Del 16, p.17).

Difficulties can be shown with regard to counselling services. The elderly often do not have sufficient information about available types of medical aids and how they can

get access to them.

Access is often achieved through the professional system, e.g. after hospital discharge or by professional carers. Elderly people who are not connected to the professional systems, risk not receiving adequate medical aids. Here the general practitioner could take on an important role. They should make referrals to a special counselling service, to technical aid centres, or care services as needed. The establishment of such technical aid centres as in Norway or Italy is recommended.

In the future care providers and educators will have to advise and assist with the use of medical aids, assistive technology and housing adaptations to a larger extent than today. In our research in WP3 "Instructive Deviance – Interaction between users and service providers" we have seen too many cases were 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 contribute to occupational health (cf. CARMA Del 13, p. 18, 19).

Special research and design centres which offer customized solutions for the care dependent – adapting available technical aids to the individual needs – should be promoted and should be encouraged to network with care providers, occupational therapists etc. in order to make contact with older people who could benefit from their service.

5. Accessible public transport and transport services

Older people who live in areas without adequate accessible public transport services are at high risk of marginalization because they are denied access to education, friends or reasonably priced products, etc. Accessible public transport and affordable and flexible transport services that form a part of the regular care package are needed to guarantee social inclusion of elderly people.

The care providers should enlarge the supply of mobility and transport services and integrate them with their offer of home-based care and day centres in order to facilitate elderly´s participation in the social life of their communities. Buses or underground should be adapted to their needs, e.g. by elevators. A well developed

infrastructure of shops, public transport and additional mobility services make it possible for the elderly to carry out daily activities independently, e.g. shopping and participation in social life (cf. CARMA Del 1, p. 13, 15, WP 5).

6. New indicators for CSR - corporate social responsibility

We have seen that the exclusion factor 'poor infrastructure and remoteness' is actually a result of budget cuts in the public transport or mail services which leads to closing of post offices and other necessary public facilities. Citizens have to compensate for these cuts in the provision of public services with their private income – they buy cars and have to accept longer journeys for various errands. However, when they become care dependent and are not able to compensate for the lack of public services with their private means any more, they may be offered publicly subsidised services to overcome the shortages. All of these cases ought to be documented and be published, e.g. in a balance of the companies that declares the social accountability. According to the originator principle the transport companies and mail services etc. should have to reimburse the social services for their efforts - to establish real transparency of costs. Otherwise the losses are carried by the social budgets that are constrained anyway and the gains stay with the infrastructure service companies (cf. CARMA Del 13, p. 24, 25). This measure should at last also increase budgets for social services.

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11. Training of Care Personnel

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1. 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 basic educational standards and curricula should be developed in all European countries which would also enhance mobility of employees and combat black market and low quality care. A European quality certificate (cf. ECDL – European Computer Driving License) could act as a lever in this respect.

2. Communication and Training of Soft Skills

Educators should put particular emphasis on training of 'soft skills' like emotion management in care personnel.

There are two major goals in this kind of training: to improve understanding of the care dependent's situation; and to better understand one's own feelings as a carer (see also Recommendation 3).

Too often carers suppose that the older people 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. Also, 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 of personal development namely about the positive dimensions of old age. For all these reasons there is a need for training in constructive communication between carers and the elderly.

Persuasion skills and empathy are key competencies when handling aggressive clients or clients unwilling to cooperate or even rejecting help. 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 for 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 people experience considerable psychological problems, i.e. feeling downhearted or lonely. This applies especially to those living alone and with few social contacts, and also to people 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 for the carers.

3. 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.).

4. Balanced education

In medical education there is a need for a holistic view on care and on the developmental process of ageing. The training of competencies must be considered; in some countries education is dominated by theoretical knowledge. In addition, medical education neglects social, emotional, and sometimes even psychological processes. The training of medical skills does not necessarily imply that a care worker is qualified for the task of caring for a person.

Research of care provision reports a lack of practical skills and self reflection by the students.

On the other hand, in some countries, 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.

A new balance in the distribution between theory and practice in the curricula must be found in order to complement the theoretical expertise with practical competencies which are nevertheless based on sound research results.

5. Continuous education

We recommend that the knowledge and skills of the care workers be constantly updated in order to make their work ever more effective and coherent with the users' needs. Both service providers and the states/NHS should invest in continuous vocational training.

6. 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.

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12. Working Conditions of Care Workers

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1. Combat bad working conditions, low reputation and low income of professional carers

Bad working conditions and the low income of professional carers leads to a significant shortage of staff (cf. CARMA Del 11, p. 17). We learned in our WP3 study of "Instructive Deviance – Interaction between users and service providers" that in systems where care provision involves both care staff with 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 (civil servants or private employees).

Integrated care following a client centred approach will also have a positive impact on the working conditions of professional carers. The need for improved interdisciplinary collaboration, flexibility and "multidimensional working" within geriatric care may make the care work more meaningful since the clients' needs are the final goal. Especially in complex cases, care workers often have a need to combine various professions in difficult circumstances. It is imperative to tear down the existing barriers between medical specialists/hospitals, community health care, informal carers/family and the patient. Care tasks have to be correctly and reliably defined and assigned to avoid confusion.

2. 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 similar needs and feelings. Some organisations offer their employees round-the-clock telephone support. Care workers who experience troubles or conflicts with clients can get their 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 reporting 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.

3. The right for further training

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