Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage

EUROFAMCARE

National Background Report for Germany

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July 2004

The project EUROFAMCARE is supported by the European Union - Contract: QLK6-CT-2002-02647

This report is part of the European Union funded project

"Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage" - EUROFAMCARE

EUROFAMCARE is an international research project funded within the 5th Framework Programme of the European Community, Key Action 6: The Ageing Population and Disabilities, 6.5: Health and Social Care Services to older People, Contract N° QLK6-CT-2002-02647 "EUROFAMCARE"

http://www.uke.uni-hamburg.de/eurofamcare/

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This report reflects the authors' view. It does not necessarily reflect the European Commission's view and in no way anticipates its future policy in this area.

Design: Christopher Kofahl

Final Layout: Maik Philipp, Florian Lüdeke

Hamburg, 25th August 2004

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Summary of Main Findings

- Representative organisations of family carers and older people

In Germany families are still the most important care-givers; but due to demographic developments and social shifts in society future generations will be involved to a much lesser degree in family care-giving than at present. The traditional reliance on –mostly female- care resources within the family will become less and less relevant in a "cultural" sense and the moral orientation will also lose it's meaning regarding the decision to take on family care-giving as the costs involved begin to play a central role in decision-making.

These trends will be intensified in the future because it can be expected a decrease in the family care-giving potential with increasing trends in female employment rates and an increase in single-households.

As a result of recruitment problems and a general decrease in nursing professionals the professional care-giving sector cannot take over the whole responsibility for family caring and fill up future care-giving gaps.

The future covering and provision of family care-giving will only succeed in the form of *mixed care-arrangements* and as well professional as informal care networks will gain more and more importance to manage family care-giving.

Representative organisations should act on family carers to accept professional support in an earlier stage in their ‘care-giving career’ to relieve their burden of care.

On the one hand they should continue and strengthen their efforts towards political decision makers to represent the interests of family carers, and on the other hand make efforts to strengthen the family care-givers’ position enabling them to make demands on political decision makers with respect to the following areas:

- the further local development of advisory centres for older people in critical situations,
- the improvement and differentiation of services towards more complementary supplies and the development of quality criteria to strenghten the consumer protection. Accredited quality criteria could ease family carer’s decision-making in comparing and finding appropriate services,
- the mobilisation of new Care- and self-help-potentials through the further development of training concepts for volunteer workers,
- prevention measures in order to avoid health- or mentally- related impairments to ensure older people's rehabilitation and participation in social life,
- the further development of palliative care facilities in order to support and relieve family carers,

- the checking of the prerequisites of a Germany-wide family carers' hotline,
- training for general practitioners, professionals and the police to identify signs of elder or carers abuse at home and more action-plans within the senior citizens organizations themselves in order to make this issue more public and make it a part of the organisations' political work,
- a systematic discharge management in cooperation with family carers, professional services, the general practitioner and the medical doctor in hospital in order to avoid a loss of quality in the care of older people and to assess the family carer's situation,
- new forms of "community housing" beyond the in-patient-out-patient dichotomy particularly for older persons suffering from dementia in order to relieve the family carers.

- Service providers

The enactment of the long-term care insurance brought an economical relief for many families. Although family carers and older people in need of care in general state a high satisfaction with the benefits of the long-term care insurance which have shared in the stabilisation of family care-giving, it didn't fulfil the expectations related to more systematic support, advice, training and organization of family care giving.

There is a current trend towards professional caregiving in residential care on the one hand, and on the other hand there is a decrease of benefits in cash with simultaneous increase of benefits in kind in family care-giving. Although there is a sufficient provision of „classical" benefits in kind highly visible gaps dehisce in the network of low-thresholded care supplies and volunteer services e.g. visiting services. Simultaneously it should be taken into consideration that future generations will be involved to a much lesser degree in family care giving caused by a decrease in the family care-giving potential with increasing trends in female employment rates and an increase in single-households and the society and social policy cannot reckon on the "natural female care-resources". These developments show the need for more professional support and informal care networks yet play an important role in care giving.

Enforced needs for more professional controlling and management of care-arrangements from outside the informal care network will be forecasted. Limited economic resources will have to concentrate on the organizational structures of service provision and to strengthen the efforts towards more coordinative and cooperative structures and building up locally based networks in service provision to meet the needs of family carers and the older person in need of care.

Professional care-services must redefine their role taking consideration of care-givers as partners in *mixed care-arrangements* and it's essential to develop new care- and case-management structures.

The current discussions, efforts and recommendations concentrate on the following:

- the improvement and differentiation of services towards more complementary supplies and the development and delivery of integrated care and management concepts in the kind of *health-centres* or multidisciplinary *service networks* with a comprehensive service provision in order to make service provision more transparent and efficiently,
- the training and assignment of professional care- and case-managers,
- the closing of "intersectional gaps" between the in- and out-patient sector through the development of a systematic discharge management in cooperation with the medical doctor and the professional staff in hospital, other professional services, the general practitioner and last but not least the family carers, to avoid a loss of quality in the care of older people and a loss of information for family carers. With regard to the introduction of Diagnosis Related Groups -DRGs- in German hospitals -aimed at the reduction of the patients' hospital stay down to 4 days on average- this issue will get a high priority on the agenda: older people will be discharged 'sicker and quicker' from hospital –either into residential care or into their domestic environment- with a higher and more comprehensive amount of maintenance and care. Many family carers would also like to play a more important role when their elders are admitted to in-patient institutions, especially because this would give them the opportunity to find out what problems they might have to face when their elder is discharged from hospital and transferred home again. For this reason family carers need more professional advice and support in order to assess their own role-taking to decide if they are able to manage care-giving and to prepare for a mixed care-arrangement. Related to the introduction of the DRGs it must be feared that the family carers' situation could become aggravated: counselling and instruction of family carers in general is still very rare and needs to be developed in a more systematic way in order to avoid disruptions in caregiving tasks and medical treatment in particular between the in-patient and out-patient sector,
- more offers for talks to exchange experiences as well as the extension of psycho social support and self-help groups for family carers which are the key elements for quality assurance in family care-giving. This could ease the process of counselling family carers particularly in difficult or precarious care giving situations who need comprehensive structures of coordination,

- the further education of professionals in geronto-psychiatric and geriatric care,
- the introduction of "preventive home visits" – which is in experimental stage in Germany and yet no regular professional task- to assess comprehensive needs of both: the older person in need of care and the family carer's situation. Related to "preventive home visits" professional care provider should be better trained in assessing the complementary needs to relief family carers in domestic care by using standardised assessment instruments,
- the mobilisation of new Care- and self-help-potentials including training concepts for volunteer workers ("care-sitter") and the provision of a "volunteer-agency" as an inherent part of a comprehensive service network,
- the development of care services specific to the needs of older people and family carers from different ethnic minorities. This issue is nearly completely neglected in German gerontology and nursing sciences and apart from single research projects and community activities there is a lack of comprehensive care-concepts,
- the further extension of day-care centres in particular in rural areas to relief family carers who care for older people suffering from dementia; this will also include the provision of new forms of "community housing" beyond the in-patient-out-patient dichotomy particularly for older persons suffering from dementia,
- the further extension of short-term care places all over the country,
- the further development and contouring of hospital and community-based palliative-care services with mixed care-arrangements including volunteers, professionals and family carers. This area needs more public attention to relieve the family carers burden because only about 6 % of the 850,000 terminally ill or dying persons in Germany are cared for by one of the 1200 Hospice societies and most of them are living together with a spouse as family carer. Efforts should be strengthened in motivating general practitioners to prescribe on more domestic palliative care.

- Policy makers

The current and future provision and maintenance of the wide range of different services in the health and social sector in Germany just as the supply and demand for care work is influenced by limited financial resources as well as some critical demographic and labour market trends: It is expected a scarcity of human resources with a peak in the working age population at the end of the current decade, and then to decline with an overall labour shortage. This will significantly change labour market behaviour and bringing with it the need

for considerable organizational innovation in the provision of care. In particular the health care sector is already influenced by a shortage of professionals.

With regard to the organisation of work during the working life the life-course perspective is still neglected and the system of social security for the population in many EU Member States is closely linked to traditional life-course patterns, particularly to the (male) model of continuous full-time employment. This model is increasingly becoming obsolete and new and more flexible structures are needed also from the perspective of life-long-learning. In Germany it has been mostly higher qualified employees who have used flexible working time options to secure a better balance between work and caring tasks and lower skilled employees are disadvantaged. The increase in the number of smaller and more unstable family types and increased employment rates for women could undermine family networks of solidarity and make the provision of health and care within families more difficult to sustain. Economic objectives in terms of employment rates reconciling the needs of work with social and family goals could be especially problematic and is a central challenge for national and EU policy makers.

Recommendations to policy makers include the following:

- from a family carers' point of view efforts should be strengthened to make care giving and employment compatible,
- time sovereignty should be seen as an important contribution to improve the quality of life and has still to be achieved as a central point of reference for planning life flexibility in order to be able to combine working and caring tasks for both: men and women. This should lay down a right to re-employment after a period of care leave in the same way as this is laid down in the context of parental leave. Respective suggestions are made by the Saarland. Critics fear that women will once again have to shoulder the main burden of family caregiving if these plans are translated into action,
- possible strategies for meeting future care needs and make care giving and employment compatible should include policies towards a "Welfare-Mix" and stimulate public-private partnerships. This will also include informal care as well as volunteer work, more differentiation in vocational education, using migration and other mechanisms to increase the pool of low-skilled care workers, the improvement and differentiation of services or professionalising care work to attract a more highly educated workforce,
- to finance and to facilitate the implementation of new forms of "sheltered housing" beyond the "in-patient –out-patient dichotomy" to allow older people to live at home as long as possible or in housing communities. This could avoid long-term residential care particularly for older people suffering from dementia and would relief family carers,

- to promote research with regard to the role of domestic care-workers and their employment situation which is a nearly totally neglected area. It has to be paid more attention in a new role of private households as private employers in general and particularly in the area of domestic care-giving. On the one hand the professionalising of domestic care work could be a future area to qualify (also migrant) women and to develop new models of employment. The economic distinction between the public and the private household could be abolished and also the difficult situation of domestic care giving would become known. On the other hand professional care-work could contribute to a more differentiated and more needs-led service provision within private households to relief family carers and to support older people without stable family networks,
- to stimulate the development of migrant care services and migrant family caregiving. Only a few attempts have been made in Germany to take a look at the experience of other countries,
- to improve the prerequisites for developing innovative and integrated structures of Case- and Care Management in order to optimise the service provision and to build up more cooperative, coordinative and effective networks in service provision aiming on more transparency and more support for both family carers and older people in need of care,
- to promote research in the issue of elder abuse at home and also in residential care facilities.

Introduction – An Overview on Family Care

The current and future provision and maintenance of the wide range of different services in the health and social sector in Germany just as the supply and demand for care work is influenced by some critical demographic and labour market trends: It is expected a scarcity of human resources with a peak in the working age population at the end of the current decade, and then to decline with an overall labour shortage. This will significantly change labour market behaviour and bringing with it the need for considerable organizational innovation in the provision of care.

In Germany currently (2001) the proportion of > 60 year-olds amounts 24.1 % and the > 80 year-olds is 3.9 % in the total population. Until the year 2030 it is estimated a proportional increase of > 60 year-olds up to 34.4 % and the proportion of the > 80 year-olds up to 7.3 %. At the same time it is estimated a growing number of older people in need of care.

In this context the supply and demand for care and care work has to be addressed in the light of declining numbers of children, an increase in the number of one-person-households, more equal workforce participation between men and women, growing numbers of older people living alone without children in private homes, and their emerging preference for formal services - possibly linked to the disappearance of family care resources (European Foundation, 2003).

The family is still the central institution providing instrumental and emotional support to older people in Germany and family care giving is still often considered to be a private matter dealt with by the closest members. Caregiving within the family often begins with care of the spouse and then shifts to the children as advancing age makes it increasingly difficult for older persons to care for their partners. Friends and neighbours are rarely involved, especially when the person in need of care suffers from dementia. The long-term care insurance motto "out-patient before in-patient" expresses the intention of the legislative to promote the willingness to provide family care giving and is a reflection of the fact that the German welfare state still reckons with the stability of family networks of informal helpers (Daatland et al., 2003).

In Germany meanwhile a wide variety of care services are offered for elderly people; but the structure of service provision is characterised by a strong disintegration because it is financed from different sources, such as social security contributions, public revenues and private funds. One of the main difficulties in finding one's way through the German care service provision system is attributable to these different sources of financing.

As a result there are still many deficits in providing effective and comprehensive care and support and due to a lack of coordination of services the system

is not transparent to users and providers and the client finds it very difficult to find his or her way through the "service jungle".

The enactment of the long-term care insurance law in 1995 as the fifth pillar of the social security system provided a new basis for both the persons requiring care and for family carers, as it allows to cover the risks which are associated with need for care (Döhner, Kofahl, 2001). It also fixed the legal separation of medical treatment and illness, nursing and rehabilitative care, informal and formal care-giving and prevention, rehabilitation and medical care and last but not least the separation of the in-patient and out-patient sector which now belong to different areas of social security benefit (Rothgang, 1997).

Since the introduction of the long-term care insurance and market principles an open market of public, independent charitable and private commercial out-patient care services has evolved which then pushed the responsibility of the local authorities for the provision of social and health care services into the background. This quantitative expansion of services with varying regional density of care provision and the financial orientation towards the classical "long-term care insurance patient" did not automatically lead to qualitative and structural improvements (Schaeffer, 1999).

Experts for the further development of domestic care (Klie, 1999, Runde et al., 2002, Rothgang, 2003) reckon that the willingness to family care giving will decrease as a result changing social normative attitudes, increasing costs and shifts in social milieus and that formal forms of support will become more important. This trend can be seen in the data collected over the last five years. The "problem" with the long-term care insurance is that it is not adapted to either the inflation rate or income levels. Purchasing power will sink dramatically and many more people, especially in residential care, will become dependent on social welfare. The original aim to ease the burden on local authorities will therefore be missed as the local authorities finance social welfare. The legislation on supplementary care benefits will provide more opportunities to family carers taking care of persons suffering from dementia to make use of low level forms of support such as "Granny sitting" and will offer voluntary helpers possibilities to qualify for their work.

The long-term care insurance only pays for services such as basic care related to the activities of daily living -ADL- such as assistance with personal hygiene and with meals, mobilisation and domestic help. This is the reason why besides the regular care-market a second privately and irregular paid care-market evolved because the long-term care insurance can't cover the comprehensive needs of family carers and older people in need of care. Important complementary services such as visiting and accompanying services, psycho-social care, gardening, cleaning and housework are not offered by the professional service providers although they do realize that there is a great demand for these services. These complementary services must be paid privately by the patient or the family or, under certain circumstances, by social assistance.

Compact analyses have shown that a paradoxical situation concerning out-patient support and care for older people has developed: The mutual stimulation and competition between different service providers as a reaction to an increase in the services on offer as well as the growing demands for such services has not actually taken place. The prices, the services offer and the range of services on offer are defined from the start by reimbursement agreements between the service providers and the long- term care insurance companies and are therefore not influenced by market principles (Ühlein, Evers, Busch, 2000).

A comparison of urban and rural areas shows that especially carers living in rural areas do not have access to the services they require in order to ease the burden of care because the service spectrum is underdeveloped due to specific structural conditions (Schultz-Nieswandt, 2000, Walter, Schwartz, 2000). Only 16 % of the services demanded are complementary services (Schneekloth, Müller, 2000) which is partly due to the fact that carers often experience extreme physical and psychological strain but are unable to react accordingly at an early stage (Ühlein, Evers, 1999 / 2000).

Besides the "regular" and privately paid care market also an "irregular" privately paid care market evolved with an estimated number of 50,000 “care workers” and “household help services” from the future eastern EU member countries. Until recently the people offering these "grey" services were usually in Germany with a three month visitors visa and therefore illegally employed. In the mean time "Greencards" have been introduced for these household helpers who now contribute to the social security system and are therefore legally employed. However there is no data available on the further development of this market.

In addition to the above mentioned market for professional services there is also a "grey market" for complementary services mainly based on voluntary work which is hardly to be overviewed. Theses services are rendered regularly by neighbourhood help, family support services and self-help groups and are organized and financed by churches, municipalities and charitable organisations or on private basis (Ühlein, Evers, 1999 / 2000, Infratest Sozialforschung, 2003).

Demographic projections of future needs for care are considerably influenced by assumptions on the age-related prevalence of the further life-expectancy. In Germany different model calculations are available which figure on different data-bases calculating the life-expectancy (BMFSFJ, 2001 p. 88). It is estimated an increase of older people in need of care up to 2.04 Mio until the year 2010. The Federal Ministry of Health estimates an increase up to 2.04 Mio. until 2010; until 2030 it is estimated from 2.16 until 2.57 Mio.; until the year 2040 it is estimated an increase between 2.26 and 2.79 Mio. of older people in need for care. The lower limit is based on the assumption of no further increase in life-expectancy (BMFSFJ 2001 p. 87). The figures presuppose con-

stantly age-related frequencies in need of care up-dating the 'status quo'. Recent national and international research outcomes clearly show the improvement in health status of older people within the different age-cohorts and one can assume that functional impairments or disabilities will be slowed down, forced back or weakened in the future (BMFSFJ 2002).

Anyway, there is no doubt, that the future take up of health and social services and the needs for care will continuously grow.

Up to now an essential desideration in research is to be seen in the fact that it is founded on the reduced definition of "need of care" in the long-term care insurance law and therefore predictions on the future needs for care are very limited.

So far investigations on the estimated needs for care are focussing the question how the total number of people in need of care will develop in the future, what kinds of benefits provided by the long-term care insurance will probably taken up and the future development of expenditures by the social security system.

As a result of demographic developments one of the most urgent current problems facing German social and health politics is that of ensuring a continuation of the social security system. This problem has arisen due to the relationship between the part of the entire population capable of gainful employment and the number of older people in the population as a whole, the so-called age dependency ratio. This relationship shall continue to shift and put more and more strain on the working population with the ratio between those aged between 20 and 59 years and those over 60 years of age of 100:71. In 2001 this ratio was only 100:44 (Statistisches Bundesamt, 2003c).

The Implementation of the Health Care Insurance Modernisation Act (GMG, 2004) led to heavy cut-backs in the healthcare system which were necessary in order to keep social contributions stable. Amongst other things co-payment regulations were passed for medicines, practice fees, in-patient treatment, prescriptions from the GP for home health care and remedies, etc. The long-term care insurance was not excluded from this process. It had been planned to reduce the benefits granted for institutional care drastically, adapting them to the benefits in cash granted for domestic care, on the grounds that this could make domestic caregiving more popular. The threshold for putting family members into residential care would have been be much higher as a result of the reduction of benefits in cash for this form of care. However this could have caused an increase on the strain put on family carers as it has been observed that family carers only transfer their elder relatives in need of care into residential care when they themselves are physically and psychologically exhausted.

There were fears that these measures, which could have led to an increased financial strain on persons in need of care, could have resulted in an increasing number of people in residential care becoming dependent on social welfare

(Roth, Rothgang, 2001). In 1999 this proportion was 33 % of all older people in residential care (BMFSFJ, 2002 p. 88). Due to political reasons the decision about the reform of the long-termcare insurance is put off for the moment.

The co-payment for prescriptions for domestic care in combination with the introduction of DRGs (Diagnosis Related Groups) in German hospitals will probably result in a greater burden on family carers due to the fact that older patients in need of comprehensive care will be discharged from hospital at an earlier stage. DRGs are designed to make treatment in hospitals more effective and efficient and to shorten the average length of stay. In addition, the consequences of the Diagnosis Related Groups (DRGs) for geriatric patients cannot yet be foreseen. They will affect the treatment of older and chronically ill persons who will probably be discharged quickly and therefore also be more ill when they go home, a "sicker and quicker" situation. This must lead to increased strain on family carers in future and the consequences of these developments for out-patient care cannot yet be foreseen.

These measures are intended to provide incentives for the utilization of quality controlled out-patient care services.

Related to the health care provision of older chronically ill people disease-management-programmes and integrated care management are currently under discussion. It is criticised a strong medical and disease orientation rather cross-sectional care-networks should build up with a participation of all professional groups. Due to the administrative separation of the health and social sector in the social security system and between medical treatment, social, nursing and rehabilitative care these incentives will remain difficult to realize but are absolutely necessary (Kofahl et al., 2003, Ewers, Schaeffer, 2003).

1 Profile of family carers of older people

1.1 Number of carers

In Germany 1,37 Mio. people in need of care, and living at home, received benefits in accordance with the statutory long-term care insurance and around 1,2 Mio. people are main care-givers and responsible for persons in need of care and support. Since the introduction of the long-term care insurance there has been a slight increase in the number of informal carers involved in support and care at home. 36 % of all persons in need of care are cared for by one main care-giver, 29 % are cared by 2 persons and 27 % are cared by 3 and more persons. On average 2 persons, including the main family care-giver, are involved in domestic care arrangements and providing regularly care and support (Schneekloth, Müller, 2000, Infratest Sozialforschung, 2003, BMGS 2003a, Stat. Bundesamt, 2003).

1.2 Age of carers

About 32 % of all main family care-givers are over 65 years of age and usually belong to the same generation as the person in need of care. Every second carer (54 %) is between 40 and 64 years old, only 11 % of carers are younger than 39 years of age. According to these figures increasingly aged carers must take care of relatives who are ever more advanced in years. As a result there is an increasing risk of the carers themselves becoming dependent on care (Schneekloth, Müller, 2000, Infratest Sozialforschung, 2003).

Table 1: Age groups of main carers in private homes (%)

Age of main carer	Proportion in %
< 39 years	11 %
40-54 years	27 %
55-64 years	27 %
65-79 years	26 %
> 80 years	7 %

Source: Infratest Sozialforschung, 2003

1.3 Gender of carers

Family care giving still shows a clear gender bias with women carrying the main burden of care and performing 73 % and men with 27 % of all care tasks. (Infratest Sozialforschung 2003; N = 1,060). While 39 % of men in need of care in the age group 65 to 79 years old are cared for by their spouses only 22 % of the women in need of care in the same age group are cared for by their spouses.

With regard to both the care of persons suffering from dementia, as well as that of persons whose need of care is a result of other circumstances, there is a highly significant relationship (p > 0.00001) between the gender of the main family carer and the degree of relationship between them and the person in need of care: It is more often women who take on the main load of family care giving, especially of persons suffering from dementia. While two thirds of all male caregivers look after their spouses it is one half of the female carers who look after a parent. With the exception of their spouses men are far more reluctant to look after persons in need of care at home. Gräßel (1998a) assumes that this phenomenon is encouraged by traditional social roles which *"favour man's orientation towards activities and acknowledgement outside of the home. This is why the son in law as a care-giver is practically non-existent"* (ibid.).

Based on the results of quantitative data analysis Runde et al. (1999) have observed a retreat of the daughters from family care giving and attribute this phenomenon to the long-term care insurance which brings about a social "normalization" by opening up new possibilities for action to women. Prior to the introduction of the long-term care insurance daughters in particular felt compelled to take on family care duties in accordance with their moral codes and in the absence of alternatives. The retreat of the daughters from family care giving is expressed both in the increase in the number of cases in which close relatives are not involved in caregiving as reported by interviewees, as well as in a decrease in the care organization type *"care for relatives only"* (ibid.). One plausible reason for this phenomenon may also be attributable to the legal rights to welfare benefit which are laid down in the long-term care insurance law and which open up alternatives regarding the organization of care. Working daughters no longer see themselves as the first in line when it comes to taking on family care giving. The retreat of daughters from family care giving appears to be compensated by the emergence of incentives to those who are less busy. Daughters in law belong to this group as well as other relatives who can stabilize the family care giving situation in accordance with the "restrictions to relatives" (ibid.). It's not clear if there is really a retreat of daughters from caregiving because other research data show that the daughters still holds the second place (26 %) in caregiving (Infratest Sozialforschung, 2003).

1.4 Income of carers

It is of high socio-political interest to clarify how the caregiving household's net-income is different from the average household's net-income and what are the social consequences of caregiving. This question is difficult to answer because carers earnings are directly connected to the question of to what extent paid employment is compatible with caring tasks or to what extent a loss of income is caused by a reduction of paid employment. Married women between 41 and 50 years of age are particularly hard hit by this compatibility problem -although

this should not distract from the fact that an increasing number of men will become involved in family care giving in general in the future- (Reichert, Naegele, 1997). The question of income is also closely associated with school education and occupational qualifications of the mostly female main carers on the one hand and with their extent labour participation (e.g. part-time, full-time) and the resulting earnings on the other hand (Schneekloth et al., 1996).

Data on the average private household's net-incomes where collected in a representative survey conducted in 1998 to analyze the effects of the long-term-care insurance (Schneekloth, Müller, 2000).[1]

Table 2: Net-income of carers households compared to the population (Percentage)

Income (in Euros)	West		East	
	Caregiving household	Households in total	Caregiving household	Households in total
Below 511	4	1	1	5
511-766	7	6	10	11
766-1,022	9	10	9	13
1,022-1,278	12	14	13	15
1,278-1,533	10	11	12	12
1,533-2,045	26	22	34	22
2,045-2,556	14	18	11	11
2,556-4,090	11	14	3	10
4,090 and more	2	3	3	1
No statement	6	1	3	2
Average income	1,698		1,519	

Source: Schneekloth, Müller, 2000

The data show: about 11 % of the caregiving households in the old federal countries in contrast with 7 % of all households, compared with 11 % of caregiving households in the new federal countries in contrast with 16 % of all households have less than 766 Euros at their disposal. This is caused by structural reasons because of the higher proportion of elderly people among caregiving households. Compared with carers households it's not surprising that the proportion of households having 2,556 Euros and more at their disposal altogether is higher. This is due to the fact that elderly couples in households normally are retired and are no longer in paid employment (Schneekloth, Müller, 2000).

[1] Recent data according to the private household's net-income as well as the individual's net-income of the person in need of care will be available in the final report of a representative survey '*Persons in need of help and care in private households in Germany 2002*' mid of 2004. (Hilfe- und Pflegebedürftige in Privathaushalten in Deutschland 2002), conducted by Schneekloth et al. Infratest Sozialforschung).

In the long run an exact evaluation of the social consequences of care giving at home regarding carer's incomes can only be carried out when more information about the size of caregiving households is available. However it is certain that the limitation or giving up of paid employment and the cessation of the earnings involved always has negative consequences regarding the individual social security situation of the mostly female main caregivers (Dallinger, 1997).

1.5 Hours of caring and caring tasks, caring for more than one person

As a rule family care giving is a full-time job: an average of 64 % of all main carers are available to the person in need of care round the clock, about 26 % by several hours daily, about 8 % by several hours weekly and 2 % are rarely available. About 76 % of all carers must interrupt their nightly sleep more than once (Gräßel, 1998a). Family carers are actually engaged in care giving and supportive tasks for an average of 36.6 hours a week. The caregivers assist with many activities of daily living, most of them several times daily. From their point of view the most frequently daily task carried out is personal care (e.g. conversation) which is received by 68 % of the persons in need of care several times daily and 14 % at least once a day. The daily or almost daily tasks carried out are those connected to activities of daily living such as personal hygiene, dressing, assistance with meals and housekeeping as well as treatment care interventions and personal care in the form of conversation and walks. In addition bureaucratic matters are dealt with, social contacts are supported and maintained and auxiliary personnel is organized for the person in need of care.

Table 3: Individuals in need of care in private homes with main carer in order of nature and degree of care and support received (%)

Type of care / help	Frequency of care	
	Several times daily	At least once a day
Personal care (e.g. conversation, emotional support)	68	14
Personal hygiene (washing and dressing)	54	21
Assistance with food intake	48	7
Household activities	55	18

Source: Infratest Sozialforschung, 2003.

The data result from a representative study conducted in 2002 and demonstrate indisputably that the family constitutes the largest group of carers on a more or less voluntary basis.

1.6 Level of education and / or Profession / Employment of family carer

Employment and labour participation amongst the family care-givers of working age (16-64 years) is not an exception. About 68 % of all family carers must reconcile labour participation with the support and care of elders. Two out of three family carers are still not in paid employment. 8 % are in minor employment, 13 % are in part-time employment up to 30 hours and 16 % are in full-time employment. It is noticeable that there is a distinct difference between East and West Germany with regard to labour participation: Whereas on average 65 % of all family carers of working age in West Germany are not in paid employment, this is only true of 56 % of family carers in East Germany. It is also noticeable that nearly every third family carer (31 %) in East Germany is in more or less full-time employment of at least 30 hours a week (Schneekloth, Müller, 2000).

The extent of labour participation of family carers correlates closely with the level of need for support and care of the elder as well as with the experience of strain: The more time is spent administering care-giving to the elder, the less labour participation takes place. It is quite obvious that the opportunities for labour participation and simultaneous administration of caregiving to an elder are far more limited for the full-time employed than for persons in part-time employment. As a result the number of persons in minor or part-time employment rises slightly with an increase in the degree of need of care up on a daily basis (Dallinger, 1997).

Table 4: Main carers of individuals in need of care in private homes, aged 16-64 years) - in order of employment status (%)

Employment status	Total	West	East
Not employed	64	65	56
mini-job	8	9	2
Part-time employed < 30 hours	13	13	11
> 30 hours	16	12	31

Source: Schneekloth, Müller, 2000

The family carers level of education is closely connected to occupation and to the question of whether or not labour participation is limited or even given up completely. In general one can say that those who take responsibility both regarding labour participation as well as caring duties tend to be civil servants, salaried employees or self-employed. Unemployed carers tend to have been employed as labourers, farmers and or helping hands within the family. However the level of school qualification seems to suggest a clear tendency towards a higher qualification of main carers in paid employment. The occupational qualification level should be seen as another important indicator: In this case the main carers in paid employment also tend to be more highly qualified.

Dallinger's analysis shows that main caregivers who have completed secondary modern school make up a total of 70.8 % of the group of those who limited or gave up paid employment whereas they make up only 54.5 % of the group of those in continued labour participation. On the contrary the percentage of main carers continuing labour participation (41.8 %) exceeds that of those limiting labour participation (28.8 %) in the group of family carers with a higher school education (O-levels, A-Levels) (ibid. 147). There is practically no difference in the group of family carers in qualified employment regarding the limitation or continuation of labour participation (Dallinger, 1997).

Table 5: Level of education and labour participation of main carers

Level of education	secondary modern / no final exam	O-Levels	A-Levels
Labour participation Continued	54.4 %	31.9 %	9.9 %
Labour participation Limited	70.8 %	23.6 %	5.2 %

Source: Dallinger, 1997

Dallinger points out that the lower employment rates of main carers must not necessarily be the result of opting out of labour participation. This difference could just as well be interpreted as a result of the fact that unemployed persons more often tend to take on the family care of elders. It must also be taken into account that many main family caregivers belong to the group of older employees among which the employment rate decreases anyway, especially at the end of the fifth and beginning of the sixth decade of life. It can be projected that roughly 350,000 main carers draw a standard old age pension[2]. This figure makes up 39 % of all main family carers with an entitlement to contributions toward an old age pension (Schneekloth, Müller, 2000).

In general family carers looking after elders who do not suffer from dementia are significantly more often engaged in labour participation (30.9 %) than those taking care of elders suffering from dementia (25.3 %). This can be partially explained by the fact that male caregivers are significantly more often involved in the care of elders not suffering from dementia, making up 20 % of this group of main carers, than in the care of elders suffering from dementia where they make up only 15 % of the group of family carers (N = 1,911) (Gräßel, 1998a).

[2] This projection refers to main family carers who are entitled to contributions toward a pension in accordance to the Long-term care insurance law, who do not provide professionally domestic care to a person as defined in § 14. According to § 44 she / he provides care at least 14 hours per week to a person in need of care (§ 19) and who are employed not more than 30 hours a week.

Table 6: Extent of labour participation of main carers of elders suffering / not suffering from dementia

Variable	Main family caregiver of elder suffering from dementia	Main family caregiver of elder not suffering from dementia
Age	58.1 (+ / - 11.9)	57.4 (+ / - 12.4)
Gender (% female)	84.5	79.5*
Employed (%)	25.3	30.9*
Extent of employment (hours / week)	25.0 (+ / - 11.0)	30.0 (+ / - 10.0)*

Source: Gräßel, 1998a, p 58 (N = 1911) distinctiveness between the groups: *p < 0.01)

1.7 Generation of carer, Relationship of carer to OP

The rise in life-expectancy has led to a situation in which care-giving for the very old in the family is no longer an exception but has rather become a situation which is to be expected in the course of the family-cycle. Family caregiving is considerably provided within the same generation: about 60 % of the main carers are 55 years and older. The closer family relations determine who takes on the main carer's role and it's evident that the most important helpers are still the spouses of the persons in need of care (Infratest Sozialforschung, 2003). This means that many helpers find themselves on the threshold to old age or beyond it. Even the helpers belonging to the subsequent generation are persons who are getting older, most commonly women looking after the parental generation. As the persons in need of care become older the support shifts from the spouses to the generation of their children. The amount of support shifts in inverse proportion so that the amount of support given by spouses decreases to the same extent as the amount of support given by the younger generation increases. The change occurs in a relatively continuous manner across the generations (Blinkert, Klie, 1999).

According to the position of the person in need of care within the family it is either the male / female partner / spouse, the daughter, the mother, the son, other next kin, the neighbours or acquaintance, the daughter in law, the father or a grandchild who takes on the role of the main carer (Infratest Sozialforschung, 2003, BMFSFJ, editor, 2002).

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Table 7: Main carers of individuals in need of care in private homes (%)

Relationship	Proportion
male / female partner / spouse	28
daughter	26
mother	12
son	10
other relatives	7
neighbours / friends	7
daughter in law	6
father	2
grandchild	2

Source: Infratest Sozialforschung, 2003

If the main caregiver has taken on the care duties as a result of intense social pressure then a statistically relevant increase in the emotional strain on the caregivers, which is intensified by a negative relationship between them and the person in need of care, becomes evident. Fortunately the relationship between the main caregiver and the person in need of care is not always dominated by such strain but rather the role as a carer can also lead to valuable changes which have a positive effect on the relationship (Wahl, Wetzler, 1998).

1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc.)

The take-over of the role of family care-giving doesn't necessarily presupposes that the family care-giver lives together with the person in need of care: About 62 % of the persons in need of care live in the same household with their caregivers. About 8 % of family carers live in the same house or very nearby, about 14 % live less than 10 minutes away, about 8 % live more than 10 minutes away whereas the remaining 8 % of persons in need of care don't receive any regular family care-giving or support.

The fact that a person in need of care lives in a single private home does not necessarily mean that he or she must do without support from the family. Elderly in need of care who live in a private home with several persons are cared for in most cases by a family carer living in the same household or less than 10 minutes away.

The situation of persons living alone who are in need of care is somewhat different: Only 57 % of them have a family carer available who lives only up to 10 minutes away, whereas 14 % of them rely on family carers who live up to 30 Minutes away, 7 % can only be reached in more than 30 Minutes and 21 % do

not receive any family care-giving or support whatsoever (Infratest Sozialforschung, 2003).

Table 8: Place of residence resp. distance of family caregiver to the person in need of care (in %)

Family carer's place of residence	Persons in need of care in total	Persons in need of care and living alone (31 %)
Living in the same household	62	0
Same house	8	20
Up to 10 minutes away	14	37
Up to 30 minutes	5	14
More than 30 minutes away	3	7
No regular care giving or support	8	21

Source: Infratest Sozialforschung, 2003 (missing to 100 = no data)

Living in their own private homes is as well from the older persons' as from the family carers point of view the clearly preferred kind of living and housing. Only 4 % of the family carers (N = 1,060) considered the move of the older person in need of care into residential care being possible. Every second family carer stated that a move into residential care will be out of the question (Infratest Sozialforschung, 2003).

1.9 Working and caring

For a long time experts (Reichert, Naegele, 1999) have been demanding political decision makers to implement far-reaching measures in order to make working and caring more compatible with each other. The results of an international expert conference were documented as a catalogue of recommendations concerning state and non-state options for action with the aim of promoting equal opportunities for family carers. These recommendations are particularly relevant to EU member states and include:

- the expansion of legal regulations for the exemption from work comparable with the american "Family and Medical Leave Act",
- the promotion of further professionalisation in nursing,
- the promotion of equal opportunities on the labour market in order to prevent or minimize discrimination due to care obligations, especially in the case of women,
- the promotion of the willingness to care amongst men,
- the promotion of further education intended to make the return to work easier for people who have fulfilled private care obligations.

Due to the fact that the public sector is the largest employer this sector should be a forerunner and should make efforts to improve the situation regarding job-

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sharing and care leave. The expansion of company interventions includes increased flexibility of regulations on working time as the most important instrument needed to avoid problems pertaining to the compatibility of working and caring. The role played by superiors on low and middle leadership levels is estimated to be central, due to the fact that the search for formal and informal solutions to arising problems is influenced most by these decision-makers, who can contribute measurably to the development of a working atmosphere which does justice to caregivers. In order to promote company acceptance of working and caring, comprehensive measures which appeal to all groups and which cover their needs independent of certain "problems" should be developed. This could prevent caregivers from being identified as a "problem group" with special rights within the company (ibid. p. 330). Small and middle-sized companies could be granted tax relieves to enable them to implement measures regarding working and caring. Local social and nursing services should structure their range of services more effectively and cooperate with companies to a greater extent. This means that their services must be orientated towards the needs of working family carers.

Finding ways of making working and caring compatible is not the responsibility of a few social groups but should rather be regarded as the responsibility of society as a whole (ibid. p. 333). In this context the Ministers of Equal Opportunities and Women's Issues demanded that the head associations in German industry intensify their efforts concerning the agreements passed in 2001 on the promotion of equal opportunities for men and women in private industry and to implement measures which improve the situation of families within companies (GFMK, 2003)

1.10 General employment rates by age

The structure of labour participation with regard to occupational status has changed dramatically over the last five decades with a trebling of the number of those employed as civil servants and salaried employees and a massive reduction in the number of "helping hands" employed in the agricultural sector. The overall employment rate in 2001 (with special focus on men and women aged 45-50 years) amounted 81.3 % (Statistisches Bundesamt, 2002). About 42 % of working women in West Germany and 23 % of working women in East Germany were working in part-time jobs in the year 2000. In East Germany full-time employment is still the most common form of employment, even among women with children. The average working time among male employees was quite constant over the last ten years whereas it clearly sank among women, especially among West German women (Klenner, 2002).

Table 9: General employment rates in Germany according to occupational status and gender (%)

Occupational status	Men	Women
Salaried employees incl. trainees	39.4 %	64.1 %
Labourers	40.0 %	22.9 %
Civil servants	7.4 %	4.6 %
Self-employed	12.7 %	6.3 %
"Helping hands"	0.5 %	2.1 %

Source: Statistisches Bundesamt, 2002

Although the overall women's employment rate have risen up to 64.9 % it is the women who have shared the reduction in the overall volume of the economy between them: The increase in the number of jobs for women in West Germany in the last decade was made up solely of part-time work and to a large extent of so-called "mini-jobs".

The table 10 shows a ~10 % difference between the employment rates of women in East and West Germany. The employment rate of women in East Germany has gone down due to dramatic problems on the labour market although it must be mentioned that the original employment rate of East German women was very high. The most obvious between East and West can be observed in the age groups 50-55 years (70.1 / 90.1 % employment) and 55-60 years (55.2 / 76.9 % employment) (Stat. Bundesamt, 2002).

Table 10: Rate of female employment according to age groups from > 40 years in 2001 (%)

Age from … to under …	Germany	West Germany	East Germany and East Berlin
40-45	82.0	79.2	94.1
45-50	81.3	78.4	93.0
50-55	73.6	70.1	90.1
55-60	59.5	55.2	76.9
60-65	14.9	16.4	9.0
65-70	3.9	4.6	1.5

Source: Statistisches Bundesamt, 2002 p. 89

1.11 Positive and negative aspects of care-giving

It can be expected that carers who spend large amounts of time looking after persons in need of care experience a lot of strain which can in turn have a negative effect on the quality of the relationship between them and the persons in need of care. If the main carer has taken on the caring duties as a result of intense social pressure then a statistically relevant increase in the emotional strain on the carers, which is intensified by a negative relationship between them and the person in need of care, becomes evident. Fortunately the relationship between the family carer and the elder person in need of care is not always dominated by such strain but rather the role as a carer can also lead to valuable changes which have a positive effect on the relationship (Wahl, Wetzler, 1998). As Table 3 showed many family carers, often together with the person they care for, are confined indoors because they have to be available around the clock. Consequently, they can rarely take part in social activities outside the home, don't have the opportunity of relaxing by taking part in leisure activities or talking to friends. They get more and more socially isolated.

Investigations of N = 1,911 caregivers showed that family caregivers who spend large amounts of time looking after persons in need of care, reported physical complaints such as exhaustion, pain in arms and legs, heart trouble and more severe stomach pain than in the general population. These symptoms are found to be more pronounced in carers of cognitively impaired persons than in persons who care for elderly who are largely unimpaired in their cognitive performance (Gräßel, 1998b).

The investigations of Schacke and Zank on mental stress factors in N = 78 carers of demented persons showed that the main factors impairing their quality of life were role conflicts and the feeling of not being able to provide adequate care. This mental stress can in turn have a negative effect on the quality of the relationship between them and the persons in need of care (Schacke, Zank, 1998).

Recent representative research data confirm these investigations and revealed that 42 % of all family carers assess to be rather heavy and 41 % of all family carers assess to be extremely physically and mentally burdened and only 7 % assessed no to be burdened (Infratest Sozialforschung, 2003).

Difficult domestic care arrangements who are characterised by long lasting mental and physical stress and strain on both sides, the carer and the person in need of care, are endangered to escalate in physical or psychological violence if no professional support is received. The German government and the committee of experts responsible for a report on the elderly regarding risks, quality of life and care for the aged with special focus on persons suffering from dementia agree that more research on the subject of abuse and old age must be done. Old women are more often the victims of domestic abuse than old men and *"also the allocation of domestic caring tasks according to gender and the relative frequency of female abuse in cases involving neglect and abuse in care giving should be focussed on as central themes for discussion…"* (BMFSFJ, 2002, p. 34).

However representative data on the prevalence of domestic abuse in Germany are still not available (Brzank et al., 2003) because this issue is very difficult to investigate. Research data available (e.g. Hirsch, Brendebach, 1999) have to face with specific problems like selectivity, low response-rates and generalisa-

tion: About 10.8 % (n=46) of all persons questioned by Hirsch and Brendebach (N = 425) reported experiences of violence in the home, whereas psychological maltreatment and financial damage were reported more frequently. The authors regard the response rate of 10.8 % as high in comparison with anglo-american research findings. It became evident that an increase in the experience of violence goes hand in hand with increased need for support and care in connection with a decline of physical strength. Domestic violence was shown to occur often amongst couples or in family relationships between children and their parents and is hidden well from public view (ibid.).

The public and subject-specific discussion on abuse against older people is often narrowed down to the theme of violent family care-givers suffering from the stress and strain of caregiving. On the basis of their research results Görgen et al. (2002) do not agree with this focus. On the basis of an analysis of counselling cases concerning abuse which were dealt with on a crisis- and counselling telephone service, they claim that explanations for abuse against elderly persons in need of care which use "strain on the carers" as the main explanatory variable cannot do justice to the heterogeneity of the cases involved. The analysis of data from N = 59 reported cases of abuse showed, that the constellation of family carers acting violently towards their elders constituted only 22 % of all reported cases of abuse against older people. The authors point out that even the *neglect* of persons in need of care is not always considered by family carers as abuse and therefore was not always reported by potential informants because they did not realize that the model project also targeted neglect as a form of abuse. Görgens et al. (taking the very small data base into account) found that violence against older people is almost always violence against women with partners / husbands or sons acting violently towards their partners / wives and mothers respectively.

It should however be remembered that family carers themselves are often subject to acts of domestic violence. These are often a result of excessive demands on the carers due to their self-sacrificing care and their total concentration on the person in need of care, due to putting aside their own needs, as a result of reproaches from third persons or feelings of guilt as well as subjection to verbal and physical abuse from the person in need of care (Hirsch, 2000). A range of differentiated preventive and intervening measures are necessary in order to prevent domestic abuse and neglect and to improve domestic care on a long term basis (BAGSO, 2002).

Hirsch and Meinders (2000) suggest a. o.:

- Advice in advance of caregiving,
- Professional's sensitisation to be aware of domestic abuse,
- information on dementia,
- support in dealing with problematic situations related to caregiving,

- easing the density of the relationship between the caregiver and the person in need of care,
- services to relieve the burden of care for family carers,
- advice and therapeutical supplies (p. 215 ibid.).

1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand

The fragmented and intransparent system of service provision also favours the fact that the legal and illegal domestic care workforce is widely unknown and less investigated. Currently there are no representative or official data available on the subject of care services provided by migrants and legally or illegally employed persons. In 1994 the socioeconomic panel -SOEP- determined about 4 mio. households in Western Germany which regularly employed a "domestic help" and according to estimates about 50,000 foreign persons do undeclared work in the domestic care sector. Private households are the second-greatest grey employment market in Germany. It is estimated that every second female unemployed migrant is employed in the grey labour market particularly in private households (Thiessen, 2002).

In the course of the last few years there has been an influx of domestic careworkers from eastern Europe, particularly from Poland, Czechia and Slovenia, into Germany, mainly in regions near the border, who tend to be employed in private homes. These careworkers are much cheaper than their German counterparts and hold many different types of qualifications. Officially they are employed to do household tasks but in fact they almost certainly take on some caring duties and are often at the disposal of their employers 24 hours a day. The type and amount of tasks carried out by these persons cannot be quantified. The working conditions of domestic care workers in private homes are highly variable and there is no legally minimum quality standard. This emerge also new challenges for protecting care workers with regard to health and safety issues.

Up until now foreign care workers were illegally employed because they only possessed a three month visitor's visa which does not allow employment rather than a work permit. It became necessary to think about issuing green cards for these domestic care jobs. Based on a special decree concerning the ban on recruitment (ASAV, 2002) foreign domestic careworkers can be issued with a work permit for up to three years of full-time, compulsorily insured employment doing as a home help in private homes with persons in need of care in accordance with the Long-term care insurance law. The introduction of the so-called "green card" led to the disappearance of the status "illicit worker". The number of those employed care workers since the introduction of the green card is unknown. However it is thought that the numbers of those still

employed illegally in domestic care are probably still quite high due to the cost of compulsory insurance for those in possession of a green card.

Recent political discussions highlighted the situation of migrant “domestic workers” who care for people in need of care in private households and there is a disagreement related to a limited access to the German labour market. In the course of the EC eastern enlargement and a new legislation it is claimed to make the access easier and to facilitate a three-years social security-based employment in domesitc care (Forum Sozialstation 9, 2004).

Possible strategies for meeting future care needs include policies to stimulate informal care, using migration and other mechanisms to increase the pool of low-skilled care workers, or professionalising care work to attract a more highly educated workforce. Experts concern that the EU enlargement brings with it an imbalance between the location of labour and the availability of jobs, and hence the possibility of migration to take up openings in the care sector in more affluent Member States and the danger of undermining efforts to enhance and professionalise the sector there (European Foundation, 2003).

2 Care policies for family carers and the older person needing care

To illustrate care policies for family carers and the older person in need of care a short overview will be given on the social security legislation and it's consequences for the care and health market:

The German social security system is mainly financed through social contributions and in part through public revenues. The system is based on six pillars:

- Old-age pension insurance (19.5 % of the gross income),
- Unemployment insurance (6.5 % of the gross income),
- Health care insurance (depends on the individual statutory health insurance provider, but on average about 13.5 % of the gross income),
- Accident insurance,
- Long-term care Insurance (1.7 % of the gross income),
- Social aid (taxes).

The scope of the long-term care insurance was extended in order to do justice to the requirements of older people with "considerable general care needs" (§ 45a, SGB XI,) and their families by developing service structures which offer low-threshold care services. Examples of such services are the instruction of voluntary workers who can relieve family carers for periods of a few hours at a time, the further development of groups for persons suffering from dementia, day-care and individual care for these persons and improved counselling (§ 45c, 3 PflEG, 2001). It was necessary to complement the long-term care insurance since the legal definition of "need of care" in the long-term care insurance is heavily related to the amount of "hands on-care", but does not include the amount of time spent on elderly in domestic care who are cognitively impaired.

Due to the fact that a wide range of highly specialized care services are financed through different sources (social contributions, public revenues or private funds) locally different structures developed with the allocation of various responsible authorities, agencies, non-profit and private institutions and the system of care and health provision remains intransparent and disintegrated (Schmidt, 2002). Both the historically rooted institutional and financial separation between the health- and social sector and the separation between the in-patient and out-patient care sector is deeply fixed (Roth and Reichert, 2002).

This makes it very difficult for those in need of care and their family carers to find appropriate services which cover their special needs. Since the early eighties it is complained about the lack of transparency, coordination and efficiency of the social and health care provision associated with gaps especially concerning the transition from the in-patient to the out-patient care sector.

Quality criteria and the implementation of a widespread system of care and case management as well as interdisciplinary collaboration and cooperation between service providers are necessary in order to solve these "interface problems" (Schaeffer, 1999).

Summarizing the German system of healthcare provision can be partitioned in the following levels and sub-systems:

- Care-sectors: out-patient care, intermediate care and in-patient care,
- Care-stages: Primary care up until specialized facilities,
- Areas of care: Health promotion, prevention, curative treatment, rehabilitation and palliative care,
- Professional groups: medical doctors, nurses, therapists, social workers, pastoral care et al.,
- Professional and non-professional care from high-specialization to laymen (family members, neighbours or volunteers),
- Purchaser: statutory health insurance (SGB V), Long-term care insurance (SGB IX), private health insurance, purchaser of rehabilitation measures, (SGB IX), the Federal Law on Social Assistance –BSHG-, pension insurance companies (SGB VI) et al.,
- Purchaser of benefits: state-run, non-profit or private (Döhner, Kofahl, 2001).

2.1 Introduction: Family ethics and expectations - the national framework of policies and practices for family care of dependent older people

In Germany domestic care takes principally a higher priority than in-patient care as well as medical rehabilitation before care and the long-term care insurance motto "out-patient care before in-patient care" expresses the intention of the legislative to promote the willingness to provide family care for persons in need of care. It is a reflection of the fact that the German welfare state still reckons with the stability of family networks of informal carers (Daatland et al., 2003). Based on their research outcomes Runde et al. (1999) assume that social expectations, attitudes and the emergence of "family ethics" related to family care- giving depend on the internalization of social norms and are independent of the individual caregivers situation.

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2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important?

Representative data (Runde et al., 1999, 2002) on the influence of the long-term care insurance on expectations and behaviour towards family care-giving show that two thirds (N = 2,130) of all interviewees have attitudes towards family care-giving which are influenced by social-normative expectations. The results confirm the hypothesis that family care-giving is not so much something that can be legally recovered but is rather a culturally influenced and a regulative model for social relationships within the family.

About two thirds of all interviewees are also of the opinion that family members are morally obliged to look after each other. Only around 5 % of all care-households had solely attitudes that were orientated towards their own advantages. Nearly every second interviewee (42 %) do not see that the social-normative obligation for family care-giving is being completely free of utilitarian considerations und therefore they do not perceive it as purely altruistic. Moral obligations and financial considerations are not mutually exclusive because most of those who felt morally obliged naturally took over family care-giving; but financial compensation is to be seen in a sense of support for the family carers efforts.

A comparison of the generations 30-50 years old, 50-70 years old and > 70 years old showed that older people (> 70) are more often of the opinion that relatives are morally obliged to take care of family members (67.5 %) than the younger generation in the age group 30-49 years. Only 58 % of this age group were of the same opinion. No significant differences in the normative attitudes towards taking care of relatives were found between different occupational milieus specific to certain social strata. The importance ascribed to moral obligation is a general attitude independent of social strata. However the proportion of those who feel morally obliged and who at the same time also expect financial compensation is 10 % higher in workers households than in academic households (ibid.). The willingness to take on family care-giving is in the foreground in low class milieus whereas residential care is least accepted. In middle class milieus among people with a high social status the willingness to take on family care-giving is minimal whereas residential care is widely accepted (Klie, Blaumeister, 2002).

According to comparative data (Runde et al., 2002) from 1997 and 2002 the authors assume, that the willingness to take on the family care-giving is decreasing (see table 11): It is noticeable that only 45 % of all interviewees asked in 2002 were of the opinion that parents have a right to be cared for by their children. This represents a decrease of 10 % since 1997. The decrease concerning the care of marital partners from 71.1 % in 1997 to 62.3 % in 2002 is also conspicuous. Fewer and fewer people see the statutory long-term care

insurance as a measure which promotes solidarity between the generations and which encourages people to take care of their relatives.

Table 11: Changes on the willingness to take on family care-giving attributed to be an effect of the long-term care insurance in %

Moral attitudes in care-giving households	Year of data collection	
	1997	2002
Moral obligation to take on family care-giving **	58.7 (N = 1,060)	52.1 (N = 1,189)
Parents are entitled to care through children	55 (N = 1,057)	45 (N = 1,187)
Entitled to mutual care by a marital partner	71.1 (N = 1,041)	62.3 (N = 1,176)
The Long-term care insurance promotes solidarity between generations *	49 (N = 1,036)	46.3 (N = 1,142)

Source: Runde et al., 2002, pp. 9,13 (own translation) * $p=0.05$; ** $p=0.001$

Solidarity between the generations continues to be a cultural model and is still important within society. However it is losing it's meaning to be a societal norm in the sense of a moral obligation to take on family care-giving. The social normative attitudes concerning moral obligations are losing ground and at the same time rational calculations are on the increase due to the fact that resources provided by the Long-term care insurance law puts at the disposal of family members which can be used according to rational choices. The sum of benefits available and a norm which is orientated towards individual preferences and needs will be gradually pushed through as motivation to take on family care-giving.

The research data confirm the trend seen in 1997 when 40 % of interviewees were of the opinion that the state was exclusively responsible for the provision of concrete support concerning family care-giving and quality control of the care given. Runde et al. assume that the socio-political aim of the long-term care insurance to promote the willingness of family members -or other informal carers- to take on family care-giving must be called into question due to a decrease in acceptance of this insurance (Runde et al., 2002).

The recent research data of the Freiburg carers study ("Freiburger Pflegestudie", N = 1,432) show how the effects of the long-term care insurance have been integrated into arrangements for domestic care under very different social and biographical conditions. According to Klie and Blaumeister (2002) future generations will be involved to a much lesser degree in family care-giving, not only as a result of demographic developments but also due to shifts in the social milieus. The traditional reliance on care resources within the family will become less and less relevant in a "cultural" sense and the moral orientation will also lose it's meaning regarding the decision to take on family care-giving as the costs involved begin to play a central role in decision-making.

2.1.2 Are there any legal or public institutional definitions of dependency - physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?

The legal definition of dependency related to "need of care" connected with a legal entitlement to benefits for caring was defined and laid down as an insurable risk with the enactment of the long-term care insurance in 1995 as the last pillar of the social security system. It allows to cover the risks which are associated with the need for care. The political goals were to stabilise domestic care arrangements, reducing individual poverty and public welfare spendings as well as enhancing the infrastructure and improving the quality of social care services (Tesch-Römer, 2001).

The provision of care to those in need of it was expressed as the responsibility of the population as a whole (§ 8, SGB XI) and as a legal entitlement based on specific criteria. The need of care is defined as follows: *"Persons who require a moderate or considerable amount of assistance with habitual and recurrent daily activities over a longer period, probably for six months, as a result of physical, mental or psychological illness or disability can be defined as in need of care"* (own translation, § 14, ibid.). The benefits include medical and other benefits necessary for rehabilitation in order to prevent disablement or need for care, to eliminate or minimize an existing disablement or need of care or to prevent a deterioration of the situation (§ 11, 2 ibid.).

The need for care of individual persons is not related to age and is assessed by the medical advisory board which is a part of the statutory health insurance institutions (Medizinischer Dienst der Krankenkassen). Based on their assessments persons in need of care are assigned to one of the 3 care categories (The table 12 lists the care-dependent benefits). There is also a regulation for cases of particular hardship when the need for care is in excess of the third care category. Entitlement to claim benefits is based on needing help with carrying out at least two basic and additional instrumental activities of daily living (ADLs and IADLs) for an expected period of at least six months. Persons in need of care at home can either choose between benefits in kind for community care or for benefits in cash, but it is also possible to combine the different kinds of benefits.

Roughly 71 % of those in need of care draw benefits in cash instead of applying for benefits in kind and then organize care themselves; 12 % of those in need of care draw benefits in kind and make use of professional services and 15 % combine benefits in kind and in cash (Infratest Sozialforschung, 2003).

Table 12: Long-term care insurance benefits in order of care categories in Euros and amount of care (SGB XI)

Care cate gory	Amount of care	Outpatient Monthly benefits in kind in € (professional care)	Outpatient Monthly benefits in cash in € (non-professional care)	Inpatient Benefits in kind in € (for professional care)
1	at least 90 minutes a day	384	205	1,023
2	at least 3 hours a day	921	410	1,279
3	at least 5 hours a day *and* need of care round the clock	1,432	665	1,432 (hardship case: 1,687)

Source: Long-term care insurance (SGB XI, §§ 15,36,37)

2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psycho-social support or similar)?

The legal provision for providing physical care can be derived on the one hand from the benefits for activating nursing care in the case of need for care granted by the long-term care insurance (see also 2.1.2) and on the other hand from the hospital mandate for the provision of services (§§ 108, 109, 111 SGB V). These are responsible for the provision of physical care in the form of medical treatment, domestic care, home-help and the provision of medicines, remedies and therapeutic / technical aids as well as medical rehabilitation (§§ 28, 37,38 40, SGB V). These measures are intended to avoid an impending disability or need for care, to correct the disability or to prevent the deterioration of the state of health (§ 11, SGB V).

Related to care provision in primary health care the general practitioner -GP- holds the responsible key position when it comes to gaining access to therapeutical, medical-rehabilitative and caring measures (§ 73, SGB V). Apart from medical treatment the GP can also prescribe other measures such as ergotherapy, physiotherapy, speech therapy and domestic care as so-called treatment care to avoid or shorten a hospital stay (§ 37, SGB V). This is to be given to those in need of care by suitable nursing staff for a period of up to four weeks. The professional nursing staff are not permitted to write prescriptions and rely on the GP to do so for them.

Persons who are in need of psycho-social support in daily living and are not able to take adequate care of themselves due to physical, psychological or mental disabilities and who are therefore dependent on care given by third persons are legally protected to safeguard their civil rights (BtÄnG, 1998). An increasing number of older people suffering from dementia fall into this category. This legislation is enacted to allow as much integration of these persons into the rest of society as possible. It should also promote an independent lifestyle or help those involved to regain independence. This law applies to persons who are over 21 years of age. In the course of the psychiatry reform community-based social-psychiatric services were enlarged. Based on the country-specific legislation these services act (not only) for older people who are in need of psycho-social support. It is also imperative that out-patient care takes a higher priority than in-patient care and these services perform advisory functions as well as preventive or psychosocial care and partly also medical treatment. Furthermore social-psychiatric services are entitled to administer mandatory tasks in order to admit mentally ill people to the hospital. There is still a great lack of community-based social-psychiatric services with local and regional varieties (Bäcker et al., 2000).

This form of psycho-social support or care can only be ordered when a need of care is evident which can be put down to one of the diseases or disabilities which are listed in the care legislation. These include: psychiatric illnesses, psychological, physical and mental disabilities such as dementia or other forms of age-related mental decline. Disease or disability alone do not make persons eligible for the protection of the care legislation (BtÄnG, 1998). A need of care must also be determined. A third person who takes charge of matters for the person in need of care can only be appointed when the persons involved are partially or totally unable to deal with their personal matters due to the disease or disability. A medical report must be written on the expected duration and extent of psycho-social support required. The legal position of the person in need of care is only intruded on when absolutely necessary and the legal representative can only act to a very specifically defined extent on behalf of the person in need of care.

Under consideration of an allocation limit older people who have become dependent on financial support in daily living can apply for social assistance and so-called "help in difficult situations" (§ 27, BSHG, 1984) financed from public revenues in the responsibility of the local authorities[3]. Usually the following forms of support are provided: Support in order to build up or secure the basis of livelihood, support for the ill, preventive and other support, support for the integration of the disabled, domestic support, support for the blind, care support, support in particularly difficult social situations and support for the elderly (§ 27,1 ibid.). There are no age limits for these forms of support.

The "help in difficult situations" can be applied for when it is not possible for the person in need of financial support to require the money from his / her income and savings. The subsidiarity principle applies; this means that state

[3] In the course of the ongoing social legislation's reform the social assistance and unemployment benefits are merged under one administration.

support can only be provided when no other resources within the family are available. Older people often do not apply for social welfare benefits because they fear that their children will have to pay for support instead or because they find it humiliating to be forced to ask the state for support. In the course of the pension reform a law on the cover of basic social security came into force on January 1 / 2003 with the intention of preventing old-age poverty among elderly people who will be ashamed of taking benefits from social aid (GSiG, 2002).

2.1.4 Is there any relevant case law on the rights and obligations of family carers?

Apart from the entitlement to benefits which guarantee social security for the family carer under certain circumstances and access to courses on caregiving techniques free of charge (§§ 44,45, SGB XI) there are no particular laws which lay down family carers rights and obligations.

2.1.5 What is the national legal definition of old age, which confers rights (e.g. pensions or benefits)

The legal definition of old age stems from the conditions which must be fulfilled in order to draw an old age pension and which are laid down in the social pension insurance: *"Insured persons are entitled to an old age pension when they 1. are 65 years of age and 2. also have fulfilled the general waiting time"* (§ 35, SGB VI). Many companies and also the public sector negotiate with their employees to enable them to retire earlier under certain financial conditions.

Demographic and economic reasons led to a current political discussion on more flexibility and higher legal age limits for an old-age pension.

In many public areas people aged over 60 or 65 years are conferred benefits in the form of cheaper tickets for public transport (bus or railway), museum, swimming-pools or theatres.

2.2 Currently existing national policies

As aforementioned the German social security system as well as the related legislation is fragmented and intransparent, and as a result various different measures for family carers, disabled persons or working carers represent different areas of responsibility within social rights.

2.2.1 Family carers

The long-term care insurance (SGB XI) was introduced to allow seriously ill patients and persons in need of care to stay at home as long as possible and to encourage family care giving. It isn't aimed at fully financing all the long-term

care benefits, but is supposed to reduce the financial burden of persons in need of care and the family carers (Igl, 1995, Klie, 1996, Döhner, Kofahl, 2001). This political goal can only come into reality when family carers are encouraged and maintained to take over the role of caregiving. Therefore a set of benefits is financed through the long-term care insurance in order to ease the burden for family carers:

- Benefits in kind (§ 36),
- Benefits in cash for self-organized support (§ 37),
- Combination of benefits in kind and benefits in cash (§ 38),
- Professional domestic care in the absence of caregivers (§ 9),
- Nursing aids and technical aids (§ 40),
- Day care and night care (§ 41),
- Respite care (§ 42),
- Care in nursing homes (§ 43).

Based on the world action plan of ageing, which was passed in Madrid in 2002, and as a part of the federal government coalition agreement a new law on structures for the support of the elderly (Altenhilfestrukturgesetz, 2002) has been under construction. It is composed of one section on the subject of participation of the elderly and one section on support for the elderly. The second section is designed to improve the quality of counselling and care. It's aim is to do away with structural deficits which are caused by a confusing range of different services and service providers who take on various tasks and whose services are often of uncertain quality. It is intended to systematize, coordinate and ensure preventive measures, counselling and other support and care services. In addition this law tries to target gender-specific differences among family carers in order to improve their situation accordingly. The further discussion about this law has been postponed due to political reasons.

Another important initiative pertaining to the improvement of the quality of care in the home health and in-patient sectors, the so-called 'Round Table on Nursing' (Runder Tisch Pflege), which was called into being in August 2003 (until 2005) by the Federal Minister of Family, Senior Citizens, Women and Youth and the Federal Minister of Health. This "Round Table" is intended to describe examples of best-practice in the in-patient and domestic care sectors as a means of orientation. Examples for possible fields of action are:

- an improved support and promotion of low-threshold care services to strengthen the position of domestic care,
- an improved support and promotion of new residential forms and
- the increased integration of volunteers into current service structures.

With regard to family carers the "Round Table" should answer the question of how the position of persons in need of care and their family carers can be improved and it should search for ways of promoting public awareness (DZA, 2003, BMGS, 2004).

2.2.2 Disabled and / or dependent older people in need of care / support

Germany has taken over the WHO's international classification of disability (WHO, 2001) in it's legislation -Rehabilitation and Participation of Disabled People (SGB IX, 2001). The term does not concentrate on deficits but rather on the possibilities and limitations of participation in the society. The political goal is to guarantee disabled (not only elderly) people or those threatened with disability self-determination and equal participation in society as well as enforcing the ban on discrimination which is laid down in the German Constitution. Participation in society should be guaranteed with the help of medical, occupational and financial benefits. In the year 2001 6.7 million severely handicapped persons lived in Germany and the quota of disabled persons rises with increasing age: Two thirds of all seriously handicapped persons in 2001 were older than 60 years and in about 90 % of these persons the disability can be put down to illness (Hoffmann, 2003).

According to the formulation a person is disabled and in need of support when *"their physical functions, mental abilities or psychological health most probably deviate from the state typical for their age group over a period of more than six months and therefore impends on their ability to participate in society. A person is threatened with disability when the above mentioned situation can be reasonably expected"* (own translation, § 2, SGB IX, 2001).

Benefits for medical rehabilitation (§ 26) and prevention (§ 3) are supposed to prevent the occurrence of disability including chronic illness. These have priority over the benefits granted by the long-term care insurance - "rehabilitation before care" (§ 8, SGB IX). The following benefits belong to this category:

- General medical, psychological and educational support such as medical treatment, alternative healing methods,
- remedies, physiotherapy, speech- and occupational therapy,
- arrangement of contacts with consulting agencies and self-help groups,
- the promotion of self-help potential,
- psychological support to stabilise and enhance social competences and psycho-therapeutical treatment,
- training in everyday abilities are preventative measures implemented to ease the strain on family carers
- and instruction and motivation to take up the benefits of medical rehabilitation.

2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job sharing, part time work, etc)

Up until now working carers in Germany have not been entitled to any legally defined company measures to help make caregiving and occupational activity more compatible. Flexible working hours are one of the widespread methods implemented in order to promote the compatibility of family responsibilities and occupational activity. In 2001 a law on part-time work was introduced which makes it possible for employees to demand a reduction of their working hours. However employers can refuse this on certain internal company reasons. Up until now only scattered initiatives from usually large firms which agree on flexible hours or job sharing with employees can be observed. Leave in order to take care of relatives can be granted for short periods or for up to one year and can be granted with or without wage adjustment. It can be estimated that roughly one third of all employed adults support or administer family caregiving (Reichert, Naegele, 1997,1999).

On the basis of their research Bäcker and Stolz-Wittig (1997) have a very pessimistic view on the compatibility of occupational activity and care-giving in Germany: It is not predictable when unions and management will be willing to give widespread attention to matters concerning the implementation of working time regulations which make family care-giving possible for employees. The federal government has made specific suggestions regarding job-sharing, flexible working hours, working time accounts, home and long distance work and leave over long time periods. In order to make company managements and works committees more aware of this problem the Federal Department for Family, Citizens, Women and Youth -BMFSFJ- issued practical guidelines for *"the compatibility of occupational activity and care-giving: company measures to support family carers"* (BMFSFJ, 2000). The CDU (Christian Democratic Party) in Düsseldorf (Northrhine Westfalia) recently demanded the CDU federal fraction to bring an initiative for the creation of unpaid care leave for employees into discussion in parliament. This should lay down a right to re-employment after a period of care leave in the same way as this is made laid down in the context of parental leave. In addition an entitlement to the payment of pension contributions financed by income taxes such as the entitlement during parental leave shall be considered. In it's last session the Conference of the Ministers of Labour and Social Affairs decided to examine the suggestion made by the Saarland to introduce care leave comparable with the existing legal parental leave because the introduction of care leave "would be of great relief to home health care (…)." (Forum Sozialstation, 2003).Critics fear that women will once again have to shoulder the main burden of family caregiving if these plans are translated into action.

2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people ?

Federal laws must be implemented in each federal state through state laws or the states statutory orders. The federal law decrees that the federal states, the local authorities, the long-term care insurance companies and the medical services should work together on regional and local level to work on the further development of the structures of care provision and to adapt on the special regional or local needs (§ 12, SGB IX). There are great differences between the federal states as well as the aims in their regional health and care policies. Regional, institutionalized teams, so called 'Care Conferences', were called into being as coordinating instruments in order to network all activities related to the process of care provision (§ 8, SGB XI). Their task is to work on the securing and the further development of care provision structures including supplementary support. The counties and cities, the representatives of care institutions, the health care insurance companies including their medical services, the local senior citizens representatives and local self-help groups for the disabled, for persons in need of care and for people suffering from chronic illness are members of these teams. The work of these conferences has several aims:

- Information and transparency through mutual briefing and public relations work,
- the building up of networks which connect all committees, work groups and other bodies which are responsible for the provision of care on the local level with each other and the coordination of institutional procedures,
- the planning of a care infrastructure which is laid down as the responsibility of the local authorities and in which the Care Conference should participate.
- The Care Conference is also responsible for the implementation of the quality standards
- and for the development of quality control instruments.

These Care or Health Conferences have taken place at different times from state to state and also vary greatly in structure, even on local and community level and from suburb to suburb; they focus on different topics with a strong orientation on special local or regional needs.

To illustrate the resulting heterogeneity of activities and approaches three projects will be exemplified from the town of Hamburg:

- The 'Harburg Care conference' (a district of the town of Hamburg) has been implemented in 1998 and incorporates several service providers such as purchaser, the social welfare office, the advisory board of the elderly and the advisory board in residential homes. Among other activities the health conference gives information about advice centres for persons in need of care and for family carers.

- The model project for regional Case- and Care management in help for the elderly -MoCCA-, a community-based project in the Hamburg district Wandsbek tested the working-methods care- and case management in the course of a regional action plan for building up networks and individual planning of help and has been accompanied by research (Kofahl et al., 2003). The main aim also focussed on a better support for elderly in need of care and their family carers.
- The third example which has been conducted in two model regions in Hamburg is the model project -PAGT- 'the out-patient gerontological team' (Das Ambulante Gerontologische Team). The main aim of this project was to keep or to regain the quality of life and the self-determination of elderly people in medical treatment through their general practitioner and their relatives. To achieve this aims an individual needs-orientated treatment should be carried out by an interdisciplinary cooperation between the general practitioner and a patient's attendant (Kofahl, Döhner, 1997, Döhner et al. 2002, Kofahl et al., 2003).

2.4 Are there differences between local authority areas in policy and / or provision for family carers and / or older people ?

As aforementioned in 2.3 the federal laws must be implemented in each federal state legislation through state laws or the states statutory orders which explains local differences in general. In addition the local authorities play a role in the granting of mandates for the provision of care in their function as the providers of social security benefits. Therefore they have the chance to identify and define shortcomings in the local organization and implementation of care provision for family carers or / and for older people (see also 2.3).

3 Services for family carers

Recent representative research data revealed that only a minority of family carers fall back on complementary services like counselling and other supplies of support. Only 7 % (N = 1,060) of family carers regularly talk with professionals. About 4 % regularly use counselling by telephone, about 19 % occasionally; about 6 % regularly visit coffee-groups for family carers or counselling hours. Only 2 % meet in private self-help groups and 3 % regularly meet in groups for family carers with professional counselling. Only about 16 % of all family carers regularly and about 37 % occasionally take up counselling and advice (Infratest Sozialforschung, 2003, p. 24).

Related to a broad provision of different services the Alzheimer Society Germany and the Federal Association of Advice Centres for Older People and Family Carers (BAGA) belong to the most important pressure groups in Germany who attend older people's and family carer's interests. Their work is mainly voluntary based.

The Alzheimer Society founded in 1989 in Germany is a federation of family carers of older people suffering from dementia, professionals and self-help groups in order to stand up for the interests of older people and their family carers. The society is the federal association of several regional associations as well as of 77 local Alzheimer Centres.

The society calls for

- adequate consideration of older people suffering from dementia through the long-term care insurance (realized meanwhile by the 'Law on Supplementary Care Benefits'-PflEG-),
- support for family carers and self-help,
- the development of a nation-wide network of advisory centres for family carers,
- the diagnose of the Alzheimer disease in an early stage
- and infrastructural changes in nursing homes - e.g. special training for professionals- in order to improve the quality of life of older people suffering from dementia in residential care.

In order to achieve these aims the society has developed a great variety of activities such as:

- comprehensive information to the public,
- support, advice and counselling to family carers and older people,
- information exchanges for family carers and professionals,
- courses on the subject of dealing with persons suffering from Dementia,

- an Internet chat forum,
- discussion rounds as well as self-help groups for family carers
- and publishing brochures dealing with different topics.

The Federation of Advice Centres for Older People and Family Carers (Bundesarbeitsgemeinschaft der Beratungsstellen für ältere Menschen und ihre Angehörigen) -BAGA- is another important pressure group in Germany. The BAGA has elaborated standards for psychosocial advice of older people and their family carers as well as criteria for giving successful advice to elderly people (BAGA e.V., 1999).

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)			X	X[4]				
Counselling and Advice (e.g. in filling in forms for help		X		X[5]				
Self-help support groups		X		X[6]		X		X
"Granny-sitting"		X		X[7]		X		X
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X		X[8]	X[9]			
Weekend breaks		X		X[10]		X[11]		
Respite care services		X		X[12]				
Monetary transfers			X	X[13]				
Management of crises				X[14]		X[15]		
Integrated planning of care for elderly and families (in hospital or at home)				X[16]				
Special services for family carers of different ethnic groups		X			X[17]	X		
Other								

[4] laid down in the long-term care insurance law and conducted by the Medical Advisory Board assessing the level of dependency
[5] The long-term care insurance companies are bound to counselling and advice (§ 7 SGB XI)
[6] can be funded by the health insurance § 20, 3a, SGB V
[7] Long-term care insurance promotes model projects who educate people as "voluntary senior citizens companions" for older people suffering from dementia aimed to releave family carers. This could be named "granny-sitting" in a broader sense.
[8] Long-termcare insurance companies are obliged to offer courses for family carers and volunteers (§ 45)
[9] The courses are also offered by professional nursing services and charitable organisations and are for free.
[10] Day care is sometimes offered also on week-ends but is scarcely developed and less available
[11] Partly offered by some non-profit organisations or private charitable societies like "Hamburgische Bridge"
[12] Benefit of the long-term care insurance but with great differences in availability between rural and urban areas
[13] Only benefits in cash through the long-term care insurance which can be seen as cash-allowance for family carers
[14] In the course of 'benefits for medical rehabilitation' to prevent, remove or to lessen handicaps or chronic illness (§ 26, SGB IX)
[15] also offered by self-help groups or charitable societies
[16] In the state of planning: Introduced in the course of the "Health Modernization Legislation" in 2004: § 104 a-h 'integrated care' to reduce intersectional problems in the continuity of care provision. See also the different model projects described in ProNetz
[17] Regional model projects

3.1 Examples

3.1.1 Good practices

See 3.1.2

3.1.2 Innovative practices

In the different federal states there are many model projects with various foci and aims. They all aim to promote the transparency of the social and health services by building up networks and supporting cooperation between the different services offered, especially between the in-patient and out-patient care sector. The relevant subsystems should then be able to tailor their benefits more fittingly to the needs of family carers and persons in need of care. A solid cross-section (N = 58) of innovative and good practices aimed on improving the quality of life of elderly people in Germany have been gathered through the research project ProNetz (Kofahl et al., 2003) and investigated innovative elements such as the existence of:

- community-based networks,
- the orientation towards institutions,
- a focus on target groups,
- a network management,
- public relations,
- interdisciplinary work groups,
- further education for professionals (interdisciplinary; N = 38),
- information and advice centres (N = 41),
- coordination centres for professionals,
- Guides (N = 19),
- A full-time Case manager (N = 34),
- a disease-focussed management,
- screening / Assessment-instruments (N = 41),
- case-management elements (N = 33),
- individually focussed documentation,
- accompanying services,
- support services for family carers,
- work with volunteers,

- the project is accompanied by scientific research (N = 36).

(see also the Appendix for more details)

Nearly all projects have integrated supplies to support family carers: either information and advice, training, measures to relieve the burden of care or all together such as talking rounds or weekend breaks for family carers and the older person suffering from dementia (ibid. pp. 81-90). One example for this kind of care and support is the 'Hamburg Bridge' (Hamburgische Brücke), a society for private social work founded in 1913.

Some of the model projects being investigated through ProNetz are listed in the following and should act as an example for good and innovative practices:

- The "Network for the Aged" (Netzwerk im Alter) was grounded by the organization "Albatros" in Berlin-Pankow (Berlin) in order to promote the cooperation between all institutions concerned with the provision of care for older people. A binding case management and transition system and qualification programmes for networking were developed and tested. In additon relatives were qualified and a complaints management office was called into being. This network made the social services more transparent to family carers and improved their consumer competencies.
- The Network for Geriatric Rehabilitation (GeReNet.Wi) in Wiesbaden (Hesse) concentrates on problems which arise in the context of intersecting areas between old age care institutions and the health care system (Dialog, 5, 2003). A course which qualifies people as "voluntary senior citizens companions" is offered by the Department for Social Work in Wiesbaden with the intention of lessening the burden of care and giving support to family carers. The main focus of this service is on voluntary work and the psychsocial assistance of family carers who are in need a few hours of free time.
- The project "Fourth Phase of Life" in Stuttgart (Baden-Wuerttemberg) and "KUNZ" which is a church neighbourhood centre set up by a parish in Bielefeld (Northrhine Westfalia), also put the idea of voluntary helpers and community centres into practice. In addition to the reduction of strain on family carers through voluntary helpers a main aspect of these projects is the development and promotion of services for older people living alone which cater to their specific needs.
- The project "HALMA" e.V. in Würzburg (Bavaria) offers support for cognitively impaired people by arranging volunteers to releave family carers by the hours.
- The project "GeNA" -a gerontopsychiatric network of family carers in Neustrelitz (Mecklenburg-Western Pomerania) focusses on building up networks of existing supplies to support family carers and to look for needs- orientated supplies.

- Caregiving courses are also offered to the target group of migrant caregivers, for example a course in Wiesbaden offered to Turkish migrants in the Turkish and German languages, a future-orientated service which is tailored to fit the needs of the growing group of migrant carers (www.seniorennet.de/). Another project taylored for elderly chronically ill migrants and their family carers is carried out by two charitable organisations in Berlin: Arbeiterwohlfahrt -AWO- and Caritas (for more details: Kofahl et al., 2003).

Furthermore the Federation of Advice Centres for Older People and Family Carers –BAGA- has published a manual for professionals on how to give advice and support family carers of older people suffering from dementia. This manual incorporates best practice and innovative projects focussed on groups for family carers, practical training, support groups for older people suffering from dementia, advice and counselling in domestic care environment, volunteer services, café for family carers or the Alzheimer-dancing-café. The reader is completed by comprehensive information related to family caring, folders and the relevant legislation (BAGA 1999).

4 Supporting family carers through health and social services for older people

According to data collected by the German Board of Trustees of Help in Old Age (Kuratorium Deutsche Altershilfe –KDA–) there is little general knowledge about the services on offer in the population as a whole (KDA, 2003) and recent representative data revealed (Infratest Sozialforschung, 2003) that about 18 % of the households (N = 3,622) refer to the fact that the older person in need of care or help doesn't receive sufficient help (ibid. p. 32).

In some regions -mainly in rural areas- there are still large gaps in service structures which have a particularly negative effect on caregivers taking care of terminally ill relatives and persons suffering from dementia or from chronic illnesses as well as on migrant families or people in precarious social situations.

In order to analyse the situation regarding service provision it is necessary to take a closer look at small area analyses; general statements about service provision are not possible (Walter and Schwartz, Schultz-Nieswandt, 2000). The research data revealed that the provision of doctors, therapists, in-and out-patient services and hospices is best in cities and the surrounding countryside, whereas a positive correlation between decreasing community size and lower provision scores could be observed. A lack of suppliers of remedies and aids and of provision with speech therapists and chiropodists was determined. In comparison to urban areas with many self-help groups and associations there is a general lack of diversified counselling and provision of services for family carers in rural areas. Family carers and the persons in need of care complain about the lack of information services pertaining to professional care giving and experience deficits with regard to social communication and participation in society because mobile services combined with meeting places and visiting services are few and far between (Busch, 1999, 2000, Haupt, 2001).

On the whole the service structure does not reflect a need led approach but rather still tend to be organized according to the categories of a service led approach which does not necessary offer family carers the services they really need (Schaeffer, 1999).

In urban areas networking activities are more frequent to be found which expresses the tendency towards a higher complexity of urban care provision with a greater variety and higher density of supplies than in rural areas (Kofahl et al., 2003, p. 39). According to research data from Northrhine-Westfalia Roth and Reichert (2002) assume that the structural differences in social and health service provision between rural and urban areas will come into alignment with each other in the long run due to processes of “suburbanisation” (ibid. p. 15, 2002).

4.1 Health and social services

Since the introduction of the statutory long-term care insurance a diversified and intransparent market of independent charitable and private out-patient services has emerged. This quantitative expansion and the regionally dense network of services as well as a focus on types of financing tailored to the "classic long-term care insurance patient" (Schaeffer, 1999) has not been followed by qualitative improvements in the social and health care services tailored to the special needs of certain groups. Complementary services such as shopping, visiting services, accompaniment to doctors and other local services, gardening and household maintenance are not offered although the need for these "light" services has been determined (Ühlein, Evers, 2000). In general the density of health care institutions decreases according to a reduction in community size and centrality. Community based intervention programmes for the improvement of health care in particular in rural areas are difficult to implement as a result of the lack of cooperative structures and partners (Walter, Schwartz, 2000).

4.1.1 Health services

4.1.1.1 Primary health care

The primary health care sector is widely developed with doctors, therapeutic groups, professional nursing services and social services[18]. The office-based physicians or general practitioners have a legal monopoly on the provision of primary health care (Busse, 2002). They play a key role in the access to medical treatment, rehabilitative measures or other therapeutic groups and professional nursing services. The access to the primary health sector is open for every person statutory or privately secured and has been for free at the point of use until January 1st 2004[19].

According to the work of the different professional groups in primary health sector there is generally neither cooperative relationships nor benchmarking of the contents (Kauss et al., 1998).

The family practitioner is usually the first person family carers consult if they need advice and information about the domestic care situation. There are considerable regional variations in the medical service density. With regard to the availability of health care provision through general practitioners in rural areas it is considered to be quite serious because of the fact that country doctors

[18] The association of panel doctors takes the responsibility in order to fulfil the service guarantee in the provision of medical doctors and specialists (§ 72, SGB V); the long-term care insurance takes the responsibility in order to fulfil the service guarantee in the provision of care (§ 69, SGB XI).

[19] In the course of the health modernization law (GMG 1.1.2004) statutory insured patients have to take a stake in the costs for the health insurance: Among others they have to pay a 10 Euro one-off-bill charge (‚Praxisgebühr') quarterly. See also the table in 5.7.5 for more details.

have the longest working hours and the lowest incomes. This makes such work unattractive for the forthcoming generation and many family doctors in rural areas cannot find any successors and must close down their practices (Lichte, 2000).

However, regardless of his or her extensive medical knowledge the general practitioner is limited in his / her ability to give advice on matters concerning caregiving, social and psychosocial support. Further qualifications in geriatric medicine also tend to be rare. This is one reason why general practitioners often don't seem to see the need for rehabilitative interventions such as physiotherapy, occupational therapy or speech and language therapy for older people, which he or she must usually prescribe.

General practitioners and dentists offer various home services such as fitting of dentures or home blood tests although it is important to note that there is a difference between the services available in urban and rural areas.

The concept of health visitors is not part of the German primary health care system and could represent an important new professional area of responsibility for specialised nurses. In the context of health promotion, counselling and advice and also quality control the concept of "preventive home visit" by nurses, geriatricians or occupational therapists is currently being tested as a form of individual support (von Renteln-Kruse et al., 2003). This concept in particular focussed on the older person in need of care could be systematically broadened towards family carers and they could be given close-meshed advice on questions of caregiving, prevention and complementary support and precarious home care situations could be avoided.

Another important link in primary health care is the hospice movement in the out-patient sector who care for terminally ill or dying people and visit them as well in domestic care as in in hospitals and also residential care (see 4.1.1.4 for more details).

4.1.1.2 Acute hospital and Tertiary care

In Germany there is a high medical service density in hospital beds (see table 13) and in general the hospitals are easily accessible without long waiting lists.

EUROFAMCARE – National Background Report for Germany

Table 13: Type and capacity of hospitals

Hospital type	Total number	Capacity (beds)
General hospitals < 49 > 1000 beds	1,195	500,441
Physician attendance hospitals	202	8,768
Other hospitals	196	36,438
Day and night clinics	49	No entry
Military hospitals	5	807
Total number of institutions	2,242	559,651

Source: Statistisches Bundesamt 2003b

Several problems occurring in the management of discharge from in-patient to out-patient care sector also concern older people in need of care with chronic diseases and multi-morbidity who need support and care from different social and health services and family carers. Recent research data (Braun, Müller, 2003) confirmed once more the gaps in the continuity of care provision when patients are discharged from in-patient to the out-patient care sector:

- 88.9 % of the patients being interviewed (N = 2,953) didn't receive a place in short-term care,
- 92.2 % (N = 2,957) didn't receive a place in residential care,
- 69.9 % didn't receive professional nursing services,
- 32.7 % (N = 3.000) didn't receive a medical prescription through the general practitioner on domestic care to avoid hospital treatment (§ 37, SGB V),
- 29 % didn't receive a medical prescription on remedies and adjuvants,
- 66.2 % (N = 2,970) of the interviewees didn't get home help,
- but more than 80 % (N = 3,078) easily received family care provision.

It has to be taken into consideration that the persons have been interviewed between 8-14 weeks after their discharge from hospital. They realized that these benefits would have been really necessary and no individual wishful thinking (ibid. pp. 136-136).

One should be very careful in interpreting the data because there is no data about the age of patients and does the fact that more than 80 % could easily reach family caregiving also reflects that family carers have to fill in the gaps when no other benefits or measures are available?

Many benefits necessary are only available after spending a lot of time for co-ordination- and application procedures and additionally persons in need of care and their family carers don't know much about existing benefits (ibid. p. 135).

It was of evidence that most of the non-received benefits would have been available only by medical prescription through the general practitioner -who holds the key position in providing physical care in primary health-, through an application form to the health insurance or by cooperation with institutional care providers (pp. 134 ff. ibid.).

Starting to fill the intersectional gaps between in-patient and out-patient care the country of Bremen currently started a model project (which will be evaluated by research) and implemented a family carers advice centre in one of it's central hospitals to support and to prepare carers for their tasks in family caring when the person in need of care is discharged from hospital. This centre will also train volunteers for certain support or advice. It is planned that these centres will be established in all central hospitals in Bremen to be a permanent institution for regular counselling and advice for family carers.

In-patient geriatric care is a central element in the health care sector and the federal states play an important role in the organization of clinical geriatrics. The aim of in-patient geriatric facilities is not only to provide medical treatment but also view each individual situation from an integral perspective and to offer rehabilitative and social therapy services which cannot be provided by other institutions (§§ 109, 111, SGB V).

The total number of in-patient geriatric facilities has increased by 35 % since 1997 (Fuhrmann, 2001). During the same period the number of beds available increased from 7,214 to 16,120. According to these figures there are 19. 6 beds per member of the population. However the density and availability of geriatric care provision varies greatly from state to state. In it's "guidelines for geriatric rehabilitation" the Federal Task Force of Rehabilitation Institutions assumes that there is a need for at least 50-60 beds per 100,000 members of the population.

The geriatric treatment of older persons in need of care fails because of the lack of geriatric facilities in the respective federal country. As a matter of fact there were 555,561 hospital beds in the year 2000 but only 9,348 beds in geriatric facilities. Even if 6,398 beds in geriatric rehabilitation facilities are added on this would only be 2.82 % of the total capacity with hospital beds. Therefore the current situation cannot be described as satisfactory and geriatric facilities are unequal spread (Borchelt, Steinhagen-Thiessen, 2001, Steinhagen-Thiessen et al., 2003).

According to the trends figured out in the data (mentioned above in 4.1.1.2) and in view to the implementation of the Diagnosis Related Groups -DRGs- in German hospitals, aimed on reducing the length of stay because of more cost effectiveness, one cannot foresee the consequences for family carers. In this context another problem raises in the delimitation between geriatric-rehabilitative treatment and acute medical treatment within DRGs, because rehabilitative treatment would increase the length of stay (Braun, 2003). This could aggravate the situation of family carers when patients are discharged

"sicker and quicker" and don't receive appropriate rehabilitative treatment if necessary.

Table 14: Development of in-patient geriatric facilities in Germany

Year	Number of facilities	Number of beds
1993	84	~7,214
1994	118	~7,500
1997	235	~12,500
2000	318	~16,120

Source: Fuhrmann, Uhlig, 2001

Geriatric day clinics provide treatment 5 days a week and 8 hours a day. It offers follow-up treatment after acute illnesses such as stroke and is defined as a form of treatment which allows the transition from in-patient to domestic care and which has the aim of stabilizing the outcomes of the in-patient therapy. The number of such clinics has risen by roughly 138 % and the number of places by 104 % in the period 1997-2000, but there are still only about 2.5 beds per 100,000 members of the population (Fuhrmann, 2001, Uhlig, 2001, BMGS, 2003a). Nearly 50 % (12 from 25) of all newly established geriatric day clinics are located in Northrhine Westfalia and one federal country therefore has 35 % of all geriatric day clinics in Germany which shows the clear imbalance and unequal availability of those facilities!

Apart from acute geriatric day clinics part in-patient geriatric rehabilitation institutions also exist. These institutions offer patients who are almost capable of self- reliance with regard to the activities of daily living and who are at least mobile with the help of a wheelchair a wide range of rehabilitation treatments such as occupational therapy, physiotherapy, neuropsychological therapy or Balneo therapy. The patients go home in the evenings and over weekend, which means that the rehabilitation is orientated towards the domestic environment.

The aim of this type of geriatric care is to render the patient capable of self-help, self-reliance, to avoid or reduce the need for family caregiving, to prevent the necessity of in-patient treatment and to improve the quality of life.

Since 1997 the number of such day clinics has risen to the order of 65 %, from 29 to 48. Most day clinics are in two federal states Baden-Wuerttemberg and Northrhine Westfalia and out-patient geriatric rehabilitation is still the "missing link" in the chain of geriatric care provision (Borchelt, Steinhagen-Thiessen, Uhlig, 2001).

The provision with geriatricians in out-patient primary care can be described as inadequate and family carers often do not have access to a geriatrician to discuss special problems related to the cared for older person. Within the 'Regulations for Specialist Training' for general practitioners it is possible to do 2 years further training in clinical geriatrics (MWBO). Up until now few practitio-

ners have completed this training (e.g. only 1.3 % of GPs and 1.4 % of specialists for internal medicine in Hessia) which means that there are still large deficits in the provision with geriatricians. The German Geriatric Society has developed a programme of training and education in "Out-patient Geriatric Rehabilitation" for GPs because of widespread difficulties concerning communication and cooperation between GPs and other occupational groups and with residential care facilities. Chronic health problems of elders and their family carers are often not noticed, appropriate pain therapy is often not implemented and there are deficits regarding the differential diagnosis of patients suffering from dementia: 40-60 % of all cases of dementia are not diagnosed, especially among the age group > 75 years (Heusinger v. Waldegg, Stamm, 2002).

4.1.1.3 Long-term health care facilities

There are special long-term health care facilities specialized on certain groups of persons such as people suffering from persistent vegetative state after accidents or people with special cognitive impairments who have special needs in professional caregiving. There are also great long-term care facilities for handicapped or disabled persons of different stages. These facilities are linked to special workshops for the handicapped. These facilities are mainly run by charitable organisations and are partly financed by the public sector.

4.1.1.4 Hospice / palliative / terminal care facilities

In Germany hospice facilities play an important role in the provision of care in the primary health care sector and are organized in different ways: "hospital-based" or "hospice-based" such as the Hospice Bridge (Hospiz Brücke) with 8 beds, run by a private non-profit care society in Bremen, or out-patient and "community-based". The work of hospice societies whose members visit terminally ill or dying patients in their domestic environment or accompany them to death in hospital or in residential care are partly financed by public revenues and the position of the coordinator is financed by the health insurance. The work of these societies is mostly on private and voluntary basis. In addition to donations the hospices are also funded by the health care insurance companies since 2002 who support out-patient hospice services if they fulfil certain criteria regarding qualifications. It is important to note that the selection of services financed by the health insurance has been extended by these significant non-medical benefits: Those who work in hospice societies or hospice houses in Germany must have particular knowledge and experience with palliative therapy and those at management level must have a qualification in palliative care.

Work in hospices is subject to certain ethical principles and the care for the dying includes palliative-medical and nursing measures as well as psychological and social care. Statutory insured persons are entitled to benefits through the long-term care insurance e.g. for day care in a hospice or receive domestic care by prescription through the general practitioner (§ 37 SGB V).

Recent research on palliative home-care services in Northrhine Westfalia (Ewers, Schaeffer, 2003) revealed an unequal distribution of patients in community based hospices and indicate to strengthen the efforts in motivating general practitioners to prescribe on more domestic care. About 89.9 % of the patients (N = 603) cared by a palliative home-care service live in their own home and 59.3 % are living together with a spouse as family carer. More than 81 % of the family carers were female: wives, daughters or daughters in law. It has to be noticed that 32 % of these family carers were additionally in paid employment and related to the daughters the proportion amounts 61 %!; 87 % of them additionally were responsible for their own household (ibid. p. 28). These figures demonstrate the situation of family carers related to the care of terminally ill relatives and the challenges they have to deal with. According to the German Hospice Foundation only about 6 % of the 850,000 terminally ill or dying persons in Germany are cared for by one of the 1,200 Hospice societies and the further development and contouring of hospital and community-based palliative-care services needs more public attention to relieve the family carers burden.

It has to be mentioned that palliative home care teams are also organized through hospitals to accompany terminally ill patients from discharge to domestic care. But the financing of these teams is not ensured because the legal commitment to ensure adequate palliative-care at home still remains an unsolved problem and is handled divergently by the federal countries (Anonymous, 2004).

4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?

Many family carers would like to play a more important role in health care matters when their elders are admitted to in-patient institutions, especially because this would give them the opportunity to find out what problems they might have to face when their elder is discharged from hospital and transferred home again. Usually their role is limited to the provision of clean laundry, personal contact and support regarding contacts with health care personnel; assistance with meals or personal hygiene is seldom. Active participation of family carers in health care matters is not expected from the onset. In fact it is often experienced by health care personnel in acute hospitals and residential care as a disruptive factor and such relatives are often seen to be getting in the way and preventing "trouble free" care. Counselling and instruction of family carers is still very rare and needs to be developed in a more systematic way in order to avoid disruptions in caregiving tasks and medical treatment in particular between the in-patient and out-patient sector.

4.1.2 Social services

The differences between rural and urban areas related to availability, the great variety and density of health services as described under pt. 4 are also applicable to social services with certain regional and local variations.

4.1.2.1 Residential care (long-term, respite)

Up until now the residential care have played an important role in the provision of care for people in need of care who cannot be taken care of and given care by family carers and they will continue to be of importance despite further development in the out-patient sector. Conceptual changes will be necessary in order to do justice to the growing number of residents suffering from dementia. In 1999 8,659 long-term care institutions with a total of 645,456 places existed. Over half of these institutions are financed by independent charitable organisations (56.6 %), about one third of them by private commercial organisations (34.9 %) and the rest (8.5 %) by the public. Most of the private institutions are small, with less than 50 beds, whereas the charitable organisations and the public sector tend to run larger institutions with more than 100 beds.

Table 15: Residential (long-term care) facilities according to sponsorship in % and to the number of beds in 1999

Places / beds	long-term care facilities in %				Total number of beds/places
	Private	Public	Charitable	Total	
1-20	29.4	13.6	8.8	18.7	1,656
21-50	36.8	21.9	25.7	27.4	2,429
51-100	23.2	41.2	35.7	34.5	3,054
> 101	10.6	23.3	29.7	19.4	1,720
Total	**3,092**	**5,017**	**750**	**8,859**	**8,859**

Source: BMFSFJ, 2002, Statistisches Bundesamt, 2001

Residential care facilities are financed by different sources: On the one hand they are financed for people in need of care by the care allowances (§ 43, SGB XI) which are calculated according to the care categories which pay for medical treatment care and social care. On the other hand all other costs must be paid for by the person in need of care, either with his or her pension and savings or by reverting to the resources of close family members. If the person in need of care and his or her relatives have no resources at their disposal then the social welfare pays in accordance with the Federal Law on Welfare Benefits "support in difficult life-situations". In 1998 36 % of all residents of old peoples homes were dependent on social welfare (Rothgang, 2003, 2003a). In the course of the current discussions on reforms in the health it had been planned to decrease the monthly benefits of the long-term care insurance for residential care and to adopt onto benefits in domestic care. Apart from the

fact that an increasing number of residents would probably depend on social assistance in the future there were fears that due to financial barriers family carers would wait longer than is absolutely bearable until they would give the older person in need of care into residential care.

In Germany there are 4,150 respite care institutions -mostly run by residential care facilities- with a total of 14,200 places/beds (BMFSFJ, 2002). Respite care is one kind of the complementary benefits of the long-term care insurance either to relieve the burden on family care-givers or following a hospital stay. Influenced by the introduction of the long-term care insurance respite care has changed dramatically over the last few years and patients' average stay decreased from 45.7 days in 1995 to 26.3 days in 2001; other surveys state the figure 22.4 days (Hartmann and Heinemann-Knoch, 2002). There is a certain danger that the patients' self-help potential is not made use of if he or she is admitted to in-patient care again straight after hospital stay. It is obviously possible to make respite care much more effective under other circumstances, for example by building networks between respite care institutions and GPs (Kolip and Güse, 2002).

4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of residential care (sheltered housing, residential homes)

According to the microcensus 2 million people in Germany were in need of care in 1999 (Statistisches Bundesamt, 2001). Nearly 28 % (554,000) of people in need of care are cared for in residential care. According to this survey the persons in residential care are on average older than those cared for in the domestic setting. 66 % of those in residential care are older than 80 years of age but only 44 % of those taken care of in the domestic setting are > 80 years old.

Table 16: Age of persons in residential care (microcensus 1999)

Age from … to …	Total in thousands	Male	Female
under 25	/ *	/ *	/ *
25-60	27	16	12
60-70	42	21	21
70-80	117	29	88
80-90	240	35	205
> 90	127	14	113
Total	**554**	**116**	**438**

Source: Statistisches Bundesamt, 2001, p. 13. (/ * number < 7000)

In recent years sheltered or so-called service housing has been propagated by building contractors as the best solution to future housing problems among the elderly. Longitudinal surveys in 7 sheltered housing developments have shown that 70 % of the residents (N = 173) see their move into a sheltered housing development as a precautionary measure in order to have access to support in

the event of a crisis. Most of the persons interviewed (83 %) knew nothing about measures to adapt living space, organized counselling on the subject of living conditions or organized household help.

There are various different types of sheltered housing available to older people: 1. Independent housing developments with service offices and services available through external providers, 2. Independent housing developments including internal service providers, 3. Housing projects connected to a nursing home and 4. housing projects which are run like hotels or as foundations. Two main models, the service model and the care model, can be discerned. Regional demands are reflected in the different types of sheltered housing offered. Unfortunately there are no standardized quality control procedures for these residence forms so that the quality of sheltered housing varies greatly. It has not yet been established exactly which types of sheltered housing projects come under the protection of the Nursing Home Act. This causes problems because it has consequences with regard to protection regulations pertaining to such issues as planning permission, personnel in residential care, rights to participation in decision-making and monitoring. An estimated 1.6 % of all persons older than 65 years of age live in one of the roughly 3,600 sheltered housing developments, a figure much lower than the figure in Great Britain or the United States of America (5 %) (BMFSFJ, 2001, pp. 249).

4.1.2.1.2 Criteria for admission (degree of dependency, income etc.)

Persons in need of care are entitled to residential care when family caregiving is not possible or cannot be considered due to special circumstances (SGB XI, § 43). The need for care must be determined by the Medical Advisory Board (Medizinischer Dienst der Krankenkassen) which are part of the health care insurance. The amount of benefits granted depends on the care category. "Hotel costs" must be paid for by the insured person in need of care. If the person is not in any of the care categories and is not in need of care according to the above mentioned criteria then he or she must pay all costs either with his or her pension or savings.

4.1.2.1.3 Public / private / NGO status

The stay in a residential care facility is always financed according to the criteria described above, independent of the type of institution: public, private or charitable.

4.1.2.1.4 Does residential care involve the participation of carers or work with carers?

Residential care facilities work with professional carers and volunteers. No systematically developed work with family carers.

4.1.2.2 Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)

Community care services show a great variety and are organized by different service providers or organisations (see also 4.1.1).

An example for an effective form of community care network can be observed in Bremen where "Social Service Centres" have been set up (although there are also out-patient service centres on county level in other federal states). Because of it's small area Bremen was able to set up a form of community help 25 years ago which pointed the way ahead for further development. Within this system persons in need of care and their family carers can inform themselves about all types of available support and services in one single office in district centres. 18 of these social service centres in different districts of the city were set up by charitable organizations and are funded partly by the city of Bremen:

The following services as "community care services" are available: Meals on wheels, counselling and discussion groups for family carers and neighbourhood help which includes organizing domestic caregiving, help in matters concerning the authorities, help filling out forms, assistance with shopping, household tasks, laundry and cooking, going for walks, visiting the doctor and collecting prescribed remedies. The person in need of care or his or her carer sign a contract with the social service centre in which the amount and type of assistance is laid down. The contract costs 20,- Euros a month and every service hour after that costs 7.15 Euros. This sum is seen as compensation for the mostly voluntary workers. This community care and the meals on wheels are refinanced either by the personal contributions from the consumer or to a certain extent from the social welfare office.

Bremen has reduced it's contributions to these community service centres considerably so that the charitable organizations are forced to balance out their financial deficits by offering new services. In the context of a project training for voluntary helpers is planned on the basis of the Law on Supplementary Care Benefits (PflEG, 2001) in order to be able to offer basic services for the relief of family carers who take care of persons suffering from dementia.

4.1.2.2.1 Home-help

Home-help is part of community care and there are different solutions to the home-help question in different regions (see 4.1.2.2). Home help is provided by non-profit and profit companies and generally they offer nursing care as well as different kinds of home help.

If need for care is determined according to the long-term care insurance law then domestic care services will also offer home help (§ 36, SGB XI) to a certain degree. If home-help is needed and no need for care has been deter-

mined then the older person or the family carer themselves must pay for it. Means tested social assistance is also available to finance home help. The kind of home help offered by formal services is also reflected in the qualifications of their staff. Although less than 3 % are home-helpers, home help is the main working area for 19 % of the employees and nurses also provide home help (Rothgang, 2003).

Table 17: Qualification of employees of providers of home care

Qualification	% of employees	Main area of work	% of employees
Nurses	64.4	Care management	6.3
Professionals allied to medicine	2.0	Nursing care	65.0
Social workers	0.8	Home help	19.0
Home helpers	2.9	General administration	5.0
Others	17.5	Others	4.5
In training	11.3		

Source: Rothgang, 2003, p. 34-35

4.1.2.2.2 Personal care

Apart from the legal arrangements pertaining to support and care benefits already mentioned in this chapter people of course can pay for personal care themselves, for example for "granny-sitting" type services.

4.1.2.2.3 Meals service

There is almost blanket coverage with meals on wheels services which are offered by various providers. Some residential care facilities offer their meals out of house or allow older people to come for their midday meal. There are also commercial providers who prepare and deliver hot meals. These meals, which can also be adapted to special diets, are ordered for a certain period in advance and regularly delivered at agreed times. Many charitable organizations also offer this type of service. The consumer must pay for this service in the event that the social welfare office does not pay the costs. The meals on wheels service is usually made use of by older people and makes sure that they eat a warm meal every day even if the are not willing or able to cook for themselves.

4.1.2.2.4 Other home care services (transport, laundry, shopping etc.)

Apart from the services already mentioned a selection of different services has evolved, especially in the cities. Supermarkets deliver shopping home, laundry services collect and bring back washing and there are repair services which work on a voluntary basis and only claim for a small reimbursement. Pharmacies deliver remedies and dentists fit dentures at home. Medical and technical

aids are delivered to the home and installed if necessary. There are special transport services for severely disabled persons, some of which are free of charge.

4.1.2.2.5 Community care centres

Community care centres -"Altentagesstätten"- are run by charitable organisations or church communities and are partly financed by the local authorities. These centres offer several activities such as memory clubs, informal meeting groups for family carers and / or older people and coffee breaks in the afternoon and work mostly on voluntary basis. These community care centres don't offer comprehensive advice and support through different professional groups.

4.1.2.2.6 Day care ("protective" care)

Day care in it's function as part in-patient care provision is an important component of the care provision system and can be seen as the bridge between domestic care (including professional care services) and residential care. This type of care is of particular importance because it maintains the relative self-reliance of older people in their own households and relieves the burden on family caregiving at the same time. Day care aims to give activating care and social care as well as providing medical and rehabilitative care. Many day care centers are primarily specialised in the care of dementia patients and provide special programmes with trained staff.

Up until the introduction of the long-term care insurance there were no nationwide uniform regulations on the financing of day care. When day care was laid down as a benefit in the long-term care insurance the federal states started to promote investments in this sector and the number of day care institutions began to increase. However there are still very few day care institutions in comparison to the availability of domestic care services and in-patient institutions. In rural areas for many family carers it is not possible to make use of day care because the distance from their homes to the day care institution takes more than the half hour to cover, which is laid down as the maximum length of transports carried out by mobile services.

Table 18: Development and number of day care institutions in Germany

Year	Number of Institutions	Number of Places
1988	54	801
1993	227	3,178
1998	1,777	(23,000)

Source: BMFSFJ, 2001a (1,777 institutions were licensed 1998 but it is not clear if all of them actually went into business. This is why the number of places is in brackets).

The number of places is based on the assumption that there are an average of 13 places per 100,000 members of the population. This figure in turn is based on experience gathered in the context of a survey done for the state North-

rhine Westfalia (BMFSFJ, 2001a). When older people are entitled to benefits the long-term care insurance pays all care-related costs over an indefinite period if family caregiving cannot be guaranteed or if day care is necessary to ease the burden on family carers (SGB XI, § 41). Social care is paid for as well as medical treatment care for the time being until 31.12.2004.

Table 19: Monthly upper payment limits for day care

Care Category	Monthly Payment (€)
1	384
2	921
3	1,432

Source: SGB XI, § 41

If day care is made use of in addition to benefits in kind, then the difference in cost must be paid by the insured person. Most of those in day care are > 80 year-olds and are classified as care category 1 or 2. Persons continually confined to bed are excluded from day care, whereas a momentary need for bed rest is not a hindrance. It is difficult to run day care institutions from a financial point of view: With capacities of 10 to 14 patients less than complete capacity utilization can quickly cause financial problems. Financial risks are minimized if day care is offered by long-term care institutions as a supplementary service. A different conceptual orientation is required in order to run day care institutions because, unlike many in-patient institutions, day care is provided in close cooperation with domestic care and professional out-patient care (BMFSFJ, 2001a).

4.1.2.3 Other social care services

As mentioned above the social care services provided and the quality of these services are subject to regional variation. In general service and quality tend to be better in urban areas. Many charitable organizations run counselling services partly funded by the local authorities. This is particularly often the case in cities. Counselling is also offered by consumer advice centres and sometimes from professional nursing care services. Persons who are in need of care according to the long-term care insurance law are entitled to technical aids such as wheelchairs, special or raised beds, bathroom lifts and a general improvement of individual living conditions. Technical aids are usually lent to the person in need of care to avoid unnecessary costs. The costs of improvements of living conditions which include measures such as getting rid of physical barriers, for example by widening doorways, can be paid by the long-term care insurance and are paid for according to the principle of subsidiarity if they can be expected to make family caregiving possible or easier or if they help to restore as much of the patients self-reliance as possible. The maximum payment for a single measure paid by the long-term care insurance is about 2,557 Euro (SGB XI, § 40).

Family carers and voluntary helpers are entitled to caregiving courses given free of charge (SGB.XI, §§ 28,45) by professional out-patient care services, private care services or charitable institutions.

4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modelling of both home and other support care services

Since the long-term care insurance law doesn't know the overall responsibility related to the infrastructure of formal care provision the regulations reflecting the institutions overall responsibility and competences remain unclear. To ensure the societal care provision the "overall responsibility" can only be realized by institutional cooperation and coordination in order to develop quality control criteria (Klie, Schmidt, 1999, p. 17).

4.2.1 Who manages and supervises home care services?

Different providers on the commercial home care market manage the provision of home care services and are more or less the only controlling body at the moment. If persons in need of care or family carers are not satisfied with the service provided then they can submit a complaint to the provider or look for a new provider. There is no general monitoring body which lays down criteria for the assessment of service quality in out-patient health care. However the long-term care insurance is attempting to influence the quality of care interventions and thus the services provided by regulating care benefits.

4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorized to run these quality controls?

In July 2001 an additional legislation was passed (PQsG, 2001) aiming to guarantee certain quality levels through the long-term care insurance law (§ 80 SGB XI). Moreover, the long-term care insurance and service providers have to agree contracts, regulating quality standards. But these standards only relate to structures and process rather than to the outcomes of care. There is hardly any quality control in the care provided by families (Rothgang, 2003).

The only legal monitoring process on quality control in out-patient / domestic care consists on the review of the need for care by the Medical Advisory Board at regular intervals and on the other hand of self-responsible promotion of quality through the family carer. Specially selected professional community care services control the quality of care provision on behalf of the long-term care insurance. Persons in need of care who receive benefits in cash in the care categories 1 and 2 must be make use of professional care services with a mandate from the long-term care care insurance at least twice a year and per-

sons in care category 3 every three months in order to secure the quality of family caregiving and to provide and advice and support to caregiving households. These services supposed to determine whether or not the necessary family caregiving can be administered, if it is wise to involve professional out-patient care services or even necessary to suggest the transfer of the person in need of care from the home to residential care. Experience shows that these intervals, which are laid down on the basis of the medical advisory board report and on the prognosis regarding the future need for care (SGB XI, § 18), are far too long and do not guarantee continual quality control.

4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?

The long-term care insurance can control the quality of care on the basis of it's regulations for professional service providers. These regulations lay down the content of services offered, organizational modes and the required qualifications for carers / nurses: Carers in management positions in professional out-patient nursing care services must have completed a nursing training programme recognized by the state (in adult, child or geriatric care) and must have worked full time in the nursing profession for a total of at least two years within the last five years and have at least one year of full-time experience in the out-patient setting (SGB XI, § 75). All other members in nursing care services can have different types of training (fully qualified nurses, auxiliary nurses, short training as nurses aid) and some of them are persons doing community (instead of military) service and have no specific qualifications). There is no state controlled training programme for community care. However specialist community care training is offered by various educational institutions.

There is another occupational group with a professional qualification involved in domestic care the family carer / social assistant. Social assistants are qualified in social education and social work in families. Their work includes care, household help and education in the home and they are called in when the person usually responsible for the household is absent for a certain period of time or is unable to manage due to physical or psychological strain or illness.

The social assistant gives support in the case of emergency and makes family life possible even in the event of crises. He or she looks after many types of client including older or disabled persons. The social assistant is responsible for prevention or shortening of hospital stays, for supporting geriatric, rehabilitative interventions, for taking care of persons with acute illnesses and older people living alone and preventing their admittance to in-patient care or their transfer into residential care. This service is financed for older persons in need of care by the health insurance in the context of "domestic care" and "home help" and in accordance with the Federal Legislation on Welfare Benefit which

finances such services in cases of illness or disability or in order to guarantee that the household can be further maintained.

Home or family care workers / social assistants are trained according to regulations which vary from state to state. The training is offered by special school and is completed after 2 to 3 years with a state exam. Family carers / social assistants are usually requested by the social services office or professional nursing care services.

There are also legal regulations pertaining to the certification of professional qualifications for those who work in residential care. According to the Regulations on Residential Care Personnel (HeimPersV, 1993.) at least 50 % of the nursing care staff employed in residential institutions must have a professional qualification if they care for more than 4 persons in need of care and if special care interventions are necessary. Professional qualifications in the sense of these regulations are either completed 3 year adult nursing or geriatric nursing training. Geriatric care training only lasted 2 years up until the recent introduction of nationwide Geriatric Care Legislation. In addition to persons with these qualifications other persons with qualifications other than those laid down in the above mentioned regulations are employed in residential care. (ibid, § 6).

The Regulations on Residential Care Personnel also lay down the qualifications management personnel should have (§ 2): He or she must have a state-approved qualification in health or social services or in business / commerce or in public administration and have at least two years of full-time work experience in order to run a long-term care facility. Usually there is dual management of residential care institutions with one manager qualified in business or commerce who is then responsible for financial affairs and another manger responsible for all matters pertaining to the organization and management of nursing care and who is usually qualified in health care personnel management, geriatric studies or nursing care management

4.2.4 Is training compulsory?

Yes.

4.2.5 Are there problems in the recruitment and retention of care workers ?

In the professional sector there are dramatic problems regarding the inadequate provision of care professionals, especially in the geriatric care sector. The legally defined minimum quota of qualified personnel is often exceeded. As a result of these changes work-loads, overtime and the amount of sick leave are on the increase. On the basis of a survey in N = 613 long-term care facilities (dip, 2003) it can be estimated that up to 9 million hours of overtime have accumulated up to present in long-term care facilities. This is the equivalent of 5,000 full-time jobs. The total number of older people living in residential

care in also on the increase. Each year about 15,000 new residents are admitted to these institutions and these numbers will continue to increase. About 20,000 new jobs would have to be created in long-term care in order to fill all existing and new jobs and to reduce the amount of overtime. The numbers of applicants for such jobs are however dropping, despite the fact that the Federal Labor Office has registered over 27,000 geriatric care professionals as unemployed, and the quality of applicants qualifications is also deteriorating. This situation is also an indicator of the fact that many geriatric care professionals are no longer capable of working in their profession due to physical or psychological complaints (ibid.).

The situation in the home care sector related to the recruitment of informal care workers cannot be estimated.

4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels)

In the course of the modernization of the health insurance (GMG, 2003, § 140 a-h) as well as on the basis of model contracts (§§ 63-65 and 73a, SGB V) a legal basis was introduced to test innovative methods of solution in the care provision for older people and also for family carers. Concrete approaches for building up networks of social and health services are to be seen in integrated care planning, disease- as well as care and case management programmes.

There is no systematic case management and integrated care. It is only possible to build up networks and coordinate services when all involved go to great organisational lengths (cp. 'ProNetz': Kofahl et al., 2003).

4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?

No.

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5 The Cost - Benefits of Caring.

The GDP for the country[20]

5.1 What percentage of public spending is given to pensions, social welfare and health?

The total sum of employers' contributions in the year 2000 in Germany was 680,833 million Euros. In the mean time expenditure on health makes up 10.9 % of the GNP. The table 20 show the amount spent on various social contributions / benefits in the year 2000.

Table 20: Expenditure on social benefits in the year 2000 (in €)

Pension insurance	217,430
Health insurance	132,046
Long-term care insurance	16,665
Accident insurance	10,835
Social services and benefits	48,917

Source: Statistisches Bundesamt, 2002a

5.2 How much - private and public - is spent on long term care (LTC)?

The private expenditures spent on long-term care are hardly to estimate. The figures below are taken from Rothgangs (2003) own calculations based on the information given from the Federal Department of Health (BMG). The table 21 shows that about 70 % of long-term care expenditures are financed publicly. Rothgang points out that *"within public financing, public long-term care insurance alone covers almost 80 %, which is almost completely met by insurance contributions and premiums"* (ibid. p. 40).

[20] This will be obtained from OECD / centrally

Table 21: Sources of funding for long-term care -LTC-

Source of Funding	In million €	As % of public / private spending	As % of all spending
Public Funding	**21,386**	**100**	**70**
Public LTCI	16,700	78	55
Private mandatory LTCI	920	4	3
Social assistance	2,300	11	8
Investment financing	1,400	7	5
Public accident insurance	66	0	0
Private Funding* on	**9,118**	**100**	**30**
Nursing home care	7,038	77	23
Home care	2,080	23	7
Total	**30,504**		**100**

Source: Rothgang, 2003 p. 39; *estimated

5.3 Are there additional costs to users associated with using any public health and social services ?

In the context of the services described above carers must pay for all costs which are not covered by the long-term care insurance and when the insured person is not entitled to social welfare benefits which would cover these extra costs. The supplementary benefits described in this report belong to this category of costs. As a result of the reformation of the healthcare system all mandatory insured people are now obliged to pay a share of healthcare costs. They must pay 10 % of the costs for remedies and domestic care and a one off bill to the order of 10 Euro every three months for each prescription written within that time frame. 10 % or at least 5-10 Euros must be paid by the person for technical aids such as wheelchairs, hearing aids, special beds etc.). These figures also apply to social therapy and in-patient prevention and rehabilitation (GMG, 2003).

5.4 What is the estimated public / private mix in health and social care ?

According to the "Care-Mix" being chosen by beneficiaries of the long-term care insurance different types can be identified as shown in table 22:

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Table 22: Private and public mix in domestic care-arrangements by beneficiaries of the long-term care insurance (in %)

Exclusively privately financed care by family or friends	55
Only privately financed care plus other self-financed help	9
Private and professional care	28
Only professional care	8
Exclusively privately financed help	0

Source: Infratest Sozialforschung, 2003, p. 28

Table 23 shows the beneficiaries' share of costs connected to caregiving and other care services in order to the care category.

Table 23: Average monthly self-costs for domestic care according to care category in %

Category	Total	Care category 1	Care category 2	Care category 3
No private payment	35	33	39	35
No comment	16	17	16	12
Average monthly costs (€)	130	107	135	196

Source: Schneekloth, Müller, 2000

5.5 What are the minimum, maximum and average costs of using residential care, in relation to average wages ?

As mentioned above the long-term care insurance only provide capped benefits. As the table 24 shows there are clear gaps between the fees charged and the care allowances granted by the long-term care insurance. There is considerable monthly co-payments (Rothgang, 2003).

Table 24: Residential care fees and Long-term care insurance benefits in € / month

Care Category	Average monthly rates	Long-term care insurance (LTCI): Monthly Benefits	Private co-payment	% of fees covered by LTCI
1	1,982	1,023	959	51.6
2	2,347	1,279	1,068	54.5
3	2,804	1,432	1,372	51.1

Source: Social Code, Vol. XI, § 43, Rothgang, 2003, p. 38.

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities) ?

The care and support of older people is financed through social contributions to the long-term care insurance -from employers and employees (50 % each)- and through taxation. Pensioners pay half of the contribution the other half is financed from pension funds; contributions for the unemployed are completely financed by the unemployment insurance. Contribution rates are calculated as 1.7 % of the gross income.

The long-term care insurance law established public long-term care insurance and mandatory private long term care insurance covering almost the whole population. Approximately 89 % of the population is now covered by public and 9 % by private long-term care insurance. Supplementary services are financed through taxation in the form of social welfare benefits which are financed by the local authorities. In 1994 the social welfare net-expenditures for ‚assistance to meet the costs for care' for older people beyond residential care constituted 1,571 billions. After the enactment of the long-term care insurance the expenditures decreased on 776 Mio. in 1999 (Roth, Rothgang, 2001).

The following table shows the proportion of older people funded by the local authorities through public revenues.

Table 25: Proportion of older people funded by the public sector and receiving "*assistance in difficult situations*"[21] from the Social Welfare Office in order by age (2002)

Total number of recipients	Men: 1,216.241	Women: 1,540.971
Age from … until	Among them:	
65-70	33,469	42,048
70-75	18,858	30,204
75-80	9,056	23,217
80-85	3,416	14,619
> 85	1,667	12,820

Source: Statistisches Bundesamt, 2002b

5.7 Funding of family carers

It can be assumed that some of the money granted by the long-term care insurance for persons in need of care is used as a sort of compensation for family carers and can therefore be seen as a form of indirect financing of family carers. Family carers are only entitled to contributions towards their own social security under certain circumstances. The table below shows the number of

[21] No further differentiation; "*assistance in difficult situations*" also contains 'assistance to meet the costs for care' and 'assistance for old age' (§ 27, BSHG).

beneficiaries according to care categories and the amount of money which has flown into care households.

Table 26: Number of recipients of benefits in cash (in €) according to care category in 2001

Care Category	Benefits in Cash	Number of recipients
1	205	556,098
2	410	324,999
3	665	81,033
Total		962,130

Source: BMGS, 2002

5.7.1 Are family carers given any benefits (cash, pension credits / rights, allowances etc.) for their care ? Are these means tested?

The long-term care insurance law laid down the conditions under which family carers are entitled to benefits from the social security system: Around 580,000 of all such carers in Germany are entitled to contributions towards their old age pension and insurance cover in the statutory accident insurance (SGB XI, § 44). In order to be eligible for these entitlements the carer must not draw his or her own pension, must care for his or her elder for more than 14 hours a week and cannot be in regular paid employment for more than 30 hours a week

	Attendance allowance	Carers´ allowance	Care leave
Restrictions	Yes[22]	Yes	Currently under discussion (open-ended)
Who is paid?	Person in need for care	Family carer	
Taxable	No	Partly	
Who pays?	Long-term care insurance (SGB XI, § 37)	Long-term care insurance (SGB XI, § 44)	
Pension credits			
Levels of payment / month	See table 26	See footnote[23]	
Number of recipients in 2002	962,130 (cp table 26)	N=554,000 (2000) N=505,000 (2001)[24]	

5.7.2 Is there any information on the take up of benefits or services?

About 50 % of the households (N = 3,622) spend on monthly co-payments related to social or health services. The monthly average amount is estimated at 355 Euro. About 9 % of the households who spend money for self-financed help invest in privately employed "domestic help" and about 4 % spend their money for "meals on wheels". Complementary and voluntary services to relieve family carers are taken up one- or two times a week by 11 % of all persons in need of care (N = 1,111) (Infratest Sozialforschung, 2003, pp. 26- 27).

5.7.3 Are there tax benefits and allowances for family carers?

Family carers can claim money back from the tax office if the additional financial burden caused by caregiving exceeds a certain percentage of the disposable income.

5.7.4 Does inheritance or transfers of property play a role in caregiving situation ?

The experience shows that property often changes hands in the caregiving situation and has a form of compensation for the carer. However no official figures are available.

[22] Entitlement to benefits of the long-termcare insurance

[23] The amount of contributions differs according to the grade of dependency of the person in need of care and the time spent for caring. Contributions to pension funds require a minimum of 14 hours care-work a week. The minimum contribution paid is 26.7 % of that of a full-time employee with average salary, the maximum is 80 % of this amount (Rothgang 2003a p. 25).

[24] Temporary number (BMGS,2003a)

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5.7.5 Carers' or Users' contribution to elderly care costs

a. Medical, nursing and rehabilitation services	**General access:**			**Access based on:**		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
General practitioner	X[25]					
Specialist doctor	X[26]					
Psychologist	X[27]		X			
Acute Hospital	X[28]					
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)	X[29]	X				X
Day hospital	X[30]					
Home care for terminal patients	X[31]					
Rehabilitation at home	X[32]	X				
Nursing care at home (Day / Night)	X[33]		X			
Laboratory tests or other diagnostic tests at home	X[34]					
Telemedicine for monitoring			X			X[35]
Other, specify: “home care”	X[36]					

[25] In the course of the health modernization law (GMG 1.1.2004) statutory insured patients have to take a stake in the costs for the health insurance: Among others they have to pay a 10 Euro one-off-bill charge (‚Praxisgebühr') quartely.

[26] Referral is necessary by the general practitioner

[27] By prescription through the general practitioner in the course of the SGB IX (rehabilitation and participation of handicapped people) or privately paid

[28] Referral necessary and patients have to pay 10 Euro per day in hospital but limited up to 28 days per year

[29] Referral necessary by the GP

[30] In the course of medical geriatric rehabilitation paid by the health insurance; see also chapter 4.1.1.2

[31] By prescription through the GP and paid by the health insurance or long-term care insurance; volunteer visits by members of hospice societies

[32] prescription by the general practitioner and reimbursed by the health insurance

[33] entitlement to benefits through the long-term care insurance

[34] in the course of medical treatment by the general practitioner

[35] in experimental stage and poorly developed

[36] The home-care area is a new branch and doesn't means care-giving by a nurse. It is offered a new service by the federal association of medical technology and provides professional counselling and advice for family carers and people in need of care on how to deal with e.g. technical appliances, nutrition, air-dressing, home-dialysis, remedies and more. The service is free at point of use and is part of medical treatment using technical equipment which is paid by the health insurance. These services will bridge between the professional groups and institutions who take part in integrated ca-

b. Social-care services	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Permanent admission into residential care / old people's home	X[37]		X[38]			
Temporary admission into residential care / old people's home in order to relieve the family carer	X[39]		X			
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)			X			
Laundry service			X			
Special transport services		X[40]	X			
Hairdresser at home			X			
Meals at home			X	X		
Chiropodist / Podologist			X			
Telerescue / Tele-alarm (connection with the central first-aid station)		X	X[41]			
Care aids		X[42]				
Home modifications		X[43]				
Company for the elderly		X[44]	X			
Social worker					X	X

re management and will close the gap between hospital dischargement and domestic care-giving (Bundesverband Medizintechnologie e.v. 2003)

[37] older people have to claim on benefits through the long-term care insurance; private co-payment for the "hotel-costs"

[38] also paid by private savings

[39] benefit through the long-term care insurance -short-term care- and based on the assessment of the Medical Advisory board, otherwise completely privately paid

[40] statutory insured patients have to share with 10 % of the costs for transports related to ambulatory or hospital treatment: a minimum of 5 Euro up to a maximum of 10 Euro (GMG 2004). The health insurance only pays in exceptional cases if people are severely chronically ill and are in need of care on a dependency level I or II and are in continuously medical treatment (Carekonkret 2004).

[41] The monthly costs vary between 18 and 39 Euro. Tele-Alarm (Haus-Notruf) is offered by several charitable organisations. Interestingly these systems are poorly accepted (BAGSO).

[42] Entitlement and paid by the long-termcare insurance (§ 40, 2, SGB XI) up to a monthly maximum of 31 Euro; to support older people

[43] Entitlement and paid by the long-termcare insurance (§ 40, 4, SGB XI) up to a maximum of 2,557 Euro to support older people to stay as long as possible at home.

[44] Paid through the long-term care insurance focussing on older people suffering from dementia (§ 45, SGB XI) through volunteers and under certain conditions

c. Special services for family carers	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Day care (public or private) in community centre or old people's home		X[45]			X[46]	
Night care (public or private) at home or old people's home			X[47]			
Private cohabitant assistant ("paid carer")			X[48]			
Daily private home care for hygiene and personal care			X			
Social home care for help and cleaning services / "Home help"			X		X	
Social home care for hygiene and personal care	X[49]				X	
Telephone service offered by associations for the elderly (friend-phone, etc.)			X			
Counselling and advice services for the elderly	X					
Social recreational centre	no[50]					
Training courses on caring	X[51]					
Telephone service offered by associations for family members	X					
Internet Services	no					
Support or self-help groups for family members	X[52]					
Counselling services for family carers	X[53]					
Regular relief home service (supervision of the elderly for a few hours a day during the week)			X[54]			

[45] Benefit by the long-term care insurance with co-payment by carers e.g. for meals; great differences in availability between rural and urban areas

[46] social service for older people or family carers who depend on social assistance

[47] no regular provision, mostly organized with private carers from the grey market

[48] mostly privately organized, see the chapter migrant care work 1.12

[49] paid in the course of the long-term care insurance if people are entitled to benefits; also paid by public revenues if people depend on social assistance

[50] no regular service provision

[51] provided by the long-term care insurance, nursing services or charitable organisations

[52] mainly offered by older people's "pressure groups" on voluntary basis

[53] a task of the long-term care insurance companies and also offered by older peoples' pressure groups

[54] no regular service provision

c. Special services for family carers	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)	–		X[55]			
Assessment of the needs	–					
Monetary transfers	–					
Management of crises		X[56]				
Integrated planning of care for the elderly and families at home or in hospital	–[57]					
Services for family carers of different ethnic groups	–[58]					
Other, specify						

[55] no regular service provision, privately organized from the grey market
[56] In the course of 'benefits for medical rehabilitation' to prevent, remove or to lessen handicaps or chronic illness (§ 26, SGB IX)
[57] in the state of planning but in the course of the DRG's absolutely necessary
[58] no regular service provision and remains being developed

6 Current trends and future perspectives

Research data show a current trend towards professional caregiving in residential care on the one hand and a decrease of benefits in cash with simultaneous increase of benefits in kind in family care-giving on the other hand (Roth and Reichert, 2002, p. 15; Rothgang 2003a, pp. 12-14). Although the data show in general a high satisfaction with the benefits of the long-term care insurance which have shared in the stabilisation of family care-giving (Schneekloth and Müller, 2000, p. 85; Runde et al. 1997, p. 84; Blinkert and Klie, 1999, p. 163) Rothgang states that the trend off benefits in cash towards benefits in kind as well as residential care will intensify in the future because some secular trends were not influenced by the long-term care insurance:

- a decrease in the family care-giving potential,
- increasing trends in female employment rates,
- an increase in single-households
- and a middle-term trend in the opposite direction: fewer widows and an increasing care-giving potential with the spouses (Rothgang 2003a, p. 24, Rothgang 1997, pp. 131-144).

Although there is a sufficient provision of „classical" benefits in kind highly visible gaps dehisce in the network of low-thresholded care supplies and volunteer services e.g. visiting services (Forum Sozialstation 2003). Based on recent experiences with projects in the model programme future structures in help for the Aged -Altenhilfestrukturen der Zukunft- (BMFSFJ, 2003) the current discussions and efforts concentrate on the following:

- The mobilisation of new Care- and self-help-potentials through the further development of training concepts for volunteer workers,
- offers for talks to exchange experiences as well as qualification which are the key elements for quality assurance in family care-giving,
- the improvement of building up networks, controlling and coordination of social and health services,
- new forms of "community housing" beyond the in-patient-out-patient dichotomy (Roth and Reichert, 2002) particularly for older persons suffering from dementia in order to relieve the family carers,
- the improvement and differentiation of services towards more complementary supplies and
- the development and delivery of integrated care and management concepts in the kind of *health-centres* or multidisciplinary *service networks* with a comprehensive service provision (ibid. p. 21).

There is a broad consensus in the necessity of cooperation, coordination and networking to constitute synergies between all actors in gerontological fields of action but the "core-problem" is to be seen in the predominant "particular interests" and the purchaser's competition among each other. Apart from a lot of model projects in the last years networking of services is still a "blind spot" in the legal service provision (Kofahl, 2003; Schneekloth, 2002).

6.1 What are the major policy and practice issues debated on family care of the elderly from the carers' point of view? Are older people and / or carer abuse among these issues?

The issue „family care-giving" recently seems to attract more public attention and local authorities, health insurances, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth arrange workshops or hearings and invite "pressure groups" to hear their statements. The Alzheimer society and the BAGA issued papers to state their position referred to different policy issues (see also chapter 3).

For example the Federal Association of Senior Citizens Organizations -BAGSO-, attend to the interests of older people and family carers. Among others they call for:

- the further development of palliative care facilities,
- prevention measures in order to avoid health- or mentally- related impairments to ensure older people's rehabilitation and participation in social life,
- a systematic discharge management in cooperation with family carers, professional services, the general practitioner and the medical doctor in hospital to avoid a loss to quality in the care of older people in the context with the introduction of the Diagnosis Related Groups -DRG's- in German hospitals,
- starting medical rehabilitation already during hospital treatment,
- the further local development of advisory centres for older people in critical situations,
- the checking of the prerequisites of a Germany-wide hotline,
- the enlargement of quality control of community services,
- training for general practitioners, professionals and the police to identify signs of elder or carers abuse at home and more action-plans within the senior citizens organizations themselves in order to make this issue more public and make it a part of the BAGSO's political work,
- more advice and supplies for carers groups (BAGSO, 2002, 2003).

The 'Rürup Commission'[59] has been charged with the task of the developing reform proposals for the sustainability in the financing of the social security system including the health- and long-term care insurance (BMGS, 2003b, Busse and Wörz, 2003) which also aimed at strengthening the willingness of family caregiving. This aim is not yet accompanied by appropriate measures and the family carer's perspective has not been taken into consideration at most indirectly in the course of the debate about the introduction of "personal budgets".

The problem of older people and / or carer abuse is still among the major policy and practice issues and is not unknown as well in social-political circles of experts as in society.

For some years there is a broad variety of mainly community-based programmes, models, initiatives and action plans run by different foundations and sponsorships so that centrally organised advisory centers in the federal countries are the exception. In many towns a telefone help-line service has been established to offer counselling and advice in difficult and critical care-giving situations. These offers are adressing family carers and older people in need of care in domestic care as well as older people in residential care settings. The need for education, counselling and call for action is high and a future increase will be forecasted (Sowarka et al., 2002).

6.2 Do you expect there to be any changing trends in services to support family carers, e.g. more state or more family support, more services or more cash?

It can be expected that the public social security system as well professional services as long-term care facilities will gain more great importance in the future (Roth and Reichert, 2002; Klie, 1999).

The enactment of the long-term care insurance brought an economical relief for many families on the one hand but didn't fulfil the expectations related to more systematic support, advice, training and organization of family care giving on the other hand. According to Klie and Blaumeister (2002) and mentioned above future generations will be involved to a much lesser degree in family care giving, not only as a result of demographic developments but also due to shifts in the social milieus. The traditional reliance on care resources within the family will become less and less relevant in a "cultural" sense and the moral orientation will also lose it's meaning regarding the decision to take on family care giving as the costs involved begin to play a central role in decision-making. There is also a solid evidence for a continuing increase in the labour force participation of women in general and of midlife women in particu-

[59] Named after its chairman, economics professor and long-time economic advisor of the government, Bert Rürup, composed of academics as well as representatives of employers, trade unions and other groups.

lar. As a result future societies can no longer fall back on the „natural female resource " in family care-giving (Jenson and Jacobzone, 2000, Spiess and Schneider, 2001).

Limited economic resources will have to concentrate on the organizational structures of service provision and to strengthen the efforts towards more coordinative and cooperative structures and building up locally based networks in service provision to meet the needs of family carers and the older person in need of care. The further development of counselling and advice services for family carers will be of great importance in the future and should be conceptualised as case-and care management which could ease the process of counselling particularly in difficult or precarious care giving situations who need comprehensive structures of coordination (Schulz-Nieswandt, 1999, Wissert, 1999). Professional care provider should be better trained in assessing the complementary needs to relief family carers as well as to develop more specific and complementary services and e.g. introduce also "preventive home-visits" by nurses.

6.3 What is the role played by carer groups / organisations, "pressure groups"?

Pressure groups and organisations like the German Foundation of Help in Old Age (Kuratorium Deutsche Altershilfe –KDA-) or the German Centre of Gerontology (Deutsches Zentrum für Altersfragen –DZA-) play an important role in order to support professionals in gerontological fields of action, to inform the broad public about ageing issues as well as to accompany and "influence" the process of policy making for the elderly population by academic counselling:

The DZA (founded in 1974) in Berlin is the leading national research and documentation centre which focus on the investigation of the living arrangements, life situations and life-styles of ageing people in the societal and policy context and one objective has always been to meet the needs of policy-makers in order to provide them with informations on the situation of the elderly population. The DZA has the legal status of a (non-profit) registered association and is partly funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the Berlin Senate Department for Labour, Social affairs and Women Issues. The DZA's bye-law defines the tasks of the centre: to increase, to collect, to interprete, to process and last but not least to disseminate gerontological knowledge (see also: www.dza.de).

The KDA[60] can be characterised being the pathfinder of the "modern" help for the aged in Germany. The reasons given to the foundation were the conditions in residential care felt being inadequate as well to improve the living conditions of elderly people in general as to keep their interests. The KDA's work is

[60] founded in 1962 by the former Federal President Heinrich Lübke and his wife Wilhelmine (Wilhelmine Lübke Foundation)

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mainly application-oriented and supports professionals in gerontological fields of action with advice, workshops, books, training, manuals or handbooks dealing with different issues in practice. Another objective is the information of the broad public about the living conditions of the elderly. The KDA initiated many established concepts in gerontological fields of action e.g. meals on wheels, clubs for elderly people, concepts of barrier-free living, day- and short-term care, quality standards in residential care or concepts of small housing-communities for people in need of care (see also: www.kda.de).

Several great "pressure groups" in Germany represent the interests of older people and family carers and play an important role in the public discussion on elderly affairs, e.g. the Federation of Senior Citizens Organizations - BAGSO - which is the parent organization of 78 societies acting all over Germany, the Alzheimer Society and the Federation of Advisory Centres for Older People and Family Carers –BAGA- (for more details see also chapter 3 and 3.1.2).

6.4 Are there any tensions between carers' interests and those of older people?

Family caregiving can affect the intra-familial relationships and the role allocation because family carers as well as the older person cared for have different needs which have to be brought in line: Older people in need of care want to be cared for in their own home as long as possible and more or less expect being cared by a family member; family carers often have to balance between their own psychosocial or economic needs (employment, social participation, leisure interests, the own partnership) and the older persons' needs and often are afflicted by a feeling of guilty not being able to please everybody.

Research data revealed that tensions and the emotional burden of care between the person in need of care and the carer will increase if the role of family care-giving is taken over under a high social pressure. In particular the lack of time-autonomy in order to structure the day is experienced to be seriously burdening (Wahl and Wetzler 1998, pp. 191-194).

From an economical point of view and according to Beckers (1974) „rotten-kid-theorem" financial incentives (Bergstrom, 1989, Kritikos and Bolle, 2002), e.g. the settlement of heritage, should not be underestimated in order to secure family care-giving and to avoid tensions between children and their parents. The point is how to guarantee family care-giving by negotiating appropriate contracts.

It's also important that in Germany benefits in cash paid through the long-term care insurance are allocated to the person in need of care and not to the family carer. This could also generate conflicts and tensions.

6.5 State of research and future research needs (neglected issues and innovations)

In Germany gerontological research has been very well institutionalised for more than 40 years, for example the well known gerontological research institutes e.g. at the Universities of Heidelberg, Dortmund, Erlangen-Nürnberg or Kassel. The German Centre of Gerontology (Deutsches Zentrum für Altersfragen –DZA- in Berlin began operating in 1974 and has been influenced and arranged strongly socio-political decision making with a lot of publications, enquiries, expertises and studies (for example: “Gerontology and Social Policy” 1979, “Health and Social Care for the Aged” 1990 or the major report “Aging in the Federal Republic of Germany” for the UNO meeting in Vienna 1982). The DZA is the only institution in Germany which offer the combination of applied research and documentation. The office of the Expert Commission for the Report on the Aged set up at the DZA by the federal government is directly responsible for policy advice. The report takes stock of the life situations of older people in Germany, dokuments the needs and measures in social policy for the aged and in society and develops policy perspectives for the 21st century.

Ongoing or more future research is needed in:

- Migrant care services and migrant family caregiving. This is a neglected area as well in gerontological as in nursing science research. Gerling (2003) points out that *“only a few attempts have been made in Germany to take a look at the experience of other countries”* (ibid. p. 216). In the course of the EC-project “Services for Elders from Ethnic Minorities – SEEM- conducted by the University of Dortmund the research data revealed a lack of cooperation and networking, a lack of consultation policies, a strong competition between self help organisations and charitable associations, a hesitantly behaviour of the black voluntary sector, a lack of information on the situation of migrant elderly, poorly visible needs and demand (poor lobby), a lack of political influence, a lack of information and advice about community care services in native languages and a lack of commitment on the relevant persons in charge (Gerling 2003a, pp. 20-21; Gerling and Miller, 2002). According to these findings the authors formulated several socio-political recommendations on the planning and the development of social services for ethnic minorities[61]. Services are not specialized on the specific migrant needs related to cultural, religious and language barriers, which make the migrants' take up of services more difficult (Wingenfeld, 2003) and the latter would confirm the research data found in SEEM.
- Evaluation research has to be continued towards innovative structures of Case- and Care Management in order to optimize the service provision and to build up more cooperative, coordinative and effective networks in service provision aiming on more transparency and more support for both family carers and older people in need of care (dip, 2003a).
- Evaluation research has to be continued towards model projects to develop new care concepts and service structures and to introduce "personal budgets". The aim of the personal budget is to transfer more client-sovereignty to family carers and the older person in need of care in order to buy their own "care-package" from the care-market. In the course of the law of rehabilitation and participitation (SGB IX) several model projets already tested the “personal budget” for more client’s autonomy in decision making (Wansing et al. 2003). The socio-political starting point based on new orientations in the help for the handicapped and recommends a needs-led approach with monetary transfers. This form of financing requires obligatory quality criteria which have to be developed but also depends on well coordinated Care- and Case-Management structures.
- More research is needed on the situation of family -particularly female- carers because the increase in the number of smaller and more unstable family types and increased employment rates for women could undermine family networks of solidarity and make the provision of health and care within families more difficult to sustain. Economic objectives in terms of employment rates reconciling the needs of work with social and family goals could be especially problematic and is a central challenge for national and EU policy makers (European Foundation, 2003).
- A nearly totally neglected area is the role of domestic care-workers and their employment situation. The access is difficult because of mostly illegal and precarious employment. It has to be paid more attention in a new role of private households as private employers in general and particularly in the area of domestic care-giving. On the one hand the professionalising of domestic care work could be a future area to qualify (also migrant) women and to develop new models of employment. This could increase the value of domestic employment in general through social contributions and training. The economic distinction between the public and the private household could be abolished and also the difficult situation of domestic care giving would become known (Thiessen, 2002). On the other hand professional care-work could contribute to a more differentiated and more needs-led service provision within private households to relief family carers and to support older people without stable family networks (Schmidt, 1999).

[61] Related to the consequences and the future development of social and health services this issue is still debated divergently: Supposing on the one hand a stable migrant family carers' potential with older people being cared for in their own home, no changes in the demand of services will temporarily be expected. On the other hand an increasing erosion of migrant family care-giving potentials will be expected with increasing demand towards services.

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- More research is needed on the issue of elder abuse at home and also in residential care facilities (Hirsch, 2000).
- Research is needed in the development of diagnostic measures such as dementia telemedicine centres and telephone assessment to improve the medical treatment of older people through a specialist doctor and to ensure the early diagnosis of dementia (BMFSFJ, 2002).
- According to the support of family carers by electronic information- and communication systems there is currently no research in the German speaking countries. Meanwhile there is a huge amount of IT-services but a quality control of these services remain underdeveloped. Applied research is absolutely necessary (ibid.).
- On a community-based level the further development of new forms of "sheltered housing" necessary to allow older people to live at home as long as possible or housing communities for older people suffering from dementia to relief the family carers (ibid.).

6.6 New technologies - are there developments which can help in the care of older people and support family carers?

There is a widely developed market with a lot of innovative technologies in the field of "gerontechnology" in Germany to support as well the older person in need of care as the family carer. Many greater towns maintain centres with permanent exhibitions and counselling -which is free of charge- in technological innovations: e.g.: so-called "Skala-mobiles" for older people who aren't able to climb stairs, complete barrier-free furnishing, emergency-calls, adapting sanitary environment or several appliances in order to balance functional handicaps or impairments. These centres are equally financed by the local authorities or charitable organisations and the gerontechnological industry provides the exhibits mostly for free because there is a great interest in selling new technologies.

6.7 Comments and recommendations from the authors

No special comments.

7 Appendix for the National Background Report for Germany

The increase of older people in population is particularly connected with an increase of the very olds' proportion and > 80 year olds people won't be a future exception. This poses challenges onto economic and societal restructuring processes.

7.1 Socio-demographic data (This section is of specific importance for countries where little is known about family carers and the socio-economic conditions under which they care.)

7.1.1 Profile of the elderly population-past trends and future projections

The demographic projection shows growing numbers of older people in each age band between 2000 and 2030 with a 61 % increase for older people aged 65 and over. From 2030 to 2050 the total number of older people remains constant, but shows dramatic changes in composition. While the numbers of persons between 65 and 75 are declining and the numbers of those aged 75-80 remain almost constant, the number of the very old (> 80 year-olds) is increasing rapidly (by 51 %). Since it is particularly the very old who are in need of long-term care, the number of dependent people can be expected to grow considerably between 2030 and 2050 even though the total number of older people (> 65year-olds) is not noticeably growing in that period (Rothgang, 2003, p. 27, Deutscher Bundestag, 2002).

7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

As shown in the following table it's the women who perform a higher life-expectancy than the men and old age remains female.

Table 27: Average future life-expectancy of older people at birth in order by age groups

Table of death			1996 / 98	1997 / 99	1998 / 00
Age 0	Men	years	74.04	74.44	74.78
	Women	years	80.27	80.57	80.82
Age 20	Men	years	54.82	55.21	55.52
	Women	years	60.86	61.15	61.38
Age 40	Men	years	35.84	36.18	36.46
	Women	years	41.35	41.62	41.84
Age 60	Men	years	18.73	19.01	19.25
	Women	years	23.06	23.30	23.50
Age 65	Men	years	15.13	15.36	15.56
	Women	years	18.85	19.06	19.25
Age 80	Men	years	6.75	6.91	7,01
	Women	years	8.23	8.37	8.47

Source: Statistisches Bundesamt, 2003c

7.1.1.2 % of > 65 year-olds in total population by 5 or 10 year age groups

Currently 3.2 Mio. older people aged > 80 years live in Germany which corresponds to a proportion of 3.9 % referred to the total population. With growing life-expectancy this proportion will increase considerably and it is estimated that in 2050 about 9.1 Mio. or 12 % of the total population will be > 80 years-old (Statistisches Bundesamt, 2003c). The table below shows the proportion of > 65year- olds population by 5 year age groups.

Table 28: Population of older people > 65 year-olds in order by age groups (in %) and by gender 2002

Age groups from … until	Total Population N = 82,440,309 (%)	Male	Female
65-69	4,378,060 (5.3)	2,072,547	2,305,486
70-74	3,604,682 (4.3)	1,584,122	2,020,560
75-79	2,838,177 (3.4)	982,712	1,855,465
80-84	1,704,711 (2.1)	503,089	1,201,622
85-89	989,385 (1.2)	245,188	744,197
90+	550,707 (0.7)	123,082	427,625

Source: Eurostat, 2003

7.1.1.3 Marital status of > 65 year-olds (by gender and age group)

The table below evidently shows the differences in marital status by gender and between the different age groups. Women are at a higher risk being wid-

owed. A majority of older men is living together with a female partner whereas women are living alone with increasing age (Statistisches Bundesamt, 2002a).

Table 29: Marital status of > 65 year-olds (by gender and age group in % in 1999)

Material Status	Age and gender					
	70-74 years		75-79 years		80 years and older	
	Men	Women	Men	Women	Men	Women
Single	3.0	7.3	2.5	8.0	2.7	6.4
Married and co-residence	81.6	46.6	76.1	29.4	58.9	10.5
Married and living apart	1.4	1.2	1.3	1.1	1.7	1.1
Widowed	11.3	40.1	17.9	56.9	34.8	78.4
Divorced	2.6	4.8	2.1	4.7	1.7	3.6

Source: BMFSFJ, 2002 p. 124

7.1.1.4 Living alone and co-residence of > 65 year-olds by gender and 5-year age groups

The proportion of older women living alone will increase quickly and considerably with increasing age whereas the proportion of older men living alone remains relatively constant until 75 years in order to increase clearly in later life. The proportion of women > 75 year-olds living alone is about 65 % which is 2.7-fold compared to the reference value of older men aged > 75 old (Statistisches Bundesamt, 2002).

Table 30: Living alone of > 65 years old people in order by gender and age groups

Type of residence	65-70	70-75	75+
Men living alone	~12	~15	~22
Women Living alone	~30	~42	~65

Source: Statistisches Bundesamt, 2002, p. 26

7.1.1.5 Urban / rural distribution by age

According to the regional distribution of the aging population there are as well regional differences as between the federal countries and one has to differentiate into urban and rural areas with a high pressure of internal migration from the eastern to the western countries and scarcely settlements on the one hand and agglomerations with intensive internal migration and suburban structures on the other hand (Bundesamt für Bauwesen und Raumordnung, 1999).

Table 31: Urban / rural distribution by settlement structures and types of districts in 1993 (in %)

Settlement structures and types of districts	Migrant population		German population	
	In Total	> 60 years old	In Total	> 60 years old
West-Germany	100	100	100	100
Agglomerations-Cities > 100,000 inhabitants	42.1	42.2	23.6	25.6
highly densed districts: > 300 inhabitants / square km	20.3	18.5	15.6	15.5
densely districts > 150 inhabitants / square-km	5.6	6.4	8.3	8.2
urban areas < 150 inhabitants / square-km	1.6	1.4	4.4	4.1
Urban areas	21.2	20.8	30.6	29.9
Rural areas	9.2	10.7	17.6	16.8

Source: BMFSFJ, 2001, p. 231

7.1.1.6 Disability rates amongst > 65 year-olds. Estimates of dependency and needs for care

Cognitive impairments such as dementia play a central role in the origin of disability and need of care in old age. About the half of all people cared for at home are mentally disabled so that regularly advice, support and help in the activities of daily living is necessary. Since the incidence and prevalence of cognitive impairments will increase with old age it is estimated that the number of people in need of care will increase considerably. Currently (2000) about 950,000 people are suffering from dementia (conservative estimates), among them about two thirds suffer from Morbus Alzheimer (Deutscher Bundestag, 2002). Based on calculations on the further development of the population it is estimated that the number of older people suffering from dementia will increase up to 1.4 Mio. in 2020 and more than 2 Mio. in 2050 in case that no medical or preventive breakthrough will appear. The huge amount of older people suffering from dementia also will imply economical consequences[62].

The table shows the estimates in the development of the number of older people suffering from dementia.

[62] In 2000 43,767 Euro were calculated per capita and year (BMFSFJ 2002, p. 181)

Table 32: Estimates in the development of the number of older people suffering from dementia assuming that prevalence rates will constantly remain (in order by age group and stated in 1000)

Age group from…until	Year 2000	Year 2010	Year 2020	Year 2030	Year 2040	Year 2050
65-69	49,8	52,1	58,8	75,0	54,1	
70-74	100,7	133,4	110,1	140,0	151,9	112,2
75-79	170,1	186,4	197,2	228,6	296,3	216,9
80-84	196,0	295,4	402.5	343,8	447,8	495,7
85-89	260,3	304,8	347,6	379,2	469,4	633,9
> 90	176,6	183,1	272,0	394,8	382,3	533,1
Total	**953,5**	**1,155,2**	**1,388,2**	**1,561,4**	**1,810,8**	**2,046,2**

Source: Bickel, 2001 in BMFSFJ, 2002, p. 182

7.1.1.7 Income distribution for top and bottom deciles

The following table shows the income distribution for top and bottom deciles but not available in % of aged > 65 year-olds.

Table 33: Current Total Monthly Net Hsd Income[63]

N	5693
Mean	4,157,61
Median	3,600,00
Minimum	190
Maximum	28,000
Deciles	
10	1,613,00
20	2,100,00
30	2,600,00
40	3,000,00
50	3,600,00
60	4,200,00
70	5,000,00
80	6,000,00
90	7,375,00

Source: Rothgang, 2003 own calculations

The proportion of > 80 year-olds women in private households and having a net-income[64] less than 511,- Euro at their disposal is three times higher than

[63] Interpreting the table it has to be taken into consideration that the average increase in monthly wages amounted in 1999 in contrast to the last year 2.6 %; in 2000: 2.3 %; in 2001: 2.1 %; in 2002: 2.2 % and until the third quarter of 2003: 2.5 % (Statistisches Bundesamt 2004)

[64] figures are equivalence weighted

of > 80year-olds men. The following table shows the monthly net-household income for pensioners in general and for the > 80years age groups by gender.

Table 34: Monthly households' net-income distribution in West-Germany in order by age group in % (in 1998)

	Euros (mean)		%				
Type of household (main income receiver)	House holds' net-income	Equivalence weighted to personal net-income	Related to the average in all house holds	Household with less than… % on the average. 40	50	60	Households with two- or forth-fold than the average
Households in total	2,615	1,708	100	5.3	12.7	22.0	5.2
Pensioner	1,760	1,382	81	5.7	16.6	30.0	1.6
Civil servant pensioner	3,468	2,504	147	/	/	/	16.3
Main income receiver by age group							
Female > 80 year olds	1,326	1,280	75	9.4	24.8	41.8	–
Male > 80 year olds	2,183	1,677	98	/	11.0	19.1	–

Source: BMFSFJ, 2002 p. 81

A quarter of the > 80 year-olds women households received a net-income below the 50 % threshold of the average households' income. The proportion of a relative income-poverty among > 80 year-olds women is twice as high than the national average which amounts 12.7 %.

In total about 19.5 % of the > 80year-olds households have a net-income[65] below the 50 % - threshold in comparison to 12.7 % of all households on average.

Nearly 9 of 10 women aged > 80 years and more depend on social assistance and the broad majority of them live in one-person-households (BMFSFJ, 2002, p. 88).

7.1.1.8 % > 65 year-olds in different ethnic groups

The total number of migrants in Germany amounts 7.3 Mio. (8.83 %) with a proportion of 3.96 Mio. (54.3 %) male and 3.34 Mio. (45.7 %) female migrants. Among them 4.7 % were > 65 year-olds. Compared to the German population the migrant population is essentially younger but will adapt in the future. The proportion of the different migrant (> 60 year-olds) nationalities show considerable differences: The proportion of EU-Migrants amount 12.2 %, 8.7 % are

[65] figures are equivalence weighted

from former Yugoslavia, about 7.2 % are of Turkish and 6.3 % of Polish nationality whereas the Asian and African migrants amount 3.8 % each. The proportion of migrant population considerably varies between the federal countries: the highest proportion related to the respective population is to be seen in Hamburg which is 15.7 % and the lowest in Saxony-Anhalt which is 1.69 % (Die Beauftragte der Bundesregierung für Ausländerfragen, 2000).

Table 35: Proportion of migrants by age group in 2000

Age group from …until	In Total	% [66]	Among them born in Germany	% [67]
60 -65	282,866	3.9	3,105	1.1
> 65 year-olds	341,188	4.7	15,733	4.6

Source: Die Beauftragte der Bundesregierung für Ausländerfragen, 2000

7.1.1.9 % Home ownership (urban / rural areas) by age group

About 80 % of the 1.7 Mio. > 65 year-olds- households amounting > 100 square meters are in ownership and more than one-third of the persons presiding over a one-family house are > 50 years old. In particular in the suburbs of western German cities many older people live in their own one-family-houses and with increasing trend (BMFSFJ, 2001, 2002).

7.1.1.10 Housing standards / conditions if available by age group e.g. % without indoor plumbing, electricity, TV, telephone, lift (if above ground floor), etc.

In 2000 the average living-space per capita amounted 42 square meters and there is a clear trend towards more home-ownership and to make households smaller. Older people are very much settled down and don't give up their home with increasing age. Anyway, the homes are too big because they originally were allocated for more family members. (Bundesamt für Bauwesen und Raumordnung 1999 p XV). The table shows the housing standards in older people's private homes in order by age group.

[66] related to the total number of migrants
[67] related to the total number in this age-cohort

Table 36: Housing standards in older people's private homes in order by age group and selected equipments, 1998 (per 100 households)

Gadget	Age group from… until		
	55-64 years	65-69 years	> 70 year-olds
TV	97.2	97.2	97.6
Telephone	98.1	97.8	96.7
Refrigerator	99.4	99.6	99.2
Dish washer	47.5	36.9	21,0

Table 37: Level of equipment of older people's private homes with indoor-plumbing and heating,1993

Age group from…until	Proportion of households with indoor plumbing and heating	
	Households in total	One-person-households
65-69	73.5	71.2
70-74	72.0	69.7
> 75 year-olds	69.8	66.9

Source: BMFSFJ, 2002, p. 110 ff.

Due to the small number of cases for the very old in the socioeconomic panel -SOEP- in 1999 / 2000 the interpretation of the results is very difficult. According to basic housing standards only figures from 1993 are available (BMFSFJ, 2002, p. 111 ff.).

7.2 Examples of good or innovative practices in support services

In Germany innovative practices in support services are based on building up networked structures and working with elements of cooperation and coordination on personal and institutional level. Kofahl et al. (2003) have identified three basic categories of approaches for network activities as well as elements who avoid or improve networking activities:

- community-based networking,
- networking orientated towards institutions,
- networking orientated towards target groups.

Factors who improve networking on a structural level:

- a physical centre is available (office, café, seminar-room),
- a virtual centre is available (Website, events, flyer, documents),
- a personal centre is available (such as a network manager / care manager, clerical secretary).

Factors who improve networking on a level of processing:

- definition of aims,
- contracts,
- responsibilities carried out permanently and reliable,
- process of networking accompanied by an external moderator,
- further education across all professional groups,
- reimbursement.

Factors who obstruct the process of networking:

- Lacking of financial support,
- high fluctuation in personnel,
- excessive competition between the institutions,
- lacking support through the purchaser or chair,
- confusion about areas of responsibility between insurance companies and municipalities.

This summary worked out in the research project ProNetz can help the staff in social- and health care provision or in health or long-term care insurance companies to identify innovative care concepts and -models in order to give incentives, examples or support in planning own networking activities and to help sponsors in decision making towards the provision of financial subsidies (Kofahl et al., 2003).

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