interlinks

Health systems and long-term care for older people in Europe
Modelling the interfaces and links between
prevention, rehabilitation, quality of services and informal care

Informal Care in the Long-Term Care System

Germany

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in cooperation with

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1 Introduction and background

1.1 What is understood by "informal care" and "formal care" in your country? What are the main definitions used to distinguish between the informal and formal care sectors?

In Germany the terms "formal care" and "informal care" are generally used in at least two different contexts:

- On the one hand when it concerns the responsibility for the delivery of services to meet a concrete need for care. Is it the task of the state in its role as welfare state, or is it an individual responsibility? In the first case, support is often referred to as formal care; in the second it is often referred to as informal care (Büscher, 2007: 12).
- On the other hand, when it concerns services involving the long-term care of a needy person where a differentiation has to be made between the actual institutions or persons delivering the services. When they are provided by an institutional facility or by a home care service, support is often referred to as formal care. When the services are provided by family members or other private persons, the support is usually referred to as informal care.

The terms "formal care" and "informal care" are mainly used in the second context described above. Here, formal care describes care provided as a source of income (Mager/Eisen, 2002: 14), while informal care is not provided as a source of income. The literature cites family members, friends, acquaintances and neighbours as typical providers of informal care.

1.2 Legal aspects of care – how are the relative responsibilities for the care and financial support of dependent older people shared between family and state? What is the estimated contribution of family care to the total provision of care for dependent older people?

When a person becomes dependent on care, then their resources are of importance. The following brief description indicates the most important resources when clarifying the resulting responsibilities for covering the costs of care.

- *Insurance benefits*: Each person of any age with health insurance is covered either by social or private statutory long-term care insurance.[1] When the need for long-term care arises, the affected person can find out whether he or she is entitled to insurance benefits. On application, the medical service of his or her health insurance provider establishes the level of care needed.[2] After the level and

1 The benefits of both systems are identical. There are also additional private insurance options which provide higher insurance levels. Compulsory long-term care insurance is regulated in the code of social law: Sozialgesetzbuch (SGB) – Elftes Buch (XI).

2 The medical service classifies the care required in Care Category I, II, III or III hardship case. If the assessment fails to establish the minimum "considerable" need for care, the application will be rejected (Care Category 0). Care Category I: need for care at least 90 minutes per day. Here, more than 45 minutes per day must be devoted to basic care (particularly personal hygiene, nutrition, and mobility). Care Category II: need for care at least 180 minutes per day with a basic care requirement of at least 120 minutes per day. Care Category III: need for care at least 300 minutes per day. Here

type of care needed has been established, it can be provided accordingly as care at home, partial or full institutional care. Care at home can be carried out by informal carers or by home care services. Partial or full institutional care is carried out by care facilities, such as nursing homes. When informal carers look after the needy person at home, the long-term care insurance pays a care attendance allowance to the person in need.[3] Otherwise the beneficiary is entitled to receive benefits in kind.[4] The long-term care insurance normally only assumes responsibility for the costs of care when the established needs exceed a certain minimum scope[5] and are anticipated to last for more than six months. If the insurance does meet the costs, then only within a framework of maximum rates. On their own, the current levels of financial support granted are generally insufficient to fully cover the services necessary for the established care requirements (Robert Koch-Institut, 2004: 21). The services which cannot be financed through these channels have to be financed other ways or provided by other means, if they are not to be abandoned.

- *Income and assets*: the person requiring care may have available financial resources (including maintenance payments) at his or her disposal, which enable such persons to avail themselves of care services against payment. Here again, it applies that not every person requiring care has (a sufficient amount of) such resources at his or her disposal.
- *Family members and private networks:* the person requiring care may know people who are prepared to informally care for them or help them in everyday life. Not all of the people in need of care can resort to this option. Some no longer have any close relatives or more or less consciously decide to do without their support. Others have no acquaintances who would be prepared to support them.
- *Voluntary helpers*: the person in need of care can make use of the services of people who are available for help through a voluntary scheme. Again, this kind of help cannot be accessed by every person in need of care. Neighbourhood help groups, family services and self-help groups offering voluntary support do not exist everywhere.
- *"Care Assistance":* when the four above resources are insufficient to meet the established care needs, there is a fifth resource available: the person in need is entitled to "Care Assistance". This is a

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basic care must amount to at least 240 minutes per day. When the care requirements greatly exceed the level of Care Category III, the person in need may qualify as a hardship case. Meanwhile there is a report by the long-term care advisory committee reviewing the definition of the need for care ("Beirat zur Überprüfung des Pflegebedürftigkeitsbegriffs") which proposes a classification of needs into five care categories rather than the current three (BMG, 2009). However, the proposals still have to be codified in law. This present text uses a very broad definition of the need for care and includes persons whose need for care does not qualify for a care category classification.

3 In addition to this the long-term care insurance offers a series of extra services to support informal carers (see paragraph 2.4).

4 Here is an overview of the most important insurance payments according to categories of care (as of 1 January 2010):

	Care category			
	I	II	III	III hardship case
Care attendance allowance	225 €	430 €	685 €	685 €
Benefit in kind	440 €	1,040 €	1,510 €	1.918 €
Full institutional care	1,023 €	1,279 €	1,510 €	1.825 €

5 This is the case when the applicant has been classified in one of the three care categories. There is an exception: People in need of care who have not been classified in one of the care categories may, under certain circumstances, qualify for services (benefits in kind) for persons with "considerable general care requirements" (§45a,b SGB XI). This applies especially to people suffering from dementia. For the sake of completeness: These services are also available for people with "considerable general care requirements" who are classified in one of the care categories.

special social benefit based on needs[6] and designed for people who require care, but are unable to secure this from their own means (Robert Koch-Institut, 2004: 21). It is available to persons who fulfil the conditions for receiving social security benefit. "Care Assistance" finances all of the care services which are not covered by long-term care insurance.[7]

The following details on persons in need, informal carers in general, and what we call "caring persons" (persons for whom care attendance allowance is received[8]) are based on figures in the official statistics and on an analysis of the Socio-Economic Panel Study of 2005 by Schnabel (2007):

- *Persons in need of care who are looked after by caring persons.* In 2005 a total of approx. 2.13 million people were being cared for, irrespective of their ages.[9] Approx. 677,000 of them were in institutional facilities (Federal Statistical Office 2007: 4). Approx. 1.2 million were being looked after at home solely by informal caring persons (approx. 980,000 who only receive care attendance allowance) or together with the help of a home care service (approx. 225,000 who receive both care attendance allowance and benefit in kind) (Schnabel 2007: 5). The remaining persons in need of care are only receiving benefit in kind for using a home care service.
- *Informal carers.* In 2005 a total of approx. 4.96 million people of all ages were providing care; 760,000 were working as full-time or part-time carers in care homes or with home care services (Federal Statistical Office, 2007: 5ff.) and 4.2 million were informal carers (Schnabel, 2007: 6).[10]
- *Time given by informal carers.* Of the approx. 88.5 million hours of care per week provided in 2005, approx. 66.7 million hours were given by informal carers[11] (calculation based on Schnabel, 2007: 6).

6 "Care Assistance" is provided in the individual federal states by the "supra-local bodies responsible for social assistance benefit". In Hesse, for instance, it is the Landeswohlfahrtsverband (a welfare association formed by the local governments of the state of Hesse), and in Bavaria it is the administrative regions.

7 On the one hand, care services necessary to cover a considerable need for care (at least Care Category I). On the other hand, care services necessary to cover a need for care which is not classified as considerable (Care Category 0) or is anticipated to be necessary for less than six months.

8 "Caring persons ... are people who, on a non-profit basis, look after a person in need of care in the sense of § 14 in that person's domestic environment" (§19 SGB XI). Correspondingly, "main caring persons" are those people who solely or primarily perform the activities involved in caring for the person in need (with Care Category I or higher) (Mager, 2007: 71).

9 This figure includes all of the people requiring care and who have been assessed as needing at least Care Category I. In other words, not only elderly, but also young persons who are in need of care due to some form of disability. In 2005 approx. 82% of people in need of care were 65 years old or more, approx. 33% were 85 years old or more (Federal Statistical Office, 2007: 4).

10 The number of informal carers also includes persons who are looking after people who are not in considerable need of care and do not qualify for one of the care categories (Care Category 0), as well as persons who assist in caring in addition to the main caring person. The figure has been gained from an analysis of the Socio-Economic Panel Study of 2005. This study asked whether, and to what extent, persons in need of care were being financially supported and/or cared for.

11 Similarly, this figure also includes who are looking after people who are not in considerable need of care and do not qualify for one of the care categories (Care Category 0), as well as people who are involved in addition to a main caring person.

1.3 Very brief description of main component services in national LTC systems (public, private, NGO); how are they organised and delivered; strengths and limitations, including coverage.

In the following a description will be given of the main components in the German LTC system 1) coordination of the activities to guarantee concrete support, 2) needs assessment, 3) concrete care, 4) support and relief for informal carers, 5) quality assurance and 6) care funding:

1. Family doctors and the social services of hospitals, rehabilitation facilities and inpatient facilities for the elderly are responsible for coordination.[12] The family doctor generally acts as coordinator when the need for care arises (Meyer, 2006: 42). The social services assume the coordinating role when the need for care arises during a hospital stay, or when the person concerned is already living in a facility for the elderly. The social services are bound by the national Expert Standard for Discharge Management (see section 3.1 for the national Expert Standard).
2. Care assessment is carried out by the medical services of the health insurance funds (§18 SGB XI).
3. Care is divided into home care and (semi-)institutional care (including short-term care, day care and nighttime care). The former can be performed by informal carers, but also by formal care services (home care services). In Germany home care services and institutional facilities are run by private, charitable and public bodies.
4. Support and relief for informal carers are available in various forms, such as information, courses in caregiving, psychological support and replacement solutions for caring persons who need relief (see also section 2.4).
5. Quality assurance for care services provided by institutional facilities and home care services is the responsibility of the health insurance funds' medical services (§114 SGB XI). In so far as the person in need of care receives a care attendance allowance, the care given by informal carers is discussed during the recipient's regular, obligatory counselling sessions carried out by home care services, recognised advice centres or authorised professional carers (§37 Section 3 SGB XI).
6. Care funding is met by the health insurance fund and the person in need of care, and where necessary supplemented by "Care Assistance" (§§61ff. SGB XII).

The LTC system is so designed that the individual receives the care services necessary to cover his or her needs. Nevertheless, in reality there are limitations to the (all-round) success of the system:

- The key actors – family doctors, home care services, ergo therapists, social workers etc. – do not always cooperate to the full extent required to meet the care needs of the person involved (van den Bussche, 2006: 31f.).
- The social services of hospitals, rehabilitation facilities and inpatient facilities for the elderly do not always succeed in fulfilling the national Expert Standard for Discharge Management. This might be because there are shortfalls in staffing, but also because the Expert Standard can only be partially met for structural reasons.[13]
- The institutional facilities, home care services and informal carers do not always fulfil the quality standards required of them.

12 "Social work" is always a part of the work carried out in the listed types of facilities. The responsible service is usually called "social service". Its tasks are defined in the specific laws governing hospitals in the individual federal states.

13 For example, the success of operations or the course of recovery processes can only be forecast to a limited degree.

- The concrete care requirements of the person in need of care can be classified too low during the assessment carried out by the health insurance funds' medical services. If the person in need of care is anxious to acquire adequate coverage of his or her requirements, this can result in an additional financial burden or, if no personal funds are available, it can lead to a gap in care provision.
- People in need of care do not always avail themselves of all the care services necessary to cover the established care requirements, especially when they or their relatives would have to finance them or apply for "Care Assistance".

1.4 Data on informal family carers and other informal unpaid workers (volunteers, neighbours, friends, church etc.). Number; Age; Gender; Income; Hours of caring and caring tasks; caring for more than one person; Level of education and/or Profession/Employment of family carer; Generation of carer; Relationship of carer to OP; Residence patterns (household structure, proximity to older person needing care, kinds of housing etc.); Working and caring.

In 2005 the number of informal carers totalled an estimated 4.2 million people. Approx. 1.2 million of them were either the main caring person, or were supported by a home care service in looking after a person in need of care who had been classified in at least Care Category I and was receiving care attendance allowance (Schnabel, 2007: 5f.). The remaining 3 million were people who, together with a main caring person, provided care services and/or cared for people in need who were not classified in at least Care Category I (Schnabel, 2007: 6). According to a survey carried out in 2002, 92% of the main caring persons were related to the person being looked after, in other words "informal family carers" (Schneekloth/Wahl, 2005: 77). The following data on informal carers are contained in the same source:[14]

Table 1: Socio-demographic characteristics of the main caring persons (in %)

Relationship to person in need of care	
(Married) partner	28
Mother	12
Father	1
Daughter	26
Daughter-in-law	6
Son	10
Other relatives	9
Friends, neighbours, acquaintances	8
Gender	
Male	27
Female	73

14 No details were available for the parameters "Income" and "Level of Education" because the available data are not sufficiently up-to-date (the most recent studies are from 1997 and 2000).

Age	
under 45 years	16
45 to 54 years	21
55 to 64 years	27
65 to 79 years	26
80 years and above	7

Source: Schneekloth/Wahl, 2005: 77.

Amongst the terminally ill, 81% of family carers were wives, daughters or daughters-in-law (Mestheneos et al., 2004: 24).

67% of the main caring persons lived together with the person in need of care, 9% in the same house, 15% up to 10 minutes away and 5% up to 30 minutes away (own calculations based on Schneekloth/Wahl, 2005: 76).

The average time per week given by the main caring persons was 29.4 hours for people with Care Category I, 42.2 hours for those with Care Category II and 54.2 hours for those with Care Category III (Schneekloth/Wahl, 2005: 78). Approx. one third of caregivers were caring for more than one dependent person (BMFSFJ, 2002: 198).

51% of the main caring persons were not in employment at the beginning of their caring activities, 10% gave up their employment and 11% reduced their employment. 26% continued their employment at the same level parallel to their caring activities (Schneekloth/Wahl, 2005: 79). Civil servants, the self-employed and the salaried were most likely to combine work with care, though their share also decreases if an older person with dementia is cared for (Mestheneos et al., 2004: 26).

1.5 Cultural and current political context: attitudes to ageing/older people and their care needs. How are issues of informal/family care and LTC services discussed?

Aging and the need for care from the scientific perspective. The scientific discussion differentiates between the third and fourth age of life. The third age denotes the period of life which begins after the conclusion of employment and is generally characterised by good health and an active lifestyle.[15] The fourth age of life denotes the period in which a person requires help and care and is correspondingly dependent to a greater or lesser extent on supportive people. At the moment a controversial debate is under way surrounding the issue of how the spans of the third and fourth ages of life are developing in view of increasing average life expectancy. Is this leading to additional years of active life or to additional years where care is needed? There are however signs that "there have been definite improvements in the state of health and at least partially in the everyday functioning abilities of elderly people" in recent decades (Schneekloth/Wahl, 2005: 16).

Aging and the need for care from the perspective of the elderly and that of professional carers. For some time now signs of a new culture of age and support and care services are beginning to show: for the

15 The third age is often given as the span between 65 an 85 years of age (Schneekloth/Wahl, 2005: 15f.).

majority of elderly people old age has now become an employment-free phase that enables the continuation and even diversification of existing interests (Schneekloth/Wahl, 2005: 16). These older people possess high levels of self-confidence and a distinct sensitivity to age discrimination. They are particularly interested in the prevention of chronic illnesses and view themselves increasingly as customers in the provision of preventative or supportive services. There are also promising beginnings in the complementary development of a new culture in professional help, which views elderly people increasingly as customers with a demand for quality (Schneekloth/Wahl, 2005: 17).

Aging and the need for care from the perspective of the planners. When looking at the images of aging in the minds of planners and decision-makers in the administrative and political spheres, there is evidence to suggest that their images of aging are not negatively biased, but that they do still seem to be rooted in traditional ideas: "This means that, for instance, demands among the elderly for high levels of independence may be recognised, but no importance is attached to integrating them personally into planning decisions … or to systematically addressing elderly people when examining the effects of implemented measures" (Schneekloth/Wahl, 2005: 19).

Aging and the need for care from the perspective of health and care policy. Germany's population is aging very rapidly, and the number of very old people in particular will increase drastically in the coming decades. At the same time there is a great reduction in the proportion of people of productive age. This is relevant to the issue of providing for people in need of care in two respects: on the one hand, because the people of a productive age have to account for a section of the carers, either as family carers or other informal carers, or as professional carers; on the other hand because in Germany they have to provide a large part of funding for the health and care expenses within the framework of a means assessment system. Consequently the political discussion about aging and the need for long-term care focuses primarily on questions surrounding the extent to which care services can be provided in the future, who will provide them, who will meet the ensuing costs and to what extent (Schnabel, 2007: 2). Facing prognoses about the reduction of family carers in the next decades, the need to foster self help activities and civic engagement in this context is stated as also friendship and neighbourhood networks will not be able to compensate for the shortfall of services (BMFSFJ, 2002: 193).

2 What are the main links and interfaces between informal carers and the health and long-term care systems?

2.1 Policies for informal/family carers of disabled people or dependent older people

The principles of German care policy can be characterised in two points: 1. People in need of care should, as far as is reasonable and feasible, be cared for at home (motto: "home care rather than institutional care"). 2. Home care should, as far as is reasonable and feasible, be given by informal carers or at least supported by them. Support from long-term care insurance for care given by informal carers is correspondingly regulated by law (§3 SGB XI): however, people in need of long-term care can choose between home care services and informal caring persons when being looked after at home (or they can

opt for a combination of the two). Informal caring persons are offered a diversity of support possibilities, especially by long-term care insurance funds and charitable associations (see section 2.4).

2.2 Links and/or gaps between informal carers of dependent older people and their use of formal care services in each country. Papers bringing evidence based on information about how formal and informal carers work together and distribute their time; how they share responsibilities for the patient care while avoiding (or not) potential conflicts; issues of mutual ill treatment/abuse should be specifically noted, as should papers analysing gaps in care provision, their locations and determinants, as well as possible solutions to them

Basically, the following variations in cooperation between formal and informal care providers are conceivable: 1. The person in need of long-term care has opted for a combination of benefit in kind and care attendance allowance. In 2005 this applied to approx. 15% of the support and care arrangements (own calculations based on Schnabel, 2007: 6 and the Federal Statistical Office, 2007: 4). For instance, a home care service may be the exclusive provider of basic medical care, while an (informal) caring person carries out the remaining care tasks. 2. The person in need of long-term care has applied exclusively for benefit in kind: the home care service then meets the care requirements of the affected person to the level that these services are covered by the statutory long-term care insurance. An unpaid informal carer covers the remaining necessary requirements. No data are available on the frequency of this form of arrangement.[16]

The legislator attaches great importance to the development of productive cooperation between informal carers and home care services. Their coordinated work should be set in motion and promoted especially by the social services of the hospitals and rehabilitation facilities, as well as by the long-term care support centres with their case management advisory services, which are currently in the process of being established (see section 3.2.5). However, there are as yet no evaluations of the contribution made by these institutional social services and the long-term care support centres towards enhancing cooperation between informal carers and home care services.

When home care services are being used, the satisfaction of informal carers is generally high (BMFSFJ, 2002: 204). Critical remarks are found especially on the following points: “Firstly, there is criticism of work organisation which is not very user-friendly. In the home care area the home care services’ deployment times are felt to be unsatisfactory. Secondly, there is criticism of the lack of staff continuity in long-term care situations … The lack of time on the part of home care service staff is the third main criticism. The fourth quality defect is seen as an above-average frequency of inadequate social competencies on the part of formal care staff” (BMFSFJ, 2002: 206). Conversely, criticism from the perspective of the professional carers complains about informal carers monitoring the way they fulfil their tasks, interfere in more or less awkward situations during their care activities and often try to draw them into fami-

16 According to data from 1997, the share of carers making use of professional support amounted to 37% in East Germany but only 19% in West Germany (BMFSFJ, 2002: 203). On the average, in 1999 approx. one quarter of main carers provided help alone, approx. half of them were supported by other informal carers and approx. one quarter was supported by professional carers (BMFSFJ, 2002: 204).

ly internal conflict constellations. As professional carers are not prepared to these kinds of conflicts by their basic or continuous education, they can only delevop coping strategies on the job (BMFSFJ, 2002: 205).

A survey carried out in 2002 (Schneekloth/Wahl, 2005: 88) shows that gaps in the area of home care were indicated in the case of 18% of long-term care patients (Schneekloth/Wahl, 2005: 88). The majority of instances involved households in which dementia patients were receiving care.

On the one hand, gaps occur in the provision of care "when there are no sustainable private (informal) care options available and priority has to be given to professional care services to meet the person's needs. On the other hand, a potential home care boundary is recognizable in the provision of care and support for persons with psychic disorders who need suitable help throughout the night. An additional risk factor lies in the existence of deficits in assistance provision and quite generally in the existence of a low income" (Schneekloth/Wahl, 2005: 88).

Gaps in the provision of home care do not occur, or if they do, they can be successfully filled when "the available potential among family, neighbours and friends can be combined in the best possible way with the various professional and semi-professional support options available in the environment. Long-term care insurance benefits can create sustained relief when effectively combined with an appropriate domestic arrangement suited to individual needs" (Schneekloth/Wahl, 2005: 89).

2.3 Positive and negative aspects of caregiving: Carers' physical and mental health problems and estimated needs for their own care and support; Emotional aspects; Elder abuse etc.) Data and surveys to measure family and/or informal carers' "burden" and satisfaction from caring, their related tools and the use made of this type of survey and by whom?

Positive aspects. Informal care has a whole series of positive aspects for the person in need of care: he or she is able to live much longer in his or her accustomed environment. The informal carers may well be able to look after him or her better than a home care service because of their close relationship and their knowledge of personal preferences and habits (BMFSFJ, 2002: 205; Knauf, 2004: 49). In addition to this, a care arrangement based wholly or partially on informal care saves spending large amounts on home care services or even on accommodation in institutional facilities (Mager/Eisen, 2002: 17). Potential heirs can also benefit from such arrangements at home (motto "long-term care insurance as inheritance insurance" (Mager, 2007: 74). Apart from these points, the literature seldom details any positive aspects of informal care. Köppe et al. (2003: 39) refer to findings which are often overlooked. They state that people involved in care and support often refer to the long-term care period as one of the richest and most intense experiences of their lives and as an "enriching" phase.

Negative aspects. The question of burdens experienced by informal carers is addressed, among others, in the studies MuG III (Schneekloth/Wahl, 2005), LEANDER (Zank et al., 2007) and EUROFAMCARE (Meyer, 2006).[17]

Looking after people in need of care in private households is felt as a strain by the large majority of informal carers: on being asked how stressful their care giving is, 41% of the main caring persons say "very" stressful, 42% "rather" stressful, only 10% "less" stressful and 7% "not at all" stressful (Infratest Sozialforschung, 2003: 23). Burdens are caused especially by: loss of leisure time, limitation of social contacts, financial sacrifices, physical and emotional strain, and the necessity to combine profession and care giving (Dettbarn-Reggentin/Reggentin (2004: 26ff.). The most frequent results of these burdens are psychological and physical symptoms (exhaustion, stomach and heart trouble etc.) and illnesses (damaged discs, heart and circulatory illnesses, severe depression etc.) (Dettbarn-Reggentin/Reggentin 2004: 27f.). The self-perception of one's health status is worse in caring wives than husbands, although their levels of stress is comparable (BMFSFJ, 2002: 199).

Usually the highest level of strain is reported at the start of the care situation; in its course the feeling of stress as well as the evidence of depression are declining. Relief is found through emotional and instrumental support, mainly given by spouses, sisters and brothers. Very important coping strategies are the retention of different households and the upkeep of social networks and friends; sometimes professional activities are also experienced as a counterbalance (BMFSFJ, 2002: 199f.).

The objective strain experienced by informal carers looking after persons suffering from dementia is measured with a special scale. Schneekloth/Wahl (2005) use the "Home Care Giving Stress Appraisal Scale" (HPS) by Grässel/Leutbecher (1993); Zank et al. (2007) use the "Berlin Inventory for Stress in Carers – Dementia" (BIZA-D) by Zank et al. (2006).

"Difficult home care arrangements, which are characterised by long lasting physical and psychological stress for both family carers and the elderly person in need of care, run the risk of escalating into physical or psychological abuse" (Meyer 2006: 33). Since it is difficult to illuminate the questions associated with this topic in the framework of empirical research, no representative data are available at present on the frequency of domestic violence towards people in need of care in Germany.[18] In an interview of over 500 carers belonging to home care services in Hanover, which was carried out by the Criminological Research Institute of Lower Saxony, two thirds of the interviewees had directly or indirectly witnessed problematic behaviour among others towards persons in need of care over the past 12 months. There were especially frequent reports of verbal aggression/psychological abuse, care neglect and physical aggression (Görgen et al. 2007: 8f.).

17 The first two studies were supported by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, the third by the European Commission.

18 On the broader topic of violence towards the elderly, Lehner et al. (2009, 5) write: "In fact there are not sufficient representative data at European or national level on the frequency of violence towards elderly women. The majority of statistics concerning violence against elderly people quote a rate of up to 10 per cent and a high level of unreported cases."

2.4 Support for family carers. The existence and/or type and/or efficiency of all forms of support directed specifically to family carers:

2.4.1 Services in kind – information on services and how to access; counselling or the existence of mutual self help groups; respite care etc.

The spectrum of support open to informal carers in Germany is broad and varied. Some of the services are – as specified by law – provided and/or financed by long-term care insurance funds (and partly by the health insurance funds and pension insurance bodies),[19] others are offered by additional bodies, such as charitable associations in particular, where services may be liable to payment on a private basis.

To a certain extent the long-term care insurance funds are obliged to finance a substitute and/or supplement informal care: persons in need of care have a legal right to up to four weeks of attendant care (§39 SGB XI), up to four weeks of short-term care in an institutional facility (§42 SGB XI) and if necessary to supplementary day/night care (§41 SGB XI). Furthermore, the long-term care insurance funds are legally bound to provide information and counselling services (among others §§7,7a SGB XI), especially obligatory counselling sessions with the person in need of care in his or her home (§37 Section 3 SGB XI) and care giving courses for informal carers whose attendance is voluntary (§45 SGB XI; see also section 2.4.3). More recently the long-term care insurance funds and the health insurance funds have started setting up long-term care support centres (§92c SGB XI) for local counselling close to home, for the provision and care of people in need of care and for their informal carers (see section 3.2.5).

The health insurance funds are legally bound to take measures to prevent the need for care from occurring, to reduce it or to help overcome it (§5 SGB XI). They particularly include the funding of geriatric rehabilitation.

Under certain circumstances the health insurance funds and pension insurance bodies meet the costs of spa treatment to restore fitness which can also be applied for by informal carers.[20]

According to the "Care Leave Act" (PflegeZG) employees can claim leave or partial leave from work by law, for a limited period of time, with the aim of enabling employees to care for close relatives at home, without giving up their employment or having to fear dismissal. There are two options: a) Employees have the right to leave for up to ten days ("short leave") to organize care or to care themselves for a relative in case of emergency. No further payment during short-term leave is made unless resulting from a claim under other legal regulations or arrangements (eg. labour agreements). No social insurance contributions occur during this period, but the employee's insurance coverage is maintained nonetheless. b) Employees have the right to leave or partial leave for up to six months ("care period") to care for a close relative. The employer has to be informed at least ten working days before the leave commences. The employee is not eligible for further payment during the care leave period. Companies with 15 or fewer employees are exempt. In general, the employer has to comply with the employee's wishes, unless there are strong internal reasons for refusal. The scope of the leave period has implications for the em-

19 The majority of support services offered by the long-term care insurance funds and the options of the "Care Leave Act" (PflegeZG) are only open to the affected persons and their caring persons involved in Care Category I or higher.

20 To date only few health insurance funds in Germany offer their members special spa treatments for carers (see section 3.2.5).

ployee's health, nursing care, unemployment and pension statutory insurance status. The employee is no longer subject to statutory social insurance contributions during care leave if fully absent from work and is de-registered by the employer accordingly. The employee is then either medically insured (health and nursing care) through family insurance, some other general insurance policy or a voluntary private scheme. Relevant subsidies are available from the Statutory Care Insurance Fund. Furthermore: the carers are subject to pension contributions if delivering care for more than 14 hours per week. In this case, the care recipient's care insurance pays the carer's pension contributions. Carers continue to be subject to unemployment contributions, however many hours of care they deliver. These are paid out of the Care Insurance Fund. In both cases ("short leave" and "care period"), employees are protected against dismissal from the date they inform the employer about their impending leave.

Charitable and commercial care providers (companies, local authorities, charitable institutions, senior citizens associations, self-help groups) all offer a variety of options, which vary regionally in scope and quality,[21] to help both people in need of care and informal carers in managing the tasks of everyday life:

- Meals-on-wheels, home services (goods deliveries, transport, laundries, medication delivery, mobile hairdressers, pedicure etc.);
- Support possibilities, visiting services, hospice services, domestic emergency call systems;
- Information services, relatives' cafés and counselling services, discussion groups, telephone advice, exchanges with professional carers, care accompaniment, crisis management, psychological support.

Of the possibilities mentioned in the last point of this list it can be said that: "Although the private main caring person bears the 'major burden' of caring, only a small proportion of these persons (16%) regularly resort to supportive counselling or other relief options. A further 37% use such possibilities at least occasionally. Based on these figures, almost every second family carer is not integrated into any kind of external support network" (Schneekloth/Wahl, 2005: 79). Information deficits are the primary reason for not making use of existing support offers (BMFSFJ, 2002: 203).

2.4.2 Services in cash – care allowance and/or fiscal aids; working arrangements; reimbursement of costs in providing care; tax exemptions etc.

People in need of care receive care attendance allowance from the long-term care insurance when they have been classified in at least Care Category I and when their care is wholly or partially carried out by an informal caring person they have organised by themselves (§37 SGB XI). If the care tasks are not shared with a home care service, the monthly payment for Care Category I is 225 euros, for Care Category II it is 430 euros and for Care Category III it is 685 euros. In 2005 approx. 1.45 million persons were being cared for in the domestic environment. Approx. 980,000 of these people were exclusively receiving care attendance allowance, approx. 225,000 had opted for a combination of benefits in kind and care attendance allowance, the remainder received exclusively benefits in kind (see section 2.1).

Caring persons looking after a person in Care Category III can claim a flat rate of 924 euros per year on their application for income tax return.

21 "In general the quality of services is better in urban areas due to greater competition. Many charitable associations have advice centres in towns and cities which are partially co-financed by the local authorities" (Meyer, 2006: 75).

All informal caring persons are insured through the statutory occupational accident insurance. People in employment, who are occupied for more than 14 hours per week as a caring person, are subject to pension insurance contributions in so far as they are not otherwise employed for more than 30 hours per week. These contributions are met by the long-term care insurance. Under certain circumstances caring persons can continue making voluntary contributions to unemployment insurance at their own expense.

Further relief for the caring person can be created through suitable modifications in the home of the person receiving care. On application the person in need of care can receive a subsidy of up to 2,557 euros per measure undertaken, whilst the person's own contribution is dependent on his or her income (§40 SGB XI).

In additon inheritance law benefits informal caring children and grandchildren in the event of their succession (§2057a BGB).

2.4.3 Training of informal/family carers

In keeping with legal requirements (§45 SGB XI) the long-term care insurance funds offer courses for caring persons in order to improve the quality of informal care. They often delegate the provision of courses to home care services. These training courses can take place centrally or in the home of the person needing care. The courses provide family carers or other interested persons with a basic knowledge of home care for the elderly and the sick, strategies to ease and improve care, strategies for conflict prevention, and they teach essential hands-on techniques in looking after persons in need of care.

2.5 The impact on the care process of different forms of family carer support in terms of:

2.5.1 Carer outcomes e.g. reduction of carer burden/negative impact, improved carer satisfaction/positive value, improved health and/or QOL, improved carer/cared for relationship

There are no representative studies on the concrete effects of German support services for the informal carers themselves. There are occasional exemplary studies on the effects of selected types of support carried out with a small group of interviewees. For instance, Knauf (2004) investigated the influence of a local visiting service on the family carers of dementia sufferers. The study accompanied and interviewed 20 persons each acting as main caring person and looking after a relative suffering from dementia. The study showed that by using the visiting service the subjectively felt quality of life increased in the observed informal family carers (Knauf, 2004: 127, 142). In addition to that, in groups for relatives for dementia patients high relief effects were observed for approx. 70% of their members (BMFSFJ, 2002: 214).

2.5.2 Older person outcomes e.g. better quality of care, satisfaction with care, improved carer/older person relationship

Here again, there are no systematic studies addressing the concrete effects of German support services for informal carers and their outcome for the persons in need of care.

2.6 (WP3) How do informal carers participate in: promotion of their own and their older people's health? Measures to reduce the development of higher levels of older people's dependency? Rehabilitation following acute or chronic declines in health?

There are no relevant studies on informal carers' promotion of their own health. As already mentioned they can apply for spa treatments and use a whole spectrum of support options. No research has been done on the extent to which such options are implemented by informal carers. The area of prevention and rehabilitation includes the advisory services and geriatric rehabilitation services already mentioned above.

2.7 (WP4) How are informal carers and older people themselves involved in issues of quality of services such as: clinical outcomes and quality of life / clients' perceptions: satisfaction, knowledge and empowerment?

As already mentioned, long-term care by informal carers is welcomed by politics. However, there exists no systematic consideration of the wishes and needs, assessments and opinions on quality of people needing care on the one hand, and informal carers on the other, despite the fact that this lack was already pointed out in the "Fourth Report on the Situation of the Elderly in Germany" of 2002 (BMFSFJ, 2002: 206).

The interests of both groups are politically articulated primarily by self-help organisations[22] and consumer protection associations on the one hand and "Care Conferences" (Pflegekonferenzen) on the other hand. The implementation of "Care Conferences" is stipulated by some German states (e.g. Hamburg, North Rhine-Westphalia and Berlin) in order to enhance and strengthen the structures of care on the municipal level. Care Conferences are advisory boards which also include informal carers and older people. The main task of these conferences is to participate in the development of care structures in the municipalities (the planning of care, the coordination of the tasks of all relevant groups and actors related to care).

3 Description of the 'good practice discourse'

3.1 How and by whom is good practice defined? How are good practice criteria and models developed, disseminated, implemented? Illustrate with

22 E.g. the organisation "Wir pflegen – Interessenvertretung begleitender Angehöriger und Freunde in Deutschland" (We care – the body representing informal carers among family and friends in Germany) which was founded in 2008. http://www.wir-pflegen.net.

good practice models (useful approaches, positive interactions, innovative projects etc.) related to the WP5 objectives of linking informal and formal long-term care policies and practices and identifying valid elements of good practice for supporting informal carers

The following remarks on the "good practice discourse" refer to two dimensions: (1) "good practice" in the sense of "good care" for a person in need of care and (2) "good practice" in the sense of "measures, which support the person in need of care and the informal carer in the tasks of caring".[23]

"Good care". There is no comprehensive definition of "good care" in Germany. Basically, we can differentiate between two aspects of good care: 1) its suitability to matching the requirements of the person in need of care, and 2) its suitability to matching the strengths and requirements of the informal carer. The first aspect is, on the one hand, addressed (in parts) in the so-called Expert Standards.[24] On the other hand it is the implicit subject of the assessment materials used by the medical services of the health insurance funds to monitor the quality of home care services (MDS, 2009a) and long-term care institutions (MDS, 2009b).[25] The second aspect is implicitly addressed in the DEGAM guideline No. 6 "Informal Carers" (DEGAM, 2009).

The national Expert Standards are developed by the German Network for Quality Development in Care (DNQP), which includes representatives from care science, -management, -education and -practice. The binding quality assessment guidelines and assessment sheets for the medical services of the health insurance funds were developed by the umbrella organisations of the health insurance funds. Finally, the guideline "Informal Carers" was developed by the German Society of General Practice and Family Medicine (DEGAM), a charitable organisation of experts.

How criteria for recognizing "good care" and "good care" models are developed, publicised and implemented can be illustrated by the example of the Expert Standards. These are developed in a five-stage process: 1. An independent group of experts is formed. 2. This group prepares an analysis of the relevant national and international research literature and produces a draft of the Expert Standard. 3. This draft is presented to the professional public within the framework of a consensus conference and discussed together with them. The insights and results gained in this way then flow into the final version of the Expert Standard. 4. The Expert Standard is introduced as a six-month model, accompanied by scientific experts, in around 25 institutional and home care services provided by the health system and aid for the elderly throughout Germany, in order to assess its level of acceptance and practical suitability. This

23 In the first case "good practice" is the ideal practice from the perspective of long-term care science, in the second case "good practice" does justice to the political decisions on long-term care, according to which long-term care should ideally be carried out in the home environment by informal carers.

24 The Expert Standards focus on selected aspects of long-term care. At present the following standards already exist and have already been implemented: "decubitus prevention", "discharge management" "pain management", "fall prophylaxis", "continence promotion" and "chronic wounds". An additional aspect is currently in the implementation phase: "nutrition management". For explicit details on "good care" see the first six Expert Standards (DNQP, 2004a, 2004b, 2005, 2006, 2007a, 2009).

25 In this context see also the guidelines for the assessment of the services and their quality as provided by long-term care institutions (MDS, 2009c).

is followed by a comprehensive book publication and the dissemination of the standards via additional channels.[26] 5. The Expert Standard is updated at regular intervals (DNQP, 2007b).

"Measures which support the persons in need of care and informal carers". In Germany there are numerous initiatives, pilot projects and innovative offers designed to support persons in need of care and the informal carers in their work. The following lists a selection of examples:

- "Advice and coordination centres": Already in 1995 Rhineland-Palatinate created a widespread network of low-threshold advice and coordination centres for persons in need of care and their relatives. The advice and coordination centres embrace various tasks including: qualified counselling, arranging help, coordinating the support options, gaining voluntary carers, advice on amenities and accommodation.[27]

- The "care budget" pilot project. In a pilot project carried out in several German municipalities the participants received the whole of their care assistance budget as a cash payment instead of the benefits in kind to which they were entitled. The purpose of the care budget was to purchase individually compiled service packages, and when necessary it was topped up by the person's own contributions or subsidised by "Care Assistance" payments. Each person using the care budget model was accompanied by a case manager who provided advice.[28]

- Some health insurance and long-term insurance funds offer their members special spa treatments for informal carers. During their stay at the spa the participants can use special information and counselling services tailored to the situation of informal carers. In addition they receive suitable psycho-social support (support in coping with and overcoming problems, developing social contacts, exchanging experiences etc.).

3.2 (WP6) What mechanisms are being used to try to embed good practice in the support of informal carers into everyday practice (e.g. incentives, sanctions, legal frameworks, training etc)? How successful have these been? What are the main disincentives to good practice in this field? How do different systems try to ensure equity and effectiveness? How financially sustainable are the approaches being adopted?

This point focuses on two questions: 1) How are "good support services for informal carers" being spread and embedded into everyday practice? 2) How is it being ensured that informal carers provide "good care"?

26 Among other things these include references to the participants involved in implementing the model as institutional reference sources, lectures by the members of the steering committee and the scientific team at meetings and congresses, publications in specialist journals, specialist works and textbooks, further education seminars at diverse educational institutions etc. (DNQP, 2007b). The majority of expert standards are also published in a simplified form for the general public by the consumer advice centres.

27 More details available at: http://www.masfg.rlp.de/Soziales/Pflege/Beko.asp?highmain=6&highsub =4&highsubsub=0

28 More details available at: http://www.pflegebudget.de.

On point 1): the key mechanisms determining the further spread of good support services for informal carers are a) administrative mechanisms (laws and regulations), b) market mechanisms and c) publicity work on successful solutions to issues. An example of the way the first mechanism is working is the nationwide establishment of "long-term care centres". These are based on the experiences of the "advice and coordination centres" which were set up in Rhineland-Palatinate as part of a pilot project (see section 3.1). An example for the second mechanism is provided by "Homepower" – a temporary-work agency now offers home services against payment after a pilot project funded by the state of Rhineland-Palatinate showed that a market existed for these services (see section 3.1).

On point 2): the significant mechanisms directed towards ensuring "good care" by informal carers are regulations on the one hand, and on the other hand offers of easily accessible (free) counselling and further education services. An example of a significant regulation are the obligatory counselling sessions which persons who are in need of care and are receiving care attendance allowance call on: every six months in the case of Care Category I and II, and every three months in the case of Care Category III. "The aim of counselling is to ensure the quality of the home care, and the regular support and qualified practical care support for the home carers" (§37 Section 3 SGB XI) and takes place in the home of the person in need of care. If the person in need of care does not call on the counselling service, the care attendance allowance may be reduced, and in the case of a repetition it may be cancelled completely. Examples of easily accessible counselling and further education services are the (free) counselling services for the persons in need of care (§§7,7a SGB XI) and the (free) care giving courses for informal carers (§45 SGB XI) – the long-term insurance funds are obliged by law to provide both of these services. In addition to this, telephone advisory services, relatives' cafés, consultations for relatives, supervised groups for relatives and all kinds of self-help initiatives should be mentioned here.

No systematic statements can be made on the question of the effectiveness of the mechanisms given here. However, the assumptions of many professional carers about their tasks in the compulsory counselling sessions are only vague, and it is not self-understood to also include the family carers as addressees of information and advice. There is evidence that those for whom the services offered are of utmost importance – very depended people, informal carers without professional support and those without stable social networks from lower societal strata – are worse informed than others. Although women are mostly involved in family care, nuring male relatives make more use of information and counselling offers (BMFSFJ 2002: 257).

Table 2: Main caring persons' use of advice and support services (in %)

Advice and support services	*used regularly*	*used occasionally*
Exchange with professional expert	7	14
Telephone advice service	4	19
Relatives' café/relatives' consultations	6	12
Supervised groups for relatives	3	8
Private self-help initiatives	2	9
Use of at least one option	37	16

Source: Infratest Sozialforschung, 2003: 24.

This indicates "that no more than 16% of the main caring persons have taken part in a special care giving course provided as a service by the long-term care insurance funds within the framework of long-term care insurance" (Infratest Sozialforschung, 2003: 24).

Two contexts can be identified in which the current regulations of SGB XI might possibly be counterproductive to the "good care" of the person in need of care and the adequate implementation of political objectives concerning long-term care.

- The care category system offers no incentives to formal and informal carers to provide "good care": "People who manage to reactivate as many abilities as possible with the help of physiotherapy or ergo therapy have performed good services, but this paradoxically creates a financial problem. According to present-day logic, an improvement in health, an increase in independence and a reduction in the need for care still mean that the elderly people are then reclassified in a lower care category. In other words, bad care is financially rewarded whilst good care is punished" (Fussek/Schober, 2008: 188).
- The home care services, recognized advice centres and care professionals who carry out the obligatory counselling sessions in the home of the person receiving care attendance allowance are entitled to payments from the long-term care insurance funds of just 21 euros (in the case of Care Category I and II) or 31 euros (in the case of Care Category III) per counselling session (§37 Section 3 SGB XI). This level of payment harbours the danger that counselling sessions may be kept too short, thus failing to meet the necessary specifications of measures designed to assure the quality of care at home.

4 Family carers' private solutions to care and their links with the formal health and long-term care systems

4.1 Is there a debate in your country about the use of migrant workers in the field of LTC and specifically at home? Or is it hidden on the political agenda or not relevant and why?

Germany is among those countries which, as a result of their specific policies and legal regulations[29], tend to encourage the option of legally (or illegally) employing migrant care workers at home to look after people in need of care, if they are interested in saving costs (cf. Theobald 2009: 37). The topic of migrant care workers in private households is thus relevant and has been the subject of political discussions. These led to the so-called Exemption from the Recruitment Stop (ASAV §4, Section 9a) originally established in 2002 to "regulate the procurement of 'domestic helpers in households with people in need of care'..., enabling citizens from the former EU accession countries of Poland, Slovenia, the Slovak Republic, the Czech Republic and Hungary to legally work as a domestic helper for a maximum of three years. This regulation was integrated into the Immigration Act which entered force in 2005, and the number of countries for recruitment were extended to include Romania and Bulgaria" (Lutz, 2009: 44).

However, this did not close the debate, since this offer is only used to a minor extent, and people continue to illegally employ migrant domestic helpers or care workers. "Irregular work is preferred although both sides live with the daily fear to become detected and punished. On the other side there is no con-

[29] Here, especially the limited social security contributions against the risk of long-term care and the provision of largely uncontrolled cash benefits in the event of long-term care.

trol on quality or abuse – an argument against this form of support used mainly by professional providers." (Döhner et al. 2008 : 13)

4.2 If relevant can you give a rough estimate of the proportion of directly paid workers that migrants represent?

There are only estimates for the numbers of (usually illegally employed) migrants working in private households with persons in need of care:

- Meyer (2006: 35) names two estimates according to which 50,000 to 60,000, or 100,000 "more or less illegally employed Eastern European, especially Polish, care workers are working in German households".
- Lutz (2009: 43) considers it possible "that of the almost one million people being cared for in private German households and receiving care attendance allowance, a proportion is being cared for by migrants, and that consequently the estimates of up to 200,000 employing households correspond to the real situation".

4.3 Profile of migrant care and domestic workers (legal and illegal)

According to Lutz (2008a and 2008b) the majority of care and domestic workers are women aged between 30 and 65. The proportion of domestic helpers is increasing both in urban and rural areas. They are mainly migrants from Eastern Europe, who often have a high level of formal education, from Latin America but also from Asia and Africa. In many cases the stay in Germany is planned as temporary, or repeated stays in Germany are interrupted by periods in the home country where the migrant's family lives.

4.4 Intensity and type of tasks they provide

Again reliable data on this point are scarce. However, Lutz (2009: 45) sketches the work situation and the spectrum of tasks of migrants who have been recruited via the International Placement Services (ZAV)[30] as domestic helpers in German households with people in need of care, and consequently are legally employed. Lutz states that

- "limitations on working hours are not adhered to in most cases;
- the migrants are expected to provide care giving tasks, …;
- the migrant workers' spectrum of tasks embraces all household tasks, such as cooking, shopping, cleaning, washing, ironing and the so-called patient-related tasks such as washing, combing, changing incontinence pads and turning the patient etc. in cases where they are confined to bed;
- the presence of the migrants is desired around the clock and especially through the night ..."

These findings are correspond to the results of Döhner et al. (2008: 4), resulting in the conclusion that the heigh dependence of the worker on the employer makes it difficult for her to declare her own needs and to refuse work she feels not comfortable with or capable to do which is especially problematic in long-term care.

30 More details on the ZAV and its recruitment service can be found in section 4.6.

4.5 How many and which kind of families use this kind of assistance?

In the context of migrants providing care for people in need of care in private households, Lutz (2009: 43) refers to an estimate of up to 200,000 employing households.[31] No information can be provided on the specific structure of the employing households.

4.6 Which kind of employment contract is used?

Apart from illegal employment, there are currently three possibilities for migrants recruited from abroad to enter a legal (or at least initially legal) employment relationship in German households:

1. The migrant[32] is recruited with the help of the International Placement Services (ZAV) of the German Federal Employment Agency as a domestic helper (who is also entitled to perform basic nursing tasks) for the household of the person in need of care. She then possesses a work contract, an EU work permit (with time limit) and is liable for social insurance. Her pay must be in line with the tariff conditions, and the employer has to guarantee suitable accommodation. The weekly working time is 38.5 hours. The recruitment option may only be used by households in which a person is classified in Care Category I or higher, or has substantial general care needs (§45a SGB XI). The length of her term of employment is limited to a maximum of three years (cf. BA, 2010). Among other things, this option is designed to legalise illegal, or legally unclear, employment situations (see also section 4.7.1)
2. The (East European) migrant and the private household utilise the regulations for the freedom of services in EU member states. In this way the household can make use of the services not only of a domestic helper, but also of a domestic carer. In Germany contacts are created by a private recruitment agency. The person in question is employed by a company in her home country and is sent to Germany by her employer for a limited period of up of one year maximum. The person in need of care pays the foreign company which in turn pays the taxes and social security contributions of the migrant in her home country (WDR2, 2009).
3. The (East European) migrant is registered in her home country as a professional domestic helper or domestic carer and works on a self-employed basis. The domestic helper or domestic carer enters a service contract with her commissioning household in Germany, but has to provide proof of more than one contract partner, otherwise it would be a case of “fictitious self-employment”. Since this is impossible in the case of round-the-clock care, many self-employed migrants find themselves in a legal grey area (WDR2, 2009).

31 Infratest Sozialforschung (2003: 27) assumes that 9% of the households accommodating persons in need of care privately employ a domestic helper (cleaner) and 4% of the households accommodating a person in need of care privately employ a domestic carer.

32 The migrant has to come from one of the following countries: Bulgaria, Poland, Romania, the Slovak Republic, Slovenia, the Czech Republic, Hungary (BA, 2009: 4).

4.7 Is there a policy or programmes to promote the use of migrant workers, such as developing public services providing support for families that intend to employ private migrant assistants?

4.7.1 Information

The International Placement Services (ZAV) of the German Federal Employment Agency is a German authority which enables the legal employment of East European domestic helpers: "Based on the prevailing laws on residence and work permits, the German Federal Employment Agency has agreed with various employment agencies in the new EU member states to recruit domestic helpers for private households accommodating persons in need of care. This means that foreign workers from the respective countries can be employed in the Federal Republic of Germany for one to three years in full-time positions as domestic helpers with compulsory insurance" (BA, 2008: 2).[33] Apart from the limited term of employment, there are two more essential conditions: 1) The private household must be accommodating a person with Care Category I or higher, or with substantial general care needs (§45a SGB XI). 2) If a household calls for a person already known to them, then the local employment agency must first check whether privileged potential employees are available (e.g. an unemployed German domestic helper).

4.7.2 Recruitment of the assistant

Basically there are two methods of recruitment:

- "Employers can name an applicant already known to them for the position.
- If the employer is unable to name an applicant, the International Placement Services (ZAV) recommend applicants from the respective countries of origin" (BA, 2010: 4).

4.7.3 Contract

The potential employer fills in a bilingual form "Employment agreement/work contract" (EZ/AV) and sends this to the local employment agency which then carries out a so-called job market check. If the agency finds no privileged potential employees, the agency forwards the EZ/AV form to the International Placement Services office in Bonn. "The EZ/AV is processed there and sent to the partner authority in the respective country". "The partner authority forwards the papers to the responsible local institution where they can be collected by the person to be recruited" (BA, 2010: 4).

4.8 Education and training programmes for private assistance

In the ZAV recruitment scheme the migrant is employed as a domestic helper, so that no specific qualifications are required. When a private German household makes a contract with a foreign company which sends a migrant to Germany, then she must possess the qualifications required in the home country. When a contract is made with a migrant who has registered a business in her own country, she must possess the necessary qualifications required for this. Consequently, in all these cases the question of recognition of qualifications or (further) education and training does not arise.

33 The migrant must come from one of the following countries: Bulgaria, Poland, Romania, The Slovak Republic, Slovenia, the Czech Republic, Hungary (BA, 2009: 4).

Migrants who are already living in Germany can participate in education and training programmes for care assistants the same as German citizens, in order to qualify in this area. Recognition of professional qualifications acquired abroad is very difficult in Germany and strictly regulated.

4.9 Guaranteeing the quality of the services. Are there any guarantees or support services for families that employ private assistants? If yes who provides them? Who coordinates them?

In the case of unsatisfactory services, the contract alternatives listed in section 4.6 can always be called into effect against the contract partner. If a migrant falls absent who was sent by a foreign company, or if she has registered her own business in her home country, a replacement can be demanded from the contract partner on the basis of the contract agreement.

Since the domestic helper or carer is being financed privately, there is no monitoring by the medical services of the health insurance bodies. If the person in need of care is receiving care attendance allowance, there are still the regular counselling sessions which he or she is obliged to call up (§37 Section 3 SGB XI) and which, among other things, serve to guarantee the quality of the home care.

5 Summary of main findings and conclusions

The above-mentioned findings can be summarised according to their main aspects as follows:

As a rule, informal care in Germany is provided on an unpaid basis. The relevant German literature names family members, friends, acquaintances and neighbours as typical informal carers.

Responsibility for care and the financial support of people in need of care is distributed between the state and the family and is oriented on the existing resources, such as insurance benefits, income and assets, family members/close relatives, private networks and voluntary help. If these resources are insufficient to cover the affected person's needs, needs-based social assistance services will be awarded to support the person in need of care. Within this spectrum informal care forms one of the most distinct resources: in 2005 approx. 66.7 million hours per week were provided by informal carers out of a total of about 88.5 million hours of weekly care provision.

Coordination functions in the provision of long-term care are carried out by family doctors, the social services of the hospitals and rehabilitation facilities and institutions caring for the elderly. Needs assessment is carried out by the medical services of the health insurance funds. Home, full or partial institutional care services are offered by private, charitable and public providers. Quality assurance for care services provided by institutional facilities and home care services is the responsibility of the medical services of the health insurance funds. The quality of informal care is monitored during obligatory counselling sessions whenever the person in need of care is receiving care attendance allowance. The long-term care system is designed in such a way that in principle the affected person receives the services required to cover his or her assessed needs. Nevertheless, in reality there are limitations to the all-round success of the system.

In 2005 the estimated number of informal carers totalled 4.2 million. About 1.2 million of these carers were acting as main caring person, or being supported by a home care service, and were looking after a person with at least a substantial need of care who was receiving cash benefits from the long-term care insurance fund. The remaining 3 million were people who provided care services together with a main caring person, or looked after persons in need of care who were not classified as requiring substantial general care services. According to a survey carried out in 2002 92% of the main caring persons were related to the person needing care, i.e. "family carers". These were mainly the partners or daughters, followed by mothers, sons and other relatives. 73% of the main caring persons were female, 27% were male; over half of them were between 55 and 79 years of age.

On the one hand German care policy is based on the maxim of "home care rather than institutional care"; on the other hand it adheres to the principle of promoting informal care. Within the framework of home care financing, people in need of care can choose whether they want to be supported by a home care service or by an informal caring person, or by a combination of the two (combined services). In addition, informal caring persons are offered a series of support options provided especially by the long-term care insurance funds.

In the case of combined formal and informal services it can be said that approx. 15% of the domestic support and home care arrangements combine both a home care service and one or several informal caring persons, for whom the person in need of care receives care attendance allowance. In approx. three quarters of all informal care arrangements there are only two touch points with the formal care system: in the assessment of the care category and in the compulsory counselling when care attendance allowance is received. The social services of hospitals and rehabilitation facilities, as well as the currently emerging long-term care centres, have the task of initiating and promoting productive cooperation between informal carers and home care services. Their contribution in this respect has not yet been addressed by evaluation studies. Gaps in the area of home care were established by a 2002 survey in 18% of the cases. These usually involved households where a person suffering from dementia are being cared for, or where – in view of the primacy in German care policy – no viable private care potential is available and care giving has to be based primarily on professional care services.

In private households looking after people in need of care, the caring tasks are felt to be a burden by the large majority of informal carers: 41% of main caring persons say their care giving is "very" stressful and 42% feel it is "rather" stressful. The research literature recognizes that difficult home care arrangements run the risk of escalating into physical or psychological abuse. Since it is difficult to illuminate the questions surrounding with this topic in the framework of empirical research, no representative data are available at present on the frequency of domestic violence towards people in need of care in Germany.

The most important support options for family carers include the right to up to four weeks of substitute care when incapacitated, up to four weeks of short-term (respite) care in an institutional facility and, where necessary, the right to additional day/night care; information and counselling services provided by the health insurance funds, a range of free courses for informal carers, access to the new local long-term care centres with counselling close to home, provision and support for the people in need of care and their informal carers, unpaid leave from work for up to six months and numerous supporting measures, such as meals-on-wheels or domestic emergency call systems offered by commercial or non-

profit providers. However, these options are being used with restraint; almost every second family carer is not integrated into any kind of external network.

Informal carers may receive care attendance allowance via the person in need of care who is the direct recipient. The level of care attendance allowance depends on the affected person's care category; tax concessions are also available in the case of the highest care category. In addition to this informal carers are covered by the statutory occupational accident insurance, and when providing more than 14 hours of care per week they are also covered by pension insurance. Informal carers (children and grandchildren) may also benefit from inheritance law in the event of their succession.

Isolated evaluations of the concrete effects of support services for informal carers confirm that as a rule they provide relief. There are no systematic studies on the concrete effects of support services for informal carers as experienced by the persons in need of care, or on services to promote the personal health of informal carers.

There is no systematic consideration of the wishes and needs, the opinions and quality assessments of the persons in need of care, nor of the informal carers. The interests of both groups are politically articulated primarily by self-help organisations and consumer protection associations on the one hand and "Care Conferences" (Pflegekonferenzen) on the other hand. Care Conferences are advisory boards (in order to enhance and strengthen the structures of care on the municipal level) which also include informal carers and older people. But only few German states (e.g. Hamburg, North Rhine-Westphalia and Berlin) stipulate their implementation.

"Good care", which does justice to the requirements of the people in need of care, is specifically addressed by the so-called Expert Standards. In addition to this it is the criterion applied by the medical services of the health insurance funds to monitor the quality of home care and care in institutional facilities. Good care, which does justice to the strengths and needs of the carer, is the implicit subject of the DEGAM guideline No. 6 "Informal Carers". There are numerous initiatives, pilot projects and innovative options for people in need of care and for informal carers which are aimed at further developing support structures and approaches.

In view of the political and legal frameworks, the legal or illegal employment of migrants in households with increased care needs is a clear option. Consequently the topic of "migrant carers" is the subject of ongoing debate. A recently introduced opportunity designed to legalise illegal employment situations is only being used to a very limited extent.

Estimates of the numbers of (usually illegally) employed migrants in private households vary between 50,000 and 100,000 persons. The majority are women aged between 30 and 65 who come from Eastern Europe, especially Poland, often with high levels of formal education.

Migrants fulfil all kinds of tasks in the domestic context ranging from household services to care giving activities, even when these are excluded in their work contracts. As a rule the limits to working hours are not respected, and the migrant's presence is required especially during the night.

A number of options are available for legally employing migrants in the household, but the specifications are often not observed so that migrants themselves operate in legal grey areas. Within the framework of agreements with the employment authorities in the new EU member states, the International Placement Services (ZAV) of the German Federal Employment Agency enable the recruitment of East European domestic helpers for households with persons in need of care. There are no programmes designed to qualify such migrants in care giving or to assure the quality of their work, with the possible exception of a few isolated pilot projects.

In general it can be said that, in view of the political and financial significance of informal care in Germany, numerous efforts are being made to promote it. Nevertheless, there is still a crucial need for systematic research on the compatibility of care and career and for development in the field of practical support for family carers and in their active inclusion in questions concerning quality assurance in respect of "good care", "good personal care" and "good support for family carers". Strategies for better information on existing support options and encouraging family carers to make use of them should aim at different structures: it should be given in a targeted way, approaching the person individually. Written information can only provide limited support. In addition to that, professional carers must be qualified in passing on advice and information.

There is a need for even greater developments, and for research, in all the areas associated with migrants involved in care. The general legal and administrative frameworks surrounding the activities of migrants here still stand in the way of well-grounded findings about their living and working situation. What is more, they still do not offer a secure foundation for measures and programmes which would benefit themselves in addition to the persons in need of care and their relatives.

References

Bundesagentur für Arbeit (BA) (2008) *Vermittlung von Haushaltshilfen in Haushalte mit Pflegebedürftigen nach Deutschland. Hinweise für Arbeitgeber.* Retrieved 21 July 2009 from the World Wide Web: http://www.arbeitsagentur.de/zentraler-Content/Veroeffentlichungen/Merkblatt-Sammlung/Merkblatt-zur-Vermittlung-in-Haushalte-mit-Pflegebeduerftigen.pdf

Bundesministerium der Justiz (BMJ) (2008) *Pressemitteilung: Kabinett beschließt Erbrechtsreform.* Retrieved 21 July 2009 from the World Wide Web: http://www.bmj.bund.de/enid/0,c6f348706d635f6964092d0934393833093a095f7472636964092d0935323933/Pressestelle/Pressemitteilungen_58.html

Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) (ed.) (2002) *Vierter Bericht zur Lage der älteren Generation in der Bundesrepublik Deutschland. Risiken, Lebensqualität und Versorgung Hochaltriger – unter besonderer Berücksichtigung demenzieller Erkrankungen.* Berlin.

Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) (2008) *Runder Tisch Pflege.* Retrieved 21 July 2009 from the World Wide Web: http://www.bmfsfj.de/Politikbereiche/ aelteremenschen,did=16378.html.

Bundesministerium für Gesundheit (BMG) (ed.) (2009) *Bericht des Beirats zur Überprüfung des Pflegebedürftigkeitsbegriffs.* Retrieved 21 July 2009 from the World Wide Web: http://www.bmg.bund.de/cln_091/nn_1168248/SharedDocs/Downloads/DE/Pflege/Bericht__zum__Pflegebed_C3_BCrftigkeitsbegriff,templateId=raw,property=publicationFile.pdf/Bericht_zum_Pflegebed%C3%BCrftigkeitsbegriff.pdf.

Büscher, Andreas (2007) *Negotiating helpful action. A substantive theory on the relationship between formal and informal care.* Retrieved 21 July 2009 from the World Wide Web: http://acta.uta.fi/pdf/978-951-44-6843-8.pdf.

Dettbarn-Reggentin, Jürgen; Reggentin, Heike (2004): *Freiwilliges Engagement in der Pflege und Solidarpotenziale innerhalb der Familie.* Berlin.

Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin (DEGAM) (ed.) (2009) *DEGAM-Leitlinie Nr. 6: Pflegende Angehörige.* Gekürzte Internetfassung. Retrieved 21 July 2009 from the World Wide Web: http://www.degam.de/leitlinien/LL_PA_web.pdf.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2004a) *Expertenstandard Dekubitusprophylaxe in der Pflege, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2004b) *Expertenstandard Entlassungsmanagement in der Pflege, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2005) *Expertenstandard Schmerzmanagement in der Pflege, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2006) *Expertenstandard Sturzprophylaxe in der Pflege, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2007a) *Expertenstandard Förderung der Harnkontinenz in der Pflege, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (2007b) *Methodisches Vorgehen zur Entwicklung und Einführung von Expertenstandards in der Pflege.* Retrieved 21 July 2009 from the World Wide Web: http://www.dnqp.de/MethodischesVorgehen.pdf.

Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (DNQP) (ed.) (2009) *Expertenstandard Pflege von Menschen mit chronischen Wunden, Entwicklung – Konsentierung – Implementierung.* Osnabrück.

Döhner, Hanneli/Lüdecke, Daniel/Eickhoff, Verena (2008) *Migrant Workers in Home Care for Older People in Germany: The Use and Problems of Legal and Irregular Care.* Retrieved 21 July 2009 from the World Wide Web: http://www.gerobilim.com/index.php?id=33

Fussek, Claus/Schober, Gottlob (2008) *Im Netz der Pflegemafia. Wie mit menschenunwürdiger Pflege Geschäfte gemacht werden.* München: Verlag C. Bertelsmann.

Gräßel, Elmar; Leutbecher, Marlene (1993) *Häusliche Pflege-Skala HPS zur Erfassung der Belastung bei betreuenden oder pflegenden Personen.* Ebersberg: Vless.

Görgen, Thomas; Rabold, Susann; Herbst, Sandra (2007) *Ist die Hand, die pflegt, auch die Hand, die schlägt? Ergebnisse einer Befragung ambulanter Pflegekräfte zur Misshandlung und Vernachlässigung älterer Menschen in der häuslich-professionellen Pflege.* Hannover: Kriminologisches Forschungsinstitut Niedersachsen e.V.

Infratest Sozialforschung (2003) *Hilfe- und Unterstützungsbedürftige in Privathaushalten in Deutschland 2002. Schnellbericht.* Retrieved 21 July 2009 from the World Wide Web: http://www.tns-infratest-sofo.com/downloads/mug3sb.pdf.

Knauf, Antje-Franziska (2004) *Demenz und pflegende Angehörige. Eine Intervention zur Steigerung der Lebensqualität von pflegenden Angehörigen.* Retrieved 21 July 2009 from the World Wide Web: http://deposit.d-nb.de/cgi-bin/dokserv?idn=972835636&dok_var=d1&dok_ext=pdf&filename=972835636. pdf.

Koeppe, Armin / Mausberg, Dorothee (2003) *Zur Lebenslage pflegender Angehöriger psychisch kranker alter Menschen.* Köln: Diözesan-Caritasverband für das Erzbistum Köln e.V.

Lehner, Erentraud/Schopf, Anna/Stiehr, Karin/Ohms, Constance (eds.) (2009) *Breaking the taboo. Gewalt gegen ältere Frauen in der Familie: Erkennen und Handeln.* Retrieved 21 July 2009 from the World Wide Web: http://www.roteskreuz.at/fileadmin/user_upload/PDF/GSD/Brochure-Germany.pdf.

Lutz, Helma (2009) Who Cares? Migrantinnen in der Pflege in deutschen Privathaushalten, pp. 41-50 in Larsen, Christa/Joost, Angela/Heid, Sabine (eds.), *Illegale Beschäftigung in Europa. Die Situation in Privathaushalten älterer Personen.* München, Mehring: Rainer Hampp Verlag.

Lutz, Helma (2008a) *Who cares? Wer kümmert sich und wen kümmert das schon? Migrantinnen in der Pflegearbeit in deutschen Privathaushalten.* Powerpoint-Präsentation zum Vortrag auf der IWAK Konferenz in Frankfurt am Main am 20.10.08.

Lutz, Helma (2008b) Sprich (nicht) drüber – Fürsorgearbeit von Migrantinnen in deutschen Privathaushalten, pp. 59-74 in Jansen, Mechtild M. (ed) *Pflegende und sorgende Frauen und Männer. Aspekte einer künftigen Pflege im Spannungsfeld von Privatheit und Professionalität.* Wiesbaden: Hessische Landeszentrale für Politische Bildung.

Mager, Hans-Christian (2007): *Wenn Angehörige die Pflege übernehmen. Von Kosten und Nutzen intrafamiliärer Pflegevereinbarungen.* Retrieved 21 July 2009 from the World Wide Web: http://www.forschung-frankfurt.uni-frankfurt.de/dok/2007/2007-02/71-74_Pflege.pdf.

Mager, Hans-Christian./Eisen, Roland (2002) *Noch ist häusliche Pflege Familiensache. Die Pflegeversicherung und ihre Folgen.* Retrieved 21 July 2009 from the World Wide Web: http://www.forschung-frankfurt.uni-frankfurt.de/dok/2002/2002-1u2/Pflegeversicherung_15-21.pdf.

Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS) (2009a) *Erhebungsbogen zur Prüfung der Qualität nach den §§ 114ff. SGB XI in der ambulanten Pflege.* Retrieved 21 July 2009 from the World Wide Web: http://www.mds-ev.org/media/pdf/QPR_Anlage_1_2009_06_30.pdf.

Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS) (2009b) *Erhebungsbogen zur Prüfung der Qualität nach den §§ 114ff. SGB XI in der stationären Pflege.* Retrieved 21 July 2009 from the World Wide Web: http://www.mds-ev.org/media/pdf/QPR_Anlage_2_2009_06_30.pdf.

Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS) (2009c) *Richtlinien des GKV-Spitzenverbandes über die Prüfung der in Pflegeeinrichtungen erbrachten Leistungen und deren Qualität nach §114 SGB XI (Qualitätsprüfungs-Richtlinien – QPR).* Retrieved 21 July 2009 from the World Wide Web: http://www.mds-ev.org/media/pdf/QPR_2009_06_30.pdf.

Mestheneos, Elizabeth/Triantafillou (2004). *Supporting Family Carers of Older People in Europe – the Pan-European Background.* Retrieved 21 July 2009 from the World Wide Web: http://www.uke.de/extern/eurofamcare/deli.php

Meyer, Martha (2006) *Pflegende Angehörige in Deutschland. Überblick über den derzeitigen Stand und zukünftige Entwicklungen.* Retrieved 21 July 2009 from the World Wide Web: http://www.uke.de/extern/eurofamcare/documents/nabares/nabare_germany_de_final_a4.pdf.

Robert Koch-Institut (ed.) (2004) *Schwerpunktbericht: Pflege.* Berlin.

Schnabel, Reinhold (2007) *Zukunft der Pflege.* Retrieved 21 July 2009 from the World Wide Web: http://www.muenchonline.de/resources/Pflegemarkt_final.pdf.

Schneekloth, Ulrich/Wahl, Hans Werner (eds.) (2005) *Möglichkeiten und Grenzen selbstständiger Lebensführung in privaten Haushalten (MuG III).* Retrieved 21 July 2009 from the World Wide Web: http://www.handbuch-kindertagespflege.de/bmfsfj/generator/RedaktionBMFSFJ/Abteilung3/Pdf-Anlagen/ mug3-ingetrierter-gesamtbericht,property=pdf,bereich=bmfsfj,sprache=de,rwb=true.pdf.

Statistisches Bundesamt (2007) Pflege*statistik 2005 – Pflege im Rahmen der Pflegeversicherung – Deutschlandergebnisse.* Wiesbaden.

Theobald, Hildegard (2009) Pflegepolitiken, Fürsorgearrangements und Migration in Europa, pp. 28-38 in Larsen, Christa/Joost, Angela/Heid, Sabine (eds.), *Illegale Beschäftigung in Europa. Die Situation in Privathaushalten älterer Personen.* München, Mehring: Rainer Hampp Verlag.

Van den Bussche, Hendrik (2006) *Wie kann die Versorgung von Demenzkranken (in Hamburg) optimiert werden?* Retrieved 21 July 2009 from the World Wide Web: http://www.uke.de/institute /allgemeinmedizin/downloads/institut-allgemeinmedizin/Open_University_HH. pdf.

WDR 2 (2009) *Häusliche Pflege aus Osteuropa. Informationen aus dem Beitrag von Anna Florenske.* Retrieved 21 July 2009 from the World Wide Web: http://www.wdr.de/radio/wdr2/quintessenz/505665.phtml.

Zank, Susanne/Schacke, Claudia/Leipold, Bernhard (2006) Berliner Inventar zur Angehörigenbelastung – Demenz (BIZA-D). *Zeitschrift für klinische Psychologie und Psychotherapie*, 35 (4), 296-305.

Zank, Susanne/Schacke, Claudia/Leipold, Bernhard (2007) Längsschnittstudie zur Belastung pflegender Angehöriger von demenziell Erkrankten (LEANDER): Ergebnisse der Evaluation von Entlastungsangeboten. *Zeitschrift für Gerontopsychologie und -psychiatrie 20 (4),* 239-255.