

Master European Studies

1. Supervisor: Dr. Duco B.D. Bannink
2. Supervisor: Dr. Minna van Gerven-Haanpaa

Master Thesis

Dementia as a political issue - (De-)familialism in dementia care policies

Anna Waldhausen

Käthe-Kernchen-Str. 71

D-50827 Köln

Phone: 0049 221 16835358

Anna.waldhausen@arcor.de

S0214876

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¹ These are the same amounts which are paid for professional nursing care at home.

1. Introduction

Rising life expectancy and demographic aging induce an alarming number of people concerned by dementia. Although figures about exact prevalence rates are difficult to identify (Inserm 2008: 363), the OECD 2004 speaks of “dramatic increases in the projected prevalence rates for dementia in 2010” (Moise et al. 2004: 19). Today over six million individuals in Europe suffer from dementia. Scholars predict a doubling of patients within the next twenty years (Alzheimer Europe 2008: 19 referring to Ferri et al. 2005). This phenomenon needs a political answer at various levels: in for example the area of diagnostic, treatment and social care.

Dementia or Alzheimer² refers to a number of symptoms due to an abnormally fast damage and loss of brain cells. What follows is a constant deterioration of a person’s ability to ‘function’ with regard to memory, attention, language, thinking etc. Those who are directly concerned by this gradual process are first and foremost the patient’s close environments, i.e. the family. Nowadays, family members carry out the major part of the caring work: estimations say that between 60 and 80% of patients in Europe are looked after at home through informal caregivers (Innes 2002, Schneider 2003); in the majority of cases by family members such as spouses or children.

The paper’s focus lies on caring function of families for dementia patients and the interplay with the welfare policy, i.e. the political dealing with of the problem. To speak with the words of Esping-Andersen: Is the welfare provider *family* supported by welfare state policies? How is the social risk of dementia managed by the two actors family and state?

Why is it interesting to focus in this way on dementia care? A number of studies deal with the division of responsibilities between family and state concerning caring for disabled individuals (elderly). These studies are valid; however, it is striking that dementia ‘changes the pattern’. The argument is that dementia care is different to ‘normal’ (elderly) care. It is this difference, primarily determined by the fact that dementia requires a different kind of long-term care, that has a crucial impact on the informal caring function of families.

² In 1901 Alois Alzheimer diagnosed the disease for the first time; Alzheimer is the most frequent reason for the long-term decline in cognitive function called dementia. Dementia and Alzheimer will be used throughout the thesis as synonyms as the distinction does not yield more results in a political science analysis – different than of course in medical sciences.

How can this difference be explained? A short look on dementia nursing theory sheds some light on this crucial question: One main characteristic of dementia care in comparison to normal elderly care is the fact that dementia patients need less medical health care but require more caring time in terms of supervision, activation and motivation (Alzheimer Europe 2007: 97). The MuG I-III survey³ shows the difference: Only 3% of the questioned carers of patients with a medium severe dementia disease could leave the patient alone at home for one or more hours without supervision. By contrast, 84% of the cases of dependent elderly persons without dementia, the latter could be left unsupervised for a certain time (Schneekloth 2008: 137). A second characteristic of dementia care is the prolonged care period⁴. It is clear that these characteristics have extraordinary consequences. “There is evidence to suggest that caring for a person with a cognition-impaired disability, such as dementia, may be more burdensome on the caregiver than caring for a person with a physical disability” (Moise et al. 2004: 51). Caregivers for persons with Alzheimer describe the care as “life changing (94%), difficult (91%), exhausting (89%), demanding (86%) and stressful (86%)” (Rimmer 2005: 20). The patients’ personalities change, resulting often in extreme behavioural symptoms such as social withdrawal or resistance to help and aggression. These symptoms may have a dramatic impact upon the carers’ psychological well-being (Marriott 2003: 188). Not surprisingly, carers of advanced cases of Alzheimer patients suffer more often from depression than the general population (Schneekloth 2008: 129). Also sleep disturbances and social isolation are frequent consequences of dementia care because of the perceived need to be constantly alerted (Eichler, Pfau-Effinger 2005: 180). To summarize, the burden of caring for a dementia patient is associated with “higher levels of psychological morbidity and stress than does caring for older people with enduring physical health problems” (Marriott 2003: 188).

Finally, the need for constant supervision has in many cases also an impact on the carers’ employment possibilities and therefore leads to financial shortcomings – more than in the case of normal elderly care. According to the ‘facing dementia study’ conducted by Rimmer et al., 22% of the questioned dementia caregivers in six European countries changed their working routines. With respect to the prolonged care period the carers’ interruption of paid employment is also emphasised by resulting difficulties of re-employability. This aspect is of

³ A survey investigating the situation of informal carers in Germany over a period of 10

⁴ “survival of 10 years is not uncommon” (Moise et al. 2004: 50)

course of special importance to younger carers in working age – often caring spouses of younger dementia patients⁵ (Seipp 2007: 286).

These points show clearly, dementia care differs from ‘normal elderly care.’⁶ Thus, the question of responsibility assignment between family and the welfare state raises once again. This assignment of tasks will probably be seen most explicitly in the case of familialistic welfare states.⁷

Hence, the central research question for this paper shall be:

How do (familialistic) welfare states deal with the changing patterns of informal family care caused by dementia?

In order to approach this central research question it is necessary to address the following sub questions:

- a) How would (de-)familialism in dementia care policies would look like? How can (de-) familialism in dementia care be conceptualized?
- b) Are there different strategies familialistic welfare states choose? Is there a general tendency towards more de-familialism?
- c) Are there any (structural) impediments that encumber the development of clear (de-) familialistic tendencies?
- d) How can different policies and political choices be explained?

The thesis is structured as follows: First, certain methodological issues are presented and discussed. Then, a typology is introduced and adapted to the special case of dementia care in order to allow profound analyses of the political reactions to dementia family care. It is this typology that guides through three case studies revealing some interesting answers concerning different (de-)familialistic strategies, countries choose in order to deal with the ‘dementia problem’. The thesis concludes with an attempt to explain the extracted findings.

⁵ Younger dementia patients are those affected under the age of 65. In most cases, dementia correlates with old age but this is not always the case. Early onset dementia constitutes increasingly a central issue for dementia research.

⁶ Which is understood in the following as care for elderly with first and foremost physical diseases at the last stage of their lives.

⁷ A more detailed explanation will follow.

2. Research design and terminology

The present analysis is to be made with reference to Sigrid Leitner's typology of "Varieties in Familialism" (2003 and 2008). Leitner's work is of special interest for this thesis because it focuses on the caring function of the family and the respective policies which support (or not) the family in its caring function. The central notions of familialism and de-familialism are deployed as units of analysis. The notions shall be understood as follows: Familializing policies are those political measures that strengthen the family in its caring function. A welfare regime can dispose of strong or weak familializing policies. De-familialism on the other hand means the welfare regimes' offer to discharge or liberalize the family from the role of the main caregiver. Once again, de-familialistic measures can be either implemented with great or weak emphasis.

As different strategies of 'dementia care regimes'⁸ constitute the core interest of the paper, a comparative country case analysis seems to be the most efficient method. For the selection of case studies, Leitner's country cluster for elderly care is taken as a starting point.⁹ Without going into detail now (see detailed presentation of Leitner below), it makes sense to choose country cases exclusively from the field of 'explicitly familialistic types' of care regimes. Within this field, caring is seen as a family task and the welfare state supports the family in this function. Thus, the two welfare providers, which are of interest in the present analysis, are traditionally involved and active with regard to elderly care. In this field, the interplay between family and state will be more visible.

France, Germany and the United Kingdom have been chosen for the country case analyses. All of them are classified in Leitner's elderly care typology as 'explicitly familialistic'. Furthermore, all three countries are in the medium range of dementia prevalence. According to the Euroderm survey, the three countries range between 1.11% and 1.36% prevalence rate of the total population with a EU 25 average of 1.27% (Alzheimer Europe 2006a: 21f). Thus, they are confronted with a comparable impact of dementia.

⁸ Dementia care regime shall be understood with reference to the notion of the welfare state regime as the combined and interdependent way in which welfare for dementia patients is produced and allocated between state, market and family (Esping –Andersen 1999: 35). The focus is on the state's support for family welfare production. Those measures shall be analyzed which focus on, or that have unintended implications for, carers for people suffering from dementia.

⁹ Leitner develops clusters for child and elderly care –although dementia differs to normal elderly care it is nonetheless more comparable to classical elderly care than to child care.

The case studies are elaborated on the basis of secondary literature. Furthermore, political programs dealing with dementia are analysed with the help of afore identified indicators for (de-)familialization. Relevant data is taken from national statistics and governmental reports.

3. ‘Varieties in familialism’

3.1. Conception of (de-)familialization

As indicated above, the thesis will basically work with the typology of Sigrid Leitner (2003) “Varieties of Familialism”. Nevertheless, a first reference has to be made to the work of Esping-Andersen as his conceptions of welfare regime and familialism serve as a basis for the following reasoning.

Esping-Andersen’s ‘Three worlds of welfare capitalism’ (1990) can still be described as the most influential typology of welfare states. Esping-Andersen points out to one characteristic of modern welfare states: members of society are enforced to commodify their workforce in order to guarantee their survival. In his book, he analyses up to which degree welfare regimes¹⁰ allow people to maintain a certain living standard independently of their market participation. He measures the level of independence from market processes with de-commodification¹¹ scores. The data give reason to assume that the examined 18 countries can be classified into three ideal types of welfare regimes: the social-democratic with a high, the corporatist with a medium and the liberal welfare regime with a low level of de-commodification.

Esping-Andersen developed his findings further in reaction to various critiques expressed by feminist authors, such as Jane Lewis, Diane Sainsbury or Ilona Ostner. His publication of “Social Foundations of Postindustrial Economies” (1999) includes a deeper analysis of the family. His concept of welfare regimes refers to the potential differences how the production of welfare, i.e. the management of social risk, is distributed between the three members of the welfare triad consisting in state, market and family. He introduces the notion of a familistic welfare regime which assigns a maximum of welfare obligations to the household (1999: 45). De-familialization instead “capture[s] policies that lessen individual’s reliance on the family; that maximize individuals’ command of economic resources independently of familial or conjugal reciprocities.” (1999: 45)

¹⁰ ‘Welfare regimes’ shall be understood in the way Esping-Andersen defines it (Esping-Andersen 1990: 2)

¹¹ The definition of de-commodification can be found at (Esping-Andersen 1990: 22 and 37)

As already elaborated, the thesis central focus lies on de-familialism in dementia policies. In “Varieties of Familialism” in 2003, Sigrid Leitner focuses on the caring function of the family and the respective policies designed to support or discharge the family in or from this function. As dementia policies can be seen as sub-category of care policies, Leitner’s work seems to be therefore the ideal starting point for the following analysis. The concept will be presented now in detail.

With regard to familializing policies, Leitner distinguishes between time rights, transfers and social rights attached to the caring function in opposite to all sort of direct service provisions (2003: 358). Hence, de-familialization with respect to the caregiver implies that the caregiver is independent from other family members in order to provide informal care. Financial transfers support the financial independence to enhance the ‘right to care’. On the other hand a sufficient supply of social services guarantees the caregivers right ‘not to care’.

The second perspective that has to be taken into account is the one of the care receiver. This perspective must not be forgotten as “de-familializing processes change the care relationship as a whole and therefore also have an impact on the care receiver.” (Leitner 2007: 250) In this case, de-familialization means the degree to which the care receiver is independent of his family in covering his or her own caring needs. Guaranteed access to a high quality of welfare services would be highly de-familializing from the care receiver’s perspective (2008: 10). Nevertheless, for the elaboration of the typology ‘Varieties of Familialism’, Sigrid Leitner concentrates on the caregiver’s perspective and identifies different ‘care regimes’ by analyzing childcare and elderly care in fifteen EU member states. With regard to the topic of this thesis, I will exclusively concentrate on elderly care in the following.

Leitner identifies the degree of de-familialization of the respective care regimes on the basis of how many people aged 65 years and more make use of home help services. Consequently, the absence or existence of direct transfers for care indicates then to what extent the regime provides support for the families’ caring function. The combination of strong or weak familialization and strong or weak de-familialization leads to the following four-scheme matrix:

Figure 1: Varieties of familialism

Familialization	De-familialization	
	<i>Strong</i>	<i>Weak</i>
<i>Strong</i>	Optional familialism	Explicit familialism
<i>Weak</i>	De-familialism	Implicit familialism

(Leitner 2003: 358)

According to this matrix, *optional familialism* supports the family in its caring function. In the case of elderly care, welfare regimes offer financial transfers to carers. Nevertheless, de-familialistic political measures exist– hence, families can, in case they want, be de-charged of the care work. In this case, it is evident that the right to care does not automatically imply the obligation to care.

Explicit familialism also offers familialistic measures. These measures are, however, confronted with a lack of de-familialistic political measures. Thus, the family is supported in its caring function, but there is no mechanism to dissociate it from this caring responsibility.

De-familialistic care regimes have a weak familialization and provide care services (either through state or market provisions) to a high extent. As a consequence, the family is (partly) unburdened, but care is also not honoured and there is no social right to care.

Implicit familialism implies neither familialistic nor de-familialistic measures. As there is no alternative, the family will be the main provider of care without any compensation (Leitner 2003: 359, 2008: 15f).

With the help of the abovementioned indicators for elderly care, Leitner classifies the fifteen EU member states in the following way:

Figures 2: (De-)familialism in elderly care in fifteen EU member states

Familialization (measured by payment for elderly care)	De-familialization (measured by home help coverage)	
	<i>Strong</i>	<i>Weak</i>
<i>Strong</i>	(1) Denmark, Finland, Sweden	(2) Austria, Belgium, France, Germany, Ireland, Luxembourg, United Kingdom
<i>Weak</i>		(3) Greece, Italy, The Netherlands, Portugal, Spain

(1) Optional familialism, (2) explicit familialism, (3) implicit familialism

(Leitner 2003: 365)

As it can be seen in the chart, no country is classified as de-familialistic. Not surprisingly the Scandinavian countries are in the category of optional familialism as they provide a payment for elderly care and a considerable rate of home help coverage (between 16 and 24% whereas all other countries do not provide more than 10%) (Leitner 2003: 364). All other countries can be characterised as having weak de-familialistic elderly policies. Only five countries do not pay for family care (at least not country-wide with reference to Italy) and are classified as implicitly familialistic; the ‘rest’ belongs to the category of explicit familialism.

If we compare the results in the field of childcare, it becomes evident that classifications of countries differ according to the analyzed policy field. “Since there are still other care policies to consider, it will be difficult if not impossible to subsume each welfare state under one exclusive category of familialism” (Leitner 2003: 365). Countries do not only cluster differently with regard to different policy fields but also with regard to different points in time. To identify differences in time, a historical approach would be needed. This is subject of Leitner’s postdoctoral lecture qualification in 2008, where she investigated the evolution of different variants of familialism in the four conservative welfare regimes Austria, Germany, Belgium and France.

The idea of country classification based on the investigation of the potential of policies to (de-)familialize caring functions shall be applied to the field of dementia care policies. In the following, it will be argued that the indicators used by Leitner are not valid in the case of

dementia care policies. Indicators have to be adapted in order to enable an application of the typology to the field of dementia policies.

3.2. Need of adaptation for dementia policies

The presumption is that the indicators Leitner uses for classifying countries in terms of their elderly care cannot be adopted for dementia care because the latter is different from normalelderly care. Hence, the support for a family caring for a dementia patient should differ to the support for someone caring for a frail old person suffering from a physical disease. Familialization therefore has to be conceptualized differently. The same applies to de-familialising measures.

In Leitner's typology familialism is 'measured' by the *payment for care* of elderly people. It is obvious, expenses are also one aspect for dementia care. "In some European countries, AD¹² care takes approximately 10-25% of a family's average net annual income" (Alzheimer Europe 2006b: 4). Nevertheless, in the case of dementia it can be assumed that the mere existence of care allowances is not a sufficient indicator because it is very common that care systems provide elderly care allowances under the condition of 'dependence.'¹³ The notion of dependence is often defined in a way that discriminates against dementia patients – it remains to be seen if this is the case in the country analyses. So although financial aspects are as important in dementia care as in normal elderly care, the mere existence of care allowances is not a sufficient indicator for familiaism.

De-familialism in Leitner's elderly care typology is measured by the provision of *home care services* for elderly care in the respective country. Already for 'normal' elderly care, this indicator can be contested as Leitner admits herself "[...] to some unknown extent this indicator represents also familialization, since home help services are not in all cases simply a substitute for family care but are also an incentive for family care." (Leitner 2003: 363). It is evident that home help services unburden the family by taking over a part of the family's caring function. Therefore, it could be identified as an indicator for de-familialization. Nevertheless, it can be argued that home help services only absorb very limited and clearly defined tasks, while the main care work continues to be provided by the informal carer. According to a study by Peter Zeman, 70% of those informal carers in Germany who do not draw upon home help services declare that they do so because they think that the family

¹² AD = Alzheimer Disease

¹³ In the analysis of elderly care allowances of Jane Jenson (2003) for example all of the eight analyzed countries have this condition (among others as a certain age or existing financial resources).

would continue to provide the bulk of the needed care anyway (2000: 207). This argument is supported by the fact that the percentage of old people that are exclusively cared for by professional home¹⁴ help services is very low, apparently because this type of intervention seems to be insufficient. This questionable sufficiency is even of higher relevance in the context of dementia care due to the latter's specific needs such as the extensive requirement for supervision.

To sum up, the indicators Leitner uses for elderly care can be misleading or insufficient in the context of dementia care. Dementia changes the caring circumstances so that we can assume that other 'factors' become relevant in order to support or discharge the caring family. To identify those factors in detail, the following differentiation shall help to distinguish between familialistic and de-familialistic measures within dementia care:

De-familialism connotes that the family is either completely or to a large extent unburdened from the caring work. This could be realized by half- or full-time institutionalization for example. Thus, it offers a veritable alternative to care that is solely based on the family. This implies that the dementia patient becomes more independent from the caring function of the family. A second criterion is the consideration that the de-familialistic service becomes more professional. If we take the provision of one or two hours of supervision or a sitting service for the dementia patient provided by voluntary associations as an example, it seems obvious that this measure cannot be seen as de-familialization. This service neither absorbs a main part of the caring function nor does it lead to more professionalization in the field.¹⁵ Therefore, it cannot be a de-familialistic service.

In the following, dementia nursing theory will help to identify those measures which support the carer in his or her caring function and those which discharge from this role.

4. (De-)Familialism in dementia care: Recommended measures and appropriate indicators

4.1. Categorization

How could the Leitner typology be adapted to the case of dementia care? In a first step, it is necessary to identify the political measures that either support or de-charge family care and

¹⁴ See for example Knapp and Prince 2007, page 67: only 9% of dependent elderly in UK receive only formal care

¹⁵ Volunteers are not professionals although they may possess a basic education in Alzheimer disease for example

have a special impact on dementia care. In the following, the supporting and de-charging measures are discussed. Furthermore, additional indicators that are crucial for the subsequent comparative analysis of dementia policies are identified.

First of all, political interventions need to be looked at and differentiated. This is important for the subsequent argumentation and thus for a thorough analysis of the implemented political measures. There are several propositions of categories for these interventions that can be found in the literature. For the following purposes a classification derived from Warner et al. (2002) seems to be appropriate because it does not focus as much on the medical aspect of dementia as other classifications do (see for example Marriott 2003). Three categories can be distinguished: measures which focus on (1) financial independence; (2) dementia specific services as respite and day care and thirdly any kind of (3) practical and emotional support for the informal carer (derived from Warner et al. 2002: 88ff). These three groups do not yet say anything about the potential (de-)familializing effect of the respective measure. To what extent measures have a (de-)familializing impact remains to be seen with regard to every single measure. In a first step it can be assumed that it is possible to find for all three groups familializing as well as de-familializing measures. In the following, the focus lies upon an analysis of what measure is recommended by academics in each category. The measures will be classified as (de-)familializing on the basis of the definitions introduced above.

4.2. Category I: Financial independence

This first category, i.e. financial independence regroups measures that help to assure the financial independence of the caregiver. In the UK for example, more than 50% of all caregivers in the UK for example live together with the person they care for (Audit Commission 2004: 2). As it can be assumed that caregivers and care-receivers that live together in one household manage their resources commonly, it is appropriate to take into account also allowances paid to dementia patients.

However, it remains questionable to what extent allowances can be consulted as a good indicator for family support. The argument can strongly be supported with the help of Leitner's concept of the "Existenzsicherungs-Schere"¹⁶. This allegory indicates that ensuring the survival of the informal carer becomes difficult for at the moment when the elderly person gets to at a medium level of dependence. The time needed for care increases and it becomes difficult to reconcile this task with any – even part-time – employment obligation. On the

¹⁶ Literal translation: "Securing existence – Scissors". The term illustrates the gap between two 'secure' levels of income– living on paid employment and living on care allowances.

other hand, the care allowances are not yet high enough to ensure a sufficient income (Leitner 2008: 193). In the case of dementia care the phenomenon is even aggravated. In order to determine the amount of allocated care allowances, the degree of dependence is established on the basis of how much time is needed to care for a person. As supervision does not constitute a recognised category in the system (Eichler, Pfau-Effinger 2005: 17), the degree of dependence will systematically be too low for dementia patients. As a result, the problem of too much caring time for paid work and too low care allowances to assure income maintenance will arise at an earlier point for dementia care than for normal elderly care. What could thus be an appropriate indicator to look at financial help? Payments for care allocated in relation to the degree of dependence are still of some importance as they correlate in many cases with dementia care and they show the ‘general willingness’ of a welfare regime to financially support dependent people and informal carers. But the following analysis of dementia programs will try to identify expenses allocated specifically in relation to dementia care. This spending is linked to the mere existence of the disease without further conditions.

These payments for informal home care are clearly familialistic measures as they support the caring function of the family and assure the right to care. Nevertheless, in this category, there are also measures that can be conceived as de-familialistic: payments for professional care of dementia patients in institutions. The country analyses will try to identify financial aid which could give ‘incentives’ for institutionalization¹⁷ of dementia patients.

Another point has to be mentioned with reference to the carer’s financial independence, although it concerns the future rather than the current independence. As already stated an important part of dementia carers in working age give up employment. Thus, they risk their future employability and pension payments. It is worth investigating if dementia policies in the respective countries provide any help to stabilize also future financial independence constrained by dementia care.

4.3. Category II: Supportive or discharging services

Supportive or discharging services include any kind of external caring service. The quantity and the kind of the care provided (is the care provided by professionals?) determine if the measure is regarded as familializing or de-familializing. Given the vast number of different care services, the present analysis is restricted to the following services for feasibility reasons: respite, day- and night care, and full-time institutional care.

¹⁷ This means: care is provided by professional care homes

First, *respite care* allows a caring break for a certain period of time; the patient is placed in a nursing home during that time. The idea is to give caregiver and patient the chance to leave behind the everyday caring routine, therefore allowing a consolidation of their relationship. This off-time allows the caregiver to recover and improve his or her psychical and physical well-being. It is obvious that the caregiver's well-being is of crucial relevance for the subsequent resumption of the caring work. Respite care is even more important when the patient suffers from night-time disturbances. Arksey et al. (2004: 10) underline the positive impact of a caring break on the caregivers sleeping time and quality. Already in 1988 Brudz et al. investigated the impact of respite care on informal caregivers of dementia as well as non-dementia patients and compared it with a control group – not receiving respite care. In addition to the positive impacts on the caregivers, respite care may be an appropriate measure for caregiver support for the following reason: “Regardless of diagnosis, [...], positive effects from respite exposure were found for caregiver reports of the patient's memory and behaviour.” (1988: 38).¹⁸

Day and night care are the two other forms of caring services that could also be of special interest for dementia care. *Day care* encompasses daytime supervision of and care for dementia patients in institutions such as nursing homes. It therefore is of special interest to caregivers who are still of working age. Evidence suggests that day care has a positive effect on both, caregiver and patient as caregivers benefit from the daily respite from caring and “patients enjoy the company, the sense of belonging and the activities provided” (Arksey et al. 2004: 9).¹⁹ *Night care* can be necessary if the patient suffers from night-time disturbances such as agitation or wandering. Yet, the temporary change of location, especially during sleeping-time, can be stressful and confusing for the patient and the reason for behavioural problems. As the utility of general night care services for dementia patients can be contested, night care will be neglected in the following.

With regard to the below-mentioned country case studies it has to be defined which of these measures discussed in category II, belong to the category of familialism or de-familialism. Respite care constitutes a singular break of the informal care for a certain, clearly defined

¹⁸ However, these findings are not uncontested; see e.g. Lee and Cameron (2004). Nonetheless, the authors admit that their results could be caused by a multitude of methodological problems. Given the fact that respite care is demanded for caregivers support by the WHO, in the following it is assumed that respite care is desirable in a familialistic dementia program.

¹⁹ Similar to respite care, the scientific research yields different results concerning the effectiveness of day care. Nevertheless, there is some evidence that a longer break during the day allows some emotional relief. In some cases, daily contact between the caregiver and the personnel of the day care centre even allows a decrease of the carer's social isolation (Arksey Jackson et al. 2004: 52f).

period of time. Rather than an alternative to family care, it represents a support, a temporary unburdening. The idea is that the informal carer can continue his or her caring role afterwards. Thus, it is a familializing measure – the family is supported in its caring function. By contrast, day care fulfils an important part of the care function as it is a form of part-time institutionalization²⁰. For normal elderly care this can be seen differently, as the essential help with the “activities of daily living” (ADL) certainly remains within the responsibility of the informal carer. But regarding the fact that supervision is so central in dementia care, day care takes over this task during an important part of the day. Hence, it can be classified as a de-familializing measure – part-time institutionalization as an alternative to exclusive family care.

Finally, the most obvious of all de-familializing measures has to be discussed: the percentage of the patient’s institutionalization. Despite the lack of valid data about the share of dementia patients in elderly care institutions,²¹ it is worth taking into account the general percentage of elderly person in institutions. Firstly, because there is some evidence that the share of dementia patients in institutions is very high.²² Therefore, it can be supposed that institutionalization often works as a discharge of families dealing with dementia. Furthermore, total figures (of all elderly institutionalized) can give an idea about the ability or willingness of a government to provide institutional solutions. Last but not least, the number of people suffering from dementia living in institutions depends also on the offer of places in these institutions, not only on the demand for them (Gallez 2005: 64). Leitner does not take into account this indicator because it “shows hardly any variation between the EU member states” (2003: 362). In contrast, other authors such as Bettio and Plantega (2004) use this indicator and identify various differences. The two authors refer to data of Pacolet et al. from 1999 to demonstrate that for example the UK has the highest category for elderly residential / institutional care; whereas Germany and France range as medium (2004: 16). Dietmar Rauch (2007: 259) also analyses the rate of institutionalism (figures from 2003 to 2005, extracted from national statistic institutes) and yields results from these observations. In a tentative conclusion, it appears reasonable to carefully take the rates of institutionalism into account. For the focus on dementia care it will be interesting to see if national governments support

²⁰ Institutionalization: professional care provided by any kind of institution

²¹ This is also the case for respite and day care.

²² The official report about elderly care institutions in Germany estimates for example that 50% of all residents suffer from dementia, the real figure will be even higher as the most important part of people suffering from dementia is undiagnosed (BMFSFJ 2006: 11).

specific dementia care units and to what extent innovative forms of dementia living facilities and pilot projects exist and are subsidized – as for example group living programs.

Home care services are excluded from the analysis. As discussed above, they do not grant important relief with regard to the special needs of people suffering from dementia. They focus on basic care – i.e. the activities of daily living. They can only provide supervision (which we have seen is essential for dementia care) to a very low extent. Therefore, they are not likely to serve as good indicators for dementia care, neither for familialistic nor for de-familialistic measures.

4.4. Category III: Emotional and practical support

This third category compasses a wide and complex range of measures. Many can be seen in relation to information, education and communication. They try to tackle several of the problems occurring during dementia care, which were mentioned in the introduction. First, the measures focus on the social isolation of the caregiver. Particularly support groups, functioning in the most cases on a voluntary basis, also try to promote the carers' social contacts and provide emotional support. Information and education are two other crucial aspects. Educational programs and information about dementia can contribute essentially to the caregiver's understanding of possible extreme behavioural symptoms. This can reduce conflicts in the relationship of caregiver and care-receiver. Marriott for example presents a 'cognitive behavioural family intervention', which provides information on dementia, knowledge about stress management and communicates carer-coping strategies. She reports that the fourteen sessions "had a positive effect upon stress and depression in family caregivers as well as significant results in terms of the behavioural disturbance and activities of daily living of people with dementia" (Marriott 03: 195f). The WHO also underlines the importance of various forms of psychosocial interventions such as individual and family counselling (WHO 2001: 71). In fact, a study by Mittelman et al. tested the effects of counselling and supportive interventions on the institutionalization (entrance into residential care) of the patient. The caregivers who received this kind of intervention "experienced a 28.7% reduction in the rate of nursing home placement compared with usual care controls." (2006: 1592)

With regard to the following country analyses it has to be mentioned that data about offers of e.g. support groups or counselling do not exist. Even the number of associations providing such services cannot be determined. Nevertheless, it shall be possible to identify those

dementia programs which give incentives (for example financial support for associations) to offer these measures. Eventually, observations of some innovative interventions can be made.

Measures in category III will in any case have a familializing impact, per definition they support and do not discharge the family completely. Emotional and practical support with de-familialistic effects is hard to imagine.

The following table resumes the measures identified as important indicators for dementia care, classified according to the categories introduced above and differentiated in terms of their in familialistic and de-familialistic impact:

Table 1: (De-)Familialistic measures for dementia care

		Familialistic measures	De-familialistic measures
I	Finances	Care allowances, special payments for dementia care, entitlement for pension payments	Transfers for institutionalization
II	Services	Respite care, services with specific dementia focus (e.g. voluntary organizations)	Day care, rate of institutionalization, alternative living arrangements for dementia patients
III	Support	Support groups, information about the disease, how to care etc.	

I: Measures focusing on caregiver's financial independence as social transfers; II. Provision of services; III. Emotional and practical support

5. Country analysis: United Kingdom

In the following, the focus lies upon three case studies: UK, France, and Germany. In a first step, the three countries are discussed separately in order to identify specific characteristics. Afterwards the data is put together in order to establish a more complete comparative picture of the three countries. The thesis intends to discuss dementia policies with a focus on family care. Needless to say, there is no benefit system – such as an insurance scheme for example – exclusively for dementia patients.²³ “Dementia care is seldom treated as a policy issue in its own right” (Cantley 2001: 201). In general, the needs of dementia patients are addressed

²³ Even if there are some measures with a special focus on dementia patients.

within the more general system of elderly care. Therefore the case studies point out in a first step some very essential characteristics of the country's general elderly care system. Of interest are especially those elements that can be found as a central theme also in dementia policies. In a second step, the focus lies upon the measures that were identified earlier on as being important for informal dementia care.

5.1. General tendencies in elderly care and dementia as a political issue

The United Kingdom does not possess a single social protection scheme for elderly in need of long-term care, but offers a range of cash-benefits and benefits in kind financed by tax payments. Several of the cash-payments are not exclusively designed for elderly people, but the latter can fulfil the eligibility criteria (Holdenrieder 2003: 185). Social services for older people in need of long-term care have a long tradition in the United Kingdom and they are well developed. In 1987 for example, public authorities spent eight times as much on institutional elderly care as on childcare (Bahle 2007: 85, 87f). The origins of elderly care can be traced back to the tradition of poor relief, which is of high relevance to social services until today. The tradition of accommodating the elderly in poorhouses explains a traditional strong leaning on the importance of residential care. Until 1995 places in residential homes were increasing – a fact that can be regarded as very special in the European context of elderly care (Bahle 2007: 96). As a result of crucial reforms in the 1990s, community care slowly managed to get onto the political agenda of Britain's social policy. The “National Health Service and Community Care Act” was of special importance for this development. This Act, adopted in 1993, marked the beginning of a deep and structural change in social services towards the promotion of community care (Bahle 2007: 83). Another important characteristic of the British caring system is the importance of voluntary organizations. These organizations founded in the UK in the 19th century have developed in a unique way compared to other European countries. They provide a large extent of the services needed, even if they are not institutionally integrated into the public sector as it is the case in Germany (Bahle 2007: 82). Although the government and voluntary sector agreed with the ‘Voluntary Sector Compact’ in 1998 to improve their cooperation, their work remains poorly coordinated.

A last essential characteristic for the UK is the institutional division in competences concerning tasks of elderly care. Income support in the form of cash-benefits lies traditionally within the competence of the central government. Local authorities are in charge to provide personal social services (Bahle 2007:81). And although medical and personal social services cannot be delimited easily in the everyday care of elderly people, they are divided

institutionally. All medical services are provided and paid by the National Health Service; personal social services by the local authorities (MISSOC 2006: 1).

To what extent are these characteristics of relevance to dementia care? It seems that the UK tends to institutionalise more than other countries do. Institutionalisation could be a guiding principle in dementia care as it represents one solution for the complex needs of a dementia patient²⁴ - de-familialization is a path, the UK could take. The institutional division, finally, could bear some important complications for dementia care. Given the specific characteristics of dementia care such as supervision, financial support etc. and the division of competences of the UK system, it is likely that a wide range of actors would need to be involved. This bears a huge coordination challenge.

Dementia as a political issue has recently made an entry onto the political agenda of the UK.²⁵ On 3 February 2009, the Department of Health published the 'National Dementia Strategy' (Department of Health 2009a). The Strategy will run for five years; £150 million are envisaged for the first two years. The Strategy admits the current shortcomings in dementia services and envisages significant improvements in key areas such as improved awareness, earlier diagnosis and intervention, and higher quality of care. Seventeen objectives are formulated. Central to these are public awareness, early diagnosis, research and workforce. The quality of care is fundamental to every form of dementia care. Thus, the Strategy considers dementia care in hospitals, in the community and in care homes (Department of Health 2009a: 13). The analysis of this Strategy and other dementia related political measures shall be done with regard to the following questions: Are there any tendencies towards (de-)familialism? Does the focus also lie upon the dementia carer? Are there any measures newly introduced that are tailored to the dementia carer?

In the following analysis of the British dementia policy, familialistic and de-familialistic measures will be discussed separately. The analysis will be guided by the classification of table 1. In order to allow a structured argumentation, it is divided into the three categories (I) Finances, (II) Services and (III) other forms of practical and emotional support,

5.2. Familialistic tendencies

In the first group 'finances', two sorts of 'familialistic' transfers are necessary to mention as they contribute to the financial independence of caregiver and care receiver. The first is the

²⁴ Without opening a debate about the normative difference between family and residential care.

²⁵ The following data refers to England if it is not indicated differently

Attendance Allowance, which is paid to people aged 65 or above, who are in need of care because of physical or mental disabilities. The allowance is granted without means testing;²⁶ it is non-contributory and tax free. There is no special reference to dementia (see Social Security Contributions and Benefits Act of 1992 part III, No 64ff). Nevertheless, it can be assumed that a lot of dementia patients are beneficiaries because of their mental disabilities. What could have a special impact on dementia patients is the explicit age qualification of 65 or above. This could pose problems for early onset dementia.²⁷ The ‘National Service Framework for Older People’ (an important document for treatment and care of dementia) states that about 17,000 people under the age of 65 living in England and Wales suffer from dementia (Department of Health 2001: 97). Although it is not designed for that, younger dementia patients could benefit from the Disability Living Allowance (designed for younger people with disability). There is no data available allowing an estimation about the number of dementia patients younger than 65 absorbed by the Disability Living Allowance. The Attendance Allowance grants £ 70.35 per week (80.31€²⁸) for more severe cases and £ 47.10 (55.12€) for less severe cases. The former are defined by their need of night-time help whereas the latter only requires help during the day.²⁹

The second transfer of interest is the *Carer’s Allowance*, paid directly to those caregivers who are unable to work because they spend more than 35 hours caring for a person eligible for Attendance or Disability Living Allowance. The allocated amount depends on the caregiver’s overall income; it is for example reduced if the person receives other social benefits. According to Holdenrieder, approximately 64.82€ per week is paid in average (2003: 196). If the person cares less than the required time limit or earns more than £95 (about 109€ net) a week, no allowances will be granted.³⁰ By analyzing the concrete formulation, it becomes clear that the Carer Allowance is designed as compensation for lost income and shall support those carers who do not have enough funds available. Unlike other care allowances, there is no intention to honour or to remunerate for the provision of informal care.

Those caregivers who are still of working age risk their future financial independence in form of *pension payments* if they resign from paid employment for informal care (at least that part that is earning related – as the State Second Pension in the UK). If the dementia carer is

²⁶ This is the only measure within the field of long-term care, which renounces means testing.

²⁷ Early onset: younger dementia patients - under the age of 65

²⁸ Exchange rate of July 16th 2009: 1 GBP = 1.17€

²⁹ http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG_10012438 (18.09.2009)

³⁰ The actual amounts are derived from <http://www.direct.gov.uk/en/index.htm> (the government’s website providing information about all public services) (26.07.2009)

entitled to the Carer's Allowance, he or she can build entitlements to pension. Additionally, for every week the carer is impeded to work, he or she will be credited with National Insurance contributions.³¹

To conclude, the allowances designed exclusively for old age frailty (which is the only one for the target group Holdenrieder (2003: 192)) could pose problems for dementia patients because of the age limit. Secondly, the absolute amounts are in general relatively low (it will be seen that the amounts paid for severe cases in Germany are almost twice as high). The carer receives allowances and is assured by National Insurance contributions and pension entitlements, but only in the case of need – that means if there is no sufficient income from other sides and if they care more than 35 hours a week. An important part of carers therefore is excluded from these payments. There is no mechanism that intends to pay for informal care or to reimburse costs resulting from dementia care.

With regard to category II 'Services', it has to be mentioned that service development for dementia patients has not been on the political agenda for several years. The 'Forget Me Not' report was published by the Audit Commission³² in 2000 and updated in 2002 in order to draw an overall picture of the current situation of mental health service delivery for older people. The 'National Service Framework for older people' published in 2001 focused on the quality of service provision and reinforces the results of 'Forget Me Not'. Standard 7 of the report defines the aim "to promote good mental health of older people and to treat and support those older people with dementia and depression." (Department of Health 2001: 90). However, reports and frameworks do not necessarily ensure a good service provision, as it will be shown in the following.

Before discussing the provision of familialistic services (category II), a special UK problematic regarding *care assessment and service funding* has to be addressed as it applies to all sorts of social care services. One problem consists in the fact that there are neither national eligibility criteria, nor a national guideline for care assessment. Those terms therefore are free to interpretation (Holdenrieder 2003: 208 and Le Bihan-Youinou, Martin 2003: 342). General assessment is further complicated by long waiting times. Especially if there are family members available, local authorities assume that there is a lower risk of unmet care needs of the dependent. Consequently, the assessment of service needs can take months (Holdenrieder

³¹ http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10038111 (27.07.2009)

³² Audit Commission for Local Authorities in England and Wales, established in 1982 to enhance efficiency and effectiveness in local public services (see: <http://www.audit-commission.gov.uk/aboutus/Pages/default.aspx> (26.07.2009))

2003: 201). This could result from the fact that benefits are still granted for those in financial need and not as a social right. Furthermore, it is difficult to draw the line between services for dementia patients falling into the competence of the National Health System (NHS) and the social service sector. However, this is decisive for the question of funding, as services of the NHS system are free of charge whereas personal social care is means-tested and subject to charges, which differ among the various local authorities. “A few years ago the Audit Commission (2002) described wide variations in the extent of NHS funding of continuing care for older people with mental health problems, and the problem persists” (Knapp, Prince 2007: 45). Thus, it is of central importance for the respective service, if the service is identified as necessary during the care assessment and if it falls within the competence of the NHS or not.

Respite care has been identified as indicator for familialistic services. The report ‘Forget me not’ yields interesting results concerning service provision: In the 2002 update, two thirds of the questioned carers³³ of dementia patients reported that they could get the help they needed to have a break (Audit Commission 2002: 29). It has to be mentioned that the availability of planned respite care differed enormously from region to region. Emergency respite care was only available in approximately half of the areas, home-based services (like sitting services) in even less, in approximately a quarter of all areas (Audit Commission 2002: 28). “This left a considerable number of areas where respite care was not available in one or other of these settings, or only available in part of the area.” (Audit Commission 2002: 28). Besides the geographical availability, financing is important for usage of a measure. Respite care may (partly) be financed by local authorities after a need assessment and means testing. Otherwise, the patient has to finance it from private funds.

The ‘the2001Act’ from 2001 introduced another clearly supportive measure for the dementia carer: *the direct payments for carers*. It was first allocated at the discretion of the respective local authority. In 2003, these payments were made obligatory for each local council (Department of Health 2006: 1). Since 2000, carers have had the right to a need-assessment independently from the person they care for. If certain services are assessed as necessary for supporting the carer in his or her caring role, the carer has the right to receive direct payments instead of benefits in kind. In this way he or she can choose to buy services from organisations or employ someone for assistance. These services can vary in their kind and therefore be easily adaptable to the specific situation. It can range, for instance, from domestic

³³ 5184 carers were questioned in 65 areas.

help, holiday, to emotional support or even taxi fares (Department of Health 2003: 35). It has to be added that local councils take into account the carer's income and capital for deciding which of the services the carer is charged for. It is difficult to properly measure the impact of this measure, since official evaluations are imprecise (Audit Commission 2004: 43). "It appears that many carers are not being assessed separately in their own right" (Audit Commission 2004: 43).

For the realm of category III 'emotional service and practical support', *voluntary organisations and NGOs* constitute a central actor by providing service and support for carers. Which support is provided by the state to give incentives for this kind of support? With regard to dementia, the Department of Health is the department in charge (Alzheimer Europe 2007: 232). The former program 'Department of Health Section 64' (in 2009 it has been replaced by the so called 'Third Sector Investment Programme') allocates grants to voluntary organisations in the UK with innovative proposals in order to promote the Department's policy priorities such as dementia care. As it can be seen in annex 1, grants for dementia related projects are very scarce and the budget is limited. Only a minority of projects explicitly refer to the caregiver (Annex 1). Nevertheless, voluntary organisations are of great importance, especially in terms of information provision. The Alzheimer's Society for example has a network of over 200 branches, support groups and education courses. "Support groups exist in almost all areas" (Audit Commission 2002: 28). The National Dementia Strategy also tries to elaborate further practical help and emotional support for carers. Two innovative measures are supposed to promote the provision of information and advice services: the *Dementia Adviser Service* and the so-called *Peer Support Networks*. The various, already existing measures shall be reviewed and evaluated for a potential implementation throughout the whole country. Before this implementation can take place, a demonstrator side programme shall find out what works best for which group of people and at what costs. Forty of so-called "Local Authority-led partnerships" will be funded for two years, twenty for each demonstrator theme. Application is now open for funding and for participation in the evaluation process. Councils can be funded for the dementia adviser service demonstrator sites with up to £207,500 for two years; the peer support network demonstrator sites will be funded with up to £140,000 for two years (Department of Health 2009b: 14). Given the initial phase of these pilot projects, it is too early to draw conclusions about their effectiveness. Nonetheless, the programme's necessity may be questionable – especially given the fact that comparable initiatives already exist with, for instance, the 'Landesinitiative Demenz-Service NRW', a publicly funded pilot programme in North Rhine-Westphalia (Germany).

5.3. De-familialistic tendencies

With regard to category I, it needs to be asked if there are any *payments made for institutionalization* – payments that promote de-familialization. In the UK, public support for personal care (it is differentiated between nursing and personal care) in residences is granted in relation to the income and capital of the dependent person. People with a capital of more than £22,500 have to pay the fees for residential care themselves. If the personal resources range from £13,000 to £22,500, the dependent has to make contributions; under the limit of £13,000, the existing capital is not taken into account.³⁴ The respective capital limits have been increased constantly throughout the last years. Until 2001, the limits were considerably lower ranging from £10,000 to £16,000 for requiring contributions from the dependent. The Royal Commission on Long-term Care ascertained in 1999 that “only around 44% of single old people above the age of 75 were entitled to some public support” (Holdenrieder 2003: 193). Given the continuous increase of income limits it can be supposed that this figure has slightly risen.

The ‘Forget me not report’ also provides insights into de-familialising services. According to the report, *specialist residential and nursing home care* for dementia patients are available in about two-thirds of the regions. A consistent, good quality of the physical environment was available in only half of them (Audit Commission 2002: 32f). The current use of care homes in the UK ranges between 2.5% of the population over 65 years living in English Councils with Social Service Responsibility (CSSR) in England and 4.0% in Scotland and Northern Ireland. Wales has a medium percentage of 2.8% (Knapp, Prince 2007: 59ff). The general trend of residential care is declining. As we have seen above, there was an extended public nursing home sector until the 1990s. But after a period where local authorities tried to transfer their residences into private or voluntary sectors, more and more homes are closing today. As a result, this even leads to under-capacities in some areas (Knapp, Prince 2007: 50).

Day care is an important de-familialistic measure as it unburdens the family from an important part of its caring function and enables in general the caregiver’s employment. Similar to other forms of service provision, the “nature and extent” of day care vary considerably from one area to another. In less than half of the areas, day care were available. According to the ‘Forget me not’ report, there is a particular shortage of services for older people with functional mental illnesses as. A further problem is also that day care is often not available before 10 am during the week and 4 pm at weekends. It is obvious that this reduces

³⁴ http://www.direct.gov.uk/en/HealthAndWellBeing/HealthServices/CareHomes/DG_10031525 (25.08.2009)

a flexible usage of the services; it also makes reconciliation with normal employment requirements difficult (Audit Commission 2002: 26f). The actual level of usage of day care by older people is very low and ranges between 1.1% in Northern Ireland and 1.7% in England (Knapp, Prince 2007: 64).

To sum up, there is certainly a general development towards a more specific dementia service improvement, with regard to, for example, special dementia care units and day care (Knapp, Prince 2007: 53 and Bahle 2007: 112). Nevertheless, the current coverage is far from being sufficient so that Knapp and Prince even speak of “evidence...that suggests a failure of services for older people with mental disorders” (2007: 54). Generally, it can be assumed that people suffering from dementia cannot escape the current ‘caring trend’ that prevails in the UK. Residential care is in clear decline – de-familialism only is on the agenda if the family retains a part of the responsibility as in the case of day care.

5.4. UK Conclusions

Central to this chapter was the question if there are any de-familialistic tendencies in the UK strategy. This does not seem to be the case. Objective 11 of the Dementia Strategy refers to the life of dementia patients in care homes (Department of Health 2009a: 12). Quality of professional care shall be improved; the quality of care homes assured by inspection regimes is stated in objective 15 (Department of Health 2009a: 13). Nevertheless, the general trend of residential care is declining. This can also be seen in the report’s argumentation: institutionalisation shall be avoided if possible (Department of Health 2009a: 34 and 77). ‘Day care’ is not mentioned at all in the Strategy and there is no discussion about the necessity to extend the provision of this kind of service.

And yet, are strong familialistic measures identifiable? The importance of family care is underlined various times in the Dementia Strategy (Department of Health 2009a: 12 or 34) as well as the potential negative impact dementia care can have for caregivers and the necessary support. With regard to support in form of information (to deliver better access to services etc.) the Strategy proposes a ‘dementia advisor’ as already mentioned. Although the government now helps with research and implementation, this service is considered to lie within the responsibility of the third sector, i.e. the non-profit and non-governmental sector. Public provision is not envisaged. Apart from the ‘dementia advisor’, new measures cannot be identified. Concerning the support for carers, the Strategy refers to other governmental projects which focus on the caregiver such as the government’s ‘New Deal for Carers’ announced by Gordon Brown in February 2009 and endowed with £33 million. In fact,

various recent initiatives had the intention to facilitate life for carers. The carer's strategy from 2008 "Carers at the heart of 21st century families and communities" is one of them, the White Paper "Our health, our care, our say" from 2006 announcing the New Deal another (Department of Health 2006a). The provision of information facilities, training programmes and emergency respite care are only examples of various measures within the initiatives. Legislation such as the "Carers and Disabled Children Act 2000", the "Community Care Act" and the "Carers (Equal opportunities) Act 2004" strengthen the carers' rights. Additionally, high expectations have resulted from the new carers' grant paid to "enable local authorities to continue to develop innovative and personalised outcomes reflecting the needs of their local carers." (Department of Health 2008b: 3) This grant is especially designed for breaks and crisis situations. It is, however, commonly managed together with childcare; the usage depends on every's local authority's priority (Department of Health 2008b).

Thus, the support for carers is a central issue on the government's agenda, at least theoretically. In practice, however, the agenda lacks implementation. Already in 2004, the Audit Commission reported "[t]he present situation is not satisfactory. The government's aspirations for carers of older people are not being realised in practice for the majority of them." (Audit Commission: 62). A special focus on the 'dementia carer' is also missing. This is noticeable for example in the point that the additional supervision needed for dementia patients is not dealt with at all. In fact, one may even argue that there is a danger to neglect the focus on the dementia carer. The following illustrates this point very well: The Dementia Strategy refers to the Carers' Strategy that addresses the effects dementia care can have on carers (Department of Health 2009: 5). On the other hand the Carers' Strategy "Carers at the heart of 21st century" points to the forthcoming National Dementia Strategy – precise and clear announcements are still missing (Department of Health 2008a: 118). Other familialistic measures discussed in the case study are characterised by a difficult access because of means-testing and time and age barriers (e.g. 35 hours caring work per week) as well as modest transfer (e.g. Attendance Allowance).

6. Country analysis: France

6.1. Central characteristics of elderly care and dementia policies

In France, a long debate on how to address the risk of old age frailty has influenced the public and political agenda. For a long time, the problem was debated emotionally but remained unsolved (Bahle 2007: 152). Elderly in the need of long-term care and with a lack of resources were referred to social aid. The benefit ACTP (Allocation Compensatrice pour Tierce Personne) was originally introduced in 1975 for disabled persons. But under some conditions, frail elderly people could also benefit from it. In 1996, the PSD (Prestation Spécifique Dépendance) replaced the ACTP. For the first time a special social benefit was introduced for elderly people (Bahle 2007: 169). Nevertheless, right from the start this benefit was introduced as a transitional solution before the ‘big reform’, which should take place at the moment of a more favourable economic situation. This was finally instantiated in 2001 with the introduction of the APA (Allocation Personnalisée d’Autonomie). The APA works as a national solidarity allocation and is today’s basis of the French long-term care system. At the beginning, APA was presumed to be prohibitive in the long run, but the *Canicular Days* in 2003³⁵ got the topic back onto the agenda and endowed the APA with stronger legitimacy.³⁶ Furthermore, the foundation of the ‘National Solidarity Fund for Autonomy’ was initiated in 2005. It is today in charge of different assignments for the whole of the elderly sector (Frinault 2005). The APA can be conceived as a real improvement compared to the precursor PSD as the eligibility has been broadened (Holdenrieder 2003: 132).

Although standards and eligibility criteria etc. are decided at the national level, the French departments are the administrative units that are in charge of providing the social services. They therefore take up an intermediary role, operating between the regional and local level (Missoc 2006: 2). The provision with benefits is generally means-tested. Like in the UK, there is no clear separation between medical and social long-term care. This makes the public health sector important for elderly care and, at the same time, it causes some coordination problems (Holdenrieder 2003: 258). Bahle (2007: 143) describes the French elderly care system in general as modestly developed. The system was not given a clear path at one moment. This becomes obvious in the design of the APA: it was inspired by the wish to

³⁵ ‘La Canicule’ describes a period of very hot days in August. In 2003, these days caused a sanitary catastrophe for older people in France. The considerably increased mortality rate of elderly was partly retraced to malnutrition and bad maintenance (IGAS 2004).

³⁶ <http://www.travail-solidarite.gouv.fr/espaces/personnes-agees/grands-dossiers/allocation-personnalisee-autonomie-apa/apa-pour-quoi.html> (20.07.2009)

introduce a universal instrument with a high level of formalization. It standardizes the regulation of access (with creation of a nationwide eligibility system) and the level of benefit. Nevertheless, the APA introduces the principle of co-payment; it reduces therefore the universal access and comes back to the logic of welfare aid (Le Bihan-Youinou, Martin 2003: 349).

With regard to ‘dementia policy’, France can somehow be called a special case. After two preceding governmental plans from 2001 to 2004 and 2004 to 2007, the French President Nicolas Sarkozy announced the Alzheimer Plan 2008-2012 in February 2008. With its third national plan facing Alzheimer disease, France can already look back on a tradition of dementia policy. One of the results certainly is that France ranks highly regarding the medical treatment of Alzheimer. France is the country prescribing the most anticholinesterase inhibitors – a drug used for mild to moderate forms of dementia (Cantegreil-Kallen et al. 2006: 321). In the following it will be investigated if the position of the dementia carer is as important as the medical side of the disease and if incentives towards more (de-)familialization can be identified.

6.2. Familialistic tendencies

Once again, the discussion will be guided by the classification of table 1. With regard to familialistic measures it has to be mentioned that the *place of informal carers* in the system is very poor. “Family or voluntary carers do not have any particular legal status.” (Missoc 2006: 3) although some new rights (as the right to receive formation) have been introduced with law n°2005-102. There are no transfers / payments especially for the carer (which is different from the UK system) and no special payments for dementia care.

The only payment which could be classified as a care allowance is the aforementioned APA.³⁷ It is of great importance for dementia patients as 72.3% of the APA beneficiaries suffer from a form of dementia (Gallez 2005: 20). APA is paid for dependent elderly above the age of 60.³⁸ Once again, the age limit could exclude people with early onset dementia, although the age limit is not as high as in the UK.

The actual maximum monthly amounts of APA (from 1 January 2009):

GIR I: 1212.50€

GIR II: 1039.29€

³⁷ Code de l'action sociale et des familles article R. 232

³⁸ Code de l'action sociale et des familles article R. 232-1

GIR III: 779.47€

GIR IV: 519.64€

With regard to table 1, it has to be mentioned that APA cannot be categorized easily in category I ‘transfers’ as it does not constitute a cash transfer at the carer’s or the dependents free disposal but a support provided as a benefit in kind. That means that it is a reimbursement of the beneficiary’s expenses to finance assistance which needs to be proven³⁹. It is controversial if APA appears more as a familialistic or a de-familialistic measure. It is de-familialistic in the sense that it is not paid for informal family care. It is familialistic as it cannot assume the whole dementia care work itself and appears only in addition to family care, thus as support for family care – we come back to this point when discussing the service provision. As APA is means-tested it is reduced by a co-payment determined with regard to the monthly income of the disabled elderly. For 2009, the applicant does not have to contribute if he or she earns less than 682.67€ per month. The co-payment goes up to a rate of 90% for incomes more than 2,720.49€. ⁴⁰

Before focusing category II ‘services’, a short reference to the French *eligibility criterion* has to be made in order to identify problems of access for dementia patients. For identifying those elderly persons who are in need of help, the French system uses the so called *AGGIR system* (Autonomie, Gérontologie, Groupe Iso-Ressources). Seventeen variables measure the degree of loss of physical and mental autonomy (items as orientation, washing, eating, mobility and ability to undertake leisure activities). With the help of the AGGIR scale the dependent person is classified in one of six degrees of disability ranging from completely independent (VI) to “those who are confined to bed or chair and whose mental functions are considerably disturbed, so that the person needs to be looked after permanently.”⁴¹ The AGGIR scale has not been changed during the change from PSD to APA. And although some minor adjustments have been made, “a weighting of the AGGIR scale towards physical restrictions and a neglect of forms of mental disturbance” can be identified, leading to disadvantages for dementia patients (Holdenrieder 2003: 129, see also Roudier, M; Al-Aloucy, M J 2004).

³⁹ <http://www.travail-solidarite.gouv.fr/espaces/personnes-agees/grands-dossiers/allocation-personnalisee-autonomie-apa/apa-pour-quoi.html>

⁴⁰ The actual amounts depend of the yearly ‘montant de la majoration pour tierce personne’ and can therefore be matter of change in each year

⁴¹ Code de l’action sociale et des familles article R. 232-3 ; translation from Holdenrieder : 117 – these levels are called GIR

Central to category II, the supporting services, is the '*aide ménagère*' (home help). In France, there is a long tradition of this form of help in order to promote elderly care at home (already demanded in the Laroque report of 1962; see also Nogues 2003: 137). Enhancing the employment of non-qualified home help for elderly dependants has had two advantages in the governmental perspective: first, the provision of employment and second, a care for elderly at relatively modest costs. Therefore the employment of home helps is facilitated in legal terms and promoted by tax reductions and exonerations of social security contributions. Home help can also be reimbursed by the APA. It could be of special importance for dementia patients because persons providing home help can be appointed very flexibly for different tasks. This could be an advantage with regard to the additional need of supervision and support of dementia patients.

Does home help have a familialistic or de-familialistic impact when regarding dementia care? It can be categorized under category I only to a restricted extent because it is declared impossible to use APA for the employment of a beneficiary's spouse, common-law husband or wife (Missoc 2006: 3). Instead, the employment of the dependent's children is possible. In this case the employee has all the social rights attached to paid employment, like for example entitlement for pension payments. With regard to category II, it is unlikely that unqualified home help that supports the patient's home for a limited time can provide sufficient dementia care to discharge the family members to an important extent. At least in advanced cases of dementia disease, it is very unlikely that home help alone can cope with the challenges dementia provokes. Hence, it is here classified as a familialistic measure in category II 'services' – it supports and unburdens the family to some extent.

The support of the carer was already mentioned in the first 'Plan Alzheimer'; it plays a crucial role in the second report. The current plan prioritizes the support for carers. Already the first measure under the first objective focuses on development and diversification of respite structures (Président de la République 2008: 14). *Respite care*, as one of the indicators identified above, can thus be seen as an objective with priority in the French dementia policy. The plan sets the clear goal to expand the offer of respite and day care to a large extent. The initial number of 3,600 places of respite care in 2008 shall be increase to 5,600 by 2012 (Président de la République 2008: 14). Furthermore, pilot projects of innovative forms of respite care shall be promoted and provided nationwide in the case of success (Plan Alzheimer 2008: 14). The Plan does not only set concrete ambitious goals, but also defines clearly the funding available and the actors in charge (Président de la République 2008: 8ff).

A monitoring commission meets three times a year for the current evaluation of the plan's implementation. In March 2009 this commission declared that the goal to establish 1,125 new respite places in France in 2008 had not been achieved, but that (at least) 229 new places had been set up (Comité de suivi 2009a: 1). The construction of new places seems to be necessary. In 2006, Cantegreil-Kallen reported that a lot of services for dementia patients could not be used because they were not available. Respite care was only available in 26% of the cases (2006: 320). Villez comes to the conclusion that in France respite care for Alzheimer patients is not yet organised in a satisfying way (2008: 41). Similar to the situation in the UK, an important problem in France is the geographical disparity of available services, including various kinds of the latter. The solution to this problem is one of the central claims made by Cécile Gallez in her famous report on Alzheimer in France (Gallez 2005: 19). To what extent a more homogeneous distribution of available places can be achieved in the future remains to be seen.

With regard to category III, 'emotional and practical support' the Alzheimer Plan suggests several arrangements as well. Of special interest in the field of practical support for the family are the carer's rights. In fact, the plan introduces a two days *information workshop* per year which shall be proposed to all dementia caregivers (Président de la République 2008: 16). Even the concrete content of this workshop is centrally decided upon and therefore determined for the whole of France. The implementation of this project has not yet taken place – an evaluation of the project's impact therefore is not possible at this very moment. The invitation for organisations to tender and the beginning of the concrete organisation was scheduled for August 2009 (Comité de suivi 2009b: 1).

Furthermore, there are also measures that focus on the emotional support. The Plan refers explicitly to the important psychical burden that dementia care represents for the 'natural carer' as it is stated in the first objective "helping the helpers" (Président de la République 2008: 13). In order to ameliorate the caregiver's psycho-social and medical well-being, the Plan suggests one annual medical *consultation* for each caregiver (Président de la République 2008: 18). These regular consultations shall initiate a basic trust between the doctor and caregiver. If the caregiver's health deteriorates, any needed help such as psycho-social support will be made available. In order to assure this special engagement of local health professionals, the latter will obtain additional formation in the so-called MAIAs (centres for autonomy and integration of Alzheimer patients).⁴² These centres shall be founded as a central

⁴² « Maisons pour l'Autonomie et l'Intégration des malades Alzheimer »

point of contact nationwide. They shall coordinate the medico-social and the sanitarian sector under one umbrella and give out all necessary information for a first handling of the situation. Until now some points have been identified as future MAIAs but there is no MAIA labelled yet (Comité de suivi 2009b: 1).

To sum up, some new measures concerning practical and emotional help as well as the future expanding of respite structures have been decided. Nevertheless, some central points as the financial support of informal caregivers seem lacking behind.

6.3. De-familialistic tendencies

We have seen that some familialistic tendencies exist but that their range of coverage is restricted by means-testing and other regulations. Can the French dementia policy be classified on the other hand as de-familialistic? The French law on dependency does not give explicit priority to one form of care (home or institutional care) (Missoc 2006: 4). Therefore APA can also be demanded for care in institutions – for financing a part of the residential costs. The costs for living in a caring institution consist of an amount for boarding and lodging, nursing care costs and a so-called ‘dependence rate’⁴³ linked to the level of dependence. Nursing care is paid by the health insurance, boarding and lodging by the dependent person (or from social welfare in the case of lack of resources). The dependence rate is financed by the APA together with a co-payment of the dependent person if the latter disposes of enough income or capital. The amount a dependent person pays monthly for institutional care depends thus on his income/savings, on the institution’s tariff and on his dependence level.⁴⁴ In contrast to the PSD, the APA suppresses the obligation for family members to support institutional care of a dependent person financially. The demand of reimbursement of institutional care costs after heritage (Bahle 2007: 170) and thus the financial familialisation was abolished.

The Alzheimer Plan allows an extension of de-familialistic forms of dementia care. The 16th measure defined by the Alzheimer Plan states that in the current *long-term care institutions* (EHPAD⁴⁵ in French), special units that are adapted for residents suffering from mental disturbances like Alzheimer shall be expanded to a large extent (Président de la République 2008: 42ff). This initiative also responds to the Gallez report, which criticizes the low number

⁴³ « Tarif dépendance »

⁴⁴ All information from the Ministry of work, social relations, family, solidarity and town at: <http://www.travail-solidarite.gouv.fr> (21.07.2009)

⁴⁵ Etablissement d’hébergement pour des personnes âgées dépendantes

of institutions specialized on dementia patients (2005: 20). 30,000 places in these special units shall be constructed until the end of the planning horizon in 2012 (Président de la République 2008: 43). 18,000 places exist already and have to be adapted to the special needs of dementia patients; 12,000 have to be constructed completely new ('Plan Alzheimer 2008-2012'). Last but not least, *day care* is on the agenda for further expansion. The number of 6,100 existing places in 2008 shall increase to 11,000 in 2012 (Président de la République 2008: 14). It took quite some time until day care was accepted as reasonable measure and expansion was officially promoted (Villez 2008: 34). However, when dealing with day care, simple expansion is not sufficient. Research has shown that two additional aspects are of special importance for good access: transport to the day care centre and flexible opening hours (Villez 2008: 37). The Plan announces a possible financing of transport to and from respite and day care institutions, but with some caution.⁴⁶ Also, the abovementioned analysis of day care let emerge its low availability and geographical disparity (Cantegreil-Kallen et al. 2006: 320). Recent evaluations show that also in this field, the Plan's efforts fall far short of their initial announcements. The monitoring commission ascertained the establishment of 1,414 new places, compared to 2,125 places that were envisaged for 2008 (Comité de suivi 2009a: 1). Thus, it can be said that the ambitious objectives are not yet achieved. At least, however, concrete plans exist.

6.4. French Conclusion

The Alzheimer disease, with aspects of treatment and care, is not a new topic on the France's political agenda. But is French dementia policy de-familialistic? It cannot be said that there is a special encouragement for people to choose the institutional form of dementia care - the patients can choose freely. Benefits within APA are means-tested for familialistic as well as de-familialistic measures. The Alzheimer Plan envisages expanding the existing structures so that other possibilities such as main family care exist, also specially adapted to dementia patients' needs. It remains to be seen to what extent these objectives will be implemented in practice. Already the earlier versions of the Alzheimer Plan had the objective to further develop for example day care; the Gallez report and others deemed the supply of existing facilities not to be sufficient. But unlike the previous suggestions, the Alzheimer Plan announces concrete figures, allocates the needed funding and controls the general implementation through the Audit Commission. Nevertheless, some caution is appropriate.

⁴⁶ « Cette mesure répond à une attente très forte des familles, mais ses effets doivent être évalués. » (Plan Alzheimer 2008 : 14) "Families have high expectations with regard to this measure but the effects have to be evaluated first."

Not without reason the Gallez report already mentioned in 2005 problems of equipment and sufficient recruitment of sufficiently qualified personnel (Gallez 2005: 112).

Are there on the other hand strong familialistic tendencies in the French dementia policy? The Alzheimer Plan suggests new forms of support such as information workshops and regular consultations. These are especially designed for the needs of dementia caregivers. All measures identified above as helpful for dementia carers are introduced or further developed in the Alzheimer Plan. Nevertheless, two points remain to be mentioned: the construction of respite structures lags behind ambitious aims and the financial independence of the informal family caregiver is not guaranteed in all cases. Regarding caring children of dementia patients, the informal care can be changed to formal care by the help of a formal engagement (the aforementioned home help) – payment and social insurance thus become possible. Spouses are excluded from this regulation and therefore condemned to pure voluntarism. This point gains in importance when regarding the following aspect: far more than fifty percent of dementia caregivers are female spouses (Andrieu, Grand et al. 2008: 34). It can be concluded that the system of informal care support of dementia patients lacks some central points.

7. Country analysis: Germany

7.1. The German long-term care insurance and dementia policy

Germany is the only country among the three cases that disposes of an explicit compulsory insurance scheme, which has covered the risk of dependency at least since 1995. Until the insurance's introduction, "the responsibility for long-term care has almost exclusively been ascribed to the societal sphere of the family" (Eichler et al. 2005: 8). In the case of no family member being available for informal care, caring services had to be paid from personal resources. If all savings were spent and (pension) incomes turned out to be insufficient, social welfare paid the costs for care. "In sum: the solution to the problem of long-term care was often either private or charity" (Ostner 1999: 117). When municipal social assistance authorities were no longer able to cope with the financial burden of too many long-term care dependents, a long discussion about the care system started in Germany and ended with the introduction of the fifth pillar of the German social insurance scheme in 1995: the Care Insurance Act "Pflegeversicherungsgesetz"⁴⁷. Comparable to the other pillars, the scheme is compulsory and based on the concept of mutual solidarity. It is financed in equal terms by

⁴⁷ Gesetzes zur sozialen Absicherung des Risikos der Pflegebedürftigkeit (Pflegeversicherungsgesetz), regulated in: Sozialgesetzbuch XI – in the following SGB XI (Lampert et al 2007: 340)

employees and employers (Skuban 2004: 128). According to Eichler and Pfau-Effinger, the long-term care insurance assured the introduction of new social rights: the right to receive care and the right to care (Eichler, Pfau-Effinger et al. 2005: 9) – for the first time payments were made for informal caring. According to SGB XI §2, the dependent person has the right to choose freely between informal and formal care and care at home or in an institution.

The long-term care funds are holding the administrative responsibility for the scheme. “The work of these long-term care funds is actually performed by the existing health insurance funds through their existing network of offices” (Holdenrieder 2003: 165). Given this close institutional link, it could be supposed that the German system does not suffer from the difficult distinction between the health and the (social) long-term care sector like the French and the British one. But nonetheless, it is difficult to draw the line between the ‘artificially’ separated sectors in Germany (Holdenrieder 2003).

The policy field of dementia is completely integrated within the field of long-term elderly care. There are no specific policy plans like in the case of the UK and France. Nevertheless, the provision of accurate care for dementia patients has been on the political agenda for a certain time (Warner et al. 1998: 32). Especially the recent reform of the Care Insurance Act in 2008⁴⁸ aims at taking dementia patients more into account.

Like with the other two case studies, the analysis is guided by the previously elaborated table 1 and the following questions: Is there a special focus on the informal dementia carer? Are there any tendencies towards (de-)familialism with regard to dementia care?

7.2. Familialistic tendencies

The *German Care Insurance Act* (called CIA in the following) grants help for long-term care independently from the dependent person’s age (there is no age limit in SGB XI). Here, the German case differs from the UK and France. Grants for early onset dementia are not excluded a priori because of a required age limit. A financial payment for informal caring, called “*Pflegegeld*” can be subsumed under the category of familialistic measures. In opposite to the British Invalid Care Allowance, it is distributed to the dependent person and not to the carer; but with the intention that the dependent person passes it to the caring person.

In order to become *eligible*, the person has to need help for personal hygiene, eating and preparing food, mobility and housekeeping for at least six months. If the person is categorised as ‘dependent’ by the medical service of the health insurance institutions (that are in charge),

⁴⁸ „Gesetz zur strukturellen Weiterentwicklung der Pflegeversicherung (Pflege-Weiterentwicklungsgesetz)“ adopted on 28 May 2008

he or she is assigned to one of the three levels of dependence (called “Pflegestufen”). The level of dependence is measured on the basis of “*activities of daily living*” (ADL) (regulated in SGB XI §14). This means that the elderly person receives money in relation to his or her competence to perform the regular ‘activities of daily living’. This concept was developed with reference to elderly people with physical diseases and takes into account issues such as bodily cleaning activities, nourishment, mobility and homemaking (SGB XI § 14). The difficulty is that dementia patients very often do not fit into these categories, as they are often physically able to carry out these activities but need supervision and guidance instead. Therefore, an important number of dementia patients (or caregivers) do not receive care allowances, despite the official diagnose of the disease (Skuban 2004: 71). For each *level of dependence* a concrete amount of caring time is calculated; e.g. 90 minutes of care per day for the first level, five hours of care for the third one. According to Le Bihan-Youinou and Martin (2003: 343) this German ‘specialty’ makes it to the most regulated and standardised model of dependence grants existing. In the definition of care dependency of §14 SGB XI, care is defined in a very narrow way, excluding all psychosocial aspects (Skuban 2004: 71). Since their introduction, experts have criticised the eligibility criteria for CIA benefits. Nevertheless, the definition remained unchanged. The coalition agreement between the two parties Sozialdemokratische Partei Deutschlands (SPD) and the Christlich Demokratische Union (CDU) preparing the work of the government 2005-2009 envisaged the revision of this narrow definition. In May 2009, the special advisory committee published its propositions for revision (Bundesministerium für Arbeit und Soziales 2009: 142). A concrete implementation has not yet taken place. It remains to be seen if the winning parties of the recent national parliament elections, CDU and FDP, will elaborate this issue.

The classification into the three levels is made regardless of the form of care the person chooses (formal or informal, at home or in an institution). However, the allocated amount of cash payment differs from one type of care to the other. The following amounts of “Pflegegeld” are paid per month in the case of informal care at home. Informal care is provided in most cases by a family member (Schneekloth (2003: 19).

Table 2: Long-term care insurance benefits for informal home care - Pflegegeld

Care-level	I	II	III
1995 – 06/2008	205€	410€	665€
07/2008 - today	215€	420€	675€

The payments are not means-tested. With the reform in 2008, payments for informal care were raised as shown in table 2. The general principle to keep the contributions to the CIA constant, which had been valid from 1995 to 2008, was abolished. The idea was to adjust the payments to inflation. Furthermore, a constant increase is planned for the following years. Every two years up to 2012, payments for informal care will be increased by 10€ for each dependency level (see tables in Bundesministerium für Gesundheit 2008a). Despite this effort, however, it is questionable if the envisaged increase is really enough to cover inflation.⁴⁹

As stated above, in general the dependent person has a free choice between different forms of care. Nevertheless, one of the *basic principles* of the SGB XI is the preference of ambulant care (at home) to institutional care.⁵⁰ The payment of the “Pflegegeld” sets an initiative for informal care at home to assure the implementation of that principle (Schütte 2007: 155). It is tax-free and not subject to social insurance contribution and constitutes therefore a net improvement of the household budget (Bäcker, Bispinck et al. 2000: 102). Pflegegeld can also be used for “*Pflegesachleistung*”, that is a ‘care in kind’ by a professional nursing service. If informal care is delivered in addition, the two measures can be combined and cash payments are reduced accordingly (SGB XI § 38). More than two-thirds of all dependent elderly receive informal care at home; only every third caring household is supported by professional home care (Statistisches Bundesamt 2007). Bahle analyses this trend consisting in a high demand for the full amount of cash payment and the renouncement of additional formal help. He explains the trend by the fact that the Pflegegeld, which is not cost covering anyway is reduced disproportionately high (2007: 33). Hence, it can be said that the impact of Pflegegeld is familialising: the informal carer is supported financially in his or her caring role. The CIA explicitly speaks in favour of informal home care and sets incentives to choose the informal caring role.

⁴⁹ One example: if you suppose an inflation rate of 2% annually, there will be a net devaluation of payments for dependency level II of 12€ in 2012 (own calculation)

⁵⁰ See §3 SGB

Also, *pension entitlements* fall under the category of (future) financial independence of the informal carer. Like in the UK, the German informal carer has in general the right to pension entitlements. The contributions for the National Insurance are paid for him or her, if the carer has no paid employment for more than 30 hours a week (SGB XI, §44). The comparison with the UK has to be made with some caution, as the barriers for receiving this status in the UK are much higher than in Germany. In the UK the informal carer has to spend at least 35 hours on caring during the week to receive this status (entitlements are linked to the Carer's Allowance). In Germany, fourteen hours weekly are sufficient (SGB XI §19).

Another measure worth mentioning under this category is the only clear dementia-specific payment in the three cases: *payments for additional services* for those dependents in need of a “considerable level of supervision” (§ 45b paragraph 1 SGB XI). These payments were introduced in 2002 to reform the CIA for the first time. An additional amount of 460€ per year could be used for additional services. During the reform of 2008, these payments of 460€ per year – which are in fact benefits in kind because costs for services are reimbursed – were extended significantly to 100€ or in severe cases to 200€ per month (Bundesministerium für Gesundheit 2008b: 9). This measure was designed with a special focus to the needs of dementia patients (see §45b) as a response to the constant critique of the definition of care dependency in §14 SGB XI. Eligibility criteria for the additional payments were widened in 2008, clearly advantageous for dementia patients. Hence today, beneficiaries do not have to be assigned to a level of dependence (members of “Pflegestufe 0” can be eligible) – including thus those patients with dementia not suffering from physical diseases (who are traditionally privileged during the categorisation in the dependency levels (Bundesministerium für Gesundheit 2008b: 9).

Like in the UK and France, there are familialistic supportive measures belonging to category II; services are offered in order to support the family carer. The carer has, for example, the right to make use of a maximum of four weeks of *respite care* per year (SGB XI § 42). The CIA reimburses costs up to the amount which is paid monthly for institutional care. Although there is the formal right for reimbursement of respite care, there is no sufficient amount of places in institutions available (Schneekloth 2006: 131). The statistics of the Federal Ministry of Health reveal, that the amount of potential beneficiaries is rising constantly but still remains at a very low level. Only 0.6% of all potential beneficiaries made use of respite care in 2006 (Bundesministerium für Gesundheit 2008a: 109).

The so-called “*easy accessible*” *supervision services* (“niedrigschwellige Betreuungsangebote”) can also be subsumed in the category of supportive services. They were introduced with special focus on dementia patients. The head organization of long-term care insurance funds is obliged to subsidise and support the construction and enhancement of these supervision services and new models of caring structures especially for dementia patients with 50 Million Euros each year (see §45c SGB XI). The above-mentioned payments can be used to access these kinds of services. Voluntary groups and self-help groups can be entitled to subsidies according to this regulation. During the reform in 2008 the subsidies for these easy accessible services and new care-models increased from 15 to 25 million Euros. But it has to be added that only two thirds of the available resources were actually exploited in 2006 (BMG 2008: 149).

Various measures can be listed under category III, i.e. ‘practical and emotional support’. SGB XI §45 states that the long-term care funds shall offer training courses for informal carers. §45 mentions above all practical caring skills. There is no reference to the specific needs for dementia carers in terms of information. Nevertheless some charity organisations such as Caritas⁵¹ offer specific dementia courses. The costs to attend these courses can be reimbursed by the CIA. Important to the everyday caring life is also one particular criterion for receiving ‘Pflegegeld’: Dependant elderly of dependency level I and II receive a consultation for the care household once every six months - dependants of dependency level III even every three months (SGB XI §37 (3)). These consultations are executed by an officially accredited caring institution such as, for instance, a local home care service. These sessions are carried out for two reasons: first, they shall guarantee the quality of informal home care and second they shall be a regular practical support for the caregiver. Those dependents who are in need of supervision (this includes above all dementia patients) are entitled to use the consultation service twice as often as ‘normal dependants’ (SGB XI §37 (3)2). If they are not yet categorised according to the dependency levels, they can nevertheless use the service every six months.

In addition, there are various *self-help groups* to help with emotional support. They are above all provided by the third sector (especially the regional Alzheimer organizations).

⁵¹See for example:

http://www.caritas-hassberge.de/bwo/dcms/sites/caritas/dv/cv_hassberge/hilfe/pflege/demenz.html (04.08.2009)

7.3. De-familialistic tendencies

With regard to the de-familialistic part of category I: the CIA makes financial contributions to formal care in institutions. The amounts paid are considerably higher than the allowances allocated for informal home care. Thus, the higher costs of professional institutional care are taken into consideration. With the reform of the CIA in 2008, Pflegegeld for informal care has been raised for all three dependency levels. The amounts for formal care in institutions staid the same except for dependency level three. It can be assumed that this one-sided concentration on informal home care expresses the government's wish to further encourage this form of care.

Table 3: Long-term care insurance benefits for institutional care

Care level	I	II	III
1995 – 06/2008	1.023	1.279	1.432
07/2008 - today	1.023	1.279	1.470

Payments for institutionalization could effectively set incentives for a de-engagement of the family in its caring function. This assumption, however, needs to be put into the following context: the German regulation does not discharge the family from a financial point of view. The CIA payments do not cover the totality of costs for institutional care. Since the CIA's introduction, the legislator has admitted that the scheme only offers a partial coverage that differs from, for instance, the health insurance (Klie 2004: 4 or Bäcker et al. 2000: 97). Similar to the French case, fees for institutional care are split into several parts. Whereas the CIA covers a flat rate for personal care, the costs for board and lodging and a part of the costs for personal care are paid by the dependent person. If the dependent person does not dispose of enough resources to cover these additional costs, they are covered by social welfare in the first place. Afterwards, social security funds test the capability of the dependent's children to reimburse these costs. They are obliged to reimburse if the monthly net income is superior to 1400 Euro.⁵² The actual amount, which has to be paid, depends on a variety of factors and has to be calculated individually for each case. The following illustration shows that the accordant amounts can be quite important: the average private payment for institutional care for dependency level II in the region of North Rhine-Westphalia is 452€ for caring costs plus 774€ for board and lodging (Borchert 2008). Thus, it can be said that there are some obstacles

⁵² This is the general regulation – costs for childcare or the own old-age provisions are taken into account.

integrated in CIA regulations in order to render complete de-familialisation more difficult. High-income family members remain in financial charge

Dependent elderly – and dementia patients assigned to one of the caring levels – are entitled to use de-familialistic services: *day or night care*. Costs for care and the transport to the institution and back are reimbursed up to the following amounts:

Table 4: Long-term care insurance benefits for institutional day or night care⁵³

Care level	I	II	III
1995 – 06/2008	384	921	1,432
07/2008 - today	420	980	1,470

For these forms of semi-institutional care, the same problem arises as for respite care. The level of usage is increasing but remains at a low level. Only 0.8% of potential users benefit from these forms of service (Bundesministerium für Gesundheit 2008: 109). Strictly seen from a quantitative point of view, they do not play a role in the provision of social services (Bahle 2007: 33). One reason is certainly that costs are not covered in their totality by the CIA. Secondly, there are not sufficient places available. The care statistics of 2007 state that up to 107,3% of the existing capacities are used and thus overexploited (Statistisches Bundesamt 2007: 21).

The German institutionalisation rates give some interesting insights into de-familialistic services. As already discussed, the CIA does give priority to informal home care. Nevertheless, the rate of full-time institutionalisation of dependent elderly has constantly been rising from 22,7% in 1996 to 28% in 2006. The share of dependants demanding ‘Pflegegeld’ has been incessantly decreasing since 2000 from 50.7% to 47.4% (Bundesministerium für Gesundheit 2008: 109). Given the CIA’s priority for informal home care, this trend can be rather regarded as a result of current developments in family structures and different female employment behaviour than as a reaction to altered policy institutions.

With regard to category II of de-familialistic measures, we have to come back to the above-mentioned subsidies for new models of caring institutions according to SGB XI §45c. Here, “full-time” institutions designed for the special needs of dementia patients are also promoted (SGB XI §45c (2). The so-called “Wohngemeinschaften für Demenzerkrankte” where the

⁵³ These are the same amounts which are paid for professional nursing care at home.

psycho-social supervision and motivation are subjects to the main focus, rather than the physical caring activity is a good illustration (Bundesministerium für Gesundheit 2008: 70). With this establishment the ministry tries to develop the supply of dementia specific institutions. Nevertheless, the impact of these institutions is not fully de-familialistic because their concrete usage is not promoted further with financial payments for institutional caring costs.

7.4. German Conclusions

What can be concluded from this last case study in order to draw a more complete picture from all these aspects? Obviously, the German system can clearly be identified as strongly familialistic. The facts that the informal caregiver has a legal status with pension entitlements and receives Pflegegeld for informal care work⁵⁴ or the right to paid respite care are of great importance. Furthermore, some regulations have been introduced recently in the SGB XI to explicitly take into account the special needs of dementia patients. Above all, these regulations aim at supporting the informal family care: examples are the easily accessible supervision services reimbursable by the CIA and the numerous consultations for informal family care. The de-familialistic tendencies on the other hand are weak. This is in clear line with the scheme's priority formulated in the SGB: home care is preferred to institutional care.

8. A more complete picture

The aim of the preceding chapters was to profoundly analyse dementia policies in the chosen countries UK, France and Germany regarding their (de-)familialistic tendencies. At this stage, the respective findings have to be brought together in order to visualize potential, more general strategies and set into a broader context. For this, a short summary of the most important country specifics will provide an essential basis.

In the UK, the importance of familialistic measures is constantly underlined. The wellbeing of the family caregiver is addressed in the national strategy and other progressive papers. Nonetheless, the factual importance of familialistic measures (such as the direct payments for carers) is questionable. A special focus on the dementia carer, as opposed to the 'normal' elderly carer is lacking. It can be claimed that one central aspect of all benefits and helps prevents measures from becoming important for general family support: it is the means-

⁵⁴ If the dependent person, receiving Pflegegeld passes it over to the carer– what can be assumed

testing of every kind of benefit. There is no general benefit provided with special reference to dementia care. The provision of support (financial transfers and services) depends on the patients or the carers' financial resources (as Carer's Allowance, direct payments for carer, pension entitlement, supportive services). The Dependence Allowance is the only exception but weighs little as the amount is relatively low. A second central point hinders the national government to extend the service provision of either familialistic or de-familialistic services: social services are provided by local authorities. Although the existence of a 'National Strategy' pretends the possibility of a nationwide delivery of services, there are no means of enforcement at the local level. Thus, the existence of supporting or discharging social services varies to a large extent from one local authority to another. These are structural impediments for more de-familialisation in the UK. Furthermore, de-familialisation does not seem to be the political will either. A complete discharging of the family through full-time institutionalisation for example shall be avoided if possible. It can be thus concluded that although the UK addresses the problem of increasing needs for dementia care by political programmes and papers, a concrete governmental implementation in form of enhanced family support or an explicit discharging strategy has not yet become apparent. It could be called the 'strategy of factual ignorance'. To come back to Leitner's typology: as it is hard to identify familialistic and de-familialistic tendencies, it can be argued that the UK assumes more and more characteristics of rather *implicit* than explicit *familialism*.

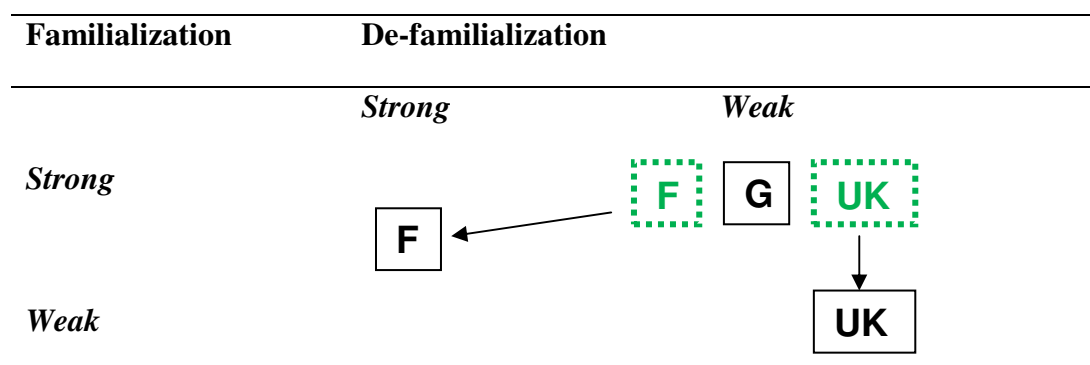
Compared to the UK, is the French 'model' vitally different? In France, the place of the informal caregiver is generally poor and so is the place of the dementia carer. One exception is the 'aide ménagère'. Informal care can be raised to the status of paid employment and reveals thus the French 'specialty' of promoting formal employment in the elderly care sector. Nevertheless, this is not a viable option for informal carers in general as spouses are officially excluded from this regulation. Although some more supportive measures are introduced with the Plan Alzheimer, they are not designed to enhance the legal and the financial status of the dementia carer (as the information workshops). Co-payments for APA benefits and the geographical disparity of available services are further characteristics of the French system. The recently published Plan Alzheimer announces important service extensions in the future of both: familialistic ones such as respite care but also de-familialistic ones such as day care. In contrast to the English Strategy, the Plan evaluates the concrete figures of current dementia caring structures and plans the concrete expansion of structures at a national level. In case France implements all objectives one day, it will play a leading role in service provision adapted to dementia needs. Thus, France opts for a different strategy: enhancing the service

provision in order to unburden or even discharge the family carer. Referring to the Leitner model, France therefore moves towards stronger de-familialism (although this is not yet completely achieved) via *optional familialism*.

Last but not least, Germany pursues a third strategy. The German dementia policies are completely integrated into the social insurance of long-term care. In general, the German scheme provides relatively high benefits for informal family care, which have been even slightly increased in the latest reform in addition to a clear legal status with social insurance benefits. Some newly introduced measures focus on the dementia patient and the support of the dementia carer. Germany is the only country that tackles the issue of need for additional supervision (with reimbursement of costs and subsidies for easy accessible supervision services). The analysis yielded that with the help of different institutional arrangements (such as “Pflegegeld”, reimbursement of institutional care costs by patients’ children) the CIA assures the implementation of the official principal of the long-term care insurance. This implies that care at home (by informal care givers) is preferred over professional care in institutions – assuring or supporting thus the traditional family caring function. In answer to the increasing challenge of dementia care, German dementia policies pin all hopes to the informal family giver, and enhance family support consequently. With regard to the Leitner model, Germany does not adapt other tendencies and remains clearly in the cluster of strong family support and weak de-familialism, thus in the field of *explicit familialism*.

To visualize these findings:

Figure 3: (De-)familialism in dementia care policy in UK, G, G



(according to Leitner 2003: 358)

Germany remains in the category of explicit familialism, the UK tends to implicit and France to optional familialism. Nevertheless, it has to be mentioned that the position of France is not

that clear. It can be argued that it assumes an inclined position between strong and weak familialisation because of the financial instability of informal carers.

How can the different strategies be assessed? Can any statement be made if there is one strategy more recommendable than the other?

In general, it is difficult to assess the general quality of dementia programs as the different strategies are according to different categories which cannot be easily counterbalanced: Is a caring course for informal carers, for instance, more valuable than 50 Euros more Attendance Allowance per month? Furthermore, no general statement can be made if familialism or de-familialism per se is a prevailing strategy as this would imply a normative argumentation. Nevertheless, one statement seems to be obvious: A strategy should be coherent. Against the background of growing challenges for informal care through dementia, political measures should reflect a reaction to current needs. This reaction could imply either enhanced support for the family or the development of de-familialising structures. A third consistent answer would be enhancing both, family support and discharging opportunities – thus, making a choice possible. The German and the French strategy could be denoted as consistent as they react either with more family support or more de-familialising structures. The UK instead does not choose a clear path of adapting existing measures to new, increasing demands. Confronted to a lack of alternatives, the family in Great Britain is left alone with the caring responsibility.

9. Attempts of explanation

Obviously, the countries choose different paths in their dementia policies vis-à-vis informal family care. Each case deals with family care in a different way. Against this background, it is questionable how these different approaches can be explained. The UK stands out because of its means-tested assistance and relatively modest universal transfers. Thus, benefits are not provided for informal dementia care work or to support the family in this financially difficult situation. They are granted only in the case of low income. In contrast, Germany demonstrates an explicit support of the traditional caring role – somehow extended as reaction to the increasing demands resulting from dementia. All efforts are integrated into the general insurance system. Institutionalization appears to be a last resort. The state takes over the caring role if the family's capacity is exhausted. France chooses some kind of third way with a classical statist approach of a national solidarity program. The announced extension of services for family support as well as family discharge resembles the well-developed system

of French childcare and thus translates the country's general will to take over responsibility for issues of common interest.

It is striking that all these points are similar to the countries 'classical' regime characteristics identified by Esping-Andersen in "The three worlds of welfare capitalism" in 1990. As already mentioned in paragraph 3, Esping-Andersen investigates to which degree welfare regimes allow people to maintain a certain living standard independently of their market participation. The UK as a liberal welfare regime is characterised by a relatively low level of de-commodification with means-tested assistance where modest universal transfers and social-insurance plans predominate (Esping-Andersen 1990: 27). Germany and France are categorised as corporatist or conservatives regimes with a medium level of de-commodification in relation to the socio-democratic regime (for example Denmark and Sweden). The corporatist regime model is characterized by the provision of important social rights, the tendency to uphold status maintenance and the traditional family model.

The present findings allow the assumption that (de-)familialisation of dementia policies is in line with Esping-Andersen's model of welfare regimes. This result would support findings of Esping-Andersen analysing parallels of familialisation and welfare regimes in 1999. He found consistency among the three models of welfare regimes and the degree of familialisation. Consistently, social democratic regimes generally have a high score of de-familialisation, corporatists a medium and liberal regimes a low level of de-familialisation. Esping-Andersen tested his model empirically on the basis of indicators such as state expenditures for family services and provision of childcare for children under the age of three. Guo's and Gilbert's (2007) research went in the same direction by analyzing the relation between de-commodification and de-familialisation. They intended to find out if distinct welfare regimes tend to support different levels of family policies. Although their findings were not as unambiguous as those of Esping-Andersen (as they analysed also a temporal trend instead of a snapshot), they found a statistical significant relationship between de-commodification and de-familialisation (Guo, Gilbert 2007: 307). Referring to Esping-Andersen's work they also focused on total public spending on family services and public childcare coverage. This emphasis on childcare was attenuated by taking into account home help coverage for seniors (Guo, Gilbert 2007: 310). Given the results of this paper, dementia policies also seem to match in terms of de-familialism with de-commodification scores. Thus, dementia policies fit into the development of other spheres of family policy. Also with regard to the French case it can be said that "social policy reforms are heavily regime dependent" (Gough 2001: 167) – once established regimes follow the path of development. The regime addresses new

challenges – such as dementia for informal care – within their existing systems (as for example the long-term care system in the German case). System inherent characteristics hinder the development of dementia policies, which are contrary to existing structures.

10. Conclusion

The aim of this paper was to reveal the political implications of the new challenges in form of dementia on informal family care. (De-)familialisation of dementia policies was conceptualized by the help of Leitner's 'Varieties of Familialism' adapted to the case of dementia care. The paper makes a contribution in examining how welfare regimes react to these new challenges under the angle of (de-)familialism. The examined country case studies head for different directions of either supporting further family care or developing means of discharging the family's caring function. The categorisation of the countries' strategies was made once again with reference to Leitner's framework. The findings point towards the conclusion that de-familialisation of dementia care are in line with levels of de-commodification and thus with welfare regime models. Consistently regime characteristics determine or at least influence patterns for dementia policy development. What does that mean for the potential of independent dementia policy development? If the degree of (de-)familialisation is influenced by system inherent characteristics, it becomes difficult for countries to react adequately to external challenges. This tendency results in the serious risk not to go ahead with important changes. The German case for example shows a strategy of relying on the family as main care provider and extending help in answer to dementia. This is a coherent strategy in itself. Nevertheless, the strategy ignores important current changes in society. It can be expected that the future informal caring potential will be strongly reduced. One reason for this development is, *inter alia*, the growing female employment rate (especially of women in the age of 50-65; a group who is of crucial importance for care of dementia patients).⁵⁵ Furthermore intergenerational family relations are changing. Declining birth rates and important geographical distances between family members reduce the chances that children assume caring responsibilities for their parents (cf. Tesch-Römer et al. 2005). Given these developments – developments that will become extremely relevant for future caring generations – it is highly questionable if a strategy that counts on the family as caring provider is very reasonable. Hence, although the German case seems to provide a consistent

⁵⁵ See table 2 in the annex

strategy in itself, system inherent characteristics hinder the development of policy taking into account current changes in society. Yet, neglecting or even ignoring the problem, as the British strategy does, is not a better alternative either.

Nevertheless, with regard to the range of analysis, a word of caution has to be made. The analysis was made with the help of governmental reports and legacies of social benefits and not on the basis of quantitative statistical analysis like for example in the case of Guo and Gilbert. Although their approach is somehow more limited as they concentrate on some exclusive indicators such as childcare and senior home help coverage (without justifying further their choice), a quantitative verification proved to be helpful in their case. Therefore, the present findings should be regarded as suggestive of a trend, which needs to be verified by statistical analysis – in case, one day, appropriate data will be available (like for example the institutionalisation rate of dementia patients).

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Annex

Table 1:

Approved and Continuing grants for Voluntary Organizations for dementia related projects in 2006-2010⁵⁶

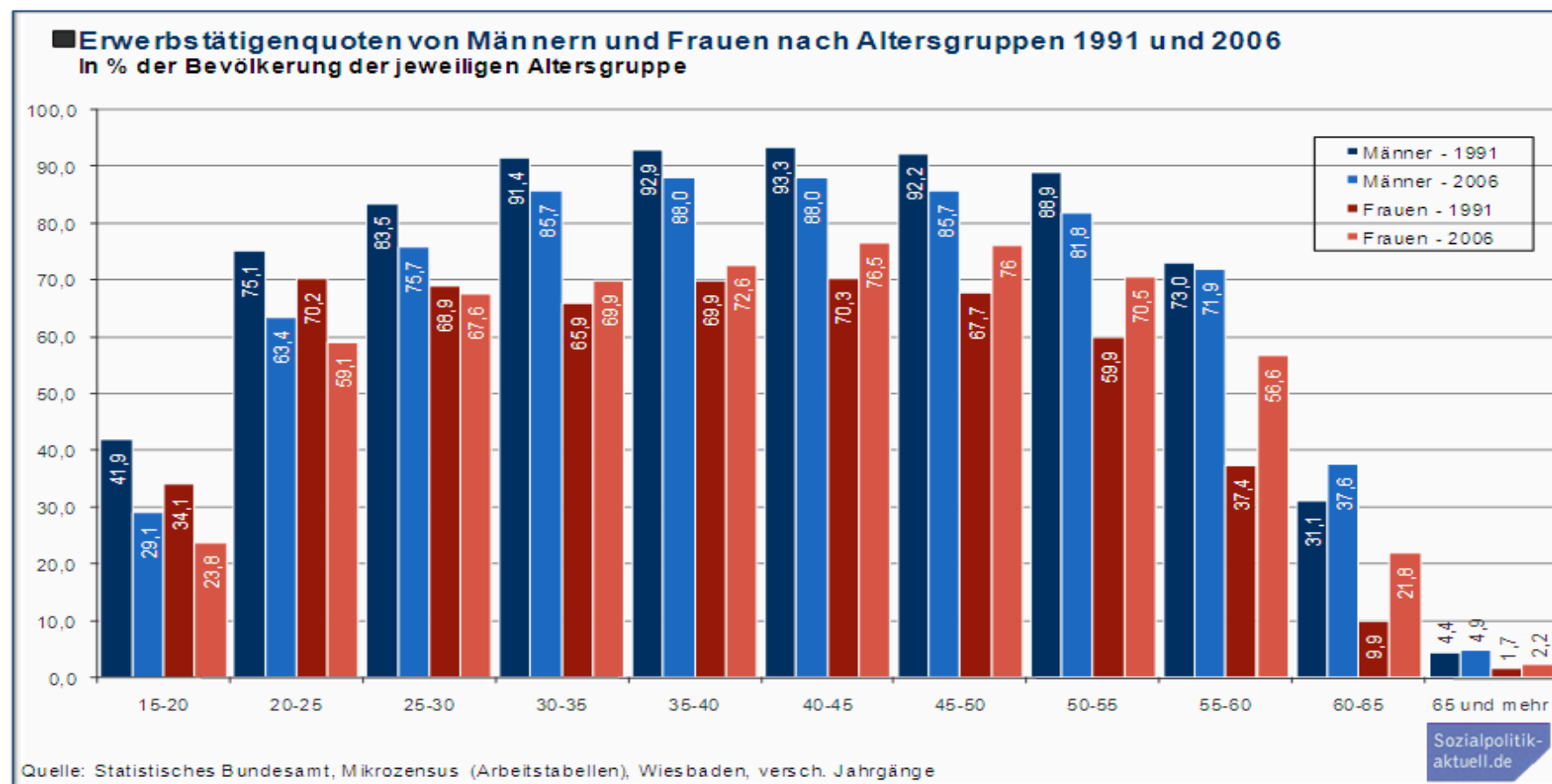
Date of approval	Reference	Voluntary Organization	Project	New amounts	Continuing amounts
2009-2010	IESD1	The Mental Health Foundation	Dementia Choices	51,901	
	IESD2	Trent Dementia Services Developmet Centre (in partnership with the Disabled Living foundation)	An online guided advice tool to support self-assessment and decision-making on assistive technologies for people with dementia and their carers	89,778	
2008-09	2005/062	Trent Dementia Services Development Centre	National Information Resource of Assistive Technologies for People with Dementia		13,528
	2006/103	Westminster Advocacy Service for Senior Residents	Project: Ethnic Minority and Dementia Advocacy Project		54,005

⁵⁶ All data extracted from lists published by the Department of Health 2009:
http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Section64grants/DH_100660

2007-2008	2004/400	Alzheimer's Society	Vascular Dementia Awareness		8,000
	2005/021	Down's Syndrome Association	Improving diagnosis of dementia in people with Down' syndrome		31,451
	2005/062	Trent Dementia Services Development Centre	National Information Resource of Assistive Technologies for People with Dementia		49,841
	2006/103	Westminster Advocacy Service for Senior Residents	Ethnic Minority and Dementia Advocacy Project		42,000
2006-2007	2004/400	Alzheimer's Society	Vascular Dementia Awareness		61,000
	2003/263	Dementia North	Better Management in Dementia Care		11,731
	2004/608	Dementia Voice	Older People and their Carer		38,000
	2005/021	Down's Syndrome Association	Improving diagnosis of dementia in people with Down' syndrome		33,211
	2004/712	Jewish Care	Dementia Development Tear		25,000
	2005/062	Trent Dementia Services Development Centre	National Information Resource of		61,985

			Assistive Technologies for People with Dementia		
	2006/103	Westminster Advocacy Service for Senior Residents	Ethnic Minority and Dementia Advocacy Project	40,005	
	2004/545	Westminster Advocacy Service for Senior Residents	Develop the National Dementia Network Project		41,000

Table 2: Employment rates of men and women, different age groups



Statistisches Bundesamt: <http://www.sozialpolitik-aktuell.de/index.php/arbeitsmarkt-datensammlung.html#I.4>