



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

## **The role of informal care in long-term care**

### **National Report France**

Michel Naiditch

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European Centre for Social Welfare Policy and Research (AT) • Ecole d'études sociales et pédagogiques (CH) • University of Southern Denmark (DK) • National Institute for Health and Welfare (FI) • Institut de Recherche et Documentation en Economie de la Santé – IRDES (FR) • Institut für Soziale Infrastruktur (DE) • Wissenschaftszentrum Berlin für Sozialforschung – WZB (DE) • CMT Prooptiki Ltd. (EL) • University of Valencia – ERI Polibienestar (ES) • Studio Come S.r.l. (IT) • Stichting Vilans (NL) • Institute for Labour and Family Research (SK) • Institute of Public Health (SI) • Forum for Knowledge and Common Development (SE) • University of Kent – CHSS (UK) • University of Birmingham – HSMC (UK)



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# 1 Introduction and Background

## 1.1 What is understood by “informal care” and “formal care” in France? What are the main definitions used to distinguish between the informal and formal care sectors?

Informal care in the sector of LTC is understood as care delivered at home primarily by family members of disabled persons, more than by “life related” persons, or by volunteers from a non-profit association. Informal carers in France are usually understood as “family carers”. This lay view fits with empirical data as this last category represents 90% of the former one (Dutheil, 2001). So time spent in helping a relative or a friend when the latter is in any type of “residential institution” is not considered as belonging to informal care even if the time duration spend and the care provided may be considered comparable.

In this general understanding, Informal carers are also supposed not to be professionals and not to be pay for their caring work as opposed to formal care being services provided by paid, trained, licensed and qualified professionals and somehow controlled and/or supervised) professionals.

But more and more, informal carer may benefit from training and education in caring (Alzheimer’s carers) and through the new care attendance allowance called APA may also be paid and/or be salaried by the cares old person. So informal care does not entail as it used to be before the 2000, a clear-cut with its formal counterpart as it used to be the case ten years ago.

This blurring of frontier is enhanced by the fact that in the “real life”, both type of care are frequently intertwined and interact in a rather complex manner (complementation and/or substitution) giving to informal carers in France an ambiguous position in terms of role and status which makes the framing of support measures a difficult task to conceive.

## 1.2 Cultural and political context: How are issues of informal/family care and LTC services discussed?

Caring for a relative is mainly considered a duty nobody should escape from, a form of “moral obligation”. It is conveyed in the expression “family solidarity” and informal carers used to be for a long time called “natural helpers”. All surveys show a strong commitment of people for caring for their old relatives. In a 2008 survey (Institute Bva, 2009), 82% of the respondents declared that in case of disability, they would not place their relative in an institution but rather try to help them financially or even care for them. These results are in line with results (85%) coming from the Eurobarometer survey (Repkova, 2009).

But economic determinants are also at stake and may interfere negatively with these “good will” as demonstrated by the poor intake of the attendance scheme (PSD) that existed before APA as the former

allowed the state to recover on the wealth of the old cared person, a means tested amount of the publicly granted funds.

In the vast majority of cases, caring for a relative or a friend takes place at the beneficiary's or at the informal care's home and thus tends to be considered a "private affair". This does not entail that public authorities should not intervene in this matter. In fact, according to the quoted survey, 52% of the population share the opinion that the state should bear main responsibilities for LTC (compared to 16% for the family) in order to organise and fund care provision. This correlates with the fact that 79% of the respondents in Eurobarometer (Repkova, 2009) declare that "caring should not lead them to sacrifice, to some extent, their social and professional life".

Contrary to the prevailing situation in the French health care system or in the LTC system of some European countries (UK, DK for example), as "voices", older people are no politically strong group. This is the case at individual level where informal carers are not actively involved in the needs assessment process where their needs are not taken into account but also in the care plan construction with no legally binding obligation to ask for their opinions. The same situation exists when they are in need of respite care (CNSA, 2009).

This is also the case at collective level: as in many European countries, French informal carers have been, for a long time considered by policy and law makers implicitly as an "almost free resource" in providing home services, rather than as a group whose needs and expectations should be acknowledged and answered by providing them with the specific resources their caring activities deserve. Only when informal carer's availability began to be an issue were they envisaged as a scarce resource that could be of interest and thus deserving a specific policy.

Numerous groups consider themselves as natural advocates of older persons at large including thus also those without care needs. This is the case of groups of pensioners, family representatives, not for profit groups of volunteer organisations ...). But other organisations with a more specific focus on LTC issues are competing: for example, groups representing residents of nursing homes or families of older people being cared for at home). In this regard one specific organisation of informal carers (<http://aide@aidants.fr>) is trying to unify families at the 'ground level' by directly supporting them with various tools but very limited means and families members. So the number of groups does not translate into power in the political bargaining as each one usually competes for their own "specific clients" instead of building a common platform. Only at collective level the powerful lobby of families of Alzheimer's patients and linked organisations seem to have attracted most public compassion and gained strong political support and media attention. It has been pushed through the third Alzheimer plan actions toward innovations to support families. This interest in supporting Alzheimer families may act as a trigger for all informal carers. But it may also deter their generalisation by capturing all resources that are still scarcely distributed among the general carer population.

Finally this collective weakness may also come from the fact that social care and medical care are not valued at the same level, the latter being considered as a right of all citizen made effective through the national mandatory health insurance scheme while the former relates more to social assistance which carry a negative image which is enhanced by the negative representation of the ageing phenomenon.

So regarding policy aiming at supporting informal carers France faces an ambiguous picture: Even when regulators acknowledge that carers' health may be at risk as they carry a caring activity carry the risk of a heavy burden, they continue to blame them if they do not take their ("normal") place in the caring process (Ennuyer.2008). So the rhetoric about supporting informal carers runs parallel to an attitude of taking their presence as granted and 'shaming attitude' when they do not comply to social norms.

Even if support actions for informal carers can spare money for funding the LTC system, formal carer resources will still be necessary as expected needs of older people are supposed to raise (). So the debate of what kind of policy to support informal carers is closely linked with the issues of funding principles for the LTC system and its optimal level. Regarding specifically the issue of informal care, this debate includes the choice of the care attendance scheme (cash for care) with regard to the way it can (or not) be turned into financial resources for informal carers but also the control of its use with regard to the quality of services (see Naiditch/Com-Ruelle, 2009).

### 1.3 Legal aspects of care

According to the French civil code (JORF), children have the legal obligation to supply economic support when their parents cannot financially face any needy situation with obligation extending to other family members (next generations + step family). All types of needs are concerned in particular those relating to disability. The article L132-6 of the family and social action code stipulates that state assume responsibility and substitute for the family only if they are unable to pay. This gives the obligation for the potential beneficiary to prove family's inability to pay (which may be not easy and places him in difficult situation if he wants to avoid conflict) In addition and in order for an older person to benefit from social welfare, she must first use 90% of her revenue to pay for residential stay (the most common case of social intervention), keeping only 10% for themselves (with a "minimum" of €75). Also, the remaining home member of the household must have a "minimum amount to live" of €620. This law is not very popular and proven to have an anti-redistributive effect (Gramain/Wittwer, 2006).

Family direct financial contribution concentrates on payment for residential care (Accounting court, 2005). In 2004, the national fund for retirement pension (CNAV) estimated that the average out-of-pocket money of an older person with care needs over 80 exceeded by €450 their monthly revenue (€1,150) compared to an average monthly cost for a residential home of €1,600 (Brun, 2007). Also in 2007, the average monthly amount to be paid by a resident was estimated at €1,800 to compare with the mean household net revenue: €2,050. A recent report of the "social affairs general inspectorate (IGAS, 2: 2009) estimate that average level of family payment was € 2200 with very large geographical variations, showing escalating family contribution to residential costs. But family assumes also an important share for home care (Accounting court, 2005). Also, notwithstanding informal carers' effective financial contribution, the costs of the services they deliver home has been estimated as ranging from €6.1 to 8.3 billions (to compare with the € 3.5/4.7 billions of range of professional services), thus accounting for more than 60% of the cost of all services (Davin et al, 2008).

## 1.4 Main component services in the national LTC system

### 1.4.1 Historical background

In France, the LTC system has two historical characteristics:

- First, for a long time the LTC system (with its medical subsystem coined *medico-social*) and the health system have been separately regulated, organised and funded even if they are in constant interplay when curing and caring older people with care needs. The French health care system has primarily been organised around acute public hospitals with a relative strong system of state central planning and regulation. But since the last fifteen years, there is a constant trend to delegate to hospital (ARH) and since 2010 to health regional agencies (ARS) more responsibilities in planning, organising and regulating hospitals. The primary care sector is still regulated separately from the hospital sector, mainly by the national health insurance Agency (CNAM), even if the central state has a growing control on its regulating body. Also there exists a strong for-profit hospital sector with working specialists as in the ambulatory sector, being paid fee for services. So coordination between primary care secondary and tertiary hospital sectors is weak despite efforts to organise them in networks based on a more territorial approach (JORF, 2010).
- The second specific characteristic of the French LTC system consists in the “age barrier” dividing the disabled population into two groups: the first one consists in persons less than 60 called “handicapped” and the second one of those above 60 (and called “dependant”) with two specific policies and organisations for each population. Policy actions targeting the dependent elderly population (more than 60) remained for a long time rudimentary. Disabled and aging persons used to be easily placed in LTC institutions some time acute, but more frequently nursing homes poorly staffed because of a dramatic lack of specific funding. Institutionalisation also dominates also because as disability was mostly considered linked to chronic conditions, the medical approach was prevailing. And even if measures aiming at keeping elderly persons in their usual home environment had been on the social policy agendas for more than 50 years (Rapport Laroque, 1962), no specific policy targeting globally LTC existed and more specifically, home care until the beginning of 2000, at the exception of the development of “housekeeping aid” in 1981 and since 1983 “geriatric coordination” which are networks set up at departmental level in order to connect the primary and the secondary sectors.

A dramatic change happened in July 2001 when after a five-year experiment of a first version of care attendance (called PSD) dedicated to persons aged more than 60, the present attendance allowance scheme called (APA, Personal Autonomy Allowance;) was passed into legislation (JORF, 2001) and launched in 2002. It was followed by a series of laws, passed in a five-year period, and marking a renewed interest in policies specifically aiming at considering the LTC system as a whole with a strong focus on home care while simultaneously trying to reinforce the level of staffing and management of nursing homes.

- The Law of 2 January 2002 (JORF, 2002) reshaped the way medical-social establishments (LTC wards in acute hospitals and nursing home called EPHAD) were to be authorized, managed and staffed.
- The Law of 13 August 2004 (JORF, 2004: 1) for “local liberty” gave major responsibilities to the “General Council” (the executive body of the local political level named “department”) to plan, organise and regulate policies related to residential and home care in relationship with the state

division of social affairs either at regional (DRASS) or at departmental (DDASS) levels. This “delegating process” has led to a complex mix of funding mechanisms and to a blurred balance in responsibilities between the different political levels involved. For example, even if the General Council is supposed to take the leadership in planning and regulating the LTC system through the “departmental gerontology plan”, its real capacity is frequently challenged as some planning process also exist at regional level (PRIAC, CROSMS) with other decisions being made at national level (DGCS) regarding nursing agencies and some type of residential homes. Notwithstanding that General Councils must also deal with market forces put in place by the Borloo laws (see below) and has no control on self employed physician working in the primary care sector.

- The Law of 30 June 2004 (JORF, 2004: 2) called for a national day of solidarity where all collected social contributions related to work but also other types of revenues were to be used to fund extra measures for the elderly or handicapped persons. The same law called for the creation of a specific independent agency called CNSA (national agency for autonomy and solidarity: (<http://www.cnsa.fr/>)) to be the “coordinating body” at national level, of policies targeting all types of disabled population. In this regard, the law for ‘the equality of rights and opportunities, participation and citizenship of disabled persons’ voted on 11 February 2005 (JORF, 2005: 1) was considered as marking a genuine conceptual turning point in that it stressed on the necessity to create a converging process, in order to reconcile separate policies regarding disability issues (with the hope that the more favourable legislation of handicap in term would trigger the one directed at older people with care needs). It thus called for a LTC insurance scheme (called “fifth risk”) that would apply to any disabled person not depending on age. The “Gissereau report” (Gissereau, 2007) financial projections which boosted a hot debate.
- Shortly following the launch of the CNSA in 2005, another national agency called ANESM was put in place in 2007 in order to organise quality management at national level for all home services agencies and nursing homes (<http://www.anesm.sante.gouv.fr/>).

These laws were completed by numerous plans. The first plan (*plan for ageing and solidarity with elderly*) was drafted in November 2003 shortly after the August 2003 “heat scandal”. It was followed by a second one in 2006 based on a report “Building the free choice scenario for old disabled persons” (2006). In regards to informal care, one should also mention the “Family conference” of June 2006 which aimed at facilitate inter generation solidarity while supporting informal carers and specifically the ones caring for Alzheimer’s patients (<http://www.plan-alzheimer.gouv.fr/>).

Undoubtedly, all these legal regulations tackled the problem of LTC globally and called for a better quality of services mainly through the reinforcement of quality assurance methods and of the professionalization of all LTC specific providers. Rhetorically at least, regulators stressed the crucial role of the families and (to a lesser extent) the support they needed.

But this evolution also should be placed in the broader context of the *employment policies* which, from the Seguin law of 1987 until the first Borloo law of July 2005 (JORF, 2005: 2) followed by a second one issued in 2009, aimed at developing employment in the “home services sector” (to be understood as all types of services delivered at home, thus including “leisure services”. The creation of a specific governmental agency (ANSP: <http://www.servicessalapersonne.gouv.fr/ANSP.cml>) aiming at developing this labour policy testifies this strong political orientation. Another one is the development of market mechanisms in order to enhance efficiency of LTC services providers through competition between the long-standing public and private not for profit agencies with the new comers or for-profit organisations in the field.

In this regard fiscal incentives were put in place and directed not only to LTC provider organisations but also to the old person considered as a potential for employers in order to give more opportunity to buy home care services. These fiscal incentives were not specifically targeted towards services addressing the needs of the frail old and disabled population as they apply for any type of services when delivered home (even if there exist some specific ones in the case of an older person with a disability).

#### 1.4.2 Funding and reimbursing for health and social care in France

Funding for health related services comes mainly from social security contributions linked to employed work, but also from a portion of a more general social contribution (CSG) which is similar to a taxation as it is based also on other types of revenues (assets, stocks). Services delivered by acute and intermediate care hospitals are reimbursed by the mandatory national health insurance agency (CNAM). Services delivered by Hospital at home delivering care to severely chronically ill and/or disabled by the rehabilitation hospitals and medical and nursing care delivered by self employed nurses or nursing home agency (SSIAD) are also covered by this system. The reimbursement average level was 75.5 % of total expense in 2009 (HCAM: [http://www.sante.gouv.fr/htm/dossiers/hcaam/rapport\\_2009.pdf](http://www.sante.gouv.fr/htm/dossiers/hcaam/rapport_2009.pdf)).

There exists also a “voluntary based” system of competing (for and not for profit) insurances, covering 85% of the population (2010) and which complement reimbursements (13% of overall expense) by the CNAM. Also, a specific publicly funded scheme (called CMU/CMUC) enable people with revenue below a define threshold level (650 € in 2010) to be reimbursed for health care with overall expense of 5%. So if only 0.1% of the population was not insured in 2008, 6% did not benefit from any complementary insurance. So even if regarding the services publicly reimbursed, the system can be considered as universal, it remains that access is not free at the point of delivery with more and more difficulties for a significant portion of the population in accessing well-reimbursed specific services (surgery and out of hospital specialists); thus with a much higher level of out-of-pocket spending which overall amounted to €2 billion in 2008 (HCAM, 2009).

For “social services”, funding comes from the national health insurance fund, the central government including the solidarity funds, local taxes and users charges. All sources (except those related to hospital and ambulatory health related services) are then gathered by the CNSA in order to be redistributed to the local level (general council and regional health agencies since 2011). The overall budget of CNSA amounted € 19 billion in 2010 for both the health and social services. But the overall LTC budget was estimated according to latest data (May 2011)<sup>1</sup> to be € 24 billion based on the method of the accounting court (Cour des comptes, 2010) thus corresponding to 1.3% of GNP (compared to 10.5% for health).

There is no LTC insurance scheme but a care attendance allowance (APA), for which all people older than 60 are eligible. APA is granted based on the results of a national disability assessment tool called AGGIR. This tool classifies OPs according to their disability level into one of 6 different groups (GIR groups). Only a person belonging to group 1 to 4 will be entitled to the allowance. A special commission of the General Council for each assessed person APA twill then set the he granted amount according to the assessment result and knowing that for each group there exist a ceiling amount. Even if eligibility is universal, the amount granted is means-tested as there exists a mandatory co-payment based on revenue (except for people with a revenue below minimum pension; see appendix 1).

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<sup>1</sup> <http://www.dependance.gouv.fr/Consulter-les-documents-des-quatre.html>.



The care plan is set according to assessment results but the choice of services is not only based of the theoretical level of disability but on the performance level of the old person which takes into account the family's "caring capacity" and also housing conditions.

For less disabled old person (GIR5) other collective funding may take place coming from the national fund for pensioners (CNAV); or, for specific subpopulation from the national health insurance agency or other complementary health insurance companies or even some General Councils.

At the end of 2010 (Debout, 2009), 1.2 millions older people with care needs benefitted of the scheme with 62% leaving home with overall amount of € 5.1 billion (2/3 by general councils, 1/3 by CNSA). Overall surveys have shown (ERS) that APA covers less than 80% of the needs defined in the care plan for highly disabled population. Furthermore, the care plan itself in general does not cover all real needs (Espagnol, 2008).

Lack of collective funded needs or difference in the way services are reimbursed can thus create tension from the service user's perspectives: either because the amount of granted services do not meet all necessary needs with only the more wealthy person being able to cover the gap ; or because the care pathway (which is not standardised) lead to different profiles for service's use according to the same needs: for example personal care can be met in certain areas more easily (professional availability) and with lower out of pocket money (financial availability) as they are on average better reimbursed by CNAM (100% for chronically ill) while the same service provided by a home helper may be less available and will entail a higher level of out of pocket money.

#### **Nota Bene**

Handicapped and older people under 75 years of age are entitled to a different attendance scheme called PCH where needs are using a different instrument called GEVA. This process results for a comparable level of disability in a higher average amount than APA (Debout, 2009). That is one reason that to achieve a convergence between these separated systems more funding would be needed, which in our time proved to be difficult.

### **1.4.3 Provider organisations**

There exist more than 30,000 organisations providing care to frail older people in the LTC sectors ( home care agencies, nursing agencies, all type of residential care and which are regulated under either the health or the social legislation.

In 2008 (Bertrand, 2010) 2,095 home care agencies (which funding and regulation depend on the health legislation) delivered predominantly (96%) home care to older people (9,500 >60; 80,000 > 75). They were staffed mainly (75%) by employed assistant nurses delivering most of the personal care and home help and aid. Free nurses under contract with the agencies provide also personal care while delivering technical nursing services prescribed by physicians.

Hospitals at home (HAH) deliver medical and social care to disabled older people who are chronically ill. There exist 164 providers delivering care to 4,500 older people with care needs with an average stay of 20 days (Chaleix, 2009; Afrite, 2009).

Regarding the home sector (Prévoit, 2009: 1, 2) at the end of 2007 there exist 10,300 residential homes corresponding to 657,000 residents (710,000 in 2010). Among these residential homes, 6,750 (67%) called EPHAD were legally authorised, to operate in the sector of frail and/or disabled older persons as they follow legal requirements regarding staffing (management and health and social professionals) and principles of organisation (see Naiditch/Com-Ruelle, 2009). The majority of them were public (56%); the others either private not for profit (27%) and for profit (17%). In 2010 EPHAD delivered care to 540,000 older people among which more than 50% were highly disabled (GIR level 1/2) and with an average age when entering of 84 (see <http://www.dependance.gouv.fr/>).

Home help services (IADL) are delivered by home help agencies. They are numerous (around 20,000) and heterogeneous, some being very small, other quite big. In 2009, the majority (65%) were managed by private not for profit organisations having a long-standing record in this field. The others were either public (25%) or private for profit (15%) organisations being relatively new comers (1996) in this field but supposed to boost the sector and to bring more quality through competition.

All these agencies are networked through their corresponding umbrella organisations with different labour legislation but also in terms of legal obligation in training their employees. Regarding profit agencies, their specific umbrella organisations called “Enseignes” mainly developed by insurers or banks were supposed to supervise their work and make them benefit from their “claimed expertise” in quality management and efficiency but with mixed results (see Naiditch/Com-Ruelle, 2009).

#### **1.4.4 LTC Services utilisation and regulation**

If a person qualifies to APA after s/he has been assessed, s/he can either decide to have his care managed (whether in institution or at home) by a professionals working on behalf of authorised agencies (in kind benefits); or s/he may decide to use APA money to hire and pay a home carer to provide home services (in cash benefits). In the latter case s/he can directly choose and employ a home carer or hire him/her through a special intermediary agency (Mandataires).

In both cases, s/he can benefit of a system of vouchers with large fiscal deduction (see paragraph 2.4). Because of these social charges exemption (as employer) and tax reduction (as a tax payer) the average hourly cost of the directly employed home worker (9 €/hour) is less than if he was hired through an intermediate agency (12 €/hour) and much less than if services are delivered by a salaried worker working on behalf of an authorised agency at the cost of 20 €/hour (Devetter, 2008). But in the latter case, local authority can check if the delivered services are in line with the care plan. While in the two former ones and even if it is the responsibility of the intermediate agency to do so, there exists only a weak control, mostly checking that the cash has been really used for the care of the old person (Experts).

A home care worker, whether he is salaried by an agency or employed (directly or indirectly via an agency) by the older person him/herself will thus face very different situations regarding social rights, training and education, supervision (Cerc, 2008). But also his working conditions may not be the same. When he is salaried, surveys have shown that his activity was not constant during the year. His work was very fragmented with multiple employers while having to care for many older people with care needs with few hours for each, still resulting in a less-than-full-time job (Cerc, 2008). These poor labour

conditions are reinforced by the low services tariffs, leading to low wages even for full time licensed workers (120% of the minimum salary) (Bony, 2008).

So home worker (and frequently the most qualified ones) prefer to be directly employed as they will have to care only for one or Two clients with more time dedicated to each as their individual employer can pay more (because cheaper) hours. This will result in higher revenue notwithstanding they can also sometime benefit of grey money in case the older person can pay for the (non APA funded) remaining needs (experts). It has been estimated that in 2008, 85% of new home-helpers of disabled and frail OPs chose to be directly employed by them with a low use of intermediary agency (Jany-Catrice, 2009). But many licensed home worker may be incline to leave their jobs in home agencies in order to work in EPHAD were working conditions, supervision and access to training are considered to be better (Experts).

There also exist large geographical disparities in agencies availability and access. But also in the ability of beneficiaries to pay for that social welfare (either national and/or departmental can partially compensate for persons with low revenue (means-tested).

## **1.5 Data on Informal family carers and other informal unpaid carers**

### **1.5.1 Source of data**

The first reliable survey on the disabled population at large was set up in the beginning of the 2000 and based on a national representative sample with a reliable data collection process based on answers to a detailed inquiry. Results came from a sound statistical methodology (HID survey 99: see ERS 94). It was complemented by the Health survey in 2002-2003 using also a population representative sample. But resulting demographic projections (Bontout, 2002; Due, 2006) done for various time horizons (2010/2030/2050) and according to different disability evolution scenarios (life ending compression or not), tend to largely underestimate (even in the worse case) the known 2010 data regarding the number of disabled old persons benefitting from APA for which there exists a good system of bi-annual monitoring by the statistical service of the ministry of health and social affair (DREES).

Regarding old disabled persons and their informal carers the most recent national survey representative of the French population was collected in 2008 (HSM and HSA) with first national estimate issued in 2011. They can be compared to data coming from other surveys (BVA, 2009; Macif, 2008; Credoc, 2006) done on behalf of different stakeholders some based on representative samples but with some limitation in their methodology.

Regarding service's users and their informal carers data also come from less recent (2003/2004) survey on the behalf of DREES (Petite, 2006; Rivard, 2006; Campeon, 2006) and based on representative samples of household in which a subsample of main carer's have been interviewed. There exists also more recent qualitative survey supplementing the former studies on specific points. These studies altogether give relatively coherent results that are based on evidence.

## 1.5.2 Main Results

### National number (estimate) of “older people in need of care” living at home

According to 2008 survey, 4.1 million persons aged more than 60 (representing 31% of the 60+ population) needed some type of care. Among them, 3.6 million received informal and/or informal home care which means that at least 12% had uncovered needs. This case corresponds to older people living alone a situation that, according to projections, is not going to deteriorate in the coming years (Gaymu, 2008). Also among cared old persons, 1.2 million depended on ADL services.

In this regard estimate number of APA “potential beneficiaries” in the total population was 1.3 million, in line with the 1.2 millions of APA beneficiaries in December 2010. The estimated number of people with care needs in level GIR 5 was 595,000 (to be compared with the 3,000,000 people receiving home help (only IADL) services that are funded by various bodies (CNAV, CNAM, General councils).

The estimate number of “regular informal carers” was 4.3 million in 2008, 54% were female. Their average age was 58 with 46% being retirees or about to be, 39% in the labor market; 6% out of work and 9% with another status (unable to work). Also 9% could not manage to have some respite while a large majority of them declared having this need.

### Informal care for APA beneficiaries

Informal care takes place in the vast majority in households composed of a couple without children: 60% for the age group 60-74; 32% for the age group 80+ (Delbes/Gaymu, 2003).

75% of APA’s beneficiaries received care from one informal carer alone (7%) and/or with the help of professionals (68%), with 25% cared for only by professionals. 71% receive help only from one informal carer (family in 86% of cases). In the latter situation, the carer is a child (69%) or the spouse (26%, of which 47% wives).

41% of informal carers are in paid employment (90% of men full-time employed, compared to 75% for women). 40% are retirees. Only 8% are paid for their care (88% women).

There exists a complex relationship among siblings in terms of complementation and substitution and type of tasks (Fontaine, 2007) and the configuration of help is different for older people suffering from cognitive impairment (Baguelin, 2008). Children who are not employed tend to care more and to become a main carer.

The percentage of women delivering informal care was around 60%, but men represented 55% for those over 75 years of age (probably due to the higher prevalence of Alzheimer’s and related diseases in women). In 2003, the mean average age of informal carers was 58 (70 if spouse and 51 if children).

The average mean time of care was 5.5 hours/day in case a child is the main carer, but 8.5 hours if it is the spouse. If only one informal carer is involved, the average hours/day delivered are 5 compared to 2.5 if two informal carers are involved. And informal carer tends to deliver twice as many hours than a professional (for a similar case) and 4 times more when s/he works with a professional.

Revenues: according to surveys the mean revenue of an informal carer is not significantly different of the general population. But high CSP level are more prevalent in informal carers (42%) than in the general population (32%), while being equal for low and middle levels workers Pensioners are less represented (14%/19%).

A clearly gender-specific distribution of working tasks can be observed: women care for twice the time of a man of the same generation; while men concentrate on paper work and external tasks, women tend to take over the domestic tasks. Also, if the older person in need of care is male, his wife will take on care responsibilities in 70% of all cases, while in the reverse situation only 30% of spouses will care for their wives. In cases where there is more than one informal carer, the spouse concentrates on ADL tasks while children take over social rights management and paper works. When both children are involved, females focus on personal care while male tasks concentrate on social rights.

## **2 Links and interfaces between informal carers and the health and long-term care systems**

As acknowledged in the first paragraph, until now there existed no policy to support informal carers – if we define such a policy as a coherent set of various types of measures, addressing consensual main issues placed at high level on the political agenda, with respect to the “social treatment” of a target population and with appropriate funding. That is precisely what the family conference of 2006 aimed to impulse by building experiments regarding support of families as a starting point through the 2008/2012 Alzheimer plan. However, the rhetoric about the necessity to support the family stands along with the fact that families continue to be considered more as a (cheap) resource, rather than as a social group with collective needs linked to their caring task and thus deserving specific support. So what really exists is a set of “various tools” put in place sequentially without a clear overall vision and logic and no adequate funding scheme that could ultimately serve as milestones for such a policy

### **2.1 Policies for informal/ family carers of disabled people and/or elderly people**

#### **2.1.1 Source of data**

Two surveys facilitate comparisons concerning the use of services for APA beneficiaries, thus showing the links and gap existing between informal and formal care. The first survey compared the situation in the year 2000 (before the implementation of APA) with the one in 2002, i.e. one year after it the APA had been implemented (Kerjosse 2003; Bresse 2004; Bresse/Dutheil 2004). The second survey in 2003 (Petite, 2006; Rivard, 2006; Campeon, 2006) focused on the differences in the service mix between different types of care that occurred within a two-year period. It thus also provides information on informal carer’s perception and the level of care burden.

It should be considered, however, that both these studies relate to the period 2000-2003. In particular the declared statements of informal carers are to be qualified in a context, in which policies targeted on the direct employment of domestic care workers had only just started. The services analysed were thus to a large degree those delivered by traditional public and non-profit home care agencies.

### 2.1.2 Results

65% of the population over 60 (9.3 million) who had not received any type of care before 2000 experienced no change two years later, while 20% who had received some care before 2000 continued to receive it in 2002. As a result, only 15% of those who had not received care before 2000, reported a change in their caring status.

*These results show that the introduction of APA, which allowed beneficiaries to use more professional services, did not reduce the volume of care provided by informal carers, but it had some impact on the type of delivered services:* In 75% of all cases, older and disabled persons still benefited from the contribution of their informal carers whose average care amount still superseded by 3 the contribution of formal care. Also, the number of involved family carers enhanced dramatically (more than doubled).

*Informal carers' relative contributions were estimated at 60% of all provided services. And even if more care was given in a mixed (formal/informal) configuration, total time of informal and formal care did not add up showing that both complementation and supplementation takes place in the care distribution.* More precisely, the type of care delivered by informal carers changed in 17% of all cases resulting in:

- more informal care in 50% of these cases;
- less informal care for 25% and
- the same amount but with a new distribution of tasks in the remaining 25%.

If a shift happened, it was mainly domestic tasks that were turned back to professionals. Families tend to concentrate on ADL tasks while professionals target IADL and sometimes personal care. Household chores (domestic aid) is the key area where most of the substitution has taken place, while the informal carer still continues to be highly involved in personal care. Less frequently, if an informal carer intervenes in personal care, s/he also tends to carry out many of the other IADL tasks while formal carers concentrate on the most intimate elements of personal care.

Only 11% of family carers were paid for their care (8% when they worked alone, 3% with the support of a formal carer). In both case, the old cared person was highly disabled but with a specific gradient: when both types of carers were pay, high disability was more frequent (77%) than when the family carer (68%) or the formal carer (57%) stand alone.

Also on the individual level, data show that services included in the care plans do not cover all needs:

- Services included in the care plan were usually more extensive than what could be covered by APA. In 2007 (ERS 748, Bérardier) on average 28% of the amount of care stipulated by the care plan reached the ceiling for APA funding; 44% for the group with the highest level of care needs (GIR1). This means that real needs are not entirely covered by APA, and that this gap rises with the disability

level. For residential care, costs of the services covered by APA and included in the care plan reached the ceiling in 32% of all cases (28% for GIR1/2; 58% GIR3/4).

- These gaps are higher for women, bachelors (with less probability of having a family carer) and long standing beneficiaries of APA. Also there exists a social gradient in accessing and using APA funds “optimally” and also in the distribution between home and residential care. In this regard, older people with care needs who used to receive informal care before APA and switched to formal care alone, while they experienced (on average) a growth in their disability level, received less formal care hours than before, a phenomenon which probably relates to the inability of APA to cover for all costs of necessary care.
- Also and with respect to the population of highly disabled people, the declared “caring time” in cases in which family carers were paid largely superseded the time funded by APA, once more showing the gap between publicly funded and needed care, with family carers having to bridge this gap.
- If we look at the overall financial impact for users, as publicly funded social services are far from covering all real needs, it is up to the older person or his/her family to cover the gaps from his/her own income or savings or assets. It is even harder to quantify how much households spend on “undocumented” care which are services not included in the care plan but corresponding to real needs. Nevertheless it has been estimated (same sources from May 2011) that overall out of pocket money for users and their families and linked to disability amounted to € 8.4 billion among which a large amount (€ 4.8 billion) was used to pay a fraction (58.5%) of overall housing cost (€ 10.1 billion) in nursing homes. Overall out of pocket money linked to related care services amount to € 0.9 billion for nursing home residents and € 0.8 millions for home residents but with large inequalities regarding revenues and geographical locations. To these private expenditures one should also add the “hidden costs” corresponding to all caring tasks (services in kind) delivered by informal carers, 90% being family carers and estimate to be 9Billions Euros (Accounting court, 2010). Also health related costs paid by out of pocket money has been estimated to be € 1 billion. So overall private costs amount to approximately € 18.4 billion. Finally if one adds up all costs (public and private), the real cost of LTC services amount to € 42.4 billion which represent 2.3% of the GDP and fall only minimally short if compared to the average level of expenditures for LTC in Nordic countries.

The above mentioned gaps may be linked to the following reasons (Experts):

- First, as the volume and the disability level of disabled persons are growing in a constraint budget, as financial transfers from the central government do not cover the real social needs of the local population and as their political and legal capacity to levy taxes is weak, General Councils tend to be “conservative” in the delivery of funds they are responsible for.
- Second, all APA beneficiaries with revenue above the minimum pension (€640 per month) have to contribute with a mandatory copayment and this payment must be effective before the APA funds are granted and used. As the beneficiary’s capacity to pay is at stake, the level of services is often adjusted to this capacity during the assessment process, resulting often in less service hours being granted. But the discrepancy may also stem from the fact that family contributions in kind are considered to cover some of the necessary services, i.e. less services will be included in the care plan, as the family is supposed to bridge the gap either in kind or in cash.
- APA was also put in place to cover previously uncovered needs for the GIR4 population (with lower caer needs) that had previously – though not correctly – been covered by voluntary contributions (CNAV, General councils). With the actual coverage level by APA for GIR4 in fact having been set too low and the exit of previous funding (now partly covering GIR5 population), results in yet another gap.

- As quoted before, fiscal incentives have been considered by the accounting court (Accounting court, 2005; IGAS, 2010) and by the general social affairs inspectorate (IGAS, 2009) as having a strong anti-redistributive effect and thus as increasing the ‘service gap’ between the best and the least well-off.
- Finally, the responsibility to coordinate the overall delivered services remains frequently up to the family even if services are delivered by workers of authorised organisations as the latter are only weakly controlled either internally or externally by local authorities (see Naiditch/Com-Ruelle, 2009). But as informal carers are usually not considered to “intrude” into the professional domain – which may be necessary to carry out their supervising task – they are often in a difficult position to assume this role, thus enhancing their care burden. Case managers could be a possible solution that different experiments are trying to assess (see MAIA good practice example).

### **2.1.3 Social welfare: The roles of the State, agencies and general councils**

For poor people, APA may be combined with other funds coming from social welfare at national level (minimum pension) or at local level (general council). Also the national health insurance agency target specific sub-groups of the population. 2007 data show that 28 of APA’s beneficiaries had a care plan with costs of granted services that superseded the APA upper ceiling amount. In these cases, some General councils and/or municipalities may provide “extra legal” coverage. However, this phenomenon is limited as it does not concern all councils while not excluding extra funding by users.

### **2.1.4 Private insurance**

Data show that the market of private LTC insurance (which constitutes at any rate another form of out-of-pocket payment) is well developed with a total volume of 3.5 million contracts in 2006 (Duffour-Kippelin, 2008). The number of policies is rising quickly: more recent data show that the figures are at 5.5 million in 2010. Still, conditions for provisions from these insurance contracts are very restrictive and usually are provided only in case of very high disability levels and/or for terminal care: only few policies cover costs incurred by mild or medium disability and preventative programs are very seldom proposed.

## **2.2 Positive and negative aspects of care-giving**

### **2.2.1 Health**

The excess mortality rate of informal carers compared to non-caring family members is 63%, and depression prevalence in Alzheimer’s patients informal carers is twice as high than in the general population (Alzheimer Foundation, 2008).

In a population-based survey results show that the compression scenario may be challenged as women experienced a higher level of functional limitations compared to a similar cohort ten year earlier (Cambois et al, 2011).



### 2.2.2 Social life

The quality of social life of informal carers is poor: According to 1999 data, 15% of informal carers declared they could not let the cared person alone during the day with only 40% taking a few day leave. This percentage increases in parallel with disability level. Also 55%, needed to be substitute in order to have a day leave for GIR1/3. 40% of informal carers could not take holidays, this percentage raising to 65% for GIR 1,2,3 but declining to 30% for GIR4. All these data should be considered as “minimum estimate” as it is known that respondents usually underestimate their burden level.

### 2.2.3 Working and caring

While 39% of informal carers declared they were “working carers” (HSM, 2008), in another survey only 2% of informal carers of older people with care needs (GIR 1,2,3) declared to have been forced to quit their job (ERS Debout, 2007) while according to Macif (2008) 11% said they had to find new working arrangements (changing hours, partial time) but without financial compensation and no real involvement of their employers. These data are also in line with the 2008 Eurobarometer data. So caring and working remains often a conflicting issue.

### 2.2.4 Caring burden

According to the above survey, in 2003 48% of main carers declared not being troubled by their caring tasks. 32% declared some wellbeing problems either physical and/or psychological they linked to caring. While 31% declared caring had a positive impact (10% declared both effects). All these figures are “disability level related”: for GIR1/3, 41% said caring had only a negative impact. Furthermore, they are also “generation related”: 32% of caring children declared that caring had a negative impact compared to 37% of spouses (probably linked to cohabitation).

Other frequent types of burden were: physical and moral stress, depression, anxiety, feeling guilty, social isolation, family conflicts appeared at least one time in 75% of cases.

Finally, the frequency of ill treatment has proven to be correlated with the existence of physical and psychological distress states (burn-out syndrome).

## 2.3 Support for family carers

Legal resources (whether in cash or in kind) put in place to help informal carers directly or indirectly are outlined in the following.

### 2.3.1 In cash (indirect) support

The yet quoted attendance allowance scheme (APA) enables beneficiaries to redirect the money they receive in order to pay informal carers (possibly a member of the family at the exception of the spouse/husband. But according to a survey in 2007 (Debout, 2009) only 11% of family carers were paid, 88% of these being female.

### 2.3.2 Indirect support: Fiscal incentives

They are numerous and apply (except APA) for all types of services (Vérollet, 2007; Vasselle, 2007) :

- No taxation of APA amount.
- Social security employer charges: exemptions (15%) for a directly employed domestic worker (or through an intermediate agency).
- The older person and/or his family living in the same household benefit from tax reduction up to 50% of the costs for home care services with a ceiling of € 6,500 (up to €7,500 if above the age of 64 and €10,000 for highly disabled).
- A system of tax credit for technical devices and housing accommodation + the application of the lowest rate (5.5%) of the added value tax (TVA) on their costs.
- There also exists a system of individual prepaid vouchers (Cesu) with a specific type delivered by firms to their employees that are also designed to facilitate direct payment of domestic services. Data show that Cesu's use could lower the cost of an hour of work up to 60% (Dewetter, 2008).

Foregone income for the state linked to these measures has been estimated (Accounting court, 2010) to amount up to €10 billion among which only 30% are regarding services purchased by older people. Also, as all these incentives can be used for any type of services, they mostly benefit to the well off (Gramin, 2008; Cour des Comptes, 2005) creating a social and economic gap between older population groups according to their revenues.

### 2.3.3 Direct support by services in kind

These include measures such as:

- counselling, training and education to help informal carers to perform their caring task;
- work leave
- respite care in order to relieve carers from their caring burden;
- Technical support and housing adaptation in order to provide carers and the older person in need of care with a more secure and appropriate care environment.

Even if these measures to support informal carers are available, no data exist on their real access and, more importantly, the take-up rate.

#### Work leave

In case the health status of the older person in need of care is worsening, one member of the family may benefit of an unpaid work leave (but with no loss of retirement pension rights) for a limited period of time. This leave can not be renewed more than 3 times a year for a total period of 6 weeks (JORF, 2007).

For the end-of-life period and in order to permit one member of the family to participate in palliative care, the French parliament has discussed and voted on a legal right for a 3 weeks period of work exemption with a flat-rate payment of € 47 per day. However, this law has not yet been implemented.

### **Respite care settings**

Informal carers may also benefit from the existence of day care centres and temporary stay in a residential care facility which, however, are only scarcely available: among the total 684,000 places in all types of residential care facilities, only 6,000 are dedicated to day care and 500 to night stay. Only 1% of the 657,000 residents are temporary residents and only about 100 care homes are dedicated to temporary stay (Debout, 2009).

The paradox about these data is that funding planned for a 4-year period in order to enhance the number of day care (+ 12,125/year) and temporary places (+ 1,124/year) has not been consumed.

The main reason for the low use of respite services is that carers often feel guilty leaving their family members in need of care, in particular if they are not convinced of the quality of the proposed services. Furthermore, the older person may not accept to go to the day care centre. For short-term care in care homes the reason for the low offer is more managerial: as it may prove difficult to manage temporary stays with a high rate of turnover in an organisation where “steady full stay” is the rule, care home managers are hesitant to extend places in short-term care.

### **Other types of support**

Technical devices and home adaptation may be funded by APA, partially with co-funding coming from the health insurance agency or complementary insurance companies. CNAV also fund temporary day custody. Again, as the availability of these measures is not well known and as funding usually covers only a small portion of costs these measures are not enough developed.

Other in-kind support such as education, training, supportive peer-groups, psychosocial support, technology (Carré, 2009) are not legally defined. Most of the experiments aiming at supporting informal carers and especially family carers concentrate on older people with Alzheimer’s diseases with the hope that the plan will trigger similar policies for the informal carer population at large.

Finally, no labor policy encompassing measures to allow a better balance between caring and working such as flexible working arrangement has been put in place.

## **2.4 Impact on the care process (old person/informal carer) of support measures**

There are very few data targeting specifically on outcomes for informal carers, at the exception of the already quoted quantitative studies from DREES. Systematic surveys or research using tools such as the Zaritt score to measure the impact on the care burden of supportive measures have not been developed in France. And no administrative data base is available on this topic.

However, there exist some econometric studies using the SHARE data base which help understand how care work relates to health status and to access to the labour market for informal carers (Fontaine et al, 2009; Davin et al, 2009).

Also some excellent monographic studies on the life dynamic of informal carers show how support measures for informal carers may impact on the care and life quality of the old person, but as no specific quantitative surveys target these topics, representative data are lacking.

## **2.5 Preventive and rehabilitative support for carers**

### **2.5.1 Health promotion for carers and older people in need of care**

There are some organisations providing this type of services, in particular Alzheimer families groups, but no publicly available data exist to measure their potential impact. CNAV and the CNAM Health have launched some programmes or fiscal incentives in order to prevent disability and care burden, but no assessment of their impact has been undertaken.

### **2.5.2 Measures to reduce or stabilise the level of care needs**

See above

### **2.5.3 Rehabilitation following acute or chronic declines in health**

Rehabilitation centres are now growing at a fast rate (+8% over the past 5 years). No data exist regarding their specific impact on the care pathway and quality of life of beneficiaries.

## **3 Description of the ‘good practice discourse’**

### **3.1 How and by whom is good practice defined and implemented?**

Good practices regarding professionals and organisations are defined at national level by two agencies: CNSA and ANESM (and to a lesser extent by ANSP and ANACT for home care services). Both agencies are supposed to work in close relationship with specific divisions of department of social affairs (DGCS) and General councils’ services. Professional’s organisations (gerontologists, physiotherapists, managers, public health ...) are also involved in various ways, for example as members of the scientific board of these agencies.

### 3.1.1 Innovation in provider organisation: the major role of CNSA

#### General Background

The CNSA is a national agency that not only acts as a distributor of funds for the LTC system, but also uses its budget as a lever to develop innovative practices and organisations. In 2008, € 290 million were directed toward “innovative actions” related to investments and the modernisation of provider organisations, training and professionalisation of staff. CNSA also collects funds from national programmes in LTC such as, for instance, the Alzheimer plan. CNSA staff can either support experiments (in terms of research and innovation programmes) or give advices regarding their assessment, e.g. helping promoters to identify and fund an assessment team. It also directly supports and monitors at national level various types of innovative experiences that it has initiated through tender processes directed to research actions and using local initiatives. CNSA assumes this “monitoring and expertise role” function through different instruments:

- Enhancing information exchange between promoters about the design and the methodology of the experiments and their assessment;
- Monitoring the experimental period while consulting and supporting promoters;
- Synthesizing results and disseminating information on good practice;
- Transferring reproductive and validated innovation into legislation;
- Helping to monitor the diffusion of innovation on a routine basis.

#### Focus on informal carers

The following experiments, both related to the Third Alzheimer plan (2008/2012) (Mission Alzheimer, 2008) are examples of an “innovation procedure” through similar processes: candidates already engaged in similar actions were selected using specific criteria defined in the respective research tender. Both programmes began in 2009 and are supposed to deliver first results in 2011.

- Certification of a multiprofessional and multidisciplinary point of entry in a defines area (called MAIA: House for autonomy and integration of old age) and dedicated to Alzheimer patients and their families. Each MAIA must network with all professionals and organisations in the area in order that at each point of entry, the situation of the family will be analysed and, according to their specific assessed needs, an answer will be provided by using all available resources of the area and in the same way, whatever the point of entry is. For complex situations, a case manager called “life course coordinator” is to be chosen in order to coordinate the work between the house’s professionals, monitor the care process and be the “voice” of the family (see <http://interlinks.euro.centre.org/search/node/MAIA>).
- The development of multi-faceted respite care platforms in order to simultaneously support the patient and his/her family by using different types of settings.

For the MAIA experiment, a specific support team at national level (CNSA) but also at regional level closely monitor the development of all experiments according to the above process. For the second experience (respite care platform) a team of assessors has been chosen in order to deliver an external judgment, participants being given all freedom at the cost on limited advices.

Among other research programmes for informal carers at large, one consists in experimenting various new education and training programmes for a total funding of €2.8 million. It followed the same bidding scheme with 96 experiments being chosen (see CNSA site).

### **3.1.2 Research**

CNSA also operates in the research area through research tenders with other agencies specialised in research (ANR, IRESP...). Recently CNSA jointly with the Ministry of Health's Research Department (MIRE) launched 3 research bids devoted to quality measurement methods in France and in foreign countries. Some of them are targeting innovations in supporting informal carer's (<http://www.sante.gouv.fr/>). First international surveys on the reform of home care provision and regulation will be issued in October 2011.

CNAV (national fund for pensioners) has also launched, through its research division, numerous studies about informal care and its link with formal carers (Attias-Donfut, 2007; Ogg, 2008).

### **3.1.3 Good practice: The growing role of ANESM**

The first Professional practice guidelines (PPG) have been issued in 2008 according to ANESM's own methodology. With regard to informal care, some of them give advice on how professionals should behave in relation with informal carers in order to deliver shared care. Still, it is not yet evident, how much this problem has been given importance within the overall methodology. The same applies to how this aspect of care work has been given importance in the training and education programmes for future home care professionals. Also the newly designed certification process for residential care homes and home care agencies with more than 750 recognised audit agencies involved, has not yet shown a clear focus on giving more voice to informal carers, considering them as an important component of the accreditation process and in the ensuing quality assurance process (see Naiditch/Com-Ruelle, 2009).

## **4 Family carers' private solutions to care**

### **4.1 Is there a debate about the use of migrant workers in the field of LTC?**

This question has remained hidden on the political and social agenda and also, but to a lesser extent, in research on LTC as the debate regarding immigrants, whether from ancient or recent origin, even if they have gained momentum, takes place in a specific political discourse that is less oriented on LTC.

Migrant workers, due to the strict immigration policy put in place over the past three decades with a restrained delivery of working permits, are often forced to work in the grey or black labour market. The employment policy put in place in the area of LTC was supposed to respond to this issue with fiscal incentives (subsidized vouchers) to boost their direct employment while providing them social rights

and a decent salary by joining the formal work market. In this regard and in order to assess the efficiency of the LTC policy employment, a focus on this population should be a priority. That has not been the case for the following reasons:

- First, France has a long tradition of being an immigration country as shown by the percentage of immigrants in the population estimated roughly at 10% of the 63.5 million French citizens in 2008. The stock of immigrants is thus “old”: a recent survey (Enquête Santé Insee, 2003) shows that, in the “French born population”, those over 70 years of age represent 14% compared to 18.6% for the naturalized immigrants (corresponding to old immigration) and only 6.6% for the not naturalized population (the latter corresponding roughly to those most recently arrived).
- Second, over the past three decades France attracted mainly people from “black Africa” (as against immigration mainly from Maghreb regions that took place during the 1950s to 1980s).
- Third, the question of migration raised hot debates over the past two decades linked in particular to the specific “republican” conception of rather abstract and universal citizenship with a still strong opposition to “community based policies”. This leads to a long tradition of avoiding “ethnic statistics” reinforced by the tragic precedent of the “Jews file” during the Second World War. As a result, in the national statistics, information about the country of origin is not routinely reported and other information which could be related to the “community” or “origin” of a worker is not accessible as no “ethnic recognition” of an individual should be possible. This is particularly the case in the area of LTC.

Therefore, instead of focusing on issues related to migrants’ position in the labour market, research has mainly focused on how the immigrant population is ageing in France (Attias-Donfut, 2006) and in particular if and how they use health and LTC services. It has been shown (Jusot, 2008; Dourgnon, 2008) that on the “demand side” the objective and the subjectively declared health status of this population were both significantly lower than for the French born population. This is in particular the case for women whose health seems to deteriorate. This is less linked to a lower access and/or use of health services (mixed results) but rather to their everyday life and working conditions in France. For this population, the PRI (Wolff, 2007) survey has shown that most of their disabled members rely on a broad network of family members and experience a lower use of social services compared to the French born population as they rely more on their family and community based networks.

Looking at migrants as suppliers of labour, the “black” community represented in the PRI survey a small sub sample of 7% who, however, happen to be the majority of the migrant population delivering LTC services. More precisely, even if there exists a consensus between experts to estimate that, when delivered through authorized agencies, the majority (50/70%) of the IADL services comes from employed Africans; and even if there may exist some information about their country of origin, their naturalized status (but not on their legal or illegal status), no such data exist for directly employed workers. And statistics related to the existing information are banned due to the ethnic statistical barrier.

Even in cases where immigrants are legally entitled to stay and work in France, it is difficult to find their working status in routine statistics (how many of them work on behalf of different types of home care agencies?) and under what status they operate (salaried or directly or indirectly employed by beneficiaries); all variables considered to be linked with the quality of the services.

For all those reasons, it seems very difficult, if not impossible, to answer in a sound and elaborate way to questions regarding the real position of migrant workers in home care although they are also relevant for any directly paid home worker in order to assess their work's quality and their contribution to the LTC system. But even in this case, studies are lacking.



## 5 Summary of main findings and conclusions

At the end of this presentation of the state of informal care in France, three issues naturally arise: one relates to APA and its direct impact on informal caregivers in their caring tasks. The second relates to the 'non-existence' of a policy directed specifically to informal carers in order to address the issue of their caring burden. The third issue is linked to the debate about the reform of the LTC funding scheme.

Regarding APA, a first question concerns the type of political process which led to the chosen type of the attendance allowance scheme in relation with the strong market orientation by which this policy is being characterised. In regard to informal care, the main question is: what has been the APA's impact in terms of the relationships between care users and care givers (informal and formal carers) and in terms of their choice regarding caring and/or working? The answer is that, while guaranteeing the older person with care needs a minimum purchasing power to access professional care, APA only marginally changed the "care mix" between formal and informal care while not reducing the volume of help delivered by informal carers. Its overall amount did not meet the entire range of needs and thus did not allow carers to reduce "hands-on care". Also, it did not allow them to find better solutions for reconciling care and work.

The second issue concerns French LTC policies relying mainly on fiscal incentives directed to older people who are supposed to use APA money (or other income) to directly access professional services associated to an employment policy in the "domestic service sector" that, however, does not need to focus on older people. This strategy is underpinned by programmes to professionalise the LTC work force with the CNSA as a central stakeholder of a still not convincing quality policy. Still, despite a strong rhetoric toward "helping the helpers" a clear gap in supporting family carers can be observed as systematic measures to support them in *performing informal care* or providing enhanced framework conditions *to be able to care* (for example by allowing for a better care/work balance) are missing.

### How can we explain this deficit?

During the past two decades, the shift between paid and unpaid work for many social tasks and in particular the existence of blurred boundaries between informal and formal care have been put on the social and political agenda (Glendinning, 2006). In this regard France does not look different from many other European countries when the system of attendance allowance (APA) was introduced, coined as 'services in cash' as opposed to 'services in kind'. These cash benefits were seen as a way for older people in need of care to access professional services by offering more flexibility to choose between those that suited best their needs. Based on this rationale, paying for a family carer was considered an important part of the scheme's design.

In France the launch of the attendance allowance (APA) in 2001 was framed by a fundamental public debate regarding its potential use and impact, while in other European countries where similar schemes had been introduced earlier (e.g. Nordic countries, Netherlands, Austria) this debate was more closely related to political issues such as women's citizenship and gender equity (Dang/Letablier, 2009). Focussing on the care activities in the domestic domain the main questions to answer in France was therefore:

- Can informal care delivered to older people be recognised and compensated for in order to allow family members – and particularly women that are highly involved in it – full access to citizenship in terms of their economic status but also with respect to social rights that are not necessarily linked to carers' access to the labour market?

In this perspective, cash payments were conceived as a form of compensation for care tasks undertaken by women within the home and considered as a possible solution in the arbitrage between caring and an effective access to citizenship (Glendinning, 2006). But whether focused on women's rights or set in more general terms (considering both older people in need of care and their family carers), international surveys (Ungerson/Yeandle, 2007; Da Roit/Le Bihan, 2010, Triantafillou et al, 2010) show evidence that supporting families by various types of measures was one of the key components of LTC policies in most countries – with a different mix of supportive measures.

### **The characteristics of the French debate on LTC and informal carers**

In theory, one could have learned from existing initiatives to develop a coherent set of measures responding to the needs of informal carers in relation to their caring tasks, including direct supportive services (Lavoie, 2000). The French debate, however, had mainly been shaped by an atmosphere of demographic “disaster scenarios” and respective funding difficulties due to an ageing society – that later studies have tended to modify (Albouy, 2009) – as well as by the (still existing) age barrier of 60 set between people with disabilities ‘at working age’ and older people with care needs (Le Bihan, 2002).

A first reason for the specific stance of the French discourse on LTC may be explained by the fact that, compared to other countries, the feminist movement in France, even if influential, has been weaker (see, for instance, the low ratio of women involved in higher executive posts or in important political positions). This may relate to the abstract conception of French republican citizenship which makes gender issues a still not suited and/or recognised way to tackle equality and equity issues for public debate regarding their social position in all social, economic and political domains through specific measures coined “affirmative actions”. Feminists as a group are still lacking even today influence to place the gender-specific division of labour high on the political agenda: Why do women work predominantly as informal carers? How detrimental is this situation in regard to their citizenship rights? What actions can and should be taken to change this situation?

Secondly, the older population as tax-payers and voters could have been another strong political stakeholder to support policies focusing on informal carers' support. In reality however (see 1.2), this ‘grey’ power happened to be weak as ageing, in France, correlates with a low consideration of older people who are not contributing productively to the formal economy. This results, for instance, in one of the lowest percentages of all European countries of workers over 55 who are still in the labour market (Eurostat, 2010). In this regard measures aiming at maintaining older workers (aged 55-65) in the labour market have not been very successful compared to other countries.

Thirdly, as seen before, the division between policies for people with disabilities ‘at working age’ (below 60) and older people with care needs has further weakened the ‘grey’ power, especially regarding coherent solutions for the social and political treatment of disability issues. But notwithstanding the impact of the age barrier between disability policies and care policies for older people, leaving grey power in competition with the “handicap lobby”, care for older people had also to compete with the

long-standing and politically strong “baby and mother-oriented” lobby. In this respect, the power of the “family lobby” might provide another clue. The family movement has always been politically strong in France – as almost the only consensual domain between the right and left wing parties – and has thus been able to push for measures to support mothers (strengthening the one-bread winner model), to ensure one of the highest birth rates in Europe and to strengthen the economy through an available workforce. In a situation in which caring for frail older people is considered a moral obligation anyway, measures to support women will be likely to become ‘baby-oriented’, rather than being focused on older people. The difference between the level of support for a woman as “an informal carer for a child” as against an “older informal carer” comes as a natural consequence.

The French family council of 2006 represents the only exception from this traditional antagonistic orientation when it stressed the necessity to launch a real policy for families supporting older people with care needs. It did so by trying to reconcile both perspectives based on the lived experiences of the meanwhile well-known “sandwich generation” (Renaut/Ogg, 2006), with mothers caring simultaneously for their children and their older parents. The powerful Alzheimer lobby used this situation as a lever to reinforce its strong political support and to make such policies a priority for the former and the current French president. However, this general reconciliation did not last long as economic realities tend to reinforce the traditional cultural divide between the two stakeholders.

The goals of the APA cash benefit scheme thus ‘naturally’ turned to be more oriented toward providing older people with public funding to prevent black markets for care work and to create employment for low educated workers, who would then benefit from social rights attached to the labour legislation. This “employment-oriented policy” (Debonneuil, 2008) based on tax and social contribution reductions for direct employers of a domestic worker was reinforced by two well-known discourses: “free choice” for consumers and “more competition” between private for-profit, public and non-profit agencies with the aim to increase quality by means of market-mechanisms.

However, these mechanisms were not able to fully deliver the expected outcomes as supporting direct domestic service provision through fiscal incentives did not really address the risk for care users and their informal carers of such a policy (see Naiditch/Com-Ruelle, 2009; IGAS, 2009). Neither did these mechanisms address the issue of a better reconciliation of care and work. This was highlighted by the debate about potential support for working carers in relation to end-of-life-care. This issue was not really publicly debated but quickly framed into legislation (yet not implemented!) based on a very narrow orientation on issues of costs and reduced budgets.

Given these experiences, even if the ongoing innovative research launched by the CNSA to develop new tools aiming at directly supporting Alzheimer families seems to push in the right direction, mainstreaming of such innovations may be hampered by a corresponding lack of funding.

This last point is directly linked to the ongoing debate about the necessity to raise more collective resources for the construction of a LTC system in relation with the still not arbitrated choice of a renewed LTC insurance scheme. According to numerous surveys (BVA, 2009; SOFRES, 2010) a growing portion of respondents (53%) consider that a LTC insurance should be mandatory as opposed to 42% of respondents who are in favour of a voluntary scheme. Among the first group, two-thirds favoured the “universalist option” instead of limiting the obligation to older people. Concerning the service users, a large majority (74%) of respondents declared that financial support should be means-tested and thus be

paid only to older persons with low income. In addition, even if 62% of respondents declared they were willing to pay for a personal LTC insurance, this percentage – which has declined over the past five years (Weber, 2006; David, 2008) – is higher among the well-off population (72%).

The debate was strongly boosted by a report issued in April 2010 (Rosso/Debord, 2010): While reinforcing the ‘rationale’ for maintaining the distinction between people with disabilities below 60 years of age and older people with care needs, the direction for the older population was not to pour more public funding into the LTC system through an appropriately publicly funded mandatory universal LTC insurance scheme; but rather to restrain and target public funding to the poorest and/or the highest needs. As the option for enhancing the general taxation level was excluded, the main issue discussed was about how to find (mandatory or voluntary) extra funding. One favoured option was to rely more on a scheme based on voluntary private insurance where each person would seek coverage either individually or through their employers. Many experts considered that this scheme would lead to more social and economic disparities (Elbaum, 2007; Henrard, 2008; Ennuyer, 2007) and that, if this private insurance system should be chosen, it should be made mandatory and through a mutualised fund. Up to now, insurers (whether for-profit or not) have not yet found a common agreement neither between themselves nor with the state. Open issues are: the type of population to be publicly covered and whether private LTC insurance should be mandatory or voluntary. Also the more technical issue of how to define in a common way entitlement criteria and what type of tool to be used by both types of insurance (public and private) have raised a hot debate. So one year from the presidential election (May 2012) the government has now launched a political process consisting in organising forums and “electronic debates” while four expert groups have been put in place to provide more scientific evidence in the debate and to construct different scenarios with their final conclusions to be delivered at the end of June 2011. It appears that insurers are now less prone than initially expected to enter the Rosso Debord options and that a more conservative approach of consolidating the current publicly oriented design is more in line with the risk linked to the coming election.

So even if the rhetoric on a policy to support informal carers has thus gained some audience, this topic has not yet emerged as a major dimension in the strongly “budget-oriented” debate. Whatever the final decision will be, there is a high risk that informal carers’ contribution will rise without any guarantee of being supported in an appropriate way.

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## 7 Appendix

**Table 1** APA Beneficiaries according to their disability level (01/01/09)

GIR level	Beneficiaries living...				Overall	
	at home		in a nursing home		Number in thousands	%
	Number in thousands	%	Number in thousands	%		
1	17	2.5	67	15.7	85	7.6
2	124	18.0	184	43.1	307	27.5
3	149	21.7	69	16.2	218	19.6
4	399	57.8	106	25.0	505	45.3
<b>Overall</b>	<b>689</b>	<b>100.0</b>	<b>426</b>	<b>100.0</b>	<b>1,115</b>	<b>100.0</b>

**Field** • Metropolitan France & French overseas departments, extrapolation from 85 participating dpts.  
**Sources** • DREES, quarterly survey on APA carried out among General Councils.

**Table 2** Beneficiaries' co-payment according to their disability level (01/01/09)

in €

A - Mensual amount for a beneficiary LIVING AT HOME						
	Average amount (AM)	Percentage of average AM according to national standard	Amount paid by the General Councils	Theoretical copayment amount	Share of beneficiaries having a copayment obligation (%)	Amount paid by obligatory copayers
GIR level 1	1,007	83	833	174	73	239
GIR level 2	785	76	635	149	77	194
GIR level 3	577	74	474	104	77	135
GIR level 4	349	67	289	59	78	76
<b>Overall</b>	<b>494</b>	<b>71</b>	<b>406</b>	<b>88</b>	<b>78</b>	<b>114</b>
B - Mensual amount for a beneficiary LIVING IN A NURSING HOME						
	Overall	Amount paid by the General Councils	Theoretical copayment amount			
GIR levels 1 & 2	547	396	151			
GIR levels 3 & 4	335	195	140			
<b>Overall</b>	<b>460</b>	<b>313</b>	<b>146</b>			

**Field** • Metropolitan France & French overseas departments, extrapolation from the participating departments.  
**Sources** • DREES, quarterly survey on APA carried out among General Councils.

**Figure 1 Co-payment level variations over time (2002 – 2008)**

